GREAT RESPONSIBILITY:
RETHINKING DISABILITY PORTRAYAL IN POPULAR FICTION
& CALLING FOR A MULTI-CULTURAL CHANGE

by

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Abstract

This thesis is an occasion to examine how normalcy – as a phenomenon constructed in society and so not natural but human-made – is reproduced as a hegemonic ideal through oppressive portrayals of disability in literature. Many of the fictional texts I analyze reproduce the privileging of normalcy.

I therefore work to disturb normalcy’s hold through critical analysis of a wide variety of currently popular fiction for youth and adults. Combining interpretive inquiry and personal narrative, I bring forward new understandings of normalcy, disability and culture. Along with showing how normalcy’s supremacy is upheld within the book industry, and critiquing texts that do disability as usual (through both survey and close analysis approaches), I discuss at length several literary works that write disability in anti-oppressive, anti-ableist ways. To close this thesis, I discuss my own transformation as an author and scholar through disability studies.
Acknowledgments

“I can’t teach them!”
“Yes, you can. All you have to do is get their attention.”

For many years, this exchange from the movie Dangerous Minds has stayed with me. The memory of Michelle Pfeiffer playing the role of Louanne Johnson -- an out-of-her-element teacher at an American inner city school experiencing intense racial tensions -- often surfaces when I am faced with ableist resistance to my progressive perspective on disability. But ‘getting their attention’ has been no easy task, especially since that process first involved opening myself up to the idea that I, as a disabled woman myself, had internalized many ableist notions about disability. If I were going to impart change, I would need to change first, to understand disability in new ways. Disability studies would have to get, and keep, my attention.

For achieving this in captivating, life-altering ways, I extend profound gratitude to Dr. Tanya Titchkosky, who has guided me patiently from ‘infancy’ to maturity with respect to the disability studies approach over the last three years. My time as a graduate student within the Department of Sociology and Equity Studies in Education (SESE) at the University of Toronto’s Ontario Institute for Studies in Education (OISE) has been enriching, invigorating and rewarding to the highest degree. Tanya has been instrumental in creating a safe and intellectually challenging place to think, and re-think, disability, justice, and human rights, and their role in education. Tanya lives what she teaches, teaches with passion, and passes it on. I am forever changed.

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of teaching as a one-size-fits-all experience. Grace revitalized my love of learning when I, in a burnt-out, demoralized state, first took a course at OISE in 2004. Since then, she has given me the privilege not only of exploring personal narrative as a valid research approach, but has also demonstrated the power of teaching as an act of honouring difference and imparting healing. I thank her for restoring my faith in education and in myself, and for sharing her own journey of healing and also becoming part of my own. My own story would not be what it is today had it not crossed paths with hers. I thank her for not only teaching multi-culturalism and peace education, but living and breathing them. She is truly a border-crossover.

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I wholeheartedly thank all the authors who have generally granted me copyright permissions, in order that I may quote large portions of their text within these pages. I also express gratitude to all the authors of the novels and book reviews discussed in this thesis, for writing text that is fertile ground for disability studies to move in and ‘talk back’. You have all written important books, and if I have critiqued your work ‘negatively’, it is not because your fiction or your reviews are ‘bad’. We have all internalized the myth of normalcy’s supremacy, and I couldn’t have written a thesis that notices the oppression coming from this ‘supremacy’ without you. To all those already writing disability differently, keep going and don’t compromise! I salute you.

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Dedication

This thesis is dedicated to:

All those who are passionate about making disability matter, and making it come alive in exciting ways. And to all those who will think differently because of this work.

My nephew William and my niece Abigail. May you always know what incredible power lies in education. May you always know for sure that all life and all difference are miraculous gifts, and oppression doesn’t have the last word. I love you with all my heart.

I also dedicate this work to the memory of my wonderful father, Mike, and my beloved, beautiful niece, Charlotte – two treasures gone too soon.

I’ll see you both in the morning.
Chapter 1: Grounds for Inquiry

In elementary school, like many students of my age, I was an avid reader of Jean Little’s fiction. But, unlike the non-disabled students around me, I had my own specific reasons for reading Little’s work featuring disability with such gusto. I devoured *Mine for Keeps* (1962) and *From Anna* (1972) as someone ‘looking for herself’ within the pages of fiction.

Growing up with Cerebral Palsy, I quickly grew tired of dealing with -- and hearing excuses for -- a society clearly not welcoming to disability. Buildings lacking ramps and elevators, schools lacking accessible classrooms or bathrooms were everywhere. Churches, hotel rooms, or pools I couldn’t get to or enter were the rule more often than the exception. There was never a productive discussion of the worthwhile education and jobs that would be open to me when I was ready. So the message was unmistakably clear, if most often implicit rather than explicit. ‘You aren’t welcome here. Disabled people don’t come here, and if they do, they better be normal enough to handle the world as it exists.’ It was clear that if I wanted to belong, I would have to change. If I couldn’t do so, I would have to settle for being an outsider.

There was not much discussion of the fact that it was the response to disability that was a problem, or of the fact that my exclusion resulted from systemic negativity toward my disabled embodiment. Furthermore, there was little critique (except in my mind) of the fact that my exclusion was, in most cases, taken for granted, even normalized.

My very grim medical prognosis introduced me exceedingly early to the medical model of disability. (It is worth noting that ‘grim prognosis’ seems to be associated with ‘death’, so in this terminology, disability is medicalized as a kind of death.) Since I could not be cured, the ‘experts’ blamed me for not working hard enough to ‘become normal.’ In short, no one came anywhere close to dealing with me as a whole person. Most memorable for me is the fact that hope itself seemed to be missing from my “projected forecast”. This absence of hope turned out to be a very instructive, formative experience that shaped me as a person and an educator. From its absence (a lesson
in reverse), I learned that disability, taken through the lens of the medical model, was understood as a hopeless, futile and pitiful embodiment. Intuitively, I knew there was much wrong with that.

All the health professionals I dealt with – doctors, physio and occupational therapists, social workers and the like – seemed both unable and unwilling to accept me as a partner in my own care, and to approach me in ways that took into account my intellect and my expectation to live a fulfilled life. Although my physical health has always been and remains very important to me, I knew from a young age that it was not – indeed could not be – the whole picture. I refused to sit quietly by while my disability was taken up and understood as grounds to ‘erase’ me from society’s picture. How is it possible, after all, for disability to assume the important role of teacher if it is erased?

Dedicated as I was -- and continue to be -- to the written word -- I determined very early that through books I would instigate necessary change. And here I am.

As an author, educator, creative writing teacher, children’s and young adult book reviewer, professional speaker and former librarian, I’ve experienced the field of education and the book industry from many angles.

In my roles as librarian, author and book reviewer, it didn’t take me long to notice that, in the majority of fiction I read within these professional roles, disability was being portrayed in disparaging ways. Disabled characters either died, were cured, or ‘beat’ their ‘tragic’ embodiments through overcoming them and doing what disabled people ‘shouldn’t’ be able to do. While reading these books, I often remembered my painful experiences of exclusion when I was growing up. I had the distinct feeling that this pain was being repeated as I read fiction that erased disability either by ignoring it completely or releasing it in oppressive ways that were made to appear ‘normal’.

From the basis of all these experiences has grown the necessity of critical analysis of the pervasiveness of normalcy, understood widely as a constant to be upheld in literature. My own experiences have convinced me that instead of being upheld, normalcy must be deconstructed and toppled, and its oppressive nature exposed. The good news is that just as literature can be (and is) so often used to more
deeply entrench normalcy’s unquestioned position, it can (and must) be used to shake that unquestioned position. That shaking up is in fact the purpose of this thesis.

A Strange ‘Gift’ Indeed

I once thought that my passion for the intersection of disability and multiculturalism was propelled forward in me a long time ago, most especially during the process of writing my first novel for children, entitled Zoe’s Extraordinary Holiday Adventures (Minaki, 2007). While that’s certainly true, it’s not the whole story. Certainly, disability and multiculturalism have been dear to my heart for a very long time (otherwise I would never have written this children’s novel in the first place), but what really ‘lit a fire in me’ was the following event. In fact, it changed me forever.

In 2007, (the year I applied to OISE and the year my first novel was released -- in fact, just weeks before its launch) a close friend of mine had a cousin, Peter, visiting from Germany. He is highly intelligent. In fact, at just 22, he was in medical school in Germany.

My friend and I both noted that he was ‘independent and stubborn,’ but, all factors considered, a really good guy. I met him fairly early on in his trip, and I must admit, I was quite impressed at the time. We discussed plans for his vacation, his experiences in medical school, his family, his life in Germany, and his first impressions of Canada. I told him about my first children’s novel, which was due to launch the next month. We talked about how the book ‘marries’ my passions: education, disability advocacy, multiculturalism and peace education with an overarching interest in the empowerment of children. We talked about my plans to pursue a second Master’s degree at OISE. I felt very at ease and Peter seemed to like me well enough.

All went well until near the end of his trip, when, while with my friend in private, he let his true colours show.

While talking to my friend, he asked her some questions about my second Master’s, and so she talked to him a bit about the need for disability activism. According to him, here is the ‘truth’ about disability:
• Parallels shouldn't be made between inequalities on the grounds of race and inequalities on the basis of disability. While racism is unfair, discrimination on the basis of disability ‘makes sense’, since there is an ‘evolutionary basis’ for fear of and resistance to disability. I should consider what would have happened to me in pre-historic times if there was a tiger at the mouth of my cave, threatening me. If I wouldn’t have been able to run, then it shouldn’t surprise me that ‘survival of the fittest’ has left us with negative attitudes toward the ‘inferiority and weakness’ of disability. These attitudes stem from a drive for our species to survive, and they are therefore healthy. Working to change prejudices toward disability in the young is a form of ‘conditioning’ (read ‘brainwashing’). Society already went through that with Hitler, and look what happened…People have a right to their attitudes.

• There are already enough safe-guards in place to ‘protect’ people with disabilities. If going to school or working is so hard for people with disabilities in society as it is, that's too bad, and has nothing to do with discrimination. If life is too hard, people with disabilities should just stay home.

• People with disabilities complain too much. They are whiners who need to learn to be more grateful. He expressed ‘concern’ that my friend and I are, in fact, friends.

For a long time after I received my friend’s phone call in which she detailed what happened and told me of her subsequent enraged reaction, I was of course shocked, hurt, and enraged myself. His ‘tiger at the cave’ argument was especially distressing. If it is held to be sensible that a fear of disability is justifiable because disability amounts to evolutionary ‘inferiority’, we haven't progressed far past cave people. Doesn't it follow that a truly advanced society would understand that since we are no longer cave people, fear of disability doesn't make sense on the basis of ‘evolutionary disadvantage’? How could racial and ethnic injustice have nothing in common with discrimination on the basis of disability, when it has been estimated that Hitler exterminated 275,000 disabled people in the Holocaust (Russell, 1998)? It seems to me that that chilling statistic alone forever establishes an irrevocable connection
between the two, and destroys any notion that oppression is wrong when applied to one group, yet understandable toward the other.

Also disturbing is the echo of his voice in my mind, asserting that concerns about racism and attempts to build ethnic and cultural peace are legitimate, but efforts to revolutionize assumptions about disability in education and wider life are not. A brazen attempt at the discounting and erasure of disability is clearly evident as the root of the problem here. The ugly idea underpinning this is that racism is ‘of course’ oppression but that the ableism entangled within normalcy’s approach is somehow true and should therefore be left unquestioned. The perception is that ‘of course disability is bad. Who in their ‘right mind’ would question that?’

I must say that while this man enraged me, he did me the ‘favour’ of pointing out for me a shocking instance of ‘disability as usual’: worthy of exclusion and othering to the extreme. For example, the logic of this form of exclusion says ‘They should conform or just stay home and have no role in the world and no friends, lest they pollute or brainwash anyone with their ‘abnormalities’ and quest for justice’. The significance of this logic, or this ugly idea, is that it underscores the taken-for-granted notion that disability can and should be erased, and that it only exists to showcase the supremacy of normalcy.

Yet, even then I knew that having no role was indeed a role for disability -- the role of “rolelessness” (Fine & Asch, 1981, p. 233). I was amazed that this man’s brief interaction with me, along with his brief exposure to my book and my academic intentions, had inspired such venom from him. I asked myself what it was about my disability, my first book, and his desperate cling to normalcy that had him in such a state -- a threatened state, really? This nags me still, and underpins my work in these pages.

My purpose in writing Zoe’s Extraordinary Holiday Adventures (Minaki, 2007) was the same as the purpose I have now in undertaking this thesis: to show (not only tell) the truth: that disability, ethnic culture, and identity belong squarely among people, woven in with the stories, conflicts, and challenges of unique characters – not relegated to the outside, pushed aside as ‘border issues’, separate and forgotten, with their
legitimacy at the mercy of ignorance. In my thesis, I want to address, ‘unpack’, and theorize the following question: How do normal conceptions of disability in literature reproduce oppression, and wherein lies the possibility of change? As a way to demonstrate the importance of asking this question, I turn now to narrative.

Coming Up Against Normalcy

I wanted badly for my novel to fit into Canada’s schools, libraries and bookstores without being (mis)understood as a story written exclusively for disabled readers. This (mis)understanding of books featuring disability is all too common and feeds the marginalization of disability and disabled people. It perpetuates the notion that disability has ‘nothing to do with’ the wider world. Disability is thus (again) taken up as a misfortune that can’t and shouldn’t touch the vast majority of society.

In my efforts to avoid this misconception of my work, I reasoned that every child experiences difference in some way, whether disabled, poor, new to a country or struggling on the grounds of countless other challenges. Every child can relate to the ache for freedom and adventure, to the restrictions of protective parents, to arguments with a sibling, to yearning to grow up. As an urban adventure story, I reasoned that my book can speak to any number of readers. Circumstances may vary, my logic continued, but a wide spectrum of emotions, and many themes -- anger, frustration, loneliness, relief, isolation, forgiveness, friendship, love, belonging -- are universal, and, I thought, the lessons Zoe learns about herself and others could be transplanted effectively.

Quite deliberately at the time, I stayed away from describing where exactly Zoe’s character is growing up, or her physical traits in detail. I told myself that this way it was easier for readers to see themselves in her, whoever and wherever they are.

What I realize now is that in doing that, I was, in a sense taking Zoe ‘out of her body’ and allowing readers to forget about her body -- even as the story told is one about her body’s place in the world. This move of making her body absent (effectively erasing it to make the story more ‘accessible’ to readers) is a frighteningly ableist contradiction. Truly, what I know now is that readers won’t ‘see themselves’ in Zoe
unless her body is made real to them (not absent) -- unless they are made to face that
disability belongs to all of us, that we cannot face and discuss disabilities unless we
face and discuss bodies, and that “we are never in our bodies alone” (Titchkosky, 2007, p. 5).

My first novel reaches for the spirit of a vibrant, interdependent young girl, and for
a window into the cultures that enrich her world. I placed Zoe in the context of many
characters and issues so that her story could be a learning tool on many key levels. At
the time, I did not realize how my efforts could and would be misconstrued into
disability as usual, nor did I realize how I may have internalized and reproduced
disability as usual, at least in some ways.

What didn’t occur to me until after my novel was published was that by placing
Zoe in that wider context, I created fertile ground for others to think that this story
‘wasn’t threatening’ because it ‘wasn’t really about disability at all.’ I was shocked to
witness that others chose to believe that I had placed Zoe in a wider world not because
she belonged there, but because I (who was taken up as ‘just like them’) wanted her
disability to disappear. Parents and teachers have stated this repeatedly while
‘complimenting’ my work. Once again, in these comments, disability is erased and in
these complex moves of normalizing Zoe (i.e., if disability is gone, the book becomes
‘normal’), attempts are made to force my character into representing the oppressive
norm. Clearly, this is a role I never intended.

However, there is silver lining to this cloud. I can (and I choose to) take this
desire to make the book less threatening as proof that it does in fact threaten
normalcy’s oppressive work. If society has to tell itself a false story about Zoe as a
character not pointing to disability, then it is true that my novel is truly creating a space
for disability to do what it does: threaten norms. Since people tell themselves
comforting stories when their norms are shaken, there remains the pressing need to tell
new stories or to tell old stories in new ways!

I have done several readings and talks in schools and libraries, based on my
book. In my experience, students love it and the discussions I facilitate. Their eyes
light up at the very idea of having a student like Zoe in their classroom, and the vast
majority of students have seemed excited to re-think their ideas about disability, excited to see several cultures and traditions represented in one engaging story, and thrilled to learn about the age-appropriate taste of disability advocacy and activism that I give them in our discussions.

Teachers, as well, love my novel – many even rave about it. But I’ve also had exchanges with educators who have felt intimidated by my book and its role as a tool in peace education and disability advocacy. The idea that, in the story, Zoe’s teacher is celebrating the cultures of her students as well as supporting and engaging Zoe as a student while taking her disability ‘in stride’ is sometimes resented. The portrayal of her teacher as someone somehow ‘managing it all’ has at times been misread as my expecting too much of teachers whose plates are full to the point of tipping. But I refuse to believe I have set the standard too high. The notion that teaching students living the reality of disability in classes which are also ethnically diverse is above and beyond, or ‘too much’ is distressing to me. After all, a classroom is a microcosm of the larger world, and disability, along with ethnic and cultural diversity, is part of the world – a part we need to learn from together.

Also, what is disturbing here is the implicit discriminatory thought process as it impacts cultural diversity. The presumptions of these overwhelmed, disillusioned teachers (and they must be disillusioned to be thinking this way) is that teaching an ethnically/culturally/linguistically diverse student body is enough of a ‘burden’. This is difficult and troubling to digest -- especially since this attitude negatively impacts the depth and breadth of literature available to students, and the effectiveness -- or lack thereof -- with which this literature is approached and taught.

An important point must be made here. In my novel, Zoe’s teacher is caring and generally very good at her job, but the belief that she ‘has it all together’ is a fallacy. To truly bring Zoe’s disability into the social space of her classroom in a seamless manner that shows it belongs there as part of the classroom’s community, the craft activity would have had to be planned as a collaborative project (Minaki, 2007, pp. 70-73). This would have been an advantage for everyone, and would have meant a lack of needless frustration for Zoe. Zoe’s access to the activity would not have been
compromised because of her need for accommodations. But, in my experience, few educators have noticed this prior to my delving into it during discussions. Left unexamined, Zoe’s disability is taken up as the reason for her ‘tantrum’ -- not the oversight of those around her. This is a misunderstanding linked to ‘disability as usual’, and a stereotype of disabled people as short-tempered tantrumers. It is fascinating to watch the work of taking Zoe up this way, so that -- against my will as the author of this fictional character -- she is misconstrued to represent disability as usual (and I with her). Far too often in my experience with disability professionals, I’ve come up against the deep-rooted belief that disabled people have ‘tantrums’, but not nearly as often have I met a conventional professional working with disabled people who has any understanding that these ‘tantrums’, when they occur, happen for good reason, and do not define disabled people -- as a group -- as ‘whining, ungrateful, immature complainers.’

Although the vast majority of reviews of my novel have been positive, I was disappointed — though, I must admit, not surprised — to witness Zoe’s character ‘described in certain reviews as confined to her wheelchair, wheelchair-bound, even “stuck” (Cole, 2008, p. 13). The sting of these descriptions was made all the more palpable because of my efforts to put to paper a young girl eager and excited about life experiences – the very antithesis of someone boxed in by her disability. Through these descriptions, such as they were, I saw the truth of Dr. Tanya Titchkosky’s assertion that: “taken-for-granted conceptions of disability are one way in which disabled people are viewed as irrelevant and absent” (2008, p. 39). We take for granted what a wheelchair means even when people come face to face with someone using a wheelchair and speaking about it as a mobility device and even creatively casting the wheelchair into narrative that takes us all, so to speak, on an imaginative trip. ‘What then is confining whom?’ This question returns us to the need to rethink ‘normal’ everyday conceptions of disability.

The descriptions in these reviews portray Zoe as ineffectual, as an absent presence from her own story. Thus, she is excluded, and this exclusion is made to seem predictable and understandable. This way, Zoe’s and my attempt to bring
stereotypes of disability into a space of questioning and examination is rejected. The prejudicial mindset appears to be this: Why would anyone have to go searching for Zoe and for what is available to be interrogated here? It is no mystery what Zoe would want recognized (her ‘courage’) and where we can find her (sitting in her wheelchair). She is confined, -bound, and stuck, after all.

**Best Books?**

The most striking example of taken-for-granted notions of disability prevailing over disability being done in a new way is the exclusion of *Zoe’s Extraordinary Holiday Adventures* (Minaki, 2007) from the 2008 edition of *Best Books* (Canadian Children’s Book Centre, 2008) a buying guide of books – distributed to teachers, librarians, and parents – chosen by a jury for highly recommended content.

The exclusion of my novel from this list showed one more instance of the oppressiveness of normalcy, and the stranglehold with which the book industry clings to its role in the reproduction of normalcy as an accepted, zealously encouraged ideal. I am eager for much change in the industry, and to that end, my goal in these pages is to point to “the difference that disability makes” (Michalko, 2002, title page).

What I find most disturbing is not the exclusion of my novel as much as the title that was included in the catalogue instead. The only source of representation of disability in the catalogue (since *Zoe’s Extraordinary Holiday Adventures* had been left out) is a novel for teens called *Wings of a Bee* (Roorda, 2007) a story told from the point of view of a character named Bronwyn, whose severely disabled sister preoccupies the family until her sudden (largely unexplained) death, in the middle of the book, from a cold. This exclusion is an affront not just to my novel, but to the entire book industry and society at large. This solo representation of disability as usual perpetuated the oppressive idea that there is nothing new to say or think about disability – and no new ways to represent it. The vastly erroneous idea that society at large ‘has it right’ when it comes to disability was sadly confirmed.

This reinforces for me the assertion that there is an accepted norm for disability and disabled people -- a norm for the ‘abnormal’, if you will. Disability is powerless, in
need of erasure, equivalent to -- and deserving of -- death. This norm is clearly oppressive and is reinforced (not subtly) through this story.

In *Wings of a Bee* (Roorda, 2007), disability is not portrayed as a viable way to be in the world. Instead, it is a source of sadness, regret, ‘othering’, and loss – the reason behind leaving the world (being erased). Living well in disability (as opposed to ‘despite’ or ‘with’ disability) is not so much portrayed here, as is dying with it. And, I might add, dying easily. The implication here is that it wouldn’t take much to be rid of disability. One cold, and it’s gone. The content of this novel, and its implications for disability studies, will be revisited in considerable detail later in my thesis, but for now suffice to say that the erasure of disability is very evident here.

Although I am distressed by such stereotypes, I do want to say that books like this one are valuable if approached with critical reading -- so that the stereotypes underpinning the writing are uncovered, critiqued, analyzed and discussed. *Wings of a Bee* (Roorda, 2007) can be an important tool if what the author communicates about disability is not automatically taken up as Gospel truth. This is where educators come in.

In the interest of delving further into the problems with disability portrayal in literature for young people, I will explore the coverage of disability in the children’s literature textbook by Donna E. Norton, entitled *Through the Eyes of a Child: An Introduction to Children’s Literature* (1995). Here we have an excerpt from this textbook, describing how disability should ‘ideally’ be dealt with in literature:

Authors who develop realistic plots around credible characters who have physical disabilities often describe details [about]…a disability, the feelings and experiences of the person who has the disability, and…of family members and others who interact with the character. Well-written books help other children empathize with and understand children with disabilities. While adults should evaluate such books by literary standards, they also should evaluate them by their sensitivity…

1. The author should deal with the physical, practical, and emotional manifestations of the disabling condition accurately but not didactically.

2. Other characters…should behave realistically as they relate to the individual with disabilities.
3. The story should provide honest and workable information about disabling conditions and about the potential of individuals with disabilities.

The resolution of conflict can be a special concern in realistic fiction dealing with physical disabilities. Does the author concoct a happy ending because he or she believes that all children’s stories should have happy endings, or does the resolution of conflict evolve naturally and honestly? Through fiction that honestly deals with disabilities, readers can empathize with children who are courageously overcoming their problems, and who, with their families, are facing new challenges (p. 472).

It is impossible to ignore the fact that much is missing from the above guidelines. What is not said is as telling as what is. Absent, for example, is any mention of children’s literature being an empowering vehicle for disabled children themselves. Such literature is understood as necessary in order for able-bodied children to understand the disabled ‘others’, the ‘courageous’ ones who are ‘overcoming’ great odds. This only perpetuates stigma surrounding disability, since it ‘does’ disability as an individual problem and tragedy. Disability understood this way has nothing to do with anyone else and is definitely not between us as a teacher of any lesson other than the oppressive one of disabled lives as hardly lives at all. It is also interesting to note the implication that ‘natural and honest’ endings to stories about disability are here understood not to be happy ones. Once more, we can observe normative, oppressive assumptions rearing their heads, since endings to stories told about disability are understood in these guidelines as tragic endings. As well, it is distressing that these guidelines are meant to inform how future stories featuring disability will be written -- thus perpetuating the problem and carrying it further.

Disability portrayal in children’s literature is thus reduced to another source of “overcoming stories” (Titchkosky, 2007, p. 181). It is also difficult not to notice that it is disabled “children […] who, with their families, are facing new challenges” (Norton, 1995, p. 472). There is no evidence of an understanding of the necessity for disability in society’s midst (since the only function granted to it in the above description appears to be as a phenomenon to be overcome), or an understanding that disability does not only belong to disabled people and their families, but to all of society.
In his book, entitled *Stigma: Notes on the Management of Spoiled Identity* (1963), Erving Goffman states:

…[T]he standards [which the stigmatized individual] has incorporated from the wider society equip him to be intimately alive to what others see as his failing, inevitably causing him…to agree that he does indeed fall short of what he really ought to be. Shame becomes a central possibility…(p. 7).

Donna Norton’s assertion that author’s of literature for young people must provide “honest and workable information about disabling conditions and the potential of individuals with disabilities” doesn’t seem to suggest that that potential would be high. Honesty appears to imply low potential in the case of disabled people.

In order to fully illustrate this and discuss what is playing itself out here, allow me to contrast the above guidelines with the ones put forth, in the same textbook, for the portrayal of women, girls, and gender roles in realistic children’s fiction:

- Published materials should…present females and males in a variety of jobs. Stories should suggest that both females and males can prepare for and succeed in a variety of occupations.
- Literature should recognize that both males and females share the same basic emotions, personality traits, and capabilities...
- Sensitivity, taste, and non-stereotypic images should be employed in humour used to characterize the sexes.
- Literature should present a broad range of historical references to women…
- …include reference to legal, economic and social issues related to women...

…Contemporary realistic fiction contains more girls who are distinct individuals. Girls may be brave, they may be tomboys, and they may be unorthodox. Mothers in realistic fiction…may even have jobs more demanding than those of their husbands 

Louise Fitzhugh’s hero in *Harriet the Spy* is an eleven year-old girl whom other characters describe as exceptional, intelligent, and curious…Harriet hides in her secret places, observes her neighbours and classmates, and writes down her observations… She is far from the fainting female of most [stereotypical] literature and Victorian fiction, who must be rescued from their failures by the males in the story (Norton, 1995, pp. 470-1).
In absorbing the above guidelines for the depiction of women, girls, and gender roles in fiction for young people, it is obvious that the efforts to portray women and girls as dynamic, capable, curious, creative, self-confident, resourceful, intelligent, un-stereotypical, career-oriented, accomplished individuals is not matched in the guidelines for the portrayal of disability. The notion that disabled people can also be any or all of the above doesn’t seem to have occurred to the author of this textbook. Some of them may not be any of the above, just as some women also may not be, but many are. Why is the very possibility of disability as dynamic unmentioned and unexamined? Why is it understood that to portray Harriet as a fainting female, awaiting and in need of rescue would be ridiculous, but disability is most often portrayed this way, even today?

While empowerment is ‘job one’ for Harriet in Harriet the Spy, empowerment of disabled people in fiction appears to be restricted and defined – in many cases, but not all – by inspiring compassion in the able-bodied, for those with “reduce[d … ] life chances” (Goffman, 1963, p. 5).

Children’s literature experts Deidre Baker and Ken Setterington begin their book, A Guide to Canadian Children’s Books in English (2003), this way:

[One of the] abiding passions [that] inspired us to write this guide… [is] our passion and love for language, rooted in a firm belief that in words lies the preservation of the world. “The world stands on the breath of school children,” one sage comments, speaking of children reciting text. Particularly in our current climate, when the globe seems so small and every action so consequential, this statement rings frighteningly true. What children learn determines the future. It is all the more important, then, that they learn, through the imaginative experience of

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¹ Note the following: “Stories should suggest that both females and males can prepare for and succeed in a variety of occupations...Literature should recognize that males and females share the same (emphasis mine) basic emotions, character traits and capabilities” (Norton, 1995, p. 470). It is worth noting that ‘saming’ (and not necessarily addressing) is the recommended approach to think about and deal with stereotype.
reading, how to see the world… in diverse ways. In stories lie understanding, information, and wisdom; in language lies the possibility of new perception, alternate vision, and life-saving, critical analysis. (p. 1)

In the above statement lies the hope, and the task, of disability studies. It is true that novels function to perpetuate norms and “reproduce...normative signs that help readers read those signs in the world [and] the text” (Davis, 1995, pp. 41-2), but novels written with new insight and imaginations of disability can disrupt those norms, produce new signs, and offer new readings of texts and the world. Literature for young people is a key tool in their education. Writing of such literature that is imbued with a commitment to ‘do disability’ in a new way – a way that awakens society to perceiving, examining, and critiquing its own perceptions of disability – will undoubtedly lead to ‘new perceptions and alternate vision.’ I hope my thesis supports this direction by both uncovering and critiquing normal conceptions of disability in literature and text, and also examining how disability can, should -- and is, at least in the margins -- being done and written differently. In order to make the next move in this endeavor, I turn now to a discussion of some other issues that arose from my own novel. In this way, I demonstrate that our everyday lives with and in disability have much to reveal, upon analysis, of the cultural conceptions and assumptions that organize the ongoing marginalization of disabled people.

**Issues With My Own Novel**

I am very proud of my first published novel, yet if I could re-live the experience of writing it, knowing what I know now, it would be a very different book that disrupts norms even further. Obviously, my own novel is not perfect. Some of its flaws originate from the fact that it was written before my immersion into disability studies, and so, despite my steadfast belief, even then, that there was much wrong with how society perceives of disability I had internalized many of the ableist notions around me. Of course, some of these came out in the writing.
My novel is full of the life of disability, and I am glad of that. I would not have it any other way. Yet, when I examine the novel’s text through a disability studies lens, I can’t ignore the issues before me. Notice the excerpt below:

[Samir] had been telling her that people in wheelchairs weren’t the only ones who felt misunderstood or frustrated or left out. Other people had things they couldn’t do, or weren’t allowed to do. Sometimes they too were teased about being different. Sometimes people were rude about what they couldn’t do, and sometimes people said mean things and told lies. Sometimes people thought they knew the truth about someone, but they didn’t really know at all...

Samir knew how unfair it was that some people noticed what made Zoe different, without noticing that in many, many ways she was just like everyone else (Minaki, 2007, p. 78).

What I regret about the above passage is that it collapses difference. Zoe is portrayed as ‘just like everyone else.’ Her difference is written up as making no difference, at the same time as it makes all the difference in the world. Furthermore, what difference is acknowledged is negative. Zoe’s disability is taken up only as the reason why she is ‘misunderstood...frustrated...left out’. There is no mention in this passage of what Zoe’s disability gives her. In the section of the novel, Samir proceeds to work with Zoe on finishing the craft, yet I make no mention that her disability has given her the gift of working creatively and collaboratively (interdependently) on her art with another student, and that her embodiment is a valuable part of her that allows her to notice the ways in which the privileging of normalcy is enacted and sustained. It also allows her to disrupt that normalcy. I am disappointed in myself for the shortcomings of this passage, yet my determination to theorize it now, through a disability studies lens, shows how much my own lens has changed through disability studies. I am relieved that by discussing it here, I am also making interdependence come alive to an extent that my novel does not.

I can’t miss how easy it would be for Zoe to become part of an ‘overcoming story.’ So many fans of my book have commented on how Zoe ‘overcomes’ her disability to become part of her class, her school, her friends’ lives, and her neighbourhood. These comments show no understanding that disability is indeed part of people’s lives, part of community, part of society. It does not have to ‘overcome’ itself to be among us. It is
already there. Furthermore, there is definite “normative violence” (Titchkosky, 2007, p. 178) in suggesting that disability must be overcome (i.e. must disappear) in order to exist in classrooms, schools and communities. It is ironic and disturbing to witness disability being done this way -- done so that Zoe must be ‘normal’ before she can be disabled.

I can’t help but notice, too, that novels featuring disability are often automatically categorized as books exclusively for people with disabilities. This is exactly the restrictive stereotype I wanted to avoid in the writing of my book. I wanted it to fit into the multi-faceted diversity of Canadian society, Canadian bookstores, libraries, and classrooms without being stereotyped as a book exclusively for children with disabilities. The story is Zoe's, but at the same time it is designed to fit in a wider context. But this has proven to be an unpopular conviction. It is almost as if ethnic and cultural diversity is seen as enough of a ‘problem’ on its own and shouldn’t be ‘compounded’ by disability coverage. Could it be that a book that covers disability along with ethnic and cultural diversity in an inclusive manner that lends itself to both advocacy and peace education is considered an intimidation – considered too complex or utopian? If so, there is a huge problem here, because the education system is contradicting itself: on the one hand, teachers are told they should be teaching respect, inclusiveness, equality, and peace; yet those teachers are sabotaged on the other as governments and so-called 'experts' crowd out the time and space for “soulful education” (Feuerverger, 2007, p. 5) by legislating that it be replaced with “agendas of efficiency and control” (p. 5).

Reading Grace Feuerverger’s words about her experience of children’s literature only confirm how essential it is for children and youth. Feuerverger -- as the daughter of extremely traumatized Holocaust survivors -- has this to say about the saving grace of children’s literature:

[These stories] gave me the greatest gift – a sense of belonging to the family of humankind and a sense of community…They spoke about universal issues…They offered me faith in the knowledge that, in spite of all the terrors and injustices, humanity does exist and that I too was a part of it. These stories revealed that there was connectedness to life even in the midst of
destruction...And how else could I have made sense of my own...story?... The realization that reading could be a liberating force was overwhelming. And I was hooked forever.

...Years later I also shared [this wisdom]...with my graduate students (most of whom are teachers) in my university course "Children's Literature in a Multicultural Context." This is the first quote in my outline for that course: "Remember only this one thing," said Badger. "The stories people tell have a way of taking care of them. If stories come to you, care for them. And learn to give them away when they are needed. Sometimes a person needs a story more than food to stay alive. That is why we put these stories in each other's memory. This is how people care for themselves" (from the folk tale "Crow and Weasel" by Barry Lopez, 1990, as found in Feuerverger, 2007, p. 39, 44).

**Significance**

The concluding statement is a powerful, profound one. If we, as educators and theorists -- indeed, as human beings -- take stories seriously, then we must concede that the content of stories (the quality of our sustenance and the messages it carries to us) is essential. This is, of course, absolutely true when we consider the kind of stories we are telling about disability, through the text of fiction (In the case of this thesis). For example:

The title of my novel, and its cover, has always been a problem for me. As a title, ‘Zoe’s Extraordinary Holiday Adventures’ brings Zoe and her disability into the world as ‘out of this world’, out of the ordinary and outside of everyday life. The very idea that Zoe would be living in her disability and having adventures in her life is made to seem just that: ‘extraordinary’. This does the not-so-subtle work of othering disability. In reviews of the novel *Wings of a Bee* (Roorda, 2007), for instance, the book is described as “...[a} deeply perceptive portrayal of family life under extraordinary circumstances” (back cover). The making of disability into an extraordinary phenomenon (literally, outside of the ordinary) enables society to perceive of disability as a rare phenomenon instead of as a cultural phenomenon made by and between people (Titchkosky, 2003). My novel’s cover features photos of a model posing as the fictional character of Zoe. There are three photos: one main enlarged one of Zoe alone, and two smaller ones of Zoe with her dog. Granted, her dog is an important character in the novel, but Zoe’s
family, her classmates and friends, her teacher, her neighbours -- the people who make up her story and are part of her life -- are absent from the book’s cover. This troubles me, since it perpetuates the erroneous assumption that disability is an individual matter that only ‘happens’ to a few, and ignores the wise assertion that “We are never in our bodies alone” (Titchkosky, 2007, p. 5). As stated in Titchkosky’s *Disability, Self and Society* (2003):

> To live with [disability] is to live with the plethora of ways that people have to make up the meaning of their culture...The ways in which the matters of [disability are] experienced by any of us have something to reveal about the cultural meaning of disability...[C]ulture is dynamic -- culture receives its meaning from people, while, at the same time, giving people their meaning. Therefore, living with disability provokes a continual wrestling with the question of identity...Everyone, disabled or not, who interacts with disability is engaged in producing its meaning and its social identity. A ‘disability identity’ does not belong strictly and only to those of us who are identified as disabled...[A]ll [disability] experiences are configured within a culture that has much to say and do about disability. It is impossible to experience disability outside of our relations with others. Whole cultures and whole societies experience disability, and this too is done within the confines of a commingling of various ways that disability is identified and made meaningful (pp. 4-5).

This understanding of disability as a cultural phenomenon is one I intend to stay with throughout this thesis. I intend to ‘take back’ disability and ‘re-appropriate’ it in these pages, to resist and question understandings that perceive of it as a problem, and a tragedy in need of erasure. I also intend to expose the valuing of ‘sameness’ over difference as a kind of profound “normative violence” (Titchkosky, 2007, p. 178). I am at once amazed and disturbed by society’s persistent privileging of norms, such that our differences are not commonly respected as difference but instead taken up as a disguise for homogeneous humanity.

**Methodology**

I intend to show that the fictional texts I analyze in this thesis continue the privileging of the “normality genre” (Darke, 1998, p. 184). Yet, analysis of said texts can disturb normality’s hold on them and bring into the world new understandings of normalcy, disability and culture. I will also examine texts that do the complex work of
putting disability out in the world in a new way, thereby instigating necessary change, which upsets normalcy’s widely unquestioned status. Normalcy, in this thesis, will be brought forward in order to question its hegemony. Through the work of such theorists as Tanya Titchkosky, Rod Michalko, Lennard Davis, Tom Shakespeare, Sharon Snyder and David Mitchell, to name a few, I will approach this thesis through the lens of interpretive inquiry. Interpretive inquiry will enable me to work with texts as an interactive process, wherein the text acts on the reader, and in turn the reader acts on the text -- acts on it and makes new understandings out of it through interpretation and re-interpretation (the making and re-making) of understandings of disability and culture through text. Studying the act of interpretation here will allow me to upset the power of normalcy by uncovering what is being said to disability, and made of it, through texts and the messages underpinning them. Put another way:

If it is true, as Mikhail Bakhtin (1986: 70-1) suggests, that each and every utterance is bounded by the expectation that others will respond, then articulating the experience of disability and attempting to understand it can be conceived of as ‘re-appropriation.’ Re-appropriation means taking back, talking back, and staying with the experience of disability so as to reveal the meaning that has already been granted to disability by culture, by others, and by me…

Henri-Jacques Stiker says in A History of Disability (1999: 14, 18), ‘A society reveals itself by the way in which it treats certain significant phenomena,’ …Disability is certainly a significant social phenomenon, and it is so in a variety of ways. It is significant numerically in that many people are disabled and many more will become so… [A]ccording to the International Disability Foundation there are more than half a billion disabled people in the world and this number is rising (Priestley, 2001: 3). While disability touches the lives of many people, Stiker implies that the ultimate significance of this social phenomenon lies in the quality of the appearance of disability issues and in society’s treatment of its disabled people (Titchkosky, 2003, pp. 5-6).

Through this study, then, I want to examine the stereotypes, prejudices and biases which are uncovered through texts and which surround disability, and use close readings of pertinent texts to uncover and confront these. I also want to examine the biases that exist in the book industry, which are preventing books containing the themes of disability and (true) multiculturalism, i.e., a multi-faceted view of culture, from being written more frequently and used with more confidence and critical readings by
educators. This is a crucial undertaking. What is available for children to read and deconstruct impacts that which is (or is not) available for them to learn.

**Rationale**

In what follows, I provide a variety of reasons as to why I am convinced that both disability and multiculturalism need to be featured, and honoured together as significant themes in children’s, young adult, and adult literature.

It is temptingly easy to compartmentalize. To categorize. To confine the multiple human diversities and differences in separate boxes and attempt to deal with them only one at a time. As an educator, I've seen the fallout of this mentality many, many times. I've seen the aftermath of making disability ‘the other’, making multiple multicultural experiences into multiple ‘others’. This infuriates me every time I encounter it, since both my personal and professional lives are devoted to breaking down the isolation that so frequently comes with the manifestation of any combination of differences. I have long believed that difference is a great enricher. All differences are not misfortunes. They are cultural experiences. This also means that what we experience both comes from and reflects the cultures of which we are a part.

Since it is true that novels “reproduce…normative signs that help readers read those signs in the world [and] the text” (Davis, 1995, p. 41-2), it is also true that stories and novels--any text--that represents disability, multiculturalism, sexual orientation, etc., as natural parts of life and society, are doing the necessary work of bringing these themes into our social space as legitimate, important gifts that add to the richness of real life.

Both disability and multiculturalism are not static phenomena. (No form of difference is static.) They are actively ‘done’ and re-done, made and re-made through the ways in which perceptions of them are taken up and reflected by people, the media, etc.

Children and youth need to feel that their lives are legitimized when they read books. Self-concept, self-esteem and identity are built this way. Real-life realities that are not reflected in books in dignified, positive, well-researched, non-stereotypical ways
are subtly--and sometimes not so subtly--communicated as illegitimate. I don’t need to
tell you that the consequences of this can be dangerous.

The bottom line is this: Disability and race are both culturally constructed.
Impairment may be biological, but disability is (re)-made and (re)-done in society,
through society’s response to difference. Through the media, through education and
politics, and through books as tools in this cycle, disability is made and re-made
(understood as inferior, unwanted and incapable, among other things). Redefining the
way it is understood, taken up in society is the work of disability studies and advocacy.
Culturally conscious education can do the same for perceptions of ethnic groups -- and
it must. On both fronts, literature is absolutely essential. Children and youth especially
need effective literature to enhance self-concept. Furthermore, neither the disability
experience nor the multicultural one occurs in isolation in the world. Yet, in most
books, multiculturalism is not realistically portrayed as multi-faceted at all. The book
industry is not properly reflecting the ‘real world’ in this case. The industry is resistant
to the concept of both disability and multiculturalism as a complex, rich cultural
experience. The idea that the disability experience would have anything to ‘say’ to
multiculturalism -- and vice versa -- is difficult for the book industry to swallow. There
are, of course, encouraging exceptions. And it is my conviction that these exceptions
must become the ‘norm’. These exceptions -- in the margins -- are the stories for which
I advocate, the ones I need “more than food to stay alive” (Lopez, 1990, as quoted in
Feuerverger, 2007, p. 44).

I have corresponded with Beverley Brenna, a children’s author specializing in
disability portrayal in children’s literature. Brenna, a professor at the University of
Saskatchewan, recently completed her dissertation in which she looked at patterns and
trends among 50 contemporary Canadian books that involved characters with
disabilities (Brenna, 2010a). Very few cultural references were included among the 64
caracterizations…in fact only 6 had any specific references at all to cultural
background and/or religious differences, and these were minor. None of the 64
characters were described as homosexual, and 32 were female and 32 male.
Disabled bodies, and so the experiences of disabled people in those bodies, are so often alienated from life in the mainstream centre of society – on the grounds of their 'inferior' embodiments, their unwelcome difference from 'normalcy'. As Titchkosky (2007) states in *Reading and Writing Disability Differently: The Textured Life of Embodiment*: “The expressions of disability, seemingly everywhere in the mass media are provocative...because viable status is not granted to disability” (p. 6). Society accomplishes this 'doing', this alienation of disability through specific ways in which it is treated in the world.

In his book, *Notes on the Management of Spoiled Identity* (1963), Erving Goffman discusses stigma as it connects to the tainting, discounting and discrediting of people. I personally have been repeatedly hurt by the ‘disability as disqualifier’ stereotype. But I am heartened and energized by the fact that I know disability as always more than the routine ways in which it is seen and done in our social space. My hope is to use this research undertaking to peel back the layers of routine – to find disability moving, changing, growing, and pulsating against the boundaries of the ‘box' society attempts to put it in. When I succeed, I know I will have done something important.

Seeing hope in expulsion, in the ‘casting out’ of disability, or racial difference, or any ‘transgressive’ embodiment at all, does not always come easily. Yet, there is hope here, not so much in the fact that one is cast out, but in the fact that one is always cast out to another location, an alternative place, ‘another somewhere’ that offers another way to be in the world.

The alienation, disqualification, dehumanization, and incapacitation of disability are well-known moves, commonly performed. Yet, what is not well known is that hope can be found in the fact that another life is possible, a life full of the possibility of transgressive embodiments: life in the margins!

When my own children’s novel was released in 2007, (ironically the same year as *Wings of a Bee* (Roorda), a colleague suggested to me that the real test for me as an author will come when I prove that I can write about something other than disability. I was shocked and hurt, but from a disability studies perspective, also fascinated. Why was this woman imagining that my ‘true’ qualifications as an author would only come if I
passed the test’ of ‘stepping’ outside of disability? I knew that disability was being understood by her as other than a legitimate focus. It was being disqualified – and me as a writer with it – unless I could prove myself, write about a ‘normal’ topic like a ‘normal’ author, despite my disability. In her eyes, I needed to choose a topic for my fiction work that ‘normal people’ do not wish to cast out. This is an odd request, especially considering that heeding it would mean becoming alien to my own social location. Her statement was especially ironic, considering that she herself has written about disability. She left me wondering how someone who has focused on disability in some of her own fiction could reveal so clearly that she thought of disability as a ‘less worthy’ topic. Upon reflection, I realized that she had spoken to me this way only because I myself am disabled, so she assumed that my writing about disability was ‘taking the easy way out’. In this move, she discredited my writing on the basis of my disabled embodiment. In her mind I was ‘the other’, ‘simply’ telling my own story – whereas when she writes about disability, she is perceived as an exemplary writer, ‘inspired’ to take ‘the risk’ of writing about a tragic topic.

But this woman’s biases are little surprise, since when it comes to disability the divorce from social location that she proposed for me is widely encouraged. Disability is commonly held at a distance – for example, through keeping disabled people marginalized as a separate and disadvantaged group, and through language manoeuvres such as ‘persons with disabilities’ as opposed to 'disabled persons'. So it is second-nature for her to request of me to 'leave disability behind', to separate myself from it. It probably didn’t even occur to her that what she was asking me to undertake was the violence of my own social dislocation. She probably thought she was doing me a favour by encouraging me not to take ‘the easy way out’ by writing about my own social location.

This is a fascinating, ironic ‘encouragement’. It proves that when someone disabled (such as myself) writes about disability, it is almost as if they are 'cheating'. It is clear that disability in the book industry is so often treated as unwelcome. Society prefers to think it knows everything it needs to know about disability, that there is nothing important left to think, say, or learn on the subject. This allows society to
maintain its illusions about disability – that it is a far off, 'far out' phenomenon, irrelevant to the majority of society. So, under the guise of giving me a 'healthy' professional challenge, my colleague was doing what the 'norm' expects of her: attempting to call me off the path of portraying disability in a new way, and back into the mainstream territory of a 'safe' topic.

I will choose no such topic – even if keeping disability separate were possible. My voice, and the voice of disability studies, needs to be heard. I will not be silent.

In her Masters thesis on Critical Race Theory and Korean-Canadian voices in children’s literature, Carolyn Kim (2008) makes a similar point:

With overlapping issues and ideas, critical race theory has important implications and connections to education, multiculturalism, and literary analysis in that it casts a new perspective and focus on race, racism and equity in the respective areas. Applying critical race theory to these areas can shed new light on existing paradigms on how we read past and present children’s literature. In turn, this can have a profound effect upon how we produce books as well as what kinds of books we need to produce if we are to achieve the goal of not only reducing stereotyping of minority groups, but also publishing books that are true to the Korean-Canadian experience by enlisting Korean Canadians to write about their experiences for children (pp. 62-3).

Through disability and disability studies I have found my voice as an educator, scholar and writer. I have much to say and much work to do. There is much education needed on disability as a legitimate way of being in the world. For as long as there are attitudes, and so books, out there, that alienate, disqualify, dehumanize and stereotype disability, I will be writing and educating to counteract the damage and honour my own voice.

In her paper, “Life With a Hyphen: Reading and Writing as a Korean American”, Linda Sue Park (2006) writes: “[T]he countless, daily…encounters—the assumptions people made about me based on my race alone—have worked to shape what would eventually become my writing sensibility” (para. 7).

And there you have it…a woman ‘after my own heart’!
Conclusion: Pay Attention, We’re Going In…

In Chapter One, I have discussed part of my personal narrative, part of the background that led me to this thesis. I have delved into the intended significance of these pages, the theoretical background informing and underpinning my work. In Chapter Two, I will work to uncover and point to the expressions of disability in literature that are oppressive. I will discuss and interrogate the “normality genre” (Darke, 1998, p. 184) and examples of disability expressed in literature in ways that enforce the norm and depict disability in widely accepted, ‘politically correct’ ways.
Chapter 2: Facing Normalcy and Oppression

I Can’t Be Oppressed, I’m Normal!

In Chapter One, I raised the provocative notion that normalcy is an oppressive construct. So in the following chapter I will explore this idea further. I will turn to the work of Paul Darke and “the normality genre” (1998, p. 184) to further support my conviction that this oppression is in need of further inquiry.

I will also demonstrate the efficacy of this oppression by undertaking a brief survey of a number of fictional literature texts, which underscore the fact that normalcy is a social construct that serves to uphold itself and oppress disability. This survey approach is designed to demonstrate that normalcy’s work of oppression is ubiquitous and not anomalous. I will show how these texts represent normal conceptions of disability, which entails ignoring any perception of disability as a multi-layered and worthy cultural experience. First, I will turn to a personal narrative designed to bring these points to the fore as a way to begin this analysis of the oppressive character of ‘normal’ conceptions of disability.

Getting Nowhere Fast: Maintaining Oppression

In 2006, while my children’s novel was in the later stages of the draft process, I took a private writing course designed for professional writers and taught by one of my colleagues in the book industry. During that course, I met a woman working on a manuscript, a woman who had her own photography business and was also completing a degree in journalism. I was intrigued by her writing, richly informed as it was by her immigrant experience of moving from South America to Canada. I was also impressed by her approach to learning as a lifelong process. Whatever the reasons, we quickly became friends. Soon she began discussing with me the idea of writing a feature article on me and my book, polishing it in her journalism classes, and submitting it to Reader’s Digest. At first, I was happy and excited about the publicity this might garner for my novel, and my friend (who I will call Gwen) even became the official photographer at my book launch.
Problems between us began when Gwen started calling to read me drafts of the article she was writing about me -- with the guidance of her journalism professor and the students in her journalism class. In these drafts, I heard myself described as ‘suffering from Cerebral Palsy’, ‘confined to a wheelchair’ and ‘courageously’ working against the odds to pursue a career. Each time I heard this (and other mortifying statements like it), I would stop Gwen and we would discuss why these portrayals bothered me. I worked hard to reconfigure her incredibly ableist mindset, then coached her as we reworked the article. Three times this happened, and each time I felt let down at the beginning of the conversation, and better by the end when Gwen finally seemed to ‘get it’. The fourth time, however, I lost my patience.

“How come,” I asked, “each time you phone me with a new version it’s more ableist than the one before? We keep editing it, I trust you again, and then we end up back at square one! Why?”

“Because,” she said, sounding rather sheepish, “my journalism prof keeps telling me to stop being influenced by what you say, and that I should ‘get the dirt’. He says you have a disability, so there must be dirt. He says your disabled character isn’t depressed enough, either. And she’s too smart. My prof says she’s not normal enough -- you know, for a disabled kid.” (Anon, personal communication, October, 2007)

On my side of the phone, complete silence followed these remarks as I struggled to digest them. The next time I spoke, it was to call off our collaboration on the article. Gwen and I have not been in touch since.

This narrative represents many of the issues of concern regarding disability and normalcy that demand my attention and animate this chapter. Once more, this narrative brings to my attention that there is an expected, normalized version of disabled person: among other descriptors, unintelligent and depressed seem to fall under the category of ‘normal’ for the ‘abnormal’ disabled person. During my interactions with Gwen, it became clear that I was being penalized for going some distance in debunking that norm in my writing.

The directive from Gwen’s professor that she was to ‘get the dirt’ that must exist on me (it appeared self-evident to this professor that there must be dirt on me, because of my disability) points to the automatic assumption that disability -- and so the bearer
of said disability --- must have a dark, sinister, questionable side. Here the reproduction of normalcy’s oppression is unmistakable. I felt the weight of it both during and long after these interactions.

Consider the following quote:

“In Western dramatic and performance traditions, outward physicality is most often used as shorthand for the character's inner psychological or emotional state. [Whether a symbol for] denial of truth...a beacon of evil...[or]...a mark of shame...disability in the dramatic canon always signifies...[Mitchell and Snyder’s] "narrative prosthesis" (Sandahl, 2005, p. 255).

Just as this is true in the dramatic canon, it is also true in the literary one. Normalcy’s reproduction of oppression was clearly evident in the journalism professor’s assertion that Gwen not be influenced by my desire to change her perceptions of disability and therefore ensure that she would write an anti-ableist (or at least far less ableist) article. Gwen was told to stay away from my ‘bad’ influence, which threatened normalcy’s oppressive stronghold. So writing an article ‘in support’ of my novel was not at all about bringing disability to light in a non-oppressive way. Quite the opposite. It was about maintaining that oppression.

This oppressive characterization of the normal disabled person is easy to witness throughout the book industry. Mitchell and Snyder’s words in their book, Narrative Prosthesis (2000), bring out this point:

...[D]isability entails a kind of immediate prefashioned notoriety--that of the one who overencumbers the visual scene. The one with the “slurred” voice, the thick glasses, the wheelchair, the pale skin, the unsightly protuberance, the birthmark, or the blemish. In order to be disabled, one must narrate one’s disability for others in sweeping strokes or hushed private tones. And this narration must inevitably show how we conquer our disabilities or how they eventually conquer us. The lack of other options refuses us the pursuit of anonymity in ordinary involvements. These were the increasingly personal and political stakes of disability representation (p. xii).

My refusal to write of my character being conquered by her disability made me hugely unpopular to Gwen and her journalism class. There was no room made for me to say anything new about disability; yet again, the assumption was that there wasn’t -- that there couldn’t possibly be -- anything new to say. That I was neither writing of Zoe
as though her disability was the all-consuming ‘elephant in the room’, (i.e., sweeping strokes) or hiding it as the untold story within the story -- at once pointed to in expected ‘tragic’ or ‘overcoming’ ways, and simultaneously masked (hushed tones) was inconceivable. Zoe’s story told matter-of-factly, with disability woven as part of her into the fabric of her life as revealed in the novel, was nowhere near readily accepted, because this threatened normalcy’s ability to encase my book in stigma.

I now turn to Paul Darke’s (1998) article on the normality genre to help me further theorize normalcy’s oppression. He discusses film, and I will be using his hypothesis to inform my discussion of said oppression in literature. To put my theorizing in context, I will illustrate the relevance of Darke’s work through a brief discussion of a few young adult novels.

**The Same Old Story: The Normality Genre and Sylvia McNicoll’s *A Different Kind of Beauty***

*A Different Kind of Beauty* (McNicoll, 2004) is the story of Kyle, who goes blind in his teens due to complications connected to diabetes. It is also the story of Elizabeth, a girl Kyle’s age who goes to his school and is also puppy raising Beauty, the seeing eye dog that Kyle will eventually own.

In this novel, Kyle’s disabilities (blindness and diabetes) are done only as misfortunes to be overcome and managed. He is “the blind dude with the attitude” (McNicoll, 2004, p. 81) who wants nothing more than to fit in, ‘be normal’. Failing that, he wonders openly if he and others wouldn’t be “better off had [he] not been saved” (p. 129) from a diabetic coma. These are considered understandable, normal reactions to the tragedy of disability. It is considered the work of ‘good’ literature to portray the journey toward healthy ‘adjustment’ to disability. In accepted literature, projecting the ‘normal’ conception of disability involves portraying the disabled person going to ‘normal’ school and acting as normal as possible despite the disability. It is this very normalcy that is oppressive, and it is reproduced as the ideal response to disability. The fiction I am referring to is therefore not interested in disability itself, but in indoctrinating young minds into the central ‘truth’ that normalcy is the supreme ideal,
and disability is its opposite and thereby rejected. Nothing illustrates the “normative violence” (Titchkosky, 2007, p. 178) more clearly than the fact that if a character is disabled, wishing for death (the death of disability) is undertaken as a normal response. Consider the following excerpt of Paul Darke’s article, which illustrates the conscious nature of the erasure of disability in film and literature:

Davis (1995), writing about images of Deafness on film and in the canons of English literature...has moved on to the identification of the social, national and political significance of such images to argue that they, in total, are the result of the social construction of normality; a construction that has resulted in the need for the construction of abnormality as a means of social, national and political order...the use of abnormality in cultural imagery...is not haphazard, it is quite coherent; nor is it the by-product of the social construction or illusion of normality. Quite the opposite: abnormality is used in cultural imagery to define the parameters of normality, not vice versa (1998, p. 182-183).

Constructing normative reactions to disability is a way to ‘keep disability in line’. Negative reactions to it serve to maintain hostile perceptions of it as the life that no sensible person would/should want. This means that there is a way for ‘even’ disabled people to be normal: have a ‘normal’ reaction to disability through rejection of it. As Davis suggests, the manufacturing of abnormality creates the space for normality to exist. Normalcy would have no stronghold without abnormality contrasting it.

Several times in A Different Kind of Beauty (McNicoll, 2004), Kyle refers to passing as sighted, a tactic that creates the illusion of normalcy. He expresses this ability to pass as a relief -- rather like someone wanting to ‘strut their stuff’ and discovering they’ve ‘still got it’. It is ironic that in the case of disability (Kyle’s blindness, in this instance) it is considered an accomplishment for the disabled person to ‘put on’ normalcy -- to fake being something (able-bodied) that they are not. This passing brings out the disturbing length society goes to in order to uphold normalcy as ideal -- something always “devoutly to be wished” (Davis, 1995, p. 27). This puts the disabled person in a constant state of admiring, coveting, even lusting after manufactured ‘perfection’ that actually exists for no one on the planet. Note the following excerpt from A Different Kind of Beauty:
But Ryan hadn’t recognized me as the blind guy and that made me feel strangely proud, as though I’d achieved something. Kids wear dark glasses inside all the time. Without the cane, who could know for sure? Maybe this would be OK; maybe I could be myself (p. 43).

Kyle thinks he can ‘be himself’ by passing as non-disabled (without the white cane as a signifier of his blindness), and this is extremely problematic. By being put down in this way, Kyle’s disability is erased, negated, and certainly not understood as a valued, viable part of the self he wants to be in the world. This violent denial and divorce from his own social location is disturbingly something in which he takes clear pride. It doesn’t occur to Kyle that his blindness may make him into a new self, but he can no longer be himself (his new self) without it. By passing, he has indeed ‘achieved something’ -- enabling normalcy to achieve his oppression and serving as a signifier of normalcy as the only good worthy of living up to in society. Of course, the novel, busy as it is upholding normalcy, does not reflect on the fact that this point has been made.

In Darke’s article, we read:

The normality drama follows its own genre conventions: a physically or mentally impaired character is represented to reinforce the illusions of normality: a normality exhibited either in...non-impaired character[s], or by the impaired character’s rejection of their impaired self (1998, p. 184).

The portrayal of disability solely as something to overcome is another facet of normalcy’s oppression. At one point in the novel, Elizabeth, the fellow high school student who trains Beauty, describes Kyle this way: “He sang a solo, too, called ‘Too Many Girls for One Guy.’ He strutted and sang, so sure of himself, I didn’t feel sorry for him at all, no matter what [my boyfriend Scott] said [about Kyle being pitiful]” (McNicoll, 2004, p. 146).

Note that in the above passage, Elizabeth says she ‘didn’t feel sorry for’ Kyle after watching him play his guitar, sing, and strut. These actions are often taken up as ‘what normal guys do’. So, the more normal (non-disabled) Kyle appears, the less credible pity appears as a reaction to him. Without these normalized actions, though, the implication is that pity for Kyle would return and be understandable. In other words, these normalized actions are enabling Kyle to pass, and enabling those watching him
to forget (erase) his disability. Someone who is ‘really’ disabled, the logic goes, would not be doing all of those ‘normal’ things. They certainly would not be singing ‘Too Many Girls for One Guy.’ That song -- indicative as it is of being sexual desirable -- is not associated with the unwanted status of disability. Consider the following:

You could tell she wasn’t happy. Every boyfriend’s a potential husband, Maddie explained. She wouldn’t want a drug addict for her daughter’s future mate. And I could tell by looking at her mom’s face, as I explained about my diabetes, that she wouldn’t want someone suffering from an incurable disease as a potential father to her grandchild, either. What would her eyebrows have done if she’d seen me with a white cane? (McNicoll, 2004, p. 40)

Once more, this passage makes the connection not only between disability as an unwanted affliction which one suffers alone, but also to the taken-for-granted conviction that no one would want to run the unthinkable risk of spreading disability to the next generation. Eugenic impulses are normalized as expected reactions. Nowhere is there any understanding of the disabled life as a good, viable life experience. Kyle therefore understands himself in this novel as having only an unmarried, childless future -- a future conceived of as a natural one for the ‘unnatural’ disabled person. In short, Kyle’s reaction to his blindness is done as only a tragedy that stole his future. But it is made reasonable and sensible that blindness/disability would be this. According to normalcy (the widely accepted standard) this is what disability does: steals all good things from a life. That disability itself is a good thing is a concept firmly relegated to the margins, where its threat to normalcy’s supremacy can be ignored and denied by society.

Throughout, Kyle is described as having a bad attitude. Kyle’s ‘bad attitude’ does much improve with the acquisition of his guide dog, Beauty, but even this is done in such a way that says only a ‘normal’ guide dog can make abnormal tragedies like blindness and diabetes bearable. Again, this links to the normality genre’s representation of disability as ‘disorder and chaos’ so that stability can be achieved by “the denouement of the narrative thrust” (Darke, 1998, p. 184). In this way, Beauty ‘normalizes’ Kyle.
It’s Complicated: The Normality Genre and Sylvia McNicoll’s *Beauty Returns*

My frustration with *Beauty Returns* (2006) (which is the sequel to *A Different Kind of Beauty* (2004)) is complex, and in some ways even more pronounced than the annoyance I felt toward McNicoll’s first novel in the series. That is because, at a few memorable points, the novel appears almost to perceive blindness from a disability studies perspective, and at these points the story was a joy to read. This joy, however, was very short lived, because these flashes of understanding blindness in a new way do not last throughout the novel. In fact, McNicoll contradicts herself repeatedly. Allow me to illustrate: Early in *Beauty Returns*, we read, from Kyle’s perspective:

Freedom.  I inhale deeply.  Even though it’s hot today, I can smell the fall coming.  It’s a spicy, almost smoky scent that hangs over the warmth.  In another few weeks, the air will bite and leaves will change colours... To me, red and orange have changed into tastes, like apples and tangerines...Since...my blindness...the rest of my senses seem hungrier.  I love to listen to beautiful sounds: the water tumbling over the rocks at Little Stone Bridge in the park, my knife scraping across the toast as I butter it, and the coffeemaker heaving and sighing as it brews.  And Elizabeth’s voice.

I also love the feel of her face, her skin, warm and smooth, and her lips.  When we kiss, it just opens one long ache that throbs right through me, and my skin wants more.  Like an amoeba that eats through its pores, I want to feel Elizabeth close to me all over (pp. 19-20, p. 76).

The above passage is an encouraging instance of blindness being shown giving Kyle another avenue of perception; enjoying the Fall through scents and tastes, and enjoying ‘beautiful sounds.’ He says that red and orange have ‘changed’ into tastes for him. His blindness is refreshingly written here as offering a shift in how he experiences the world. Blindness is not the thief that stole his sight; it is the gateway to a new difference for Kyle. For me, this is a welcome departure from the tragedy that blindness (disability) is so often assumed and made to be. Kyle’s beautiful description of his relationship with his girlfriend Elizabeth is a lovely example of showing his love through touch. This is a far cry from disability as unthinkable, untouchable, unknowable, and undesirable. Kyle finds and sustains a happy romantic relationship, instead of being represented as single and lonely because of his disability, which would
have brought his blindness forth as a purely individual, tragic matter. Kyle is thus represented as not only desiring but also desirable. In a section written from his girlfriend’s point of view, we read: “I feel the blood rush to my face because I want it to be Kyle [on the phone] so badly” (p.46). Again, this portrayal is a relief, as compared to the perception of disability as completely asexual.

What can be regarded as most representative of a disability studies-oriented perspective, in this novel is:

“I’m going to sit near the swing,” I tell Shawna, and I put my headset on to listen to more of that awful book, Blindness, as I wait.

In the book, more and more people are losing their sight, and all are sent to an institution because whatever they have is contagious. The blindness spreads to everyone anyway, and society breaks down. That makes it easy to compare with Lord of the Flies. It’s as though blindness represents death to mankind. Let’s face it, that’s what sighted people think anyway. One of the soldiers in the book shoots himself when he catches the disease. They’d rather be dead than blind. Isn’t that the way I once thought, too?

I smile because something is different now. I’m close to being happy. I feel like I absorb life now through my skin, inhale it through my nose. Whatever shape and form I can experience life in, I certainly don’t want to give any of it up (McNicoll, 2006, p. 64-5).

I was thrilled when I read these paragraphs, because they confront the “normative violence” (Titchkosky, 2007, p. 178) of the doing of disability as a sort of death -- a weakened, compromised, inferior state of being inevitably leading to and worthy of elimination. It also deals with the perception of disability as an unimagined and unimaginable life, according to the normative and oppressive ways in which disability is understood in the world. Most exciting for me, in terms of my literary commitment to a disability studies perspective, is the fact that this passage confronts the oppressive ways in which disability is done in literature -- through it’s critique of another (prize-winning) book. It criticizes the oppressive portrayal of blindness as an infectious disease that causes chaos as it spreads. The passage also offers a life-affirming portrayal of blindness --(‘I feel like I absorb life now through my skin, inhale it through
my nose. Whatever shape and form I can experience life in, I certainly don’t want to give any of it up.’

**What Went Wrong...**

So, the question must be addressed here. Considering these passages that seem determined to portray disability in a new way, where are the aforementioned contradictions that essentially undo all of McNicoll’s progressive work?

The problems begin with Kyle’s ‘positive’ determination to prove his competency at school, “like everyone else” (p. 34, 50). They continue with his numerous references to the fact that his blindness “sucks” (p. 41), with his guilt over not giving his guide dog “a regular life” (p. 99), with his agreement to beg for beer on behalf of his underage friend because “[y]ou don’t want to ask a blind kid for ID, after all” (p. 83). He does make reference to his humiliation, but never stops giving in to the requests to beg for more beer.

Then there is the final blow: Kyle dies at the end of the novel, and he dies an ‘inspirational hero’, saving a little boy’s life. So in this move, disability becomes a case of and for heroics -- not a life experience that is between us in society every day. I am puzzled and sad by the fact that McNicoll went from heavily critiquing the oppressive link made between disability and death to re-making it herself. The pervasiveness of the oppressive norm remains undisturbed because, for all the encouraging disability portrayals, the norm is upheld. The perceived threat to the normal conception of disability as signifier of doom and of inferior, pitiable lives is first established and then completely wrecked. Kyle can threaten nothing if he is cleared away. With Kyle off the scene, all the subversive work of his against-the-norm portrayal is done as useless. The norm is ‘safe’ again -- although what can be safe about such oppression is confounding. Notice Kyle’s death scene, as follows:

What is happening to me? The white bursts behind my eyelids. I feel myself lifting, lifting.[…]

Where’s Beauty? No dog, anywhere, but as I look around I realize I can see. I don’t need a dog guide. This has to be a dream; but I can smell the grass and the
fresh air, and I never smell things in my dreams. A girl in her early twenties smiles at me and holds out her hands for the baby [in my arms].

Across her nose is a sprinkle of freckles. She has the same eyes as the baby, and long, curly, autumn-coloured hair. In the distance, I hear a voice calling my name, a voice I love, like chimes in the wind. But Liz is here. Why would I go back when everything I ever wanted is here? I kiss this Liz—older, more perfect—and we walk away together into our future. (p. 184-5)

The restoration of Kyle’s sight after death keeps readers from having to face and grapple with the injustice and normative oppression wrapped up in the choice to kill him off. The Heaven he describes is one where disability is erased -- his sight is restored, and his guide dog is absent. He says he doesn’t need a guide dog, but the fact that he is suddenly content without the animal he had clearly adored on Earth is a huge problem. This is another dimension of his blindness being erased and rejected. Kyle’s paradise -- his perfect world -- contains no disability at all. Thus, normative oppression returns, and this proves that Beauty was used as a normalizing device. Once Kyle is ‘normal’, the dog disappears. Beauty is not at all present, not even without her harness! And Kyle’s intentions to take the world in, while living in his blindness are thwarted. All his dreams -- of becoming a lawyer, of being with Elizabeth and becoming a father (on Earth) are done as futile. The message is clear: disabled people can dream, but in the end, disability -- and disabled people -- are destined to die, preferably quickly and quietly. This portrayal of disability is oppressive business as usual for normalcy. This ending is all the more devastating because, up to this point, the novel had given hope that, within its pages, disability could be read otherwise than it is ‘normally’ read.

These oppressive themes are continued at Kyle’s funeral, as Elizabeth reacts to the sermon and her mother’s explanation of Kyle’s cause of death below:

The minister talks about how Kyle’s quick thinking saved Donald from fatal hypothermia. My mother explained to me that Kyle had a heart defect; undetected despite all the medical attention he received for diabetes. The stress and exertion of the rescue brought on the heart attack, but it might have happened at any other time, too--just bad luck.

Bad luck that he had diabetes, bad luck that he went blind from it, bad luck that in saving a boy from drowning, his own heart gave out--but was that bad luck? For
sure, Kyle would be happier knowing he died while saving Donald rather than randomly dying while, say, Rollerblading in the park or surfing in Waikiki. How many people save a life, even if they live to be a hundred? (McNicoll, 2006, p. 191)

Yet again, disability is taken up as sinister misfortune. Kyle in turn overcomes his disabilities by becoming an inspirational hero. Thus disability returns to archetype status. Kyle conveniently fits into an oppressively normal role for disabled people: the inspirational overcomer. Normalcy’s oppression survives intact, and any idea readers may have been getting about its hold finally being shaken disappears -- along with Kyle himself.

In The Difference that Disability Makes (2002), Rod Michalko has this to say about disability’s exclusion, i.e., its disappearance from legitimate ways to be in the world, or ways to be in the world worthy of being part of classifications of ‘the good life’:

...I focus on disability as a political act that is suffered by both disabled people and non-disabled ones, albeit differently. Suffering here does not refer to the conventional sense of “suffering a disability” but refers instead to the suffering of the multitude of interpretations of disability, the political acts that culturally organize and define disability--the suffering of our society’s choices made in regard to the meaning of disability. The animating question I use to understand disability in this way is that raised by Irving Zola (1982, 244): “Why [has] a society been created and perpetuated which has excluded so many of its members?”… He did not expect an answer. Instead, he meant to issue a challenge to his society and to its non-disabled members as well as to those of us who are disabled. It is relatively easy, suggests Zola, to ask questions about matters of accessibility and their costs but not so easy to ask why these questions are necessary in the first place (p. 15).

The suffering of interpretations of disability is made very clear through what is done to disability through literature, such as the novels discussed throughout this chapter. Framing disability as ugly, dark, weak, inferior, unfortunate, pitiful, tragic, sinister, etc., both justifies and reinforces the (mis)treatment and marginalization of disability in the lived experience of disabled people. The good news is that choosing disability (Michalko, 2002) is also a political act and a political choice. Delving into Zola’s question is more than an analysis. It is an act of resistance that works to get at what grounds normalcy’s oppression. Captivating as well, is the important notion that
both the disabled and non-disabled communities suffer from attempts to erase, marginalize and oppress disability through the enforcement of normalcy. The richness of the disability experience, as much more than the oppressive ways it is understood in society -- as a legitimate form of ‘ethnicity’ and identity (Garland-Thomson, 1997) in our social space, is crucial to rethinking normalcy’s (perceived) supremacy.

When internalized as a social phenomenon belonging to everyone, disability becomes cultural and communal, not individual, medicalized and problematic. I turn again to Michalko:

...there is the struggle of creating a social identity “out of blindness” as one who is valuable and worthwhile. These struggles are political, not individual. They do not, in essence, represent the individual suffering of a condition. Instead, they represent the suffering of a collective whose taken-for-granted dichotomy of equality and difference is being exposed as artifice by the presence of the difference this dichotomy hides. At times, the “world of the normal” privileges the individual as the source of both social stability and change and, at other times, it privileges society. (Titchkosky 1998). This world privileges difference sometimes and equality at other times, but never both at the same time. Difference, as expressed in social categories such disability, gender, race, is hidden in the world of the normal through constructing the equality/difference dichotomy and thus reducing the social difference to individual difference. But when individuals “see” their difference as rooted in the social processes of oppression and discrimination, the world of the normal struggles desperately to maintain the view that such difference falls neatly to one or the other side of this preestablished dichotomy (2002, pp. 38-39).

Normalcy as an artificial construct demands that society works to box difference into ‘neat’ comfortable dichotomies. The good news is this: normalcy’s oppressive and frantic work is necessary because disability studies, and disability advocacy and activism are consistently working to uproot normalcy as the ‘true’ standard. Since normalcy and its supremacy is entirely false (normalcy is forever stuffing and forcing disability into oppressive confines where it does not belong), and theorizing disability and normalcy’s oppression is part of the act of getting disability out again (freeing it), the resulting tug-of-war thankfully keeps normalcy on shaky ground. But normalcy has been so entrenched, and is fighting so hard to make its supremacy seem natural, that
this uprooting is long, hard, uphill work. Literature that holds disability-as-usual as true and right and hides the work of upholding normalcy, is one of the weapons working insidiously on the side of oppression, to ensure it is further internalized. In Narrative Prosthesis (Mitchell & Snyder, 2000), I read: “The early scholarship also demonstrated literature’s complicity in the historical devaluation of [disabled people]…[Many critics] see the metaphoric opportunism of literature as a form of public slander” (pp. 17-8). At the very least, such ‘slander’ should not go untheorized, as we will witness in the analysis below. I turn now to an analysis of disability portrayal in another novel.

‘Nothing But Trouble’ Meets ‘Don’t You Know Your Manners Yet?’ Meets ‘He Thinks You Can’t Dance’: Disability Portrayal in Allan Stratton’s Chanda’s Wars

Chanda’s Wars (2009) is a young adult novel about child soldiers. While disability is not the focal point of its subject matter, there is a secondary character in the novel, Auntie Lizbet, who has a club foot. In the following passages, Auntie Lizbet’s difference is done as something dark to fear, something sinister, which makes her character evil, and murderous, and other-than-human yet, staring at her is regarded as a great faux pas.

“Then there’s Auntie Lizbet and her funny shoe. Her left foot is really a hoof.”

“I remember the hoof,” Soly says solemnly.

“And remember her tail, swishing under her dress? And the sharp little horns under her bonnet? Auntie Lizbet’s a witch. If you’re not careful, she’ll come in the middle of the night and eat you.”

“She will not.”

“Will too. And then she’ll throw up.” (p. 78)

Auntie Lizbet is written above entirely in animalistic terms. She is understood as ‘bad’, and her club foot (referred to as a ‘hoof’) is tied up with her assumed dark intentions. She is a witch who eats (and vomits) children -- a witch with a hoof, horns and a tail. So she and her embodied difference are to be avoided. She is written up as perilous. Also, her club foot, which is truly a part of her body, is brought into the space
between the two children along with manufactured, fear-inducing embodiments (horns, sharp teeth) which have been fabricated to reinforce the notion that Auntie Lizbet’s difference means only trouble. The idea that she does her fearful deeds at night, (‘She’ll come in the middle of the night and eat you’,) extends the dread of her ‘crimes’. She and her embodiments are entirely folklorized. They become part of a mythology that ‘does’ difference as troubling, even horrifying. This is another ‘normal’ way to perceive of difference as a great danger, signifying great, impending doom. Paul Darke puts it this way:

[T]he role...[stereotypical] images have had in the perpetuation of the disablement of impaired people...[is] that they tap into...a ‘normal’ psychological fear of bodily decay and death.

...[C]ultural images rationalize the social construction of marginalized groups as Other, liminal, or abject; they are not essentialist psychological acts but attempts to rationalize...those social constructions that seem ‘true’ but which are mere construction (1998, p. 182, 191).

This language of the text of the novel in question represents Africa as though it has a great fear of embodied difference. Written negatively in this dialogue between children, it perpetuates negative perceptions of difference in young minds.

The passage below also brings the concept of ‘manners’ into the discussion. In the passage below, Iris’ vocal reaction to Auntie Lizbet’s difference creates quite a shock. The idea of pointing out disability and difference -- instead of ignoring or shunning it, for example -- is considered rude in many cultures. This is not coincidental, especially since calling attention to disability and bodily difference interrupts attempts to pass.

Consider the following passage from *Chanda’s Wars* (2009):

“I’ll bring out the biscuits,” Auntie Lizbet says. “Just the thing to put that marmalade to the test.” She hobbles to get them. Iris follows, staring in bug-eyed wonder at her foot.

“Iris! No!” I cry.

Auntie Lizbet whirls around, catching Iris in the act. “What are you gawking at?”

“Your hoof,” says Iris.
The world stops breathing.

“My . . . what?” Auntie glares.

“Your hoof!” Iris exclaims again. It’s so . . . so . . . clumpy.”

Auntie Lizbet grips her cane. “Who taught you your manners, girl?”

“Nobody,” Iris says brightly.

“Nobody?” Auntie Lizbet pounds her cane. “Nobody???” She suddenly bursts out laughing. “Can you beat the nerve of the little thing!” She peers at Iris over her spectacles. “So, nobody taught you manners?”

“No, Auntie,” Iris says, innocent as you please. “Not a blessed soul.”

Auntie puts on a stern look. “Well, we’ll have to see about that, won’t we?”

“Oh yes,” Iris says.

Auntie beams. “What a little sweetness.”

Iris bats her eyes at me. I could smack her. (pp. 88-9)

In this passage, staring is entirely written as a sign of bad manners, to be avoided. There is no understanding of staring as a social interaction in which the “starer” and the “staree” (Garland-Thomson, 2009, p.6), can both connect, offering new insights and exploration. It is not taken up as a natural human impulse, as Garland-Thomson frames it in her academic ‘look’ at the phenomenon in Staring: How We Look. In the above passage, as in society, staring is written up as ‘bad manners’. And even as Auntie Lizbet’s loving reaction to Iris disrupts the portrayal of her, and her ‘hoof’ as evil, her commitment to teach Iris manners underscores the idea that if Iris had any, she would know that staring as a metaphor for any desire to draw attention to bodily difference, is ‘bad’. Chanda’s horror at Iris’ curiosity also reinforces this.

Auntie Lizbet’s portrayal is based on what is termed physiognomy, wherein the following is true.

For cultures that operated upon models of bodily interpretation prior to the development of internal imaging techniques, the corporeal surface was freighted with significance. Physiognomy became a paradigm of access to the ephemeral and intangible workings of the interior body. Speculative qualities such as moral integrity, honesty, trustworthiness, criminality, fortitude, cynicism, sanity, and so forth, suddenly became available for scrutiny by virtue of the “irregularities” of the body that enveloped them. For the physiognomist, the body allowed meaning to
be inferred from the outside in; such a speculative practice resulted in the ability to anticipate intangible qualities of one’s personhood without having to await the “proof” of actions or the intimacy of a relationship developing over time. By “reasoning from the exterior to the interior,” the trained physiognomist extracted the meaning of the soul without the permission or the participation of the interpreted (Mitchell & Snyder, 2000, p. 58-9).

What is most disturbing about the above is that disability is still most often done this way in literature and film. The disabled character has the bad attitude, the bad outcomes, the bad intentions or the tragic history and future. Observe what happens to Auntie Lizbet in *Chanda’s Wars* (Stratton, 2009), Kyle in *A Different Kind of Beauty* (McNicoll, 2004) and in *Beauty Returns* (McNicoll, 2006), Carey in *Wings of a Bee* (Roorda, 2007), and the conjoined twins in *The Girls* (Lansens, 2005). Events are sinister and stereotypical, bodies are stigmatized, endings are tragic. Note also that these titles are recent novels. Physiognomy is not in the past, and is not only part of ‘foreign’ cultures. Physiognomy is part of disability portrayal now and today, and is used in the defacing of real disabled lives through the defacing of fictional ones.

In the passage from *Chanda’s Wars* (Stratton, 2009) below, the bond that grows between Iris and Auntie Lizbet is somewhat encouraging, from a disability studies perspective. Iris, after all, clearly comes to understand and welcome her auntie’s club foot as part of her. It rests literally between them in the comfortable scene below. Iris talks to her aunt while “doodling” on it -- demonstrating her ease with it. The good news ends there, however:

All the while, Iris sits cross-legged on the ground beside Auntie Lizbet. During a lull, she rests her head against Auntie’s knee. “Auntie,” she asks into the silence, “do you ever miss not being a mama?”

“Oh, sometimes, I guess,” Auntie says simply, staring at the coals of the firepit. “But if I was a mama, all my love would have to go to my children, wouldn’t it?”

Iris thinks a bit. “I guess it would.”

“Then I wouldn’t have any left over, would I?”

“No, I guess you wouldn’t.”

“So maybe this is best,” Auntie says, stroking Iris’s hair. “This way I have lots of love, all stored up to give to little girls who don’t have mamas.”
A pause.

“Little girls like me?”

“Little girls like you.”

Iris smiles. She doodles a finger on Auntie’s club foot. “When I grow up, Auntie, I want to be just like you.”

“Hush now, hush. Don’t wish for that.” (pp. 120-1)

Auntie Lizbet is portrayed as unmarried, clearly because of her club foot. Once more, disability is shown as an unfortunate tragedy that makes a good and ‘normal’ life impossible. The traditional life goal of an African village woman is to reach for marriage and a family, yet Lizbet’s club foot effectively excludes her from this goal -- in her own mind as well as everyone else’s. Iris says she wants to be just like her aunt, which is encouraging for disability -- since she clearly means club foot and all -- but Lizbet’s response (“Hush now, hush. Don’t wish for that”) collapses that entirely. She wants to silence such a desire, as if having such a wish is unthinkable, unspeakable -- as if a life embodying difference is not a life worth wishing for, or having, at all. Lizbet has internalized this, and with her, the readers who take in her words. The message here is unmistakable: disability and motherhood do not mix. Thus, we can note yet another link to the normality genre:

The point...[of this genre] is about the relative worth of being, or striving to be, normal rather than abnormal; the logical corollary is that the audience leave satisfied as their own attitudes and conformist lives are validated at the expense of that group who are as equally marginalized in society as they are in film [and literature] (Barnes,1991b; 1992a)

...[T]he normality genre reassures the industry and audience that impairment is interpreted both by themselves and society at large in the correct way: the medical way (Darke, p. 188).

Like a ‘good’ disabled character, Lizbet rejects Iris’ perception of her disabled life as a desired one. Granted, life in rural Africa with a club foot would be difficult -- made so by the fact that Lizbet had to suffer the responses of others to her difference -- but the ‘fact’ of her difficult life (the logic says ‘of course Lizbet would think this way after all she has been through because of her foot’) only reinforces fear of difference. As well, Lizbet’s problems are understood to originate in her body. If she were ‘normal’, she
would be married and surrounded by her own children. The problem of her singleness and childlessness is understood to be the fault of ‘the problem’ of her body. No mention at all is made of the real problem here: the attitudes around her that understand her club foot as a misfortune that justifies her exclusion.

The fallout from this continues, and Lizbet continues to represent disability and difference as usual -- once more, that is the real tragedy here. In the novel, Lizbet dies at the hands of cruel, violent rebels who capture her village, commit terrifying mass murder, and force the children to be child soldiers. See below:

One of the rebels poked Auntie Lizbet with a stick: “This one can’t keep up, with that foot of hers.”

Granny says how Iris suddenly spoke up, too frightened to know better: “I can take Auntie’s load,” she said. “I’ll carry her sack on top of my own.”

Mandiki laughed. He had Auntie untied, made her stand apart from the others, and told her to dance. Auntie tried. The rebels pelted her with stones. She fell. Mandiki ordered the herd boys to kick her until she was dead. Iris screamed and screamed. Mandiki said if Iris didn’t stop, she’d be killed too. “Hush my sweet,” Auntie Lizbet called to her, as the herd boys swarmed. “Don’t cry. Be happy for me. Rejoice. Tonight, I shall be with the ancestors.”

Granny’s eyes fill with light. “It was then, my Lizbet began to sing,” she says. “She sang a harvest song, a song of thanksgiving. She sang with joy to the very end. Not a single cry of pain. Just joy. Joy, to keep the little one quiet. Joy, to keep her safe. Oh, Lizbet, my Lizbet, she died a saint . . . .” (Stratton, pp. 219-20).

Many people die in this novel, the vast majority of whom are not disabled. But the fact does remain that in this scene, it is disability and difference (embodied in Lizbet) that die a violent death. Disability as usual has again shown up. First, although it has been well proven by now in the novel that Lizbet is not a witch -- which was the children’s original assumption -- she is stoned to death, and dies a death often reserved for evil enemies. Lizbet dies this death because she “won’t be able to keep up” and can’t dance in the ‘normal’ way, conforming to widely accepted conceptions of ableness and beauty. Note that Lizbet is stoned to death, in part, because she cannot perform a ‘beautiful’ dance.
As is often the case in the portrayal of disability, Lizbet is at once tragic and courageous. She sings in the face of cruelty inflicted on her, in order to save a child. She is a heroine who ‘dies a saint’, thus conforming to another stereotype about disability and difference. Lizbet is a tragic, inspirational, heroic overcomer. Lizbet dies (the usual ending for disability), and stereotypes live on.

From a strictly ableist perspective, it might be argued that it ‘makes sense’ for Auntie Lizbet to die, because it would be extremely unlikely for her – impaired as she is – to manage escape. First of all, the very fact that such reasoning ‘makes sense’ is proof of the pervasiveness of ‘normal’ conceptions of disability as nothing more than a hindrance of freedom. Secondly, anyone’s stealthy escape from imprisonment by a dictator is ‘unlikely’, yet Chanda and one friend of hers – both of them teenagers – manage to free Chanda’s two younger siblings in a daring, cunning, brilliant escape, deemed “unforgettable” (Stratton, 2008, back cover). This, too, would seem unlikely, yet the escape is successful and Chanda’s siblings (both of them able-bodied) live. Auntie Lizbet’s escape, by contrast, remains unimagined.

As a way to further explore the ways in which cultural differences intersect and/or are communicated through depictions of disability in children’s literature, I turn now to a discussion of the latest novel by Rukhsana Khan.

**Who’s (Not) the Fairest of Them All?: Portraying Difference in Rukhsana Kahn’s *Wanting Mor***

In *Wanting Mor* (Khan, 2010), Jameela is a young teen from modern-day Afghanistan. Abandoned by her father after her loving mother’s death and the rejection of her stepfamily, she lives in an orphanage. Jameela’s name means ‘beautiful’, but she has never felt beautiful because of her cleft lip, which she is constantly hiding with her ‘porani’, or Muslim head covering. Her shame is reinforced by the reactions of people who know or find out about her cleft lip -- reactions like “no wonder you hide yourself” (p. 56), or [your mother’s choice to give you a name meaning beautiful] “must have been a joke” (p. 96).
Normalcy’s oppression is also evident in the ‘solution’ Khan offers to Jameela’s insecurities about her looks: the cleft lip is ‘fixed’ when a surgery is offered to ‘repair’ it, and Jameela accepts the offer, saying she “never wanted anything more” (Khan, 2010, p. 111), and musing to herself that after the surgery her face will be “perfect” (p. 112). Also interesting to note, from a disability studies perspective, is the fact that after the surgery, Jameela becomes proud of her beauty, stopping to admire herself often, and choosing to follow less strict rules about wearing her head covering. Infuriatingly, when at the end of the novel, Jameela’s father meets her again, he remarks that now that she is “whole” (p. 180), she will be able to marry well. It is understood that her cleft lip, had it not been erased, would have excluded her from marriage. This is taken for granted as true, as so commonly happens in widespread understandings of disability and difference.

That this completely violent normative assumption goes unquestioned in both the book and the wider world shows the pervasiveness of normalcy’s oppression. Wanting Mor (Khan, 2010) is a book about culture (one girl’s experience of life in Afghani culture), yet the idea of disability as a cultural experience -- one Jameela might choose to stay in -- is completely ignored, unexamined, and framed as inconceivable. Recently published, this novel brings out no new understandings of difference. These biases do not belong to Afghani culture alone. Given the power of colonialism and war, it could be fair to say that many of the oppressive understandings of disability that are clearly observable in ‘foreign’ cultures are actually heavily informed by Western influence. In fact, we don’t know if, before the spread and dominance of said influence, there were not other less or non-oppressive ways to know of disability in cultures around the world.

Here, I echo Rosemarie Garland-Thomson’s powerful words: “I want to move disability from the realm of medicine into that of political minorities, to recast it from a form of pathology to a form of ethnicity” (1997, p. 6). This, too, is my desire, and in a Western/English book industry consumed with upholding normative (mis)conceptions of disability and difference, Garland-Thomson’s words ring true:
Such culturally generated and perpetuated standards as "beauty," "independence," "fitness," "competence," and "normalcy" exclude and disable many human bodies while validating and affirming others.

... Corporeal departures from dominant expectations never go uninterpreted or unpunished, and conformities are almost always rewarded.

...Cultural dichotomies do their evaluative work: this body is inferior and that one is superior; this one is beautiful or perfect and that one is grotesque or ugly. In this economy of visual difference, those bodies deemed inferior become spectacles of otherness while the unmarked are sheltered in the neutral space of normalcy (pp. 7-8).

I’ve observed the reality of his statement repeatedly, as novels like Sylvia McNicoll’s, for instance, receive multiple awards and nominations -- and enjoy correspondingly impressive sales, while others determined to write disability differently are overlooked. (There will be more on this later.) Bodies taken up as superior or beautiful are still favored -- even in an industry that claims to be determined not to shy away from ‘real issues’ for young people. The industry’s determination to resist disability written in non-oppressive ways only proves that disability is not considered, by said industry, to be of importance -- even as disability as usual (in all its oppressive ‘glory’) saturates the industry. The dominant expectation is that disability as subject matter is either to be done as usual or avoided. Daring to depart from ‘dominant expectations’ is certainly frowned upon. Threatening normalcy’s hold is unpopular business, especially in fiction -- a powerful medium that “shapes our perceptions of the world, especially in situations about which [normates] have little direct knowledge” (Garland-Thomson, 1997, p.10).

Repeatedly in the aftermath of publishing my own children’s novel, I witnessed the trajectory of that novel’s path taking on ‘a life of its own.’ I expected this. I was even warned that it would happen, that it should happen -- that once I released my creativity into the world, I would be amazed, as it would journey in directions I never would have predicted. This would be true, colleagues told me, in good ways and bad. I took this in; I even trusted and believed they were right. What shocked me was how quickly my book was steered onto normalcy’s path -- interpreted in ways I didn’t intend. Some of
these ways have been discussed, in the previous chapter and in this one. Some -- like my being congratulated for writing a chapter where Zoe argues with her brother 'like a normal girl' -- have not fully been theorized yet. I was incredulous at how quickly Zoe was made oppressively 'normal'.

So often, it took (and still takes) my own intervention to disclose that what I was intending was not to normalize Zoe, but to disrupt what people take to be accurate about my character and about disability (for example, that Zoe would be too angelic and heroic to have a disagreement with her brother). I wanted to disrupt stereotypes like these, to create in my representation of disability some of the multi-layered complexity that is true to the life of disability. I wanted to narrow “the gap between representation and life” (Garland-Thomson, 1997, p. 12). Though I’ve faced resistance in this regard, I do believe I’ve moved some distance in a productive direction. After all, with Garland-Thomson, I need to ask myself:

What would happen to the pure pity generated for Tiny Tim if he were portrayed as sometimes naughty, like a "normal" child? Thus the rhetorical function of the highly charged trait fixes relations between disabled figures and their readers. If disabled characters acted, as real people with disabilities often do, to counter their stigmatized status, the rhetorical potency of the stigma would be mitigated or lost (1997, p. 12).

I must remember as well that we are all a product of the cultural understandings (both those that are liberating and those that are stereotypical) that we come from and ingest. We must make and re-make ourselves in this understanding, and learn to know this constant re-making as a necessary political act. So, simultaneously as Tiny Tim makes me cringe from a disability studies perspective, I am thankful that the world I come from has prepared me to theorize disability portrayals in fiction. Mitchell and Snyder (2000), in *Narrative Prosthesis*, quoting Sheri Thurber, put it this way: “The disabled have a bad literary press.” Even so, the literary archive would at least serve as a repository for documenting demeaning attitudes toward [disabled people]” (p. 18).

Consider the following words from Paul Darke:

We do not consume or interpret cultural artefacts...in a vacuum as individual subjects but as social and cultural beings with many shared views which we bring
with us as our social baggage; a baggage which not only affects our readings but affects our cultural sense of self, and the place of the self, in any given society. Thus, for a largely ‘normal’ audience...an able-bodied audience’s cultural and social baggage will be almost exclusively rooted in the socially hegemonic interpretation of impairment as a medical and individual ‘problem’ to be either overcome or eradicated (Oliver, 1991; 1996), along with a belief in normality.

...The cultural knowledge an audience, primarily in Western culture, brings [with it]...defines both the ideological intent -- and as such, any possible interpretation - - of the genre and the way in which it is constructed (to the extent that it would be illogical and irrational to expect it to be any other way) (1998, p. 190-191).

In *Wanting Mor* (2010), Khan’s cure as solution fits right into this cultural baggage. The concept that disability and corporeal difference equals brokenness, ugliness, shame, and a general lack of desirability is a common way that bodies inhabiting the margins outside the ‘norm’ are done in society. *Wanting Mor* reinforces this. This reinforcement is all the more interesting considering the repeated hegemonic appearance of disability as always already nothing more than limit and lack. As mentioned above, this appearance could have much to do with the invasion of Western conceptions of the body and the human around the globe.

While Khan makes it very clear that those singling out Jameela’s cleft lip for comments ranging from insensitive to cruel are doing ‘wrong’, ‘bad’, harsh and politically incorrect things, and while Jameela is portrayed as a wonderful person, shaped by adversity and strong faith in God, these are common, ‘normal’ portrayals of disability and difference: the ‘inspiring’ person who overcomes bodily difference to become strong, righteous and beautiful on the inside because she can’t be beautiful on the outside. The exclusion of the ‘abnormal’ body from accepted conceptions of beauty is disability as usual. There is no hint in the novel that Jameela is outwardly beautiful with her cleft lip, before (or without) the surgery. She is advised to avoid the surgery because she shouldn’t trust foreign soldiers (it is an American soldier who offers to ‘fix’ Jameela), but not because she is beautiful as she is. No one in the story tells her that before the ‘repair’, but after, very often she hears comments like “you look so nice now!” (emphasis mine) (p. 126). Beauty is only associated with Jameela once her difference is erased.
The way Jameela is treated by the soldier observing her cleft lip is impossible to ignore. The soldier, who is deciding whether she is a candidate for the surgery, is described this way:

This time the man actually touches me. He’s rather ugly, but not because there is anything wrong with him [...] He holds my chin and moves my head up to see my lip, then he pushes his grubby fingers against my lip.

“Open your mouth,” says Khalaa Ghul [in my language].

So I do [...] He says something over his shoulder to Khalaa Ghul, and she looks pleased. They talk back and forth in that foreign language...It’s so strange the way they can say things to each other that mean nothing to me.

I wish I could speak all the languages [...] At the end of [watching] their conversation, I still feel completely muddled [until] Khalaa Ghul rushes over to me...”[The army surgeon] says it’s just cleft, a small problem, easy to fix.”

My lip can be fixed? (Khan, 2010, pp. 110-11)

There are many points to unpack regarding the above passage. Most striking is Jameela’s total lack of agency. The surgeon manipulates her head without explaining anything to her, and she does what she is told, like a ‘good girl’, agreeable to the erasure of her difference. Also striking is the fact that so little (almost nothing) of what the surgeon says is translated for Jameela to understand. She is excluded from the decision, and only brought back into understanding in time to be ‘grateful’ for what is framed as most important: the surgery that will ‘fix’ her and bring her fully to the ‘normal’ world.

An important point must be made here, in the aftermath of the critical analysis of all of these works. It is not my intention to single out any of the books discussed critically in this thesis as ‘bad’ books. In fact, in many ways, the majority of the novels I bring forward in these pages are impressive, in literary terms. So instead of throwing these literary works and their creators ‘under the bus’, what I want to show is how thoroughly normalcy’s supremacy has been internalized by many well-meaning authors, and by the book industry at large. This way, the importance of doing disability differently will be made exceedingly clear.
Conclusion: Where do we go from here? Social Realism Meets Cultural Studies...Or, Wherein Lies the Possibility of Change?

In March of 2010, I was asked to give a keynote address to the Elementary Teachers’ Federation of Toronto in honour of the International Day for the Elimination of Racial Discrimination. Choosing me as keynote speaker was not a unanimous decision, and not without controversy. The line of ‘reasoning’ behind the descent can be summarized by the following question: What could a disabled woman specializing in disability studies possibly have to say to the anti-racism work that needs to be done? I was not surprised by this debate. It is raging in the book industry as well.

Dialogue with cultural studies is necessary; all kinds of parallels exist to be drawn between the two disciplines. Note, for instance, the following words from Rinaldo Walcott:

By and large, in both the city and the nation, black appeals for social justice remain unheard by those in authority, and this is largely due to the continuing ambivalent place of black peoples in the national imagination. Do we belong or do we not belong? ...[B]lackness and black people remain a “problem” in Canada (2003, p. 12).

The same can unequivocally be said about disability, in Canada and around the world. We (disabled people) are left asking whether or not we belong, and discovering, through consistent ‘public slander’ (Mitchell & Snyder, 2000, 17-8). communicated in the cultural expressions of our society (literature, film, television, etc.) that we do not. And with Walcott and Michalko, we make a home in the margins and even those of us who do not “compulsively request[] admission,” (Walcott, 2003, p. 20) wrestle with another one of Walcott’s questions which mirrors our own wonderings: “Are there not other ways to belong to a nation that seeks to render you not there?” (p. 20)

I want to state that I am not saying that the social justice quest for disabled people is ‘just like’ the social justice quest for Black people or other minorities. There is great uniqueness and differing needs in both struggles. What I suggest is that polarizing the two ‘camps’ is unwise. Behaving as though the two sides should have no dialogue denies the many ways the two movements can inform and enrich each other and also
denies the fact that disability can cross the border into any other minority group (Snyder & Mitchell, 2000).

Perhaps the best way to proceed, then, is to know there is not only one story of disability to tell -- just as no culture has only one story. It is trying to distill disability down to a definitive, single story or perspective that is the source of trouble. No matter how many stories we tell -- of the struggles, joys, and normative oppressions of disability -- there will always be more stories to tell, each in different, valuable ways. Mitchell and Snyder, too, make an important point.

The call for action in social realism centers upon a belief that disability will continue to be misconstrued and relegated to the “dustbins” of history if the able-bodied are left to construct images from their own prejudices (Shakespeare 283). The issue comes down to controlling the means of production. If disabled people take responsibility for the production of their own images, the social realists reason, images will evolve into more acceptable forms. A literal representation of disability would capture the myriad negotiations of a fraught social environment, obstacles would prove themselves of societal making rather than individual limitation, and technology previously hidden in the corners of homes and institutions would take center stage in the drama of disability as a lived experience (2000, p. 24).

Re-appropriating our own voices in our own ways is essential activism and advocacy for us, disabled people. In a book industry, and the rest of society, which constantly requires us to divorce ourselves from our social location and become either a tragedy or an “overcoming story” (Titchkosky, 2007, p. 179) in order to be accepted as fellow upholders of the oppressive norm, (re)claiming our own stories in ways that deny neither the struggles connected to impairment or those inherent in an ableist -- and therefore oppressively disabling -- society is essential. We cannot resist without ‘talking back’ and ‘writing back’ the oppressive norm. Talking and writing back is part of cultural expression, and since we live in a society that does not perceive of disability as a culture, insisting on our cultural voices can be part of forcing society to ‘see’ and read disability as a multi-cultural and widespread -- not isolated -- important phenomenon. Thus, I agree with Rinaldo Walcott, when he says: “Let me be clear: trying to write total stories of any cultural group is an impossibility and in the case of black Canadian cultures this impossibility presents itself from the first instance” (2003, p. 13).
It is also impossible in the case of disabled people. Writing 'total stories’ is a dangerous goal -- itself arrogant and oppressive. We cannot know the whole story unless we all speak, and even then, since culture and the experiences that comprise it change constantly over time, a single ‘snapshot’ (even from every single one of us) will not do, either. We must make ourselves heard through our own cultural expressions (academia, literature, film, visual art, comedy, and all manner of other cultural expressions consistently -- in truly multi-cultural, multi-faceted ways. We must never assume we have the whole story, since disability (along with any other cultural experience) is always more than we can ‘capture’ at any given moment. But we need to open ourselves up to as much as we can get.

In this chapter, I have examined the phenomenon of the global 'export’, from the West, of conceptions of normalcy in oppressive ways. In Chapter Three, I will conduct a close analysis of one particular literary text. This analysis will illustrate still more of normalcy’s oppression, and will explore these issues ‘closer to home’.
Chapter Three: Close Analysis of Normalcy’s Oppression

How *Wings of a Bee* Came Into My World

To further demonstrate normalcy’s oppression, in this chapter, I will be conducting a close analysis of two different excerpts of text from the young adult novel entitled *Wings of a Bee* (2007), by Julie Roorda.

I work with a magazine called *Canadian Children’s Book News*, writing articles on pertinent issues in Canada's children's and young adult book industry, and writing reviews of the current books in the field. The magazine has a policy that if the editor and reviewer don’t feel confident in endorsing a certain book and writing a largely positive review, then *Canadian Children’s Book News* doesn't review that book at all. Note that the magazine has not reviewed and will not review *Wings of a Bee*.

In 2007, (the same year my own novel *Zoe’s Extraordinary Holiday Adventures* (Minaki, 2007) for children was published by Second Story Press), another company, Sumach Press, released a children's novel entitled *Wings of a Bee*. It was common knowledge within the industry that this story revolved around the theme of disability. There was very positive press (I would even go so far as to call it “hype”) surrounding *Wings of a Bee* before it was released. The quote most frequently used in its publicity was that the novel “rings with intelligent humour and irony in this deeply perceptive portrayal of family life under extraordinary circumstances” (Roorda, 2007, back cover). I was instantly suspicious. I asked the magazine editor to let me know what she thought of the book when she had read it.

I was expecting to eventually receive her e-mail about it. Instead, the novel itself arrived by courier one Monday morning. My reflections and analysis in this chapter have resulted from my interaction with *Wings of a Bee* (Roorda, 2007). I am looking forward to working with the text excerpts available to be interrogated here. Both excerpts come from within the novel’s pages.
Me and It: Disability as Disqualifier

Why am I interested?

The first text is as follows:

“These are our telescopes,…We’ve got to keep an eye out for flying saucers. Tonight’s a good night for them,”…

Alannah pointed her [toilet paper] roll [telescope] to the window, but every time Carey made a noise, she stopped to look at her. Then Alannah leaned over and whispered in my ear, "Maybe your sister's an alien." Then she added in a regular voice, "You said they had skinny legs."

At first I felt indignation…It was on the tip of my tongue to tell Alannah that she was stupid… when something else occurred to me. Wouldn't it be interesting if I was related to someone who was perhaps part alien? Carey did possess some remarkable abilities.

"She can spell, you know," I said. "She could already last year when she was only four. And do you know what? No one ever taught her how. She just knew." I hadn’t occurred to me to claim bragging right to Carey’s achievements before. I had finally uncovered a way to draw some of that fanfare and prestige to myself, by sheer proximity. Alannah looked doubtful, so I elbowed her. "It's true. Carey has special powers. Sometimes her wheelchair moves by itself" (Roorda, 2007, pp. 36-37).

This excerpt portrays disability as alien – as strange and other-worldly (outside of the 'knowable' world), excludable from viable Earthly life, an other-than-human way-of-being in the world. The second excerpt points to disability as incapacity, as less than human, since it is understood as a state of being wherein 'normal' human achievements – such as writing a play – are ‘impossible’. The stereotypes in each text differ. (In the first excerpt, disability is portrayed as grounds for disqualification on the basis of alienation from the ‘norm’. In the second excerpt, disability is written as grounds for disqualification on the basis of assumed incapability. In both cases, disability is estranged from the ‘norm’).

I felt it so many times while growing up, the depressing almost sick feeling of being ostracized, excluded, misunderstood in the world because of my disability. During these traumatizing experiences, I clearly remember thinking – and in protest I may have even said, on occasion: “What am I anyway, an alien?” So now, with the approach of
disability studies in my ‘tool box’ I am eager to revisit the concept of 'alien' and its connection to disability.

In my second text excerpt, the disqualification of disability does not occur through alienation, but instead through a (mis)understanding of disability as a phenomenon that makes intelligence and achievement impossible. I can't even count how many times in my own life I've felt the sting of the automatic connections society repeatedly makes between disability and disqualification. Strangers, teachers, and even relatives have frequently belittled me and found it nearly impossible to believe that I am a disabled, intelligent professional and graduate student. Before those achievements were applicable to me, the debate and disbelief centered around whether I was intelligent at all. (“Does she really go to real school?” “Are you sure she can handle this class?” “You're kidding!”) In the minds of these people, my disability disqualified me from a life granted “viable status” (Titchkosky, 2007, p. 6). Of course, this does not only happen to me; disqualification is a common experience in the lives of disabled people.

The first text excerpt I am addressing here makes direct and disturbing references to disability as alien – an other-worldly, unwanted presence. Granted, in the scene, the two girls are looking for aliens, but only Bronwyn is enthusiastic about it. The presence of Carey in the room makes Alannah uneasy enough to look away from the window and her telescope every time Carey makes a noise. Second of all, Carey is taken up as 'exotic' by her sister's musing that it might be ‘interesting’ if she was an alien, and they are staring at her as they discuss her. (Note that the fascination with 'deformed', 'grotesque' bodies has shown up. Disability as a 'weird' spectacle worthy of voyeurism is clear here.) They are watching Carey, but they certainly don't want to be 'in her shoes', much as people may watch telethons but don't want to be the people they are watching. In fact, the people watching telethons are watching them and opening their wallets because they are convinced the children on the telethon don't want to be in their own shoes. Bronwyn may be excited about seeing aliens, but the question remains: What would she do if she did see them? Would she welcome them, or would she scream and run, terrified?
In the scene in question, Carey, the disabled character, is being observed by her sister Bronwyn and by Alannah – who is Bronwyn's sleepover guest and friend – in the bedroom the two sisters share. Bronwyn's friend, Alannah, comments that Carey, being skinny and disabled, might be an alien. The rest of the excerpt unfolds as Bronwyn reflects that Alannah could be right.

Disabled bodies, and so the experiences of disabled people in those bodies, are so often alienated from life in the mainstream centre of society – on the grounds of their 'inferior' embodiments, their unwelcome difference from 'normalcy'. I am interested in this alienating, othering disqualification process. Again and again the process occurs, and appears in society as 'business as usual'. It appears as an automatic process but is not automatic at all. I want to know what grounds this reference to 'alien', this dehumanizing process. This process qualifies the disabled body only as a disqualified 'other' who is not eligible for a 'real life' on Earth.

In my second piece of text, Bronwyn's disabled sister Carey's ability to be the author of a play she did indeed compose – with her mother acting as scribe – is negated. Here, disability as disqualifier is explored through the stereotype of disability's 'automatic' connection to incapability. Here, the possibility of Carey as alien is not at issue. Instead, what is illustrated in the second excerpt is the stereotype of disability as a phenomenon that always already points to an inability to think and create original work. In the second text, too, disability is dehumanized, since the capacity for 'higher thinking' is so often understood as a prerequisite for membership in humanity. If disability is automatically understood as a phenomenon that robs its 'victims' of a capacity for higher thinking and creativity, then disability as grounds for dehumanization 'makes sense'.

**Disability as Disqualifier: Out of This World**

Through the first text excerpt, Carey is classified in the category of 'alien.' In other words, Alannah immediately imagines and questions her as 'non-human'. Automatically, Carey is dehumanized and objectified (“You said *they* had skinny legs.” [italics mine]) Alannah does not say ‘Carey (or 'your sister' or even 'she')’ “has skinny
legs" (Roorda, 2007, p. 36). She uses the pronoun ‘they’, making it clear that she thinks of Carey as belonging to a different species, altogether separate from humanity. Carey is taken up as ‘them’ in an ‘us and them’ distancing move. Alannah effectively disqualifies Carey for membership in the human race, because of her disability.

Alannah does suggest that Carey may be an alien, and the suggestion is brought forth in the form of a question. This questioning is one of the most disturbing parts of this excerpt, yet the word ‘maybe’ means Alannah isn't certain whether this is true. Carey could be an alien, or not. ‘Maybe’ implies the possibility of ‘may be not’ -- and so there is some hope here. Alannah does not say she ‘knows’ Carey is an alien. She is at least somewhat open to other explanations of Carey's difference, her ‘transgressive' body.

It occurs to me that one of the many problems with the medical model of disability is its relentless grasp for certainty. There is great arrogance in a doctor's assumption that he or she has it all figured out and has become an authority on disability by virtue of medical training.

In *Reading and Writing Disability Differently*, Titchkosky states the following:

The meaning of disability is, at best, partly captured by medical or rehabilitative definitions of 'conditions' - medicine is but one story among many that help to constitute what we treat as a disability and how it is brought to life...... Disability can make us think, if we resist the thought that it is some kind of object of lack and limitation requiring only diagnosis, rehabilitation, and care... Despite the plethora of disability experiences there is something that remains common. The experience of disability, any experience, can teach us much about the organization of culture and the formation of our self-understanding...[R]egarding disability as a place for thought, [a legitimate way-of-being-in-the-world, an embodiment of valuable difference, not as bodies or minds “gone wrong”] is a powerfully rich formulation... (2003, pp. 35-36, 41, 42).

As uncomfortable as I am with the way Alannah and Bronwyn treat Carey in the scene mentioned above, I must concede that they are, on some level, allowing her disability to make them think. They are certainly not regarding it as a legitimate way of being, but they are just beginning to treat it as a place for thought. And yet, what they are thinking about is an attempt to ‘diagnose’ Carey. (“Maybe she's an alien” sounds very similar to “Maybe it's cancer.”)
The concept of ‘alien’ is striking to me. Referring as it does to creatures from other planets (usually pictured as green and understood as ugly and extremely foreign) elicits fear. Note that alien beings, from far off and strange planets, are most often taken up as sinister. An ‘alien invasion’ is widely understood as bad news and trouble for the Earth. Constructed this way, alien equals fear. In turn, it is fear, I believe, that fuels the ‘othering’ of disability and makes it not only excusable but a taken-for-granted ‘liberty’ for able-bodied society to refer to, conceive of, and write about disability as alien ‘other’. (Disability, after all, is bad news and trouble, according to the rationale of the status quo.) Along with analyzing and theorizing it, then, I also want to reclaim the concept of ‘disability as alien’ from a disability studies perspective.

I wonder, also, what disability must be that it is at once conceived of as a sinister, ‘alien’ threat – (and ‘sinister’, as a concept, points to dark intent but it also points to power) – yet simultaneously, it is conceived of as a state of incapability. Note the two extremes, the contradictions.

In his book, _Stigma: Notes on the Management of Spoiled Identity_, Erving Goffman (1963) states:

> By definition, of course, we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination through which we effectively, if often unthinkingly, reduce his life chances. We construct a stigma-theory, an ideology to explain his inferiority and account for the danger he represents… (p. 5).

Carey's sister Bronwyn also furthers the dehumanization, alienation and disqualification of Carey's humanity. She does not protest against Alannah's estimation of Carey. On the contrary, Bronwyn in fact reinforces the conception of Carey as deviant. She narrates the following: “…It was on the tip of my tongue to tell Alannah that she was stupid…when something else occurred to me. Wouldn’t it be interesting if _I_ [italics mine] was related to someone who was…part alien? Carey did possess some remarkable abilities.” (Roorda, 2007, p. 36-7)

It is striking that Carey attempts to make herself look good through Carey’s abilities. She narrates the following: “It hadn't occurred to me to claim bragging rights to Carey's achievements before. I had finally uncovered a way to draw some of that
fanfare and prestige to myself, by sheer proximity” (Roorda, 2007, p. 37). This is another instance of disqualifying Carey; in this scene it is clear that Bronwyn does not classify Carey as eligible to possess her own gifts; they are understood here as existing for Bronwyn’s benefit.

According to this text, Carey’s disability disqualifies and excludes her from being smart, from having it be believed that she can spell since the age of four. It makes her intelligence ‘remarkable’ -- because disability and intelligence are not ‘normally’ understood to fit together. Carey’s intellect, her ability to spell at such a young age, then, does not qualify her to be what she actually is – a smart person. Instead, Alannah and Bronwyn feel the need to bring her into their social space as ‘part alien’, ‘out of this world.’ According to Bronwyn and Alannah, Carey would have to be an other-worldly being, because intelligence and disability don’t match on Earth. Further proof of Carey's alien, other-than-human status is reinforced by her sister’s assertion that “No one ever taught her how [to read]. She just knew.” (Roorda, 2007, p. 37) Since she has been stigmatized, Carey's intelligence doesn't serve to make Bronwyn and Alannah re-think their perceptions (stereotypes) of disability. Instead, it serves to deepen those stereotypes. Bronwyn and Alannah are resisting disability as teacher.

The two girls rationalize the danger [Carey] represents” (Goffman, 1963) by further alienating her and moving ever deeper into her dehumanization and disqualification. At the end of the excerpt, Bronwyn says “Carey has special powers. Sometimes her wheelchair moves by itself” (Roorda, 2007, p. 37).

This brings out more alienation, more stigmatization of Carey, who is constructed simultaneously as super-human and as not-quite-human. (Humans aren't able to make wheelchairs move ‘by themselves’. This is classified as super-human ability.) This reference is also meant to further the ‘eerie’, alien association being made here. So all at once we have a ‘super-human’ connection to ability, but the social construct of normalcy also dictates that ‘real’ humans don't need wheelchairs. So Carey is written up as more-than-human and less-than-human. The references to her ‘special powers’ can also be understood to connect to the ‘special needs’ of disability. In either case, Carey is disqualified for ‘true’ humanity, either because she exceeds the ‘human
standard' (too intelligent and possessing ‘special [semi-alien] powers’) or because she is understood as failing to meet the same ‘human standard’, on the grounds of her disability.

The belittling, discrediting and infantilization of disability is a fascinating 'doing'. I am fascinated by how this works – how disability is taken up, understood and taken-for-granted as a non-viable, subhuman experience, and hardly a life at all.

Society accomplishes this 'doing', this alienation of disability through specific ways in which it is treated in the world – specific ways in which disabled people are treated to ‘alien talk’. For example, in my own experience, people in wheelchairs can be spoken to too loudly, spoken to with exaggerated slowness, or even in ‘baby talk’. We are also treated as absent, when answers to questions we ask or reactions to comments we make are not directed to us but instead to those who might be with us. On many talk shows, and other venues within popular culture, disability is taken up as exotic and embodiments of differentness are very often singled out as a spectacle. In all of these ways, and many more, disabled people are separated and alienated from real life.

**Disability as Disqualifier, No Can Do**

My second text excerpt is an example of disability as a 'can't do' phenomenon – and so a disqualifier from real life on those grounds. Here, the very possibility that Bronwyn’s sister Carey might be capable of being a playwright is disqualified, solely on the grounds of her disability. It is imagined only that her disability automatically means a substandard intellect.

Here is the excerpt in question:

It was a letter to the editor from a "Concerned Parent." First, the writer railed against administrators of the play competition and the school for allowing the performance of a work which was "obviously not written by the student named." She cited quotes from the article as proof that even the other students admitted that Carey hadn't written it. She then attacked the newspaper for "furthering the deception." The letter ended with these words:

"I have nothing against the handicapped. But somebody should tell the real playwright that she isn't doing her child any favour by pretending she can do things she can't, and by teaching her, along with every student in the competition, to lie."
I felt shaky and nauseous when I finished. "But it's not true. She's the one who's lying."

"Of course it's not true," Mom said softly. "I don't think we should say anything to Carey about it. It would just upset her," she added (Roorda, 2007, pp. 184-85).

I personally have been repeatedly hurt by the ‘disability as disqualifier’ stereotype. But I am heartened and energized by the fact that I know disability as always more than the routine ways in which it is seen and done in our social space. If I can analyze these texts – if I can peel back the layers of routine – to find disability moving, changing, growing, and pulsating against the boundaries of the ‘box’ these texts attempt to put it in – I know I will have done something important.

In this second piece of text, because of her disability, Carey is disqualified from being understood and accepted as a legitimate playwright. Here is some background: Carey composes her play, as a school assignment, with her mother acting as scribe. Carey doesn't have the hand control to handwrite or type, but by pointing at the letters she chooses on her communication board, she slowly spells out the words she wants her mother to write down on her behalf. In this way, working as a team, mother and daughter commit the play to paper. A school contest follows. Carey's play wins the contest and her play is therefore performed in a district-wide competition. Although her play doesn't win the competition, it garners attention in the local newspaper. (Carey as playwright becomes the latest ‘overcoming story’, since she overcame her disability in order to write the play.)

The pertinent text here contains a reference to a response to the play and the newspaper article – a letter from a “concerned parent”, published in the same local newspaper, subsequent to the play’s performance and the original article. The text I chose here is narrated from Carey's sister Bronwyn's perspective, as she reacts to the letter from the “Concerned Parent”.

The “concerned parent” claims to ‘have nothing against the disabled’, yet the letter's author does not even consider the possibility that Carey did after all compose the play using her own ideas and choices of words. Carey is disqualified and discredited as the author of her own work, because of her disability. The play is said to be ‘obviously
not written by the student named.’ It is clearly Carey's disability that makes it ‘obvious’
that she ‘couldn't’ be the author of a play she claimed to write. In this text, her disability
acts as an automatic disqualifier. She is disqualified from having a viable intellect,
disqualified from being believed when she tells the truth about her composition. Even
the author of the newspaper article is accused of enabling Carey and the play's ‘real’
author (assumed to be able-bodied) in their ‘deception’.

In Carrie Sandalh’s article, “The Tyranny of the Neutral”, she writes: “[Whether a
symbol for] denial of truth...a beacon of evil...[or]...a mark of shame...disability in the
dramatic canon always signifies” (2005, p. 255). In his book, entitled Enforcing
Normalcy (1995), Lennard Davis also states the following: “The loose association
between...disability...and mental incompetence...established a legacy that people with
disabilities are still having trouble living down” (p. 37). Both of these quotes illustrate
what grounds Carey’s disqualification. She does not embody what normalcy dictates
that a ‘real’ author should be, therefore instead of reaching the conclusion that there is
something amiss with the construction of ‘normalcy’ itself, the accepted conclusion is
that Carey could not possibly have composed the play. She (her disability) is
understood to signify deception.

Carey is actually twice disqualified. She is disqualified from her right to have a
reaction to the “Concerned Parent’s” letter, and to choose whether or not to protest
against it, and in what way. The fact that Carey would be made upset by the letter was
used as grounds not to inform her about it. The rest of the family finds out; despite the
fact that the knowledge upsets them it is not kept from them. Yet Carey, whom the
letter concerns directly, is not informed. She is excluded, thus disqualified for family life
in all its complexity. She is accepted within the family as intelligent enough to write the
play, yet not accepted as intelligent enough – human enough – to be permitted a
reaction to her disqualification from being a legitimate playwright. She is considered –
by her own family --- to be too ‘fragile’ and ‘weak’ for the truth about what is going on.
What is in-between?

So what is the meaning of all of this? What is in-between these two representations of stigma and dehumanization? What is disability understood to be, such that these treatments of it are possible? It is my understanding that in both of these excerpts disability is cast out, unwanted, as trash. Disability is unimagined as a viable identity or a place where the good life can be lived. The ‘casting out’ of disability is what these two texts have in common. Granted, this is upsetting. Of course discrimination, dehumanization, stigma, stereotype, disqualification and prejudice are infuriating. In the introduction to her book, entitled *Casting Out: The Eviction of Muslims from Western Law and Politics* (2008), Sherene Razack says:

This book explores some of the places in law and society in the West where these figures animate a story about a family of white nations, a civilization, obliged to use force and terror to defend itself against a menacing cultural Other. The story is not just a story, of course, but is the narrative scaffold for the making of an empire dominated by the United States and the white nations who are its allies. Supplying the governing logic of several laws and legal processes, both in North America and in Europe, the story underwrites the expulsion of Muslims from political community, a casting out that takes the form of stigmatization, surveillance, incarceration, abandonment, torture, and bombs (p. 5).

Seeing hope in expulsion, in the “casting out” of disability, or racial difference, or any ‘transgressive’ embodiment at all, does not always come easily. Yet, there is hope here, not so much in the fact that one is cast out, but in the fact that one is always cast out to another location, an alternative place, ‘another somewhere’ that offers another way to be in the world. In the above quote, being Muslim is described as taken up in society as a ‘menacing cultural Other’. In the excerpts used in this thesis from Julie Roorda’s *Wings of a Bee* (2007), disability is treated to the ejection and rejection of the casting out process. The alienation, disqualification, dehumanization, and incapacitation of disability are well-known moves, commonly performed. Yet, what is not well known is that hope can be found in the fact that another life is possible, a life full of the possibility of transgressive embodiments: life in the margins!

Theorizing on the meaning of marginality, Titchkosky and Michalko state the following in their book *Rethinking Normalcy* (2009):
Disability is as legitimate and valuable a part of who we are as our gender, race, sexuality, ethnicity and so on... Even though disabled people are marginalized in a whole host of ways, those processes that make people marginal are also part of what makes disability matter to disability studies... bell hooks suggests that respecting the voices, lives and events found at the margins of a society might be a way to resist and remake the centre’s norms (p. 6).

We are sometimes tempted by the desire to belong in the centre, in the social space that "appears" to be so advantageous to so many people. It is ironic that disabled people want so badly to belong to that which makes us marginal and that which excludes and disadvantages so many.

Equally as ironic, the compelling and seductive character of normalcy conceals the compelling and seductive character of the margins, and it conceals this not only from its "view" but from ours as well... From the standpoint of the centre, no one desires to inhabit a disabled body, or disabled senses or minds, since to do so is tantamount to barely living at all. The centre conceives of disability as a devalued life where its only hope for even a semblance of value is to evoke the "human spirit" and to "overcome disability," to adapt, to adjust, and to live as normally as possible. ... Normalcy imagines – "sees" – no other possibility of human life than itself, and thus, ironically, does not "see" itself. The centre understands itself as the only legitimate space of human habitation and, like all spaces, the centre too has its casualties (p. 7).

[The margins can] show the centre that its margins are not merely uninhabitable voids, but are instead spaces where it is possible to reveal...that the centre is not natural, but is human-made and can be otherwise (p. 8).

There is hope for Carey in being cast out to the margins. There, she can think and compose in ways that question the fact that she was cast out, as well as ways that express that this could and should have been otherwise. She can rebel against her disqualification. She can have freedom, be unbound from the expectations of the centre. She can reflect on and re-make her own expectations. Perhaps her next play can be about what she discovers in the margins about herself and the world. I’d like to see that play!

**Conclusion: Money to be Made**

Through close analysis of two text excerpts, which illustrate normalcy’s oppression distressingly well, I have theorized how oppression is furthered through routine depictions of disability, depictions that portray it as an unwanted and even subhuman
state. In Chapter Four of this thesis, I will show how the book industry acts on disability with the purpose of maintaining the status quo in disability portrayal. The work of this maintenance is fueled by capitalist motivations.
Chapter 4: The Business of Normalcy

Profits from Oppression: Exposing some of the inner workings of the book industry

One of the ways in which adhering to normative oppression is sustained as the ideal is through rewarding its sustenance with awards and monetary gains for the publishing industry and its creators, who dutifully write disability in disabling, oppressive, normative ways. In this chapter, I uncover, critique and examine the phenomenon of how the book industry rewards normative and oppressive literary portrayals of disability, through reviews -- a key mechanism of the literary marketing machine. I will illustrate how rave reviews for novels which portray disability as usual, and reviews which enforce normative oppression even on literary works which do disability differently, all work to uphold normative disability portrayals as ideal. I will then theorize how to respond to such oppression in ways that resist it. I will delve into what living in disability in the in-between means in this case. In other words, I will discuss how to ‘talk back’ to normative portrayals. I will address what can be done now, since these oppressive literary portrayals exist. I will discuss the disruption of normative portrayals through examining what has already been written normatively, and analyzing said portrayals in ways that cause disability to emerge -- and to matter -- in new ways.

I begin with the following quote from The Disability Business (1992), by Gary Albrecht:

The financial costs of disability are remarkable...Because of the size of the problem and monies involved, it is not surprising that huge government bureaucracies have been formed, businesses developed, and a rehabilitation industry created to deal with the problems of the disabled. There are people in need to be served and money to be made in this business...Disability, then, is a social problem in the United States when measured by any standard and has stimulated the development of a rehabilitation industry aimed to serve those individuals with disabilities, to provide jobs, and to generate profits (p. 17).

Framing disability as a dramatically costly ‘social problem...by any standard’, referring to dealing with ‘the problems of the disabled’ makes normative oppression appear as a taken-for-granted ‘truth’, which in turn causes oppression to be perceived
as a phenomenon that makes ‘perfect’ sense. Portraying disabled people as a largely unemployed and unemployable drain on healthcare, families, financial resources, and governmental programs points to disability only as a hugely negative phenomenon. The above quote also underscores the capitalist interest involved in maintaining perceptions of disability as such. The ‘service’ of disabled people, the creation of jobs, and the generation of profits are listed above as the reasons for the existence of the rehabilitation industry.

Job creation and profit generation as central aims of the industry in turn are used to ‘justify’ normative responses to disability. A whole host of professionals (from physio- and occupational therapists, to doctors, to product vendors, etc., etc.) are afraid they would lose their jobs if alternative views of disability -- without ‘normativity’ as their absolute goal -- were to take root. Within the realm of normative oppression, doing disability differently is completely unimagined. This, of course, includes disability portrayal in literature.

Even the stated intent of rehabilitation to ‘serve’ disabled people needs to be questioned, when such service as is referred to upholds normative assumptions and demands, and the oppression resulting from them. Rehabilitation as a response to disability stems from the medical model, which vigorously enforces oppressive normalcy. Also, the notion of ‘service’ brings on other disturbing implications: that disabled people, framed as a community to be served, are therefore cast as the ones who should always be unquestioningly subservient. Anything less would mean ‘ingratitude’. Perhaps most disconcerting of all to capitalism is the potential loss of profits, if disability were to be largely conceived of as something more or other than a phenomenon which creates an abnormal, “roleless” (Fine & Asch, 1981, p. 233) and dependent subclass of society.

Albrecht himself concedes the following:

The multiple stakeholders in the disability business have their own interests. Human service agencies and industries rely on the construction and maintenance of such social problems as disability to keep them in business, for without recognized and defined social problems, human service agencies would have no reason to exist. Social problems are, then, constructed within a context by people
in power who have an interest in the content area, outcome, and individuals affected by the problem. For a human service industry to exist and thrive, a social problem must be identified and defined, made to appear salient, and lie within the purview of that human service industry. Nothing about this process is insidious. I just note that for a human service to flourish, a recognized need must exist for which intervention usually benefits both the recipient and the provider. This is what has occurred in the instance of persons with impairments and disabilities. They were defined as a social problem by those in government, industry, the nascent rehabilitation field, and most importantly by the community of persons with disabilities and general public… (1992, p. 69).

To ‘simply’ state that there is ‘nothing insidious’ here is to negate or, at least, overlook, the truth of everything that was written in the above paragraph. The construction and maintenance of the ‘problem’ of disability is powered by the interests of the above-mentioned stake-holders, whose survival and widespread power would be rendered null and void if the subversive assertion that disability is a worthy, rich life experience (not something tragic to be shed, regretted, and left behind as swiftly as possible in ‘obvious’ favour of normalcy), were to be widely embraced.

Furthermore, to list ‘persons with disabilities’ themselves as a group that understands their disabilities as problems, and to include their agreement in the justification for the disability industry is to miss an essential point. The internalization of disability as problem by disabled people themselves does not speak to the ‘truth’ of disability as problem. It speaks instead to the fact that mainstream society constantly feeds disabled people the poisonous ‘certainty’ that our disabilities are nothing but huge problems. Is it any wonder that we, as disabled people, begin to believe this?

The maintenance of normalcy as ideal demands the collusion of all sorts of other stakeholders and industries, and this is where the concerns of this thesis -- the portrayal of disability in literature – come into play. Portraying disability as usual in fiction feeds the interest of the many stakeholders whose concerns keep normalcy as the central, sought-after focus of society. This self-interest is disturbing on every level. From the perspective of this thesis, however, what concerns me most is the fact that education is one of the key fields through which values, priorities, and social justice, advocacy and activism concerns are communicated to the next generation. Upholding normalcy is dangerous at every turn, but it is especially dangerous when we consider what readers
internalize about disability when they read fiction that communicates it as tragedy. The next generation of parents, teachers, librarians, scientists, doctors, therapists, lawyers, psychologists, store and restaurant owners, etc., are in our school system today, internalizing ‘truths’ about disability and absorbing ever more of those truths as they read mainstream books written -- though not always knowingly -- from ableist perspectives. Consider, then, the following:

...the media are a business controlled by a few powerful families and interests in the United States. The media are manipulated to serve the interests of those in power. Presidents play the media to win elections; large corporations use then to sell products; and governments influence them to gather support for policies. Media executives are evaluated more on their market shares, revenues generated, and ability to influence public opinion than on deep portrayals of complex issues or veracity. One way to sell copy is to cater to the sensational and deviant topic.

...In many senses, then, the media appear to be less concerned with the disabled cause than they are with persons with disabilities as a product to sell to the healthy population...The media and entertainment businesses, then, are involved dynamically in the rehabilitation industry through setting themes, identifying causes, giving altruistically, and using issues to generate profits (Albrecht, 1992, p. 173 - 175).

As ableist as much literature is (namely fiction, in terms of the scope of this thesis), the fact remains that fiction is also fertile ground for presenting disability in new ways -- ways that make use of alterity and its resistance of norms. As will become clear in the next chapter, opportunities to express resistance and explore alterity in fictional portrayals of disability are indeed being seized and put to good use. But gaining attention though they are, these alternative portrayals -- which go against normative oppression -- are still the exception. Selling the disabled as unhealthy, less fortunate, sad, impoverished souls stuck living lives no ‘normal' person would enjoy serves the purposes of the aforementioned ‘stakeholders' much more advantageously than alterity -- or so normalcy’s oppressive nature would have us believe. Normalcy steadfastly maintains that upholding its own supremacy is what is ‘self-evidently’ best for society. But normalcy only serves its own self-interest. It does not ‘look’ at itself, and therefore does not perceive of -- much less concede -- its fragility or the validity of other ways of being in the world.
Since “[a]lternative ways of comprehending disabled bodies and minds are often best explained within experiential forms, such as personal narratives, performance art...films [and literature], rather than in the often objectifying realms of "research" about disabled people” (Snyder & Mitchell, 2006, p. 4), fiction holds its own in the space of expressions of resistance to normalcy. There is great potential here. But because of this potential, normalcy’s stronghold is being defended all the more vigorously, to mask the fact that its ‘supremacy’ is tenuous at best. Witness, for example, Rod Michalko’s words below:

One of the most “abnormal” things about being “normal” is attending to its production. Once this is done, normalcy loses its self-proclaimed status of unreflexive naturalness. Normalcy blends into what is conceived of as “naturally given” and the only way to sustain this camouflage is for it to avoid any attention, especially its own...[T]he experience of impairment (the body) is existentially different from that of disability (society). Thus, who I am is what is made of my impairment (2002, p. 82, 84).

I want to make two points here: the first is that normalcy’s oppression is much more dangerous than ‘simple’ insults’ and inappropriate, politically incorrect language aimed at ‘hypersensitive’ disabled people. I am doing much more here than picking a fight with the medical model; there is much more at stake (although disturbing the medical model is in itself a very worthy undertaking). My second point is that the marketing of books is one of the ways that disability is sold to society as deficit, incapacity, dysfunction and abnormality.

Consider the following, from Marta Russell’s book, entitled Beyond Ramps -- Disability at the End of the Social Contract (1998):

The disability liberation movement has a bumper sticker that confronts physicalism by asking, "Why Be Normal?"...If "normal" has been created as a construct, then there must be a benefit. As Alex Cockburn noted in a talk at the Midnight Special bookstore in Santa Monica, "What is normal and abnormal is imposed on us at all levels. We must resist this. We must be on the alert as to how we are made objects to be disposed of." We must also ask, who does "normal" serve?

Cockburn's warning rings literally true for our minority, because disabled people have in great numbers been "disposed of" via lethal injections, gas chambers, and starvation...Cockburn too would rate as "abnormal" because of his politics;
"normal" demands political conformity as well as physical conformity, and as such can be used as a tool for social control.

The danger of the "normal" construct is that it serves to make disabled people seem less than human. When disabled people are not seen as fully human, it is easy to justify continuing inhumane policy toward us, to cut us out of the social contract, even to eliminate us at political will. We become too easily disposable (p. 17).

We need only observe the ways in which disabled people are so often killed off within the pages of fiction to grasp that our elimination and alienation is still being made to appear sensical and taken for granted as accurate and true-to-life.

Snyder and Mitchell, speak a frightening truth when they turn to Bauman and state, in Cultural Locations of Disability (2006), that:

...disability has been historically fashioned as if it were a denotative designation of biologically based deficits. "Biological worth" has been continually conflated with "social worth" as if one's own body referenced the extent to which one could meaningfully participate in and contribute to culture-making (Desrosiers 2002, 114-15) (p. 16).

So, my critique of normalcy is serious business, especially when I consider that a 'small' Holocaust occurs with each disability portrayal that does not conceive of disability as a 'real', valid life. Such 'small' Holocausts lead to the negating of disability across society.

Race, feminist, and queer studies have all participated to one degree or another in a philosophical lineage that seeks to distance those social categories from more "real" biological incapacities (Mitchell and Snyder 1997, 6). Thus, in order to counteract charges of deviance historically assigned to blackness, femininity, or homosexuality, these political discourses have tended to reify disability as "true" insufficiency, thereby extricating their own populations from equations of inferiority (Snyder & Mitchell, 2006, p. 17).

The significance of this, as far as the scope of this thesis, is that these insidious motives underpin, and in fact drive, the way disability is largely written about, marketed,
discussed, and understood in the book industry. Disability is so often taken up as ‘worse than’ any number of other human experiences of bodily difference, as if it were the bottom rung (or even beneath the bottom rung) on the ladder of ‘misfortunes’.

In what follows, I will examine book reviews -- of my own book and a few others -- to show how reviews feed ‘the marketing machine’ and bring disability out into the world in oppressive ways. Reviewers -- much like authors -- who perceive and write disability differently go some distance in troubling this status quo. In the following section, however, I will explore how normative oppression is recreated when the status quo remains undisturbed.

**Book Reviews Under a Disability Studies Microscope**

Generally speaking, authors eagerly await reviews of their books, since reviews give a taste of how a book is being perceived out in the world. Reading reviews of one’s own work is both an exciting and anxiety-provoking experience. Books can and do take on lives of their own once they leave an author’s hands, and reviews can greatly impact a book’s success, from sales to awards, through which audiences of readers are encouraged -- or discouraged -- to read a book. It is fascinating to observe how disability as subject matter is written up in reviews, how reviewers so often support normalcy’s oppression, even while writing a ‘positive’ review and ‘endorsing’ a book. I will illustrate this by delving into reviews of a few particular novels -- and one short story collection -- featuring disability. First, consider the following excerpt of a review of my 2007 children’s novel.

Zoe’s ultimate adventure draws the attention of Lisa, a classmate who is finally able to see Zoe without her chair, reinforcing the idea that ability is not about physical characteristics, but [is decided] by the spirit of [the] heart. (Donogh, 2007, p. 35)

These statements do disability as completely absent from the body. By saying that ‘ability is not about physical characteristics, but [is decided] by the spirit of [the] heart’, this reviewer has enforced normalcy’s oppression in two ways. First, Zoe has become an “inspirational overcomer” (Titchkosky, 2007, p. 182) here, overcoming her disability
through her ‘spirit’ and her ‘heart’. In other words, Zoe is portrayed as having abilities ‘despite’ her disability. Her abilities, these words imply, are divorced from and reside outside her body. In this way, her body is manipulated to represent only lack -- a lack ‘rescued’ by her power to overcome and inspire.

An important point needs to be made here. As the novel’s author, I intended to make it clear that Lisa’s revelation about Zoe as more and other than unintelligent and ineffectual came from watching Zoe make decisions and handle the escape of a pet bird (from her wheelchair). Lisa did not suddenly question and revise her assumptions about Zoe because she ‘finally’ saw her out of her wheelchair, but instead because at the end of the novel, Lisa was finally placed in a situation where she could no longer ignore, belittle, or deny Zoe’s agency. But this point is not made in the review. The point that is made within the review -- the misconception that Lisa’s attitude change came from observing Zoe without her wheelchair (in a toboggan) in previous chapters within the last third of the novel -- reinforces the falsity that her wheelchair is the oppressor. As the novel’s author, I can honestly say that this portrayal was not my intention. What is also disturbing about this point is that this misconception acts to erase Zoe’s disability, since the review suggests that Lisa did not recognize Zoe’s agency until her wheelchair (the widespread societal symbol of disability) was ‘out of the picture’. Thus, it is also interesting to learn that authorial intention does not control the meaning of a text.

Instead the meaning of the text, and ultimately disability itself, is made between readers and writers, disabled and non-disabled people. There is an important lesson here – the ambiguity of meaning, that it is never stable, holds both our promise and our demise.

It is at once interesting, frustrating, and frightening to notice wheelchairs so frequently being brought into our social space, repeatedly, as agents of restriction and imprisonment, instead of as tools of transport and freedom for disabled people. I need only refer to the many reviews that describe Zoe as “wheelchair bound” (Gilani-Williams, 2007, p. 26) to witness disability being done this way. Witness the following portion of another review:

Zoe, the protagonist, has motor disabilities... and is confined to a wheelchair. She is Christian, but has a Jewish best friend who honors Shabbat. Zoe appreciates
the fine care from her special dog, her parents, her brother, her teacher, her neighbors and her friends. The tension in the story grows from her search for an...adventure. The frame of the story is Zoe’s fourth grade classroom study of diverse winter holidays associated with light: Hanukkah, Christmas, Kwanzaa, Diwali, and Eid. As the students learn information about each festival’s celebration, Zoe learns more about herself. Minaki, herself in a wheelchair, does a lovely job of communicating the emotions of disabled persons; if you are stuck in a wheelchair, you are stuck. (Cole, 2008, p. 13)

I find this review utterly upsetting. For one, there is yet another reference to Zoe as ‘wheelchair bound’ (discussed and theorized above). Also, the review points out that Zoe -- like a good, ‘normal’ disabled girl – ‘appreciates the fine care from her special dog, her parents, her brother, her teacher, her neighbors and her friends’. Zoe’s companion dog (and by extension, Zoe herself) is delineated as ‘special’. In this way, she and her disability are set apart and individualized. In this review, there is no understanding that disability belongs to all of us and is firmly between us. Zoe is the ‘grateful’ disabled girl, and disability is brought between us as nothing more or other than a phenomenon requiring care. Here we notice the medical model at work.

The most disturbing portion of this review is the statement: “Minaki, herself in a wheelchair, does a lovely job of communicating the emotions of disabled persons; if you are stuck in a wheelchair, you are stuck.” (Cole, 2008, p. 13) The notion that disabled people are ‘stuck’ in their wheelchairs, instead of using them as one of the tools to support alternative embodiments, is disturbing and reductionist. Also, this is another instance of my message being completely misconstrued. If, as the review suggests, I have done ‘a lovely job of communicating the emotions of disabled persons’, the emotions I communicated had nothing to do with ‘stuck-ness’. Within the story, when Zoe felt stuck, it was in a society that rejects and is prejudicial toward disability.

Reviews of *Something to Hang Onto, Moon Children, and Beauty Returns*

Consider the following review of *Something to Hang On To* (2009), by Beverley Brenna:
This collection of short stories features an intriguing mix of characters facing a multitude of diverse life situations. Some are at monumental moments in their lives – like William who is at his father’s bedside as the end of his life draws near, and Dexter who is preparing to face his fear and jump out of a plane...[T]here is [also] Taylor, whom readers may recall from Brenna’s earlier novel *Wild Orchid*. In this story Taylor is doing the best she can to get through a job interview for which she feels ill-prepared. These and other characters we meet in these pages...enlighten readers as we are treated to a brief glimpse of their colourful lives.

As a whole, this is a sensitive and finely-drawn collection. This reader was particularly moved by several of the stories, most notably *Gift of the Old Wives* and *Finding Your Voice*. The first of these is based on a Cree legend and tells the story of the enormous gift that these old wives gave to their people, a gift of sacrifice, a gift that “we have earned the right to give,” says the young girl’s grandmother. The latter of these stories is a powerful story of friendship and the wisdom of children who so often see the beauty and truth where [adults] do not.

And while some of the young people in this collection contend with disorders such as autism, Down syndrome, muscular dystrophy and Asperger’s syndrome, this is not a book about disabilities. Rather, it is a book that gently but surely reminds us just how much we all need “something to hang on to.” (Doucet, 2009, p. 34)

*Something to Hang On To* (Brenna, 2009) is a short story collection that portrays disability differently. There will be more discussion of her work later as well. While her writing is anti-ableist, this review is not. In stating that this book is ‘not a book about disabilities’, the reviewer is negating disability and the fact that Brenna is endeavoring to write about it differently. In that one statement, this reviewer has erased disability, since the assumption made here is that if these stories were *really* about disability, disability would be brought between us in expected, normative ways. The implication is that since these stories are about the complexities of ‘real’ life and what we all need in order to live it, they ‘cannot’ be about disability -- since (according to this review) disability is outside of real life and the purview of this collection. This review functions to remove the ‘threat’ of disability by forcing an anti-ableist work into ableist, normative confines.

Secondly, there is the following review of *The Moon Children* (2007), another work by Beverley Brenna:

Billy is not your average 11-year-old. He suffers from Fetal Alcohol Spectrum Disorder, which makes many things other kids take for granted difficult for him. He
can read only the most simple of words and has difficulty controlling his reactions to events around him.

As a result, he’s an easy target for bullies and has few friends. On top of this, his father has deserted the family and his mom, who works as a cleaner in a local third rate hotel, is pregnant with a second child.

Billy needs a friend and finds one in Natasha, a Romanian orphan adopted by a Canadian couple, who live across the street. It becomes clear that Natasha is hiding secrets from her past. Though she never speaks, she keeps a journal with illustrations of the different phases of the moon and other curiosities linked to the secret she cannot speak about.

Billy is a warm and curious child and consequently he and Natasha form a strong bond which allows them to be open with each other about their secrets and dreams.

When Billy enters a talent competition at the local park to show off his yo-yo tricks, things don’t turn out as they planned and he and Natasha find that they need each other more than ever.

Beverley Brenna has given us a poignant and well-written novel about an unusual friendship between two children, who, despite their differences, are able to give each other hope and encouragement. (Shantz, 2007, p. 33-4)

Billy is quickly framed as ‘suffering’ from his disabilities, and as ‘not...average’. The connection made between his disabilities and abnormality is clear. His suffering, this line of thought contends, stems directly from his difference, not the normative, ableist mindset and cruelty of others. His friendship with Natasha is written as ‘unusual’, and so made ‘extraordinary’. Their differences are immediately set apart, so that in this review disability is not written as between us and belonging to everyone. Billy and Natasha are also made into overcomers, since it is written that they ‘are able to give each other hope and encouragement despite their differences’ [italics mine].

In this review, the characters are living with, not in, their differences and disabilities. There is no mention of the fact (or even the possibility) that they enrich each other’s lives because of those differences. What is missing is well summarized in the following wisdom from Cultural Locations of Disability (2006):

the cultural model has an understanding that impairment is both human variation encountering environmental obstacles and socially mediated difference that lends group identity and phenomenological perspective. ...Oedipus Rex [is an example], where the limping Oedipus solves the sphinx’s riddle because of his experience
with mobility impairment (Snyder & Mitchell, 2000, 61). This insight shifts disability from either a medical pathology or signifier of social discrimination into a source of embodied revelation (Snyder & Mitchell, p. 10).

A short, revisiting word on Sylvia McNicoll's *Beauty Returns* (2006) and her conflicting and ultimately ableist and normative portrayal of blindness (discussed in Chapter Two of this thesis) is also fitting here. It is telling and ironic that in a review that discusses *Beauty Returns* as the final novel in a series of three (often referred to as ‘the Beauty trilogy) the ending of the series -- comprised of Kyle’s death and so the death of blindness -- is described as “satisfying and dramatic.” (Hamilton, 2006, last para.) Disability’s death is therefore written as satisfying. *Beauty Returns* is a popular book in school and public libraries, and McNicoll has won several awards for this book and the one before it in the series, *A Different Kind of Beauty* (2003), including the Canadian Children’s Book Centre Our Choice/Best Books listing in 2007, and the Hamilton Literary Award Program’s Mixed Media Award for Young Adult Books. She has also been nominated for The Red Maple Award and The Manitoba Young Readers' Choice Award.

I know from in-person conversations I’ve had with Sylvia McNicoll that killing off Kyle -- her blind character -- was not her decision. In fact, through some sources, I have been informed that some publishing companies have refused to publish novels that do not contain disability as usual – including extremely frequent deaths when it comes to disabled characters. This indicates the bias of marketing in the book industry toward tragic stories of disability. This pressure creates a majority of stories of disability in the market that portray disability’s erasure and the enforcing of normalcy. Also, it creates further bias against disability and misconceptions of it, in a mainstream society that believes ‘art imitates life’.

It is interesting that this novel has wide circulation in schools and among teens. It is not designated as a book for disabled readers, and this means its ableist normative message has wide circulation. In contrast, my novel -- written without the death of disability anywhere to be found -- has clearly been singled out as a book ‘for disabled readers’. Even in 2009, when it was on the International Board on Books for Young
People’s list of Outstanding Books for Young People *With Disabilities* [italics mine] this was true. The implication is that the novel was meant to be read only by disabled people. My disagreement and discomfort with this distinction and restriction comes from the fact that, again, disability is not portrayed as between us. In a feature article I wrote for *Canadian Children’s Book News* the same year, the following statement summarizes this best: “Literature featuring disability is not only for [disabled people] and their loved ones. Ask yourself: Is *Anne of Green Gables* meant to be read only by orphans?” (Minaki, 2009, p. 13)

**Brilliance Caught in the Normative Web: Ableist Disability Portrayal in Jodi Picoult’s Novel, *Handle With Care***

To be a writer of fiction is to be consistently negotiating a balance between telling a story, putting the story first, and ensuring that it is commercially viable -- in short, that it will sell, and reach a wide audience.

It has been said that, as a writer, Jodi Picoult “delivers […] a winning combination of the literary and the commercial” (Jordan, 2007, para. 1). This is certainly true. Picoult is one of my favourite authors -- gifted in her precise, elegant use of language, her choice of plots that are intricate and fit together memorably, and her striking, thought-provoking characters. One of her latest novels, *Handle With Care* (2009), is no exception, but on several levels, her depiction of disability is worrisome. As a way into illustrating exactly what I mean, I will begin with a brief synopsis of *Handle With Care*, from Picoult’s website:

When Charlotte and Sean O'Keefe’s daughter, Willow, is born with severe osteogenesis imperfecta, they are devastated – she will suffer hundreds of broken bones as she grows...As the family struggles to make ends meet to cover Willow’s medical expenses, Charlotte thinks she has found an answer. If she files a wrongful birth lawsuit against her ob/gyn [who is also her best friend] for not telling her in advance that her child would be born severely disabled, the monetary payouts might ensure a lifetime of care for Willow. But it means that Charlotte has to get up in a court of law and say in public that she would have terminated the pregnancy if she’d known about the disability in advance – words that her husband can’t abide, that Willow will hear, and that Charlotte cannot reconcile. (“Handle with Care”, n.d., para. 1-2)
In fairness, Picoult's portrayal of disability is in some ways encouraging. It is made abundantly clear that going forward with the court case is written as what it is: a fundamentally negative, oppressive undertaking -- a huge and hurtful mistake with plenty of regret and regretful consequences. Charlotte's case hinges on the idea that her obstetrician made a 'mistake' by missing the one indicator on the first ultrasound that would have allowed her to diagnose Willow's disability in utero, and at a stage in the pregnancy when the fetus could have been aborted most easily. Though the intentions of Willow's mother are written sympathetically (she is truly convinced, at least at first, that pursuing and winning the wrongful birth suit is the only way to have enough money to support Willow in the future), Picoult makes it clear that her character, Charlotte, is misled but is motivated (by love) to make a ghastly choice in order to provide for her daughter with the proceeds from the multi-million dollar lawsuit. However, at the same time as we are made to understand her motives as a devoted mother, by exposing Charlotte's passionate opposition in the disability community, the toll this case takes on her and her children, her husband and her best friend -- and especially the psychological impact of the case on five year-old Willow herself -- Picoult makes sure readers are asked to question what they believe about disability, human life, and the right to be born and live a full, good life. Readers are also asked to question normative perceptions of who is -- and who is not -- living a good life. Jodi Picoult's message -- it seems -- is clear: the lives of disabled people are worth living.

But Picoult's disability portrayal is not straightforward, of course. The ableist, normative perspectives she has internalized are unmistakable. Beginning even before the opening of the first chapter, normativity shows up in the acknowledgements section of the novel. Consider the following paragraph:

[A very special thank you to] Kara Sheridan, who is one of the most inspirational women I've ever met: she's a scholar studying body image and self-esteem for disabled teens. She's an athlete -- a swimmer who's broken records. She's about to get married to a wonderful, adorable guy. And oh, by the way, she also has Type III osteogenesis imperfecta. Thanks, Kara, for showing the world that barriers were meant to be broken, that no one can be defined by a disability, and that nothing's ever impossible (Picoult, 2007, p. viii).
Kara Sheridan is written as an “inspirational overcomer” (Titchkosky, 2007, p. 182), whose worth stems from her success as a scholar, record-breaking athlete, and fiancée ‘despite’ her disability which is depicted as mere happenstance, i.e. ‘And oh, by the way…’ Her disability is brought forward as that which would be a barrier, but for her ability to overcome it. Kara’s worth is portrayed as coming from her ability to meet normative milestones. Also, the phrase ‘oh, by the way, she also has osteogenesis imperfecta’ serves to erase her disability, make it of no consequence, instead of presenting it as an integral, essential part of her, her life and perspective. We need to read her life and her disability as connected, but the above description does not encourage this. It encourages the opposite, instead

Furthermore, after reading Handle With Care (2009), it is clear to me that this is how Picoult portrays Willow: as a girl who has a lot of worth ‘even though’ she is disabled. To her credit, I must say that Picoult has gone some distance in stating that disability is not synonymous with people of inferior intelligence and insight, people who are -- by definition -- dimwitted under-achievers who cannot and should not be in charge of their own lives and bodies. While I am glad for this, it is a double-edged sword. For example, consider the following excerpt:

[Willow] looked up at [the doctor]. "I broke my clavicle once. It hurt more. Did you know that clavicle means 'little key' -- not just because it looks like one but because it connects all the other bones in the chest?"

Dr. Dewitt's jaw dropped. "Are you some kind of Doogie Howser prodigy?"

"She reads a lot," I said, smiling.

"Scapula, sternum, and xiphoid," Willow added. "I can spell them, too.

"Damn," the doctor said softly, and then he blushed. "I mean, darn." (Picoult, 2009, p. 111)

By writing Willow as a “prodigy”, she and her disability are brought into our social space as extraordinary, unreal -- a rare phenomenon, not a part of everyday life and embodiment that is always between us in society. We (disabled people) are oppressed and excluded because we are outside the norm, yet we must at the same time be extraordinary achievers in order to strive for as much normativity as possible, ‘despite’
our disabilities. This is an oppressive, hurtful contradiction. It is never stated in the novel (or in mainstream society) that disabled people have a right to be on the planet *because they are here.* The statement is always that we can achieve, and we have worth because of those achievements -- especially if what we achieve is a process of striving for normalcy and never questioning its supremacy. Moreover, in the case of overcoming, our ‘abnormal’ embodiments, the faulty logic goes, do not ‘stop us’ from being productive members of society. This perception does disability in two oppressive ways: first, it presents a version of disability that is nothing more than an obstacle -- an obstacle that needs human courage to reverse its ‘negative’ power. Secondly, this misconception pits us -- disabled people -- against normative definitions of productivity. For example, in court, the case is made for the validity of Willow’s life by stating that Willow could grow up, fall in love, get married, have a child, work, and live ‘independently’. The side of the argument fighting for the worth of Willow’s life hinges on the argument that Willow would have all of these abilities ‘despite’ her disability. This is inherently oppressive, since there is no mention of even the idea that her disability itself is welcome in the world, that disability itself is a valuable teacher regarding the worth and importance of alternative embodiments and other valid ways of being in the world. It is amazing to me that these ‘disability as usual’ approaches lack the creativity and imagination expected of writers. We are, after all, regularly told that as authors, it is our job to be consistently original.

Independence being the normative sign of a good life -- the life of a person who needs no one -- prejudicially assumes that independence is possible (that no one normal needs anyone else too much.) Yet, what this viewpoint denies is that independence is a fallacy. Disability brings this point forward in clear, unmistakable ways and so it is hated by normalcy.

Let us consider one more excerpt from Picoult’s novel, the scene where Charlotte’s lawyer meets Willow for the first time:

I bet there was a great deal you knew that none of us did, or ever would. It was a little disconcerting to be sitting with an almost-six-year-old whose vocabulary probably rivaled mine. "So tell me something I don't know," I said.
"Dr. Seuss invented the word nerd." I laughed out loud. "Really?"

You nodded. "In If I Ran the Zoo. Which isn't as good as Green Eggs and Ham. Which is for babies, anyway," you said. "I like Harper Lee better."

"Harper Lee?" I repeated.

"Yeah. Haven't you ever read To Kill a Mockingbird?"

"Sure. I just can't believe you have." This was the first conversation I'd really had with the little girl who was the eye in the storm of this lawsuit, and I realized something remarkable: I liked you. I liked you a lot. You were genuine and funny and smart, and maybe your bones broke every now and then. I liked you for dismissing your condition as the least important part of you - nearly as much as I disliked your mother for highlighting it. (2009, p. 225)

The erasure of Willow’s difference is unmistakable here. It strikes me that the lawyer, Marin Gates, finds it remarkable that she likes Willow -- as though it is unbelievable that she would like a disabled child. In a society where disability is so feared and hated, and perceived in normative circles as worthy only of being erased or overcome (a fact which is itself oppressive) it is interesting to note that society’s dislike for bodily difference often translates into general dislike for disabled people -- so that, when an opposite reaction takes place it is perceived as remarkable or surprising. This is troublesome. But the lawyer’s reasons for liking Willow are even more disturbing than her surprise. She says: ‘I liked you for dismissing your condition as the least important part of you -- nearly as much as I disliked your mother for highlighting it.’ In this, the reader is positioned as one to take pleasure in this common understanding.

Above, Willow is liked for making it possible for Marin to forget (erase) her disability. Willow is praised for making her disability ‘the least important part’ of herself, and her mother is disliked for ‘highlighting it.’ Marin’s admiration for Willow stems from the (mis)conception that Willow is so ‘genuine and funny and smart’ that her disability ‘doesn’t matter’. She is the one who ‘knows things no one else knows’, who loves reading Harper Lee’s To Kill A Mockingbird. In other words, Willow is such an achiever with high potential that she has ‘overcome’ her disability -- that which, by normative definition, makes people not achieve and be unlikeable. There are many sources of oppression here. Notably, there is the normative assumption that Picoult’s portrayal of Willow -- the ‘inspirational’ disabled girl -- is positive and progressive, instead of
prejudicial and stereotypical. When Willow’s disability is made to ‘not matter’, it is made
to disappear. From a disability studies perspective, this is at once an interesting and
highly offensive move. But the good news is that -- despite considerable efforts (literary
and otherwise) to erase it even while being ‘positive’ about it -- disability does matter
and does not disappear. Willow’s osteogenesis imperfecta is part of her and belongs to
her and to everyone around her, however much normalcy’s restriction attempts to
dictate otherwise.

There some more good news. Witness the passage below:

"You know why this lawsuit is so captivating? It's like a train wreck. You can't tear
your eyes away, even though you'd rather not admit these kind of torts exist," he
said. "Plain and simple: this topic is loaded. This is exactly the kind of lawsuit that
makes your skin crawl, because we'd all like to believe that we might love any child
that comes into our family--instead of admitting that, in reality, we might not be that
accepting. Prenatal testing reduces a fetus to one trait: its disability. It's
unfortunate that prenatal testing automatically makes the assumption that a parent
might not want a child who's disabled, and that it implies it's unacceptable to live
life with some sort of physical impairment. I know plenty of parents in the deaf
community who would love a child just like them, for example. One person's
disability is another person's culture." (Picoult, 2009, p. 439)

The point made here is essential to disability and disability studies: the activist
speaking here exposes the general unwanted status of disability and then makes the
important opposing shift from that normative oppression to the freedom of disability
perceived within the disability community not as tragedy to be avoided but as culture to
be embraced. For this disability portrayal I am thankful.

However, the description of the activist that precedes this portrayal is the epitome
of oppressiveness expressed through disability as an overcoming story. The character
of Lou St. Pierre is done as impressive because of his over-achieving and overcoming
of his disability -- even as he remains disabled. Note the passage that follows:

At the top of the stairs was a man I recognized from the news: Lou St. Pierre, the
president of the New Hampshire chapter of the American Association of People
with Disabilities. As if that wasn't impressive enough, he had a degree from Yale
Law, was a Rhodes scholar, and had won a gold medal in the breast stroke at the
Paralympics. Now, he traveled both in his customized wheelchair and in a plane
that he piloted himself to fly kids around the country for medical treatment. His
service dog sat by the side of St. Pierre's wheelchair, unflinching, while twenty reporters jammed microphones close to its nose (Picoult, 2009, p. 439).

On the other hand, the entire novel fluctuates between exposing the injustice of prejudice against disability and paradoxically reproducing said prejudice. It is also worth noting that Marin’s stated dislike for Willow’s mother -- her own client -- is based on the fact that Charlotte filed a case, which “highlights” (Picoult, 2009, p. 226) Willow’s disability, (which everyone would clearly love to erase.) But, from a disability studies perspective, it is not highlighting disability that is oppressive. After all, we in the disability studies community highlight our disabilities -- as valuable embodiments, as a valid state to live in by choice, as a proud way to be. The problem with Charlotte’s choice to file the suit is not her choice to highlight Willow’s disability. The problem is the way it is highlighted, the inherent statement upon which her side of the case rests: that if the obstetrician had done her job and diagnosed Willow’s disability in utero and early enough, Willow’s disability -- and so Willow herself -- would and should never have existed.

So Here We Are Again: Death Comes Knocking on Disability’s Door

I should have expected it. By now I’ve read it so many times in books that feature disability, I sometimes catch myself thinking I should be used to it -- the disabled character who suddenly, ‘tragically’ and ‘unexpectedly dies in the novel. But there is no getting used to it, nor should there be. Becoming acclimatized to such oppression of disability means coming to accept, internalize, and reproduce it -- which is unacceptable to me both as a disability studies scholar and a member of society committed to perceiving, living, writing and teaching disability differently.

So when I first read the ending of Handle With Care (Picoult, 2009), I was both stunned and angry. Willow’s death is written as follows:

You would think I'd have been scared. But I could hear my mother, telling me a story before I went to bed, about a coyote who wanted to capture the sun. He climbed the tallest tree, and he put it in a jar and brought it home. That jar, though, it couldn't hold something so strong, and it burst. See, Wills? my mother had said. You are filled with light.
There was glass above me, and the runny eye of the sun in the sky, and I beat my fists against it. It was like the ice had sealed itself on top of me again. and I couldn’t push through. I was so numb. I had stopped shivering.

As the water filled my nose and mouth, as the sun got tinier and tinier, I closed my eyes and curled my fists around the things I knew for sure:

That a scallop has thirty-five eyes, all blue.
That a tuna will suffocate if it ever stops swimming.
That I was loved.
That this time, it was not me who broke. (p. 472-3)

At twelve years of age, six years after Willow’s family had won eight million dollars in the lawsuit -- a lawsuit undertaken by Willow’s mother in the interest of gaining the financial resources to provide for her future -- Willow drowns by falling through ice in her frozen-over backyard pond. In digesting this ending -- yet another instance of the death of disability (and disability written as death) -- I realized that, like the character of Charlotte in the novel, Jodi Picoult had ‘good’ intentions in choosing this ending. I can imagine she wanted to show that all the damage done by the lawsuit should never have happened. Through Willow’s death, Picoult exposes the lawsuit as utterly pointless. All the psychological, emotional costs of the lawsuit, considered ‘worth it’ because of Willow’s long-term financial best interest, were -- it turns out -- not even necessary since Willow did not survive. The statement is this: ‘Look at all that was sacrificed by this family, all that was both nearly and actually lost. And all was for naught! So live one day at a time and don’t cause people pain.’ In fact, in an interview, when she was asked about her ending, Picoult said the following:

I do know the ending before I write a single word, and I did here too. I will tell you that I think Handle with Care is the saddest book I’ve written -- and coming from me, that's pretty dire! I never wavered on the ending, however, because there’s a bit of a morality lesson in there as well -- it's a real "Be careful what you wish for" moment. (“Handle with Care”, n.d., Answer 9 in Conversation Section)

But the death of Willow is not the only ending that could have illustrated and taught that lesson. For example, what if, when it was all over and the lawsuit had been won, Willow found the cheque and tore it up herself? This would be a shocking, effective ending that would give Willow the agency she deserves.
As per the usual in the book industry, however, Jodi Picoult has been rewarded for internalizing and reproducing normative oppression (even as she is sure she is resisting it). In the first week after the release of *Handle With Care* (2009), the novel was first on The New York Times Best-Seller List for hardcover fiction, and remained within the top fifteen books on the list for a total of ten weeks, beginning on March 22nd, 2009. It was first on the list for three weeks (New York Times, 2009).

In the final analysis, whatever her ‘noble’ intentions, we end up with another best-selling book that portrays disability as synonymous with extreme sadness and death. The norm survives and disability, firmly placed as the ‘other’, does not. Willow had intelligence and dreams, but would never see those dreams realized, despite having the money to finance them. The goals of disabled people, then, are written as pointless. Even though other disabled minor characters in the novel are portrayed as successfully living and reaching goals, Willow -- who is the focus of the story -- is not portrayed this way. Regarding Kara Sheridan, Picoult said the following in an interview:

> When I asked her what she wished people would know about OI [Osteogenesis Imperfecta], she said it's a challenging and painful condition, but it doesn't mandate a tragic life. The moments she's cherished the most have come about because of her condition, and are just as important a part of OI as the medical difficulties. (“Handle with Care”, n.d., Answer 1 in Conversation Section)

Even though Picoult wholeheartedly thanks Kara Sheridan (a successful disabled woman) for her insights, input and ‘inspiration’ in connection with the novel, it is not Sheridan’s example of a long happy life living in disability that was used in the story Picoult told. The normative ideal of disability’s death won out. My disappointment here does not stem from believing that every book should have a happy ending. But what points to normative oppression -- and so angers me -- is the fact that so many stories of disability end in tragedy, sadness and death surrounding the disabled character or portion of the book dealing with disability. Despite Picoult’s intention to show through this novel that disability should not be killed off, she ended up portraying just the opposite. Picoult may think it is positive and progressive to show that Willow did not die because of her disability, but her death still reinforces the norm. It is as if this is the message: Even when Picoult aims to show that disability is not a tragedy, she produces
tragedy and that is what disability is ‘meant’ to be. I want books that tell the stories of the death of the fallacy of normalcy and the life of disability. And I intend to write them. But that is a separate point. For now, my point, in colloquial terms, is this: Let someone else die, for a change!

**What Do We Do Now?**

In his book, entitled *The Difference that Disability Makes* (2002), Michalko states that “disability provides a ‘now that’. What shall [we] do and how shall [we] live now that [we are disabled]” (p. 19)? I would like to use Michalko’s question as a basis to ask another, related question. What shall we do and how shall we live now that we know that we live in a society where oppression of disability is the norm, where the book industry oppresses disabilities through enforcing normative portrayals of disability in literature? How do we live effectively in that tension and reach anti-ableist disability portrayals, understanding that we do not live in a perfect world and so must work at the process from within the muck and mess of the in-between space where we find ourselves.

First, we can theorize and expose oppression through analyzing normative portrayals (see above, and see the content of Chapter Two of this thesis.) Secondly, we can rework and rethink these portrayals to find ways in which they unwittingly serve and support the disability studies perspective. (See the section below for both approaches to analysis.) Or, thirdly, we can analyze, theorize, discuss and write fiction that portrays disability differently, in anti-ableist, anti-oppressive, non-normative ways. Such theorizing and discussion of fictional works that liberate disability from normative portrayals will be undertaken in the following chapter.

For an example of both critique and reading an oppressive portrayal otherwise – to bring it in line with disability studies -- consider the following analysis of an excerpt from Lori Lansen’s novel, entitled *The Girls* (2005).
Double Trouble: Choosing The Girls

In my search for another literary text that brings bodies of difference and normalcy’s oppression into undeniable focus, *The Girls* (Lansens, 2005) ‘jumped’ to mind almost immediately.

A novel about conjoined twins, it ‘does’ bodies in compelling, captivating ways and forces readers to confront definitions of ‘normal’ and ‘abnormal’ bodies and their relationship to life, its meaning, and its quality. This novel places the body between us in ways that grant the body its vital role as a physical entity that matters. Although parts of this text have been disturbing to work with, the ‘body of work’ it has fostered from me (my body) has been illuminating work to do. Witness the excerpt:

I have never looked into my sister’s eyes. I have never bathed alone. I have never stood in the grass at night and raised my arms to a beguiling moon. I’ve never used an airplane bathroom. Or worn a hat. Or been kissed like that. I’ve never driven a car. Or slept through the night. Never a private talk. Or solo walk. I’ve never climbed a tree. Or faded into a crowd. So many things I’ve never done, but oh, how I’ve been loved. And, if such things were to be, I’d live a thousand lives as me, to be loved so exponentially.

My sister, Ruby, and I, by mishap or miracle, having intended to divide from a single fertilized egg, remained joined instead, by a spot the size of a bread plate on the sides of our twin heads. We’re known to the world medical community as the oldest surviving craniopagus twins (we are twenty-nine years old) and to millions around the globe, those whose interest in people like us is more than just passing, as conjoined craniopagus twins Rose and Ruby Darlen of Baldoon County. We’ve been called many things: freaks, horrors, monsters, devils, witches, retards, wonders, marvels. To most, we’re a curiosity. In small-town Leaford, where we live and work, we’re just “The Girls.”...

Ruby and I are identical twins and would be identical looking, having high foreheads like our mother and wide, full mouths, except that Ruby’s face is arranged quite nicely (in fact, Ruby is very beautiful), whereas my features are misshapen and frankly grotesque. My right eye slants steeply towards the place my right ear would have been if my sister’s head had not grown there instead. My nose is longer than Ruby’s, one nostril wider than the other, pulled to the right of my brown slanted eye. My lower jaw shifts to the left, slurring my speech and giving a husky quality to my voice. Patches of eczema rouge my cheeks, while Ruby’s complexion is fair and flawless. Our scalps marry in the middle of our conjoined heads, but my frizzy hair has a glint of auburn, while my sister is a swingy brunette. Ruby has a deep cleft in her chin, which people find endearing.
I'm five feet five inches tall. When we were born, my limbs were symmetrical, in proportion to my body. Presently, my right leg is a full three inches shorter than my left, my spine compressed, my right hip cocked, and all because I have carried my sister like an infant, since I was a baby myself, Ruby's tiny thighs astride my hip, my arm supporting her posterior, her arm forever around my neck. Ruby is my sister. And strangely, undeniably, my child...

“Do you think I'm pretty, Frankie?”

“You're a mutt,” he said, laughing.

“Seriously,” Ruby said.

I hummed beside her.

Frankie sat up a little, appraising her. “You're ... I don't know ... I mean, you'd be, you know, you'd be ... if, you weren't like that, you'd be all right I guess.”

I felt Ruby's blood rush to her cheeks. “Ya think?”

“Sure.”

“If I wasn't like this?”

“Yeah.”

“All right enough to kiss?” Ruby asked, shocking me, and herself (not to mention that Frankie Foyle couldn't have seen that coming). I glimpsed Frankie's distorted reflection in the smooth plastic lid of the turntable. His mouth was hanging open again.

“Well?”

“I don't know,” he said. “I guess.”

“Kiss me,” Ruby said.

I had never met this bold sister, this brave Ruby, this sister who desired a kiss so badly she risked the cruelest of rejections.

“Fuck that.” Frankie laughed.

“Afraid?” she taunted.

“Yeah, I'm afraid.”

“You won't turn into a frog.”

“What'll I turn into?”

“Kiss me and see.”
There was a pause in which Ruby must have convinced Frankie with her eyes, or with her lips, or in some other mysterious way that women convince men to do surprising things because, in a moment, I heard a wet sound and knew that Frankie Foyle was kissing my twin sister. I felt sick from the booze, and the smoke, and the envy.

Frankie pulled away from Ruby's lips. “Too fuckin' weird,” he said, swinging his head from side to side.

“Aren't I a good kisser?” Ruby was asking frankly.

“You're all right. It's just weird.”

“Once more. Come on,” Ruby said. “I won't tell.”

Frankie Foyle gestured my way without actually looking at me. “What about her?”

I closed my eyes.

“She won't either. She won't.” Ruby promised.

Bob Dylan sang. Frankie kissed Ruby. I could not see, but only hear the sound of their kisses as the needle on the stereo arm popped and snapped with dust. They kissed as the next track played. They kissed and kissed as that song finished and another began. I could hear from within the sound of Ruby swallowing. I thought I could feel Frankie's tongue.

I wondered if Uncle Stash or Aunt Lovey had realized their mistake by now. I hoped they hadn't. I wanted Frankie Foyle to kiss me too and didn't want to miss my turn.

But Frankie didn't kiss me. My turn never came. Frankie kept kissing Ruby. Even when his fingers crept spider-like onto my shoulder and dropped down inside my blouse to find the nipple of my right breast. And even when his hand slid lower, traversing my flat stomach and thighs. And even when he shifted me, because he wasn't quite comfortable, and even when he parted my long legs, Frankie kept kissing my sister.

And even when...

Even then.

I didn't protest. Neither did my sister. I believe we were struck by the strangeness of the moment. We've never discussed it directly, but the kissing must have been amazing for Ruby to have endured my part in the affair.

After. Shivering. Ashamed. I asked Frankie for a tissue.

“Use the bedspread,” he said…

The following Monday, when Aunt Lovey was at the hospital, we found our seat on the bus. We had practised how we'd say hello, casually, in different ways at
different times. Frankie Foyle barely grunted and would not meet our eyes. We never spoke another word to each other. I hated his regret (Lansens, 2005, p. 1-3 & p.152-155).


Upon my urging, a relative of mine read *The Girls* (Lansens, 2005) shortly after me. We had a long discussion about Rose and Ruby, their conjoined bodies, and their experiences within those bodies. Since my relative’s conceptions of disability and bodies of difference are very different from my own, the discussion was at times a frustrating one to have. Detailed below is a small portion of said discussion:

ME: It took me awhile to get through the scene where Frankie was kissing Ruby while he had sex with Rose. I couldn’t get over how he objectified them.

MY RELATIVE: Oh, Christina, he just got confused. You think too much!

My frustration stemmed from knowing that conjoined body does confuse many boundaries and understandings, but also knowing that that confusion is part of the important, necessary work of conjoined-ness – and all forms of bodily difference. That my relative appeared ready to give Frankie a ‘free pass’ for his actions, that she had said I ‘think too much’ because I don’t see Frankie as simply a boy who got carried away while having sex, all of this annoyed me. First of all, the word ‘just’ simplifies the complexity of conjoined-ness and ‘does’ the conjoined body as object. It ‘does’ Frankie’s actions as understandable in relation to those bodies.

By saying that I ‘think too much’, my relative was minimizing the need to theorize bodies. Her words also delineate her own desire to stay near the surface of bodies of difference – to avoid confronting her own discomfort surrounding these bodies, and the ways in which that discomfort leaks into her complex struggle surrounding my disability.

I think, on some level, my relative understood that Rose and Ruby – through their conjoined-ness – have much to teach her, and all of us, about the fragility of the very normality society has come to rely upon as the absolute corporeal standard. My relative – despite having the best of intentions (she truly had not meant to upset me) – was
resisting those lessons. The understanding I believe she was most afraid of is summarized best below:

Indeed, it is hardly the broken body that is fragile and vulnerable, though clearly that may be perceived as monstrous…but the 'normal' body itself. Although the monstrosity of chronic disease, [conjoined-ness], or disability overtly undermines any notion of a securely embodied subject, that ordinary body is not given, but is always an achievement. It is a body that requires constant maintenance and/or modification to hold off the ever-present threat of disruption: extra digits are excised at birth, tongues are shortened in Down's syndrome children, noses are reshaped, warts removed, prosthetic limbs fitted, 'healthy' diets recommended, HRT prescribed. And in such cases, it is the unmodified body which is seen as unnatural, in need of 'corrective' interventions. In short, the normal body is materialised through a set of reiterative practices that speak to the instability of the singular standard (Shildrick, 2002, p. 55).

My answer to her avoidance, reluctance, and fear is to delve into and examine the very bodies and understandings she wanted to keep at a distance – to theorize, and thus disturb the very normality she wanted to keep in tact. Through the body of work that follows, I hope to make conjoined bodies (and bodies of difference) matter in all of their complexity. The writing below explores the bodies that my chosen excerpt of The Girls (Lansens, 2005) needs to do its work, as well as the ways in which this text has offered me new ways to think about the body.

**The Bold and the Beautiful, the Bad and the Ugly…Bodies Needed to Do the Work of This Text**

The bodies needed by this text can be described in many ways: interdependent (‘I have carried my sister like an infant, since I was a baby myself’), grotesque (‘My features are misshapen and frankly grotesque’), beautiful (‘Ruby is quite beautiful’), disproportionate (‘My right leg is a full three inches shorter than my left, my spine compressed, my right hip cocked’) disfigured (‘My right eye slants steeply, my nose is longer than Ruby’s, one nostril wider than the other. My lower jaw shifts to the left. Patches of eczema rouge my cheeks’), monstrous (‘We’ve been called many things: freaks, horrors, monsters, devils, witches…’) daring (“All right enough to kiss?” Ruby asked, shocking me, and herself’), shamed (‘I didn’t protest. Neither did my
sister…Frankie Foyle barely grunted and would not meet our eyes’), terrifying (‘Afraid?’ she taunted), and bold (‘I had never met this bold sister….this sister who desired a kiss so badly, she risked the cruelest of rejections’) (Lansens, 2005).

The bodies of Rose and Ruby Darlen are done in all of these ways through this text. These bodies are also intensely human and intensely connected, and so hard to pin down, define, or confine to conventional borders. Each and every body exists in relation to others, and the twins’ conjoined state illustrates this in specific, unique ways. They are bodies that lack many privileges – privacy, conventional freedom, capacity for solo activities or anonymity. The basic privileges of wearing a hat, raising arms to the moon, bathing alone, going for a solo walk, etc., are missing. And this ‘missing’, as well, only becomes clear in relation to other bodies – the freedoms they can enjoy as compared to the restrictions placed on Rose and Ruby since their bodies are conjoined, thus constantly linked together.

Furthermore, we notice that Rose has internalized the idea that she is “grotesque”. It is clear here that conventional, ‘normalized’ standards of beauty versus ugliness, and what constitutes each – have prevailed in Rose’s perception of her body and her perception of Ruby’s. She perceives of herself as ‘the ugly twin’, while Ruby is the beautiful one – in fact, the one named after a jewel. This perpetuates the ‘doing’ of these bodies along stereotypical lines. Readers, then, take Ruby and Rose into their bodies along these lines. The text, in turn, needs these ‘normalized’ perceptions of the girls and their conjoined state (ugly, beautiful, burden, parasite, trapped, etc.) to draw readers into its world using representations of the conjoined state that they are most likely to readily recognize from a (likely) non-conjoined and/or anti-conjoined viewpoint.

As previously mentioned, in the text, Rose states: ‘We’ve been called many things: freaks, horrors, monsters…witches…wonders, marvels. To most, we’re a curiosity.’ The bodies of Rose and Ruby are done in all of the above ways through the text. Their bodies feed a morbid fascination, which ultimately drives their sexual experience with Frankie Foyle.

Their bodies are objectified to a very high degree in the second portion of the text – the portion describing their encounter with Frankie. They are treated rather like dark
novelties, and for Frankie Foyle the attraction to Ruby is horrifying in its pull. Frankie describes Ruby as ‘a mutt’ – which frames her body as indistinct, its individuality indistinguishable and non-existent, since she is forever linked with Rose. Frankie’s use of the word ‘mutt’ is undoubtedly a reference to her body’s conjoined state. It is in fact a devaluing of her body, since it seems a taken-for-granted truth that ‘mutts’ are of less value than purebreds. He says that Ruby would be ‘all right’, if she weren’t ‘like that’, so the body the text needs here to construct this moment is one made undesirable because it is conjoined. ‘Like that’ implies an “excludable type” (Titchkosky, 2007, p. 5).

The fact that Ruby’s conjoined state makes her excludable is an ironic and compelling ‘double standard’. Being excludable means being separate, divided, isolated, alone. Yet, Ruby is ‘excludable’ exactly because she and her sister (their bodies) fit none of these descriptors.

The text also needs Ruby’s desperate body, desperate enough to tantalize Frankie, to coax him into a sexual encounter and risk rejection and objectification. In the end, both occur. They are understood as the price of the twins’ sexual experience. This understanding ‘does’ the unusual body as undesirable.

The following excerpt from “Jarring Bodies: Thoughts on the Display of Unusual Anatomies,” an article by Alice Domurat Dreger (2000), discusses the understanding of unusual bodies as powerless, silent, and “monstrous” and how that understanding is gradually being disturbed, by critiques like hers.

The word monster shares the root with demonstrate, the monstrous is that which portends. The ancient reaction to “monsters” was to kill the messenger. The more recent reaction has been to paint the anatomically unusual person as unfortunate, in need of paternalistic care. In this unique age of ours, between the age of killing the messenger and preventing the messenger, in the age in which the messengers are starting to speak, to object, to engage, to be heard, I wonder what the reaction will be. I know that I have found it terribly difficult to convince some that people with unusual anatomies not only do have a voice, but that they should have a voice, a say in the deal, the right to criticize and perhaps even dictate how they will be displayed…(p. 484).

However, it would be wrong to define Ruby and her body in only the above ways. Simultaneously, paradoxically, the body needed in this part of their story is desirable, as
is shown by the representation of Ruby and Frankie kissing continuously and repeatedly. The desire between them is palpable. Rose and Ruby’s bodies swing between excludable and desirable. (Rose’s body becomes desirable to Frankie, in a disturbing way, when he uses it to complete the sexual act – although ‘desirable’ may be a questionable word to use here, since Frankie shows Rose no regard whatsoever.) To be fair, neither does Ruby. She herself only refers to her sister to ensure her silence.) Although the kissing makes Frankie’s interaction with Ruby pleasurable, Ruby is demeaned by Frankie’s choice to involve her twin – as though he can swing between them without permission, as if their bodies are interchangeable or ‘one and the same’, as if Ruby and Rose are the same person, as if consent from one equals consent from both.

At one point during her dialogue with Frankie, Ruby dares him to kiss her and reassures him that he ‘won’t turn into a frog’. Ironically, the very convincing that gets her what she wants also makes reference to the ‘doing’ of her body as that of a witch. In this way, the convincing of Frankie can be read as the ‘bewitching’ of him. This lends Ruby her agency but also portrays her as evil.

Ruby (her body) is also powerful and has a strong voice in that she convinces Frankie to kiss her, and in that she takes the encounter ‘into her own hands’, reminding everyone (herself, Rose, Frankie, and all bodies reading *The Girls*) that her body is indeed a sexual one, that she is a sexual being, that this text needs a sexual body with agency to do its work. In response to Ruby’s interaction with Frankie, Rose says:

There was a pause in which Ruby must have convinced Frankie with her eyes, or with her lips, or in some other mysterious way that women convince men to do surprising things because, in a moment, I heard a wet sound and knew that Frankie Foyle was kissing my twin sister (Lansens, 2005, p. 153).

Here, Ruby’s body is ‘in the driver’s seat’, but the boldness and agency she shows are contrasted with Rose’s (apparent) lack thereof.

In fact, although Rose narrates the scene involving Frankie, and ends up participating in it since her body is used in the sexual act, she does not actually say one word. She is entirely an “absent presence” (Titchkosky, 2007, p. 55). Frankie gestures
toward Rose ‘without even looking at [her]’, she closes her eyes while Frankie and Ruby kiss – in an attempt to remove herself from the scene. She says nothing when her turn to be kissed never comes, or when her body begins to be used completely for Frankie’s pleasure, but not her own. Rose seems to exist in the scene only for Frankie’s convenience. He ‘finds the nipple of [her] right breast,’ his fingers and hands ‘creep’, ‘slide’ and ‘traverse’ along her body, he ‘shifts [her] because he wasn’t quite comfortable [italics mine], and ‘part[s] [her] legs’. Rose (the ugly twin) has no say in the matter and is completely devalued and objectified, while Ruby at least experiences the pleasure of being kissed repeatedly. The bodies needed here are clearly divided along ‘ugly’ and ‘beautiful’ lines. The ‘ugly one’ is used without regard for her need for, and right to, sexual enjoyment.

In his book, entitled *Stigma: Notes on the Management of Spoiled Identity*, Erving Goffman puts it this way:

> The attitudes we normals have toward a person with stigma, and the actions we take in regard to him, are well known, since these responses are what…social action is designed to…ameliorate. By definition, of course, we believe the person with a stigma is not quite human. On this assumption we exercise varieties of discrimination through which we effectively, if often unthinkingly, reduce his life chances (Goffman, 1963, p. 5).

The irony is that, no matter what he does, Frankie cannot succeed at dehumanizing the girls. They are very much present, their bodies taking up space in all of their conjoined glory. They are clearly human, yet their conjoined-ness makes them (their bodies) appear ‘monstrous’ and ‘unnatural’ at the same time as they are human (Shildrick, 2002). This complex duality destabilizes everything Frankie thinks he knows about bodies (the one-ness of bodies) and being human. In his resulting confusion, objectification is the ‘solution’ that is born.

Ruby is certainly objectified as well. She gets sapped of her agency and says nothing as her twin’s body is used sexually in the encounter, without the consent of either twin. Rose herself puts it this way:

> I didn’t protest. Neither did my sister. I believe we were struck by the strangeness of the moment. [T]he kissing must have been amazing for Ruby to have endured
my part in the affair...After. Shivering. Ashamed. I asked Frankie for a tissue. [He
told me to] use the bedspread (Lansens, 2005, p. 154).

Ruby endures Rose’s part of the ‘affair’ with Frankie. (‘We’ve never discussed it
directly, but the kissing must have been amazing for Ruby to have endured my part in
the affair.’) The fact that Rose refers to it as an affair is of course an indication that she
thinks of it as such, that she is overlooking the fact that her conjoined state lends the
episode a kind of ‘dual consciousness’, that being present at the scene was not her own
choice. and furthermore, she couldn’t have left without Ruby – who clearly did not want
to leave. It is also ironic that linking herself up with an ‘affair’ means that she feels a
sense of self-blame for what happened, for some level of enticement and provocation of
Frankie’s interest in her (if one can call using her body ‘interest’) – since that is
‘normally’ how affairs unfold, generated by mutual sexual interest, excitement, and
consent. It is as if Rose feels accountable (guilty) for luring him away from Ruby. With
one word – ‘affair’ – Rose’s feelings become clear. Ironically, Rose never once calls
what happens to her what it actually is: rape. Calling it an ‘affair’ delineates the fact that
she does experience the irrational guilt that often comes with being raped. It also shows
that she treats herself (her body) as though she has a singular corporeality, with all of
the ‘independence’ that would afford her. Rose has internalized the tendency to
singularize her conjoined body. Her non-conjoined version of conjoined-ness ‘frees her’
to blame herself. In re-visiting Goffman in order to help me theorize this, I read:

…[T]he standards [which the stigmatized individual] has incorporated from the
wider society equip him to be intimately alive to what others see as his failing,
inevitably causing him…to agree that he does indeed fall short of what he really
ought to be. Shame becomes a central possibility, arising from the individual’s
perception of one of his own attributes as being a defiling thing to

It is very interesting that Rose herself views what happened from a non-conjoined,
even an anti-conjoined, perspective. By calling the encounter an affair and not even
acknowledging that she did all she could to remove herself from the situation (closing
her eyes, humming, never saying a word out loud as events unfolded) it becomes very
clear that Rose blames herself for her part in the scene and for what was done to her
(as though she were a voyeur and Frankie’s accomplice). This is the ‘classic’ response of a rape victim.

While Rose’s expression of the encounter is voiced from a non-conjoined perspective, Frankie’s actions ironically reveal that his perceptions of the girls are completely conjoined. The lines between the sisters’ bodies are totally blurred for Frankie. He ‘conjoins’ Ruby’s bold agency, and so behaves as though he assumes that Ruby’s choices of enticement, her desires, would naturally apply to Rose as well. Yet, his ‘conjoining mentality’ does not include treating Rose with dignity or respecting her desire – the very desire he assumes is present.

Ruby’s objectification cannot be overlooked. For Frankie to turn to Ruby to start the sexual encounter, but not to finish it, and for Rose’s body to be used without either consent or affection illustrates that the objectification here ‘cuts’ both ways. This cutting applies to the twins, of course – to both of their bodies – but also to the writer and readers of *The Girls*, who are cut off from any new understandings of the reality of the conjoined experience. Difference – that is, any departure from ‘normal’ corporeal singularity – is taken up as grounds for objectification in the scene between Frankie and the twins. Conjoined-ness is reduced to a singular understanding here: as tragedy, as a dark reality that opens the twins up to victimization and ultimately closes them off from agency. Conjoined-ness is singularized as disadvantage. It is ironically understood as lack because of the very duality that makes it more than one and complicates embodiment.

Both of the twins are robbed of any right to “criticize [or] …dictate how they will be displayed” (Dreger, 2000, p. 484). Furthermore, it does not occur to either of them in the moment that they can demand agency at all. It is striking that Ruby ‘buys’ her experience with Frankie for the price of her and her twin’s silence (‘She won’t tell either. She won’t.’)

Frankie’s body is, of course, needed in the text as well. He is the ‘bad boy’ of the text, the one whose curiosity about the twins’ unusual bodies, and his (originally dormant) attraction to Ruby drives his actions in the scene. He is at once the afraid body (‘Yeah, I’m afraid’), the reluctant body, (‘You won’t turn into a frog…Kiss me and
see’) and the objectifying body (‘Use the bedspread’), but in the end, he, too, falls into the category of ‘ashamed body’ (‘Frankie Foyle barely grunted and would not meet our eyes. We never spoke another word to each other’)

A Blessed Mess: This Text and New Ways to Understand the Body

The first element of the text which most clearly offers up new ways to understand bodies – namely, in this case, conjoined ones – can be found near the beginning of the text, when Rose states: ‘So many things I’ve never done, but oh, how I’ve been loved. And if such things were to be, I’d live a thousand lives as me, to be loved so exponentially’. One of the routine ways to think of conjoined bodies is to assume that what they would want most is to be divided into separate, individual bodies. However, similar to disability, the conjoined state is more than the routine ways in which it is seen and done in our social space. In making reference to being loved ‘exponentially’, Rose opens up the possibility of a definition of conjoined-ness that exceeds the boundaries of routine understandings of bodies and ways of being in them. Conjoined-ness as an occasion and space for exponential love is much more than basic math – more than what can be ‘simply’ reduced to 1+1=2.

Understanding the conjoined state as, in part, a privilege, is a new way, a somewhat radical way, to ‘grasp’ these bodies. In reading that the abundance of love flowing between the twins would be reason enough to live exactly the same life, again, complete with all its struggles, discomforts, challenges and complexities, the assumption that conjoined bodies desire rescue is upset.

The text needs to manipulate the bodies of Rose and Ruby Darlen in order to offer those bodies both old and new possibilities. Rose physically carries Ruby. (‘Ruby’s thighs [are] astride my hip, my arm supporting her posterior, her arm forever around my neck. Ruby is my sister [,] [a]nd strangely, undeniably, my child.’) Placing Ruby permanently in this position lends to readings of her body as offering ‘paternalistic care,’ and in turn to readings of Rose’s body as that of a ‘parasitic’ twin.

At the same time, we see in this text the opening of understanding the possibilities for the twins’ bodies in an interdependent, bonded way. When we read, at the end of
the excerpt, that Rose and Ruby ‘practiced the way [they would] say hello, casually, in
different ways at different times’, we are treated to a glimpse of Rose and Ruby’s
opportunity to share their lives in a unique way because of their conjoined state – to
work through the difficult, complicated moments of their lives (as well as all of the other
moments) together. They are connected as best friends, only to an even deeper extent,
because for each body, there is no moment without the other.

Understandably, I think, I found portions of this text quite disturbing, i.e., the
portion describing the twins’ encounter with Frankie. Ironically, it was these disturbing
parts that offered the most innovative ways to think, re-think, encounter and re-
encounter the body. As Dreger states:

I am sure instead my reluctance came from my all-too-personal encounter with the
basic threat of unusual anatomies: they force the question of what and who is
normal, and the much tougher question of why we should prefer the 'normal". Is it
good to be “the normal one”? We like to ground particular identities (woman,
straight, adult, educated, authoritative) in particular anatomies (female, not-too-
butch, physically mature, dull haircut and glasses, able-bodied and articulate), and
the fact was that these people messed up in the anatomy/identity rules and
dichotomies and hierarchies I enjoyed keeping stable....I came to understand the
intense and almost universal attraction to these anatomies, these bodies that
loosened all the boundaries and set us all in motion....I understood finally how that
attraction to their gravity has led to so many power struggles over them (2000, p.
478).

Examining Frankie’s actions as a ‘power struggle’ over Ruby and Rose illuminates
some of the tensions behind his choices. In ‘messing up’ what he ‘enjoyed keeping
stable’ the girls' bodies brought him to a space of questions and instability surrounding
how their conjoining blew apart 'normal' corporeal singularity. Objectifying the twins can
be read as Frankie's way of trying to control them, to 'rein in' the destruction of
conventional corporeal boundaries, borders, and rules that the twins left in their wake.
Ironically, his attempt to control the twins and tighten the ‘loosened boundaries’ led to
their objectification – and a scene that brings to mind almost anything but control. In
this way, as their corporeality remains conjoined and complicated, the twins' bodies
resist attempts at normalization and docility even as their agency is stolen.
The Two-in-One Club: Living in Conjoined-ness

In trying to ‘master’ the bodies of Rose and Ruby, Frankie is attempting to live ‘with’ their conjoined-ness, not in it. He tries to separate himself from it (by ignoring Rose and focusing on Ruby) and yet he conjoins the sisters’ agency (by having sex with Rose while kissing Ruby). He dominates their conjoined-ness with his singular corporeality. He ‘puts up with’ the twins’ conjoined-ness by tolerating Rose’s presence in the room – as long as she doesn’t speak and as long as he has assurances that she won’t tell anyone about the encounter. In his book, entitled The Two-in-One: Walking with Smokie, Walking with Blindness (1999), Rod Michalko paraphrases perfectly the distinction between living ‘with’ versus ‘in’ difference, as he discusses the distinction in relation to blindness. Michalko states:

Conceiving of blindness as though it were a one-dimensional brute fact of physical nature is to abdicate any responsibility for its appearance in the world. This conception results in living with blindness in the same way that abdicating responsibility for nature results in living with it. We put up with it, we try to master it…This approach allows for no other life than the life with blindness. Living in blindness, however, requires a different interpretive distinction. It requires that humanity recognize its essential responsibility for any relation to nature. Such a recognition opens the society/nature distinction to a horizon of possibilities (pp. 182-3).

Frankie could have conducted himself in ways that would have honoured the person-hood of each twin, within their conjoined state. He could have kissed both, or kissed and made love to both – after discussing the possibilities with each of them. (This would have, of course, brought up other issues, but would have, at the very least, prevented the rape.) But instead he reduces and attempts to dehumanize them. He takes no responsibility for how his actions make the girls’ bodies appear in the world, for how he dominates their conjoined-ness while trying to ignore it (which is in itself an ironic duality).

In re-visiting Rod Michalko’s (1999) book, the following excerpt reveals much about the paradoxes and opportunities of conjoined-ness:

Smokie has reminded me, too, of the value of intimacy. Relationships, even the one between nature and society, are deepened and sustained through intimacy.
Sometimes we control and dominate nature; at other times we are controlled and dominated by it. Without intimacy, relations between nature and society become a mere matter of dominance and submission in which "society" dominates and "nature" submits. Intimacy allows the relationship between dominance and submission to become reciprocal, fluid, and dialectical. This is what life with Smokie has taught me. With his guidance, I have become intimate with him, with my world, and with my blindness (p. 188).

This intimacy is what is obviously missing in the girls’ encounter with Frankie, but through Rose’s reference to ‘exponential’ love between her and Ruby, and to ‘practic[ing] the way [they would] say hello, casually, in different ways at different times’, this text shows us their deep bond and interdependence, which is always more than that for which the singular conception of conjoined-ness allows. Here I return to Michalko (1999):

Smokie and I…are together in our movement as one and thus alone in the social world, and we are alone by virtue of our belonging to distinct species, as expressed in the togetherness of the nature/humanity distinction.…

What there is to be mastered, handled, or owned derives from Smokie and me—alone together. At times, we conceive of our togetherness in terms of mastering and handling the social world. We get through it, one as blind, the other as dog. We own blindness insofar as we treat it as belonging to us.…

…At one time, I am master; at another, Smokie is. Now I am handler, now he is. On one occasion, I take ownership for decision-making; on another, Smokie does. Recall that Smokie and I both lead and follow one another. This is a fluid relation that does not apply when leader and follower are understood as static and completely separable entities…

As Smokie and I move through our world, we are constantly in the midst of what others think of blindness. Whether we actually speak to them or not, we do respond to what they think. Our very presence to otherness is always-already a kind of response (pp. 183-188).

Although the scene with Frankie did not showcase the twins’ bonded closeness in friendship, the first part of the text showcases this very well – and the novel in its entirety supports this. The girls are partners in a true sense, and although they are both of the same species – unlike Michalko and his dog – they are ‘alone together’ in their movement through the world (a two-ness) and alone with the ‘one-ness’ of their
individual selves in each sister’s unique response to conjoined-ness. Bonded in this two-in-one dualism, they share the paradox of the two-in-one with each other.

Having read *The Girls* in its entirety, I know there are many instances throughout the book of the sisters living in many possible conjoined-nesses, of them responding to what others think of conjoined-ness with their very corporeal presences. Not the least of these occasions involved their persistent conjoined-ness in the face of Frankie’s attempts to singular-ize them. Rose and Ruby’s presences are undeniable and magnetic. As people stare at the ‘ugly’ and ‘beautiful’ conjoined twins, drawn to their unusual corporeality as they move through the world, I can almost hear them echoing Michalko’s words. Slipping them into Michalko’s text below is a kind of test to perceive whether Michalko and Smokie’s two-in-one wisdom applies seamlessly to Ruby and Rose. See below:

What there is to be mastered, handled, or owned derives from [Ruby/Rose] and me—alone together. At times, we conceive of our togetherness in terms of mastering and handling the social world. We get through it... At one time, I am [in charge]; at another, [Ruby/Rose] is. Now I am [navigating], now [s]he is. On one occasion, I take ownership for decision-making; on another, [Ruby/Rose] does. Recall that [Ruby/Rose] and I both lead and follow one another. This is a fluid relation that does not apply when leader and follower are understood as static and completely separable entities... Our situation originates in our commitment to being in touch with our world. (Michalko, p. 184-85)

It is undeniable that the bodies in the excerpt of *The Girls* I chose to study “loosened all the boundaries and set us all in motion” (Dreger, 2000, p. 478) and “messed up...the anatomy/identity rules...dichotomies and hierarchies I enjoyed keeping stable” (p. 478). Perhaps it is in this way that this text most clearly offers – in fact forces – new ways to think about the body. In insisting that the boundaries between bodies are much more elastic than we might think or prefer to admit, this text indeed forces all those interacting with it to question the ways we think about sexuality, unusual anatomies, and interactions between bodies. The fact that Rose described the sexual encounter with Frankie as an 'affair' does interrupt the text's opportunities for new understandings of bodies. The word 'affair' does represent the (constant, persistent) urge, expressed in the text, to wrestle the twins' bodies back to singularity. But even as
mechanisms work diligently to do this, the persistent conjoined state – in all its messy, non-singular more-than-basic-math two-ness is still present, still troubling singular-ization attempts. This text troubles boundaries by placing everyone involved with the text directly in the constant tension between singularity, conjoined-ness, and conjoined-ness as always more than routine definitions. In her book, entitled *Embodying the Monster: Encounters with the Vulnerable Self*, Margrit Shildrick states:

Against an ideal bodyliness – that is the being of the self in the body – that relies on the singular and the unified, where everything is in its expected place, monstrosity [i.e.conjoined-ness] in its various forms...destabilizes the grand narratives of biology and evolutionary science and signifies other ways of being in the world...What is at issue is the transformative power of the body, and whatever credit is given to the pre-existent reality of nature, biological process itself does...continually frustrate the desire for certainty...The fissures, breaks, contradictions, and indeed unexpected continuities in the...meaning of the monstrous are not then problems to be resolved, but opportunities to reconfigure first impressions. With that in mind...[conjoined-ness becomes] a complex process of contestation in which a whole range of...parameters of knowledge – truth and fiction, self and other, body and mind, inner and outer, normal and abnormal – are at stake (2002, pp. 10-11, 27).

Rose writes: ‘I could hear from within the sound of Ruby swallowing. I thought I could feel Frankie’s tongue.’ This tears the boundaries between bodies almost completely down and re-makes them, and brings new meaning to the thought of what it would mean to be ‘inside another person’s head’. Frankie’s interaction with the twins – and the twins’ interaction with him – brings the social nature of bodies to the foreground. The boundaries between bodies are shaken in their interaction, and, without question, the body is between us here in a new way. In their article, entitled “We Always Make Love with Worlds,” Gilles Deleuze and Felix Guattari (2007) put it this way:

For the prime evidence points to the fact that desire does not take as its object persons or things, but the entire surroundings that it traverses, the vibrations and flows of every sort to which it is joined, introducing therein breaks and captures—a always nomadic and migrant desire, characterized first of all by its “gigantism” ....(p. 429)
The bodies' joining to people, places, and things is denied in every facet of mainstream understandings. The disciplines of science and medicine are constantly enforcing singularity – one, uniform, 'normal', accepted way to be that operates on the taken-for-granted notion of contained, defined, clearly bordered bodies. (Notice the use of the word 'discipline' constantly associated with science and medicine.) But part of the hope and possibility of conjoined-ness comes from the fact that it points to the fragility of the rigidity of singularity. Few phenomena point more persistently to the flaws inherent in insisting on singular, normative, cleanly bordered corporeality than conjoined-ness. The following excerpt from Shildrick's book states:

What is at stake is not only the categorical integrity of bodies that matter, but also the...taken-for-granted stability and autonomy of the singular human subject as the centre of the logos, of a self that is foundational without being embodied, and a body whose integrity is so unquestioned that it may be forgotten, transcended. Against this, the confused and essentially fluid corporeality of [conjoined bodies] makes them an ideal location for an enquiry into the closure of both subjects and bodies that characterizes modernist philosophical discourse. [T]he issue is one of leaky boundaries, wherein the leakiness of the logos is mirrored by the collapse of the human itself as a bounded being (Shildrick, 2002, p. 48).

The excerpt of The Girls (Lansens, 2005) discussed here also gives us new ways to think about the body and agency. It is so easy to think about Rose’s body lacking even more agency than Ruby’s. Rose is, after all, physically carried by Ruby, and so she appears to be ‘at Ruby’s mercy’ in a unique way. As previously discussed, Rose also lacks a voice in that she stays obediently silent during the encounter with Frankie. But Rose (her body) has infinitely more voice and power than her twin in that she is the one narrating the story of what happened with Frankie that day, choosing what gets told and left out, how characters and events are portrayed. Although The Girls is narrated by both twins, Rose is the only one who describes the sexual encounter with Frankie. Viewed this way, Rose and her body have no shortage of agency – even as that agency is itself steeped in singularity. Here we are back to living with the tension.

One of the most surprising new ways to understand the body comes when we read Rose’s words: ‘I hated [Frankie’s] regret.’ After her sexual experience and the way her body is used in the encounter, the conclusion that is most easily drawn is that Rose
would regret the experience (‘After. Shivering. Ashamed.’) But her words indicate the opposite. They indicate that what she hates is not so much what happened, but more the evidence that sexual interaction with her unusual body would be a source of shame.

This in itself opens up new ways of thinking about the body, about the taken-for-granted notion that difference automatically leads to shame.

**Conclusion: “And That Will Bring Us Back to...”**

At the close of this chapter, I am left with the body, the social body between us, just as it was when I began. Yet, my understanding of the body is deeper than when I first examined the text analyzed here. I’ve seen how fluid and elastic the boundaries and borders of the body can be, how literally ‘between us’ it is, and how the conjoined experience creates a space to share the body – to re-think and re-make it in fresh ways.

A final look at Shildrick is fitting here:

Rather than attempting to recuperate the monstrous [the conjoined state], might we not [reconfigure] it as an alternative, but equally valuable mode of being, an alterity that throws doubt on the singularity of the human and signals other less restrictive possibilities? As such the monster might be the promising location of a re-conceived ontology, and an ethics centred on a relational economy that has a place for radical difference (Shildrick, 2002, p. 67).

These understandings have enriched the body still further for me. Studying the paradoxes of bodies of difference has opened up both conjoined-ness and disability for me. There are many ways in which the text in this chapter reinforces normalcy’s oppression. Yet, simultaneously, there are also ways in which this same text invites us to reconfigure bodily difference ‘as an alternative, but equally valuable, way of being.’ Shildrick’s words actually summarize my intentions for this thesis: that it might show the need and the space for alterity, ‘[throw] doubt on the singularity of the human’, i.e. independence and individuality as the ideal for humanity, and ‘signal other less restrictive possibilities.’ To that end, in Chapter 5, I will discuss texts, which do the work of portraying disability differently, and shaking loose normalcy’s restrictive hold.
Chapter Five: Possibility and Responsibility for Change

Reading as Resistance

Due to the time-consuming and intense daily program of physical therapy and training during childhood, I was home-schooled by my mother (who has never herself been qualified as an ‘official’ teacher, but who implemented a very enriched curriculum) until grade five, when I entered the mainstream school system. During my home-schooling, my mother and I were monitored closely by the Board of Education, but as long as it was proven that I was at grade level, we had a lot of freedom. In terms of my schooling, those early years were joyful times of discovery. When I started regular school in 1987, tests found that at the age of ten, I was operating at a Grade 12 academic level in every subject but Math! Although I clearly could have skipped many grades, my parents and the principal decided that, socially, it would not be a good idea to place me so far ahead of my age group.

Grade Five, though, was an awful year, an unfortunate introduction to ‘real’ school for me. At that time, in 1987, the integration of disabled students into mainstream school was a new and controversial concept. My teacher was not at all eager to have me in her class, and didn’t make much of an effort to hide it. Looking back, it is now clear that she was not at all enthusiastic about teaching itself. Her boyfriend owned a ballroom dance studio, and every day she literally ran out of the school at 3:45 p.m. in order to make it to the studio by 4:00 p.m. to teach those classes (her real passion). And when she was with us during the school day, all of us knew she wasn’t really ‘with us’ at all. Everyone received that vibe, but in my direction, she made sure the message was loud and clear. She refused to have me in her classroom for the full days. After lunch each day, I was sent to the library to finish the morning’s work and to do the afternoon’s work by myself – with virtually no guidance.

My blatant exclusion soon made me very angry. I knew my teacher didn’t want to teach me at all; so I granted her wish. When I was in her class, I put little effort into my work. Most of the time, I read novels of my own choosing, and ignored my ‘teacher’. I
felt exactly as if I had been “included as an excludable type” (Titchkosky, 2007, p. 5). I came very close to failing Grade Five, and by the end of it, I had a very cynical attitude about teachers and education.

The following year, I changed schools and had a fabulous teacher, vice-principal, and principal, who all had their work cut out for them. They took the time to make sure I learned the material I had missed, had opportunities to expand knowledge in my areas of strength, and raised my morale. This convinced me forever of the power and importance of innovative teachers and school leaders working together and being willing to take creative risks for themselves and each other. There were big challenges, of course – mean-spirited classmates (probably parroting the prejudices of their parents) who often said it was ‘not fair’ that I was in their class, other teachers who made it no secret that they thought I would never succeed in the ‘real world’, and times when my own teacher had to give me tough love to make sure she reached me through my pain and cynicism. But at last, it worked. By the end of Grade Eight (this same teacher taught me in Grade Six and Grade Eight) I was back to being an eager achiever. When tested again just before beginning high school, I was found to be at university level in every subject but Math…

The challenges and injustices were far from over, of course. In high school, there was a Math teacher who called me a ‘moron’, checked my Ontario School Record when I told him I would be going to university, and didn’t apologize until after he watched me graduate high on the Honor Roll and with three academic awards. There was the head of the school’s Music Theatre Program who cut me from a production of Hamlet, even though I had a good audition. By way of explanation, she said it would be “too complicated and awkward” to include me, in my wheelchair, on-stage. (“It’ll ruin the show, Christina. And in the end, it’s all about the show. I know you understand. After all, the show is what counts, right? The show’s the baby.”) I was so hurt and felt so silenced, I couldn’t find it within me to tell her what I really thought: that her treatment of me was horrible, and that actually, people are the ones who count. This is a nugget of wisdom that all educational policy-makers would do well to remember.
I have since forgiven all of these teachers, in an effort to free myself from the
damaging resentments. I’ve also realized that, like the rest of society, they were
saturated with normalcy’s oppression and resulting negative perceptions of disability,
left to think of it as only a source of lack, weakness, hopelessness, inferiority. In
Titchkosky’s words: “The expressions of disability, seemingly everywhere in the mass
media, are provocative...because viable status is not granted to disability” (2007, p. 6).

But there were also fabulous teachers who more than made up for the rest, who
gave me hope, fed my insatiable appetite for learning, and truly believed – and
convinced me – that I would succeed. Those teachers, and the education they
imparted, truly saved me from giving up. In *Teaching, Learning and Other Miracles*
(2007), Grace Feuerverger states:

> Again quoting Beckett, the contemporary artist in responding to "the chaos of
> experience" must "find a form that accommodates the mess." This is just as true
> for the contemporary teacher who must find artful ways in the classroom to offer a
> road toward redemption and coexistence

> ...I discovered early on in my career that teaching is not merely about curriculum
> objectives or pedagogical strategies, or subject matter, or lesson plans or state or
> provincial guidelines. It is first, foremost and always about saving lives (p. 6).

I don’t need to wonder about the truth of that statement; I lived it. Unfortunately,
because of the negative side of my grade school experience, just as I regained my
desire to succeed in my education, I simultaneously taught myself how to ‘pass’ as able-
bodied in my competencies. (I wanted to be as far from an embodiment of lack and
weakness as I could get, since I perceived the lack and weakness connected to
disability as the reason for my repeated experiences of exclusion. I initially welcomed
‘passing’ as the only way to survive.) I knew these experiences had been unjust, yet I
still understood the problem as mine.) I couldn’t avoid being disabled, of course. But I
could, I reasoned, embody the antithesis of disability. I could be fiercely independent,
stubborn, over-achieving and tough. I would be strong enough to take whatever
injustice came; I would take it, almost as though I didn’t notice. I would take it, and then
achieve anyway. My body might ‘betray me’ but my mind would run from my disability.
My mind would be ‘able-bodied’. I could run with the best of them, and I would prove it if it killed me. It almost did…

So far, I have done much work in this thesis to expose the prejudicial damage done to disability and the portrayal of disabled people through normalcy’s oppressive nature -- as illustrated in ableist literature. To this day, however, I still remember my resistance to my Grade Five teacher’s rejection of me. I remember with pride that I responded by reading books of my own choosing while she taught. I think that was the birth of my understanding that literature could be a form of resistance to oppression. I have, of course, developed this conviction much further through my work on this graduate degree, and especially through this thesis. In recognition of this understanding, this chapter’s next section will delve into literature that portrays and explores disability in anti-ableist and non-oppressive ways.

**Beverley Brenna’s Taylor Jane Simon: An Agent of Change**

This novel is about Taylor’s agency -- her search for freedom and respect.

Witness the synopsis of *Wild Orchid* (Brenna, 2005), below:

*Wild Orchid* (Red Deer Press, 2005) is a Young Adult novel about...Taylor Jane Simon...an 18 year old girl with Asperger’s Syndrome, a...form of autism. When she discovers she has to accompany her mom to Waskesiu Lake for the summer, she freaks out because she hates change. But due to her ingenuity...,the summer turns out to be not so bad. Taylor gets her first job. She sees her first real play—The Birthday Party—a unique look at social interaction by Nobel prize winning playwright Harold Pinter. And she makes headway in reaching a personal goal—acquiring a boyfriend. (“Beverley Brenna”, n.d., para. 1)

Repeatedly, her experience of life through Asperger’s is misunderstood in the novel. Her mother, her mother’s boyfriend, and many strangers -- as well as her peers - - frustrate her. Note the following passage:

I remember this one time when everybody was gathered around me on the playground. I don't know where the teacher was. Maybe there wasn't one out there; maybe she forgot she was on supervision. And the kids were yelling, “Lion King, Lion King!” That's what people were calling me because I had a Lion King lunch kit. I guess I must have been in about fourth grade, and maybe nobody by that time carried lunch kits with cartoons on them, but I had always used it and I
liked it. Anyway, when they started calling me that, I thought they had changed my name to Lion King and I couldn't stand it. You change the name of something, and then maybe everything changes. Maybe nobody would recognize me anymore, and I'd go home and my mom wouldn't even know me.

Every time they called me that name, I'd go crazy. I felt completely powerless. There was nothing I could do to make them stop. Now I know that because I went crazy, it made them want to do it more. Shauna says that some people are like that—if they can get a rise out of you, it makes them happy. So on this one day, kids were gathered around me and yelling and it was almost like I had blacked out, except I know that I was running around and trying to kick and hit kids. I know that I did more than just try because later I had to write apology notes for hurting kids and a copy was sent home to their parents.

A teacher finally came out and stopped us. This is a good thing because I don't know what I would have done if nobody had come. The thing is, when I think about it, it seems to go on forever and I can't make it stop. In my memory, the teacher separating us is like the exclamation point at the end of the paragraph. She made it stop, and if she hadn't done that, I still see myself kicking and hitting. I got expelled for three days. That's when Mom took me to the doctor, and I think she found out my diagnosis around that time. I went to a number of different doctors that year. When I went back to the school, the teachers made me and the other kids play together. That was so much like in The Birthday Party, when Stanley had to play Blind Man’s Bluff with the others. I could tell that he was miserable and wished he weren't playing, and that's why he started giggling later—because it was the only alternative to crying (Brenna, 2005, pp. 96-97).

Taylor’s rage in the above excerpt is clearly rage against normalcy’s oppression. Her peers and their mocking and exclusion, i.e., normalcy’s exclusion of disability, drives Taylor to act. Although it appears to the normal world that she has lost control here, Taylor is the one who has control. Her outburst has Taylor acting on her tormentors, instead of the opposite. In Taylor’s having to write letters of apology to the bullies, instead of them apologizing to Taylor, normalcy’s oppression asserts itself in the teacher’s ‘solution’. That said, Taylor gets ‘the last word’ here. This novel is hers, and she speaks out in it -- exposing the ridiculousness of how she was treated and how unjust normalcy as an exclusive ideal is. Even Taylor’s ‘inclusion’ upon returning to school is oppressive. She is included as an “excludable type” (Titchkosky, 2007, p. 5). Her disability is clearly unwanted, yet the students are made to pretend at including her because the teachers enforce it, for the sake of ‘the poor disabled girl’. It is little wonder Taylor hates labels. She has been firmly labeled ‘the other’ in the scene described
above. She understands that names make things matter, and she wants to keep her own name in tact, in order that she remain recognizable to herself. Her fear that her mother will not recognize her if she had another name also drives her into fear and rage. In a word, Taylor wants to matter to her loved ones, to everyone – and to matter as herself, without having to change. Yet, even in the midst of the injustice in front of her, Taylor manages to find some agency, through choosing laughter as an alternative to crying.

As illustrated above, Taylor’s experience of her disability is completely foreign to her peers and most often, she is expected to adjust to the ‘normal’ world, act ‘normal’, adjust her behaviour to meet the ‘normal’ standard, and interact and react to others in ‘normal’ ways. While Taylor genuinely wants to understand her world better and has many goals, at the same time, she makes no apologies for ‘her’ Asperger’s and the experiences of difference it brings to her life and the lives of those around her. According to Taylor’s mother and many of her peers, Asperger’s is her problem to fix and overcome. But Taylor is very clear that she does not agree. She does not perceive of her life experience in autism as inferior and tragic. Refreshingly, she locates many of the problems she deals with as connected to the misconceptions and shortcomings of others in responding to her autism. Consider the following:

So that's at least twenty unfamiliar things [that I would have to get used to on this trip]. I can see that I have been fair in the position I am taking: going to Waskesiu is not reasonable under the circumstances. The trouble with my mother is that she isn't very good at weighing decisions. She often just sees her side. It's a good thing she has me to help her with balance…

Later, I thought of another difference between Holden and me: Holden was allowed to swear in print, while I have this stupid lock my teachers put on the laptop so that certain words won't get through—they just come up blank if you try to type them. When you're trying to swear, nothing is more immature than a blank, so I've decided to stick in the symbol !!&%$%@ to represent a swear word. Not perfect, but it's the best I can do (Brenna, 2005, p. 10 & 12).

So often, autism is taken up as an out of balance ‘disorder’ involving total dependence and needing the help of others to be ‘normalized’. The above passage disrupts this (mis)conception, since this portrayal of Taylor gives us a young woman
determined to use her own voice, and who thankfully perceives of herself as offering help and balance.

Taylor also speaks out against the lack of agency inherent in not being allowed to swear in print, and therefore having her freedom curtailed. She finds a way to usurp these injustices, however, through using abstract symbols to represent swear words. Put simply, Taylor does not sit quietly under the weight of normative oppression. It is also interesting to notice Taylor’s reaction to her own solution: ‘not perfect, but it’s the best I can do.’ Notable here is the fact that it’s the available solution that is judged imperfect -- not Taylor’s difference.

Both of Brenna’s novels in the Taylor Jane series are written from Taylor’s perspective (2010b; 2005). In this way, Taylor re-appropriates her own voice and writes her experience in her own words, from within her autism. This is a major departure from instances in literature when authors construct novels wherein narrators speak for disabled characters, and enforce normalcy’s oppression on them in that way.

Autism is so often a disability portrayed as requiring constant vigilance. (This includes Asperger’s, sometimes labeled as ‘high-functioning’ autism). But Wild Orchid (Brenna, 2005) upsets this ‘norm’ by portraying Taylor as insisting on, and gaining, much freedom to meet new people, make friends, choose her own activities, experience interactions, take chances, etc. While she does experience failure and she is honest about the difficulties her disability presents, failure is not written as Taylor’s destiny. It is worth mentioning that in the sequel to Wild Orchid, entitled Waiting for No One (Brenna, 2010b), Taylor studies biology in university, gains paid employment (for the second time – she gets a job in both books), pursues dance classes, and travels without supervision to visit her father and his girlfriend, who live in a different province.

Throughout both novels, Taylor does not die, disappear, or find herself hopelessly in need of ableist rescue. In fact, she powerfully criticizes attempts at such rescue, and she acts against it. Observe the excerpt of Wild Orchid below:

“You are not to see that Paul person again, and what’s more, I’m going to get the police to put a restraining order on him!”
I didn't know what a restraining order was, but I figured it was something bad, so I yelled, “I don't have to listen to this. You don't know anything about what's possible or necessary and just because you're my mother you think you can be the boss of me and you aren't. I'm the boss of myself. And I'm not going back to Saskatoon, and I'm eighteen and a half and you can't make me and even if you do make me, I'll just run away again and keep running until I'm so far away from you that...that--” I stopped. I couldn't think of anything more to say (p. 141-142).

Taylor’s bold assertion that ‘[She doesn’t] have to listen to this’ and that her mother is ‘not the boss of her’ is a very anti-ableist statement, since her mother represents normalcy in the novel. Later in the same scene, she says ‘I will only listen to you if you forget about the restraining order’, and then she succeeds in correcting the potentially disastrous misunderstanding in a previous chapter -- a misunderstanding which led to her mother’s insistence about the restraining order against one of Taylor’s most genuine new friends. What’s more, Taylor uses her power during the conflict and outburst to secure more agency and less restraint for herself, in her relationship with her mother. The scene ends with Taylor’s statement “I couldn’t believe my victory [with Mom]” (Brenna, 2005, p. 146).

This sentence alone is revolutionary, since this kind of anti-ableist victory is extremely rare in disability portrayal. Taylor is living very firmly in her Asperger’s. This is not an overcoming story; it is instead a story of Taylor’s fierce, unflinching insistence that she -- living unapologetically in Asperger’s as she is -- be welcomed amongst the people and world around her.

**The Bite of the Mango: Resisting Rehabilitation’s Erasure of Disability**

*The Bite of the Mango* (Kamara, 2008) is unique in this sampling of anti-ableist literature, in that it is the only book discussed here that is a memoir, not a work of fiction. In this memoir, Mariatu Kamara tells her story in her own words, although the recording of the story was done through journalist Susan McClelland. Witness the synopsis below:

At the age of 12, Sierra Leoneon Mariatu Kamara [faced] more trauma than most adults could endure. Shortly after being raped (and impregnated) by a family friend, Kamara was captured by rebels who cut off her hands. [With profusely
bleeding] wounds, Kamara walked out of the bush and sought help. En route to the hospital in Freetown, she was reunited with many of her family members, several of whom had also lost their hands in the rebel attack. They moved to an amputee camp in the city, where Kamara gave birth to a son, who died at 10 months from malnutrition. When foreign journalists interviewed Kamara in the camp, her story garnered international interest, including from a man in Canada who began sending aid to her. Through this and other assistance, Kamara was sent first to England, then Toronto, where she met journalist Susan McClelland...with whom she collaborated on this autobiography. *The Bite of the Mango* testifies to Kamara’s horrific trauma, but with the aim of fostering hope and reconciliation. In a fitting gesture, former Sierra Leonean child soldier Ishmael Beah provides the introduction. (McNeill, 2008, p. 37)

While this book could be read as an overcoming story, I’ve included it here because of Mariatu’s frequent insistence that she is interdependent, and that her family, friends and supporters have welcomed her disability among them. In fact, the memoir’s title refers to the moment very soon after the violent amputation of her hands, when a stranger from a neighbouring village helped Mariatu survive by assisting her to eat a mango -- something she could not have done by herself at the time. Throughout the book, in cases where attempts were made to normalize Mariatu’s embodiment, her resistance was fierce. This will be further discussed and theorized later.

Charity and begging is an approach and response to disability that makes me -- and anyone involved in the disability rights and disability studies movement --- cringe. It does disability and differing embodiments as pathetic, pitiful, tragic and impoverished ways to be. The charity approach is demoralizing for disabled people, and anyone committed to advocating the legitimacy of disabled lives as rich lives, which belong between us. What this book made me realize, however, is that in Mariatu’s experience (and in many experiences of disability unfolding in areas of the world less privileged than parts of the West) disabled people begging in the streets can be understood as a process which gives them some power, since they are using their disabled embodiments to seize what economic agency they can. Begging, at least for Mariatu, was also a community-building experience amongst the beggars themselves. Observe the excerpt below:
Over dinner, I'd lose myself listening to my cousins talk about their day, kids they'd met on the street while begging or something funny that had happened...Begging was completely off-limits for me, even though I desperately wanted to go. I tried everything to get Marie to give me permission. "We need more food, because you're giving me so much extra," I'd plead.

"No."

Mohamed made me feel worse by poking fun at my situation. "You're a grown woman now, Mariatu," he'd laugh. "Why would you want to hang out with us young kids? Stay home with the adults. Feed your baby and we'll look after you."

The longing to join my cousins became so strong that one morning, after I'd finished breast-feeding Abdul, I handed him back to Fatmata, stood up, and declared: "I'm going with the others tomorrow!" (Kamara, 2008, pp. 99-100)

Of course, this does not mean that begging was exclusively positive for Mariatu and her similarly injured cousins. In the book, Mariatu makes it abundantly clear that she hated the shame and pity associated with begging at first (Kamara, 2008, p.77), and only learned to enjoy the experience because of the bonding it fostered amongst herself, her cousins, and other fellow beggars with whom they made friends. This points to the idea that:

Disability is always more than the disabled figure can signify or even say [...] A multiplicity of interpretive positions is a key feature of all aspects of everyday life. Disability is always more because it powerfully represents, embodies, and brings to the fore the complexity of the alterity which arises between cultural values and assumptions, societal conceptions and expectations. Disabled people, as the marginal figures of everyday life, academic research, and bodily experience, are positioned betwixt and between contrasting values, conflicting assumptions, painful conceptions, and infuriating and ordinary expectations; and, yet, they are never actually reducible to any of these. It is rare that disabled people escape the signification of this alterity, the same alterity that is downplayed or ignored in the normal order of things (Titchkosky, 2003, p. 229).

Similar to the disability experience itself, it seems much of the richness available in the interaction of begging is lost when we define it only in negative ways. Snyder & Mitchell (2006) state the following in their book, The Cultural Location of Disability:

“Disability plays a critical role in how we formulate relationships between ourselves and others” (p. 34).
But it is Mariatu’s resistant, subversive attitude toward her prosthesis that aligns her most securely with the disability studies perspective, for example:

There was nothing I could do to make those metal hands go the way I wanted them to… When the therapist with the straight blonde hair guided my arms, I could push a coin with the fingers from one side of a cardboard box to the other. But left on my own, I couldn’t get them to go anywhere near the coin. Eventually, the weight of the fake hands would topple the box and I'd sigh with defeat and embarrassment…

David and Mariama wanted me to wear the device every day to practice. My first job in the morning, after getting changed into a pair of Father Maurizio's jeans and a long-sleeved shirt, was to put the device on by myself...If it fell down, as it often did, I'd have to start all over. I tried placing it on a chair and then crawling backwards into it, but I knocked the chair over.

...In fact, I had become quite proficient without the device, using a spoon or a fork attached to my forearms with Velcro. I could eat anything with these utensils, from rice to teensy-weensy peas. I didn’t need those fake fingers (Kamara, 2008, p.148-149).

Mariatu’s extreme struggle and frustration with the clumsy prosthetic hands underscores the failure of normalcy’s attempt to erase her disability. In fact, in the process of trying to make her appear more ‘normal’ by providing an awkward, ineffectual prosthesis, an impairment was actually created. Mariatu’s own hand-less body was far better able to function when left without useless, ableist devices that served no purpose -- except to fill the space on Mariatu’s body where a ‘normal’ hand would be. It is important to note that, in other contexts, prosthetic devices – including hands – may also be a way to be disabled and to resist normative demands. But my point is that Mariatu’s particular experience with prosthetics at that time and in that situation, served as an oppressive representation of normalcy. Yet, everyone around her tried to force her to accept as part of her body something totally foreign, which offered no improvement in physical function whatsoever. This only shows how desperate normalcy’s oppression is to maintain its so-called supremacy: the ‘party line’, according to the norm, is that appearing normal (even if the device furthering the lie of normalcy is clearly a fake costume itself) is worth any humiliation undergone to achieve the appearance. The automatic assumption that rehabilitative intervention is always better
is questioned well in the following excerpt from the introduction for the book *Disability in Local and Global Worlds* (Whyte & Ingstad, 2007):

It is our argument that the energizing potential of human-rights declarations, progressive policies, and national statements of intent toward disabled citizens has to be measured in the context of local worlds. For that is where people are acting to make things work, and where the potentials may (or may not) be effected and effective as they were intended to be (p. 24-25).

Mariatu’s experience with her therapist shows how oppressive rehabilitation can be as a ‘normalizing’ force. Mariatu’s experience in therapy only reinforces her feelings of failure, of ‘defeat and embarrassment’ when dealing with the prosthesis. Witness again the words of Snyder & Mitchell:

Rehabilitation often *subjects* limitations in functional capacities to the very activities that exist outside of a body's abilities. This emphasis on "inability" is the result of a persistent historical attention to formulations of disability as excessive functional deficit. Such an approach results in the development of programs of repetitious self-care in which the ritualistic preparation of the body becomes the largest horizon of training for disabled people. What is the psychic toll of repetitiously attempting to perform activities beyond one's ability?...

The rehabilitation regimen becomes little more than a return to the site of the wound that disability has become....What would happen if rehabilitation decided to base its intervention strategies on long-term goals of value to [disabled people], developed after the primary period of adjustment? How would our rehabilitation industry work if it were not based so exclusively on elusive principles of normalcy (or prior levels of functionality) that, by definition of one's impairment, cannot be regained? (2006, pp. 8-9)

Normalcy as an absolute standard excludes and denies the legitimacy of alternative corporealities, and makes disabled people feel like inferior failures. The good news is that resistance to normalcy, such as the kind displayed by Mariatu and described below puts normalcy on shaky ground:

"There is a strong chance you will be able to remain in England," Yabom said... and once you get used to your prosthetic hands, you can go to an all-girls school."

"Why?" I yelled. My response startled me as much as it did Yabom and Mariama. But I couldn't hold my anger inside any longer. "Why do I have to wear these things?" I demanded, holding up my metal hands. "I hate them! I can do everything I need to do without them, and better. I want to go somewhere else. I want to go to Canada!"
"Don't be so ungrateful," Mariama scolded…

"I didn't ask for anything that happened to me, but I am asking to go to this place called Canada."

…”Leave me alone," I yelled…

Yabom looked scared as my arms flailed wildly. I lashed out at her in a fury…[She] took several steps backwards to avoid my attack…

My anger did go away, but not my determination to move to Canada. Despite Mariama and David's pleas that I remain in England, my mind was made up. Yabom, recognizing that further argument was pointless, began the process to acquire my Canadian visa (Kamara, 2008, p. 154-5).

Mariatu, like Taylor in *Wild Orchid* (Brenna, 2005), insists on reclaiming her agency and the legitimacy of her own altered body. In a move commonly experienced by disabled people, Yabom, Mariatu’s guardian, warns her not to be ‘ungrateful’ for the decisions and normalizing interventions undertaken on her behalf. It is also interesting and infuriating to note that Yabom states that it is only after Mariatu gets used to her prosthetic hands that she would go to an all-girl’s school in England. The insinuation is that she wouldn’t be welcome or accepted there without her prosthesis i.e., the appearance of normalcy. Mariatu, however, resists all of that and demands the right to make her own decisions.

Mariatu’s question, ‘Why do I have to wear these things?’ confronts the assumption that normalcy knows best. Like Taylor’s mother in *Wild Orchid* (Brenna, 2005), Yabom represents normalcy in Mariatu’s story. Mariatu’s victory comes after such an outburst as elicits Yabom’s fear. This is, therefore, good news for disability’s resistance to normalcy. In using her own power to make Yabom afraid of her, Mariatu in effect discovers the effectiveness of her own power and what it (and therefore she) can achieve in terms of agency. If this is applied directly to disability’s work against normalcy’s oppression, it is clear that normalcy is terrified of the ‘threat’ of disability to its widely unquestioned, unexamined status. When we, as disabled people, seize our own power as Mariatu did, normalcy’s hold is weak indeed, and its facade as a ‘monopolizing’ force thin.
This brings to the forefront the methodological move of understanding disability and normalcy as characters in conflict -- characters whose interaction can throw into question the taken-for-granted notion of normalcy’s supremacy as ‘just the way things are’ and always will (and must) be. When characters interact, they change the course of a scene, and they can even change each other’s lives. So there is hope. The character of disability is moving in the life of normalcy, shaping it and shaking it. Normalcy, on the other hand, gives disability something to question and disturb. And in this interaction, normalcy is suddenly not the only way life is and should be. And disability is so much more than what ‘shouldn’t’ happen, but does happen -- only sometimes, to a few pitiful people.

**My Wake-Up Call: Barbara Kingsolver’s *The Poisonwood Bible***

When I read Rod Michalko’s book, entitled *The Difference that Disability Makes* (2002), I nearly cried as I identified the parallels between his initial response to his blindness and mine to my own physical disability:

We moved, not a great distance, but far enough that I would go to a different high school with students who had no idea that I was legally blind. Passing as full sighted became my strongest desire and I went about it with a devastating single-mindedness (Michalko 1982, 1998, 102-27). ...[I] relentlessly pursued the life of a sighted adolescent. I employed every interactional strategy possible to pass myself off as someone who was totally sighted. I could see, even if it was just a little, and I *was* sighted. That was my *self*, my identity, and even though blindness was creeping its way into me, I held it in abeyance on what I quickly came to experience as the interactional battlefield of passing. I now made conscious use of the taken-for-granted character of sight left over from my days as a fully sighted child. But the skill I cultivated most desperately was that of observation. I came to see sightedness as a culture with customs, folkways, and gestures -- with its own language. That I did so was something I realized only later in life. Nonetheless, I imitated this culture to perfection (Michalko, 2002, p. 9).

I didn't fully leave the exhausting practice of 'passing' behind until, in the summer of 2000, I read Barbara Kingsolver's *The Poisonwood Bible* (1998). It is the story of an American family of missionaries living in the Congo in the 1950's – during the period surrounding the Congo’s fight for independence from Belgium. One of the family members is Ada, a twin who has a very freeing perspective of her disability:
Officially my condition is called hemiplegia. Hemi is half...Plegia is the cessation of motion. After our complicated birth, physicians in Atlanta pronounced many diagnoses on my asymmetrical brain...and sent my parents home over the icy roads on Christmas Eve with one-half a set of perfect twins and the prediction that I might possibly someday learn to read but would never speak a word.

I am prone to let the doctors' prophecy rest and keep my thoughts to myself. Silence has many advantages. When you do not speak, other people presume you to be deaf or feeble-minded and promptly make a show of their own limitations. [Mostly] I write and draw in my notebook and read anything I please (Kingsolver, 1998, p. 34).

Through Ada, and throughout the novel, Kingsolver skillfully critiques the fallacy of normalcy as 'perfection' and disability as 'lack'. My first reading of this complex story was the first time I had seen this cutting-edge perception of disability on paper, the first time disability-as-freedom took root for me, and I couldn't get enough. I loved Ada, and devoured the book. I began to think about disability as a space for resistance, as a site for self-determination (‘...I write and draw in my notebook and read anything I please.’) Disability as advantage, as grounds for choices, for gaining the upper hand, for a richness of experience and observation, because ‘...other people presume you to be deaf or feeble-minded and promptly make a show of their own limitations...’ was unexplored, delicious territory to me. I now know that subconsciously, I began to make connections to educational reform in cases of both disability and cultural difference at that point. My ideas continued to germinate and grow as I read on hungrily. As I read, I couldn’t help but become engrossed by Ada’s view of her disability as a gift. It is very clear when reading this novel that, no matter what others in her family think of her ‘slow’, ‘awkward’, ‘lopsided’ walk and her overall bodily difference, Ada embraces her corporeality as that which gives her insights which are lost on her ‘normal’ siblings and parents. Whereas, in the ‘normal’ world, disability is a difference synonymous with disadvantageous and unfortunate issues, Ada possesses a self-perception that is happily, unapologetically, disabled and different. Ada spends the majority of the novel choosing not to speak out loud to her family, but she expresses herself loudly, clearly, subversively, and with much to teach about disability, culture, and decidedly anti-normal
opinions. Ada’s disability and resulting corporeal diversity gives her the means and the right to impart much-needed education on the world.

Linda Nathan’s words in her book *The Hardest Questions Are Not on the Test* (2009) fit well here. They echo some of what I believe Ada would say about the need for educational reform:

I didn’t say anything then. But I was sure “those issues” did exist on her campus. [Diversity] issues are everywhere, whether we [acknowledge] them or not. I bristled inside but stopped myself from launching into a speech about how I believe that learning to talk about [diversity] is central to achievement for all students…

Again, I stopped myself from giving a passionate retort. Quietly, I responded, "Well, to me, school has to be a place where discussion and confrontation of the ‘isms’ in our society—about race, class, gender, language, sexual orientation, [and disability]…all are part of our ongoing daily work. If not, I often ask myself, 'What is the point of all this?'” To myself I thought, Don’t we have a responsibility to provide forums and places where students and teachers interact in authentic ways across differences? (p. xxiii-xxiv)

Even Linda Nathan, committed as she is to diversity education, treats disability as an “excludable type” (Titchkosky, 2007, p. 5) in the excerpt above. I, not she, inserted disability into her list of ‘isms’. But her words are still very true, and her encouraging perception of the role of education in this mission is clear: to open minds to alternative ‘views’, ways of perceiving, thinking and living that are outside of normalcy’s oppressive constriction. Literature that is anti-ableist and anti-oppressive on every level is a key tool in this process. Ada illustrates this point beautifully:

The Congo is a fine place to learn how to read the same book many times. [...] there are books, books there are! Rattling words on the page calling my eyes to dance with them. Everyone else will finish with the singular plowing through, and Ada still has discoveries ahead and behind. (Kingsolver, p. 58)

Ada makes a clear point that her experience of reading and singing both frontward and backward enriches her life. Over and over, she insists that her life is enriched by her disability and difference -- by the fact that she does things differently and approaches situations in a plurality of ways. There is more than one way to be in the world, and the disabled way is not the lacking, pitiful, inferior way. It is the way that shows clearly and inescapably that life could be otherwise. The statement under Ada’s
and therefore Barbara Kingsolver’s words is unmistakable: Disabled lives are lives full of possibilities -- possibilities which normality misses, by definition.

In my mind I invented snmyhymns, as I call them, my own perverse hymns that can be sung equally well forward or backward...Also I made use of this rare opportunity to inspect Mama Tetaba at close range. Normally she moved much too fast. I considered her my ally, because like me, she was imperfect. It was hard to say what she ever thought of Our Father's benedictions, in church or out, so I pondered more interesting mysteries, such as her eye. How did she lose it? Was she exempt from marriage because of it, as I presumed myself to be? I had little idea of her age or hopes. I did know that many women in Kilanga were more seriously disfigured and had husbands notwithstanding. Standing with naught. Husbands. Here, bodily damage is more or less considered to be a by-product of living, not a disgrace. In the way of the body and other people's judgment I enjoy a benign approval in Kilanga that I have never, ever known in Bethlehem, Georgia (Kingsolver, 1998, p. 72).

Here, the last sentence points to the fact that dehumanizing, othering, shaming and abnormalizing disability is an oppressive practice fed globally by Western (mis)conceptions of normality and wholeness. Ada’s reference to bodily difference as “damage” aside, in her anti-ableist observations, disability is part of the natural flow of using bodies in the flow of living. Life in the Congo -- and the Congo’s perception of disability -- is a perfect match with Ada’s life in her disability. Colonization and its perception of the supremacy of normalcy and control appears as what it is here -- utterly wrong.

**A Call To Be Radical**

To imagine difference as so much more than something to be rid of, as something without which society loses gifts of value and importance, is so refreshing. Through Ada, Kingsolver makes bold statements to this effect. I struggled briefly about whether to include *The Poisonwood Bible* (Kingsolver, 1998) in this discussion of literature that
works against normalcy’s oppression. After all, Ada\textsuperscript{2} was ‘cured’, and brought into normalcy’s fold near the end of the novel. Does this ending not, I argued with myself, bring the book into line with the many, many others that serve to erase disability? I decided, though, that Ada is far too delightfully subversive to ignore.

Ada is in medical school when she is “befriended by an upstart neurologist, who believes [she is] acting out a great lifelong falsehood. Ada’s Falsehood” (Kingsolver, 1998, p. 439). He believes that she can retrain her body to normalize her right side. This is troubling to Ada who is “unprepared to accept that my whole sense of Ada was founded on a misunderstanding between my body and my brain.” (p. 439)

Below are Ada’s words about the process of the erasure of her disability:

But the neurologist was persuasive, intimidatingly handsome, and the recipient of a fabulously coveted research grant. Mostly to prove him wrong, I submitted my body to an experimental program of his design. For six months he had me stop walking entirely, in order to clear my nervous pathways of so-called bad habits. Instead, I crawled. With the help of friends I rearranged my small apartment to accommodate a grown-up baby, and warily crept each morning from a mattress to my coffee maker and hotplate on the kitchen floor. I used only the lower half of the refrigerator. To preserve my dignity I went to work in a wheelchair. I was starting a rotation in pediatrics at the time—good luck, since children don’t tend to hold the disabled responsible for their infirmities, as grown-ups do. Adults listen to you with half an ear, while the Biblical prescription "Physician, heal thyself!” rings in the other. But children, I found, were universally delighted by a doctor with wheels (Kingsolver, 1998, pp. 439-40).

I find Ada’s idea that a wheelchair is a tool that preserves her dignity captivating. Wheelchair as delight is also a beautifully anti-oppressive description. By contrast, Ada describes her conflicted feelings of loss once her disability has been ‘cured’.

We all are, I suppose, [t]rying to invent our version of the story...I am still Adah but you would hardly know me now, without my slant. I walk without any noticeable

\textsuperscript{2} Note that in The Poisonwood Bible, the character of Ada’s name is spelled two ways. Her given name is Adah, but she spells her own name ‘Ada’. This is because she enjoys the fact that this name has equal richness when perceived backward as well as forward. Since this adds to the richness of Ada’s contribution to ‘more than one way to be in the world’, I spell her name as Ada in my discussions, while in some quotes it appears as ‘Adah’.
limp. Oddly enough, it has taken me years to accept my new position...No one else misses Adah. Not even Mother. She seems thoroughly pleased to see the crumpled bird she delivered finally straighten up and fly right... (Kingsolver, 1998, pp. 492).

Ada’s fury is palpable. The fact that she grieves the loss of her disability just as normalcy grieves disability itself confronts the norm and the taken-for-granted assumption that Ada (and that we all) should want normalcy and not question its underpinnings and motives.

She is angry about normal conceptions of disability and the ‘cheerful, simple morality’ of reviling disability in the West. She is thankfully nowhere near grateful for her cure, and points a finger at ‘the...staggering arrogance of the able-bodied.’ She rages against the idea of cure as solution for any disability at all, because she poignantly grieves the loss of her own disabled embodiment. Witness:

Don't we have a cheerful, simple morality here in Western Civilization: expect perfection, and revile the missed mark! Adah the Poor Thing, hemiplegious egregious besiege us. Recently it has been decided, grudgingly, that dark skin or lameness may not be entirely one's fault, but one still ought to show the good manners to act ashamed. When Jesus cured those crippled beggars, didn't they always get up and dance off stage, jabbing their canes sideways and waggling their top hats? Hooray, all better now, hooray!

If you are whole, you will argue: Why wouldn't they rejoice? Don't the poor miserable buggers all want to be like me?

Not necessarily, no. The arrogance of the able-bodied is staggering. Yes, maybe we'd like to be able to get places quickly, and carry things in both hands, but only because we have to keep up with the rest of you...We would rather be just like us, and have that be all right (Kingsolver, 1998, p. 493).

Ada confronts and vehemently opposes the idea that disabled people should automatically want to be other than themselves – should in fact hate themselves and their unconventional embodiments. Her opposition to the erasure of disability also impacts her attitude to love, romance, sexual attraction and marriage:

I have not married either, for different reasons. The famous upstart neurologist wanted to be my lover, it turned out, and actually won me to his bed for a time. But slowly it dawned upon my love-drunk skull: he had only welcomed me there after devising his program to make me whole! He was the first of several men to suffer
the ice storms of Adah, I'm afraid...Any man who admires my body now is a traitor to the previous Adah. So there you are (Kingsolver, 1998, pp, 531-32).

Through Ada, Kingsolver underscores the complexity of disability as always more than the confines of any one perspective or description. Notice these words, which acknowledge both the asymmetrical nature of Ada’s body, and, at the same time its smooth, crooked elegance:

In darkness when all cats are equally black, I move as gracefully as anyone. *Benduka* is the bent-sideways girl who walks slowly, but *benduka* is also the name of a fast-flying bird, the swallow with curved wings who darts crookedly quick through trees near the river. This bird I can follow. I am the smooth, elegant black cat who slips from the house as a liquid shadow after dark (p. 295).

And again:

How can I explain that my two unmatched halves used to add up to more than one whole? In Congo I was one-half...the crooked walker, and one-half...the sleek bird that dipped in and out of the banks with a crazy ungrace that took your breath. We both had our good points...Here there is no good name for my gift, so it died without a proper ceremony. I am now the good Dr. Price, seeing straight...And how can I invent my version of the story, without my crooked vision? (p. 493)

The connection she draws between her loss and a funeral also points at her cure as the cause of death for something incredibly valuable within herself. Normalcy understands the appearance of disability as a kind of death, but does not understand that cure (or any form of erasure of disability) is cause to mourn.

It is utterly refreshing to observe Kingsolver resisting the common, ableist occurrence of writing disability as a kind of death. It is worth noting that Ada *escapes* death twice in the novel: once when being stalked by a lion (Kingsolver, 1998, p.138-141), and a second time when she is abandoned by her mother during an emergency in their village – an emergency that causes a dangerous stampede (p. 306).

She studied me for a moment, weighing my life. Then nodded, shifted the load in her arms, turned away.

…My heels were nipped from behind by other feet…I knew when I went down…I was being trampled. A crush of feet on my chest. …I found my way to my elbows and raised myself up, grabbing with my strong left hand at legs that dragged me forward…and again and again I came up. Once I looked for my mother and saw
her, far ahead. I followed, bent on my own rhythm. Curved into the permanent
song of my body: left . . . behind.

I did not know who it was that lifted me over the crowd and set me down into the
canoe with my mother. I had to turn quickly to see him as he retreated. It was
Anatole.

That night I… [was d]esperate to save myself in a river of people saving
themselves. And if they chanced to look down and see me struggling underneath
them, they saw that… the crooked girl believed her own life was precious. (p. 306)

Ada’s mother represents normalcy in the above passage. She chooses to leave
Ada (disability) behind in favour of saving her able-bodied children, but even while being
trampled by normalcy, disability survives – believing its own life is ‘precious’.

Even after she is rescued, Ada ends up in the canoe with her mother, the very
person who had ‘weighed her life’ and ‘turned away’. It is impossible to ignore the fact
that, in the same way that disability and disabled people are always living in the tension
between normalcy and disability and cannot escape it, Ada does not escape her
mother. Like it or not, disability is always having some kind of interaction with
normalcy, described in the above passage in very oppressive terms indeed. But the
good news is that we can live in the tension in our own unique ways, “bent on [our] own
rhythm” (Kingsolver, 1998). We can also use our anger about oppression to energize
our resistance, just as Ada grabbed at the very arms and legs that threatened to trample
her in order to propel herself forward. I will elaborate on this further below, in my

Novels such as The Poisonwood Bible and the small but growing collection of
others like it are pivotal to the work of questioning normalcy’s unquestioned power and
goodness -- work that needs to be done. The central work of this thesis has been to
show normalcy’s oppressive power as reflected in ableist literature and to show, in turn,
the importance of anti-ableist literature in the quest for change in disability portrayal.
Resistance to the portrayal of disability as a non-valuable, unviable, unfortunate life
experience is resistance to oppression and exclusion. Whether disability is excluded
from wider life and so writing, or from writing and so wider life, is a chicken-or-egg issue,
a matter for some debate. Nevertheless, through interpretive and narrative approaches,
I have tried to go some distance in the journey of proving disability to be a rich, complex, multi-faceted life experience, and making a case for the importance of reflecting that in literature.

As a way to explore how disability would appear when written in completely anti-ableist ways, I turn now to discussions of one more novel.

**Harriet McBryde Johnson’s Accidents of Nature: Dealing Oppression a Blow**

The first time I read this book (Johnson, 2006), I can remember wishing I had written it myself! Having briefly met Harriet McBryde Johnson and heard her speak at length during an evening of discussion and reading of her work in 2006, I recognized much of her gumption in the character of Sara, whose determination to perceive of disability differently -- in a fiercely anti-ableist, politically charged voice -- permeates the novel.

In one review, the book is summarized this way:

It is August, 1970, and 17-year-old Jean attends Camp Courage, [with] cabin-mate, Sara. Because she has cerebral palsy, Jean depends on others for many things, but she has always felt part of the normal world. This view changes as she sees herself through Sara's eyes. Sara, an incredibly intelligent, thoughtful teen, talks openly about what it's like to have a disability, as she herself is in a wheelchair. She maintains that no matter what those who are able-bodied think about their efforts to be helpful, they'll never really get it. Nowhere is this better depicted than in the skit that Sara writes for Jean and their bunkmates to perform in front of the entire camp. Through Sara's fierce creativity, the skit turns everything upside down, showing a telethon parody in which the normal people are advocated for, pitied as not being more like the crips. The skit gets them into trouble, but it proves a point. Jean is forever changed by Sara, knowing that with her she can truly be herself. Issues of race, feminism, identity, and sexuality are looked at as well (Karbel, 2006, p. 130).

While Johnson's depiction of Sara is brilliant, her portrayal of the novel’s narrator, Jean, struck me as equally powerful. It is through Jean that Sara’s power to upset normalcy’s oppression is most clearly evident, because it is Sara who radically changes Jean’s perspective on her disability. Because of Sara’s influence, Jean begins to change from someone who had internalized the normalization process and the
attempted erasure of her disability (believing what her family believed, that she was ‘just like everyone else’ ‘despite’ her disability, as though her disability made no difference at all). Jean begins to question this, finally asking: “Would I be the same person without my [Cerebral Palsy]? My parents always say CP doesn't matter. I am just like a normal girl. But I wonder” (Johnson, 2006, pp. 29-30).

Sara criticizes everything about the ‘normal’ world. She criticizes the widely held, normative idea that walking (as an ideal mode of transport and as a symbol of human supremacy and victory over “strivings of all kinds” (Johnson, 2006, p. 70) should be “a big dramatic idea,” (p. 70) the highest goal for disabled people. She criticizes the normal world for oppressing disabled people -- keeping them un- or under-educated and un- or under-employed in mindless, pointless jobs. She criticizes the racially segregated world around her in the American South of the 1960’s. She criticizes the institutionalization of disabled people, and the common practice of treating them either as asexual or on display as pitiful ‘freaks’. Witness the excerpt below:

Sara won't be deflated. “Listen, it's real. We come to accept the views of our oppressors. We think there's something wrong with ourselves. It's like black people thinking they need to change the way they talk, lose their culture, get more white. They're fooling themselves. They need to ask why they can't be black AND equal.”

…I reach for the other book. Slim and red. Stigma: Notes on the Management of Spoiled Identity, by Erving Goffman. Again she doesn't wait to be asked. “I'm rereading that one. It's the best thing I've ever read about [disabled people]… “It's all one thing,” she explains. “It's all about stigma...But what's so exciting about this book is that it describes how we manage our stigma. We take it and do something with it. We make choices” (Johnson, 2006, pp. 111-112).

Sara’s passion -- and also her anger -- against ableism are palpable here. It is anger that the disability studies movement is using to affect change. An important point needs to be made here. We (disabled people) do need to strive for being disabled and equal, without becoming trapped in the oppressive falsehood that there is ‘something wrong with ourselves.’ We also need to resist the erasure of our difference inherent in the long-held (and currently widely held) mainstream idea that equality means we want to be and should be treated ‘just like everyone else’. Equality, for disabled people and everyone, means an approach that opens participation to everyone in such a way that
upholds justice. Participation within society should not be limited to those who can do the same things in the same way, thus upholding the status quo and its oppressiveness. As well, justice and equality should not only be for those who are willing and able to support capitalism.

I must say here that I am not against normalcy in and of itself. What I wish to do is destabilize normalcy’s generally unquestioned supremacy as a widely held and much coveted standard, which has the last word on which bodies and minds belong among us and which do not. It is ‘normalcy as king’ that is oppressive. I wish to make it abundantly clear that there are other equally valid and beautiful ways to live and be in the world.

What is effective about Sara’s anger is that it is “controlled, focused like a welder’s torch” (Johnson, 2006, p. 72). Jean also describes it as “a living presence” (p. 73). It is aimed toward getting things done for disability and difference, and dealing normalcy’s oppressive stance toward disability a serious blow. Being freed from normalcy’s constraints and pressures by Sara’s insights and the support of fellow disabled people around her, Jean finds she is happier than ever at camp, even though Camp Courage is being organized and managed oppressively -- because within that oppression there is Sara’s resistance. It strengthens them all. Jean says: “I stretch my hot, aching legs and arms, but I’m too keyed up to sleep. A long spaz [spasm] attack is like a full-body workout. As tired as I am, I'm not too tired to notice how happy I feel” (p. 60).

Sara’s wisdom and the focus of her anger -- though intense and at times hard to take -- combine to create transformative power. What Sara’s presence creates is the very power she wants disabled people to seize. And she is not resigned, or fooled into thinking that those in the margins cannot push for change. She says with conviction: “It’s our silence, our cooperation, that keeps the whole structure in place. Withdraw that support and it all falls down” (Johnson, 2006, p. 163).

But Sara does more than talk. She propels her words into actions, and stages a “reverse telethon” at camp -- which she refers to as “guerrilla theatre” (p. 163). In the performance, normalcy -- not disability -- becomes a “horrible condition” in need of pity and charitable, medical and rehabilitative intervention. Consider the following:
“Ladies and gentlemen”, Sara leans forward dramatically. "Those phones aren't ringing. How can we Stamp Out Normalcy unless we get those phones ringing? You've got to give.”"

“All of you out there, if you have a normal child or grandchild, you know the importance of this cause. Please call and give what you can.”

“And if you have a crippled child, have you ever thought, 'There but for the grace of God, go I?' It's true. Normalcy can strike any family. You should light up these phone lines in celebration of your good fortune, and thank God for your crippled child! Right, Jean?”

I nod and wish with all my heart that it were true. Thank God for crippled children! (Johnson, 2006, pp. 178-179).

The oppression normalcy forces on disability is truly horrible, and through the performance, Sara, Jean and the other campers involved ingeniously confront this. Disability (usually understood as a misfortune that can ‘strike’ any family) is appropriately celebrated here. This is a true testament to Harriet McBryde Johnson’s brilliance -- that she gave disability a liberating moment in the most necessary but unlikely place: a setting where normalcy’s supremacy was most taken for granted and the demonstrated role reversal was most unwelcome.

In the novel, Sara and her cabin-mates did not receive the congratulations they deserved from camp authorities for the skit. The ‘powers that be’ were obviously uncomfortable during the skit but then -- except for handing down punishments the next day -- continued on as if nothing revolutionary had happened. Sara did not make the widespread, lasting, systemic and sweeping change she was hoping to instigate at Camp Courage. Instead, her entire cabin was punished for their role in the play and Sara was very discouraged. As discussed earlier in this thesis, that is what so often happens: upholding normalcy is rewarded, while questioning it frequently leads to many levels of disapproval and punishment.

But Sara did make important changes. She shifted Jean’s entire perspective on her disability. Her ‘radical’ opinions made one camp counselor, Carole, rethink her role and admit that she -- from her normalcy-saturated vantage point -- “[didn’t] have a clue” (Johnson, 2006, p. 147) about disability and needed to do much soul-searching. And Sara placed the camp know-it-alls on ‘squirmy’ ground. They reacted swiftly and
negatively to re-establish their ‘supremacy’, but she had questioned normalcy’s unquestioned status, and so made it face itself -- however briefly.

One of the key lessons of this novel is that change rarely happens in a groundswell, and never happens alone. Lasting change needs community to nurture it and productive action, over time, to move it forward.

Normalcy’s unquestioned stronghold was not built in a day, and it will not be torn down in a day, either. But these anti-oppressive pieces of literature prove that change -- anti-oppressive, anti-ableist, pro-difference change -- is moving among us. Disability is between us, and is here to stay. Normalcy is resisting disability, but disability is answering, and resisting, back.

Conclusion: A Movement in Motion

What Kingsolver is advocating through Ada, and what McBryde Johnson is pushing for through Sara is in line with my own mindset and the work of this thesis. What is essential, and what needs to be reflected in literature and taught through it, is a cultural model of disability, a model which demonstrates an understanding that impairment is “a source of embodied revelation”, a case of “both human variation encountering environmental obstacles and socially mediated difference that lends group identity and phenomenological perspective” (Snyder & Mitchell, 2006, p. 10). Although the novels discussed in this chapter approach and write disability in anti-oppressive, anti-ableist ways, there is considerable danger in the temptation to think that these novels prove we have it right, as long as we ‘hold it right here’ and hang onto the social model or a cultural model of disability.

First of all, during the completion of this Masters degree and the writing of this thesis, I have spent far too long analyzing and theorizing the oppressive nature of normalcy as perpetuated in literature to think -- even momentarily -- that the work of undoing normalcy’s oppression will be anything but a long, arduous task. It is, however, an infinitely worthwhile and important one. Attempts to erase disability are rampant. Even the anti-ableist works discussed in this chapter expose this. Taylor’s mother in Wild Orchid (Brenna, 2005) frequently asks “Why do you behave so badly, Taylor?”
In *Accidents of Nature* (Johnson, 2006), the camp counselors and other authorities are constantly attempting to ‘control’ the campers and offer ‘normal’ camping activities in incredibly oppressive ways. Mariatu’s guardians tried repeatedly, in *The Bite of the Mango* (Kamara, 2008), to make her ‘get used to’ her normalizing prosthesis. In *The Poisonwood Bible* (Kingsolver, 1998), Ada’s disability was cured, to her detriment, by an ‘intimidatingly handsome’ doctor. Normalcy has always been constructed to appear as a deceivingly ‘handsome’ solution to the ‘problem’ of disability.

But disability cannot be erased, however violent and radical attempts may be to eradicate it. Taylor insisted on having agency and living unapologetically in her autism. Mariatu refused to wear her prosthesis or allow others to control her decisions or dictate her future. The camp participants voiced their resistance through the ‘reverse telethon’, and Sara changed Jean forever. And Ada remained extremely irreverent toward normalcy and openly grieved her disability.

Disability will always need to be done in new ways. In *Rethinking Normalcy* are these wise words:

Disability studies does define disability, but it does so in a way that allows disability to be fluid and not restricted in the yoke of a positivist standard of normalcy. Disability is, for disability studies, a “fluid and shifting” set of meanings involved in the greater question of what it means to be human (Shildrick & Price, 1996, 93). Thus, we understand disability as connected to, as well as reflective of, the social scenes of which it is always a part (Titchkosky & Michalko, 2009, p. 6).

As such, it will always be growing and changing. Disabled people’s “source[s] of embodied revelation”, “perspective” and “identity” (Snyder & Mitchell, 2006, p. 10) will always need to be brought to society in ways that not only broaden horizons, but also make it very clear that disability is a rich, valuable experience, and disabled people do not represent a disposable, frightening, subhuman, pitiful and/or inferior class. There will always be innovative teaching to do, new works to write and essential, powerful, thought-provoking, anti-oppression, pro-diversity, pro-difference education to impart. Education is the central value, phenomenon and principle here. The words of both Garce Feuerverger and Martha Nussbaum deserve attention:
In my view, one of the primary goals of teaching is to create a network of relationships through literature and images and art and through all manner of activities. These stir the imagination and make us capable of seeing and hearing the "other," feeling the hurt done to the "other" as a personal wound, thereby making dialogue across difference possible (Feuerverger, 2007 p 134).

It is up to us, as educators, to show our students the beauty and interest of a life that is open to the whole world, to show them that there is after all more joy in the kind of citizenship that questions than in the kind that simply applauds, more fascination in the study of human beings in all their real variety and complexity than in the zealous pursuit of superficial stereotypes, more genuine love and friendship in the life of questioning and self-government than in submission to authority. We had better show them this or the future of democracy in this nation and in the world is bleak. (Nussbaum, 1997, p. 84, quoted in Feuerverger, 2007, p. 138).

Human beings ‘in all their real variety and complexity’ need to be celebrated. This is an important quote, as long as Nussbaum’s resistance to ‘superficial stereotypes’ includes a liberating conception of disability as worthy of full citizenship. It is worth noting that in a course I took at OISE during the summer of 2010, focusing on multicultural literature in education, I prepared and presented a seminar wherein I discussed the concept of disability as a cultural experience. I demonstrated both the damage oppressive portrayals of disability can do, and the power and far-reaching importance of anti-ableist teaching and literature. I spoke at length and demonstrated the relevance of such literature in the teaching process. I tried also to impart the power of the message below, quoted from Mitchell & Snyder (2000):

Right away it seemed that disability was the only “mark” that could impinge upon each of the other categories. One could not become “female” if marked “male” (without radical surgery), one could not become “black” in a biological sense within a strictly Caucasian familial line, sexuality proved more ambiguous and slippery. But what made disability distinct was its unambiguous ability to impact every other identity category at any time. Even in the least-marked category--the “transparent” state of straight white male--disability clouded an otherwise unmarked social identity. At that time, as the beneficiaries of an earlier generation’s activism for the Americans with Disabilities Act, we understood that while disability threatened to override other identifying marks, it continued to go unrecognized as a form of cultural alliance in academia and in public life (p. x).
The truth of these words became clear as I taught the teachers in front of me that disability ‘continue[s] to go unrecognized as a form of cultural alliance.’ They were spellbound. They found my research and words nothing short of groundbreaking. But so few of them had even thought of the concept of disability as culture or normalcy as oppression before I spoke out. This reality only reinforced for me the fact that normalcy needs to be opened and become a space of self-reflection. The fact that so often disability appears alone in books (as an individual ‘problem’) proves this. Where are the disabled literary characters who come from different ethnic and cultural backgrounds or different sexual orientations? Furthermore, where are these characters, with multiple claims to difference, who are living in their disabilities and in their other diversities, recognizing them as part of identity instead of wishing they would go away? The only novels I found which discussed the disability experience along with the ethnic one from an anti-ableist perspective were The Poisonwood Bible (Kingsolver, 1998) and The Bite of the Mango (Kamara, 2008). Rukhsana Khan’s novel Wanting Mor (2010) (discussed in detail in Chapter Two) portrays an Afghan girl with a facial ‘deformity’, but hardly qualifies as anti-ableist fiction.

Teachers -- as well as children and society at large -- need to be taught how to use literature and all manner of artistic approaches to uproot normalcy’s hold, instead of further entrenching it. So few novels ‘see’ disability as a boundary-crosser across differences, let alone communicate this boundary-crossing as a good (not tragic) thing. And so few teachers know that even current ‘positive’ portrayals of disability (as that which can be overcome, and in the overcoming ‘inspire’ other ‘tragic souls) are incredibly damaging. The message to immigrant students that they must ‘blend in’ is hurtful in similar ways -- it reeks of a colonizing mentality. Disabled students also quickly internalize normalcy as the way to success. ‘Become more normal’, the unjust fallacy dictates, ‘and you can make it despite your disability.’ For disabled people, normalization operates as a colonizing force -- if we let it. I have much work to do in opposing this.

As I made my case in front of those OISE teachers, I caught myself getting frustrated with how many minds there are left to change. It is a daunting task. But even
I once thought very differently about disability -- mine and others. The past three years at OISE have changed me tremendously for the better as a writer, educator and advocate. I will never be the same again, nor would I want to be.

In honour of all of that transformative change, the closing pages of this thesis will be an exploration of my transformation, using the literary work of the late Harriet McBryde Johnson as my illustrative tool. You’ve come with me thus far. Come with me the rest of the way. There is no denying it has been -- and will continue to be -- quite a journey.
Chapter 6: Good Morning -- A New Beginning

Receiving the Torch

I woke up this morning to a world without Harriet McBryde Johnson in it. Really, this is nothing new, anymore. Johnson -- an American attorney, disability rights activist and author of the novel Accidents of Nature (2006) and the memoir Too Late to Die Young: Nearly True Tales of a Life (2005) -- has been dead since June 4, 2008, and it is now June 2011. But this morning was different. This is the day I will write the last of my thesis, in which I have worked to uncover and undo the perception of disability -- perpetuated through oppressive portrayals in fiction -- as a kind of death. And it strikes me as incredibly ironic that Johnson is ‘unavailable for comment’ when I am at the height of realizing how much work and speaking out there is to do.

But the moment I think this, I catch myself. As a writer, I should know better. She is not ‘unavailable for comment’. It’s just that, now, her words in print, and otherwise on the record, must speak for her. Her words will out-live her, and this is good news. We in the disability studies and disability rights movement can certainly learn from the irreverent wrecking ball with which she deals a blow to the status quo. At the same time, though, the immortality of words is an intimidating prospect. The fact that when we’re gone, our words will survive to be judged is something that gives me pause. What infuriating irony that, with Harriet gone, anyone who does not understand her passions can say anything they want about her and her work!

But I am wrong this time, too. It is not true that anyone can say anything they want to defile her. Now it is our turn -- those of us also engaged in Harriet’s passionate work -- to defend her and the fight against normalcy’s supremacy and for the survival and thriving of disability and difference. So it occurs to me that speaking out against Peter Singer’s controversial eulogy for Harriet would be a good place for me to start:
In my lecture, …I pointed out that physicians routinely withdraw life support from severely disabled newborns, and I argued that this is not very different from allowing parents to decide… to end the life of a baby when the child has [serious] disabilities…that the family believes this will be best for the child or for the family as a whole.

When I finished, Johnson…spoke up. I was saying, she pointed out, that her parents should have been permitted to kill her shortly after her birth. But…It is a mistake, she said, to believe that having a disability makes life less worth living.

…Her life was evidently a good one, and not just for herself, because her legal work and political activism on behalf of the disabled was valuable to others as well. I know that surveys have found that people living with disabilities show a level of satisfaction with their lives that is not very different from that of people who are not disabled. Have people with long-term disabilities adjusted their expectations downward, so that they are satisfied with less? Or do even severe disabilities really make no difference to our happiness, once we get used to them? (Singer, 2008).

Singer’s pondering on whether disabled people have learned to ‘settle’ for an inferior life is an insult to Johnson and all of us. Harriet answers him best when she says:

Because the world sets people with conspicuous disabilities apart as different, we become objects of fascination, curiosity and analysis. We are read as avatars of misfortune and misery. Stock figures in melodramas about courage and determination. The world wants our lives to fit into a few rigid narrative templates…[but] [f]or me, living a real life has meant resisting those formulaic narratives… Instead of letting the world turn me into a disability object, I have insisted on being a subject in the grammatical sense: not the passive “me” who is acted upon, but the active “I” who does things. I practice law and politics in Charleston…I travel. I find various odd adventures. I do my bit to help the disability rights movement change the world in fundamental ways (Johnson, 2005, p. 2-3)

In love, as in life, every impossibility opens a door to some surprise. However many things may be entirely foreclosed or more trouble than they're worth, the possibilities that remain are so numerous, so varied, so far beyond the capacity of one person to experience, so marvelous—that they might just as well be infinite…[It’s] good to meet each morning’s sun awakened to all the possibilities (Johnson, 2005, p. 257-258).

Disabled or not, we all adjust -- expectations, goals, opinions, etc. as we grow and change. And yes, we sometimes discover that ‘many things may be entirely foreclosed
or more trouble than they're worth.’ But to suggest that disabled lives are not worth living is to reduce the disabled experience strictly to hardship, and to suggest that some ‘normal’, ‘privileged’ humans should have the right to decide who has value and who is disposable. This is disturbing in and of itself, and the disturbance is compounded when we consider that so many able-bodied people are so saturated in normalcy’s unquestioned, manufactured dominance -- so concerned with maintaining their privilege -- that they don’t imagine that life could be otherwise. Or that a life that is otherwise is worthwhile and good, not tragic. The prospect of leaving decisions about disabled lives in the hands of these individuals is a scary one indeed. Furthermore, Singer shows no grasp of the fact that it is oppression that connects disability to hardship. In other words, disabled people “do not suffer our impairments so much as ‘we suffer our society’” (R. Garland-Thomson as cited in Michalko, 2002, back cover).

Furthermore, even Singer’s assertion that Johnson’s productivity proves the worth of her life is bothersome, since he clearly has no understanding that lives are important because they are lives among us. It is a fallacy to believe either that disabled people cannot achieve or that it is achievement that grants worth to a life. Most upsetting of all for me is the fact that, despite having known Harriet McBryde Johnson for years -- and having corresponded with her regularly -- he did not learn nearly enough from her. He still finds it necessary to ask (in her eulogy, no less!) if she is truly right. He wonders: ‘Have people with long-term disabilities adjusted their expectations downward, so that they are satisfied with less? Or do even severe disabilities really make no difference to our happiness, once we get used to them?’ In direct answer to his question, I will let Harriet herself ‘speak’:

I’ve had a lifetime of saying, “They mean well,” of telethons and the people who love them… In most ways, one thon was like the next. But in one way, MDA stood out from the pack. Its pitch had an added punch of urgency: find a cure before they die! (p. 50)

Then I reconsider my childhood death sentence and decide I have been the victim of a fraud…I have never been terminally ill the way I was led to believe… As I hear the death sentence pronounced on another generation of children, I wonder how many have actually been killed by the predictions…. How many have died for lack of a reason, when a reason was needed in the middle of the night, to hang on to
life? Worst of all, how many have lived and died without learning to value their own lives? …I want people to know our culture is playing fast and loose with the facts. While anyone may die young, it’s not something you can count on. You have to be prepared to survive (p. 13).

As a devout Christian, I do not share Singer’s and Johnson’s atheism. But I do love and share Harriet McBryde Johnson’s reverence for life. I do not share Peter Singer’s skepticism either. I know disabled lives are worth living, and I, too, have chosen to be an active ‘I’ who does things in the work against normative oppression. I speak, write, and educate…and my work is just beginning. In all my writing, speaking and educating to come, I will steadfastly work against the fraud that leads us to believe that disability is a death sentence. With Harriet, I wonder how many disabled people have begun to believe they will die -- or that they should -- because their exclusion and oppression tells them they are worth nothing. How many disabled people have come a little closer to giving up after picking up yet another book that forecasts their death through one more dying disabled character? And one more…And one more…Well, in the face of this, I will not be silent.

If I have to work in a world containing Peter Singer’s politics, and the politics of others who are less obvious and vocal but equally damaging to disability -- and I do -- then I will fight back!

**Life ‘After’ Disability Studies**

Over the last three years, I have transformed from a ‘person with a disability’ (holding my disability away from me at a distance, like a parent holding a soiled diaper and heading for a garbage can) to a **disabled person**. I respect and welcome my disability as a huge part of my identity. I do not overcome my disability in hopes of shedding it like tired skin; I live in it, not with it. There is no life ‘after’ disability studies, because the disability studies perspective informs my approach to everything I do. I won’t leave it behind.

Furthermore, in my writing, I will not write of disability in isolation, with one ‘token’ disabled character, who has the ‘normal’ problems disabled people have -- hating their
disabilities, disliking their bodies, wishing they were normal, etc.… If society has trouble imagining that life could be otherwise, it’s time to expand imaginations.

As discussed earlier in this thesis, writers who write disability as usual are not ‘bad’. But they have been misled to believe that there is a single ‘normalized’ way to perceive disability. So in light of this deception and in order to upset it, I want to show the multiplicity of perspectives available on disability. This, above all, is my job. It is essential. I firmly believe that writers are educators, and writing is important, powerful work.

And with great power comes great responsibility.
References


