Chatter that Matters:
A new path to progressive understandings of disability through the online
discussion of popular novels

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A Dissertation submitted to the Faculty of Graduate Studies in Partial Fulfillment of the
Requirements for the Degree of Doctor of Philosophy

Critical Disability Studies: York University, Toronto, Ontario

November, 2014

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Abstract
Looking to the novel as a source of information for real lives, this paper investigates the role of the popular culture book club and the informal discussion of novels in the recognition of and response to disability in contemporary society. Reviewing the books chosen for the Oprah’s Book Club as well as readers’ online posts about characters with disabilities are considered in this research. The online, middlebrow discussion of novels is assessed as a productive and developing public sphere related to the discussion of disability. Within this context readers demonstrate their interest in and ability to challenge ideas about disability. This research identifies three key areas which encourage the development of progressive dialogue around this topic including: (a) providing a challenge to traditional literary authority allowing for new and innovative ideas, (b) the recognition of the significant role of emotion and the emotional connection of readers’ with fictional characters, including characters with disabilities, and finally (c) the frequently overlooked existence of discussion surrounding disability within this sphere and the acknowledgment of the social role of disability by readers.
Acknowledgements

This project has been a journey, to say the least, one that I could not have completed without the support, friendship and love of a team of remarkable people. I would like to thank all of my family, friends and colleagues who have believed in me and who have anticipated the completion of this project even when I could not.

Thank you to all of the people who have been involved in my committee. Thank you John Radford, my superb supervisor, who has guided, supported and challenged my ideas with wisdom and kindness and somehow has always known when to leave me on my own and when to push me. I am grateful to Marcia Rioux for her ongoing mentorship, insight and support and for providing numerous opportunities that I would never have had the courage to pursue on my own. Similarly, I would like to thank Beth Haller for her time and the provision of new ideas and exciting and innovative ways to look at the world.

I would also like to thank my parents Pauline and David Stephen for their unwavering support, through all this journey has brought. You have gone way beyond the call-of-duty. To my colleagues who have helped me to develop my ideas and encourage my progress. A special thanks to Bonnie Heath who has always been there for me, to listen to my woes and support me to go on, and even to take me to the hospital.

Finally, my overwhelming gratitude goes to my husband Chris, and to our two beautiful boys Ben and Charlie, both born into the life of a student. You have all been so supportive of this momentous intrusion into your lives.
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Section 1: OVERVIEW
Chapter 1

The Role of Fiction in the Context of Disability

I love to read. I have loved to read as long as I can remember. Some of my happiest memories of childhood are my mom taking me to the library, and me coming home and curling up with my wonderful new collection of books, not knowing where to start amidst the selection of new worlds sitting at my feet. Today, a new stack of books brings me the same child-like joy it always did. Often my favorite part of the day, reading, allows me to escape into a fictitious world, if only for a few minutes before bed each night. I learn from books, about history, about geography, about lives both similar and different from my own. Characters that I come to know, to love and hate and sometimes miss, teach me about life, inspire me, and make me laugh and cry. Many novels have touched and even changed my life. I remember the sadness I felt reaching the end of *Gone with the Wind* (Mitchell, 1936), a big, long, indulgent novel, which had been part of my life for several weeks, a sadness at both what happened in the story, but also that the characters would not be with me anymore. Rhett and Scarlett and the world that accompanied Tara would no longer be part of my daily routine. I remember Holden Caulfield, my first literary love, whose outlook and adventures soothed my adolescent soul in *The Catcher in the Rye* (Salinger, 1951), how Sethe, in Morrison’s *Beloved* (Morrison, 1998) introduced to me in a second year English course, haunts me to this day. These stories are a window into others’ lives; the characters are people, and their experiences genuine. While intellectually I understand them as fictitious, in my heart they are real, their actions and experiences far more influential than most people that I meet. In my mind I have travelled to places around the world and across time. I have visited Maycomb, Alabama during the depression, (*To Kill a Mockingbird*, Lee, 1962),
Paris and rural France during the Second World War (Suite Française, Nemirovsky, 2004) and a geisha house in Kyoto (Golden, 1997, Memoirs of a Geisha) to name a few. I, like many, do not read with the intention of literary criticism. While perhaps influenced by these tools and observations, I read to escape, to understand and to become what often feels like an intimate part of lives beyond my own. Readers continually demonstrate a connection with books and characters. Author James Baldwin (1964) stated that “You think your pain and your heartbreak are so unprecedented in the history of the world, but then you read. It was books that taught me that the things that tormented me the most were the very things that connected me with all people who were alive, or who had ever been alive.” William Nicholson echoes this sentiment in his screen play Shadowlands (Attenborough, 1993) stating that “We read to know that we are not alone.” Not only do readers identify the ability to experience lives beyond their own, but also gain a sense of unity from reading. While Dr. Seuss (1978) tells us that “The more that you read, the more things you will know. The more that you learn the more places you’ll go,” George R.R. Martin (2011) writes that “A reader lives a thousand lives before he dies…”

While reading itself transports us, the discussion of books adds an additional layer to the meaning and implication of the text. Few things bring me more pleasure than to find others who have enjoyed these same books and to discuss and share what I have experienced to that point in solitude. As much as reading the books themselves, bringing them to life through discussion solidifies the connections or disconnections experienced through these presentations. With a long standing history in the Western world serving to bring people together, to study, to discuss, and to bring forth collective action (Long, 2003), the book club becomes a productive site for analysis regarding novels and the discussion of novels as a vehicle of change.
It is both the significance of the on-going social inequality experienced by people with disabilities as well as my love for reading that has brought me to this research. This inquiry looks at the novel as an entry point into others’ lives and the ways in which people are connecting to novels. More specifically, I have endeavored to understand how this experience with novels and the discussion of characters within them can be understood in the context of disability. Noting the considerable presence of characters with disabilities in fiction and our capacity to connect with characters whose lives and experiences exist outside of our own I originally intended to focus on the following question:

In what ways can the cultural meanings and discussion of meanings in the presentation of disability in popular culture books serve as a tool for social change?

However, as my research developed it became apparent to me that to link social change to the novels would be a huge undertaking for which much more preparatory work needed to be done. What emerged instead as a crucial first step was the recognition of the significance of the rhetoric around the novels by the readers.

Novels provide us with two distinctive sources of information: that which is contained within the novel itself and that which exists outside of the pages of the book articulated by both readers and authors. Literary scholars continue to debate the merit of each source of information as to its place in the study of fiction. While Bloom (2000) dismisses the role of the novel within a social context and argues that the best books transcend social issues, it is the work of scholars who identify fiction as playing a powerful role in society, purporting truths and values (Eagleton, 1983) and recognizing the link between art and social reality (Williams, 1980) that has shaped this work. Fiction is powerful because it is imitative of reality (Thomson, 1997). People learn
from other people, whether real or imaginary. Readers spend hours with characters and settings, moving between fiction and reality in their own lives. The characters that we read about and their stories become a part of what we know. The application of a disability studies frame of inquiry adds to ways in which fiction can be understood as part of cultural knowledge. The widespread presence of characters with disabilities in fiction demands research both into the creation of disability by authors and its interpretation by readers.

**Reading and Popular Culture**

The study of literature has developed into and is maintained as a valued academic discipline (Eagleton, 2003). Novels esteemed within academic contexts, however, are rarely reflective of what the general public is reading and responding to. Observing trends in purchased novels, for example, Farr (2005) recognizes that 75% of fiction is bought and read by women, and fiction markets dominated by female authors. In contrast, the majority of award winning novels (e.g. Nobel Prize, National Book Award, and Pulitzer Prize) and the resulting study of those materials have traditionally been dominated by males. Since 2005, only three of the nine winners of the Nobel Prize for literature have been female, three of nine winners of the National Book Award, and five of the nine Pulitzer winners. This discrepancy of assigned literary value, readership and authorship demands consideration of Farr’s challenge to the elitist conception that popularity necessitates mediocrity and to question the power of popular novels to influence. The role of the popular culture book club then, becomes vital to the recognition of who is reading, what they are reading and the impact of these widespread materials, especially relevant in the case of disability.

Oprah Winfrey has been repeatedly cited as one of the most powerful and prominent women in the world (Garson, 2004; Thompson, 2007). Her book club, started in 1996, serves as a source of recommendations for readers, a platform for authors and as one of the most influential sources in
contemporary publishing (Rooney, 2008). Through this popular initiative, recently re-launched in a new format under her OWN network, Oprah Winfrey has been credited with the achievement of getting America reading again (Farr & Harker, 2008). The novels of Oprah’s book club provide a relevant and contemporary ground from which to analyze how disability is being read and discussed in a popular context. While novels range in subject matter and assigned literary value, they can be assessed in their reading through a popular lens.

Sample

A case study of the novels of Oprah’s Book Club has been used for this research based on the club’s influential cultural significance, its ability to provide relevant, present-day information from which to analyze the treatment of disability in a popular context, as well as the widespread presence of disability in the novels. This includes 61 of the 70 books selected for the club from 1996-2011, excluding all non-fiction and children’s selections. The novels date from 1877 to 2011, representing both English and English language translations by authors from countries including the United States, Canada, Ireland, Germany, Russia, Haiti, Columbia, South Africa, and Nigeria. Noting the considerable focus that is placed on book club choices as representative of “a new age of cultural democracy” (Farr, 2005), the depictions of characters in these novels are ascribed the power to encourage readers to explore, share and identify with varied lives. The potential for movement towards increased cultural democracy exists in this realm but a current gap in the critical discussion of popular fiction and the place of disability within genre fiction fails to address this source of information for many readers.

“Popular narrative is not trivial…it forms part of discursive practices that support inequality, influence medical and social decisions and determine interactions between non-able bodied and non-disabled experience and identity.” (Moody, 117 cited by Cheyne, 2012). While the field of
literary disability studies continues to grow based on the influential work on disability representation by such authors as Rosemarie Garland Thomson, Lennard J. Davis and David T. Mitchell and Sharon L. Snyder, there remains reluctance by disability scholars, eager to find a place in the academy, to engage with less socially valued texts. The prominent focus on presentations of disability in esteemed novels within this growing field highlights Cheyne’s observation that in the study of literature, hierarchies of value dominate and that more is to be gained from researching new insights into disability in the works of William Shakespeare than science fiction. While this emergent area of study is rapidly changing and new areas of inquiry developing, disability has yet to find its place in the study of mainstream literature (Hall, 2012). Popular fiction lags even further behind.

In spite of this, popular fiction is gaining ground in the field of disability studies as an area of inquiry as demonstrated by the recent publication of a special issue of the Journal of Literary and Cultural Disability Studies on this topic (2012). A much-needed focus on critical work in the areas of science fiction, romance, and crime fiction is identified (Cheyne, 2012). I seek to extend this call to the broader spectrum of genre fiction as a whole. Outside of definitive categories such as science fiction, romance, or western, genre fiction encompasses the largest classification of fictional works. Defined by its distinction from literary fiction this more comprehensive category does not conform to a specific genre. Recent best sellers which highlight stories of disability such as Picoult’s (2004) My Sister’s Keeper, which recounts the story of a sibling born to donate organs to her sick sister or Genova’s (2008) Still Alice, exploring an academic’s experience with early onset Alzheimer’s, exemplify influential, popular, genre fiction. Publications in the area of disability and fiction, however, rarely identify this common category of novel, but rather tend to focus on either more traditional literary works or specific categories of fiction such as those
identified by Cheyne. Searching major periodical titles in the area of disability studies (Disability Studies Quarterly, Disability and Society) as well as the Journal of Literary and Cultural Studies demonstrates a disproportionate focus of articles discussing literary fiction. Commentaries on the works of historic and prize winning authors such as Shakespeare and Woolf are prolific. This is followed by writings on representations of disability in children’s books (see Keith (2001) for example), life writing (see Couser, 2006), and category fiction with a particular focus on crime and mystery (see Hafferty and Foster (1994), and Zola (1987)) and romance novels. While identifying the need for a disability-informed perspective in the study of popular fiction, we must not limit the scope of popular fiction to these restrictive categories.

Based on this recognized deficiency in the availability of research on popular texts, this exploration identifies themes and highlights discussions surrounding disability in relation to both literary and popular genre novels read within a middlebrow context. Identifying this medium as an avenue for disability to enter the consciousness of readers, this research focuses on the online discussion of novels and their characters. Using Habermas’s (1963) theory of the public sphere, and the internet as potential location of critique, exploration and discussion, I will identify the ways in which dialogue, or lack of dialogue about characters with disabilities uphold stereotypes and categorizations, but also its capacity to act as a new location from which to understand, interpret and react to disability.

The Intersection of Disability and Fiction

Constructions of disability have been historically underlain by powerful discourses (Barnes, 1992; Corker & French, 1999; M. Foucault & Foucault, 1972; Linton, 1998; M. Oliver, 1990b; Radford, 1991; Radford, 1994). These changing constructions have in turn given rise to specific direction in social policy (Park & Radford, 1998; Rioux, 2001; Rioux, 2003; Rioux & Valentine,
2006; Tremain, 2005) and resulting barriers and attitudes. This relationship is as vital today as ever, though in an era of mass society, mass media and instantaneous communication, it is ever more difficult to unbundle.

Fiction has been identified as particularly important and influential as a cultural force because of its commonplace presentation. Lacking the sensationalism of other media formats, this type of storytelling provides more fully developed and readily accepted versions of reality (Barnes, 1997). This recognition highlights the important role of reading fiction in relation to understandings and responses to disability considering Zola’s (1987) observation that much of the information about disability held by the public comes from secondary sources.

There exists a majority disability rights consensus that disability is an outcome of negative social conditions rather than individual deficits or medical conditions (Linton, 1998; Oliver, 1990a; Rioux, 2001; Thomas, 2002). Discourse has been identified as an ever-changing tool of politics, domination, and control representative of the interplay between language and social relationships (Oliver, 1994). Extensive disability studies research exists outlining the roles of scientific and professional discourse (Barnes & Mercer, 2010) and resulting discourses of caring and tragedy (Barton, 1993; M. Oliver, 1990a), consumer and material (Russell, 2002) and embodied and corporeal discourse (Küppers, 2004; Siebers, 2008; Titchkosky, 2007). Currently, cultural discourses of normalcy are recognized as impacting perceptions of the human body and disability. This has been shown to be especially evident in literary and artistic works (Brueggemann & Fredal, 1999; Davis, 1995; Davis, 2006b; Thomson, 1997).

Scholarship on fictitious representations of disability, previously focused on imagery, is progressing towards analysis which addresses the roots, purposes and implications of the pervasive portrayal of disability (Barnes & Mercer, 2010) applicable to contexts such as popular
fiction. Including assessments of cultural meaning can offer a better understanding of diversity in the presentation and discussion of disability in popular fiction.

**History of Disability in Fiction**

Though, historically, disability has been widely reported as absent from the purview of critical analysis, its portrayal has been pervasive throughout literature (Baynton, 2001, Darke, 1998, Mitchell & Snyder, 2006). Through the widespread characterization of various forms of disability and disabled characters, literature from both the past and present provides disability researchers and advocates with important information. There are abundant examples of characters with physical, cognitive, psychiatric and sensory impairments in literary portrayals, the most often cited being William Shakespeare’s *Richard III*, Dickens’ *Tiny Tim*, and Melville’s *Captain Ahab*. Other authors break down these molds further into precise roles such as the Vengeful or Disagreeable Dwarf (Adelson, 2005) or the Demonic or Charity Cripple (Kriegl, 1987).

In ancient tragedy, Sophocles’ Oedipus, meaning swollen or clubbed foot, is one of the oldest examples of disability in literature. Stiker’s (1999) *A History of Disability* provides additional examples of figures in classic stories with physical aberrations: Hephaestus, with an unidentified disability, expelled at birth and Philoctetes, the son of a king who has his foot bitten off by a serpent. In Norse mythology, Stiker cites Tyr, the god of combat and heroic glory, who has one hand, and Odin, the central god of Norse paganism, who has one eye.

The middle ages reflect a variety of attitudes towards disability. Impairment is viewed through a range of lenses from punishments for evil and sin to a gift of the gods, and later as the object of Christian charity (Barnes & Mercer, 2010, Stiker, 1999, Wolfensberger 1972). Literary
presentations reflect this history. That many of the characters in Chaucer’s *Canterbury Tales* possess a disease or some kind of physical difference (the Wife of Bath, the Summoner and the Cook) demonstrates the prevalence of this kind of diversity (Andrew, 1991). At the height of the Middle Ages the role of charity increased (Stiker, 1999), as typified by the prolific poetry of Francis of Assisi which upheld that assistance for the poor was noble. The view that disability was demonic or sinful, also typical of this era, is illustrated in the classic epic poem *Beowulf*, through the depiction of the antagonist, Grendel. Though Grendel is never described in relation to his own physical form, he is depicted as an “unhappy creature” from whom “…sprang all bad breeds, trolls and elves and monsters, likewise the giants…” (Abrams, 1968) as cited in Norton Anthology of Literature, 1968, 9).

The beginnings of modernity brought the recognition of medicalization, contamination (Stiker, 1999) and hospitalization (Trent, 1994). Reflecting the Enlightenment and thinkers such as John Locke, personal characteristics of rationality, consciousness, and self-consciousness became valued. Classic literature of this time period reflects an emphasis on order and the harmful effects of leaving the *irrational* or *disordered*, to their own devices. Shakespeare’s *Richard III*, widely cited in the disability literature as a stereotype, describes himself as an “ugly hunchback”, and is portrayed as evil, scheming, jealous and murderous. In de Cervantes’ *Don Quixote* (1605 & 1615) the protagonist Alosno Quixano, is infatuated with books and thought to be delusional because of his lack of sleep and constant reading. Both characters demonstrate a lack of rationality and inability to interact with society in a standard manner. They are situated outside of Locke’s categorizations of personhood and are deemed detrimental to themselves.

The rise of modernity and the progression of the industrial revolution saw the Romantic fashion of fiction as escapism (Eagleton, 1983) in which novelists such as Dickens present characters
with disabilities like the sweet, innocent Tiny Tim in *A Christmas Carol* (1843) as both the result of and the antithesis of the brutality of industrialized life. The 18\(^{th}\) and 19\(^{th}\) centuries bought widespread segregation and institutionalization, leading towards the development of Social Darwinism, a focus on progress and notions of human superiority (Malhorta, 2001). In *Jane Eyre* (1847) Brontë adheres to this socially created belief in the *mad* Bertha, who “…came from a mad family; idiots and maniacs through three generations.” (754-755) and who for the protection of herself and others is kept secret and locked in a tower. This need for protection from the dangers of violent, mad, exotic women is later justified when she burns down the house, killing herself and blinding her husband. In *The Sound and the Fury* (1949) Faulkner promotes this idea of division based on disability and danger having Benjy Compson, who has an intellectual disability, castrated after he is perceived as threatening to young girls.

The presence of disability is not restricted to adult literature, but also appears frequently in children’s books such as in *The Secret Garden* (1911) and *Little Women* (1880), in fairy tales and nursery rhymes and stories like *Three Blind Mice* or *Simple Simon* (Franks, 2001).

The continued presence of disabled characters in contemporary literature is demonstrated by Adelson (2005) who reviews the role of characters with dwarfism and shows a greater proportional abundance of characters with this condition in fiction than in actuality. The author cites nineteen novels written within the past four decades alone, with what she considers realistic portrayals including John Irving’s (1982) *The Hotel New Hampshire* and Ursula Hegi’s (1995) *Stones from the River*. Snyder, Brueggemann and Thomson (2002) suggest that disability in literature is a ubiquitous, unspoken subject which maintains an absolute state of otherness. Disability is not absent as other minority groups have been in the past, but it is silenced and left without address (Truchan Tataryn, 2007). Challenges to traditional assumptions about disability
and or the stock roles portrayed by characters with them are rare in mainstream literature and the established academic study of this field has been of little assistance in the consideration of the role of disability in fiction.

**Locating the Research in the Context of Disability**

To grasp a culture’s understanding of disability, the ideology and values of that society need to be investigated (Eiesland & Sagers, 1998). Presentations of disability in fiction commonly depict disability as one-dimensional, dehumanizing and stereotypical (Mitchell & Snyder, 2000; Mitchell & Snyder, 2001). This kind of presentation is demonstrative of the power of cultural representations to reflect and to shape societal understandings. Cultural illustrations of disability have been argued to traditionally

…form the bedrock on which the attitudes toward, assumptions about and expectations of disabled people are based. They are fundamental to the discrimination and exploitation which disabled people encounter daily and contribute significantly to their systematic exclusion from mainstream community life. (Barnes, 1992, 39)

The presence of disability in novels is pervasive across cultures and time. It is often presented in rigid typed cultural roles and is symbolic of larger social issues, used as a literary tool and ignored in the wider study of literature. Linton (1998) observes that in the humanities, “disability imagery abounds in the materials considered and produced…and yet because it is not analyzed, it remains as background, seemingly of little consequence” (110). This dearth of analysis in established academic disciplines has prompted disability scholars to study the role of disability in fiction in many ways including: as a social phenomenon; as an archive of untold histories (Mitchell & Snyder, 2001), a source of imagery, stereotypes and symbols (Biklen & Bogdan, 1977; DRPI, 2013, Gartner, 1987; Kriegl, 1987; Longmore, 1987; Norden, 1994), as a record of
attitudes and reactions towards disability (Mitchell & Snyder, 2001), as a means of imposing standards of normality, conformity and productivity (Barns & Mercer, 2010; Davis, 1995; Keith, 2001; Truchan Tataryn, 2007), as a gendered issue (Fine & Asch, 1988b; Kent, 1988; Morris, 1991) and as a contributing element of social and cultural identity (Hafferty & Foster, 1994; Mitchell, 2002; Thomson, 1997). Prince (2006) states that “what people believe about individuals with disabilities underlies the treatment of these individual in all aspects of their lives” and that “the cost of negative beliefs or inaccurate information is high, both for people with disabilities and for society as a whole.” (20). If literature, as Mitchell & Snyder (2006) suggest, has the power to both uphold and confront “cultural truisms” and to develop distorted misconceptions in reality, the realization and exploration of the reading and discussion of fiction as a cultural force is imperative to the study of disability.

**Prominent Approaches to Literature in Disability Studies**

The use of disability as stereotype or metaphor is widely discussed in early disability literature. Of the conventional presentations identified by major contributors in this area, Longmore (1987) cites three common stereotypes including disability as punishment for evil, embitterment about one’s fate, and the assumption that people with disabilities would destroy the non-disabled if given the opportunity. Other research shows people with disabilities as spectacles, as pitiable and pathetic, good people who have been sinned against, as vengeful, disagreeable, sinister and evil, as super-crip, comic mis-adventurer or object of ridicule, as their own worst enemy, the sweet innocent, as a burden, non-sexual or over sexed and threatening or incapable of participation (Barnes & Mercer, 2010, Biklen & Bogdan, 1977, Gartner, 1982, Keith, 2001, Kent, 2001, Kriegl, 1987, Longmore, 1987, McCollum, 1998, Norden, 1994, Safran, 1998). These commonly identified stereotypes emphasize a single feature while ignoring the totality of the characters
(Thomson, 1997a). In their failure to offer challenges to stigmas or stereotypes, Thomson (1997a) holds that literary metaphors “flatten” the experiences of real people. This one-dimensional presentation and a lack of respect for realism and the complexity of lived disability experience are plentiful in contemporary novels. A recent work of fiction exemplifying this is Sara Gruen’s (2007) New York Times Best Seller, *Water for Elephants*. Gruen tells the story of a travelling circus during the depression in the United States. One of the characters, August, is sometimes charming, but has an evil and abusive side and harms his wife, his staff and the animals that he trains. His violent temper and mood swings are attributed to schizophrenia. He is eventually killed by Rosie, an elephant he has mistreated on a regular basis, and his death is illustrated as poetic justice. In her typecasting of this psychiatric disability the author fails to present an accurate portrayal of a person with schizophrenia. In the author’s note following the novel, Gruen spends several pages reviewing the research she conducted for this book to understand the functioning of a 1920’s travelling circus. She cites having taken three research trips to study elephant training, body language and behavior to acquire the “knowledge necessary to do justice to the subject” (333). Though she briefly mentions the “horrific and very real tragedy of Jamaican ginger paralysis” (334) featured as a side story of disability in the book, she provides no information concerning background research or explanation for her portrayal of schizophrenia. Elephants are accorded a level of respect worthy of accurate portrayal, while a human being’s disability is shown in an erroneous and stereotypical fashion. This devaluation of disability through its presentation supports Truchan-Tataryn’s (2007) claim that literature holds up a general ambivalence towards disability.

The use of disability as metaphor, under this same pretense, is identified by Thomson (1997a) as public slander, and represents themes of isolation, defeat (1997a) deception, innocence, crisis
(McCollum, 1998), loneliness, unreciprocated love (Krumland, 2008) punishment, sin, and the wrath of God (Keith, 2001). The rendering of these metaphors occurs regularly. Symbolic images are used to represent social conflict and pain and as a segue into stories of social justice (Mitchell & Snyder, 1997).

Theorizing Literature and Disability
Recent scholarship in this field has not only looked at portrayals of disability in relation to stereotype and metaphor, but has also approached literature as a force in the wider cultural spectrum seeking to identify the roots, purposes and implications of such pervasive representation. The previous focus on imagery has been surpassed by an increased interest in qualitative inquiry and textual analysis seeking to understand meaning and power in this context of diversity (Barnes & Mercer, 2010). Highlighted areas of interest in the analysis of literature and disability include the application of a gendered perspective, analysis approached through societal understandings of otherness and normalcy and through a deeper exploration of the purpose of disability as the subject of portrayal.

Gendered Approaches
Approaches to cultural analyses of disability have been identified by Shakespeare (1997) as having to a great extent developed through feminist inspired scholarship surrounding representations of femininity, stereotypes and beauty. Kent (1987) has addressed the oppressive presentation of women with disabilities, often written by able-bodied women, which has traditionally upheld disability as a challenge to femininity thus degrading the status of women with disabilities and evaluations of self-worth. In Fine & Asch’s (1988) collection Women with Disabilities the role of gender, femaleness and otherness is explored. Disability and gender are viewed through a rights based approach and reveal negative able-bodied attitudes particularly
when applied to women. In this collection Kent (1988) investigates the roots of otherness in women due to a pervasive lack of female role models available in literature for young women with disabilities. She identifies being female and having a disability as representative of being part of a “double minority” (92). Women with disabilities, she notes, are frequently presented as victims and dependents and authors fail to provide alternate choices, outcomes or roles.

Employing a feminist perspective of embodiment, Thomson (1997a, 1997b) explores the role of societal practices of representation and the consequent production of identity and social narratives. The disabled body is explored as marginal, uncomplicated, and exotic, as a spectacle and an “other.” Accepting fiction as imitative of reality, she demonstrates literature to be reflective of cultural meanings given to bodily forms. Looking at fiction, she reviews the classic sympathetic novel in comparison with transgressive black women’s writing. Addressing the notion of subjectivity, she cites the denial of agency and physical objectification as prevalent in cultural arenas. Discussing the works of Morrison, Lorde and Petry, however, she demonstrates ways in which physical difference is re-interpreted as power. She puts forth the re-signification of meaning through a critical analysis of cultural viewpoints and seeks disabled bodies to be understood as extraordinary rather than abnormal.

In her analysis of Victorian fiction for girls, Keith (2001) concludes that this type of literature draws readers to a set of negative conclusions. She identifies general observances from the literature including: that there is nothing positive about being disabled; that people with disabilities must learn women’s submissive behaviors including patience, cheerfulness, and making the best of things; that people with disabilities should be pitied, but not punished, however, they will not be accepted by society; and that impairment is curable if you want it enough and believe sufficiently in God. Pointing to the life-long influence of children’s fiction,
Keith decries the inaccurate descriptions of disability and the absence of authors with disabilities within this realm.

**Otherness and Normalcy**

The creation of normalcy and the study of otherness have also evolved from feminist disciplines. The work of Jordonova is discussed by Shakespeare (1997) as influential in the formulation of otherness, highlighting the treatment of the other as objects, dangerous, threatening and wild, and as needing to be managed and possessed. This difference creates what Mitchell & Snyder (1997) describe as a kind of voyeurism in readers, based on curiosity, delight and repulsion. This sense of voyeurism is also identified by Bolt (2005), who in a discussion of impaired vision in literature, identifies literature as a medium for stigmatization through the use of an unseen stare. He identifies first that these presentations perpetuate a sense of curiosity among people with unimpaired vision, and that this writing has the potential to affect people with impaired vision through “incessant” representation which he compares to Foucault’s panopticon.

Morris (1991) shows that the divisive and separatist nature of disability representation is based on fear and denial, in attempts to sever connections with those who are considered unhealthy or undesirable causes them to be labeled and understood as outsiders. The objectification of this group of people is used to exemplify fears, negative values and characteristics which re-affirm the power and security of the able bodied (Longmore, 1987).

Davis (2002) cites the introduction of statistics and the study of the average in the construction of normalcy. Normality since the 19th century has been associated with progress (Baynton, 2001) and disability as a hindrance to progress (Shakespeare, 1997). With the existence of this conception of a norm also comes the creation of extremes and anomalies resulting in the average
becoming the ideal (Davis, 2002). Though people with disabilities exist as what Longmore (1994, cited in Thomson, 1997a) calls “charismatic deviants,” it is normality in modern life which defines accepted social membership (Baynton, 2001, Keith, 2001). The representation of normality and abnormality upheld by ideology are demonstrated throughout fictional accounts. The ailing female body of Victorian literature is presented as unhealthy and physically incapable (LaCom, 1997). Spiros Antonopolous in McCuller’s (1940) *The Heart is a Lonely Hunter* embodies the denial of spiritual capacity (Krumland, 2008). The solitary and mysterious Boo Radley in Lee’s (1960) *To Kill a Mockingbird* is the antithesis of what is understood to be average. These characterizations represent bodies and minds which refuse to conform and Davis (2002) argues that this source of difference acts as a controlling force of ableism, reflecting hierarchies of perfection and power. He suggests that the average fits a national mould, enforces homogeneity and upholds illusory notions of equality. This valuation of normality confirms Markotic’s (2003) identification of disability as a “physical embodiment of cultural blunders” (179), where abnormal characters are determined as a threat to the dominant social order (Darke, 1994). Davis (2006) upholds that “the very structure on which the novel rests tend to be normative, ideologically emphasizing the universal quality of the central character where normativity encourages us to identify with him or her” (11).

In contrast to the pursuit of normality, Barnes (1997) discusses the outsider fiction of Irvine Welsh whose characters with disabilities in these stories live as part of everyday society. Writing about the poor underworld of drug-using Edinburgh, he cites Tommy, in *Trainspotting* (1993), who becomes HIV positive and Johnny Swann, who has a leg removed because of gangrene, both as a result of drug use. These two characters are argued to be presented as part of the community and day-to-day life, not as an aberrance in accordance with the usual portrayal of
disability. Barnes concludes that this outsider’s world of deviance, criminality, drug use and poverty includes impairment as a part of life. Disability is not extraordinary in this context as it is where it belongs with the gritty, underbelly of society, the already rejected.

**Narrative Prosthesis, Disability and the “Double Bind”**

Mitchell & Snyder (1997) have argued that a “representational double-bind” (6) exists in the presentation of disability which demarks the consistent peripheral role of disabled characters who are accepted by readers through their own roles of power. Characters with disabilities are shown as both entrenched in marginal roles through cultural devaluation and powerlessness but also used by readers as symbols to lessen social guilt and to point to the ill-treatment of other socially oppressed groups. In addition to upholding roles of marginality and assuaging societal guilt, in a later publication the author’s present disability as a “Narrative Prosthesis” (2006) used to hold up otherwise prosaic stories. The presence of limitation, they argue, brings forth a story which begins when something goes awry. This hypothesis is upheld by many examples.

Edward’s (2005) *The Memory Keeper’s Daughter* is premised on the birth of Phoebe, a twin, born with an intellectual disability that is abandoned at birth by her father. This life-long secret then haunts him and slowly destroys him, his wife, their marriage and her twin brother. Phoebe plays only a peripheral role in the story itself, but without her the narrative is of little interest.

Mitchell & Snyder (2001) explore the conceptions of New Social Realism, New Historicism and Biographical Criticism. Through these methodologies the authors recognize the contributions of these forms of analysis which draw from lived experience used to counter prominent negative images and address contextually based understandings of attitudes, ideology and social institutions. They conclude that a “transgressive re-signification” is needed and call for the
movement of disability analysis of art from one of malcontented acceptance to one of embracing of deviance as a marker of value and as a historical framework from which to reconstruct disability.

The analysis of disability in literature, demonstrated through the development of the aforementioned frameworks no longer relies simply on the imagery put forth, but is pursuant of the reasons behind this imagery, the power and the structures which uphold it.

**Overview of Dissertation**

Silvers (2002) argues vehemently against what she identifies as the “signature thesis” of disability scholars that “…art must be oppressive when it references disability, for otherwise it could not be valued by a society that discriminates against disabled people” (236). She condemns what she observes as the inescapable trappings of a continuous conflict between disability and normality and calls instead for the valued difference of artistic subjects through the acknowledgement of and respect for difference.

Disability writers demonstrate movement towards the positive pursuit of diversity through cultural analysis in art, moving beyond the simple identification of oppressive roles. In spite of the continued use of negative representation of disability in contemporary literature, movement forward has been identified based on the increasing use of transgressive readings and presentations of literature both conscious of and from disabled perspectives. Realistic representations of characters with disabilities have the ability to deepen understandings and to integrate and to include rather than to scapegoat (Adelson, 2005). The valuation of difference sought by Silvers is cited in several analyses, including Nussbaum’s (1997) assessment of *Millennial Hall* and the alliance between feminist and disabled communities and in Hamilton’s (1997) recognition of the movement from the grotesque to political identity in German literature.
While still acknowledging the binary relations of normalcy and difference and the often oppressive conditions of society, this dissertation looks at the recognition of these factors by readers as part of working towards a valued reception and presentation of disability in its multiple forms. A comprehensive analysis of the presence, discussion and possibility provided by the manifestation of characters with disabilities in popularly read fiction is provided. The forthcoming chapters negotiate the prevalent discussion of disability stemming from fictitious accounts and the accompanying possibility for change brought forth through this discussion. It also highlights questions about the way that we read and the resulting responsibility of disability scholars along with the reading public to question, enforce, encourage and create new ways of thinking about disability for people with and without disabilities. Moving forward, the discussion which stems from disability is identified as representative of both political and individual forces and recognizes Stockholder’s (1994) observation that the “most important form of political education in the second half of this century grew in small group discussions….consciousness raising. (176)”.

This research is presented in the following sections:

**Part 1: Overview**

Chapter 2 provides an overview of Critical Theory as it relates to disability. Outlining Habermas’s theory of the Public Sphere and more recent adaptations of this theory as they related to the use of the internet in the discussion of books and their capacity for social change, the widespread reading of novels and their open discussion and criticism is discussed as a site of potential change relating to disability.
Chapter 3 provides a literature review which outlines the book club as a new public sphere, identifying the historic significance of book clubs as well as their present day impact. Underscoring research on the act of reading as both a solitary and communal activity, this chapter outlines the role that the book club has had, especially in women’s lives. Focusing on the reading of the middlebrow, the book club is demonstrated as a pertinent tool in the sharing and understanding of world views, as well as a tool for progressive change.

**Part 2: Methodology and Content Analysis**

Chapter 4 outlines the methodology used to collect information about the presence and discussion of disability in this sample of the Oprah’s book club novels. This section outlines the principles of the mixed method research which I have used in this study. Both the content and textual analysis is described in their design and implementation. The content analysis is used to identify the extent to which disability is included within the sample of novels and the countable themes and issues coming out of these stories. The textual analysis looks at existing on-line discussion of the novels and the ways in which disability and other social issues are addressed by readers through their online postings.

Chapter 5 presents the findings of the content analysis, identifying overall patterns and presentations of disability in the book club novels. This summary of the finding of 61 novels outlines the almost universal presence of disability along with types of disability present, the outcomes of individual characters and the interweaving of disability and other social issues.

**Part 3: Reader discussion and findings**

Chapter 6 provides a review of the role of reader interpretations. Chapter 7 gives an overview of the portrayal of disability as it is presented in peripheral roles. This chapter highlights the
frequency with which characters in these roles fulfill stereotypical presentations. Noting the minimal availability of discussion of these presentations, readers’ responses to disability are observed in their tendency to frequently challenge the stereotypical and flat presentation of disability.

In chapter 8, disabilities are explored through the presentation of disability in major characters, where disability is not a thematic issue of the story. Citing the character of Patty Berglund in Jonathan Franzen’s Freedom (2010), Wally Lamb’s Delores Price in She’s Come Undone (1996) and John Singer in Carson McCullers’ classic novel The Heart is Lonely Hunter (1940) readers’ online postings relating to disability are discussed in their capacity to create change in this public sphere. Readers’ discussion is categorized into its ability to challenge traditional literary authority, to offer connections with readers and to provide a location for the discussion of disability in a progressive manner.

Chapters 9 provide an in-depth analysis of three novels in which disability is featured as a prominent thematic issue. Briefly outlining the stories and characters, online discussion of each novel is addressed in terms of disability. Readers’ discussion of disability is analyzed in the characterization of Trudi in Ursula Hegi’s (1996) Stones from the river, Icy in Gwyn Hymen Rubio’s (1998) Icy Sparks and Jewel in Brett Lott’s (1991) novel Jewel. Using discussion information from the Oprah’s book club website, six additional online book clubs and reader reviews, a textual analysis of the discussion about disability is provided.

**Part 4: Discussion and Conclusions**

This concluding section attempts to answer the research question originally posed and the suitability of novels and their discussion to act as a tool for social change. Looking at the ways in
which discussion upholds or challenges more traditional notions of disability and disability presentations to-date, this selection of widely read novels is assessed in its ability to critically examine disability roles, to questions stereotypes and to serve as a tool to both identify and empathize with those outside of our own lives. Assessing this medium and the discussion of popular fiction as a tool in the development/redevelopment of the concept of the public sphere, reading and the collective discussion of novels is identified as a critical tool, and demonstrates the role of a public sphere and the discussion of books as a tool within this realm. Understandings and reactions to disability are shown as important within this discussion. A selection of positive disability presentations in fiction outside of the book club is also provided as a tool for comparison.
Chapter 2

Theory

The idea of the public sphere has a long history as a tool of democracy, a communal arena of debate and as a place of development, discussion and formation of public beliefs. An ideal, with its roots in Classic Greece, this concept continues to be influential in our contemporary understandings of the development of public opinion and democracy.

In a time when disability and people with disabilities maintain low levels of social status and influence (Goggin & Newell, 2003) recognition of the role the public sphere is central to both our historical and present-day understandings of the place of disability in the Western World. This chapter outlines the role of critical theory in the public discussion of disability and more precisely, explores Habermas’s interpretation of the bourgeois public sphere and theoretical developments which have arisen from this theory. Noting that this research concentrates on discussions which revolve around novels that contain characters with disabilities, the dialogue analyzed around these books is acknowledged as moving the experience of readers from the solitary, private act of reading to a place of public discussion. The widespread readership involved in these discussions allows for an extensive sample of contemporary readers who present their opinions and argue their perspectives on issues both about disability and outside of this topic. Using the public sphere as a theoretical base, the power of open discussion and the formation of public opinion is highlighted as a vital tool in the critical study of disability.

In 1962 Jürgen Habermas presented a grand theory of the public sphere in his seminal work *The Structural Transformation of the Public Sphere: An inquiry into a category of bourgeois society*
or *Strukturwandel der Öffentlichkeit*, originally published in German. Based on Enlightenment ideals of reason and rationality in public debate, Habermas identified this arena of public discussion as holding a significant place in the determination of social will, and political decision making. Though originally published over 50 years ago, the translation of this work into English in 1991, along with the continued development of criticism and debate in academic circles demonstrates the sustained influence and importance of this theory to date.

It is argued in this thesis that critical theory is foundational to critical disability studies and the advancement of disability issues in modern society. Developed out of the work of the Frankfurt School, critical theory is at its core is emancipatory, interdisciplinary, reflective, dialectical and critical (Finlayson, 2005). This paradigm rooted in Marxist ideas, developed as a challenge to the empirical approach of the natural sciences and is instead concerned with social context. Theory developed by the classic Frankfurt School thinkers is meant to be practical, to enhance social and political conditions, to identify both what is wrong and ways to transform society (Agger, 1991, Bronner, 2002, Held, 1992, Jay 1996). While theorists such as Theodore Adorno focused on ways to protect individuals from integration into homogenizing capitalist institutions, Habermas seeks to identify conditions which promote autonomy and individual freedom.

With an awareness of the severely lacking conditions of autonomy and freedom for many individuals with disabilities, along with the acknowledgment of the discussion of fiction as a social process (Long, 2003), a critical disability theory lens is used in this analysis of popular novels and responses to disability in those works. It is through this lens that a sense of what people are reading and how those materials uphold or challenge conceptions and responses to disability that the theory of the public sphere and the discussion of books are intertwined and
assessed as a location of social movement, changing public opinion and as a site to evaluate the potential for a relationship between critical theory, disability and the popular culture book club.

**Critical Theory and Disability Studies**

Since its inception as its own discipline in the 1960s disability studies has sought goals of emancipation, transformation and democratization by and with people with disabilities (Barnes & Mercer, 2010). This discipline, however, has been widely criticized for lacking theoretical structure, and instead centering on service provision and policy (Gleeson, 1999). Disability has been studied in numerous academic realms including rehabilitation and medicine (Williams, 2001), and in disability studies through structuralism, humanism, idealism, materialism, embodiment, and many combinations of these approaches (Gleeson, 1999). The most powerful research focus has surrounded disability as oppression (Abberly, 1987, Oliver, 1990, Barnes & Mercer, 2010) maintaining a focus on materialism. The social model developed through this lens highlights oppressive forces and negative social conditions which create barriers for people with disabilities. This model pursues research and theory for the purpose of political action. While the social model has dominated disability studies for most of its existence, recent more radical perspectives have been developed which take disability studies to its logical next step, moving further into the realm of critical theory. Exemplifying this new direction, Withers (2012) argues that modern capitalism benefits and enforces people’s oppression. Proposing a radical disability model, drawn from critical feminist and race theory, Withers highlights the role of oppression and the intersection of theory, history, and personal experience. These perspectives demonstrate what Goodley (2011) identifies as the required deconstruction and critical disability studies needed to break-down institutions and their reactions to people with disabilities. The cultural model of disability studies used in this thesis demonstrates the interdisciplinary nature of this
field connecting the importance of analysis of disability with ideas from other transformative fields.

The institutions which have perpetuated ideas about disability are examined through narrative and the structures which have upheld oppressive narrative in the formation of public opinion. The discussion is then turned so that it can be examined as a potential site of progress in their intersection of history, and personal experience. The personal experiences of readers and their perceptions of disability are analyzed based on their existence within a social framework and examined within the idea of the public sphere. Critical theory has been accused of leftist elitism which in spite of emancipatory rhetoric has provided limited access to liberation (Agger, 1991) and inadequate practical applicability (Habermas, 1989). Theorist from this tradition, however, have put forth efforts to revitalize this line of inquiry with the use of more inclusive and action-based strategies as is the practice in disability studies.

**The Public Sphere**

**Defining the Public Sphere**

The idea of the public sphere marks an arena of public discussion where the ideas of citizens are brought forth in a public forum to deliberate common issues, to assess competing ideas and to arrive at a consensus regarding public opinion. Though sometimes difficult to distinguish as a concept outside of Habermas’ influential bourgeois public sphere, this forum as a more general concept allows for issues present in the public to be raised by individuals under the assumption that they are reflective of the issues of the wider public. By presenting competing arguments, public debate allows for multiple perspectives to be represented and assumes discussion will
result in well-functioning, democratic rule (Gripsrud, Moe, Molander, & Murdock, 2010). The public sphere is identified by Fraser (1997) as “a theatre…in which political participation is enacted through the medium of talk” (70). Distinct from the state, the public sphere holds its power through participatory democracy and consensus based opinion.

The public sphere has been traditionally considered to be dependent on the quality of discourse and the quantity of participation (Calhoun, 1992). Devised as premise of equality, it is at its base considered to be an open forum. This promising ideal in the practice and development of citizen centered rule offers a transformative location to engage, explore and understand opinions outside of one’s own. It has the potential to bring forth new understandings, to emphasize issues of public importance and to bring together individuals and communities in the pursuit of common goals. While this visionary goal is critiqued throughout this research, its premise remains promising as a tool for change.

The theory of the public sphere and the more recent developments within this theory including Fraser’s (1990) more inclusive interpretation of the public and Hauser’s (1999) focus on discourse within the public sphere highlights the importance of public dialogue and the related discussion of novels as a productive grounds for analysis. This theory has helped to develop and explore the ways in which public opinion is formed and the potential power for social change which can result from public discussion. The application of this framework to life beyond the bourgeois public sphere encourages the study of culture in new and exciting realms, bringing with it the possibility to effect change across the spectrum of public opinion and specifically in the recognition of and response to disability. To study culture in relation to disability is to recognize the role of conceptions of normal and abnormal and to analyze the socialization that
takes place as part of social constructions, assumptions and rules (Barnes and Mercer, 2010).

Where better to do this than in an analysis of public discussion?

**Historical Models of the Public Sphere**

An overview of the historical presence of this model allows for a greater understanding of its influence. The ancient Greek conception of the public sphere is based largely on the distinction of the *oikos*, the Greek household as the centre of labour and exchange, the domain of women and slaves and the *polis*, as the marker of political life, for the head of the family, a place of discussion and collective action (Arendt, 1958). Rhetoric and public speaking were taught to Athenian boys in preparation for their participation in public affairs (Hauser, 1999). Without a division between social and political life, the Athenian concept of the public sphere was not set apart from the legislative assembly (Hauser, 1999). In Roman times, while the distinction of the Greeks did not exist, a private-public contrast was present. It was during the Middle Ages that this distinction became not about political communication, but about social status (Hauser, 1999). During this time the division between public and private faded, based on the top down, system ruled by the king, followed by nobility and common people. The role and power of the public as previously understood was subsumed by the ruler as the only source of public decision making. There was, therefore, a lack of representative public and collective action (Habermas, 1989). With the development of the Enlightenment and early capitalism, the feudal state was overshadowed and the idea of public and private spheres as distinct entities became prevalent, separating political from private issues. Under capitalism a new social order was developed and the private realm began to be seen as something to be defended against the dominant state (Calhoun, 1992). With the development of a new bourgeois or middle class sect of society, a new power and influence was developed along with the ability to be involved in public debate.
**Classic Theorists on the Public Sphere**

The long standing examination of the role of the public sphere has been captured by influential thinkers over the last centuries. Enlightenment thinkers discussed this idea at length. Immanuel Kant is the most readily identified theorist in Habermas’s work, based on his delineation of the ideals of the bourgeois public sphere. Kant saw the Enlightenment as an emergence from a time when man failed to think for himself, and the development of a public allowing for reason. It was reason which was tied to “…man’s emergence from his self-incurred immaturity.” (1748). Hegel (1821) argued fervently for the need for individual freedom through the right to criticism. While valuing public opinion, he was skeptical of unorganized, ill-formed and irrational opinion. In 1859 John Stewart Mill, a supporter of freedom of expression, saw the public opinion of the press as tyrannical in its focus on majority ideas. His “morality of public discussion” identified the need for people to think outside of themselves and to accord different and unpopular ideas equal respect. Within this seemingly egalitarian framework, he also argued, however, that those with higher levels of education should be granted two votes.

Arguing the role of mass society in the context of the public sphere, early 20th Century theorists had many contributions. Walter Lippman (1925) argued that social reality had become too complex for ordinary people to understand and that experts should be in charge of understanding public affairs. Identifying the illusion of informed citizens, he viewed the masses as passive, irrational and selfish. Dewey (1927) responded to Lippman’s elitism presenting ordinary people as creative, rationale and responsible. He saw the dissemination of common knowledge as a way to cultivate ability, to discuss and make decisions beyond the confines of experts and insiders.
Schumpeter (1942) saw opinions best served by the election of a representative who then holds responsibility to carry out opinions.

All of these theories and beliefs have been foundational to the work that has been developed in the later 20\textsuperscript{th} and 21\textsuperscript{st} centuries on the role of the public sphere.

**Present-Day Discussions of the Public Sphere**

The contemporary revival of interest in the public sphere was most notably brought forth by Hannah Arendt in her 1958 work *The Human Condition*. In this influential pre-cursor to Habermas’s *Structural Transformation of the Public Sphere*, Arendt argues that public space under modernity needs to recognize the call for universal political emancipation. The forgotten sense of public space in modern capitalism which has resulted in declining civic engagement and collective deliberation could be alleviated, she suggests, through the revival of the public sphere as source of human growth and self-realization.

**Habermas and the Public Sphere**

The most influential of the second generation of Frankfurt School theorists, Jürgen Habermas has been pivotal in the advancement of inter-disciplinary insights based out of the dialectical philosophies of Marx and Hegel (Finlayson, 2005). His most influential work on the public sphere brings new life to the cultural theories of his predecessors. In his less pessimistic view of the role of the masses as both consumers and citizens, Habermas identifies the potential of consumers to also become participants (Wiggerhaus, 1995). In his search for democracy he identifies that “…legitimate state power is mediated by the free and express consensus of all citizens” (Wiggerhaus, 1995). Democracy is therefore based on a process of creating conditions where citizens participate and where economic inequality does not disqualify participation in
politics. His vision includes freedom from illusion, autonomy and the realization of the good life (Finlayson, 2005, Wiggerhaus, 1995). In seeking insights into social reality, Habermas seeks to revitalize the public sphere as a tool for progression. He describes the public sphere in the following way:

By ‘the public sphere’ we mean first of all a realm of our social life in which something approaching public opinion can be formed. Access is guaranteed to all citizens. A portion of the public sphere comes into being in every conversation in which private individuals assemble to form a public body. They then behave neither like business or professional people transacting private affairs, nor like members of a constitutional order subject to the legal constraints of a state bureaucracy. Citizens behave as a public body when they confer in an unrestricted fashion—that is, with the guarantee of freedom of assembly and association and the freedom to express and publish their opinions—about matters of general interest. In a large public body this kind of communication requires specific means for transmitting information and influencing those who receive it (1974, 49).

The Enlightenment Model of the Public Sphere

Habermas centres his argument on the Enlightenment conception of the public sphere. While Adorno and Horkheimer (1947) had warned of the dangers of democratic public life, Habermas sees potential in formal democracy through inter-subjective communication (Calhoun, 1992). His reference to the term Offentlichkeit, used in the original German title, refers to the fact that government and state power should reflect the power of the public (Gripsrud et al., 2010). Using a historically specific model, Habermas’s aims to identify the ideal type of public sphere typified by the German and British developments of the 18th and 19th centuries and sees these examples as a training ground for future societal norms. This understanding guarantees its citizens certain basic rights, which amount to establishing the public sphere as a public institution. Habermas argues that this is done in order to abolish the idea of the state as a dominating force by linking law to rational debate. Based on a premise of café society where people came together to discuss common issues, early 18th century London society exemplifies this model with its over 2000
coffee houses to host such discussion (Hauser, 1999). The requirements for participation were to have read literature relevant to the discussion and to be a male, property owner. Habermas identifies the discussion and formation of opinion resulting from these dialogues apart from common opinion because of the critical reflection expected from engaged and competent public (Hauser, 1999). Committed to resolving public issues through open deliberations, this space is identified as enabling citizens to contribute politically and engagedly in an official capacity. This process therefore disengages power and decision making is based on agreement and merit rather than ideological domination (Habermas, 1970a, 1971a, 1975, 1979). Seeing public opinion as the only legitimate source of law, the Enlightenment experience centres on public opinion as truth, the recognition of the importance of mutual dependency, self-regulating society and the spread of ideas through conversation.

Offering a synopsis of this model, Calhoun (1992) identifies four important features of Habermas’s model of the public sphere:

- A kind of social intercourse that far from presupposing the equality of status, disregarded status altogether
- Rational argument was the sole arbitrator of any issue
- Discussion within such a public presupposed the problematization of areas that until then had not been questioned
- Emerging public established itself as inclusive in principle. Anyone with access to cultural products (books, plays, journals) had at least a potential claim on the attention of the culture-debating public

This model is representative of a specific account of European history and its potential for application to another historical era. Its applicability to other places and times has been widely questioned (see for example Kramer, 1992) and Habermas’s judgment of previous
periods is somewhat idealized by comparison to his analysis of the present. As Calhoun (1992) points out, Habermas judges the 18th century by Kant and Locke, the 19th by Marx and Mill and the 20th by suburban TV viewers. While Habermas identifies this model as unrealistic for a modern capitalist state, he maintains its potential as an ideal.

Public Sphere(s) Moving Forward
While I would hardly be the first to suggest the need for a model of the public sphere that is more inclusive and in line with contemporary realities, the adaptation of this model to the online discussion of popular novels and public opinion surrounding disability is not a widely researched phenomenon. Many recent interpretations of the public sphere support the need to adapt this conception into a more encompassing structure which has assisted me to form a theoretical framework. Fraser (1990) discusses the alternate publics of women and the proletarian; Eagleton (1983) identifies literary counter-publics. Eley (1994) cites the traditionally missing peasant and working class publics and Negt and Kluge (1967) discuss counter-publics and the worker movement. Hauser (1999), devising a new interpretation of the classic model, challenges the notion of a single public with multiple publics and highlights the role of everyday discussion within this context. Taking Fraser’s more inclusive concept and Hauser’s Rhetorical Model, the discussion of novels in relation to disability, can be demonstrated to be a tool for sharing, communicating and influencing public(s) opinion. Stemming from Habermas’s model of a single public, this adapted understanding of the public sphere is recognized as a tool in the development of public opinion and resulting politics surrounding disability.

Nancy Fraser
Negt and Kluge’s (1972) idea of counter-publics is picked up by Fraser in her 1992 challenge to what she identifies as troublesome aspects of the public sphere. Pointing out the continued significance of this idea to the pursuits of critical theory, Fraser sees the need for a model for post-bourgeois society. Critical of the Enlightenment model Fraser identifies it as a powerbase for bourgeois men, “who saw themselves as a universal class” (131), which sharply distinguished between public and private, excluded women and domesticity. She argues against the following four assumptions of what she determines to be the bourgeois, masculinist, conception of the public sphere:

- Assumption that it is possible for interlocutors in a public sphere to bracket status differentials and to deliberate as if they were social equals; the assumption, therefore, that societal equality is not a necessary condition for political democracy
- The assumption that the proliferation of a multiplicity of competing publics is necessarily a step away from, rather than toward, greater democracy, and that a single, comprehensive public sphere is always preferable to a nexus of multiple publics
- The assumption that discourse in public spheres should be restricted to deliberation about the common good, and that the appearance of private interests and private issues is always undesirable
- The assumption that a functioning democratic public sphere requires a sharp separation between civil society and the state.

In what she calls *participatory parity* she challenges the existence of a single comprehensive public sphere in favour of a plurality of values and opinions. Fraser concludes that there are *weak publics*, whose deliberative practices consist exclusively in opinion formation and do not also encompass decision making. This is in contrast to *strong publics* where “discourse encompasses both opinion formation and decision
making.” Public deliberation culminates in legally binding decisions or law and opinion becomes authoritative action.

Based on three of Fraser’s four main challenges to Habermas’s model (the assumption that bracketing is possible and necessary, the existence of a single public, and the undesirability of private interests and issues in the pursuit of the common good), this research follows Fraser’s attempt to interpret the public sphere as a more inclusive and democratic entity. This model provides grounds for public debate which are much more participatory than that which was put forth by Habermas while maintaining similar philosophical goals. Using Fraser’s contributions a contemporary dimension is brought to Habermas’s indispensable but dated theory.
Bracketing

A central issue to this research brought forth by Fraser is what Habermas identifies as bracketing. The idea of bracketing describes the way in which social status is to be overlooked in the practice of public debate and that the merit of argument is to supersede social ranking. The debate is described as “a kind of social intercourse that, far from presupposing the equality of status, disregarded status altogether” (37). By mediating differences in status, inclusive participation is assumed. This supposed equality, where personal identity is not considered relevant to debate, has been highly criticized for its façade of inclusivity. The prerequisite maleness, education and property ownership as criteria for admission, instead of bringing equality, links public participation with sex, academic ability and elitism. This disconnect with the multiplicity that makes up the wider public has been identified in the areas of gender and power (Boyte, 1992), sexual, racial, and cultural minorities as well as lower classes (Ryan, 2003, Eley, 1994). The seeking of the public good through this method denies the experiences and contributions of many. This idea of bracketing as noted by Fraser, though noble in its stated intention, does not produce an inclusive or equitable level of participation.

Applying Fraser’s observations to my own research, surrounding reading and dialogue about fiction as a way to create change, the potential of bracketing can be seen, not in its traditional practice of ignoring difference, but rather, in encompassing it as Fraser suggests. The act of reading fiction is one which allows us to explore lives beyond our own and the issues faced by others making the realities, concerns and celebrations of diverse publics present and accessible. The widespread availability of novels and discussion surrounding them does not suggest a bracketing of difference, but openness to
contributions and participation in discussion by a multitude of participants. Under this definition difference and varied contexts are invited to discussions which have the capability to explore and inform public opinion(s) from many walks of life. The institutionalized oppression and the structures which have created these conditions frequently faced by minorities become part of the discussion.

**Differential Public Spheres and the division of public and private**

Drawing on Fraser’s second two points of dissent surrounding Habermas’s theory (the existence of a single public, and the undesirability of private interests and issues in the pursuit of the common good) the division of private and public issues becomes central to the discussion of fiction and it’s relation to public opinion. Where Fraser identifies the importance and politics of issues from multiple parts of life, Habermas distinguishes between home life and political life as distinct entities. This is made clear in his distinction between the literary and the political public sphere. The literary public sphere, which foregrounded the practice of literary criticism (Calhoun, 1992) is centred on the discussion of problems of daily life presented in cultural products, especially novels. A new found way which allowed for the discussion of art and literature, this form of discussion was said to focus on the emotional resources that were formed within the confines of the family. This predecessor of the political public sphere focuses on reasoned debate, encourages cultural discussion originating from private issues, which when presented in public formats and discussion allow for insight and understanding into the self, desires and motivations (Habermas, 1989). Fictional meetings with strangers are
noted to allow for the explanation of conceptions of right and wrong to be explored and to
develop empathy and self-knowledge (Gripsrud et. al., 2010).

The second half of the public sphere, the political public sphere, is based around the
practice of rational debate on issues of common concern. Revolving around face-to-face
discussions, political opinion is formed through the power of the best argument resulting
in public consensus.

While noting the importance and continued relevance of this theory, it is my contention
based around Fraser’s observation that public discourse need not be restricted to the
deliberation of a single common good and that private issues are not necessarily
undesirable in this process that this distinction between literary and political public sphere
is limiting and no longer relevant considering the now widely accepted social context of
literature. Where the literary public sphere was seen to bridge public and state with
private lives, and to put the state in touch with the needs of the people, discussion of
novels in this thesis will be demonstrated to be as frequently a political exercise as a
personal one. The scope of subjects, concerns and debates brought forth by matters raised
in both political and personal-political discussion through the medium of the novel
demonstrate that the distinction between the political and the literary public sphere need
not exist independently, but to co-exist; where rationality and emotion can intermingle,
where home life and state are equally important players in the overall social picture. As
will be discussed at length in proceeding chapters, matters brought forth which are
seemingly private represent minority voices, domestic, hidden, forgotten or unrecognized
perspectives. By bringing the personal into the political; as has long been the feminist
mantra, problems, discussions and solutions which do not always touch the communal
“we” cited by Habermas are identified. Our treatment/mistreatment of sects of humanity that we may know intimately or have never met or anywhere in between demonstrates the power of story to evoke discussion, raise awareness and change minds. The need for political awareness and the power of influence on public opinion which Habermas’s theory is based on in its ability to lead to emancipation and social change is as apparent in story and the public discussion of story as it is in politics.

Habermas’s distinction between public and private is dependent on the division of issues which pertain to a single common good, for a single public over private interests and ideas. The encompassing “we” that defines “the public” limits the boundaries of who is included and whose issues become political, based on the public justification of their mutual importance. The domestic or private issues Habermas identifies in literature as showing humanity and promoting individual growth can today be seen as a ground for public debate on social issues. The private act of reading brought into public discussion, when thought of in a new light, has the potential to be as much a changing force in society as political discussion and frequently exists as a form of political discussion under the guise of book talk.

Gerald Hauser

The other most relevant addition to Habermas’s theory comes from the work of Gerald Hauser (1999) who identifies public opinion as an emergent discourse, which is constantly changing through dialogue. He cites talk as the precursor to public opinion central to deciding the course of society. Direct conversations, he notes, often shape our understandings and the ways in which we form and express our beliefs. He posits an
awareness of discursive practice and its ability to shape lives. Hauser proposes a rhetorical model of the public sphere which he defines as

…a discursive space in which strangers discuss issues they perceive to be of consequence for them and their group. Its rhetorical exchanges are the basis for shared awareness of common issues, shared interests, tendencies of extent and strength of difference and agreement and self-constitution as a public whose opinions lean on the organization of society. A rhetorical model of the public sphere would adapt Habermas’s (1974, 49) observation on locating such associative space to read: Whenever private citizens exchange views on a public concern, some portion of the public sphere is made manifest in their conversation.” (64)

Hauser’s rhetorical model has five features:

- Discourse based-not class based association
- Critical norms derived from actual discursive practices – replaces norm of critical rationality with rhetorical norm of reasonableness
- Emphasis on indeterminate bracketing of discursive exchange
- Values communication that is conducive, where possible, to the formation of shared judgments – must be accessible to all citizens, there must be access to information – recognition that in a democracy consensus is not always possible

In addition to those points already addressed by Fraser, Hauser identifies the vast importance of daily conversation in the development and proliferation of attitudes and opinions. Citing day-to-day discussion as an important source of public decision making and opinion formation, this research applies Hauser’s recognition of the significance of dialogue to the possibility of social change in terms of the use of media and online technology.

Where Hauser sees the continued and developing applications of the public sphere to contemporary life which I have extended for the purpose of this research to the informal dialogue of online chat, like his predecessors, who described the culture industry as
producing uncritical consumers (Adorno and Horkheimer, 1944), Habermas cites the mass media as a significant force in the decline of his ideal version of the public sphere. While the initial increased circulation of newspapers and journals was viewed to increase critical reflection and discussion, more modern incarnations of the media are instead shown to stifle critical ability and human flourishing (Finlayson, 2005). Reflecting fondly on 18th century London’s combative journalistic culture and the morals developed through the arts, Habermas dismisses contemporary media as favouring entertainment over analysis and as a forum for promoting viewpoints and prejudices with little room for public participation (Gripsrud et al., 2010). The public sphere it is argued to bear little resemblance to its former self. The serious involvement in deliberation of times past has given way to segmented minorities, split into specialists “at the cost of democratic functioning” (27).

Based on Hauser’s model, this focus on daily conversation allows a blurring of public and private and adds diversity to subject matter and significance of social conversation. The dialogue of everyday life is recognized as the material which forms, upholds and challenges opinion and the creation of shared meaning. Using this model allows us to move beyond a single sphere and to recognize the importance of discussion at all levels in the formation of opinion and resulting consequences. Placing discourse at the centre of public opinion creates possibilities for the collection of information which reflects its meaning. Taking day-to-day discourse seriously allows for insights into people’s realities.

**Technology and the Public Sphere**

Taking Hauser’s approach to daily conversation and vernacular and applying this logic to the assessment of online chat allows for an exploration of the role of digital technology in the development and proliferation of the public sphere in a new realm. This is especially relevant
considering the widespread availability of virtual public space for discussion and debate and Habermas’s identification of the role of the media in the decline of the public sphere ideal.

Habermas’s rejection of media as a format of participatory democracy, perhaps did not anticipate the mammoth influence of the internet on public communication. This ever growing network of interactive dialogue allows for a diverse and inclusive space with the capacity to allow for open debate and engagement by a wide variety of participants. It is estimated in the United States in 2011 that 65% of adults used not only the internet, but at least one social networking site. (Papacharissi, 2011) demonstrating the significant way in which this expanding technology is progressively becoming part of all of our everyday lives.

Over the past decades substantial debate has arisen regarding the role of technology as inclusive or divisive in deliberations about the digital divide (see for example Katz & Rice, 2002, Lax, 2000, Schon, Sanyal, Mitchell, 1998). This debate, especially important to the inclusion of people with disabilities, has recently moved from a focus on issues of economic access, to the socio-cultural aspects which create unequal access. As van Dijk and Hacker (2003), point out, what is of relevance is not only that people are able to get to a computer but what they are able to do on the internet when given the opportunity.

Digital accessibility has been discussed at length as tool to revolutionize the lives of the marginalized and especially people with disabilities (see for example Negroponte, 1995). Goggin & Newell (2003) argue, however, that disability remains a rejected knowledge, and the socially created media serves the interests of the status quo. While recognizing this technology as beneficial to many people with disabilities, the authors remind us that it has kept many others in the margins.
Much of the discussion of disability and technology stems from considerations of media and the stereotypical and mis-representational, depictions of disability that have existed in the media to date (see Clogston, 1990, Haller, 1995, 2000, 2010, Pointon & Davies, 1997). Limited opportunities have been available for people with disabilities to publicly reflect on how they might wish to be presented in media and little or no opportunity given for people with disabilities to represent themselves (Thoreau, 2006). Nelson (2011) points out, however, that “as glacially slow as attitudes have been to change, by the end of the first decade of the new millennium a remarkable face of the disabled seems to be showing up in the US media.” (274).

The author identifies a trend towards stronger images of self-empowerment among characters and stories of people with disabilities in media. Discussing the role of damaging media images, Ross and Lester (2011) identify that, rather than extend ideas of diversity in the public sphere, media frequently reproduces and redistributes the powerful message and images of major corporations and that the pledged diversity and access of new media has given way to conformity in content and perspectives supporting Habermas’s point of view. The authors identify the frequent use of stereotype and note that “stereotypes offer a blunt effective tool for communicating – and, as with most blunt tools, their impact is most often overboard and harmful.” (2).

While technology and the presentation of marginality in media have been widely criticized for upholding mainstream ideas and propagating the status quo, others have identified this space as a location for change and development. This less mediated but easily accessible information, allows for the exploration of Hauser’s vernacular in a widely observable forum giving us a sample from which to analyze the potential for this virtual space to exist as a public sphere. In their discussion of You Tube, Burgess and Green (2009) identify the internet and digital technology as a site of participatory culture. It is locations such as this,
where images which have previously dominated with stereotype, challenge perceptions through user created content. This more accessible technology allows for what Jenkins (2006) sees as a shift in power relations between media, industry and consumers through user participation and the creation of new content. When the product of culture, such as online media, shifts from a place of consumption to a site of struggle, power and self-expression, as is identified by Fiske (1987, 1989, 1992a) through participation, the production and consumption of culture becomes active. In the process of what Spurgeon (2008) has called “bottom-up engagement,” user-generated content in social networking encourages participatory culture and innovation through the engagement of consumer citizens through popular culture (Burgess & Green, 2009). Access to the use of this type of technology has been acknowledged as not only a way to access the world, but in the case of a disability centred virtual space, to bring people together, to share stories and to construct community (Cole, Nolan, Seko, Mancuso and Opsing, 2011). Though Schudson (1992) speaks of the tendency of critics to cite popular culture as a significant factor in the decline of the public sphere, he identifies criticisms of the modern era as lacking seriousness and discipline and the television as a source for the lack of democratic participation. This author notes however that inferences made about the literate, attentive and interested citizens of previous ages are not based in reality, but an idealized past.

While media most certainly brings with it consumption and control it has also brought some of Habermas’s vision to reality in its capacity for widespread discussion and challenges to dominant discourse. To present the media as a single entity, especially at this time when it is changing at historically unprecedented rates, is too simplistic. The use of online media
formats and discussions has created a significant opportunity for critical insight and public debate beyond consumption and control.

As technology and media, merge to a greater degree, the role of popular culture in the discussion of the public sphere becomes necessary. Cultural theorist Stuart Hall (1981) remarked that “popular culture is one of the sites where the struggle for and against a culture of the powerful is engaged. It is also the stake to be won or lost in that struggle. It is the arena of consent and resistance…” (239). The recognition of culture in and around popular media upholds the important recognition of technologies in the maintenance and innovation of cultures (Baym, 2000, Jenkins, 1992). Rather than only a tool of oppression or subordination, the internet and the participatory use of the internet can instead be seen as a way to analyze vernacular, to link spaces, to change the ways that we think and to build networks which cross geographical boundaries.

Considering the vast presence and influence of both media and on-line communication in public forums of discussion, new technology enables the conversation surrounding Habermas’s vision to continue in a new and productive way. Specifically speaking about the internet and the public sphere, Bohman (2004), identifies that the internet offers the possibility of a re-defined space for social interaction and participatory democracy which is not bounded by “…specific linguistic, cultural and spatial limitations” (251).

**Discussion**

I was initially drawn to Habermas’s theory of the public sphere based on the concept of a democratic and participatory space for debate and critical thinking. This vision of an inclusive arena where the public takes charge of decision making in rational and impartial terms paints and ideal picture of a progressive society. Habermas’s theory, though restrictive in its application,
unrealistic in its inclusivity and unsuited for contemporary life, provides an inspirational ground from which to explore the power of public discussion and the pursuit of social change. Habermas encourages us to understand the impact of debate in terms of emancipation and democracy.

Combining aspects from both Habermas’s literary and political public spheres, the pursuit of social change through discussion, debate, and private and public experience paves the beginnings of a path to the good life sought by Habermas. Adding Fraser’s multiple publics and Hauser’s rhetorical model brings the question of the possibility of social change through the discussion of popular novels to a clearer starting point. While each distinct contribution has gaps, the combination of parts of each of these contributions allows for a more inclusive look at who is talking about disability in books, what they are saying and how or if this has implications for changing public opinion and resulting social change related to disability.

The online discussion of the novels selected for Oprah’s Book Club are representative of a public arena. The varied groups and individuals and their conversational contributions present a multiplicity of publics and some of their various goals, interests and priorities. The casual language frequently used for discussion demonstrates Hauser’s recognition of the impact of daily speech through its focus on specific topics and use of language. From this public arena I have been able to pull and to synthesize a sample of public opinion regarding disability as it is presented in discussion forums about novels which contain characters with disabilities. I can also speculate on the potential influence such opinion might bring forth. Using this theoretical framework with a textual and content analysis a sense of what people are saying about disability and how this may impact the lives, policy and treatment of people with disabilities emerges along with an adapted interpretation of Habermas’s indispensable theory of the public sphere.
Chapter 3
A New Public Sphere: The History, Development and Contemporary Incarnations of the Book Club

Identified as far back as the 12th Century there is evidence of the existence of “textual communities” (Stock, 1983) which have arisen around the discussion of books. The printed book was the first mass medium of communication (Long, 2003) and this reproduction of texts has encouraged book based associations (Eisenstein, 1979, Johns, 1998). With this development, the general public was newly able to discuss books which became more accessible to them. Unlike publications prior to the 16th Century which were written in Latin and other classical languages, these new texts, written in more common languages allowed for widespread circulation and for readers to discuss their insights and opinions about the stories (Davis, 1975). Extending the reading public from what was once restricted to the elite, groups from different socio-economic statuses including peasant communities, were given increased freedom in their ability to participate in textual activities such as reading the bible without a priest. This practice of communal reading and discussion of books has developed into what we now commonly understand as book clubs. Moving forth several centuries reading groups continue to exist around readers desires to discuss and share novels in community settings. While Habermas identified a “literary public sphere” which he saw as an apolitical pre-cursor to the public sphere discussed in the previous chapter, I will argue in this chapter the frequently political nature of discussing books. Whether we identify the purpose of novels as artistic creations, reflections of social and political realities or a mix of both, we can acknowledge the increasing realization that the discussion of books provides significant insights into both private and public issues. Reading and
the discussion of books serves as a bridge between pleasure and enlightenment and holds in many cases a political purpose.

The Formation of Reading Groups

Critical research on the role of reading groups has been done over the last century showing reading and the existence of book clubs as vital to a variety of contexts and social movement including areas such as the development of national consciousness (Anderson, 1991), as a way to disseminate ideas and as a force of public innovation (Davis, 1975), as a way to form community, to promote political change and a source of life-long learning (Long, 2003). These groups are also identified as offering the possibility of a new way to relate to authority (Davis, 1975), to bring equality and reason beyond male citizens (Darnton, 1979) as a source of encouragement for middle-class radicalism (Thompson, 1972), as an extension of normal conversation and as a reflection of our lives through the minds of others (Oately, 2011) and an important feature in the evolution of women’s rights and progress (Seaholm, 1988, cited in Long, 2003). Incorporating all of these innovations, this research also looks at the ways in which the discussion of novels opens doors to understandings and familiarity with disability in ways which add to those seen in other popular media.

A recent survey of book clubs in the UK and America shows two-thirds of books clubs are made up of women only (Hartley & Turvey, 2001). This frequently female centered entity is discussed as such throughout this thesis. Following the American Civil War, women’s reading groups proliferated alongside social movements. The development of women’s clubs such as the New England Women’s Club, established in 1868, served as an inspiration for women across the country. At a time when higher education was very limited for women, according to Long (2003)
the ability to participate in life-long learning came in other formats such as the literary club. The book club continues to exist in contemporary incarnations in significant numbers. In 2001, there were an estimated 50,000 groups in Britain and 500,000 in the United States (Hartley & Turvey, 2001). While descriptions of the very ordered, serious clubs of the late 19th Century, often opened with a formal presentation, appear very different than the wine-drinking, social event that I attend on a bi-monthly basis, the opportunities for connections, communities and challenging the status quo in contemporary women’s book clubs mirror those that have existed in the past. Earlier clubs, for example, have been cited as allowing the opportunity for women who would not espouse their views publicly the ability to explore new and controversial ideas such as suffrage within a familial community, to innovate, to explore intellectual freedom, and to open their minds to new and changing ideas (Long, 2003). While for many, now or in the past, this may not be the stated or intended purpose of the club, these types of functions serve as secondary opportunities within them. Focuses of early women’s book clubs looked at ideas such as female role models in literature, as a tool with which to form opinions and critical appraisals of the existing state of affairs. In what Seaholm (1988, cited in Long, 2003) describes as a “democracy of brains”, traditional literary clubs brought women together, to celebrate empathy, altruism, and sisterly pride (Long, 2003). The undertaking of activism, frequently associated with these early groups, worked to “dispel prejudices and broaden…insights.” (49). This was demonstrated through both traditionally conceived ideas of maternal caring along with questioning of authority and control (Long, 2003). The purpose of book clubs beyond intellectual growth and camaraderie, is identified by Skocpol to “educate, agitate, [and] legislate” (55) in areas such as social welfare, crime prevention, child labour, juvenile justice, and re-education (Long, 2003). In fact, the women’s book club movement is responsible for the establishment of 75% of US
libraries (Seaholm, 1988, cited in Long, 2003). Many of the features which have made this a successful forum for women have included the embedding of social justice practices. That being said, some examples of textual communities continue to exist with the explicit purpose of social justice, behavioural change and social betterment. Programs such as the Changing Lives Through Literature Program (http://cltl.umassd.edu/home-html.cfm), an alternative sentencing program for those convicted of crimes uses literature to transform lives through reading and group discussion. Similarly, Literature for All of Us (http://www.literatureforallofus.org/) started in 1996 for teen mothers, uses a book group model and assists youth in underserved areas to explore themselves through literature and poetry. Literature for Life (http://literatureforlife.org/more/) serves marginalized women and in their children in Toronto in a similar way. While this type of social purpose is no longer the standard in book clubs, it is often built in and political impacts are made in less overt ways than has been the case in the past.

The Popular Culture Book Club
As the role of women has changed so has the female dominated book club. With women more highly educated and linked to larger social networks, the traditional focus on education of these groups has diminished. The solidarity that once existed however and the sense of community which comes with membership in a book club remains relatively unchanged (Long, 2003). Book clubs today tend to focus similarly on camaraderie, self-reflection through reading, and the blending of lives in books with our own lives (Long, 2003, Oatley, 2011, Rooney, 2005, Todd, 2008).

Long (2003) cites three innovations which have launched the social organization of reading groups. These include the development of book superstores and chains, television book clubs and the on-line literary world. Contrary to the common stereotype that television threatens reading
(Hall, 2008)), broadcast book clubs have proven to boost sales and public discussion of novels. These formats hold not only a network presence, but also involve an intricate web of internet resources and chat spots which have brought book clubs and the discussion of books into the fold of new media. These locations of chat are argued to encourage readers to be part of a larger, friendly literary community (Long, 2003). The approachable space provided by online discussion is set apart from the often intimidating world of literary interpretation, to some extent democratizing this aspect of culture and society. While the commercialism of this prospect is widely argued to devalue its efficacy, this widespread access also serves as a challenge to the elitism of the traditional study of literature and an inroad to the empowerment and inclusion of the masses, so frequently cited in critical theory.

The recent development of mass culture book clubs and book lists such as The New Yorker’s Online Book Club and Canada Reads demonstrate the continued desire of readers to find community and to discuss the novels that they have experienced previously in solitude. The wide array of on-line book communities shows not only that these groups exist in media, and in more traditional in-person groups, but also in virtual formats. The most influential of these mass reading groups is Oprah’s Book Club (OBC), based out of the extremely popular long running talk show, The Oprah Winfrey Show. Oprah Winfrey has been repeatedly cited as one of the most powerful and prominent women in the world (Garson, 2004; Thompson, 2007). Her vast influence is demonstrated in a multitude of ways, including her presence in Western vernacular. The terms *Oprahization*, and *Oprahfication*, for example, relating to the desire to discuss personal problems and emotions publicly are cited in the Oxford Dictionary (http://oxforddictionaries.com/definition/english/Oprahization, and Collins Dictionary (http://www.collinsdictionary.com/dictionary/english/Oprahfication) alike. Her book club,
started in 1996, serves as a source of recommendations for readers, a platform for authors and as one of the most influential sources in contemporary publishing (Rooney, 2005). Through this popular initiative, recently re-launched in a new format under her OWN network, Oprah Winfrey has been credited with the achievement of getting America reading again (Farr & Harker, 2008). Though her television program and book club have been questioned by academics, cultural critics and disability rights advocates alike (see for example Belluz, 2011, Crowley, 2009, Donalsdson, 2011, Goodley, 2011, Kuusisto, 2008) she is also admired by many as a source of inspiration, morality and progress (Illouz, 2003). The novels of Oprah’s Book Club provide a relevant and contemporary ground from which to analyze how disability is being read and discussed in a popular context. While novels range in subject matter and ascribed literary value, the existence of such clubs allows for a new and exciting opportunity for these novels to be assessed in their reading through a popular lens. A case study, the novels of Oprah’s Book Club have been used for this research, based on the club’s influential cultural significance, its ability to provide relevant, present-day information from which to analyze the treatment of disability in a popular context, as well as the widespread presence of disability in the novels.

It is with certain trepidation that I have approached this sample of novels. While the selection of novels themselves, span a wide scope of recognized literary value, the mention of anything to do with Winfrey or her infamous book club appears to bring scorn in academic circles. While providing an excellent sample of what the public is reading, reactions to novels and the discussion surrounding disability in those novels, the idea of literature approached by the masses appears to be generally disparaged by experts as inconsequential and irrelevant to the study of literature. This sentiment highlights the protectionism and elitism of so-called “experts” in this field. Many whom I spoke with about this research quickly rebuked the kinds of books that they
assumed were included in this sample, and I found myself endlessly feeling the need to justify this as a serious topic. Demonstrating my own underlying assumptions regarding literary value, in spite of my desire to challenge them, I have frequently found myself mentioning the conventionally esteemed literary selections in this sample such as the inclusion of two novels by Garcia Marquez’s and Tolstoy’s *Anna Karenina* in order to be taken more seriously. I quickly found that my apprehension about this sample was well-founded and supported by others who have completed research this area (see Rooney, 2005). The creation and proliferation of a mass media based book club, far beyond the reaches of traditional literary study, has challenged the sacred nature of this discipline and put forth a direct confrontation to traditional literary expertise and widespread disdain for the popular. As Rooney (2005) points out, in serious circles “It’s just not hip to be comfortable with Oprah’s Book Club.” (33). While greatly influencing the general public with an average audience of 13 million viewers per book segment (Rooney, 2005), an apparently inverse relationship marks the difference between book sales and cultural value as art. The development of a removable Oprah Book Club logo (Illouz, 2003) on novels, for example, and the prideful exclamations of independent book sellers advertising with slogans such as “books you won’t see on Oprah” (Rooney, 2008, 1) point to the outright snobbery associated with the popular and the blanket dismissal of the far-reaching influence associated with this type of forum. In the same way that Radway’s (1997) research on the Book-of-the-Month-Club demonstrated the disparagement and distinction of the popular from “true” literature, protectors of the literary canon continue to enforce boundaries of cultural hierarchy and exclusivity, while new definitions of what can be learned from literature and the valuation of multiple interpretations and literacies has been brought forth as a challenge to this framework by the wider public.
Section 2: METHODS AND CONTENT ANALYSIS
Chapter 4

Methodology

I have included as part of this research a content analysis and a textual analysis to look at both the subjects of the novel itself and readers’ comments about the books included in the sample. In order to conduct such an analysis I have found it necessary to categorize the presence or absence of disability. This may rest outside of the author’s intention. I have done this as a methodological strategy and recognizing the slipperiness of these categories I do not mean to suggest these as discrete categories, and they do not reflect a philosophical position.

First I have included a content analysis of the sixty-seven books that were included in the Oprah’s Book Club (OBC) in its original form from 1996-2010. The content analysis focuses on the presence and portrayal of disability and demographic characteristics of characters with disabilities included within the pages of these novels. The information within novels allows for an exploration of what has been presented through the presence of characters with disabilities, the context they are presented within, as well as the characterization of these fictitious individuals. The online discussion surrounding these novels is used to gauge public response to disability through the readers’ responses to characters with disabilities and the ability of such a forum to create social change in the case of disability. Although the larger focus of this research centres on the on-line posted reader comments related to specific works of popular fiction, the content analysis serves as a baseline from which to assess what is being presented about disability, in what context and to what degree disability is present.
Content Analysis

Sample

Books used in this data set were the novels of Oprah’s Book Club from the original Oprah Winfrey Show. The Book Club recommended a total of 70 books during its 15 year course. All works of fiction included in the club during this time have been accounted for, comprising 60 novels and 1 short story collection. Memoirs, self-help guides, children’s books and non-fiction works were excluded. Using an emergent coding method, categories of classification were established following the preliminary examination of data. Materials coded have been used to examine the presence and portrayal of disability in book club materials. All of the books which refer to disability or a person with a disability either by name or suggestion, no matter how minor the character, were included. Of the remaining 61 novels, 54 of them contained characters with disabilities. These novels range chronologically from the earliest publication of Dickens’ *A Tale of Two Cities* in 1859 to the most recent novel, Franzen’s *Freedom*, published in 2010.

The novels of Oprah’s Book Club have been used for this research based on the club’s influential cultural significance, its ability to provide relevant, present-day information from which to analyze the treatment of disability in a popular context, as well as the widespread presence of disability in the novels.
Table 1: Novels Included in Sample

<table>
<thead>
<tr>
<th>Club Year</th>
<th>Year of Publication</th>
<th>Author</th>
<th>Book</th>
<th>Disability Y/N?</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>1996</td>
<td>Hamilton, Jane</td>
<td><em>Book of Ruth</em></td>
<td>Y</td>
</tr>
<tr>
<td>2</td>
<td>1996</td>
<td>Mitchard, Jacqueline</td>
<td><em>The Deep End of the Ocean</em></td>
<td>Y</td>
</tr>
<tr>
<td>3</td>
<td>1996</td>
<td>Morrison, Toni</td>
<td><em>Song of Solomon</em></td>
<td>Y</td>
</tr>
<tr>
<td>4*</td>
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* Non-fiction, self-help or children’s selection – eliminated from sample

** No disability present in novel – eliminated from analysis
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<td>Tara Road</td>
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<td>Cane River</td>
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<td>Fall on Your Knees</td>
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*Non-fiction, self-help or children’s selection – eliminated from sample

** No disability present in novel – eliminated from analysis
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*** Collection of short stories – included
Units of Analysis – Coding Procedure

The code sheets developed to analyze novels for this research look at the following areas:
general book information, disability specific information and social capital and social change indicators. The coding book was created with the research question in mind and evolved as the coding developed. Information included contains variables that will have been used to obtain a picture of the presence and portrayal of disability in this selection of popular fiction novels. The following section describes the units of analysis more specifically.

General Book Information

General book information has been counted about the novels including the presence of disability in individual novels, year of publication, book club year, publisher, author nationality, and whether the author self-identifies or is visibly identifiable as a person with a disability. This information was collected from the novel itself, including the about the author section of the book when it was available. The code book can be found in Appendix B.

Author Information

Author information including author nationality (America, Canada, Germany, Nairobi, South Africa, Haiti, Columbia, Ireland, India), as well as whether or not the author is visibly or self-identifies as a person with a disability was counted in this section.

Geographic Information

Geographic information about the story was also collected. This information gives us a picture of where and when the story is set and an understanding of the role of location and time within a story in relation to the presence of disability. This includes information about the geographical location of the story, both by region (US – West, US – North East, US – MidWest, US – South,
Europe, Africa, Central and South America, Canada, China and India) and locale (urban, suburban or rural)

Era in Which the Story is Told

In this section the era that most accurately represents the time period in which the story takes place was counted. All dates that applied were counted for each book as some novels spanned large periods of time. Categories included: 1. Contemporary (1975-present), 2. Mid-20th Century (1949-1974), 3. Early 20th Century (1900-1939), 4. Pre-20th Century 5. Unknown.

Disability Specific Information

The bulk of this analysis has looked at how frequently and in what ways disability is treated within the novels. The areas that have been specifically addressed are: the kinds of disability present, the presentation of characters based on their role within the story, the ages of characters with disabilities as well as their and employment status. Who is presenting the information about a character with a disability i.e. a first person account vs. a friend, family member or medical professional has been counted, as well as their outcome. Character centrality, socio-economic status and education level were removed based on high levels of disagreement between coders.

Presentation of Disability by Type

The information collected in this section tallied presentations of disability by type. Categories of disability that were counted include the following: general (non-specific disability), mobility, intellectual, auditory, visual, mental health/psychiatric, addiction, physical variance/disfigurement, speech, learning disability, chronic health conditions, HIV/AIDS. Some characters have been counted multiple times to represent multiple disabilities. Because of the
subjective nature of perceptions of disability, coders did not agree on all of the types of disability present in the stories; therefore, an overview of the kinds of disabilities identified by both coders is provided.

**Character Role**

Character role was measured on a five point scale, 1 most protagonist, 3 neutral and 5 most antagonist. These measures required my interpretation to determine role as there is not an objective measure with which to count these qualities.

The 1-5 scale represents the character role in this scale, 1 most protagonist (the leading character, hero, or heroine) to 5 most antagonist (the adversary of the hero or protagonist) the perceived role of each character with a disability. Neutral roles which were portrayed as neither predominantly protagonist nor antagonist were given a score of 3 on this scale.

**Age of Characters**

Characters with disabilities were counted based on their age to assess the correlation between age and presentation of disability. The age of characters was grouped into the following six categories: 1. Child (0-12 years), 2. Adolescent (13-19 years), 3. Young Adult (20-39 years), 4. Mature Adults (40-64 years), 5. Elderly (65+), 6. Unable to determine.

**Character Gender**
Character gender was counted based on characters presentation in the novel. Categories included male, female, transgendered, and unable to determine.

**Character Employment**

The employment status of individual characters with disabilities was measured by counting the number of characters who were employed in paid or forced employment during their working years. The categories used to measure employment included: employed, unemployed, child, slave, retired and cannot determine. Characters were frequently counted more than once in this category as they often moved between categories based on age, disability onset and degree of disability.

**Main Source of Information on Person with Disability**

In order to determine who is representing people with disabilities within the stories themselves, the main source of information about characters with disabilities were counted. Groupings of the source of information included: 1. Self, 2. Family member, 3. Friend, 4. Medical professional, 5. Other or 6. Cannot identify.

**Outcome of Character with Disability**

Seeking to find patterns in these representations, the outcomes of characters with disabilities were counted based on 1. Institutionalization, 2. Death, 3. Overcoming Disability, 4. Inclusion, 5. Live with disability (but not inclusion), 6. Other and 7. Unable to determine.
Social Capital and Social Change Indicators
Finally this content analysis looks at the issue of social capital in relation to these novels. Based on Bourdieu’s (1984) conception of social capital and the shared recognition of social value, novels were looked at in terms of their value and esteem within our society. While Winfrey herself holds a significant amount of power and influence, the novels that she has chosen over the years reflect a movement towards more socially valued selections. To access this information the novels were looked at based on numbers of prizes and awards, sources of blurbs and on overall sales figures. This category was altered after the second coder had completed her work and therefore the sections on blurbs and sales figures have not been coded by a secondary coder.

Prizes and Awards

Novels were counted in this section based on their receipt of literary prizes and recognition in recommended fiction lists. Categories included major prizes and widespread recommendation lists including: Pulitzer Prize, James Tait Black Prize, National Book Award, Giller Prize, National Book Critics Circle Award, PEN Award, and the Commonwealth Writer’s Prize. Lists of recommendations included the Modern Library 100 Best Novels for both the Board and Readers, Radcliffe Rival 100 Best Novels, Canadian Readers Top 100 of all time, Time magazine all-time 100 novels (1923-2005) and author’s included in Bloom’s Western Canon.

Blurbs

Noting their place either on the front or back cover, or inside the novel, promotional blurbs were counted in number and by source as an indicator of social value. Sources included The Baltimore Sun, The Boston Globe, Booklist, Chicago Tribune, Entertainment Weekly, Kirkus Reviews, Los Angeles Times/Book Review, New York Times/New York Times Book Review, People
Washington Post. The presence or absence of the OBC logo on the novel was also counted,
noting the random selection of novels from various booksellers included in my collection.

**Sales Figures**

Using information provided by the Bowker Annual, sales figures were compared based on year
of publication and year included in the Book Club if available. Comparisons in this area were
difficult to draw, as only limited sales information was available and figures are listed by type of
novel (i.e. paperback, mass publication and hardcover).

**Categories Which were Eliminated**

Based on the inconsistent results by either or between coders, several categories were eliminated
from this analysis. These include

- *Character presentation*

  Character presentation was measured on a five point scale for both the centrality of the
  characters as well as the character role. Character centrality was measured as 1 being most
  central and 5 being least central. Results of this categorization were determined to be
  inconsistent between coders and therefore were not included in the analysis.

- *Socio-economic status*

  Both individual characters and their families’ socio-economic status were counted. Socio-
  economic status was measured based on wealth, income, education and resulting social class
  within the novels. This information was not available for a significant portion of characters (43)
  or their families (75) and, thus, this category was eliminated.
This categorization was problematic when measuring between time periods and countries. The character of Ishvar, for example in Mistry’s *A Fine Balance* (1995) who bears a facial scar and has his leg amputated near the end of the book, by Western standards would be considered poor. He and his nephew live in a shanty town with no running water or electricity. These men are tailors and come from a background of leather workers. The caste system makes them poor as leather workers, but apprenticed as tailors they are employed and earn a living. Their residence is based on a lack of housing in the city rather than their inability to pay for it. In the same realm Mama Mwanza, a neighbour who has severely burned her legs and moves around on her arms, in Kingsolver’s *The Poisonwood Bible* (1998) represents extreme poverty from a Western perspective, but is no poorer than anyone else in her own context in this village in the Congo in the 1970’s. Both of these examples along with North American examples demonstrate the additional difficulties of classifying characters into these categories between rural and urban settings. Where a cashier with limited education exemplified by Harley in O’Dell’s *Back Roads* (2000) may be easily classified as working class, a farmer, who is a self-employed landowner, in the case of Wang Lung in *The Good Earth* (1931) may not always have enough food to eat does not easily fit within a classification system.

Some characters also exist beyond the boundaries of classification within socio-economic structure, especially those in magical/other worldly roles. Hagar, in Morrison’s *Song of Solomon* (1977) does not work and neither does her mother. They are poor in terms of material things but have spiritual riches. The character’s in *The Rapture of Canaan* (Reynolds, 1998) live in a religious community outside of the standard market economy. Their existence is not within a standardized class system. Connie, the matriarch of the house of exiled women living outside of
town in Morrison’s *Paradise* (1997), does not live within the boundaries of financial concerns. How they pay for their livelihood is not discussed as being important to the story.

- **Social mobility and disability**

Social mobility is the ability to move from one class to another. In these stories of frequent hardship, upward social mobility is a common feature of characters with minor disabilities. The character of Pinch, who has a slight disfigurement of his eye, in Oates’ *We Were the Mulvaneys* (1996), comes from a family where his father owns a roofing business which leaves him destitute at the end of the book. Pinch, on the other hand, proceeds to graduate studies and a career as an academic. Social mobility is also common in Franzen’s novels. Walter, who deals with minor depression, in *Freedom*, moves from a poor working class family to become a successful Washington consultant. Connie, the depressed girlfriend and then wife of his son Joey, moves from a working class family, to the wife of a successful businessman. Similarity Caroline, in *The Corrections* (2001) comes from a poor family and marries an investment banker who improves both his own and her economic status. Both son and father, Cyrus and Adam Trask in *East of Eden* (Steinbeck, 1952) improve their socio-economic status becoming wealthy by either scandal or hard work. Kathy in *House of Sand and Fog* (1991), however, appears to come from a middle class family, but her alcoholism and troubled life direct her downwards on the scale of social mobility.

- **Character education**

The highest level of education obtained by characters with disabilities was counted. The categories used to measure this information included: 1. Less than high school, 2. High school

It was not possible to count education level with any kind of consistency based on the information available in the books. Some characters held precise educational credentials, but for the majority, formal education levels were unspecified. While the education of a medical doctor can be inferred in contemporary novels, the identification of formal training between countries, and time periods without specific identification of education level did not yield explicit enough information to come to any conclusions. In 73% of characters, I was unable to determine their specific level of education.

- **Presentation of disability according to previously identified stereotypes**

While I attempted to categorize presentations of disability into previously identified stereotypes common in disability literature (punishment for evil, embitterment about their fate, want to destroy the non-disabled, spectacle, pitiable and pathetic, good people sinned against, vengeful, disagreeable, sinister and evil, super-crip, comic mis-adventurer, object of ridicule, own worst enemy, the sweet innocent, a burden, non-sexual, over sexed and threatening, incapable of participation) I found these categories too difficult to assign and both my own and the secondary coders classifications inconsistent. While characters certainly fit into some of these categories, to consistently place all characters within these roles proved beyond the scope of this project.

- **Social change indicators**

The presence of social and political change issues were identified and counted within the stories. The issues of grief and loss and love were identified most frequently, followed by violence and overcoming adversity, social class struggle, tradition, change and development, racial issues,
change of the traditional family, religion and religious confrontation and multiculturalism and immigration. The presence of each of these indicators was counted in significantly different ways by each of the two coders and was therefore eliminated from the analysis based on the subjectivity of their inclusion.

**Coder Training**

The coding for this research included two coders: me and a graduate student with experience with content analysis. The graduate student was given the list of novels and asked to select five novels to code using the coding scheme developed to ensure a level of consistency. We had detailed discussion about the coding process and the research project. Operational definitions of the variables used in this analysis and definitions of disability were provided. The code book was edited to fix any coding issues.

**Reliability**

Inter-coder reliability was measured using Krippendorff’s alpha (Krippendorff and Brock, 2009). Five novels were selected by a secondary coder to be coded independently to measure the reliability between coders. Considering the interpretive nature of many of the categories measured, variables which contained an alpha of .60 were used in the data analysis. Table 2 shows the overall reliability of information provided.

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1 Shaded areas indicate variables that were not used for the content analysis based on lack of reliability
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Data Analysis

Data was analyzed for the purpose of identifying the presence and portrayal of disability within this selection. This data is used to demonstrate the ongoing presence of disability within the realm of popular fiction demonstrating its ongoing presence and the roles of characters with disabilities. Because of the subjective nature of disability much of the data about disability has been determined by interpretation, from the individual characterization of disability to the consideration of whether or not to include a character as a person with a disability. Disability is not a uniform concept. Presently, various understandings continue to define this term. Noting some of the major understandings, for the purposes of this research disability is considered as both a product of society and as an individual embodied experience existing in social space. As this project unfolded, a concrete definition of disability was required in order to obtain consistent
results. Because the majority of novels, 49 of the 54 books took place in the United States, disability was specifically defined under the criteria of the Americans with Disabilities Act (ADA), offering an encompassing scope within which to class disability. The ADA offers the following criteria for disability:

Someone who has a physical or mental impairment, has had such an impairment in the past or is regarded as having such an impairment…any physiological disorder, or condition, cosmetic disfigurement, or anatomical loss affecting one or more of the following body systems: neurological, musculoskeletal, special sense organs, respiratory (including speech organs), cardiovascular, reproductive, digestive, genitourinary, hemic and lymphatic, skin and endocrine…

Even with this definition, agreement about who was to be considered a character with a disability was inconsistent among coders. While many characters like Thomas, the protagonist’s brother who has Schizophrenia in Lamb’s I Know This Much is True (1998), fit neatly into this categorization, others were more difficult to classify. Eliza in Allende’s Daughter of Fortune (1999), for example, is not a person with a disability, but pretends she is a “mute boy” during the California gold rush, so she can remain hidden in America as a single female. Because she is treated as a person with a disability, she was counted as a character with a disability. An additional challenging example is presented by the character of Callie in Eugenides’ (2003) Middlesex who does not have a disability by and of itself, but was counted as a character with a disability based on the medicalization and treatment of her “condition.” Cal/Callie discovers through medical intervention that she is an inter-sexed person and chooses to live as a male towards the end of the novel. This character’s “5-alpha-reductase deficiency” is presented as a physical disorder based on a genetic mutation. Gaines’ presentation of Jefferson in A Lesson Before Dying (1993), however, was not counted even though he is described in the opening of the book as a “fool” by his defense lawyer, incapable of understanding basic knowledge, the two
coders disagreed on whether or not this should be counted as a disability, a legal tactic or a social belief surrounding race.

Addition categories such a geographic location and era of the story were not always straightforward. Marquez’s (1967) One Hundred Years of Solitude, for example, is set in a fictitious location and outside of a defined time period. While the reader is likely to infer the historical period from events such as the building of the railway, there is no definitive means of accounting for the time frame or location and, therefore, these factors must be deduced by the reader.

The practice of counting occurrences of specific words, common in content analysis was not a reliable method of gathering much of the data for this sample. Searching for the word disability or even specific types of disability did not yield useful or accurate results because these fictional accounts did not necessarily refer to such factors in a direct manner. A disability, for example, may never be directly spoken of, such as Stephen Kamalo’s use of a cane in Paton’s Cry the Beloved Country (1948). Looking for the word cane even, would yield no results; his use of a walking stick is only briefly described in the initial depiction of the character. In the same manner Hank’s depression in Morgan’s Gap Creek (1999) is never identified by name, but recognized through the context of the story and the accompanying discussion questions.

Tallying the occurrence of characters names in order to have a quantifiable comparison of major versus minor characters also proved to be inadequate as stories were frequently narrated in the first person and, therefore, rarely referred to the protagonist by name, leaving their presence unaccounted for. As a result each individual work was assessed based on the interpretations made from reading works as a whole and the overall presentation of characters as a basis for
counting. This has allowed for a groundwork to be created which gives a sense of the presence, context and portrayal of disability in the novels rather than a definitive account of what is contained within the books.

This research does not claim to give an encompassing picture of the discussion of disability in fiction, but hopes to show the presence and messages being shared about disability in this popular forum.

**Textual Analysis**

**Sample**

The textual analysis used for this research reviewed the online discussion of disability from a sample of the books included in this data set. Of the sixty-one books which were included in this example, the online discussion of six novels is analyzed along with a chapter on the presence of minor characters with disabilities in their presentation in twenty-three novels. Seven on-line book discussion forums were reviewed in this analysis in which I sought to find features of a public sphere, and threads of discussion leading to the formation of progressive public opinion in the case of disability.

Materials analyzed have been used to come up with three general categories of discussion which lay the foundation for change through the discussion of fictitious characters with disabilities in this public sphere: book clubs as a challenge to traditional literary authority, the recognition of the importance of readers’ emotional connection with characters, and the recognition and discussion of disability.

The websites that have been chosen for this research have been based on their accessibility to readers and their differential formats ranging from in-depth discussion to short reviews. Web
based conversation was used because of the temporal nature of the information. While readers
may not remember specific characters years after they have read a novel, the online content
allows for the analysis of readers’ dialogue while it is top of mind.

Table 3: Sources of online discussion

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<td>Freedom</td>
<td>Bookgroup online, Constant Reader, Booktalk.org, OBC website</td>
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<td>She’s Come Undone</td>
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<td>Icy Sparks</td>
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<td>Peripheral Character Novels:</td>
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<td>Cane River</td>
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<td>Café Libri, OBC website</td>
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<td>Great Expectations</td>
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<td>Book group online, booktalk.org, amazon.com, OBC website</td>
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<tr>
<td>Deep End of the Ocean</td>
<td>Amazon.com, OBC website</td>
</tr>
<tr>
<td>Where the Heart Is</td>
<td>Amazon.com, OBC website</td>
</tr>
<tr>
<td>Songs in Ordinary Time</td>
<td>Amazon.com, OBC website</td>
</tr>
<tr>
<td>Black and Blue</td>
<td>OBC website</td>
</tr>
<tr>
<td>Mother of Pearl</td>
<td>Book group online, OBC website</td>
</tr>
<tr>
<td>Title</td>
<td>Source</td>
</tr>
<tr>
<td>------------------------------</td>
<td>---------------------------------</td>
</tr>
<tr>
<td>White Oleander</td>
<td>Amazon.com, OBC website</td>
</tr>
<tr>
<td>Here on Earth</td>
<td>Amazon.com, OBC website</td>
</tr>
<tr>
<td>Sula</td>
<td>Amazon.com, OBC website</td>
</tr>
<tr>
<td>I Know this Much is True</td>
<td>Book group online, OBC website</td>
</tr>
<tr>
<td>The Good Earth</td>
<td>Café libri, OBC website</td>
</tr>
<tr>
<td>A Fine Balance</td>
<td>Book group online, OBC website</td>
</tr>
<tr>
<td>We were the Mulvaneys</td>
<td>Book group online, OBC website</td>
</tr>
<tr>
<td>The Poisonwood Bible</td>
<td>Book group online, Amazon.com, OBC website</td>
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</table>

Having determined the widespread presence of disability through the content analysis, I am able to explore readers’ discussion around disability within these characterizations in order to provide information about the meaning of disability to readers in this context. While disability studies frequently identifies the negative role of disability in fiction, I was inspired by the seemingly missing analysis of readers’ interpretations and the possibility of the presentation of disability as a progressive force in the public recognition of disability and the realities of people with disabilities. Noting the influence novels have on readers as well as the connections that are described between readers and characters, my attention has centred on exploring whether the discussion of these characters upholds traditional notions of disability or offers an opportunity for social change in readers’ opinions about disability and people with disabilities. By performing a detailed textual analysis of readers’ discussion in these six novels, I have been able to draw conclusions about the likely interpretations of readers regarding these representations.

This portion of the thesis does not provide percentages or scientifically based observations. Instead, I began by identifying characters with disabilities or specific disabilities in the dialogue surrounding the novels and the common points of discussion surrounding these presentations.
The book club and discussion of novels is identified in its ability to challenge accepted truths in the case of disability through its presence as a public sphere and readers’ engagement in the formation of public opinion. Through the reader comments I will demonstrate the power of this discussion as it relates to disability through readers’ ability to challenge traditional literary authority, to promote emotional connections with characters and to discuss disability in more progressive ways than is generally accepted. I do not claim to have a representative sample; however, I do feel that this selection has allowed me to draw conclusions about disability in these texts.
Chapter 5

Results of Content Analysis

General Book Information

General information related to the novels has been counted, including the presence of disability in individual novels, year of publication, book club year, author nationality, whether the author self-identifies or is visibly identifiable as a person with a disability, and the publisher, including the parent company. The year of publication and book club year are included in Table 1 in the previous chapter.

Author Nationality

The distribution of author nationality in book club choices, (noting some authors were counted more than once based on their identification with multiple countries) shows 47 American authors (including 1 German-American, 1 Haitian-American, 1 Peruvian-American), 2 Canadian (1 Indian-Canadian) 1 German, 1 Nigerian, 1 South-African, 1 Columbian (with 2 novels on the list), 1 Irish, 1 English (with 2 novels on the list), and 1 Russian author. With the exception of Ireland, all of the authors from the countries represented have portrayed disability in their novels. A comparison of the relative representation by country is impossible based on the small sample of books written outside of the United States.

Authors and Disability

Of the 54 novels analyzed, information was taken either from the about the author section or from the photo provided on the jacket of the book to determine the author was readily identifiable as a person with a disability. Only 1 author self-identified as having a disability in
the “about the author” section. No authors were visibly identifiable as having a disability through such indicators as visible physical differences or the use of assistive mobility devices. One additional author identified having a disability in an interview separate from the novel. Because this information would not be available to a reader without further investigation, the author was not counted.

**Publisher**

Upon initial review, it appeared that books were distributed by a wide variety of publishers. However, further investigation revealed that a large number of publishing houses are divisions of larger organizations. Of the 54 novels only 15 different publishing companies are represented through their smaller divisions. Of these 15 companies 5 are included in the world’s 50 largest book publishers (Publisher’s Weekly, June 25, 2012) pointing to the large scale financial interests that accompany these choices.

**Table 4: Publisher and Parent Company**

<table>
<thead>
<tr>
<th>Publisher</th>
<th>Division Of:</th>
</tr>
</thead>
<tbody>
<tr>
<td>Avon</td>
<td>News Corporation</td>
</tr>
<tr>
<td>Harper Collins</td>
<td></td>
</tr>
<tr>
<td>Harper &amp; Row</td>
<td></td>
</tr>
<tr>
<td>Harper Flamingo</td>
<td></td>
</tr>
<tr>
<td>Harper Collins/Ecco</td>
<td></td>
</tr>
<tr>
<td>Doubleday</td>
<td>Random House (owned by Bertelsmann AG)</td>
</tr>
<tr>
<td>Random House</td>
<td></td>
</tr>
<tr>
<td>Harmony Books</td>
<td></td>
</tr>
<tr>
<td>Vintage Books</td>
<td></td>
</tr>
<tr>
<td>Vintage Press</td>
<td></td>
</tr>
<tr>
<td>Knopf Canada</td>
<td></td>
</tr>
<tr>
<td>Knopf Doubleday</td>
<td></td>
</tr>
<tr>
<td>Chatto &amp; Windusq</td>
<td></td>
</tr>
<tr>
<td>McClelland &amp; Stewart (partially owned by Random House Canada)</td>
<td></td>
</tr>
<tr>
<td>Vintage International</td>
<td></td>
</tr>
<tr>
<td>Orion</td>
<td>Hachette Livre (Owned by Lagardere)</td>
</tr>
<tr>
<td>Little Brown</td>
<td></td>
</tr>
<tr>
<td>Warner Books</td>
<td></td>
</tr>
<tr>
<td>Chapman &amp; Hall</td>
<td>Now Taylor and Francis</td>
</tr>
<tr>
<td>Farrar, Straus and Giroux</td>
<td>Georg von Holtzbrinck Publishing Group</td>
</tr>
<tr>
<td>MacMillan Group</td>
<td></td>
</tr>
</tbody>
</table>
Story Location and Era

This information gives us a picture of where and when the story is set and an understanding of the role of location and time within a story in relation to the presence of disability. This includes information about the geographical location of the story, either by country or by region for stories within the United States. Novels were also classified by locale: urban, suburban or rural and the era in which the story is told.

Table 5: Story Region

<table>
<thead>
<tr>
<th>Story Region</th>
<th>Number of characters with disabilities</th>
<th>Percentage of Overall Stories by region with characters with disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>US – West</td>
<td>5</td>
<td>8%</td>
</tr>
<tr>
<td>US – North East</td>
<td>15</td>
<td>23%</td>
</tr>
<tr>
<td>US – Midwest</td>
<td>12</td>
<td>19%</td>
</tr>
<tr>
<td>US – South</td>
<td>17</td>
<td>27%</td>
</tr>
<tr>
<td>Canada</td>
<td>1</td>
<td>1%</td>
</tr>
<tr>
<td>Europe</td>
<td>5</td>
<td>8%</td>
</tr>
</tbody>
</table>
Stories took place for the most part in the United States and were therefore divided by region. While setting did not initially seem particularly relevant to reception and discussion of the stories, the strong presence of place became increasingly evident as novels were reviewed. As Housley and Norcliffe (1992) point out in their discussion of the role of landscape in literature “Landscapes are…more than an ensemble of physical and human components. They have a deeper significance, closely bound up with attitudes and values.”(3). This is exemplified by the strong presence of the rural American South, for example, in Rubio’s small town Tennessee in Icy Sparks (1998) or Faulkner’s presentation of Jefferson, Mississippi in The Sound and the Fury (1929). The role of place demands to be examined in connection with presentations of disability. Almost 60% of the novels took place in rural locations, where in contrast, according to the US census of 2010 (http://www.census.gov/geo/www/ua/uafaq.htmlonly) 80.7% of Americans live in urban areas. The US South was host to the greatest number of stories (17), followed by the North East (13), the MidWest (12), the West (5), Europe (5), Africa (3), Central and South America (4), and China (1), India (1) and Canada (1).

**Era**

Novels included in this selection range from the earliest publication of Dickens’ A Tale of Two Cities in 1859 to the most recently published novel, Freedom in 2010. The majority of books were both written in and about contemporary times (1975-2011). Twenty-five of the novels containing disability in this sample fell into this category, with 50 of the total novels containing

<table>
<thead>
<tr>
<th>Region</th>
<th>Count</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Africa</td>
<td>3</td>
<td>5%</td>
</tr>
<tr>
<td>Central/South America</td>
<td>4</td>
<td>6%</td>
</tr>
<tr>
<td>Asia/India</td>
<td>2</td>
<td>3%</td>
</tr>
</tbody>
</table>
disability having been written over the last thirty-six years. 11 books were set in the mid-20th Century, 6 in the early 20th Century and 3 prior to the 20th Century.

**Presence of Disability in Novels**

This table shows the distribution of disability in the novels from the commencement of the book club in 1996 to the final novels in 2010/2011. This sample contains a range of novels from 1-9 selections per year, showing characters with disabilities in 54 of the 61 novels. All of the novels used for the reliability analysis agreed on the presence of disability in the novels. Almost 87% of the novels contain at least one character with a disability with up to 23 characters in a single book. Shown as an average between the 54 novels, this equates just over 3 characters with a disability per novel. While the higher numbers generally reflect novels where characters were institutionalized and interacted with large groups of other people with disabilities, such as Delores who resides in a psychiatric facility in *She’s Come Undone* (1992), this was not always the case. Franzen’s *Freedom* (2010) contains 11 characters with disabilities, ranging from depression, to addiction to mobility impairments, none of whom are institutionalized.

The graphic below demonstrates that there were a higher overall number of both total novels and disabled characters earlier in the Book Club. For its duration there remained a constant presence of disability in the novels chosen with the exception of 2006 when no novels were selected. This ongoing portrayal is especially important to note as the kinds of novels chosen for the book club have changed throughout its lifespan from lighter to more serious fiction. In spite of this, the rate of disability in the novels remains relatively constant.
Disability Specific Information

The bulk of this analysis has looked at the how frequently and in what ways disability is treated within the novels. The areas that have been specifically addressed are: the kinds of disability present, the presentation of characters based on their role within the story, the ages of characters with disabilities as well as their employment status. Who is presenting the information about a character with a disability i.e. a first person account vs. a friend, family member or medical professional has been counted, as well as their outcome.

Presentation of Disability by Type

This chart shows the proportional representation of different kinds of disability in the stories. While some of the characters were not easily fitted into these definitive categories, a general sense of the types of disabilities presented gives an insight into what readers are responding to. This chart also includes some characters that have been counted multiple times to represent multiple disabilities. The character of John Singer from McCullers’ (1940) *The Heart is a Lonely Hunter*, for example, was counted once for his hearing impairment, and again in the verbal disability category because he is not able to speak.
Mental health is the most frequently presented disability in this selection, with 19% of disabilities classed within this category. This is followed by addictions and unspecified and general disability at 11% which includes characters that are presented without specific diagnosis or presentation. Physical disfigurement or difference represents 9%, including characters with embodied differences such as facial scarring, amputated/absent额外/extra or disproportionate digits and limbs as well as physical stature. Mobility impairments count for 9% of presentations, followed closely by intellectual disability, visual, auditory and speech, and Alzheimer’s. Chronic health conditions including Parkinson’s, AIDS and HIV were representative of only a small portion of total disabilities. Offering a comparison point to fictitious presentation from these predominantly American novel, the US census (Brault, 2012) identifies 6.2% of American adults with seeing, hearing and speaking limitations, 12.6% with disabilities associated with ambulatory activities of the lower body, 8.2% with disabilities relating to physical tasks of the upper body and 6.3% experienced difficulty with some kind of cognitive, mental, or emotional functioning. The table below shows a skewed image of the kinds of disabilities presented in these novels versus their reported occurrence in reality, especially in the case of mental health.
Figure 2: Disability by Type
Character Role

A 1-5 scale represents the character role in terms of being most protagonist or antagonist. Disability presentations are frequently assessed based on their conformation to previously held stereotypes (Biklen & Bogden, 1977; Gartner, 1987; Kriegl, 1987; Longmore, 1987; Norden, 1994, Mitchell & Snyder, 2000, 2001). This data shows, however, that characters with disability in this sample are most frequently, in 76 out of 162 presentations, in a neutral role. This is indicative not only of the presentation of people with disabilities but also speaks to the lack of description provided about these characters. Their presentation is commonly such that they are not explored in enough detail to give them protagonist or antagonistic characteristics. The role of Elizabeth, for example, in Letts’ *Where the Heart Is* (1995), was counted as a neutral character. She is described as the alcoholic sister of Forney, the love interest of protagonist Novalee, who is never seen, but is heard from the upper floor. She is eventually institutionalized and dies, at which point Forney is freed and able to pursue his dreams. This character is peripheral enough to not be explored in sufficient depth to give her a story, good or bad. Wang Lung’s daughter “poor fool” in Buck’s *The Good Earth* (1931) provides an additional example. She plays almost no part in the telling of the actual story beyond references to her existence and Wang Lung’s guilt over almost selling her.

The second most common category following neutral roles are characters in the most protagonist (29) or second most protagonist (15) roles. Both Edgar in *The Story of Edgar Sawtelle* (2008) and John Singer in *The Heart is a Lonely Hunter* (1940) are sympathetic heroes, who both in this case, literally do not have a voice. Edgar is “mute but hearing,” and John is deaf and does not speak.
The least common role (26%) for characters with disabilities was classed in the second most antagonist or most antagonist role, 4 and 5 on the 5 point scale. Lady Hamleigh, for example, in Follett’s *The Pillars of the Earth* (2002) is in the most antagonist category. She is described on the author’s website as “…repulsive to look at. Her face is covered in unsightly boils, which she cannot help touching all the time with her skeletal hands. She usually tries to conceal her face with a hood. She is extremely determined and strong, even vicious.” (http://www.ken-follett.com/pote/characters.html).

Figure 3: Character Age

![Age of Characters with Disabilities](image)

This graph shows the age distribution of characters with disabilities in the novels. The highest representation is in the young adult population, ages 20-39. This is followed by mature adults at 22%, adolescents at 16%, and children at 14%. The elderly, who were defined as age 65+, were the least represented age group in contradiction to contemporary statistical information which shows older populations as the largest concentration of people with disabilities. In the United
States in 2010 it was reported that approximately 5.6 million people or 18.75% of the population had some kind of disability. (US census, 2012). Of those reported to have a disability, 70.5% are adults 80 and older. Many of the novels follow characters throughout more than one chronological stage of their lives and these characters have been counted in each category that is applicable. Several minor characters who are present, but lack detail were classed in the unknown category, making up 10% of this total sample. Characters were almost equally distributed between male and females with one character who is inter-sexed.

**Character Employment**

The employment status of individual characters with disabilities was measured by counting the number of characters who were employed in paid or forced (i.e. slave) employment during their working years. Employment is frequently identified as a factor in the inequality of people with disabilities both in their access to employment and in their inability to participate in paid employment (Prince, 2009, Russell, 2002, Roulstone, 2002). Surprisingly, in these fictitious presentations, where enough detail was given to make this assessment, more characters with disabilities were employed than were not employed. Trudi, the “zwerg” from *Stones from the River* (1995) works in a pay-library that her father owns. Shankar, or Worm, who has no limbs and uses a dolly to get around in *A Fine Balance* (1995) works as a beggar on the streets of Mumbai. In *Songs in Ordinary Time* (1995) Joey who has a visual impairment, runs a popcorn stand, and “simple” twins Jozia and Howard work as a housekeeper and janitor respectively. Characters who are presented as unemployed are more often living in institutional or group home settings, this includes Brenda Kay and “the girls” who have intellectual disabilities in *Jewel* (1991), Thomas who is in a psychiatric institution in *I Know this Much is True* (1998), and Delores’ acquaintances in the group home in *She’s Come Undone* (1992). Characters were
frequently counted more than once in this category as they often moved between categories based on age, disability onset and degree of disability.

**Figure 4: Character Employment Status**

<table>
<thead>
<tr>
<th>Employment Status</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cannot Determine</td>
<td>51</td>
</tr>
<tr>
<td>Retired</td>
<td>9</td>
</tr>
<tr>
<td>Slave</td>
<td>1</td>
</tr>
<tr>
<td>Child</td>
<td>31</td>
</tr>
<tr>
<td>Unemployed</td>
<td>54</td>
</tr>
<tr>
<td>Employed</td>
<td>66</td>
</tr>
</tbody>
</table>

**Main Source of Information on Person with Disability**

Noting that only two of the authors identify as having a disability, the stories of 168 characters with disabilities have been counted. Following suit, it is rarely a character with a disability who
is telling their own story. Only 30 stories were told directly by the character with the disability, while 138 stories were told by other characters; family, friends, medical professionals and others.

Outcome of Character with Disability

The outcome of individual characters became of particular significance when it became apparent that the majority of characters whose outcome could be determined either died, were institutionalized or both. Of the 144 instances recorded for outcome 51 characters with disabilities died, and 38 were institutionalized. 22 lived with their impairment but were not considered included, 20 overcame their disability and 13 were included.

Of those consider to fall into the inclusion category the type of disability that they were characterized with is indicative of their social outcome. These characters frequently had minor or physical impairments with a seemingly strong correlation between inclusion and missing limbs. Toxie, for example in Jewel (1991) is missing a finger. In A Fine Balance (1995) Ishvar has his legs amputated while Shankar, who has no arms or legs is accepted and lives as part of the
community. Cyrus Trask in East of Eden (1952) and Leo in Stones from the River (1995) both lost one of their legs in wars. Characters that died on the other hand have more significant disabilities. Both John Singer, who is deaf and does not speak, and Spiros Antonapoulos, who is deaf, does not speak and appears to have an intellectual disability in The Heart is a Lonely Hunter (1940) die, Singer by suicide, and Antonapoulos in a manner unexplained, in an institution. Edgar, the mute but hearing protagonist, in The Story of Edgar Sawtelle (2008) dies in a fire. Of those with mental health conditions, 5 characters die, 4 while live in institutions. 6 characters with addictions die including Nikolai Levin in Anna Karenina (1877) who dies from health complications related to drinking and Plum in Sula (1973), who is killed by his mother in order to save him because of his heroin addiction. Kathy Nicolo, a recovering alcoholic, in House of Sand and Fog (1991) becomes involved in a hostage taking misunderstanding where she is shot and does not survive.

Characters that live with their disabilities but are not included are exemplified by roles such as Bok in A Lesson Before Dying (1993) who is a minor character with an intellectual disability. He is peripheral to both the story and the community. Church in Back Roads (2000) plays a similar role to Bok, a grocery bagger who works with the protagonist, who has an intellectual disability. Similarly, Icy, the main character in Icy Sparks (1998) who has Tourette’s is ridiculed and excluded by her community as a child.

Stories of overcoming disability are also prevalent. Delores, the complicated heroine in She’s Come Undone (1992), overcomes her obesity and psychiatric conditions through her willpower. Joey, a blind popcorn seller, regains his sight when he is robbed in Songs in Ordinary Time (1995). Fermina Daza briefly loses her hearing, which she quickly regains in Love in the Time of
Cholera (1985) and Adah Price, whose “right side does not work” because of a “fetal mishap” is cured in her adult life by a fellow doctor in The Poisonwood Bible (1998).

Social Capital
Finally, this content analysis looks at the issue of social capital in relation to these novels. Based on Bourdieu’s (1984) conception of social capital and the shared recognition of social value, novels were looked at in terms of their value and esteem within our society. While Winfrey herself holds a significant amount of power and influence, the novels that she has chosen over the years reflect a movement towards more socially valued selections. To access this information, the novels were looked at based on numbers of prizes and awards, sources of blurbs and on overall sales figures.

Table 6: Prizes and Awards

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<td>10</td>
<td>0</td>
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<tr>
<td>Total</td>
<td>5</td>
<td>2</td>
<td>2</td>
<td>1</td>
<td>3</td>
<td>8</td>
<td>3</td>
<td>3</td>
<td>11</td>
<td>12</td>
<td>0</td>
<td>5</td>
<td>0</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Total Novels for year</td>
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<td>7</td>
<td>8</td>
<td>9</td>
<td>9</td>
<td>5</td>
<td>2</td>
<td>2</td>
<td>4</td>
<td>2</td>
<td>0</td>
<td>3</td>
<td>1</td>
<td>1</td>
<td>3</td>
</tr>
</tbody>
</table>

Table 6 identifies the inclusion of books on the Oprah Book Club list in relation to their receipt of literary prizes and recognition in recommended fiction lists. There is a relatively consistent inclusion of award winning books throughout the span of the club, however, multiple novels from award winning authors such as Toni Morrison (4 novels) and Gabriel Garcia Marquez (2 novels) which have won multiple prizes may skew this data somewhat. Prizes that were looked at for this list include winners of the: Nobel Prize for Authors, counted once for each book included.
as a recipient of a: Pulitzer Prize, James Tait Black Prize, National Book Award, Giller Prize, National Book Critics Circle Award, PEN Award, and the Commonwealth Writer’s Prize. Lists of recommendations which were counted to acquire information about social capital included the Modern Library 100 Best Novels for the Board and Readers, Radcliffe Rival 100 Best Novels, Canadian Readers Top 100 of all time, Time magazine all-time 100 novels (1923-2005) and authors included in Bloom’s Western Canon.

Morrison’s novels have been included in this club since the first year and have been present in 1996 (Song of Solomon), 1998 (Paradise), 2000 (The Bluest Eye), and 2002 (Sula). As a winner of the Nobel Prize for Literature, Morrison’s novels have always kept the Book Club in esteemed company. While the numbers do not show a drastic increase in overall awards for progressive novel choices with the exception of 2001, 2004, and 2005, the number of books chosen per year influences the awards per year data. Over the first 7 years of the club, 24 awards were identified for 43 novels. In the last 7 years of the Book Club 32 awards were identified for 16 novels. While the raw numbers seem to indicate a consistent number of awards, the earlier novels (1996-2002) on average hold just under 1 award per 2 novels, whereas the more recent books (2003-2011) hold just over 2 awards for each novel. With some notable exceptions the books have moved from genre fiction to a stronger focus on literary fiction and classics. In 2010 the novels for the final book club were Dickens’ A Tale of Two Cities and Great Expectations, along with Franzen’s Freedom (2010). Giving a picture of the social capital that accompanies Jonathan Franzen, he was identified by Time magazine (Grossman, 2010) as the “Great American Novelist”. In 2007 the club featured 2 Pulitzer and 1 Nobel prize winner, while 2004 brought 2 Nobel Prize winners along with Tolstoy’s Anna Karenina frequently cited as the greatest novel ever written.
Table 7: Blubs by source

<table>
<thead>
<tr>
<th>Review Source</th>
<th>Total Reviews</th>
<th>Front Cover</th>
<th>Back Cover</th>
<th>Inside</th>
</tr>
</thead>
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<tr>
<td>Baltimore Sun</td>
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<td>0</td>
<td>3</td>
<td>2</td>
</tr>
<tr>
<td>Boston Globe</td>
<td>17</td>
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<td>10</td>
</tr>
<tr>
<td>Booklist</td>
<td>9</td>
<td>0</td>
<td>2</td>
<td>7</td>
</tr>
<tr>
<td>Chicago Tribune</td>
<td>12</td>
<td>3</td>
<td>3</td>
<td>6</td>
</tr>
<tr>
<td>Entertainment Weekly</td>
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<td>1</td>
<td>2</td>
<td>6</td>
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<td>Kirkus Reviews</td>
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<td>4</td>
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<td>9</td>
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<td>1</td>
<td>14</td>
</tr>
<tr>
<td>San Francisco Chronicle/Book Review</td>
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<td>1</td>
<td>5</td>
<td>10</td>
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<tr>
<td>Time</td>
<td>7</td>
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<td>6</td>
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<tr>
<td>Washington Post</td>
<td>20</td>
<td>2</td>
<td>12</td>
<td>6</td>
</tr>
<tr>
<td>Number of Books with Oprah Logo</td>
<td>25</td>
<td></td>
<td></td>
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</tbody>
</table>

Of the 54 novels looked at in this data set, 14 contained blurbs on the front covers, 61 on back covers, and 108 on the inside covers from the above listed sources. This is representative of a variety of mediums including newspapers, magazines and publishing reviews. While older books such as *East of Eden* (Steinbeck, 1952) and Paton’s (1948) *Cry the Beloved Country* had no blurbs, newer publications contained increasing numbers of these recommendations. *Say You’re One of Them* (Akpan, 2008) for example, had a total of 38 blurbs, the most of any of the novel included in the club. Following suit *The Corrections* (Franzen, 2001) had 34.

The source of blurbs serves as a key indicator of the social value attributed to these books. Who is recommending the book is a tool frequently used by librarians and booksellers to determine what books to carry (Rich, 2009). A review from a newspaper or popular magazine is indicative of a different kind of novel than that of an acclaimed literary review. Differentiating these
diverse sources of reviews, Daum (2009) of the LA Times noted “Kirkus… was notoriously harsh. Whereas Publishers Weekly often seems like a booster for the trade, and Booklist, another book industry magazine, usually manages to find something nice to say about even the most mediocre prose…” Pointing to the diversity of readers associated with the Oprah Book Club, many of the novels chosen demonstrate a crossing of boundaries between mass appeal and literature. My copy of She’s Come Undone (Lamb, 1992) that was used in this research contains blurbs from the revered The New York Times Book Review and Kirkus Reviews as well as the popular celebrity news magazine Entertainment Weekly. The same is true of Morgan’s (1999) Gap Creek reviewed by Kirkus, The New York Times and People Magazine. Quindland’s (1998) Black and Blue includes blurbs from The New York Times Book Review, Publisher’s Weekly, Booklist, Kirkus Reviews and People Magazine.

In several books the same source was used for multiple blurbs. Say You’re One of Them (Akpan, 2008), for example, has 3 blurbs from the Washington Post on the same copy of the book; each review was counted separately in the total.

Logos

Cultural capital, Farr (2005) explains is based on “cultural elite sensibilities…that are socially scarce” (Holt, 2000) and the disavowal of mass culture. The placement of Oprah logos on the Book Club choices has evoked an interesting discussion of mass-produced fiction and elitist concepts of taste (Farr, 2005). This came to the fore most notably in relation to Jonathan Franzen’s novel The Corrections (2001). This author declined to be part of the Oprah television show in part because he felt the novel was “a hard book for that audience” (Schindehette, 84,
cited in Rooney, 2008). The presence of the Oprah sticker, the author felt, implied endorsement and the book was released with copies both with and without the logo (Rooney, 2008). Rooney confirms that others have noted their concern at reading books with the Oprah logo on them and specifically choose copies without. The need to distinguish mass culture and cultural elitism, even based on the same book is evident in this example. Oprah books have recently changed from a logo on the book to a removable sticker.

In spite of the elitist concerns related to mass culture, a recommendation by Oprah is a significant force in sales. Below the sales figures for Oprah novels are outlined as recorded by the Bowker Annual, an annual trade publication recording best seller sales statistics. Where information was available from the year of publication, versus the year of inclusion in the book club, a drastic increase is demonstrated.

**Book Sales**

While buying a book does not verify that a purchaser has read it, the numbers of novels sold based on Oprah’s recommendations speak at minimum to people’s intentions to read them or at least display them on their coffee tables. Farr (2005) shows that in the first four years of the Book Club, the books averaged about fifteen weeks on the *New York Times* bestseller list. Lamb’s *She’s Come Undone* (1992) was on the list for 54 weeks. Farr also has affirmed that from 1996–2002 there was not a single week when one of Oprah’s selections was not on the best seller list. More recent choices such a McCuller’s (1940) *The Heart is a Lonely Hunter*, before being chosen by the book club had sold about 1,000,000 copies since its publication. Upon the announcement of it for the book club 780,000 copies were in print and the book reached the number 2 spot for trade publications on the best seller list (Maryles, 2004a). Similarly, the translation of Tolstoy’s *Anna Karenina* (1877), prior to its inclusion in the book club had been
selling approximately 15,000 copies annually. Upon its inclusion in the book club 961,030 copies were in print (Maryles, 2004b). Another classic, Steinbeck’s (1952) *East of Eden* sold 1,689,010 (+100,839 in re-issue) copies in 2003 when it was included in the Book Club.

The year novels were included in the club show very high book sales figures. From the years where data was available, records show sales figures ranging from the lowest included in the best sellers at 518,049, for Faulkner’s summer reading collection including (*The Sound and the Fury, As I Lay Dying and Light in August*), to the highest for Shreve’s (1998) *The Pilot’s Wife* selling 2,279,134 copies. The dramatic increase of sales from year of publication to Book Club year are illustrated by novels such as Allende’s *Daughter of Fortune* which sold 125,000 copies when published and 562,672 (+380,781 paperback) the year it was included in the Book Club. This is also exemplified by Eugenides’ *Middlesex* with comparative sales figures of 308,000 upon publication and 1,000,000 in the Club year. Oates´ *We Were the Mulvaneys* sold 1,550,000 copies the year it was included in the club and 180, 000 the following year.

**Discussion**

Presentations of disability in fiction have been criticized for commonly depicting disability as one-dimensional, dehumanizing and stereotypical (Mitchell & Snyder, 2000, 2001). The analysis of literature has been informed by the identification of stereotype, the attribution of disability as metaphor or symbolic device and in more recent movement towards a cultural analysis, beyond art and aesthetic seen as a conveyor of norms, a reflection of value systems and as a designator of social value. The data collected for this content analysis have both upheld and challenged this previous research.
The data show that the presence of disability in literature is indeed ubiquitous across cultures and time. In novels ranging from 1859 to 2010, disability is present in more than 88% of stories. Characters are presented across the spectrum of age, education level, socio-economic status, locale and borders. While the presentations of disability within the novels are frequently peripheral, this is perhaps representative of the peripheral role of people with disabilities in society reflecting a reality that needs to be changed. Stories which include people with disabilities come from around the globe by both authors from around the world and stories from Cape Breton Island, Canada to a small village in the Congo.

Based on the most frequently occurring data that I have collected, a typical book with disability would present a young adult, male, with a mental health disability, living in the rural, southern United States. As one of the least central characters, he would die by the end of the novel and likely be institutionalized at some point. The book, centering of themes of grief and loss and love, would be published by Random House, written by a white, American, female author and would have won just over 1 award.

This research shows a multitude of characters with disabilities and demonstrates that these characters do not necessarily fit into circumscribed categories. As Haller (2010) points out, disability is created through our social constructions. The characterizations of disability in fiction both transmit information and allow for messages to be interpreted and discussed by readers. Literature is particularly important and influential as a cultural force because of its commonplace presentation. Lacking the sensationalism of other media formats, this type of text provides more fully developed (Barnes, 1997) and readily accepted versions of reality. Therefore, what is being presented about disability is very important to the overall fight for disability rights.
Disability plays a major role in our storytelling. While other social issues are frequently a theme in the novels, disability as its own social issue requires further examination.
Section 3: READER INTERPRETATIONS
Chapter 6

The Role of Reader Interpretations

Disability appears throughout almost the entirety of the collection of OBC novels in characters who range from least to most central, throughout a breadth of plotlines and subject matter. Within this collection I have identified 164 characters that have a disability or are treated as if they have a disability. I have categorized characters for analysis based on the significance of their role and the thematic presence of disability in the story. Of the 54 novels included in this analysis, eight of the books chosen for the OBC over its 14 year duration centre around themes of disability.

Disability has been identified countless times as pervasive in fiction (Linton, 1998) without being recognized as holding a role within that fiction. This selection of popular novels upholds the widespread contention that vast characterizations of disability are included in the creation of novels, especially in peripheral roles. Representing a variety of age groups, disabilities and individual circumstances, this next section will look at specific examples of characters with disabilities in the novels chosen for the OBC.

I have divided the following chapters into three sections outlining reader’s discussion of the novels in which characters with disabilities are present. This chapter provides a literature review of the significant role of books clubs in society and describes the three areas of focus of the next three chapters: 1. The book club as a challenge to traditional literary authority and hence its place as a challenger to societal norms 2. The recognition of the role of emotion in reading and the ability of this to effect readers’ perceptions of disability, and 3. The existence of discussion about
disability surrounding these novels and the demonstrated potential public spheres to promote change in the real lives of people with disabilities. Chapter 7 provides an overview of books which contain characters with disabilities in peripheral roles. While these individual characters are rarely identified in the online discussions reviewed due to their minimal presence in the stories, their portrayal, inclusion and significance upholds these often forgettable characters as a noteworthy source of information. As will be discussed, the writing of these characters appears to uphold more traditional stereotypes and ableist assumptions about disability in their flat presentation or generic characterization and otherwise insignificant presence.

Chapter 8 specifically identifies novels where a character with a disability plays a central role in the novel, but the disability itself is not a principal theme of the story. Looking at responses from television discussions and webcasts from the Oprah Show, online posts and reviews, Jonathan Franzen’s (2010) Freedom, Wally Lamb’s She’s Come Undone (1992) and Carson’s McCullers classic The Heart is a Lonely Hunter (1940) are discussed. Of particular interest for this thesis are readers’ tendencies to challenge traditional literary authority in their discussion of these novels and the significance of this, their emotional connections to the novel and its characters with disabilities and the overall discussion of disability in their own lives, as a public issue and within a context of social change.

Chapter 9 provides an analysis of reader’s discussions of novels where the theme of disability is central to the story. Looking at books about disability, this chapter includes responses from online posts and reviews, television and webcast comments. The novels that are considered in this chapter include Ursula Hegi’s (1994) Stones from the River, Brett Lott’s (1991) Jewel, and Gwyn Hyman Rubio’s (1991) Icy Sparks.
Each chapter includes a brief summary of the stories and a list of characters with disabilities included in the novel. An extensive look at specific characters with disabilities and where applicable, the discussion surrounding these characters in reader posts is provided. The dialogue around each book is looked at as a potential ground for change within a public sphere and the existence of this dialogue as an example of the emergence of diverse public spheres which maintain the possibility of creating social change in relation to disability through the discussion of popular culture novels.

Based on the research completed for this thesis, looking specifically at this sample of novels, I have identified the contemporary popular culture book club as challenging assumptions regarding the impact of popular novels and the discussion of these novels in relation to social change.

The remainder of this chapter will discuss the background of these challenges and their relevance to the discussion of disability in popular fiction.

The Popular Culture Book Club as a Challenge to Traditional Literary Authority

While influential thinkers such as Bloom (2000), dismiss the role of the novel within a social context and argue that the best books transcend social issues, it is the work of scholars who identify literature as playing a powerful role in society, purporting truths and values (Eagleton, 1983, 2008) and recognizing the link between art and social reality (Williams, 1980) that has shaped this work. In spite of these recognitions, dating back more than 30 years, culture in the context of literature generally remains outside of the purview of popular culture and genre novels and fails to recognize the uses of fictional text for general readers in everyday life.

Academic approaches to literary interpretation
Academics have criticized the popular culture book club and especially the OBC based on the commercialization of literature, the fact that one person, an entertainer at that, has so much power in the literary world (Rooney, 2008), and the resulting discussion of novels as Orwellian groupthink (Farr & Harker, 2008). It has been seen as an institution supporting meritocracy and upward social mobility (Peck, 2008), and as toxic entertainment which contaminates culture (Abt & Mustazza, 1997) reflecting the earlier concerns of mass cultural theorists such as Horkheimer and Adorno. In spite of the many critically acclaimed literary selections on the list, Rooney (2005) points out that once these novels have received Oprah’s stamp of approval, they become “subject to critical scorn” (11). The more widespread approach to reading brought forth by the popular culture book club stands in contrast to the traditional hegemonic picture of reading, where how to read is authoritatively defined and linked with power privilege, exclusion and social distinction (Long, 2003). Reading groups generally tend to focus on dialogue and experience over literary analysis and the intellectual distance which encapsulates the study of literature is replaced by a passion for reading (Radway, 1997). As Oatley (2011) notes books clubs focus on “…the possibilities, the vicissitudes and the emotions of being human” (196) and it is this type of literary inquiry that replaces the image of a book critic with what Hall (2008) identifies as a cheerleading for reading. This non-hierarchical model brings forth a previously unrecognized group of readers ready to take on novels in an unprecedented way.

Discussion of literary value, so frequently brought forth in research on book clubs, invariably cites the work of Bourdieu (1984) and his concept of cultural capital based around the idea that cultural authorities create legitimacy. Long (2003) suggests, however, that while Bourdieu’s theory captures the kinds of culture that are valued and the ways in which we perceive certain types of culture, an analysis of readers’ engagement with culture and the connection between
cultural consumption, social experience and personal change is missing. This does not indicate that pretention is absent from popular culture book clubs and that cultural arbiters do not influence choices, but demonstrates instead a differential value which is ascribed to the purpose of texts. Long (2003) demonstrates cultural hierarchy beyond the ivory tower, citing our general cultural disdain for “trashy” or poorly written novels such as romance novels and points out that book selection is generally seen as representative of a hierarchy of taste. Cultural authority such as book reviews, literary awards and personal recommendations serve to legitimate choices (Ohmann, 1976, 1996). What is noteworthy is that beyond cultural cachet, books must also meet additional criteria including the issues, interests and desires of the group. The selection of books must allow for conversation, personal connection and the finding of meaning in the experiences of characters and other readers (Long, 2003, Oatley, 2011, Todd, 2008).

Clearly in this sample Oprah Winfrey serves a mediator of taste and her selections dictate what many people read. It is the type of discussion surrounding these books though, that is of particular interest in its newly valued position outside of academic and critical circles and in its ability to influence social change for general readers based on the discussion of the novels.

The Middlebrow and the Democratization of Reading

Dialogue about popular fiction is generally classed under the category of “middlebrow” reading. This term refers to the tastes, interests, assumptions and interpretations of particular readers (Aubry, 2006). Distinct from “highbrow” indicating intellectual or aesthetic superiority, the middlebrow refers to the preferences of average consumers (Levine, 1988). As Perry (2008) points out the middlebrow is not a static category and readers pass between brows dependent on context. In clubs such as the OBC, where the audience of readers is made up of a cross-section of
society, the level and sophistication of analysis of books will be variable. As Aubry (2006) describes “middlebrow modes of interpretation are not necessarily naïve or misguided…but often involve…quite complex and critical responses to literature” (166). Long (2003) challenges understandings of the middlebrow noting that this conception stringently defines readers and assumes that they are failing to achieve an academic formalism in their reading and may miss the point of their activity altogether, along with the related possibility that reading itself may not be a uniform activity. This kind of static cultural ranking obscures the delicate renegotiations that change the boundaries of legitimate culture. Conceptualizing reading as a variable social practice, however, reveals the give-and-take between literature and life experience by which audiences constantly dismantle and re-inscribe the seemingly stable hegemony of the evaluative hierarchy (128).

In Radway’s (1997) A Feeling for Books: The Book-of-the-Month-Club, Literary Taste and Middle Class Desire, the author identifies that “to label the club middlebrow…is to damn it with faint praise and to legitimate the social role of the intellectual who has not only the ability but the authority to make such distinctions and to dictate them to others.” (260). She, nonetheless, cites middlebrow culture as a challenge to academicism and elitism based on the generally accepted selection of book choices chosen for pleasure over academic value. Based on these understanding, the popular culture book club allows for defiance of traditional literary authority and to look for new understandings as to the purpose and outcomes of the widespread reading and discussion of novels and their characters and situations.

*The Popular Culture Book Club as a Challenge to Devaluation of Emotion in Reading*

Noting the commonly female dominated arena that makes up book clubs, a frequent criticism of both book club selections and the discussion surrounding them is the focus on women’s issues and women’s books (Quindlen, as cited in Rooney, 2005). While traditional visions of women reading have been linked with domesticity and passive consumption, the concept of reading for
pleasure continues to be linked with non-serious readers (Long, 2003). In what Farr and Harker (2008) identify as the collective critical disdain for the popular and the feminine, historical examples such as Nathaniel Hawthorne (1885) famously calling women writers “a damned mob of scribbling women” demonstrate the devaluation of women’s contributions in the literary field. Tompkins (1985) remarks that “twentieth-century critics have taught generations of students to equate popularity with debasement, emotionality with ineffectiveness, religiosity with fakery, domesticity with triviality, and all of these, implicitly, with womanly inferiority” (123). The selections of women’s book clubs have been highly criticized for exploiting what are considered easy issues, which play on sentiment, “reaffirm popular wisdom, to tell readers what they expect to hear […] to help them learn what they already know […] and to reinforce what they think is right and wrong in the world.” (McNett, 1999, paragraph 4). The sympathy and compassion stated as being linked with women’s novels is condemned and identified with condescension and pity (Davis, 2008). The books analyzed in this sample are more frequently by women and about women, highlight devalued women’s issues such as their struggles with poverty, disability, and family and bring forth women’s issues as a marker of value in reading. The emotional and connective capacity of books/characters frequently identified by women readers, rather than being dismissed, is now more readily recognized as an important feature of the search for meaning in novels and their discussion (Oatley, 2011). This capacity for emotional connection links the ability of novels and the discussion of books to create social change through empathetic reading and identification with others. This traditionally devalued aspect of reading is being turned on its head and re-evaluated as a prevailing force in the shaping of public opinion and the drive towards social change.

**Emotional Connections in Reading**
In attempts to understand the role of reading and the discussion of books in the lives of general readers, empathy has in the recent past has been more eagerly identified as tool for readers’ understanding of fiction and its influence in their lives. Best-selling Canadian author Yann Martel, for example, recently commented in an interview that reading makes people empathetic, specifically citing Pearl S. Buck’s (1931) novel *The Good Earth* as a way of providing insight and understanding into the cruelty of communist China (Martel, June 1, 2012 Q). Oately (2011) in his analysis of the psychology of fiction cites that “in fiction…emotions are critical; we engage with issues because they are emotionally important to us, having to do with people, with intentions, and with outcomes.” (115). Hunt (2007) supports this observation identifying reading as important in the creation of a sense of equality which has been instrumental in the creation of human rights. Additionally, Mazzocco and Green (2011) identify narrative as more persuasive than rhetorical argument based on the role of empathy. This bringing together of real and fictional lives encourages self-reflection and allows readers to use literature as “equipment for living” and texts as opportunities to see into the lives of others. Outside of expert opinions personal meaning is allowed to develop and multiple subjectivities to be inhabited (Long, 2003). The emotional connection encouraged with characters minimizes boundaries, allowing readers to identify with fictional others. A focus on the visceral connection to books rather than analytical issues, allows readers to identify with traditionally devalued emotional concerns and to challenge the conventional wisdom that the feelings created by novels are simplistic. The discussion of books provided in clubs such as the OBC show this aspect of reading as important and influential. Where Carey (1992) states that “only people incapable of aesthetic emotion look for human interest and other such ‘sentimental irrelevancies’ in artistic works” (215) Winfrey
encourages readers to connect emotionally with fictional strangers and authors and encourages their abilities to understand and improve life with these new found connections.

In addition to the focus on emotional connection, critics argue against the overly depressing nature of OBC novels. Even Long (2003) recognizes the tendency of reading groups to struggle with novels that take them to places they do not want to go and to dismiss characters rather than empathizing with them if they are too different. Todd (2008) supports this observation, citing book club member’s tendency to complain about novels where they cannot identify with characters. This being said, the bar for places readers do not want to go must be set fairly high, as books on the OBC list include tales of the effects of civil war on children, slavery, and struggles with addiction, to name a few. Novels by minority women, from countries across the world, and through three centuries do not appear to dismiss an emotional connection with readers, but instead offer insights into different lives. The encouragement of relationship building between readers and characters and an emotional connection between books and lives allows for the recognition of difference through what Todd (2008) identifies as the articulation of something of personal significance in characters and stories. This traditionally women’s role connecting emotion with books blurs the public and private, domestic and political issues which are so frequently divided. The popular reading frequently demonstrated by book clubs, and the emotional connection ascribed to women readers, while still devalued by literary authorities upholds this apparently significant aspect of women’s reading as a marker of value and this connection to novels as an important factor in the shaping of public opinion and drive for social change.
The Potential of Book Club Discussion to Challenge Beliefs and Attitudes

The book club serves as an important tool in the shaping of opinion about both domestic and social issues, challenging cultural positions of readers and bringing forth both issues through both the reading and discussion of novels. The formation of book based communities moves reading from an individual activity to a social practice, influencing not only what is read, but how it is read and the resulting action based on material learned from novels. This connection of books and book groups demonstrates an engagement with culture, personal identity and social issues. While Long (2003) argues that contemporary book clubs are no longer geared to collective social action and politics like their predecessors, this thesis argues that the reading and discussion of book still encompass these aspirations, however, in less direct ways than in the past. The historic focus on social well-being through charitable efforts and acts of betterment has been replaced by a more empathetic and experiential approach to understanding differences leading to the possibility of change rather than the fixing of social ills.

Through the experiences of text, readers gain an emotional closeness to characters. Long (2003) cites a book club member who in a discussion about slavery based on Morrison’s novel Beloved (1987) shares “It really made me see what it felt like to be owned by somebody else.” (186). This demonstrates Radway’s (1984) position that the meaning of text is defined by the community of readers who construct the text demonstrating the importance of analysis of discussion related to novels.

Davis (2008) identifies the politics in novels in OBC specifically recognizing the power of empathy in political and social change. While she notes that critics often cite emotional responses as lacking the power to challenge practices, and that compassion re-enforces subordination (Spelman, 1997), the author points to humanizing emotion and the relationship
between fiction, reading and the public sphere as an arena for change. This observation is upheld by the comments, community and call to action evident in the discussion of disability in the novels in the following chapters. In the OBC selections, for example, issues of race, violence, social class struggle, tradition, change and development, family values, multiculturalism and immigration, religion and religious confrontation, and grief and loss are all emphasized in selections and discussed extensively. These frequently politically motivated texts bring forth both personal and public issues in heartfelt ways and frequently blur the line between them. The broadcast discussion of Akpan’s (2008) *Say You’re One of Them* demonstrates apparently genuine feelings of hope and heartbreak for the African children characterized in the short stories of the book. A curiosity, but also a desire for understanding, is demonstrated in the discussion of Eugenide’s (2002) *Middlesex*, and the ensuing dialogue about and interviews with inter-sexed individuals. While not all readers demonstrate this type of connection and resulting progressive discussion in the case of disability, a far greater number of posts describing what readers have learned about disability and their newly found awareness about disability issues than was anticipated.

**Discussion**

While misinformation provided by fictional portrayals has the power to deceive, as Gerrig (1993) suggests, and fiction to enable us to believe certain things too easily, the influence of the novel and discussion of books also holds the distinct authority to implement changes in attitudes, understandings and practices, if only on a very small scale. The following sections looks at the ways in which disability is both presented and discussed in relation to popular novels and the three specific areas identified in this chapter (challenge to traditional literary authority, valuation of emotional connections and the progressive discussion of disability) as tools which have the
potential to enhance readers’ capacity for more inclusive, empathetic and realistic conceptions of disability and people with disabilities through fictitious presentations.

The political importance of feeling evoked by reading and the personal transformation that books can create is too often ignored as simply a lack of serious interpretation. Davis (2008) observes for example, that reading a novel about racism may move someone to object to a racist comment in their own life. While not offering grand solutions, small contributions such as these offer strides toward social change by upsetting ideology and conventional positions of thought and bringing private issues to public spheres.

If we accept that genre fiction, or the reading of literary fiction from a middlebrow stance, can be both emotionally and politically powerful on the basis of identification with fictional scenarios, then we can also accept that the intense emotional connections, the sadness, outrage, shock, disappointment, and hope that readers describe feeling in connection with fictitious characters and novels has the possibility to be influential in their lives beyond the pages of the books. As readers’ comments demonstrate, something they have felt passionately about in a fictitious context has the prospect of bringing forth issues into a variety of public spheres and thus offering the opportunity for change. With the high concentration of characters with disabilities in these scenarios, this is of particular importance in this realm.

The following sections provide a comprehensive analysis of the content and discussion of popular culture novels and demonstrate the exploration of personal connections, emotions and disability and other social issues within these discussions through the experiential encounters of book club readers.
Identifying the book club as a kind of public sphere, the discussion of selected novels is demonstrated to serve as an arena of public discussion where the ideas of individuals are brought forth in a public forum. The emotive pull of books is identified as the most common and compelling force behind them. The ensuing discussion allows for the acceptance, interest in and discussion of issues beyond the familiar. Issues of social justice, identification with those outside of readers own lives, the enhancement of minority issues and empathy, in a place where literature is no longer relegated to one standard of merit defined by an elite. Emphasizing Fraser’s (1990) challenges to Habermas’s (1963) original model: the assumption that bracketing is possible and necessary, the existence of a single public, and the undesirability of private interests and issues in the pursuit of the common good, the popular culture book club serves as a model from which to interpret a multitude of public spheres as more inclusive and democratic entities. This also upholds Hauser’s (1999) recognition of public opinion as an emergent discourse, which is constantly changing through dialogue, central to deciding the course of society.
Chapter 7

Disability on the Periphery: Characters with Disabilities in Peripheral Roles

Characters with disabilities appear in novels in a variety of roles and levels of significance. While some maintain such peripheral roles that they are unnamed, absent from reader’s posts and discussion, others are discussed at length. Peripheral characters with disabilities maintain a significant place of importance within this discussion as this large group of characters has been included deliberately by authors and presumably serve a purpose in the story. These often forgettable characters reflect information that is being provided about disability on an almost unconscious level to vast numbers of readers. Reviewing these characterizations, I have found that presentations of characters in smaller roles more readily uphold the disability stereotypes and categorizations brought forth by disability scholars’ to-date. These presentations include characters as an archive of untold histories (Mitchell & Snyder, 2001) a source of imagery, stereotypes and symbols (Biklen & Bogden, 1977, Gartner, 1987, Kriegl, 1987, Longmore, 1987, Norden, 1994) a record of attitudes and reactions towards disability (Mitchell & Snyder, 2001), as a means of imposing standards of normality, conformity and productivity (Barnes & Mercer, 2010, Davis, 1995, Keith, 2001, Truchan-Tataryn, 2007), as a gendered issue (Fine & Ash, 1988, Kent, 1987, Morris, 1991) and as a contributing element of social and cultural identity (Mitchell & Snyder, 2002, Thomson, 1997a, 1997b). While these acknowledged features are frequently recognized in the characterizations analyzed, these roles are also challenged by readers and questioned in both their presentation and authenticity. This probing points to both readers willingness to dig deeper and to query the typecasts put before them. Using some of the frequently identified categorizations of characters with disabilities in fictitious contexts
Stereotype, Metaphor and Symbolic Imagery are explored in relation to these characters alongside those who are so peripheral they cannot be categorized.

Table 8: Peripheral Characters and Stereotypes

<table>
<thead>
<tr>
<th>Category/Stereotype</th>
<th>Character and Novel</th>
</tr>
</thead>
<tbody>
<tr>
<td>Insufficient information to categorize</td>
<td>Palmira – Cane River&lt;br&gt;Church – Backroads&lt;br&gt;Della Jones, Hattie, Aunt Julia, “half blind lady” – The Bluest Eye&lt;br&gt;Beggar – Open House&lt;br&gt;Bok – A Lesson Before Dying&lt;br&gt;Deaf People in the Orchard – The Book of Ruth&lt;br&gt;The “Excitable Jew” – Great Expectations</td>
</tr>
<tr>
<td>Burden</td>
<td>Elizabeth – Where the Heart is&lt;br&gt;Jozia, Howard– Songs in Ordinary Time&lt;br&gt;Miss Finch – The Book of Ruth&lt;br&gt;Jennifer, Irving and Melvin – Black and Blue&lt;br&gt;Mrs. Joe and “the Aged” – Great Expectations&lt;br&gt;Mary – Mother of Pearl</td>
</tr>
<tr>
<td>Weakness</td>
<td>Violet Blue – Open House&lt;br&gt;Claire – White Oleander&lt;br&gt;Alan – Here on Earth&lt;br&gt;Sam – Songs in Ordinary Time&lt;br&gt;Plum – Sula&lt;br&gt;Concietta and Thomas – I Know This Much is True</td>
</tr>
<tr>
<td>Symbolic of Social Conflict</td>
<td>Poor Fool – The Good Earth&lt;br&gt;Shankar (Worm) – A Fine Balance&lt;br&gt;Michael Sr. – We Were the Mulvaneys&lt;br&gt;Mama Mwanza, Tata Kuvudundu &amp; Nathan Price – The Poisonwood Bible&lt;br&gt;Willy Jack – Where the Heart Is</td>
</tr>
</tbody>
</table>

Little or No Detail Provided

A number of characters with disabilities were included in such marginal roles that the reader has little or no information about them aside from their existence and the fact that they have a disability. Outside of the character of Palmira, a “deaf and dumb” slave, who works in the fields with the men, in Tademy’s (2001) *Cane River*, a work of historical fiction based on the author’s actual family, the reason for the presence of these characters frequently remains unclear. In
Hamilton’s (1988) *The Book of Ruth*, for example, the main character Ruth recalls coming across deaf people picking apples in an orchard at a farm outside of town. Describing the sounds that come from the orchard, Ruth notes that it is “the hired deaf people speaking to each other in grunts and groans from the middle of trees.” (184). Ruth considers the sounds that she imagines are “trapped inside the small space of their heads, never to reach their own ears.” (184) and reflects on how sometimes she would like to be deaf so as to avoid hearing the bickering of her mother and husband. No further information is given about these workers and their story ends with this brief encounter.

In the same way, both the characters of Church in *Back Roads* (2000), a teenager with an intellectual disability who works at the supermarket with the protagonist Harley, and Bok, in Gaines’ (1993) *A Lesson Before Dying*, also with an intellectual disability, are identified as socially excluded. Church’s attempts at friendship with Harley are rebuked but his character is given little detail beyond this. Similarly, Bok is described to exist as a marginal part of the small town depicted in the story but lacks any substantial detail outside of this presence. Beyond their outsider status, the reader knows almost nothing about these characters. The same can be said of Della Jones, who frequently does not know who she is, Hattie, who “wasn’t never right”, Aunt Julia, who talks to herself, and the “half blind lady” in Morrison’s (1970) *The Bluest Eye*. These types of presentations in other novels include the “beggar” on the street who the protagonist passes and briefly wonders about in Berg’s (2000) *Open House*, or “the excitable Jew” in Dickens’ (1861) *Great Expectations*.

The relevance, importance and reason for the inclusion of these seemingly insignificant characters which frequently appear to go nowhere, implores us to question the reason for their inclusion. While information about reader’s interpretations of these characters would provide
relevant insight, their minimal presence largely excludes them from the discussion postings and, therefore, further insight into these small but important appearances of disability is missing. The characters otherness and my own reading of them remain my only evidence as to how these presentations are being read.

In characters that are peripheral but with more detail than those discussed above, the long identified stereotypical presentations acknowledged in literature by disability scholars continue to be evident in this selection. Little character development is found and insight into the lives of these characters with disabilities is absent. These castings show people with disabilities as classic stereotypes: dangerous and threatening to themselves and those around them, responsible for the downfall or hindrance of the lives of others, symbolic of weakness and social conflict.

**Dangerous and Threatening**

Seeking to explain reader’s interpretations of specific characters, available discussion reveals the acceptance of characters with physical and psychological disabilities within dangerous and threatening roles.

Lady Hamleigh, the Countess of Shiring, in Follett’s (1989) *The Pillars of the Earth* has a facial disfigurement and is described as being difficult to look at. The antithesis of femininity, she is set in contrast to the beautiful, young Aliena, the love interest of the novel, and the intended bride of her son William. Regan Hamleigh is spoken of as “sadistic and evil” (Steve Koss, 2008) powerful, relentless in her pursuit of influence and possessions, and unapologetic for the suffering she causes others in this quest. She is described by readers as “ugly” and “hideously boil ridden” (Steve Koss, 2008). While upholding Kent’s (1987) observation of female characters with disabilities as a challenge to femininity, she also exemplifies a flat presentation.
of evil. Readers however, have not overlooked this feature in their interpretations of this character and question the realism of such a presentation. Royal Rother (2012), for example, points out that readers “…get to know the characters rather well, but never remotely deeply”. Another reader comments that “…the characters were one-dimensional and not very interesting” (Randy Kadish, 2010).

An additional female character in this category comes from Mitchard’s 1996 novel The Deep End of the Ocean. This novel tells the story of Beth whose son is kidnapped during a high school reunion. Years later when the son is found, the kidnapper, Celia or Cecil as she is known, a high school acquaintance of Beth’s, has been long since institutionalized in a mental health facility and is no longer communicative. Cecil epitomizes the stereotype of the danger and threat brought forth by those who deal with mental health issues. Cecil however, is also an unexplored character which has been noted by readers such as David Lupo (2011) who comments, “It would have been good to hear of the story of Cecil… More words should have been spent on her…” A Customer 7d, (1999) agrees, commenting “I was also dissapointed [sic] in the fact that Cecilia [sic] had mental problems, so we never really got to find out her side of that story either.” A Customer 7e, (1998) says “I felt cheated by the underdevelopment of Cecil, the kidnapper. I felt that it was a copout that she had mental problems…” An additional poster adds “I also thought that Cecil's motivation for taking him needed to be more fleshed-out. "Mentally ill" is pretty lame. I would have liked more information about what led her to take that particular child…” (A Customer 7f, 1999).

Vinegar Hill (Anasay, 1999) brings readers the character of Fritz, the father in-law of the protagonist Ellen. This antagonist who “gives off a sour cheese smell” (209) is characterized as an ever looming threat. Enforcing this presentation is his physical appearance, including his
"ugly hands notched by scars with warts and scars, the pinky finger missing from the right hand." (209) imposing a connection between his physical difference and his threatening character. He is described as sadistic, as a misogynist who mistreats his wife and as abusive to his son. He is marked by readers as “evil” (starwriter, 1999), as “a pig's head” (Wisdom Falls between the leaves of truth, 2010), and as a “repulsive man” with “…nothing redeeming about him” (Devoted Amazonian since 1996, 2000). Blacktoastintolerate (2012) referring to Ellen, the daughter in-law states “I wanted her to spit on Fritz's face”. He is “a mean, cruel man…” (prolific reader, 2011). Speaking to his representation as a flat rather than realistic character however, A Customer 7g, (2000) advises that “no inner light was shed on Fritz, to circumvent his nasty behavior.” An additional poster upholds this sentiment noting that the writing “allow[ed] us a peek inside the minds of each of the characters except Fritz (that would have been interesting)” (John W. Fienhold, 2000).

Offered as an additional power hungry, threatening stereotype, Steinbeck’s Cyrus Trask in East of Eden (1952) returns from the American Civil War minus a leg, (plus a case of Gonorrhea). Rather than simply a result of battle, this physical aberration represents his distasteful and untrustworthy personality. This “wildman” (Shashank Tripathi, 2004), “swindler” and “liar” (Y Lin, 2008) is an autocratic ruler in his home, and a relentless self-promoter in his work. Cyrus is described as a “…martinet, so overbearingly so, that Adam joins the army just to get out of his sight”. (Rocky Raccoon, 2008). He is “the amoral patriarch” (A Customer 7h, 2004) of the Trask family.

Ruby, in Hamilton’s (1988) The Book of Ruth is the love interest of marginalized Ruth. This “simple” couple initially find happiness with each other and marry. As their lives progress, during a seemingly inconsequential disagreement over Christmas baking, Ruby beats May, his
mother-in-law, to death and seriously injures his pregnant wife Ruth (for which he is jailed). Ruby is diagnosed by readers as “a very emotionally disturbed man” (Rob Darrah, 2000), “mentally ill” (A Customer 7i, 1998), as “…nothing but a drug addict and a big baby…” (Elizabeth, 2010), “a lazy slob” (Manola Sommerfeld, 2004). “intentionally and happily disabled” (A Customer 7j, 1998) and as a “high functioning retarded [person]” (Blacktoastintolerate, 2011). Ruby is described as an abusive and “vapid” husband “whose unpredictable behavior Ruth overlooks and excuses until he inevitably erupts in a murderous [sic] rage”. (J.R. South, 2000). He is “skuzzy” (stargaazor, 2006) and “a drunkard who can't hold down a job.” (Dead Kennedys, 2007).

While many are critical of Ruby, his circumstances and his actions, others find him a more sympathetic character. He is seen as “a wounded soul” (A Customer 7k, 1996), “pathetic but loveable” (Cindy Ecay, 2002), as “Not real smart and just needing to hear someone say something positive to him once in a while.” (nuts about books, 2000). A Customer 7a (1999) says “THIS BOOK SHOWS HOW AN INDIVIDUAL (RUBY) WHO IS CONSTANTLY BERATED ALL OF HIS LIFE AND WHO HAS SOME UNRESOLVED FEELINGS, CAN SUDDENLY SNAP AND LASH OUT AT THE INDIVIDUAL WHO BERATES HIM (RUTH'S MOTHER), WHILE HURTING SOMEONE HE CARES ABOUT IN THE PROCESS (RUTH).” (Emphasis Original).

The characters in this book, unlike reader’s criticisms of other flat presentations, are described as realistic and believable. “Jane Hamilton allows us into such a world of happiness, grief, torment, fulfillment, simple joy and tragic circumstances” (Nancy, 2002). A Customer 7l, (1998) describes that her own book club, made up of educators, who have all “taught Ruth, May and Ruby and their families”. A Customer 7b, (1999) describes Ruby as reminding her of a boyfriend
she had growing up in a small town. Another poster, relating to the characters and circumstances describes that “I felt repelled by the life circumstances of this troubled family. But having come from a poor, troubled family in a small town myself, I somehow found empathy even for May and Ruby.” (A Customer 7m, 1997). Feeling this connectedness to the novel, one reader says “I wept for Ruth, for May and for Ruby.” (A Customer 7n, 1998). Dead Kennedys (2007) notes “you come to really know and care about the characters…and when it comes time for the book to end, it's almost impossible to let these people go quite yet.” While Ruby is accepted as a lazy, cold hearted killer by some readers, others identify him as a troubled individual. Outside causes for his behavior are identified and his disability is not seen as the necessary cause of his threatening behavior. He is contrasted with Ruth, also a character with a disability, but who in her own way is strong and the heroine of the story, demonstrating a variety of strengths, weaknesses and personality traits amongst characters with disabilities in contrast to the singular features of Lady Hamleigh or Fritz discussed above.

**Burden**

The idea of disability and people with disabilities as a burden to society and those around them is also strongly demonstrated in this selection of novels within the peripheral characters. Several elderly characters that are no longer able to take care of themselves are found in this role. Minor characters with addiction and mental health issues are also frequently depicted as a burden to those around them.

Dickens’ “The Aged” exemplifies this (Great Expectations, 1861). The elderly father of Wemmick, who is deaf, and cared for by his son, appears happy as long as he is able to nod along to the conversations that he is unable to take part in. While there exists almost no reader
discussion of this character, Wemmick’s seemingly altruistic care of his father is cited in one comment as “…a remarkable example for any of us in caring for our parents.” (James Schmidt, 2012). Similarly, Miss Finch in Hamilton’s (1988) *The Book of Ruth* is an elderly woman with a visual impairment, who Ruth befriends. She also is demonstrated as a burden to the community and her family until her son puts her in an institution where she dies. While Miss Finch is only very briefly discussed in reader comments, her disability is noted along with her displeasure with her placement in the institution. “Miss Finch, an old blind woman who becomes a mentor for Ruth, often reminisces of times as a young woman when she and her husband would take trips to Hawaii. She longed for her restored sight-to be able to see the clear blue oceans and soft, sandy beaches” (ezabeth, 2003) suggesting her youth and the restoration of her vision is key to her happiness. In her state of loneliness, discontent and isolation from the world, Miss Finch is identified as one of the only characters who values Ruth who is labelled as “simple” keeping characters with disabilities grouped together.

Representing a younger generation of burdensome characters, Sam, the alcoholic, absent father, and ex-husband of the central character in Morris’ (1995) *Songs in Ordinary Time* lives with his mother and exemplifies what readers identify as weakness and burden in his apparent inability to stop drinking, maintain a job or care for his children. Sam is classed by readers as “despicable,” “sleazy”, and “a loser” (A Customer 7o, 2000), “a drunk” (Book Lover and Knitter, 2009), and is described in terms of his “dereliction” (The Hedgehog, 1997). Sam is “…frequently around town, drunk and belligerent, humiliating his children” (A. Luciano, 2011), While many accept Sam in this unflattering presentation, readers once again demonstrate their dissatisfaction with the lack of detail and insight provided into such characters. ESP=Math+Music+Literature (2011), comparing the novel to a soap opera criticizes the lack of depth of both Sam and many of the
other characters presented. Janice Kiriyakou (1999) looks at his positive features noting “Sam finally made the choice to seek treatment on his own.”

Mrs. Joe, is Pip’s (the affable young protagonist) older sister in Dickens’ (1861) *Great Expectations*, who cares for him but also treats him unkindly. She is hit in the head in an attack and henceforth is unable to speak understandably and has a hearing impairment. Prior to her being attacked, this character was “punitive” (Ernest Belden, 2000), “harpy” (Sherry Keller, 2000), “formidable” (Davey, A. 2000), “hard”, “abusive” (Randall, D., 2000) and “fierce” (David, 2007). Following her accident, however, now as a person with a disability, all of her spirit, good or bad is shown to evaporate and she becomes a stereotype. This new presentation leaves her as a burden to her husband. She is “left more pleasant” falling into Keith’s (2001) categorization of women with disabilities in fiction as submissive, patient and cheerful.

Additional characters included in this category are Elizabeth, the onerous alcoholic sister of Forney in Letts (1995) *Where the Heart Is*, who forces her brother to give up his own dreams to take care of her until she is finally institutionalized and dies and Mary, the mother of Joleb, who became paralyzed following his birth and is blamed for her son’s odd ways.

**Weakness**

In addition to being presented as burdensome, peripheral characters with disabilities are discussed by readers in terms of their personal weakness cited through their lacking of the strength to care for themselves. Especially prevalent in tales of addiction and mental health an absence of what is identified as personal responsibility is frequently cited as the cause of their downfall and as a point of comparison to what are accepted as stronger, more admirable characters.
Exploring addiction, the character of Plum, who is addicted to heroin, in Morrison’s 1973 novel *Sula*, stands in direct contrast to his mother Eva Peace. Eva is described to “demonstrate what freedom means” (L’Tanya, 2002), and is rumored to have cut off her own leg to get the insurance money to take care of her family. In order to “release the pain from within Plum…to relieve him of his eternal burden from drug usage and his return from war” his mother pours “kerosene over her son…to light him on fire” (Roger B. Caberera, 2005). “Suffering” (A. Price, 2005) Plum is observed in his inability to cope in his life. Eva is said to realize that “his drug addiction was turning him into a child again” (SerenaMoon, 2004) and her actions are accepted as loving.

Fulfilling a similar type of role, the character of Alan in Hoffman’s *Here on Earth* (1997) is described in his adult life as “The Coward” (A Customer 7p, 2003), and as “scary” (Manola Sommerfeld, 2001). Alan, who at one time had all the potential in the world, “had fallen so far” (A. Luciano, 2010) inept to deal with the realities of life and the death of his wife. This character removes himself from society and lives in solitude in the woods drinking.

Additional characters are shown in their weakness as comparison points to more central characters strengths. Berg offers Violet Blue in her 2000 novel, *Open House*. She is the college student who lives in the basement of her landlord Sam’s home. Violet is “a hopeless young girl…who has given up on life” (A Customer 7q, 2001). Sam, the protagonist, whose husband has recently left her a single mother, in contrast, is presented positively, having overcome her situational despair and moved on with her life.

Claire (White Oleander, Fitch, 1999) exemplifies the submissive and dependent female role of women with disabilities. Not capable of having children of her own, she acts as a foster mother to Astrid, the young heroine of the story. Claire is the antithesis of Astrid’s mother, Ingrid “…the cold serpent…” (Bora, 2001). She is loving, warm and needy. Presented as depressed and
married to a husband who is never home, she commits suicide when he leaves her. In distinct contrast, Astrid, whose mother is in jail for killing her boyfriend, is surviving through multiple foster homes and apparently continuous loss in her life. Claire takes her own life, leaving the child to move again.

Where Violet Blue is dismissed by readers through their lack of discussion of her, the character of Claire is discussed in terms of reader’s own weaknesses. Claire is identified with by readers. J. Evans (2000) says “It was easy to recognize characters such as…Claire…in one's own life…which made the tale much more thought provoking and personal”. Described as a “truly sensitive soul” (crystalofcolors, 2004) she is “kind”, “fragile” (Nancy, 2002), and “caring” (Johnny Madrid, 2000). “Claire, so desperate to be loved, [she] is one of the most heart-rending fictional characters I have ever encountered. Her fate drove me to tears, as if it was that of a real person” (An Amazon Customer, 2004). This character, given life, is identifiable to readers and their discussion shows an emotional connection to someone, though different than themselves, as representing a part of themselves. Readers recognize both Astrid’s strength and Claire’s weakness.

A final example of comparative weakness is presented by both the characters of Concietta Bridsey and her son Thomas in Lamb’s I Know this Much is True (1998). The mother of twin sons Dominic and Thomas, Connie is born with a cleft palate and her physical variation presents itself in her submissive and fragile personality. The biological father of her sons is never revealed, but the story suggests her feeling unworthy of a husband or having been taken advantage of when she became pregnant. When she later marries Ray, she tolerates his emotional abuse of the boys and herself and passively puts up with all that comes her way. Dominic’s depression, marital failure and anger with the world and Thomas’ schizophrenia are accepted by
readers as reflections of their mother and the lives that they led because of her personal weakness, rather than social isolation. Boblington (2009) notes “It's interesting too to see how a father and mother can pass on fears, and behaviours to their children and how the childrens [sic] personalities take on these traits and taught attitudes.” Thomas, who is described as developing schizophrenia as a college student, opens the story when he cuts off his own hand in the public library and is subsequently institutionalized. Thomas is highly criticized by his stepfather throughout his life for being overly dependent on his mother, for his physical and emotional weakness and his inability to act “like a man.” Unlike Claire who readers empathize with, Thomas and his mother are pitied. Binker (2012) for example says “My heart really ached for him and for his mother, who only wanted to protect her poor defenseless son. Agonizing.” Along with Plum and Claire, described in this section, both Connie and Thomas also die by the conclusion of the novel.

**Disability as Symbolic of Social Conflict**

Mitchell and Snyder (1997) discuss presentations of disability in fiction as symbolic of social conflict and pain. This observation once again holds true to many of the presentations of peripheral characters presented in this selection. Thematic social issues highlighted by characters with disabilities include the pursuit/death of the American Dream, economic and social inequality, and colonialism.

Willie Jack in Letts’ (1995) novel *Where the Heart Is*, is the “loser” (R.K., 2004) boyfriend of Novalee, the story’s female protagonist. He “abandons her” (s maier, 2009) seven months pregnant at a Wal-Mart while he continues on what was to be their journey to California. Willy Jack’s rise and subsequent fall, from a trailer park resident to an almost-made-it country music
singer epitomizes the struggle to attain the American Dream and the difficulties surrounding social mobility in that society. While “All of the characters, even Willie Jack, have redeeming qualities” (dml48221, 2000), this difficult to like individual who uses a wheelchair following an intoxicated accident is put up against the threshold of Novalee who has “a heart full of determination, pride, and unselfishness”. In what is accepted as an inspirational tale, in spite of all that is going against her, Novalee finds the American Dream that Willie Jack sought. In contrast to her former boyfriend, through a combination of self-determination, cheer and the kindness of others she obtains a job, a boyfriend and, finally, a home that is not mobile.

Michael Sr. “the head of the household, proud father and wonderful husband” (the ratmammy, 2004) in Oates’ We Were the Mulvaneys (1996) depicts a fall from the kind of success that Willy Jack sought. Michael Sr.’s picture perfect nuclear family is destroyed following the rape of his daughter and his inability to cope with this occurrence. He moves from a status driven, self-made, successful business man, included in private clubs and respected in the community to a person who is unemployed, dealing with alcoholism and who eventually dies in his dilapidated apartment, “a social outcast in the community” (Lisa K. Mills, 2001).

Neither Willy Jack nor Michael Sr. are able to maintain success. This failure is represented in part by their acquisition of a disability, showing their ultimate downfall.

At the other end of the spectrum of economic disparity, the character of Miss Havisham in Dickens’ (1861) Great Expectations represents the financial inequality of the era in which the novel is written. This “rich and powerful” (Reader2307, 2013), manipulative woman of mid-level significance to the story, has little to do other than spend her money, and play emotional games with the comparatively poor, young Pip, the protagonist, for her own entertainment.
Acknowledged as “weird” (Michele, 2013), “crazy” (C. Bassett, 2013), “mysterious” and “ethereal” (Pierre Gauthier, 2010) in her “creepy” and “lonely” old house (Mara P., 2012) she represents over-indulgence and the dangers of such behaviour. In a room prepared for her wedding as a young woman, she sits “defiantly moldering away and shut up in her never-used wedding finery” (Chicago Bookworm, 2012). This “jilted bride now in decay” (Cloggie Downunder, 2012), is “mournful and bitter” (Bookworm29, 2011). Readers find her eccentricity and unusual behavior “intriguing” and the character as “…one of the most memorable characters [I’ve] ever come across” (Reader2307, 2013). She is recognized as “…clearly a woman with a lot of potential who ruined her life because she couldn't get over a romance that went sour.” (Jeremy Richmond, 2011). Misha (2011) describes a fondness for this character. “The eccentric Miss Havisham who sits in a room with a rotting wedding cake, wearing her wedding dress seemed more alluring to me than any of the other characters. It was her eccentricity that truly attracted me to her. If she had been some old, moody spinster, I would not have liked her half as much.” Booklover (2010) upholds this sentiment stating “How bizarrely wonderful is Miss Havisham with her tattered and yellowed bridal gown and half century old wedding cake?” Demonstrating the kind of voyeurism identified by Mitchell and Snyder (1997), her eccentricity is appreciated as a characterization but she is not identified with or connected with by readers.

Looking to stories in the developing world, several novels provide examples of social commentary which include disability. Mistry’s A Fine Balance (1995) tells the story of two tailors, escaping their fate as “untouchables” trying to make their way in Mumbai during Indira Ghandi’s emergency in the 1970s. Noting the impactful message provided by this story of poverty, strife and hope, Windriver12 (2002) comments on his personal growth through the
reading of this novel commenting “Thank you Mr. Mistry for showing me the other side of the story. Thank you for putting into plain and powerful words exactly how unfair life in India is to the poor and lower castes”.

One of the friends the tailors (Om and Ishvar) make along their journey is the amiable character Shankar, known as Worm. Worm is a professional beggar who has no arms and no legs and gets around on a wheeled platform. Mohatarma (2002) comments that “Shankar, despite being relatively minor characters, will undoubtably [sic] stay in your memory.” He is friendly, loyal and representative of good in a bad world. David B (2001) remarks that he “found hope in the compassion displayed by the supporting roles, especially Shankar…” This characterization symbolically represents the social strife in India at this time and his death, mourned by many, demonstrates the death of hope in a world which does not make sense. This poor and virtuous Tiny Tim “the tragicomic Shankar, a legless beggar, also remind the reader of Dickens” (klavierspiel, 2005) is beloved by readers who cannot find fault with him.

Demonstrating disability as a metaphor for the cruelty brought forth by political agendas both Pearl S. Buck and Barbara Kingsolver use disability to exemplify social strife. Set in the Congo in the 1970s, poverty and colonialism are explored n in the novel The Poisonwood Bible (Kingsolver, 1998). Characters with disabilities and physical variations include Mama Mwanza, who has burnt her legs and gets around on her arms, Tata Kuvundundu, the medicine man with eleven toes, and most notably, Nathan Price, a “fire and brimstone Baptist preacher” who’s “…clumsy and ill-advised attempts to fit Africa to his fundamentalist beliefs…” (cookie mom, 2000) result in his downfall into delusion and his eventual death. Demonstrative of religious fundamentalism and resulting social pain, Nathan Price, who already has very “poor vision” as
the result of his cowardice during war, this character also becomes delirious at the end of the book, living in the jungle. He is eventually burnt alive by the locals who feel that he has cursed the resident children to be eaten by crocodiles. While immersed in his quest to bring Western religion to the community, he is described as “myopic” (Knitter and Bookworm, 2000), “weak” and “a fool” (Doug Vaughn, 1999), and “a hateful and vengeful man” (A Customer 7c, 1999). While readers repeatedly identify him as a depraved character, he is also recognized as playing a figurative role rather than as a whole person. A Customer 7r, (2000) felt that readers did not get to know this character or his motivations well enough. A Customer 7s (2000) agrees “I wish Barbara Kingsolver had allowed the reader to hear Nathan's inner voice.”

In the same way, Buck’s The Good Earth (1931) tells of the brutality of communist China, the self-interest of individuals in times of strife, but also the goodness that can exist amidst cruelty and selfishness. Contrary to the ruthless dominant part of his character, Wang Lung, the central character, demonstrates the goodness in his heart amidst all of the chaos around him through his ongoing care for his daughter “Poor Fool”. “…His oldest daughter…who becomes mentally retarded due to malnutrition during the famine.” is described as demonstrative of Wang Lung’s capacity for kindness. “Although she is a burden and consideration is given to selling her as a slave to a wealthy home” J. Green (2010) remarks, “seeing her smile softens his heart, and he protects and cares for her throughout his life”.

Showing the many sided Wang Lung who is able to “…both enrage the reader with his incredible cruelty (especially to those close to him), as well as delight us with his uncompromising stamina, acquired [sic] wisdom and unexpected tenderness (his relationship with his retarded daughter - "the poor fool" (kattepusen, 2005)”, his daughter maintains a very small, undescriptive role
outside of being identified as a constant in Wang Lung’s life. He cares for her in spite of his own financial situation, demonstrating his humanity, not evident elsewhere in his life.

**Discussion**

While peripheral characters with disabilities are more readily identifiable as stock, and stereotypical characters and metaphors upholding ableist perspectives than those in more prominent roles, this kind of depiction is not wholly accepted by readers. Those who post comments consistently question presentations and demand more of authors in terms of these flat illustrations and the inclusion of disability as a part of stock characters. In the tradition of critical theory, readers question both the presentation of the characterization of disability and also the author’s motives in these presentations. In this public forum, moving readers from their own solitary practice to a place of public discussion the emancipatory, reflective, and dialectical bases of this theoretical framework are brought to life. Enacting dialogue in the practical enhancement of social conditions, in this forum, critical theory is carried out by the wider public.

Readers frequently identify unrealistic portrayals and seek the further development of such characters. The most peripheral characters described in the first section of this chapter, provide little insight into readers’ perceptions of them based on the lack of discussion surrounding them. In somewhat more prominent roles, however, characters are demonstrated to have been fixed in the minds of readers enough to be discussed and frequently to be criticized, empathized with, or recognized as requiring further exploration. The identified reason for their presence to signify a societal ill or metaphoric quality does not appear to be a satisfactory explanation for their presence and depiction for many readers as demonstrated through their comments. While they may uphold threatening or dangerous, burdensome or weak personalities contrasting the strength, independence and noble motivations of other characters, readers appear to want to understand the
development of these features and the purpose of their presence as well as to connect with these peripheral characters further, bringing an important feature to the critical analysis of disability.
Chapter 8

Disability Abounds: A Sample of Novels with a Major Character with a Disability

While the previous chapter looked at characters with disabilities in minor roles, this section focuses on major characters with disabilities where the disability is not the central focus of the novel, but maintains a significant presence within the story. This includes discussion of Jonathan Franzen’s *Freedom* (2010), Wally Lamb’s *She’s Come Undone* (1996) and Carson McCullers’ classic novel *The Heart is a Lonely Hunter* (1940). By reviewing reader comments through webcasts and online posts, the dialogue surrounding these three novels demonstrates the ways in which the discussion of books holds the ability to challenge public perceptions of disability through the use of vernacular discussion of both literary and genre fiction within a public sphere. By re-defining who, how and what is being read the ways in which readers are connecting to characters with disabilities, questioning their presentation and motives, and bringing forth progressive discussion, beyond a traditional ableist framework, a pattern is revealed which demonstrates the open access book club model as a potentially productive forum for the discussion of disability and the proliferation of more advanced dialogue by the wider public on the topic of disability.

**Freedom – Jonathan Franzen**

This is the second of two novels by this author to be included in the OBC. The first *The Corrections* (2001) famously initiated a clash between the author and host based on Franzen’s publicly espoused level of literary distinction which he felt contrasted this audience’s ability to “handle” such material (Quirk, 2008). The last novel selected for the OBC before Winfrey’s move to her own network, *Freedom* (2010), which was included with the support of Franzen
provides a commentary on life in the twenty-first century. This novel tells the story of Patty and Walter Berglund as they move from their college years through their aspirations to raise the perfect family in the American Midwest. Engaging with the new millennium and the challenges that the modern-day brings, the Berglund’s and their relations work their way through socially and personally created trials in what is presented as a perplexing time. In this tale of feeling lost in the contemporary world, 11 of the characters in this novel have been classed as people with disabilities with varying levels of severity.

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<th>Presentation</th>
<th>Disability</th>
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<td>college basketball star come suburban housewife, affair with husband's best friend</td>
<td>Depression, alcoholism</td>
</tr>
<tr>
<td>2 Walter</td>
<td>Environmental lawyer, well intentioned husband of Patty</td>
<td>Depression</td>
</tr>
<tr>
<td>3 Connie</td>
<td>Teenage girlfriend and later wife of Joey, Patty and Walter’s son</td>
<td>Depression, suicidal</td>
</tr>
<tr>
<td>4 Abigail</td>
<td>Patty’s spoiled actress sister who parents doted on</td>
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<tr>
<td>6 Gene</td>
<td>Walter’s father, an alcoholic who did not understand Walter</td>
<td>Alcoholism</td>
</tr>
<tr>
<td>7 Mitch</td>
<td>Walter’s brother</td>
<td>Alcoholism</td>
</tr>
<tr>
<td>8 Dorothy</td>
<td>Walter’s mother who is deceased</td>
<td>Uses wheelchair</td>
</tr>
<tr>
<td>9 Eliza</td>
<td>Patty’s best friend in college</td>
<td>Cocaine addiction, unspecified mental health</td>
</tr>
<tr>
<td>10 Richard</td>
<td>Walter’s best friend, musician, very cool in contrast to Walter. Always gets more attention than Walter</td>
<td>Depression</td>
</tr>
<tr>
<td>11 Richard’s father</td>
<td>Drunk father of Richard</td>
<td>Alcoholism</td>
</tr>
</tbody>
</table>
Both Patty and Walter, the two protagonists, deal with depression and/or addiction at some point in the novel, though in minor ways. In addition, several of the less significant characters almost all are described as having some kind of disability, with a substantial amount of attention paid to depression and addiction. Conversation about this book and specifically about disability focuses around the character of Patty, therefore the discussion to follow relates to this character specifically.

**Reading Questions**

A list of reading questions is provided on the OBC website providing direction around the tone and themes of the discussion of the novel. The 18 discussion questions focus on the identified themes of: conceptions of love and commitment, family angst, adolescence, and the place of the individual existing in the larger world. Questions also address social issues including the college experience, the nature of attraction, child/parent relationships and the role of gender in child rearing. The connections readers have felt with characters are elicited, asking them to comment on the ways characters made them laugh, feel sadness or sympathy, or are consider absurd.

While disability appears as a central theme of this comment on modern life, only one question addresses it with a minor reference to reader’s perceptions of the very peripheral character, Mitch, Walter’s brother and his supposed freedom. While this question is asked, there is no discussion of Mitch in the online posts or webcast discussion that I reviewed to specifically address this question. In fact, the issue of disability, though all-pervading in the novel, is rarely discussed in the overall postings about the story. While noting the potential impact of the provided information to influence readers interpretations of the characters and themes of the
story, posting revealed such a variety of responses to the novel that I feel I cannot conclusively find any patterns based on the questions specifically. While disability is not directly addressed in the supplied reading questions, significant discussion of disability was present in online posts as is discussed below.

**Reader Discussion**

Reader discussion and posts provided a significant amount of information about this book. This novel had the greatest number of posts of any of the novels reviewed for this research. The OBC website as of October 2, 2012 included 985 reader posts demonstrating a significant amount of participation around this book and the growing social impact of online book clubs and discussion forums. In addition to reader comments, the website also included additional information available for readers to find further material about the book. This includes links to sections entitled: About the Author, About the Book, Excerpt, Reading Questions, Character Guide, Producer Comments/Blog, as well as a video interview with the author.

**Challenge to Traditional Literary Authority**

As chapter 3 describes, the popular culture book club can serve as challenge to traditional literary authority. Readers’ discussion of both content and style demonstrate a lack of formality and traditional literary analysis through this type of interaction. The fact that most of the discussion centres on why posters loved or hated the book confirms this. The dialogue itself upholds the importance of a connection to novels in assessing their impact outside of traditional frames of analysis. Franzen provides a noteworthy example of a literary writer, featured for a middlebrow reading of a novel and the crossing of traditional boundaries. The idea of literary authority and the challenge to this position by the popular culture book club is especially relevant considering Franzen’s initial reticence regarding his novel *The Corrections* (2001) being included on the
Oprah list, his status as a literary writer, and his agreement to participate in such a forum in relation to his more recent novel. The author, who famously maligned Winfrey’s audience when his previous novel was selected for the book club, flattered audience members regarding their worthy and insightful questions in a webcast held for this selection.

While the majority of posts uphold my findings that readers in this context demonstrate different reading goals than have traditionally been associated with literary fiction, some members of discussion boards demonstrate a devaluation of a middle brow approach to reading and uphold an elitism connected with traditional literary value. A selection of posts identify reader’s academic credentials and achievements and, thus, the supposed cachet of their opinions. skrouch (2011) , for example, prefaces his/her comment with reference to his/her “masters from Harvard” and muthsaad’s (2010) discloses that s/he has just finished “War and Peace”. Others diminish those who do not share an appreciation for the book such as moyletl (2010) who disdainfully remarks “perhaps you…should stick with simple, shiny, happy novels like the Bridges of Madison County” or jgluz (2010), who sarcastically apologizes for that fact that this book “wasn’t the usual escapist, empty-calorie, sentimental drivel that keeps the industry afloat.”

Identified by Kiki2658 (2010) as what has been called a “modern-day classic” and the “novel of the century” read by Obama, this highly acclaimed book is found to be a surprising selection for the OBC by those who disavow the sharing of highbrow culture amidst the masses. A clear example of this is provided by tonywalt (2012) who states:

I am surprised that anyone in Oprah’s book club would like a book like this i.e. a certain amount of cynicism and (highbrowish) existentialist themes. The people I see on Oprah are (generally) your Soccer Mom – you go girl- High Fiving-“everyone is awesome”- chicken soup for the soul types who for the most part, with some solid exception, would not be attracted to New York intellectualism (and you can be assured that Franzen
identifies with those birds of a certain feather). What next – Kafka or David Foster Wallace, Proust…lol.

Challenging this condescension, the ability of the masses to be exposed to, to enjoy, dislike, and have an opinion in the area of literary fiction is demonstrated by many posters who show the liberty to both admire and deride the novel in their more casual discussion. The purpose of reading is questioned at length in this online discussion. Unlike more formal literary analysis, readers demonstrate openness to reading for varied purposes at a variety of levels of complexity. Spindrift8 (2010) posts “We all read for different reasons. I think reading takes us out of our comfort boxes, takes us places we may never go and basically teaches how to live. I enjoy many different types of books but prefer those that help me to examine my own life and expose me to new ideas.” The reader continues by asking “Reading for escapism only? Well, it certainly beats many other methods that people explore…”

In spite of the novels social prestige many chose to express their dislike of the novel. hobknobb (2010) remarks “I…HATED (emphasis original) this book. What a snoozer. I read novels to be entertained not to have to analyze the characters or the motivations of the author…If I felt the need to do so much work, I would read self-help books, not fiction.” In a similar way deb_home (2010) says “…the best book you would ever read. Are you joking?” and MarilynMT (2010) describes it as “wordy, boring, and a waste of time”. The on-line discussion of Freedom demonstrates the popular culture book club that has been put forth in chapter 4 as challenging the sanctity of the novel itself and surrounding expertise that is often associated with literary fiction.

Connections to the novel
Description of Why Loved/Hated the Book

The most frequent type of comment identified through this research has been people’s descriptions of their general feelings about the book and its characters. This novel in particular
seems to have struck an emotional chord with readers who either hated or loved it. The majority of posts contain comments as to why the reader enjoyed or loathed the book, as well as their journey to this conclusion. Many readers described feeling angered about the amount of time they had committed to reading a book they saw as useless, vulgar or boring. The book was described as “disgusting” and “classic trash” (rmwagman, 2010), “one of the worst books ever picked by Oprah” and a “…waste of my precious time.” (sphynxlady, 2011). It is depicted as a “stupid depressing book” challenging how people “AUGHT [sic] to behave?!” (fgirl, 2010). Other readers who initially did not like the book described their changing perceptions as they worked through the novel. kdcalder (2011) for example stated “I wanted to hate it and almost did until reading the last chapters…the principle characters…became more likeable for their humanity, with all of their obvious flaws. I came to terms with who they were and saw in each of them, genuine growth as imperfect human beings…where choices are never simple, and consequences sometimes not so obvious.” Natorcab1(2010) upholds this sentiment stating “This book takes time to develop the characters so much so that you see parts of yourself and people you grew up with in this story.”

The majority of comments as to why readers liked or disliked the books were based on their ability to identify with characters. Those who disliked the book describe Patty and Walter the protagonists as “silly” and “shallow” (themarshhouse, 2010), “undeveloped’ (kell76, 2010), as “dysfunctional” and uninteresting (suzzieq36, 2010) and presented in ways that “do not ring true.” (lor4, 2011). Rexiedog (2011) states “I…could not connect to any character.” The lack of connection to characters was especially focused on the role of Patty. Patty in the novel is a troubled housewife. An athletic star in her youth, outside of the adoration of her husband, she is unspectacular in her adult life. Throughout the story Patty becomes addicted to alcohol and is
described as depressed. She is generally dissatisfied with her life and has troubled relationships with those around her. Her morally questionable behavior and general displeasure with her life, is both highly criticized and praised by readers. Those disapproving of Patty find her difficult to bond with. Simvet02 (2010) identifies “There just isn’t a character I care about. Patty is strange and boring” and resembles a “…catty diatribe…[that] really didn’t draw me in” (Rosesabo, 2010).

Others however identify with Patty’s struggles and difficulties. SisterMonica (2010) describes “I had reservations, at first,…but soon related to her and her frustrations.” Ergi1120 (2010) identified with Patty, her social angst and enlightenments, especially in her college years. Muthsaad (2010) expressed the difficult realization of seeing him/herself in the characters that many found so distasteful. This reader wrote “…the hardest part of reading the book – the very moment when I realized that this book is not about them, it is about me. I was every single one of them – from Patty (she was the most difficult to admit to) to Richard, punk that he was”.

Fiddildd (2010) similarly posted “It was a difficult book to read at times because I saw myself and my marriage in the characters”. This imperfect presentation led rburchette (2010) to love the characters “for their goodness as much as their flaws”. Recognizing themselves in these portrayals, rryder (2010) observed “I kept saying to myself – Oh, I’ve thought that. Oh I recognize that.” The sense of reality appreciated by readers through the flawed presentation of characters appealed to some readers as much as it turned away others. Chele789 (2011) described feeling “intrigued by each of them. I loved them, identified with them, or sometimes thought they were just plain gross!” While Rosiella (2010) recognized that it was “not easy to LIKE these characters…the book speaks to some of the less evolved traits of human nature and some predatory instincts. ANGEL DUST (2011) described the cast of characters as an
“unlikeable bunch” who the reader still cares about and within whom you “recognize your own worst moments…” Marialyce (2011) sums this sentiment up, describing these characters as “flawed but special in so many ways”.

While most posters based their assessment of the book on their ability to like or dislike characters based on their identification with them, a number of readers also described the importance of experiencing lives outside of their own in reading and that identification is not necessary for their enjoyment of a novel. Bethy47 (2010) described this, stating “I believe that sometimes we look for ourselves in books and when we do not find common feelings or traits it is difficult to identify. That is how I felt about both books. However, it is really important to me to reach out beyond my comfort zone and that is what Jonathan Franzen does, he opens the door to people totally unlike myself.” Klk0808(2010) mirrors this sentiment stating that “one of the most captivating things about reading is how OTHER people think”(emphasis original). It is recognized also that “you do not have to ‘like’ the characters to enjoy a book. And you absolutely do not have to identify with every character or every situation. That is why we read…to learn about people that are different than us…places that we may never go. S-t-r-e-t-c-h your mind a little”. (spindrift8, 2010). The exploration of the impetus of others is a significant part of reading for many. As ZebraMC (2010) describes “my favorite novels are always those which explore the motivations of the characters and where that leads.”

**Emotional Connections**

Of those critical of Franzen’s novel, many identify his lack of appreciation for women and women’s issues as a central flaw. Many posters have found that Franzen dismisses women’s issues in his characterization of the women in this novel. Sweetpotato79 says “I have a problem
with Franzen’s condescending attitude towards motherhood. Particularly mothers who chose to stay home… I wonder if some women who have chosen this path would have a thing or two to tell him about the joy which can come from staying home with your children, or at least provide him with proof that not all career moms end up bitter, angry and depressed. Pattyaks (2010) reiterates this sentiment noting “I couldn’t help thinking that Franzen is not a father, that he’s not a woman and has no real sense of living with children.” Posters identify their connections with Patty based on common issues of being mothers (tiffanycollver, 2010, jules20000, 2012), of guilt and frustration and the freedom to be happy (kind2man, 2010) and the pattern of life that is pre-cut for women (SisterMonica, 2010).

Reader’s comments speak to many issues that do not address disability specifically, but which are also identified in discussion and recognition of disability and translate into similar discussions that are prevalent around disability representation. Postings such as those provide by sweetpotato79 and pattyaks, identify this issue of representation and misrepresentation of women and particularly mothers by the author. Outside of his own experience, the author is examined based on his ability to accurately represent or understand this group. Franzen is cited as dismissive of women’s choices to be mothers and the assumed dissatisfaction that he equates with this life choice, based on his lack of familiarity with this experience. The same queries that are addressed in relation to the role of women could be put forth around an author who does not identify as a person with a mental health or addiction issue presenting information about individuals who are experiencing these disabilities and the characterization of individuals with these traits.

On the other hand, Franzen is praised for his ability to identify some of the challenges that women face as mothers which are frequently left out of public discussion. The unrecognized
guilt and frustration that is identified in the character of Patty, for example, has brought forth conversation of this seemingly domestic issue in the wider consciousness and given the opportunity for this topic to be addressed in wider public dialogue.

**Discussion of Disability and Other Social Issues**

Readers discussed the blatant social issues brought forth in this novel of overpopulation and environmental damage. Its direct attack on these issues was criticized by readers. Aardvark1978 (2011) says that “I soon came to realize that this was not a novel but rather a political rant disguised as one.” Rhondafye (2012) agrees noting that “… I’m so sick of the political opinions that go on for pages!” Recalling Mazzocco and Green’s identification that narrative is more persuasive than rhetorical argument based on the role of empathy, the overt presence of these political issues provides a convenient comparison point for the discussion of disability through characterization as opposed to directly discussing these issues. The discussion of disability and specifically alcoholism and depression are addressed extensively by readers in their posts. Jen (2011) has identified that most of the female characters in this book “suffered from (or were suspected of suffering from) depression” the discussion of depression centres on the characters of Patty, Connie (Patty’s son Joey’s girlfriend), and Patty’s college roommate Eliza.

Many of the posts about Patty and her disabilities centre on themes of blame, mistrust, and lack of personal responsibility. She is described as “self-absorbed, “pathetic” and “frustrating” (azolin, 2010), full of “self-pity and self-indulgence” (Baragan, 2010), “emotionally weak” (hazebis, 2010) and she is blamed for her own poor choices (bigjohn19, 2010). These ableist perspectives, however, are also challenged by readers who recognize Patty’s humanity over her disabilities and resulting negative personal traits, and her commonality with their own
experiences. STEVE526 (2010) identifies that Patty’s depression is “centred on her unhappiness in finding out there is no such thing as a perfect mom”. Jacieb (2010) identifies Walter’s treatment of Patty’s depression and drinking as cruel. Hehe24 (2010) sees reading Patty’s experience as “almost like reading my own diary” while Istash06 (2010) advises that “It takes someone who has experience with depression, self-doubt and self-destruction to fully appreciate the richness of these highly relatable characters.” Diana Ripley (2010) sees that “These people are a little crazy, but probably typical.”

**She’s Come Undone – Wally Lamb**

This novel was featured in the first years of the OBC and includes 13 characters with disabilities. The story tells of the life of Delores Price and her journey to adulthood in suburban New England. After her father leaves when she is a child, Delores isolates herself and finds comfort through food and television. Through the duration of the novel, she is raped by her neighbor, becomes obese, her mother dies and she is ostracized both in her neighbourhood and later at college. Delores is eventually institutionalized after attempting suicide. Following her life through significant weight loss, mental health treatment, group homes and her journey to greater independence and self-confidence Delores reflects on her youth.

The following characters were identified as people with disabilities in this novel:

<table>
<thead>
<tr>
<th>Character</th>
<th>Description</th>
<th>Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Delores</td>
<td>main character - becomes very overweight as a teen and depressed</td>
<td>Weight, suicidal, depression</td>
</tr>
<tr>
<td>2 Ma</td>
<td>Delores’ mother - becomes depressed after losing baby and is institutionalized</td>
<td>Depression</td>
</tr>
<tr>
<td>3 Gary</td>
<td>Delores’ school guidance counselor’s partner who dies</td>
<td>AIDS</td>
</tr>
<tr>
<td>4</td>
<td>Dottie</td>
<td>cleaner of residence hall – overweight, sexual relationship with Delores</td>
</tr>
<tr>
<td>---</td>
<td>---</td>
<td>---</td>
</tr>
<tr>
<td>5</td>
<td>Roberta</td>
<td>tattoo artist neighbor of Delores, becomes good friend and eventually roommate</td>
</tr>
<tr>
<td>6</td>
<td>Mr. Larose</td>
<td>minor – principal</td>
</tr>
<tr>
<td>7</td>
<td>Mrs. Ropiek</td>
<td>Minor character – patient at Gracewood</td>
</tr>
<tr>
<td>8</td>
<td>Old Lady DePolito</td>
<td>Minor character – patient at Gracewood</td>
</tr>
<tr>
<td>9</td>
<td>Manny “the masturbator”</td>
<td>Minor character – patient at Gracewood</td>
</tr>
<tr>
<td>10</td>
<td>Lillian</td>
<td>Minor character – patient at Gracewood</td>
</tr>
<tr>
<td>11</td>
<td>Anita</td>
<td>Minor character – lived in group home with Delores</td>
</tr>
<tr>
<td>12</td>
<td>Fred Burden</td>
<td>Minor character – lived in group home with Delores</td>
</tr>
<tr>
<td>13</td>
<td>Mrs. Shea</td>
<td>Minor character – lived in group home with Delores</td>
</tr>
</tbody>
</table>

**Reading Questions**

Thirteen reading questions were provided for this novel which are available to direct readers in their interpretation and discussion of the novel. Delores’ psychiatric experiences are not specifically addressed in the questions, but are instead touched upon in reference to the symbolism of water in “both Dolores' breaking points and eventual recovery”. Other questions ask readers to consider if “Delores is misguided or is she a victim of her circumstances?” to
discuss societal definitions of beauty and social assimilation based on body image, as well as the ability of a male author to capture “the female experience”. Readers are also asked to consider the author’s definition of "good literature" as writing that explores the imperfections of the world and "kicks readers in their pants, shakes them out of their complacency about a world that needs fixing."

No specific discussion is available on the OBC website which addresses any of these questions; however, the issues brought forth by the reading questions are discussed in other forums as is demonstrated below. Readers specifically respond to Delores’ status as a victim, and her ability to both come undone, and to rebuild herself. Postings also readily discussed the ability of the male writer to capture what is noted as the female experience.

Reader Comments
Challenge to Traditional Literary Authority

Upholding my contentions about mainstream reading and discussion, readers posted for the most part on their emotional connections with novel. It is important to acknowledge that though not in the same “literary” category as the other two novels in this section this is also generally considered a well-written book. As in the case of Freedom, some readers looked to traditional literary tools and authors in their critiques of the novel. Using classic literature as a comparison point, A Customer 8a, (1997) for example, states “After reading this book, I am reluctant to give my valuable and rare reading time to new authors. I’ll stick to Steinbeck”. On the other hand Bill MacDonald (2000) says “I never thought that I would ever read an Oprah’s Book Club entry” but having read the novels has changed his position noting “I can absolutely guarantee I will read his next” referring to the author, Wally Lamb. Stephanie Shaughnessey (2000) admits that “I’ve been reluctant to read anything in Oprah’s book club in the past (mainly because of the high and
sometimes “corny” drama that are presented in those books” but advises that she was
“enthralled” by this novel upon reading it. Justifying their enjoyment of the novel, seemingly
embarked upon as a guilty pleasure, many posters used their experience as readers and their
credentials to validate their endorsement of the novel in spite of its presence in the club. Stefanie
W (2009) notes “It was one of the best books I have ever read and I’ve read hundreds of books
over my years.” Amazon Queen (2007) relates her position as a psychology grad student as
giving weight to her recommendation of the book. Lamb is pronounced as a master storyteller
(Cynthia K. Robertson, 2005) and his writing captivating to the reader from the start (elizh77,
2002). This book is described by less credentialed, or perhaps more modest readers, as some of
the “most powerful” (Antoinette Klein, 2010), and “most fulfilling” (News Junkie, 2012) writing
readers have ever experienced. Lamb is described as “a genius” (Brandi Denson, 2007) who
loves his characters (Guillermo Amaro & Ninoska Titinger, 2006). Generally however, readers
have simply described their like or dislike for the novel and its main character Delores based on
their connections to her.

Connections to the Novel

Description of Why Loved/Hated the Book

In a similar way that readers described the character of Patty in Freedom, the protagonist,
Delores, in this novel provoked strong emotional reactions in readers who loved or hated her, or
struggled between fondness and loathing for her. More readers appeared to connect with Delores
than Patty, and a connection with this character is the most prominent feature of sampled
discussion for this novel. For many, the connectedness that readers felt with Delores was a
surprising reaction. Poster Stutty (2002) states “If someone would have told me six weeks ago
that by now I would have read and been completely absorbed by the tale of a 257 pound girl
named Delores I would have told them they were out of their mind”. The book is described by those who enjoyed it as “a powerful epic”, (Compulsive Reader, 2001) as “captivating” (A Customer 8b, 1997) as a “wonderful tale of triumph over defeat” (Heather, 2006) and “my favorite book ever” (A.Melrose, 2005). Tina Pangourelas (2000) describes that “…no book has ever stirred up so much emotion. It will make you laugh, cry scream, relate and always always entertain”. Delores is a character who the reader “quickly bonds with …and feels driven to stick with through every increasingly tragic event of her painful life.” (A Customer 8c, 1997) and as one who “comes alive in an amazing way” (neeterskeeter27, 2000).

For those who admire Delores, the most commonly identified reasons for their admiration of her is their ability to connect and relate with her both through her experiences and in the description of her as a flawed individual. Kathy (2005) notes that “…every young woman can relate to Delores, whether the issues are the same or not. One does not have to be overweight to feel Dolores’ pain of being alone; everyone has felt that at least once in their lives”. While the book is noted repeatedly to be depressing, it is also recognized to “touch the reader deeply (R. Zeynep Basak, 2005). Mommy of Two (2006) describes that she “could actually feel her happiness and her misery”. Remarking on her familiarity Avid Reader (2007), observes “Haven’t we all some friend, acquaintance, or even family member like this (I know I am like this myself more often than I’d like to admit!). Similarly, Claire (2007) mentions that “There are so many parts of the main character that everyone (especially women) can relate to”. Wendy Perez (2008) says “…Anyone who reads this book will related [sic] to SOMETHING (emphasis original) this woman has gone through…” such as Tracey (2006) who identifies the occurrences in the book as “things that happen every day to people.” Feeling acquainted with the character, Delores is recognized as “the girl next door to me growing up” (In Quest of a Good Book, 2001), her
vulnerability and loneliness as a universal. Diane Davis (2001) recognizes that though “Delores may be unique and larger-than-life…there’s something of her in anyone who’s ever felt unsure of themselves…” Kerrio (2005) says “I saw myself in Delores, my mother in her grandma and my own mistakes in hers. She mirrors everyone in some way and I loved the way that she weaseled her way into my life.” One reader describes “…i [sic] suddenly began to see my own personality seeping through the pages and transfixing in my heart” (Sandra, 2000).

Described as “a ‘good guy’, a heinous monster, a hero, mentally ill, incredibly intelligent, ect” (Brandi Denson, 2007), her well-rounded portrayal is frequently pointed out demonstrating readers’ capacity to both like and dislike her. One reader describes “She is caustic, lazy, whining, and self-pitying but all the more likable because she learns to get over herself and accept what she has earned as her happiness. (A Customer 8d, 1998). Melissa (2000) acknowledges “Finally, a character who is human, who is so perfectly flawed…She is so real, it is unbelievable.”

While so many readers felt connected to Delores because of her flaws, others remarked on the difficulties they had in forming a static opinion about her. While many readers described enjoying the book overall; several posts also identified having mixed feelings based on the disheartening or depressing subject matter (In Quest of a Good Book, 2001), the identified complexity of human experience (One Literature Nut, 2011), and the trauma that can be a part of reality (Irini, 2007). Green (2000) says “It made me laugh, cry and sometimes want to kill the main characters…It is very emotionally triggering, yet inspirational.” Stephen S. Mills (2001) echoes this stating “…one moment I would really like the book and the next I would want to throw it against the wall. It had that much power over me.”
In the same way that readers were inspired and connected to Delores, others posted their dislike for the book and this character. Struggling to identify with the protagonist A Customer 8a, (1997) asks “Is everyone Delores Price meets looking to seduce or rape this fat, socially inept girl?”. Describing the ongoing series of events of the book as unbelievable, A Customer 8f, (1999) describes having “no empathy for this idiot woman who could never be optimistic or look at the bright side of life”. Finding themselves unable to connect with Delores, readers found the “victim mentality…draining and disturbing” (Michael Erisman, 2002). A Customer 8g, (2000) remarks “…this is one of the most maudlin, self-pitying, annoying characters that has ever been created in the history of literature. I just wanted to reach into the pages and poke Delores in the eye.”

**Emotional Connections**

Looking again at the role of women’s issues bridging private and the public spheres through the use of fiction and a concentration on emotion, Lamb, as opposed to Franzen, is discussed at great length in his ability to capture female experiences as a male writer. A significant number of posters indicated their surprise and even disbelief that this writer was a man. A Customer 8o (2001) states “I was POSITIVE (emphasis original) that “Wally” was a woman, despite the obviously masculine name. I mean how could any man so perfectly personify that uniquely feminine struggle with beauty, weight and acceptance?” The disbelief of readers about the novel which is written from a female perspective is most notable, based on the perceived ability of the author to capture women’s emotions and women’s experiences. C.C. Johnson (2007) describes that “Mr. Lamb has succeeded so perfectly in depicting the tone and touching down on the emotional life that moves within a member of the opposite sex.” “Every character is
unbelievably real and incredibly painful to read about” and the author is able to “dig deep into a
girl’s transition into womanhood” (bak msoa, 2005).

Many readers describe the feeling and experiences of Delores in the novel reflecting their own
life situations. Tori (2002) describes that “Every girl is faced with issues that Delores Price
struggles with [on] a daily basis…” Dawnees Deals says “he really knew us, knew our feelings
of desperation, our problems with men, our fears and insecurities.” Amyob1 (2000) could relate
to the characters “sense of false-security, self-deprecation, and fear of abandonment.”
cementarygirl (2000) recalls “this book reminds me much [sic] of myself and how hard it is to go
through life being an overweight teenager.” She continues “…I could feel her pain, her
obsessions, her anger, and I felt like I was there, I WAS HER.” Eve Paludan (2011) agrees,
describing the connections of the book to her own life “….as the life of a young woman is
propelled by tragedy, travesty, failure after failure in relationships, and an undeniable connection
of me as a reader to the protagonist, a woman who battles weight issues (as I do) and blatant
victimization by acquaintances. The narrative was so true to life…”.

Other readers however who shared some of Delores experiences in their own lives disagreed
with the reality of her presentation bringing forth important questions about representation. T.
Newton (2013), for example, notes that “most people I know who have weight issues including
myself have never eaten the way “fat Delores” is described. If I subscribe to this way of thinking,
everyone who is overweight maintains a steady diet of an abundance of cokes, doughnuts, chips,
candy, cake and nothing else.” Anonymous (2005) supports this noting “the weight issues being
resolved is very PAT (emphasis original) and unrealistic – as someone who’s suffered from food
issues (not to her extreme though) most of my life, I don’t believe you can overcome it the way
she did.”

Disability and Other Social Issues

Delores has been identified as a character with a disability for this research based on both her issues with weight and the fact that she is identified as a person with a mental health disability. While some readers dismissed the portrayal of disability or found it offensive and others saw it as positive, the end result is that the emotion brought forth through this portrayal, positive or negative has demonstrated the ability of characterization to bring the impetus for change and to uphold meaning in readers lives beyond the pages of the book. Stutty (2002) identifies the “astonishingly important lessons here…for all of us” outlining the “possibly healing affects we can have as friend and the potentially destructive power we have as a family.” Erin (2006) says that “Getting to know the character in the book is so easy that you can’t help but to change your opinion and grow through her experiences”. Compulsive Reader (2001) describes the emotional ride of the novel as creating a connection with a life different than her own which left her feeling “…a certain kinship, an almost sisterly devotion towards Delores.” In Quest of a Good Book (2001) remarks that “something important is being said about never giving up on yourself and finding peace and meaning in your life”. Diane Davis (2001) feels this novel assures us “that there’s hope for us all”. Mark Latta (2001) notes that Delores experiences changed him and that “through Dolores’ “undoing” and “redoing” you are redone a little too…” Describing the influence that this fictitious portrayal has had in her own life JoeKnee (2000) posts “…the strength she [Delores] demonstrated helped me find strength in myself that I never knew existed”. In more concrete terms Tori (2002) describes the novel as very inspiring. She notes “Delores makes you feel like there is hope in the world. She gives you strength in the darkness.” Kerri Rickard (2000) speaking specifically to the treatment of others says “This book made me
look, really look at myself, my parents, and my weight….So if any of u [sic] out there have kids…please don’t let them make fun of people that are different, it really would save a lot of us good years and money on therapy…”.

The Heart is a Lonely Hunter – Carson McCullers
Originally published in 1940 and widely recognized for its literary merit, this novel was chosen for the OBC in 2004. This classic novel, by Carson McCullers tells the story of John Singer, who is deaf and non-verbal but becomes the confidant for various nonconformists in a Georgia mill town during the 1930s. When Singer’s long-time friend and companion, Spiros Antanopolous, is institutionalized John rents a room in the Kelly house where he spends hours with three characters who each tell him of their dreams and despairs. The young Mick Kelly is a teenage girl coming to terms with her dreams as she approaches adulthood, Dr. Copeland, an African American physician seeking greater equality in the South, and Jake Blount, a wanderer who deals with alcoholism and is a strong believer in Marx. This book explores the loneliness and isolation of each of these characters through their visits to John Singer where they share their troubles, ideas and inspirations.

While the role of protagonist is disputed between Mick Kelly and John Singer, Singer plays a very central role throughout the book and is the figure that connects all of the other characters. John’s contented life is disrupted when Antonopolous’ uncle sends him to an institution. Now isolated from the rest of the world, John “listens” to everyone’s problems.

Table 11: Characters – The Heart is a Lonely Hunter

<table>
<thead>
<tr>
<th>Character</th>
<th>Description</th>
<th>Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>John Singer</td>
<td>best friend of Spiros, deaf, non-verbal, reads lips</td>
</tr>
</tbody>
</table>
Noted as a literary classic, an abundance of resources are available for book club readers on this novel from the OBC Website. Resources linked to this novel include: Carson’s Home Town, Celebrities on *The Heart is a Lonely Hunter*, Character Journey’s, Genre Southern Gothic, Guide to *The Heart is a Lonely Hunter*, Julia Roberts review of the novel, Katie Couric’s Bookshelf, Life of Carson McCullers, McCullers’ Literary Crowd, Oprah’s Email, Life and Death, Quiz, Reader Comments, Reader Reaction, Reading Questions, Works by Carson McCullers, Your Questions Answered.

**Reading Questions**

There are a total of thirty reading questions available for readers of this novel, ten for each of the three sections of the book. Of those which address disability specifically or the characters with disabilities questions ask about the following issues: the friendship of Singer and Antonopolous, Singer’s devotion to his friend, and their connection outside of both being “deaf-mutes”, which

<table>
<thead>
<tr>
<th>No.</th>
<th>Character</th>
<th>Description</th>
<th>Disability/Special Needs</th>
</tr>
</thead>
<tbody>
<tr>
<td>2</td>
<td>Spiros Antanopolis</td>
<td>John's best friend (partner?) and roommate who is institutionalized by his uncle</td>
<td>Intellectual disability and deaf/mute,</td>
</tr>
<tr>
<td>3</td>
<td>Willie Copeland</td>
<td>Brother of Portia, son of Dr. Copeland,</td>
<td>Described as &quot;simple&quot;</td>
</tr>
<tr>
<td>4</td>
<td>Mr. Kelly</td>
<td>father of Mick, can't work in construction after workplace injury</td>
<td>Unspecified</td>
</tr>
<tr>
<td>5</td>
<td>Horace</td>
<td>boy who John translates for to Dr. Copeland</td>
<td>Deaf, cannot speak</td>
</tr>
<tr>
<td>6</td>
<td>Group of Deaf Men</td>
<td>John meets a group of men he can sign with in a bar but chooses not to spend time with them</td>
<td>Deaf</td>
</tr>
</tbody>
</table>
character readers most readily identify with, the symbolism of Singer as representative of God, and the significance of Singer’s death.

**Reader Discussion**

**Challenge to Traditional Literary Authority**

While all three novels in this section are generally considered well written, the approach to this book, widely-considered a classic, centres to a significantly greater degree on merits of traditional literary value. Considering that McCuller’s novel is listed within Bloom’s canon, on the Time Top 100 Novels List, and on the Modern Library Board and Reader’s Top 100 Lists, this work is accompanied by its esteemed reputation. Blurbs that were included on my copy of the novel include endorsements from Tennessee Williams, Gore Vidal and The New York Times. McCuller’s is named a “master story-teller” (Pritchett), her work compared to Melville, and said to contain intensity and nobility of spirit (Williams). The author’s “genius for prose” (Vidal) is recognized, allowing her to reflect the “lonely heart with a golden hand” (NY Times).

While the discussion surrounding the previous two novels centres a great deal on the emotions that readers felt towards the characters, the conversation about McCuller’s definitive novel, contains far less dialogue about emotional reactions and personal relations to the story and instead centres around the ability of the young writer to capture the human condition, to produce such skillful writing and to identify a variety of social issues in such a realistic fashion. Tabithajab (2007) encourages others to “read the book for it’s [sic] exquisite prose…for it’s extraordinary character development”. It is cited as “…a superb example of technical mastery of the writer’s craft” (Winston Smith, 2003). Noting this achievement in writing, McCullers’ writing is compared to that of Faulkner, O’Connor, Capote, Welty, Harper Lee, Dostoevsky,
The characters are classified with those of Flaubert (Beej Connor, 2002) and the stories to works of Steinbeck, Hawthorne and D.H. Lawrence (maryd51, 2004). Discussed in the tradition of Southern Gothic Literature (timberwolf1, 2004) the novel is demonstrated to be widely-accepted as an illustration of exemplary writing, “American literature at its best!” (akhjd, 2005).”

This highly valued piece of literature is accompanied in readers’ discussions with the same trepidation that accompanies confessing to reading Oprah books in each other case. David (2006) ensuring his place as a serious reader and not simply a cultural drone, identifies “I picked ‘The Heart is a Lonely Hunter’ up before Oprah Winfrey mentioned the book” and continues to describe that he read it based on the recommendation of Charles Bukowski. Another anonymous poster remarks, “I’m usually pretty suspicious of Oprah’s books.” (A Customer, 2004). While some readers choose to distance themselves from the Oprah connection, others advise that this should not keep readers away. R.A. Rubin (2005) cautions “don’t be put off by Oprah’s middlebrow fans, Carson McCullers was a genius.”

While some were turned off by their middlebrow interpretation of Oprah’s recommendation, others were surprised to find their enjoyment of a novel included with the classics and demonstrate the clubs ability to include a wider readership. Theresa W. (2004) says “…I realize I’m not much of a “classic novels” reader…however, I’m glad I picked it up…and finished it.” Brukman (2000) identifies “I only read this book because it was on a ‘Top 100’ list a while back. Much to my surprise, it was one of the best books I have ever read.”
The need to uphold this piece of work as a “gem” is challenged by readers who freely expressed their dislike of this highly revered classic. In a refreshingly honest way which challenges the sanctity of what has been granted significant social capital in the past, new publics bring forth varied opinions on the role of this acclaimed novel. MoonStonePearl (2011) says “I could not finish this story as for me, it just got boring”. Robert L. Snyder (2004) refutes the substantial praise for this book with the comment “Literary masterpiece? I don’t know about that…”. Noting the challenge provided by the book alone, Joan C. Franks (2005) notes “For me, reading this book is a literary accomplishment. I can check off another classic from my list of books to read. However, it was not a book that I found enjoyable.”

While readers felt free to provide their presumably honest opinions of the novel, frequently participants who endorsed it were quick to condemn those who did not enjoy the novel as having not understood it and of being unworthy of such material. A Customer (2004) observes “I think the one star reviews are from people who didn’t really understand what the novel was about. Maybe they should stick to Dean Koontz.”. Kate (2000) says “If you really think that it deserves 0 stars then you must not have understood it.” and Elizabeth Franks (2004) asks “How anyone with a brain and a heart could possibly find it boring is beyond me.” Denouncing those who don’t “get it” A Customer (1999) challenges “If you are BORED [emphasis original] by it don’t worry…there’s plenty of ‘entertainers’ eager to keep you from learning anything about yourselves or the world by refilling your trough with mindless excitement.”

Connections to the Novel
Description of Why Loved/Hated the Book
While there was both positive and negative discussion of this novel on the internet, many readers were very impressed with the novel’s ability to stick with them beyond the time they were
reading it. The book is described as a “novel that will stay with you forever.” (A Customer 8p, 2004). Beej Connor (2002) says “I just love this book. It’s one of those stories that replays in your head all through the day… such incredible insight into human nature.” The reader concludes that “…this will probably rank with the all time [sic] great reads of my life.” Ace (2004) comparably states “I love this book! It held me spellbound – the characters had life – flesh and blood, hands reaching out and picking at my sleeve to get attention, proud eyes looking at self-deprecating failures, wise eyes looking into mine.” The reader continues “I was part of that community, their joys were mine – their losses were mourned.” This “insightful look into human nature and the struggle with loneliness” (A Customer 8j, 1999) is noted to provide “an outstanding and realistic examination of the human condition.” (Yaakov (James) Mosher, 2007).

Readers praised the author, 23 at the time that she wrote the novel, for being able to truly capture the emotions and struggles that they identify as part of human life. Linda Linguvic (2002) admires the novel as a “study in what it means to be a human being…” It is described as “a complex slice of life…bringing us a little bit of hope to diminish our own sadness (A.T.A. Oliveira, 2005). The book is considered to be very real and very moving (Robert L. Snyder, 2004). dances with cats (2006) describes the novel as bringing us “…deep into the realities, the thoughts, the complexities of the human soul. The people are good, bad, ugly beautiful, selfish, depressed, found or lost.” And the book is said to have a “profound understanding of humanity.” (BJ Fraser, 2007).

While many posters identified the aspects of beauty within the novel, others found that it was a difficult journey to get through based on the characterization of the era, geographical location and all that came with the Deep South during the depression and the portrayals of the characters themselves. Readers such as Joan C. Frank (2004) found it emotionally difficult to read,
describing the people and places in the novel as “dirty, lowly, depressed, depressing and
teetering on the verge of hopelessness.” The novel is described as “difficult to read, dipping as it
does into feelings of profound sadness, grief and loneliness.” (jonnygil, 2001). This “tragic”
fiction is observed to address serious issues of the heart and society (V. Marshall, 2004,
rhymeswithoragne, 2004). Readers describe a teeter-totter of feeling and movement between
loving and hating the book based on their emotional reaction and the sadness that it encapsulates.
Katie (2004) identifies it as “the greatest yet saddest book I have ever read.” While Adele “K”.
(2012) remarks that “This book broke my heart and healed it at the same time.” Reflecting this
sentiment, Matthew Krichman (2003) says the novel is both “a well-written book and book you
may be glad to put behind you.” Highlighting this back and forth, A Customer 8k, (1999) reasons
that the book was “truly distressing, yet eye-opening as well. It showed me how difficult the
lives of outcasts can be.” Luguel (2004) describes that “…reading it one experiences real
emotions, particularly feelings of alienation from the rest of humanity.” Lynette Sewell (2004)
agrees in her statement “Light reading, whimsical – no! Realistic, introspective, entertaining, a
wonderful enlightenment into the soul – yes.” Calico30 (2002) on the other hand, “…loved this
book for its brutality” much like AnnieM (2004) who found the “sadness, desparation [sic] and
yearning” of the characters compelling. Definitively capturing this sentiment, Shine Shine Shine
(2006) while calling the book “shatteringly good” concludes “It’s a book that I should have read,
and I’m glad I did, and I’m glad it was written, but now I want to eat strawberry ice cream…and
kiss my kids.”

**Emotional Connections**

The emotional connection that readers’ identify with this novel surround the ability of the writer
to connect with the human condition and for readers to identify with the emotions, isolation and
marginalization captured through the central characters of the book. Posters speak frequently of the human emotion exuding from the characters and the author’s description of emotions that “we always feel, but can never put into words.” (buffalo25, 2003) through “…the lives of these rich and earthy characters” (bookloverintexas, 2006). Anne Wilfong (2002) describes that she was “surprised by how much emotion this 23 year old writer pulled out of me.” and the author’s ability to “have such an understanding of human nature…” Many readers have commented on the connectedness and the reminders of connectedness that the story provided to them. As A Customer 8l, (2003) notes “These characters are us. We are these characters.” Michelle Scott (2012) says the book “explores the desperation that we all experience when we feel that we are alone in the world “ and that she was “profoundly moved by the lives of each character and the loneliness and hopelessness that they all felt.” This presentation is described to emphasize readers “understanding and compassion for the loneliness in all of us.” (gammyraye, 2013), “the loneliness we all experience” (Kirby, 2002). Writer, poet & artist (2004) summarizes the widespread connection readers felt with characters saying “McCullers has an insight into person [sic] psychology that allows her to create great characters that everyone can relate to.” A Customer 8m, 1999, advises that “…the reader cannot but help to become emotionally involved in the lives of the characters…a journey of the depths of the human soul.” Readers describe the authenticity of characters which rings true to their own lives because they are not “sappy or gratuitous” (Aimee, 2002), and because they are “tenderly related to us, with all of their egos, inadequacies, (perceived and otherwise) are laid bare to our eyes.” (Mathew M. Howell, 2012). R.A. Rubin (2005) supports these observations noting that “You will feel that if you met these characters in real life, you would know everything about them.” And moonglow22 (2001) notes
that “All of these characters are fully drawn, and each one of them makes you care deeply for him/her, even though they are very hard to like.”

Disability and Social Issues

The idea of difference, exploring and understanding difference and resulting isolation is clearly laid out by posters in their discussions about this novel. As a significant issue in the debate of the role of disability in contemporary society, the understanding of difference and disability within this novel provides an insightful look into readers’ interpretations and understandings of variance.

The discussion demonstrates a connection with humanity over disability. Janet Mego (2002) states that “Loneliness, yearning for acceptance and those qualities which make one “different” from the “norm” are the focus of the novel. A Customer 9j (2001) tells readers “Most likely you will see yourself or people in your life portrayed in the novel. That is the novel’s strength. The characters may be freaks but they are hauntingly similar to yourself.” Michael A. Newman (2002) agrees that “It is a fascinating human interest story which helps us understand that even though a person is deaf, they are still a person with the same hopes and aspirations as anyone else.” Mr Wobble (2008) describes “this is an extraordinary work in the way it is the only novel written that truly catches the deaf experience and feelings.” Others saw the characters as ordinary. A.T.A. Oliveira (2005) says “…this novel X-rays ordinary lives and exposes them, bringing us a little bit of hope to diminish our own sadness.” Lightning (2004) reveals “never before had I read a novel that attempted to put into words what it might be like to be one of these lonely outcasts.” A Customer 8l (2003) identifies with the humanity of John Singer, rather than his disability saying “I am neither deaf nor mute, and I am exactly like John Singer.” Even Ryan
C Holiday (2012) agrees “The main character is a deaf mute of all things, and it still manages to be painfully relatable.” Once again focusing on humanity over disability Anne Rice (2004) describes the “tender portrait of the ordinary people of and ordinary town.” BJ Fraser (2007) highlights “These people all seem real because their hopes and desires are those hopes and desires we all have. Their dreams aren’t altogether different than those each of us seek….even if that someone is a deaf-mute who can only nod along.” Djbrkns (2004) sees that “we’re all individuals in the same boat.” As Beej Connor (2002) remarks “… They were all simply, and beautifully, human.”

Struck by the humanity of the characters so different, yet so like themselves, readers found the discussion of this difference and the resulting social isolation very sad. While it was not his disability specifically that is identified as making Singer such a sad character, his isolation and disconnectedness based around that disability create this image. Many readers critically reflected on the other characters who they described selfishly using Singer to fulfill their own needs. John is described as being used to “project the qualities they desired in a friend on to (Ee Lin Kuan, 2002), as a “sounding board” and “only a mirror” (Beej Connor, 2002) . MoonStonePearl (2011) says “the deaf man is the catalyst in which they all eventually go to to [sic] dump their stuff on but no one ever takes the time to listen to him.” Diane Schirf (2004) agrees noting “They (Mick, Dr. Copeland, Jake Blount and Biff Brannon) never step out of themselves to discover that Singer listens, but he doesn’t understand nor do they realize that he, too, is lonely and isolated – or why.” Randy Keehn (2003) also remarks on the discounting of Mr. Singer in these relationships noting “While they unload their care, they assume that their listener has no cares of his own.” Sarah Meyers (2001) notes “they worshiped him, but in doing so, they denied him their friendship.” These comments bring forth discussion of real disability issues and look at
Singer as an individual with a disability and also a product of society. Jonnygil (2001) asks an important though direct question “Is the deaf-mute a Christ figure, full of compassion? Or is he essentially a simpleton, beloved because, like the family dog, he can’t talk back.”

The hope for and possibility of change is discussed at length in readers’ posts in relation to the social issues raised in the novel. A Customer 8n, (1999) that “Some things that I just take for granted in my everyday life are expressed here. Just reading this book gave me a real look at life.” Many readers have remarked on the change that has taken place in them based on the reading of this novel and reflections on their own lives. Patty H. Sterling (2012) describes the book as very touching and that it “reminds me that we all have our own reality when it’s [sic] comes to our perceptions of those in our lives.” While Anthony Mooney (2007) hopes that “each person who reads it will come away pondering the state of their own ‘inside rooms,’ and take care to tend and spend time in that cherished space”. Baily Walsh (2004) specifically identifies the potential for social change through this kind of reading remarking that “Carson McCullers captures a beauty in sadness that leaches your soul and won’t let go, but at the same time injects in you a spiritual growth.” Laura Campbell (2000) notes the book “forced me to think deeply.”

This book is identified by readers as bringing forth significant social issues with extensive focus on racism, social class and isolation which readers identify they have learned from. The book is described as one that “makes you think about the prejudices we have against others without being preachy.” Cmerrell (2002) describes each character who specifically “talks” to Singer as representative of a different social problem, seeing that “The book deals subtly with several different social issues – racial strife in the South, a teenage girl coming to terms with her emerging sexuality, labour unrest, and the effect of the Great Depression on the middle class.” Customer – P (2004) identifies “thought provoking issues” in the novel including “racism, the
way the government is run/communism, loneliness [sic], and what it is like to be deaf in a world that doesn’t seem tolerant of difference. Tabithajab (2007) agrees, noting “The tragedy of the misfit in a callous society is mirrored in each of the characters’ lives.” Showing reader’s identification of and enthusiasm about critical social issues rhymeswithorange (2004) describes how the author has “spread a political and social commentary throughout this book. Two of the characters are devoted followers of Karl Marx and his anti-capitalist ideals of how power and wealth should be spread throughout the masses.” Robert G Yokoyama (2004) observes that he learned from this description, identifying that “I knew nothing about Karl Marx’s ideas, so I though this part of the novel was memorable”. Noting the unfamiliar relationship between friends with disabilities, the poster continues “the relationship and love between these two dear friends (Singer and Antonopolous) is one of the best things about this novel.” Ace (2004) similarly admires this friendship saying “I smiled at the way the two hearing-impaired friends shared their mornings, and wept over their loss.”
Discussion
Each of these novels contains several characterizations of disability. The discussion surrounding each of these books exemplifies that through widespread readership, new interpretations and insights are brought to the reading of novels and the presentation of disability. This is especially evident in reader’s frequent dismissal of the standards of traditional literary authority, their described emotional connections with characters and their recognition of social issues within the books which permeate lives beyond the novel. Casual on-line chat about stories shows readers’ inclination to challenge presentations, to connect with characters with disabilities and to identify social issues through fictitious portrayals. Mental health, addictions, weight, auditory and speech disabilities have been represented to a widespread reading public as is demonstrated through reader comments about these three novels. While the stories each are identified as sad, depressing and at sometimes difficult to take, it is not necessarily the disability in these novels which has created this sense of despair, but the surrounding circumstances. Challenging standard literary interpretations, the novels using a typically middlebrow approach, allows for new and innovative interpretations of the meaning and relevance of the materials found within the novel and connections between characters and readers to form. The novels are approached in a welcoming atmosphere where a variety of analyses and perspectives are met and challenged. This diversity of voices in the interpretation and discussion of book club novels brings forth the opportunity for new areas of discussion such as the role of disability in each of these books. While many uphold more traditional beliefs, the spectrum of opinions and approaches to the novels appears as varied as those who are able to post online.

Franzen’s portrayal of Patty is met with a diversity of opinions. While elitism certainly still exists in this context, the comments demonstrate a liberty to approach what is socially valued in a way that feels comfortable to readers whether that be through an identification with characters,
a lauding of the book based on its critical acclamation, an appreciation for the language and
description used, as a social commentary, or as a boring, over-descriptive waste of time.

Similarly, in the reading of John Singer, reading is approached through an alternate lens. While
the reading of a novel such as this is upheld in the literary establishment, the bringing forth of
this classic to a wider audience allows for differential interpretations and focuses. The
middlebrow connection to The Heart is a Lonely Hunter provides an important insight into the
way the information in this novel is being understood and discussed by the wider population.
Beyond the canon, where disability has typically been ignored, in this context readers are more
free to examine the aspects of the novel which they have found compelling.

This variety of responses demonstrates the ways in which the popular culture book club has the
ability and freedom to bring in a widespread audience that allows readers to approach and
discuss books from many different angles outside of prescriptive formulations and expectations.
While Winfrey herself leads the discussion of the television program, it is evident from this
sample that the topics covered by her do not restrict the online discussion either on the show’s
own board or within other reading communities and posting sites sampled. This liberty allows
for a wider readership able to experience different lives whether they are found to be sympathetic
or distasteful or identifiable with the readers’ own lives and has the ability to bring wider
discussion to a variety of social issues for the larger reading public. The opening of this type of
literary fiction to a broader audience allows for a variety of perspectives to be exposed and for a
wider base of challenges to be drawn from these viewpoints.

Emotion is demonstrated through readers’ comments to be central to their feelings about the
novel and connections with the characters. This is of particular importance when assessing the
attitudes towards characters with disabilities and providing the potential for social change for these individuals.

Disability Studies frequently identifies the maintenance of the role of “the other” in popular culture by people with disabilities as a contributing factor in the societal exclusion and devaluation of people with disabilities. While noting that the character of Patty is not discussed to any significant degree in this section as a person with a disability, she is recognized as representative of traits which are devalued, considered outside of the norm and beyond the personal experience of posters. That being said, she is at the same time, in spite of these traits, recognized as representative of some of the traits readers acknowledge in themselves and those around them, and also as an example from which to learn about experiences in other’s lives. Patty, inclusive of her depression and alcohol addiction is frequently cited by readers as indefinable in a single category. Her portrayal, while not positive, is seen by many readers as real and representative of many of the features of real life. She is not good or evil, as some of the stereotypes of disability have pointed to nor is she saintly. She is, as one reader suggests, unlikable but “flawed” in ways that are inclusive of her disability and relatable to readers (Setterfield, 2001).

While Delores prompts significant classic ableist rhetoric of personal responsibility, readers’ discussions also provides informative evidence of the varied reactions of readers to this character. Unlike the frequently accepted assumption that the public sees the disability rather than the person, comments tend to focus on Delores herself, her likeable and unlikeable traits, rather than her weight or psychiatric impairments. The majority of posters find her relatable and comparable to them in some way rather than as an “other.” Her problematic life, which is the central theme of the book, is discussed as distinct from the problems experienced by many
readers yet relatable on an emotional level. Readers tend to empathize rather than sympathize with this character’s pain and experience.

Through both Patty and Delores, what has been traditionally perceived as personal issues, comes to the forefront as in need of public examination. The identification with characters with and the proliferation of depression, addiction and weight issues, along this same line, through this dialogue become part of the wider public discourse. The acknowledged identification of readers with characters outside of their own lives and the issues surrounding those characters provide a wider base of human connection inclusive of a variety of traits and status, both positive and negative. This opens the door for public conversation, challenges beliefs and actions surrounding varied and diverse lives. These characters are not described by readers in terms of the flat presentation ascribed to the depiction of people with disabilities. Readers demonstrate that to them Delores, for example, is not simply her weight nor her institutionalization, she is not a metaphor, but a person that they can like, be annoyed with, and abhor which challenges long-held beliefs about the role of disability in fiction. The emotional connections and disconnects described by readers encourage them to address the humanity of the characters as well as their disabilities. Emotional connections bring readers to the character rather than distancing them based on difference.

Readers consistently comment on the ability of these everyday presentations to influence their thinking about social issues and the relevance of these fictional characters in their everyday lives inclusive of disability.

In the case of Patty, *Freedom* (2010) is chock-full of depression and almost every significant character in the novel deals with it at some point. Though many have described finding the
characters unlikeable on many levels and their disabilities potentially the result of selfishness and lack of personal responsibility, their presence and realism has opened the door for honest discussion surrounding ideas about disability and the role of depression in the lives of people who live with it. The dialogue around these characters also points to two aspects which highlight the ability of such presentations to serve as a launching pad for social change around understandings of disability. The fact that mental health is discussed so freely in the novel brings it forth as an acceptable topic of conversation. This casual presentation challenges this issue as something to be hidden and instead is discussed as a common, everyday occurrence. Moving the discussion of the experience of depression and addiction into a public sphere brings forth a challenge to traditional conceptions and exclusions based on these disabilities. The widespread presence of these disabilities, though potentially intended as a social commentary, also serves to eliminate some of the shame traditionally associated with such conditions. This discussion also demonstrates that while many hold a negative view towards depression, and the overall unlike-ability of the characters, some positive discussion has emerged from these presentations starting a broader conversation.

In posts regarding Delores, readers also brought forth important challenges to disability presentations. Addressing disability issues specifically unrealistic presentations are called out and the author questioned for his presentation of the caricature like nature of Delores and the level of disability she faces in the world. An additional social observation is provided looking at the role of disability in the case of women by Isabelle G Gelinas (1997) who notes “the…thing I didn’t like about this book is that the womyn [sic] portrayed in it are all nuts.”

Reader comments demonstrate both the ability to uphold and challenge conceptions of disability. While not a panacea of progressive interpretations, readers’ comments certainly demonstrate that
these characterizations have made them think, identify with characters with disabilities and consider the place of these characters in the world outside of the novel. Readers’ have shown that they do not simply accept what has been put before them, but question, reflect upon and challenge these roles. This online format and the widespread readership of these novels allow us valuable insight into these interpretations.
Chapter 9

Disability as a Thematic Issue

While the previous chapter discussed novels with major characters that have a disability, the three novels outlined in this section hold disability as a thematic issue. Of the novels in the previous chapter, two of the three books fit into the category of literary fiction. The stories which concentrate on disability more specifically in this section represent genre fiction to a greater degree. The dialogue surrounding traditional literary authority and its role in these novels, so prevalent in the discussion of Freedom and The Heart is a Lonely Hunter is much less dominant in the discussion of these books. Discourse focuses to a greater degree on why posters loved or hated the books, their connection with the characters, the use of the book as a history lesson, and the role of disability for readers both in the novel and in their own lives. The three stories here provide an interesting comparative point, representing a diversity of disabilities, as well as narrators. The first two stories are told from the point of view of the character with the disability, while, Jewel, the third novel is told from the perspective of the mother of a child with a disability. Reader comments surrounding each of these novels were prolific and exemplify the kinds of discussion held around the topic of disability based on fictitious characterizations. These discussions demonstrate readers’ strong connections with characters with disabilities, the learning that they have done from these representations and the social injustices of the books as they are identified by readers and translated into real life. Each individual novel is discussed in this chapter based on the highlights of readers’ posted discussions.
Stones from the River – Ursula Hegi
This author’s 1996 novel Stones from the River, included in the OBC in 1997 is narrated by Trudi Montag. Trudi learns early in her life that she is called a zwerg, the German word for dwarf, by everyone in the village. Rejected by her mother as an infant, she is raised by her father. Her mother is institutionalized shortly after Trudi’s birth and subsequently dies. Disconnected from the others in the small German town, because of her physical difference, Trudi learns to appreciate her own physical form and becomes the town confidant and the keeper of secrets during the Nazi rule of Germany.

While Trudi is the clear protagonist of the story, many other characters in the book also have disabilities. These include:

<table>
<thead>
<tr>
<th>Character</th>
<th>Description</th>
<th>Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Trudi</td>
<td>Protagonist – lives in small town years preceding and during Nazi Germany, works at pay library</td>
<td>Zwerg – German word for dwarf</td>
</tr>
<tr>
<td>2 Gertrude</td>
<td>Trudi’s mother who rejects her daughter at birth. Institutionalized early in the novel and later dies in the institution.</td>
<td>psychiatric impairment</td>
</tr>
<tr>
<td>3 Leo</td>
<td>Trudi’s doting father, who raises her. Owns the pay library at which he and Trudi eventually work</td>
<td>Walks with a limp based on injury from WW1</td>
</tr>
<tr>
<td>4 Pia</td>
<td>Lion tamer who is travelling with the circus when Trudi meets her. Beautiful and confident in herself and her physical variance</td>
<td>Zwerg</td>
</tr>
</tbody>
</table>

OBC Website
As one of the earlier novels included in the book club this selection lacks the breadth of content available on the website that more recent novels have yielded. Through the OBC website, however, this book does provide information on social issues, including links to Holocaust resources and recommendations for further reading on this topic, as well as movies about the Second World War. Fifteen Reading Questions are provided for consideration by readers some of which question the role of Trudi, her disability and her characterization. While no specific responses to these questions are available through the reader posts on the OBC website, the raising of such questions demonstrates the importance of Trudi’s physical aberration in this novel as well as its symbolism related to the historical period in which the story takes place. Issues of the characterization of Trudi, her place in Nazi Germany and her multifaceted personality are all addressed extensively in readers’ discussion from additional websites as is demonstrated in the posts below. These questions, responded to by readers however, do not appear to be directive as much as mirroring predominant themes in the story, which may be addressed with or without the provided questions.

Readers are asked:

1. Why did Hegi choose a dwarf as her protagonist? How do the other characters respond to Trudi’s “otherness”? How do you?
2. Hegi portrays Trudi as a woman capable of both enormous rage and great compassion. The same woman who takes Max Rudnick a note which reads "I have seen you, and I find you too pitiful to consider," risks her life when she hides Jews in her cellar. How does Hegi reconcile these differences in her main character?

Reader Comments

Challenge to Traditional Literary Authority
While the majority of readers have posted on their connection to the novel rather than its literary style or implications, some have looked at this novel using more traditional approaches. Those who commended the novel within the category of literary fiction, associated it with what they have considered comparable novels. siammuse (2002), for example, equates this book with To Kill a Mockingbird (1960) and The Grapes of Wrath (1939) noting, “Yes, it was that good”. Charlie4 (2000) describes that “This is a thinking person's book. It will sweep you away to another land and place, that was as unreal as many of the characters might, at first blush, appear to be. This is a stunning, complex book. Not for the Danielle Steel crowd. For those of you who appreciate good "books" and even the "L" word (Literature), this book is for you. Enjoy!”

Demonstrating the repeatedly identified division between the literary and general readers, several comments demonstrate the surprise at the inclusion of a novel that serious readers enjoyed within this prominent middlebrow collection. Setting the tone, JustAnotherReader (2004) says that “I picked up this book without at first knowing that it was an Oprah pick”. A Customer 9a (1998) notes “I usually try to avoid Oprah's picks for literature…I unknowingly picked up Stones without realizing that it, too, had Oprah's stamp of approval”. Carolyn Seefer (1997) observes “Never did I think that I would ever call myself a fan of Oprah, but my mind was thoroughly changed when I read that she had selected Stones From the River for her Book Club”, while Red Haircrow: Author, Reviewer, Indie Publisher (2011) similarly notes “I am glad I didn't put this one to the side simply because I don't often read contemporary fiction or because the stamp on my copy proclaimed it a "Oprah's Book Club Selection". While a handful of posters felt the novel was poorly written, “dull and pedantic” (Shara, 2007), “sappy and depressing” (oneflewover, 1999), the plot “predictable” (A. Anderson, 1999) and “slow” (Rama Kamath, 2007), the majority of posters noted the praiseworthy writing of the text. The book is described
as “beautifully written” (Kristin Winstanley, 2001), as “powerful, elegant and evocative…insightful [and] cogent.” (A Customer 9b, 2000).

Outside of literary merit, readers once again demonstrate through their comments the differential value that a wider readership ascribes to specific novels. The book is most frequently commended for its provision of historical information using a personal approach. The story is noted to offer historical and educational information about this era in a way that encourages readers to take interest in and information from it. This book that “make[s] you think” (K. Dillon, 2000) is not used as “a cudgel to beat you, but rather takes you through a masterful tapestry that brings the story to life.” Noting the information provided through this story and its absent political tirade Author and Avid Reader (2006) notes that “the writing tells so much without being explicit or manipulative”.

Rather than focus on the traditional literary merit, readers have shown their interest to be focused on the characterization of Nazi Germany, the life of Trudi as a person with a disability living within that context and their ability to identify with this character and time outside of their own.

Connections to the Novel

Description of Why Loved/Hated the Book

A significant number of comments were based around readers like or dislike of the novel.

Explicit areas readers emphasized were the ability of the author to provide insight into the lives of German people during World War Two, both the likeability of Trudi and readers’ capability to identify with the main character. In spite of her many faults, readers were particularly interested in the realism of the portrayal of Trudi and the other characters, and the ability of the novel to highlight the potential of the human spirit.

Emotional Connections
While Trudi is continuously described by readers in terms of her physical difference, her defining features appear to be observed in a more holistic sense. Trudi is presented as a fully developed (A Customer 9c, 1996) and well-rounded character whose life we share in from infancy to adulthood and whose acts of good and bad are represented throughout the novel. While some readers did not find this character compelling such as Geoff (2000) who didn’t “believe or identify with the characters”, or A Customer 9d, (1997) who found the characters “rather bizarre” and unrelatable “unless you’re a pretty off-beat person,” the majority of posters describe similar experiences to Christine Page (2009) who felt she was let “inside the head of the young dwarf during the time of Hitler” providing a window into “…what her life was like.” Comments describe falling in love with the character of Trudi (Christina B. Erickson, 1995) and “absolutely loving everything about her” (Carolyn Seefer, 1997). A Customer 9e, (1998) describes “I found that I had come to care about the characters so much that I didn't want to close the book and lose them”. Readers find her inspirational, a “compelling character, who constantly fights people's attempts to marginalize her because of her difference…” (jtm497, 2007) maintaining courage in the face of adversity (Devin, 2000, Amy T. Ruder, 2000). Readers described feeling that they know this character (Summer Acton, 1999) and that the novel is able to “transport us to a world quite different from our own, and make us feel nonetheless that we live there ourselves” (Bluebookworm, 2000). Jwilem (2001) describes “becoming a part of this time and place” and feeling a resulting “empathy for the characters and the moral dilemmas they faced”.

Citing Trudi as an example for others, readers comment on their ability to identify their own lives with hers. Describing Trudi as “The story teller in us all” (A Customer 9f, 1997), Ruth Sternberg (1999) remarks that “every reader will find something here to relate to.” T.J. Mathews
(2000) designates the novel as a “rich, colorful story written for everyone who has ever felt that they were different”. While A Customer 9g, (1999) observes that “…anyone who feels they did not quite “fit-in" with the norm would really enjoy this book”. Discussing similarities with the character, A Customer 9h (1999) describes how “Trudi's experiences articulated a lot about myself, and…The author's vision of life was highly resonant with my own”. Verid Bandisan (2003) echoes this sentiment describing that “wherever I live I'm always different, and I can't help it. But Stone [sic] From the River has proven to me that we all feel that way, we all ARE that way” connecting the fictitious with reality.

Characters with disabilities are frequently cited as one-dimensional and representative of a single feature. The perception of Trudi described by readers challenges this accepted wisdom and a significant reason for their praise of the book is attributed to the realism of this character.

Readers observe “The characters are multi-layered with rich textures…” (Avid Reader, 2010) and Trudi specifically as “a brilliant character, full of pathos and humor, and very, very human” (A Customer 9h1, 1999), Trudi is “…brilliantly molded into a complex, troubled, yet kind person” (Tom Spears, 1998). Describing Trudi, Theindianexpat (2004) shares “Stones from the River deals with a heroine who is everything a heroine is not.” The story, “Emotionally wrenching but not over sentimentalized…presents the voice of the narrator as pure, true and very real” (A Customer 9i, 1998).

The author’s attention to detail is said to bring “the characters in Trudi’s world to life.” (Atmj, 2001) and allows the “story to read like a biography” (wlmcmullen, 1999). The “brilliantly captured…essence” of Trudi (birkenchicken, 1998) is described by many readers. One poster pronounces “She is not perfect -- she gets jealous; she curses people; she betrays trusts. But she is so real, you can practically reach out and touch her.” (A Customer 9j, 2000). This realism is
represented to readers through the un-extraordinary, “believable” (robbieandrose, 2006) day-to-day activities of the lives of characters in “extraordinary times” (marina parisinou, 2005). Carina (2000) sees Trudi as “as much a real person to me as anyone I know” while Starwriter (2000) notes the “…characters seem as real as your own family and you don't want to lose them when the story ends.”

This “examination of the human spirit” (A Customer 9k, 1998) is valued for its recognition of the “human condition amidst a very cruel world of senseless destruction.” (Spideranansie, 2001). Bringing the harsh realities of humanity (I love reading and going on vacation with my family,, 2012) and emphasizing the intolerance brought forth by war (siamuse, 2002).

Readers’ comments show that they recognize Trudi’s disability and that they also identify with her and her struggles in spite of the fact that they may be different from their own. Posters have highlighted the importance of the fullness of this character. At the same time readers identify this glimpse into a different life has lessons to teach them. The interest in, caring for, identifying with and lessons learned by readers all point to this presentation of disability as holding the possibility for positive social change as it relates to disability through public discussion. This is particularly significant in the novels redefining of public and private life and the importance of domestic life in the face of social justice and the ability of fiction to bring this discussion to the forefront.

**Disability and Other Social Issues**

This novel brings forth discussion of disability in a way that has not been seen in the novels discussed to this point. While there is argument as to whether this is in fact a book about Trudi, or the Holocaust, there is significant discussion by readers as to the role of disability both in the novel and in daily life. Sometimes re-enforcing and sometimes challenging conceptions of
disability readers discuss a comparison of Trudi to this historical atrocity, the gaining of insight into the life of a “zwerg,” Trudi’s identity as an outsider and her connection with other characters with disabilities, the pity and sadness felt around her physical difference, her own experience of difference and her resulting commitment to assist others facing discrimination, as well as some hopeful discussion surrounding the presentation of Trudi, and the role of disability in society.

The fact that Trudi is seen as symbolic of the discrimination towards difference during the Nazi regime in Germany, both speaks to the acknowledgement of discrimination in the case of disability, but also the use of disability to characterize other social ills with the potential to discount disability as its own social issue. Readers recognized the comparative struggles of Trudi and the Second World War. One reader points out “Trudi's disability, if that's the word for it, is an allegory to which almost every other element in the novel can be compared. Stones connects a "biography," a story of a community, and a compelling account of a horrific time in world history.” (A Customer 9l, 1998). Likewise, Chris.collins@iname.com (1998) thinks that “The story is not just another 'lesson' about the terrible things that happened to the Jews in Germany during the war, but it's also the story of a girl whose physical differences set her apart from others her own age”. Seen as symbolic a reader describes feeling that “The main character Trudi represented our internal shame through her dwarfism…” (A Customer 9m, 1999). This discussion while frequently equating Trudi with social outrages, also highlights the dangers of labelling people as other and the dire consequences of this tendency in this extreme example.

The concept of curiosity and voyeurism is also brought forth by the specific discussion of Trudi in terms of her disability. Several readers commented on their interest in this new perspective and ability to enter a life they had not had any contact with in the real world. While some readers
appeared to be more interested in a spectacle, others comments reflect what appears to be gaining genuine insight into a different life. On the spectacular side of things doreenbecker@ENGELHARD.com (1999) describes Hegi’s “use of a dwarf as the main character was most interesting to me because I only know of one such person and couldn't dream of asking her what her life must be like.” Similarly, JustAnotherReader (2004) comments “There is something compelling about this book - maybe it's the chance to get inside the head of a Zwerg which doesn't present itself very often”. Mama Kimmberli (2001) also interested in this perspective, notes “All in all, the book is interesting, if only to get a glimpse into the life of a zwerg (dwarf).” Appearing to appreciate this representation and what has been accepted as an astute look into Trudi’s reality, other readers seem genuinely interested in the character’s life and the role of physical variation within it. marlee (2011) states that “The author has an insightful ability of describing life as Trudy lived it. How her life as a dwarf 'colored her world.'” While their insight is based on a single representation, readers felt that they were given a new perspective to consider. Mom of 3 (2008) says she “Got an understanding for what a small person goes through on a regular basis” and A Customer 9n (1997) summarizes that “Trudi's handicap, was described in a way that helped me begin to see what it might be like to be a Zwerg”. Without questioning the accuracy of this portrayal, A Customer 9o (1997) queries the creation of Trudi and “wondered how the author knew so much of dwarfism?”

The fact that Trudi is different is a central focus of the discussion. Readers identify Trudi based on and in spite of her difference. As a central theme of the novel, this recognition of variance can once again be viewed as both a positive framework for discussion and also as a way for readers to distance themselves from disability. Ableist attitudes are readily expressed and the pity of readers offered freely regarding Trudi’s existence as a person with a disability. While this
potentially damaging discussion is in no short supply, its assumedly honest sentiment provides insight into ongoing perceptions of disability. Recognizing the separation between Trudi and others in her community, A Customer 9p (1999) refers to the story “about a "vertically challenged" woman who struggles to live with her difference in a "tall" society”. DYB (2006) speaks of her as “…the resident freak, gossip, and historian of her small German town….and probably in that order…” Alternate interpretations demonstrate Trudi’s difference to be a social issue rather than an individual one. Katherine Neis (2000) tells of how “Trudi struggles with her differentness and the acceptance of herself as she is despite the cruelty of others’ reactions to her”. Additionally Always with a book (2004) describes “The principle charector [sic] is an "other" in a time when being different meant death or subjugation”.

In this discussion of difference, many posters have also recognized the connection between Trudi and additional characters with disabilities. Trudi’s mother is institutionalized for psychiatric impairments near the onset of the story, potentially worsened by the birth of her aberrant daughter. Trudi’s father is physically impaired from a war injury, and Trudi is only able to accept herself after meeting another like her. Molly (2000) repeats a commonly accepted vision of the terrible state of having a disability noting that “Trudi is a zwerg (dwarf), and if that's not bad enough, her mother is dead, and she lives in a time when any difference, physical, racial, or religion, is not accepted.” Reflecting on her mother’s rejection of her daughter and the prominence of disability in the family Red Haircrow: Author, Reviewer, Indie Publisher (2011) describes “She is visibly different, painfully and emotionally aware of the fact…Trudi's birth, her dwarfism is yet another trigger into her mother's slow descent into madness…” Showing the possibility for connection and self-value through other people with disabilities, Trudi’s encounter with “another zwerg woman named Pia, a lion tamer” (Stillborn Messiah, 2007) demonstrates an
ongoing support for separation over inclusion and the ability to find solace only in those like ourselves. DYB (2006) discerns that “It takes meeting another small person who is very comfortable with her size…before Trudi finally finds acceptance in who she is.” Beverly Diehl (2013) comments that “I felt very sorry for her, and was moved by her experience of meeting another Zwerg, a beautiful and talented woman named Pia who was comfortable in her own skin” Through this encounter she "feels more positive about herself and the possibility of "normalcy” (stillborn messiah, 2007). While in some ways this presentation is troubling, identifying the place of people with disabilities as with others like themselves encouraging segregation over inclusion, in other ways, the presentation of Pia is seen as inspirational. Pia is strong, and proud of who she is, unlike the shameful way that Trudi has perceived herself to that time. She is not a super-crip or a spectacular figure (outside of the fact that she faces lions), but is instead a woman who has embraced who she is. The pride in one’s disability is a new angle for both the character of Trudi and readers to consider.

The difference equated with Trudi is met with pity and sadness by some readers, demonstrating traditionally ableist attitudes. Siamuse (2002) reflecting on the social situation of WWII Germany asks “Who understands better than Trudie[sic] about the ugliness of being different...." Author of the Crystal Palace: Rescue of the Baby Fairy Prince (2010) recounts their hesitance to read the novel “because it seemed dreary and sad: a "handicapped" child and a deranged mother in a cruel world.” In a similar way Beverly Diehl (2013) says “Trudi is a Zwerg, a dwarf… and what makes matters worse, her mother is crazy. As in, going to church and taking off all her clothes for the angels, crazy…” Grateful for not being in this position K. Dillon (2000) identifies that “It makes you give thanks for not being in that situation, let alone having to live with the physical differences that she did. I admire her spirit to keep going, for struggling with her
circumstances and being an example to us all on the inner strength that is within us all, but sometimes seems too deep to reach”.

While this discussion is disappointing and mirrors a reality too frequently faced by people with disabilities, it is not the only, nor the dominant discussion that is being had around disability in this case.

While the previous section demonstrates the ongoing ableist attitudes of many readers, intentioned or not, posters also recognize disability issues in their discussion. One way that readers acknowledged the importance of disability issues was in their recognition of the discrimination that Trudi experience based on her disability which affect not only people with disabilities but society as a whole. A Customer 9k, (1998) points out the discriminatory attitudes put forth by some comments and their judgment “BECAUSE [emphasis original] she was born with physical deformity”. Encouraging other readers to look beyond just her disability Booklover and Knitter (2009) points out a tendency to discount this character based on her size. She remarks “Because she is tiny in stature she is often discounted and thought of as childlike. This is far from the truth. She is intelligent and wise.” Reflecting on other’s perceptions of Trudi (Nancy M. Levy, 2013) notes that “She wrestles with differences from how people perceive her and how she and others face a very judgemental [sic] world full of persecution...” Bringing this example forth for others Read27@yahoo.com (1999) feels that “It also reveals some of the problems handicapped people go through to find acceptance in the normal society.” And that “This would be a good one for parents of handicapped children or older children to read.” Recognizing their own prejudice A Customer 9q, (1998) states that “Reading a book about a "dwarf" didn't really appeal to me.” And through this interaction
with Trudi was able to gain a new perspective realizing “Trudi is not just a dwarf. She is me. She is anyone who feels uncomfortable in themselves. I related to Trudi’s character as I am sure many, many readers did”. Another reader recognizing Trudi as a person rather than simply a body through his/her reading of the novel, describes how “…the reader is able to share both the many pains and unexpected pleasures of a soul far greater then [sic] the dwarf body portrays” (T. Nelson, 2000).

Based on both attitudes towards Trudi and her difference and the events of WWII many readers posted about the novel’s impact on their perceptions and the lessons that they learned from reading this novel which apply to the wider social sphere. Observing the ability of stories to affect us outside of the novel itself, Mary Whipple (2006) comments that “Hegi shows the power of storytelling to influence lives.” Author and Avid Reader (2006) pinpoints the ability of readers to learn through fiction noting “The best way to teach is through gifted storytelling, when the listener is so caught up in the story and characters that he or she forgets that there may be a lesson inside it.” Observing the role of story and the learning that can be done through story Robert Spencer (1998) finds this theme as prevalent both within the novel itself as well as being applicable to the learning readers take away into their lives. The book, he remarks, “is about stories and their power to bind, heal or destroy, about being different in the world, about learning self acceptance [sic] and growing to adulthood, about recovering from self hatred [sic] and learning to love, about the total tragedy of both world wars.” Molly (2000) says “This book makes a person think about what still goes on today and how many people are apart [sic] of it”. Serving multiple roles, A Customer 9r, (2000) comments that “this book not only educates, it does so while at the same time entertains. Not a small feat.” Forcing readers to reflect on their
own behavior and acceptance, A Customer 9s (1998) explains that “The author makes one think hard about the complicity of silence” and all of our roles in this.

In their procurement of knowledge about Trudi and her struggles with social discrimination, posters described the development of further empathy and connection with this character who they may not have considered in the past. Kay Mitchell (2000) tells that “Stones From the River is a book about being different, as all people are different… it teaches the lesson that all people are different, some physically, all mentally and emotionally, but all longing for the same things, love, family, security, and safety.” Recognizing her difference, but also her humanity, Marina Parisnou (2005) describes “Her struggle to come to terms with her condition which makes her so different and consequently the target of discrimination, in the form of taunts, pity or fear, allows her – and us – to understand how, however “normal” we may appear, each of us has his story to tell while at the same time, as humans we share so much even if our exteriors differ dramatically at times.” Dusty in Delaware (2012) echoes this sentiment in her comment “The message is powerful and just as relevant today as it was during the period portrayed in the story; we are all different and yet we are all the same when it comes to the basic things that make up our humanity.”

Signifying a desire for change and recognizing individual responsibility around issues of discrimination A Customer 9t, (1998) states “By the middle of this book, you wil [sic] know the agony of being prejudiced against, in more ways than one. You will be as angry as Trudi is when people treat her like a scrap heap reject, the first of whom being her own mother. You will sit and wonder, why can’t they just treat her as they would anyone else? You will be disturbed when you realize your own prejudices”. Bringing hope for action in this realm, A Customer 9u, (1999)
contents that “Trudi is a character that will stay with me forever and I am eternally grateful to her for giving me a new and interesting perspective on life.”

More generally readers identified the lessons they have taken away from this novel including the realization of our past and contemporary intolerance, their developing empathy, the dangers of silence and complicity and the need for kindness in the world. Bev Danielson (2013) says that the novel “Makes you realize how prejudice still remains even today” and L. Borell (2013) reflects this feeling commenting that “We continue to be intolerant and close-minded…” Remarking on the indifference of many Stillborn Messiah (2007) says that “it was people’s lack of empathy and compassion that allowed such a horror as the Holocaust to occur.” Hegi however is seen to “excels at showing just how normal people can change, and how the world around can change you.” (Red Haircrow: Author, Reviewer, Indie Publisher, 2011). Demonstrating this change Booklover (2012) states that the book “…not only kept me intrigued but it has made me more empathetic.” Summarizing the essence of these comments, Shelia J. Holt (2000) writes “Through Trudi’s eyes, we understand that beliefs are less important than knowledge, silence is complicity when evil is abroad, differences in our lives are necessary and beautiful, how the politics of a time can warp and nearly destroy a whole generation, but especially that acknowledgement and forgiveness are prerequisites to healing.”

**Icy Sparks – Gwyn Hyman Rubio**

*Icy Sparks*, included in the book club in 2001, is the story of a young girl in the American south who lives with her grandparents in the 1950s and ‘60s. While never officially diagnosed through the course of the novel, Icy is identified at the novels conclusion as having Tourette’s syndrome. Embarrassed by her “fits” and socially excluded from her peers based on this, Icy befriends
another social outsider in her town. Trying to determine what is causing Icy’s behavior; her grandparents reluctantly place her in a psychiatric institution where she continues to elude an official diagnosis. Remaining a social outcast and removing herself from the external world upon her return home, Icy eventually turns to religion where she finds her place in the world along with her singing voice.

Table 13: Characters – Icy Sparks

<table>
<thead>
<tr>
<th>Character Name</th>
<th>Disability</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Icy</td>
<td>Tourette’s Syndrome</td>
<td>heroine, not accepted by community because of different presentation</td>
</tr>
<tr>
<td>2 Miss Emily</td>
<td>Overweight</td>
<td>Adult, community outcast because of weight, befriends Icy</td>
</tr>
<tr>
<td>3 Gordie</td>
<td>Mute, OCD, “head butter”</td>
<td>Another patient at the psychiatric facility</td>
</tr>
<tr>
<td>4 Mary</td>
<td>Mobility impairment</td>
<td>Another patient at the psychiatric facility – Can't move, eat on own, bites herself</td>
</tr>
<tr>
<td>5 Stevie</td>
<td>Unknown</td>
<td>Another patient at the psychiatric facility – soils himself regularly</td>
</tr>
<tr>
<td>6 Rose</td>
<td>Mobility</td>
<td>Wheel chair - mobility - nonverbal</td>
</tr>
<tr>
<td>7 Deirdre</td>
<td>Mobility, intellectual</td>
<td>Another patient at the psychiatric facility</td>
</tr>
<tr>
<td>8 Ruthie</td>
<td>Mobility</td>
<td>Another patient at the psychiatric facility – uses braces to walk</td>
</tr>
<tr>
<td>9 Reid</td>
<td>Intellectual</td>
<td>Another patient at the psychiatric facility - the “bird boy”, only makes bird noises, ate paint as a baby</td>
</tr>
<tr>
<td>10 Ace</td>
<td>Unknown</td>
<td>Another patient at the psychiatric facility – doesn’t speak, just draws</td>
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</tbody>
</table>

OBC Website

This book has additional information on the website which gives us insight into the way both Tourette’s Syndrome is being presented and understood in both the character of Icy and more generically. A description of the experience of Tourette’s syndrome is provided by the site (http://www.Oprah.com/Oprahshow/Tourettes-Syndrome/7) as follows:

Imagine knowing that at any moment, you could lose control of your body, twitch uncontrollably, shriek out strange words or begin blinking repeatedly. For those living with Tourette’s syndrome, this nightmare is their reality. Tourette's is a mysterious neurological disorder that is more common than one might think. According to the Tourette's Syndrome Association, one out of every 1,000 people is affected and there is no known cure. Based on the statistics, there is at least one student who suffers from this
hereditary disorder in almost every school in America. **Tourette's syndrome often causes a person to have "tics" or uncontrollable urges. Tics can be anything from the incessant need to flap your arms and shake your head to the repetition of random words like "coffee" and "metal."**

This description is followed by the highlights of a discussion panel made up of three children who have Tourette’s discussing their experiences. The provision of these individuals’ voices recounting their own experiences provides an interesting insight into personal perceptions of this condition and the lives of children who are experiencing it, and it also does not necessarily uphold the earlier observation that their reality is a “nightmare”. While 14 year old Amanda says that the OCD associated with her Tourette’s has taken over her life and makes her feel like she is “not wanted in this world,” Colin, “another child who suffers from Tourette's, isn't shy about his disease”. He is described as “an advocate of sorts for other children with the neurological disorder.” Each relating themselves and their experiences to other “normal” children, the kids all focus on the fact that this is just one aspect of who they are. Colin says “We put on our pants the same way that everybody else does. Except maybe sometimes we're shaking our head or saying "metal."”. Jasper remarks that “We're average human beings with a drawback” and Amanda says that “I wanted people to know that we [are] just as normal as any other kid that walks in the school each day. We dress the same.
We do things the same. I just want people to know that people with Tourette's … they're not different. They're just plain old regular people.”

Reading Questions

Of the 10 reading questions provided for readers to think about and discuss in relation to the novel seven were directly related to Icy and the experience of being a person with Tourette’s. The reading questions show the predominance of disability in this story, as compared to its role in some of the works discussed earlier. These questions include:

1. Through her grandparents' memories of her mother and father, Icy learns that she was born "a frog child from Icy Creek" with eyes the color of heaven's "golden light." In what way does the mythology of her birth help Icy to accept her affliction?
2. Why does Icy compound the consequences of her fits by lying; either denying they happened or fabricating excuses for her outbursts? Is this a symptom of her Tourettes or a reaction to it?
3. Do you agree with Miss Emily's assessment that Icy's affliction is similar to her own? Should people who are "different" form a community with one another? Should Icy have been less critical of Miss Emily's weight problem? Lane's effeminate behavior? Peavy's "frog" eyes?
4. Icy's Tourettes makes it difficult for her to keep any secrets. Yet she never reveals what she saw Mamie Tillman do near Little Turtle Pond. Why?
5. Was Icy's confinement in the Bluegrass State Hospital ultimately a good or bad experience? Would she have considered becoming a therapist if she hadn't met Maizy and Rose?
6. Icy's outbursts are usually violent and profane. How does Rubio use humor to offset some of her more harrowing moments?
7. Icy lives almost eight years of her life not knowing that her tics and pops are symptoms of Tourettes—a neurological disorder. Neither Icy, nor her family, nor the members of her rural Kentucky community know whether she's ill, "crazy," or "possessed." If she had been diagnosed, would Icy's childhood have been any easier? Would the townspeople have been kinder or would they still have shunned her as "different"?

While there is again not an adequate number of reader posts on the OBC website to interpret how readers are thinking about and answering these questions, other web sources provide significant discussion relating to these topics.
Reader Discussion

Of all of the novels that I sampled during this research, none has had more divisive opinions as to the quality of the writing, the story itself and the characters than Icy Sparks. Readers largely either loved or hated the novel and the characterization of Icy.

Challenge to Traditional Literary Authority

In discussion, readers generally upheld Winfrey’s taste in books and recommendations and commented on the influence that this novel has had on their lives and how it made them feel. While writing style was briefly touched on by some readers, the most prevalent line of discussion was, once again, the readers like or dislike of the novel. Commenting on the kinds of discussion prevalent beyond the confines of traditional literary authority, those who posted appeared honest about issues such as their reading history and preferences, demonstrating a level of comfort in participating in discussion, no matter their level of expertise. Cockatielgirl (2006), for example, advises that “This is the first novel I have read in about 15 years.” Without the necessity to defend this fact or to counter or question the recommendation, Reader’s demonstrate their support for the selections chosen by Oprah. One reader comments that “without fail I have enjoyed Oprah's choices and I purchase each as soon as they are announced”. (A Customer 9v, 2001). Kim Roberts (2012) remarks that “you usually can't go wrong with an Oprah's Book Club pick” and AmyClarke (2001) says that “I always find the novels that Oprah picks much more diverse than my average reading choices.”

Raising issues of social capital, while the discussion of writing style is not nearly as prominent for this novel as it has been with other books, the quality of the book based on this factor was still raised by posters with a significant discrepancy between those who thought the novel was well written and those who did not. The writing style was described as magnificent, impressive,
clear and memorable (Mauricewms, 2001, nomenclature, 2006, GaylaCollins, 2001). A Customer 9w, (1998) explains that “The excellent narration of these events is fluid and believable” and Donald Harrington compares the characterization of Icy with other notable youth figures including Huck Finn and Jo in Little Women (1998). Other readers are very critical of the novel and its writing. The book is cited as “a big disappointment” (Audrey@sofa-kingdom.com, 2001), “the dialogue is unconvincing at best and unbelievable at worst. The story is disjointed, with characters popping in and out at random and the plot is very predictable” (K. Rutland, 2009). anne f penn (2013) adds “It was hard to follow the story because it was poorly written. And it was very, very uninteresting...” Ercie Berwick (2001) even questions “how such a book got published. ” Erin E Ward (2001) summarizes “ If you want some light fluff, go ahead and read. If you want some interesting character development, I suggest going somewhere else”.

Connections to the Novel

Description of Why Loved/Hated the Book

Posters are very strongly divided in their like or dislike of this novel. Three areas in particular stand out in the discussion which have encouraged/discouraged readers’ connections with the novel, including the identification with Icy herself and her experiences of isolation, the clear demarcation of good and evil in the novel and the religious connotations contained within the book.

Emotional Connections

Many posters described the ways in which they both loved and identified with Icy and her experiences, and a familiarity with her plight based on their own, or of someone they know. In stark contrast to the character of Patty in Franzen’s Freedom (2010) who was berated by readers
for her weakness, readers support and admire Icy wholeheartedly for her strength in the face of adversity. Icy is described over and over in terms of her bravery. This “delightful heroine!” (Sharon Kinman, 2012) is said to catch “your heart in the first few pages…” (Lisa Fischbach, 2002). This likeable, funny (L.M. Boilard, 2002), charming, bright and beautiful (Kay Mitchell, 2002), fun and complex, (Bob Artege, 2005) character is one readers “couldn’t help but love” (Ellen Teo, 2012) and who will “win your heart” (Kay Mitchell, 2002).

This positive identity is not only based on the strength identified with Icy but also with the strong connection that many posters describe feeling in relation to her. Kristine (2001) for example describes “As I read, I was consumed by Icy’s life. I felt her pain and confusion and have asked myself many of the same questions Icy asked herself. I have felt alone, fearful, ashamed, angry, hopeless and confused.” The author is said to bring readers along on this journey where “She makes you cry with Icy’s defeats and leave you elated with her victories.” (Brandi Stewart, 2002). This link is identified through the author’s ability to put the reader in Icy’s place (gregsjewel, 2001). Posters describe knowing this character and sharing her emotions. A Customer 9x (2002) describes “I was so [pulled] in to Icy's life!! I felt pain with her, I felt love with her, I felt joy with her, I felt sad with her”. Readers identify Icy’s experiences in their collective applicability. A Customer 9w (1998) remarks that “the novel describes the universal plight of a young girl trying to understand the differences which set her apart from her peers.” And A Kid’s Review (2001) identifies that “Reading this, you will realize you are no different from anybody else. Also you will reconize [sic] that there are many people out in the world that have many of the same kind of problems as you may.” Common painful experiences of “loneliness, sadness, frustration, anger, etc” were identified with “Maybe…because I was once a kid having to deal with the ridicule of others”. (A customer 9z, 2001).
While many saw these experiences as relatable to their own in a broader sense, a number of additional posters commented on their connection to Icy through their own, or their loved ones experiences with Tourette’s and the ability to gain insight into their experiences. Barbrajvh (2001) identified that the novel “…was recommended to me because I have a daughter with Tourette Syndrome” the reader feels that “The story is an interesting study of feeling out of place and trying to find a way to connect to those around us.” A customer 9a1, who also has a child with Tourette’s, says that “I read this book with interest trying to see, hear and feel what he feels. I enjoyed reading it and was, in fact, able to understand in a small way what she (and my son) might be thinking and feeling.” Sylsbooks (2001) felt that Rubio was “descibinig [sic] my son!” As a person with Tourette’s herself Lisa (2001) describes “I have had it [Tourette Syndrome] all of my life. It is a cross I have had to bear, and it fills me with shame as it did Icy Sparks. I can relate to her just wishing that the tics would go away.”

Beyond relating to the character of Icy, many readers described admiring her strength and courage in the face of adversity. Treated as an outsider in her own community, she is praised for her ability to go on. “Icy's willingness to succeed in her rural Kentucky lifestyle stood out to me.” (A kid’s review, 2006). She is described as “a survivor” (Kelsana, 2001) to demonstrate a “triumph of the human spirit” (beachrunnerjkn@netscape.net, 2001), full of the “inner strength and courage we wished that we had” (Kristy, 2001). She is “unforgettable” with “tremendous spunk and spirit” (Elizabeth Madison, 2001) which is described to allow her to “deal with being different” (kerrio, 2005). The admiration for her is summarized by Kelly Budd (2001) who says that “the rejection that Icy experiences is unforgettable and her strength over adversity is courageous…Icy began as a strong willed child who eventually blossoms into a determined woman.”
While Icy played out credibly with many readers, the distinct differentiation between good and evil in the novel is branded as contrived and unrealistic and the story itself as what one reader sees as “unbearably schmaltzy and saccharine” (A Customer 9b1, 2001). Susan Keller (2001) feels that the “characters were stereotypical [sic] all-bad or all-good, the descriptions fell flat…” georgia_l_moses (2001) observes the “…weak, over-used one-dimensional characters who apparently had to be either nicey-nice or the vile and wicked in order to rate a mention in this story”. These one-dimensional, over-dramatized (rfrank1031, 2002) characters are pointed out by readers to seem artificial (mcphec, 2001, mama kimmberli, 2001) and that their motivation for either good or evil as lacking exploration (Erin E. Ward, 2001). aznurse (2001) concludes “The characters are almost cartoonish, drawn broadly and without depth.”

The most common reason for reader’s dislike of the novel was its ending. In direct contrast to the compliments given to Stones from the River, where life/societal lessons were noted to be a part of the story rather than a forced message, this novel was perceived to make use of the “cudgel to beat you” observed by K. Dillon (2001) in the previous chapter with its overtly religious ending. While many readers described enjoying most of the novel, a significant number commented on the fact that they were very turned off by the ending. rfrank1031 (2002) observes that “I was subjected to three chapters of bible beating and "Praise the Lord Jesus...." eighty thousand times”. LLJoe (2009) notes that “Icy goes to a revival and things take a weird religious turn.” A Customer(z) (2001) says that “the ending was horrible. i felt like the author was trying to convert me to some religion in the end.”, and mcphec (2001) remarks that “the end turned into religious proselytizing”. Heather Willard (2002) echoes “the ending just ruined it for me...I was really hoping for something interesting...but the last three chapters [sic] warped into this huge religious freakshow...all of a sudden...they're all bible beating their way to the end...”
Pointing to the ability of this type of forced message to ruin the overall effect of the novel dellapace (2011) says “…while I was interested in the situation a child with fairly dramatic Tourette’s was going through, it drove me nuts at the end that all her social problems would be solved with religious epiphany…”. Readers felt that her “cure” discounted the reality of her disability. poerocks1 (2010) observes “BAM! Her now diagnosed Tourette's is a gift from God, and her seemingly agnostic grandparents and herself have found Jesus, and the world is good.” Kathryn Brooks (2002) sees this conclusion as diminishing Icy’s disability saying the ending “suggests that there is a right way to "cure" a mental disorder”.

Readers demonstrate their connections with the character to be based on their ability to accept her as a real person. While readers identified with the life, social isolation and trials of Icy, the quick fix of religion, or the perceived forced religious connotations that appeared at the end of the book diminished the message.

**Disability and Other Social Issues**

Readers’ present different interpretations about the understanding that they feel they have gained into Tourette’s as a condition and the experience of living with it. While some readers sought and were disappointed by the lack of medical information provided regarding the condition and its treatment, others upheld the presentation of the experience of living with Tourette’s as the sort of insight that they sought from reading a novel such as this. Describing their pursuit of knowledge about this particular disability, readers described their interest in learning more about Tourette’s. The opportunity to acquire knowledge about this disability was something posters describe that attracted them to the book. SummerKY (2009), for example says “Tourette's is not something I've read about a great deal and that part of the story was certainly appealing in its...
unique nature.” Robert G Yokoyama (2001) also noted that “I enjoyed reading this book, because I learned about a subject I knew nothing about before”.

What readers are looking for about this type of disability, specifically, is varied. Some posters told of their own seeking of medical and factual information, while others sought the more experiential insights offered by the story of Icy. A Customer 9c1 (2006) describes their disappointment identifying that “…I don't believe I learned anything about Tourette's Syndrome that didn't already know”. Similarly, debbie emery (2001) notes that “After 300 pages…I do not know any more about the disease than I did before.” Seeking a more in-depth exploration of Tourette’s, Longmei (2006) highlights her/his disappointment in this missing examination and feels that “Not much research had been done by the writer part with regards to Tourette syndrome”. Feeling that s/he did not have adequate information to properly understand Tourette’s and the implications of this disability, F. Cohen (2001) remarks that “…unless you are knowledgeable about Tourette Syndrome you'll feel like you are watching from the outside wondering what is going on”. Looking for solutions to alleviate what is considered a problem, L.M. Boilard (2002) notes “what was disappointing is that there was no real answers of how to deal with the disease”.

Speaking to the purpose of the novel, KDMask (2007) challenges these readers’ comments finding it “Very strange that some reviewers wanted this book to be a more of a manuel [sic] for a disorder rather than the fictional story it's meant to be.” butterfly (2007) similarly remarks that “A lot of reviews are so focused on the depiction of Tourette's Syndrome that they lose the whole point of the book…If what you are looking for is an accurate depiction of T syndrome...get an informational book”. K. O’Connor (2006) says that “I can understand the disappointment of those who picked it up because it appears to deal with Tourett Syrndrome; in fact, it's more a
story about a young girl trying to fit in than a disease”. While some readers felt that they were not given adequate information about the disability itself, others commended the reality of the presentation offered by the author. In addition to demystifying this disability as noted by Linda Linville, PhD. (1999), several readers praised the awareness given to Tourette’s through this presentation. J. Hartman (2001) cites Icy Sparks as “…a wonderful book that gave insight into how people, and especially children, live and deal with Tourette's Syndrome” and Sylsbooks (2001) thanks the author for “…opening the doors for others to understand this disorder” concluding “I applaude [sic] you as a parent of a Tourettes [sic] child.” Gayla Collins (2001) feels that the presentation in the novel lets “…us inside the head of someone suffering Tourette Syndrome.” Amber Cannon and Wilner Bolden (2001) comments on the overall presentation of Tourette’s and notes that “I did research the syndrome to get a brief overview of what I was reading, but I should not have bothered because Gwyn Rubio, author, covered the more important parts of the disorder as it was diagnosed with Icy”.

Highlighting once again readers’ concern over portrayals of disability some posters question the accuracy of this depiction, demonstrating an additional important challenge brought forth by readers related to disability. msmsmith (2001) says that “The manifestations of Tourette Syndrome are never clearly detailed. The book gives the impression that the disorder comes and goes (especially when convenient for the plot of the book)” Teefus (2001) does not think that “it portrayed [sic] tourettes [sic] in the most accurate way” while Barbarajvh (2001) address common assumptions and the spectacle presented by Icy observing “…that a relatively small percentage of Touretters [sic] actually swear as part of their illness.” Ercie Berwick (2001) also remarks that “never have I come across any information that would lead me to glean that a Tourette's Syndrome sufferer's eyes can pop out like a frog's.” as Icy’s do in the novel. An
additional reader questions the ability of Icy to control her symptoms as described in the later part of the novel commenting “The reader is led to understand that Icy could control her symptoms and that all her symptoms came over her at one time, lasting for an hour. Is this really how Tourette's inflicts itself?” (A Customer 9d1, 2001). A Customer 9e1 (2001) relating the novel to their personal experience says “I don't know whether this book helps or hurts victims of Tourettes. The only person I ever knew with Tourettes was nothing like Icy Sparks…”.

As with the character of Trudi in Stones from the River, readers remark on the humanity that is brought forth through the character of Icy, rather than her disability alone. This type of dialogue emphasizes the importance that readers place on relating to people on a human level rather than based on standards of normalcy. Kerrie (2001) advises that "I do not have Tourette Syndrome, nor do I know anyone personally with this syndrome" asking “so why am I so moved by this story? I suffer from the same syndrome that Icy suffers from. The 'I need to be accepted and loved' syndrome". Many readers recognize and identify with the difficulties of not “fitting in” and resulting stigma (A solo cello outside a chorus, 2001). Detecting the importance of such portrayals, A Customer 9f1 (2001) applauds “Rubio for breathing life into this unique, brave and quirky character and for giving a voice to those who have had little understanding and too much stereotyping.” Mauricewms (2001) concludes “Icy's trials seemed no greater than anyone who doesn't fit within the confines of what our culture deems normal. Then came the light bulb moment. Perhaps that's exactly the point Rubio is trying to make, that it matters not what our differences are, we deserve to be accepted for them, included with them.”

Readers regularly identified Icy’s issues, as socially created and her barriers as not her own, but those of the wider community. Readers’ responses demonstrate a call for change in our
perceptions of people with disabilities and our responses to and valuation of difference. One reader remarks that “This book could have descended into the misery these people often suffer, but instead it's a book of self discovery, and even triumphs...” (fisher, 2001). Referencing society’s role in the treatment and acceptance of disability Scorpiogirl (2001) observes that “the reader is consistently challenged to question their response to the incidents and situations that occur in this novel...In the end, this book is not simply about Tourrette's [sic] syndrome. It is about human ignorance [sic], fear and tolerance.” Seen as providing wisdom and “lessons for living” (Kay Mitchell, 2002) the novel is said to “promote acceptance and kindness” (Janine Johnson, 2001), “to broaden minds through reading” (admeyer, 2001), “to explore the effects of being "different." (A Customer 9g1, 2001) and discover “responses to difference” (Kelly Budd, 2001. “This book pulls you out of your small world” and “takes you along on an emotional journey that reminds you just how boring the world would be if we were all "normal" (S. Broumley, 2012). The book can be used “to show that everybody has differences and that empathy can help people be more understanding...” (Gregsjewel, 2001).

Jewel – Brett Lott
The Novel Jewel (1991) by Brett Lott, serves as an interesting comparison point to the previous two novels, as this story is told from the perspective of a mother with a child with Down Syndrome. Included in the book club in 1999, the character of Brenda Kay, the daughter, is not given a voice throughout the novel. This book recounts her mother Jewel’s trials, tribulations and joys with her daughter and the effects that Brenda Kay has on the family as a whole. The birth of their 6th child Brenda Kay, is the catalyst for this novel which follows the life of the Hillburn family (Jewel and Leston and their children) in the 1940’s and 50’s. From their life in rural Mississippi, to their move to California, where Brenda Kay has access to a special school to meet
her needs, the experience of being a mother and a mother of a child with a disability is explored. Based on Brenda Kay’s attendance at a special school and her living in a group home, she encounters many other people with disabilities including:

<table>
<thead>
<tr>
<th>Character</th>
<th>Description</th>
<th>Disability</th>
</tr>
</thead>
<tbody>
<tr>
<td>1 Brenda Kay</td>
<td>Daughter of protagonist Jewel</td>
<td>Down Syndrome</td>
</tr>
<tr>
<td>2 Toxie</td>
<td>Leston’s (Jewel’s husband) brother</td>
<td>Two missing fingers</td>
</tr>
<tr>
<td>3 Dennis</td>
<td>boyfriend/friend of Brenda Kay’s from school</td>
<td>Down Syndrome</td>
</tr>
<tr>
<td>4 Friends from School</td>
<td>Candy, Randy, Marcella, Jimmy, Nancy – friends from the special school that Brenda Kay attends in California</td>
<td>Various Intellectual Disabilities</td>
</tr>
<tr>
<td>5 The Girls</td>
<td>Jenny, Adelaide, Margaret, Jo, Rachel, Patty, Karen, Sammy, Wendy, Olivia, Martha, Janine – Residents of the group home Brenda Kay goes to live at in the end of the novel when Jewel realizes she can’t look after her anymore</td>
<td>Various Intellectual Disabilities</td>
</tr>
</tbody>
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**OBC website**

Written in 1991, the website content surrounding this book is once again limited. The website includes sections about the book, about the author, the author’s favorite books section, book reviews and reading questions. A total of 18 reading questions are provided on the website for readers to consider. While many of the questions address issues of race and social mobility in the American South, several also discussed the role of Jewel as a mother and the place of disability within this context. Of these, the following 6 questions are relevant to the discussion of disability including:
1. "I say unto you that the baby you be carrying be yo' hardship, be yo' test in this world. This by my prophesying unto you, Miss Jewel." These words of Cathedral not only carried great portent, but haunted Jewel throughout her life. Discuss the various implications of Cathedral's prophecy. With this same statement, the author interjects a spiritual element to the story. Is it believable? Or does it seem to run counter to the tone of the rest of the book?

2. Did Jewel's determination and action-oriented path to help Brenda Kay diminish Jewel's religious faith?

3. How would the experience of a woman today giving birth to a child with Down's syndrome differ from Jewel's? How would it be the same?

4. Jewel considered Brenda Kay both a burden and a blessing. Were these in equal parts? What blessings did Brenda Kay bring? In the end, did Jewel see her as the hardship she had to bear?

5. If Brenda Kay had been born a normal child, what would have happened to Jewel and her family? Would they have stayed in Mississippi?

6. Did Jewel love Brenda Kay more than her other children?

Reader comments were not available on the OBC which respond to these questions specifically. Because of the lack of responses on the OBC site, I am unable to comment on the link between these questions and direct reader responses. Comments, however, do reply to some of these questions more generally and, as in the case of Icy Sparks, demonstrate the more prominent role of disability in this story and the greater amount of discussion surrounding the role of Brenda Kay, her disability and her relationship with her mother.

**Reader Comments**

**Challenge to Traditional Literary Authority**

Upholding these popular book club choices as a challenge to traditional literary authority, the novel *Jewel*, is discussed by readers for the most part in their ability to connect with the main character, questioning her treatment of her family and the social learning that they acquired from reading and discussing the novel. Readers found the exploration of Down Syndrome, the raising of a child with a disability and insight into the American South during the mid-1900’s of particular interest.
While most readers described their satisfaction with the novel, the selection was once again criticized and rejected based on its popularity and association with Winfrey. Some readers warned of their weariness of these novels based on previous selections. Debbie Lee Wesselmann (2005) however cautions readers not to disregard the novel based on its recommendation by the talk show host. She advises that “…serious readers who were originally more inclined to pick up Lott's work instead shunned it as an "Oprah book."” Commenting on the literary value of the novel, readers varied interpretations were represented through their comments. A Customer 9h1 (1999) felt the book is “…vastly over-rated. The plot is more TV movie of the week than great literature.” Comparing the novel with the literary classic *To Kill a Mockingbird*, A Customer 9j1 (1999) was disappointed in this choice. Others found it a more compelling choice, challenging perceptions of popular novels and their equation with mediocrity. Ercie Berwick (2000) remarks that “This novel is definitely not for the Danielle Steel crowd. It has a great deal of depth and substance”. Diminishing those who did not like the novel A Customer 9i1 (2000) finds “…all the bad reviews of this book shocking. But then, I guess it takes a certain amount of intelligence and patience to read such beautiful prose and enjoy it for the poetry. Maybe those who find it slow should go back to their Barbara Cartlands.”

**Connections to the Novel**

**Description of Why Loved/Hated the Book**

Readers both uphold and admonish this novel based on their interpretation of Jewel, the protagonist, and her story. The book is seen in many different lights ranging from “full of humanity” (Loubr, 2013) to one that “does not invoke any compassion” (kaek8t, 2000) or emotional engagement. Readers who connected with the novel and its protagonist were influenced by the realism of the character of Jewel and their shared experience of being a mother and the challenges that that presents.
Many readers commented on the realism of the novel, based on what they feel is the day-to-day representation of family. While sometimes considered “pathetically dull” (A Customer 9k1, 1999) others found the ups and downs of their own lives represented in this fictitious account. Wildwoodldly (2002) admires that “As life will have it, there are valleys and mountain tops. The family finds themselves in the valley a few months after the baby, Brenda Kaye, is born. From that point on, Jewel and her family ride the roller coaster of life; sickness, children leaving home, marriage, divorce, etc. Every family does not face the same trials as did this family. But every family has its own trials and can relate to the strong bond in Jewel's family that makes it possible to indure [sic] the heartaches life can bring to a family”. suz, (1999) likewise, notes the story “touched the "mama" inside me. No, it's not some action packed drama that's full of glamour and intrigue. It's the story of a family, they way they fail and connive [sic] and struggle...and love each other.” She continues “These people were neither saints nor sinners -- they were ordinary human beings hanging on for dear life.”

Jewel is described as “so believable, so real…” (A Customer 9l1, 2000), like a person you know intimately, (A Customer 9m1, 1999). amy knight (2002) describes that “Not only Jewell [sic], but her entire family have to be the richest characters I have ever "met". A Customer 9n1 (1999) replicates the sense of knowing the characters, saying “I got to know Jewel so well that I felt like a good friend was gone after I finished the book. Even though I personally haven't been in her situations, I felt like I was right there with her going through her life”. Ellen Isaacs (2001) concludes “This book could have been one of those formula "triumph over adversity" stories that are frequently made into Hollywood movies. Instead, I found this book to be a rich character study that gave a realistic portrait of how people make do when faced with hardship”. The same reasons some readers found the novel so compelling left others questioning its value. C. Likely
describes that “Jewel's voice didn't fit. It didn't ring true” Chris (2000) says that “it veryfairy-tale-like[sic], despite the hardships. The characters were flat -- they were all so good, so sacrificing, so helpful to each other.” These observations whether praising or diminishing the novel demonstrate the importance that readers ascribe to their connection with the characters in their overall evaluation of the novel.

Seeking to understand the difference between the private and public spheres of discussion and the impact of bringing private issues to the public fore, the role of mothering and the intense connection that readers describe in their identification with the character of Jewel as a mother provides us with an insight into the importance of this differentiation in wider society, as well as the crucial role of domestic life in the lives of many readers, and more specifically, women readers. Readers describe repeatedly their connection with the motherly love felt by Jewel for her family. Jeanne Anderson (2001) describes the story as “a true testament to the power of a mothers love and I would have to say to the love of family.” Carmen W. Willis (2000) admires and identifies with Jewel’s “…constant devotion, strength and energy, determination and dedication, tender love, wisdom and understanding, forgiveness”. Pointing to the everyday presentation of these characteristics as traits that are associated with mothers more generally, A Customer 9o1 (1999) remarks that “Jewel is not heroine, she's just a mom doing anything and everything to get her kid what she needs, no more or less than any other good mom. Jewel gets frustrated, she gets angry, she blames others, she's human.” She is “strong and forceful” (A Customer 9p2, 1999), and has an “indomitable spirit” (Bearette24, 2000) and her love for her family is “breathtaking in its clarity” (Cag4444@mindspring.com, 1999). While supportive of the role of Jewel, other questioned the lack of voice of Brenda Kay. A Customer 9q1 (1999) notes that “What really bothered me the most about the whole book was how Brenda Kay's
character was poorly developed. Just because a character has a disability doesn't make the reader care about him/her. Perhaps the author felt that it wouldn't be realistic to develop a character who really couldn't develop all that much in real life? Although parents of children with Down's Syndrome would probably disagree.

While some posters found Jewel hard to identify with and the story as “a boring aimless tale of a selfish woman's life” (A Customer 9r1, 1999), many posters identified that their own role as mother’s made them more appreciative of this character. A Customer 9s1(2000), for example, identifies that “I can easily see that if I read this book before I was a mother I wouldn’t have enjoyed it as much, not understanding a "mother's love".” A Customer 9t1 (2000) notes that “As a mother of three healthy children, I found this story to be incredibly powerful and touching.” Game misconduct (2001) speaking directly to her role as a mother of a child with a disability notes that “I identified with her [Jewel] in so many ways, including the intense love I have for my 5-year-old with Down Syndrome and the pride I feel in his every accomplishment. This is an incredible view into the challenges a family can face when presented with a child with a disability, not just Down Syndrome.” And from a male perspective Big_man_big_heart_fine_mind (2000) remarks that “This book gave me great insights into motherhood and the special brand of motherhood involved in caring for a special child”. This discussion highlights the ease with which readers identify with those who are like themselves and that being a mother, over being a mother of a child with a disability is frequently identified as a unifying point.
Disability and Other Social Issues

There is extensive discussion about the role of disability from a mother’s perspective and also the ways in which having a child with a disability effects family dynamics. Breda Kay is seen by readers from a variety of perspectives. She is identified as the cross which both Jewel and the rest of the family have to bear. Readers remark on their concerns over the sacrificing of the family unit for the good of Brenda Kay, and their differential interpretations of her as both a burden and a gift. Others share their personal experiences with children with disabilities and their identification with this story in their own lives. Lawyeraau (2001) describes “Brenda Kay’s birth is the catalyst for a journey that would take this family in search of a better life for its newest member”. While this journey is seen by some as the tale of a family “burdened by God with a daughter with Down's Syndrome” (Twohounds, 2000) other readers such as Monica Krieger Faria (1999) identified the way in which the novel “engages one into the life of a parent with a disabled child” and the character of Brenda Kay as both “both the burden and joy of all their lives” (Compulsive Reader, 2002). Opening new worlds of experience to many readers who have not had any experience with children with disabilities, both positive and negative sentiments were attributed to this scenario.

Readers repeatedly discussed the understandings that they gained into the Hilburn family life and what it might be like to have a child with a disability and the importance of this perspective in their own lives. This demonstrates the power which fiction has to influence both positive and negative. A Customer 9u1 (2000) notes “It gave me insight into what it must be like to raise a Downs syndrome child…” and ---jroberts@telepak.net describes that “I am glad that someone wrote about the great along with the hard times of having a handicapp [sic] child (along with all children!).”. A Customer 9v1 (2001) describes their appreciation of this glimpse into a different
life saying “As someone who has never had a family member with mental handicaps, I could only imagine what a change such a child would bring to the dynamics of the family…”

Katherine Neis (2000) describes how for her the book created a “window into the lives of mentally-disabled children and the lives that lay before them and their families as a result of their condition”. This “not every-day subject”, (A Customer 9w1, 1999), is described as “intriguing” offering “readers the chance to look into the lives of ordinary people in an extraordinary situation” (A Customer 9x1, 2004). While sometimes representing out-moded views of disability, the ability to learn from fiction is clearly outlined by readers as well as their interest in learning about disability, pointing to the importance of accurate and well-rounded portrayals of disability within these novels.

Although readers were generally supportive of Jewel and her dedication to her family, a significant number of posters commented on their reaction to her “sacrifice”. While many readers supported her choices, others felt that this character sacrificed her other five children and her husband in order to care for Brenda Kay, revealing both attitudes about the place of a child with a disability in the family, and raising questions about equity and equality within the home.

Many readers perceived Jewels actions as detrimental to the rest of her family. “Special educator” Mary Haunreiter (2000) for example confirms the reality of this scenario describing that in her experience “many mothers like Jewel who place their high needs child first.” Justine Cardello (2000) observes that “Yes, a special child like Brenda Kay needs special attention, but not at the cost of your whole family.” A Customer 9y1 (2000) remarks “I realize Jewel's Down's syndrome child needed her but not to the detriment of the rest of her family” and A Customer 9x1 (2004) feels that “it was terrible the way she abandoned her other five kids.” In addition to this other readers felt that the jealously and abandonment that would likely occur with her other
children were not addressed in the book. A Customer 9z1 (2000) says, “If you are looking for some insight into the psychological ramifications of having a disabled sibling, don’t look here. Everybody loves Brenda Kay and nobody seems to resent her.” And Books are like shoes (2005) posts that “having a mother give all of her energy to one sibling, no matter the circumstances, should have involved some instance of jealously and then guilt for feeling jealous”. This criticism, however, was not universal and many additional readers describe feeling that Jewel was simply doing what she needed to do as a mother, and that her faults only make her more human. While some readers such as Lia (2000) did not feel that Brenda Kay received disproportionate attention and that “‘Jewel'[sic] focuses on the unconditional love of a mother for all her kids, not only Brenda Kay the retarded child.” Others felt that in her situation she had no other choice. A Customer 9a2 (1999) writes “I really believe that if one has a child like Brenda Kay, there is no other choice but to devote your whole self to bringing her though life” and A Customer 9b2 (1999) observes that “I did not see Jewel as a woman who neglected her family for the sake of one child. Rather, I saw her as a woman who devoted much of her energy to raising her special child and who did not realize how much she was giving the rest of her family, as well”. Recognizing Jewel’s struggles with this situation A Customer 9c2 (2000) comments that “Jewel was acutely, and sadly, aware of how the care for her youngest child took away from time she would have spent with her older children.” Ercie Berwick (2000) upholds this stating “Yes, Jewel short changed the other members of her family due to the birth of a defective daughter, but human beings are imperfect, and they do not always deal with difficult situations in a perfect fashion”. Christeena (2001) agrees that “Although many readers may not like the fact that Jewel devoted her life to Brenda Kay much to the exclusion of her other children, it touched
my maternal heart to know that Jewel would not just whisk her off to an institution.” Noting the choices that must be made in the raising of differently abled children.

Contributors to these posts frequently identified their own experiences either professionally or personally with the experiences of Jewel and Brenda Kay. sajh (2001) writes that “I found her thoughts and feelings about Brenda Kay and her diagnosis of Down Syndrome as being almost identical to the process I went through at the birth of my daughter with Downs”. As a sister MelRose (2000) states the “portrayal of life with a mentally disabled family member was so incredibly true. I have a retarded sister, and so often through this book I felt it was her I was reading about”. As the “mother of a developmentally disabled daughter” Lfmp9 (2000) “could totally relate to this book…so typical of a mother's thoughts and emotions..when dealing with a child of special needs” She concludes “I suspect those who found this book boring are the same who turn away from these children…or feel uncomfortable with the segment of our society who is less than perfect....”. bmspoll@epix.net (1999) reflects on her experience writing that “Having a retarded daughter is heartbreaking; I know from personal experience, and I stopped to cry about 15 times during the reading of this very realistic novel. I was amazed at how clearly Lott could imagine and describe the issues, dilemmas and frustrations that families face when they have a family member like Brenda Kay. I could relate, and relate, over and over again.”

While some of the language and sentiment towards disability provided in this discussion is clearly outside of the context of critical disability studies, it is important to also recognize that which provides progressive and hopeful directions in the changing of societal perceptions and inclusion of disability. Readers identified their appreciation of the recognition of both the difficulties and rewards of having a child with a disability. Pamela Wolfe (2000) notes “It truely[sic] portrays the mixed blessing of a special child as well as the devotion and angst of a
loving mother and family.” Giving a more holistic presentation than may be provided by more stereotypical presentations that have been provided by other examples of disability in fiction. These “non-sentimental stories about families rearing children with handicaps are hard to find and I think this book qualifies as one.” (armchaircritic, 2000) While the role of Brenda Kay is criticized for not being fully developed (Twohounds, 2000,) failing to recognize that “ALL people with handicaps, regardless of their level of functioning, are real, full human beings (armchaircritic, 2000), it is recognized to ring true to those who have had similar experiences and to provide an “alternative point of view” (Just looking for a good story, 2006) than what is generally expected of a work of fiction about disability.

The book is seen to identify difference and disability as larger social issues, especially within the racialized context it is presented in. Writer, Business Owner (2008) sees the novel as one which “probes how the mother, father and siblings deal with and interact with a Downs syndrome child...paralleling, perhaps, today's autism pandemic”. Sabel (2007) sees the book as presenting “realistic and accurately reflect the culture and attitudes towards minorities (African-Americans and people with disabilities).” A Customer 9d2 (2000)Sees the novel as highlighting “the importance of the struggle to gain equality for the Brenda Kays of our world” and A Customer 9e2 (2000) identifies the larger issues of “compassion, forgiveness, disappointment[sic] and acceptance”.

Readers reported that this insightful novel has also provided them with a better understanding of Down Syndrome and provided an empathy that they would not have experienced prior to reading the novel. Janine Johnson (2000) says she “finished this book with a whole new perspective of what families really go through when raising a mentally challenged family member”. A Customer 9f2 (1999) is “very moved (and changed) by it… but it left me above all with a feeling
of hope.” And gene dude (2001) notes that while “Many of us have encountered [sic] mentally challenged individuals sometime in our lives…untill [sic] this book I never could empathize with having a Down Syndrome child of my own”. LaDonna Woodly (2000) notes that “It was the first book I’ve read that dealt with living with and loving someone with a disability”. A Customer 9h2 explains (1999) “I have never had any experience with Down’s Syndrome, and this novel made it a little more “real” for me”. The power that this novel has had to influence readers’ perceptions of disability and potentially their actions in the future is summarized by MelRose (2000) who writes “To feel these emotions so strongly, to become so engaged in a book as to let those emotions take hold, is all a person can ask from a book.”

**Discussion**

The discussion of each of these three novels provides insight into the ways in which people are reacting to and learning about disability through their consumption of popular fiction. Readers’ posts demonstrate that although some attention is given to writing style and assumed literary merit, the majority of discussion centres around readers’ connections with characters demonstrating that the social capital of a novel is not as important to them as their own connection with the story. This is of great importance when looking at the novel and the middlebrow reading of popular fiction as a tool of social change as this connection is not one which is studied readily in the analysis of novels. Readers repeatedly cite the ways in which they feel bonded with Trudi, with Icy and with Jewel. These connections are described in the characters ability to fit into readers’ own lives, as flawed, but good characters, either familiar or distant. They are frequently viewed based on their humanity, inclusive of their disability over a single characteristic. Rather than the more stereotypical presentations offered by peripheral characters, these main players demonstrate the popular novel as a location in which readers can
learn about disability, to lessen the gap between who is like them and who is not, while allowing these fictitious people to penetrate their reality.

The wide range of emotions that are described towards, Trudi, for example, are not focused on her disability. It is recognized as an important part of her, and that which makes up some of who she is, but she is a well-rounded character: petty, wounded, courageous and kind. Icy, a child, is more sympathetic, but is identified with in the shared loneliness and isolation that she feels along with readers’ recognized collective desire to fit in. Jewel on the other hand, speaks to the mother in many readers and helps them to understand some of the realities that may be faced by mothers with children with disabilities. Many of these posts, rather than diminish it, acknowledge and respect the diversity of these characters and their multi-faceted experiences.

The ability to learn from novels is highlighted not only by issues of disability but by the many social issues that surround these characters. Racial issues, violence, social class struggle, overcoming adversity, tradition, change and development, change in the traditional family, religion and religious confrontation, multiculturalism and immigration, grief, loss and love are all addressed by these three characters are commented on by readers. Readers describe their interest in and learning about a variety of issues, including the experience of German people during the Nazi regime and race relations in the American south. This indirect forum allows readers to learn without the pressure of a formal learning setting.

Lastly, the reading of these novels is demonstrated to have influenced reader’s conceptions of the need for change. This is specifically identified in relation to the acceptance and understandings of disability as they are presented in the novels. The acknowledgment of accepting ourselves and those around us for who we are, rather than trying to force people to change is celebrated as an
important lesson of the novels through these characterizations. The presentation of Jewel, Icy
and Trudi serves to “educate” (Caroline Gibson, 2013) and also allows for the opportunity to
normalize difference (Georgia_L_moses, 2001). The novel in general is seen as something that
“…gives us hope for the future” (A Customer 9g2, 2001).
Section 4: DISCUSSION AND CONCLUSIONS
Chapter 10
Discussion

This project originally asked “In what ways can the cultural meanings and discussion of meanings in the presentation of disability in popular culture books serve as a tool for social change?” Through the review and analysis of the numerous novels included in this sample and the characters identified with disabilities, I have been able to look at both the characterization of disability and readers’ discussion of those characters. The novels themselves show the presence of disability in fiction. This is evidenced by 54 of the 62 novels read containing characters with various levels and types of disabilities. New insight is found through the analysis of the discussion of these portrayals by readers and their subsequent interpretations of disabilities in the novels and in their own lives. The discussion itself can be seen as one pathway to the deeper understanding of social change.

In summarizing what I have found in reviewing readers’ online posts, three specific areas stand out in relation to the potentiality of the discussion of popular culture books to serve as a tool for social change. Each of these factors points to the significance of widely read and discussed novels and their ability to influence perceptions and the place of disability on a wider social scale, reinforcing the necessity of identifying novels as socially impactful in the lived realities of individuals and groups.

First the concept of traditional literary authority is challenged by the popular culture book club. This type of informal association, outside of the scope of traditional advanced education and literary criticism, through readers’ comments, demonstrates a wider scope of readers and access to a broad spectrum of interpretation. Beyond the constraints of formal criticism, readers are more at liberty to bring forth ideas and issues which are important and impactful to them. As
demonstrated through reader discussion, these ideas and issues are inclusive of the recognition of, approaches to and new and innovative ideas about disability.

**Second, this research highlights the recognition of emotion and emotional connections as driving forces in readers’ experiences of novels as described in chat rooms.** Readers tell of forming relationships with characters. Through these relationships characters with disabilities are frequently connected with by readers calling into question assumptions about otherness and the presumed distance between abled and disabled in this context.

Finally, **readers do, in fact, discuss disability in novels and its place on both individual and societal levels and this discussion in some cases demonstrates more progressive movement in the case of disability than is readily identified in disability studies literature.** Popular novels through this discussion are demonstrated as a way for disability and disability issues to enter the consciousness of a widespread readership. This opportunity to discuss disability in fiction serves to bring private issues to the forefront as well as to highlight the experience of disability on both individual and societal levels.

Based on the above-mentioned findings and the discussion of readings of the now vastly popular novels that have been included in the OBC I have come to several conclusions about the role of the middlebrow reading of fiction and the discussion of narrative in this sample as it relates to social change and disability.

**Popular fiction and the middlebrow reading of literature need to be reflected upon as forces of change in the consideration of the role of disability**

Disability is repeatedly cited as present in literature, but unaccounted for. The common portrayals of characters with disabilities are noted by disability writers to exist, but lack
interpretation (see chapter 1 for examples). These readily cited illustrations of the missing discussion of disability in literary fiction, however, are not necessarily representative of the discussion and recognition of disability found within the arena of genre fiction and middlebrow readings of literature demonstrated in this sample. Disability is, instead, shown, through many readers’ comments, to be present in their discussion. In contrast to the previously-noted lack of acknowledgement of disability, readers in this case, in addition to upholding stereotypes, also question presentations of disability, applaud insights into disability provided by characters and authors, and share life experiences with fictional characters. Experiencing novels on this basis demonstrates the importance and influence of both genre fiction and the middlebrow discussion of literary texts and challenges the all-too-frequent diminishment of popular interpretation and texts.

The selection of novels discussed in section two of this work span the spectrum of social capital and standards of literary merit. While readers show that they give some deference to the novels which are considered within the scope of literature, books they should read and authors they should know, much of the dialogue from this sample highlights a general lack of interest in and regard for what should be done in relation to these stories. While noting the ongoing relevance of literary analysis for some purposes, middlebrow reading and this lack of deference to convention is important because it offers a supplementary way to view reading and demonstrates the impact that novels are having in everyday readers’ lives and, thus, the importance of studying this effect. The reader posts reviewed in this sample show that consumers feel free to like or dislike novels based on their personal connections with the book and its characters. Showing a high level of indifference for literary value, and a preference for personal interpretations, readers openly assert their opinions about books and their characters and describe them most frequently
based on the value of books to them personally. This forum, open to anyone with the ability to read, use, and access a computer, reduces barriers of power and privilege, encouraging a broader interpretation of novels. Looking at the novel as a perpetuator of social truth and values (i.e. Eagleton, Williams) and linking art and reality, the voices of everyday readers allow us to see novels in unique ways. This sample of dialogue and, specifically, the discussion of disability within these novels, provides a window into the perspectives about disability and impact of the presentations of disability on readers. These loosely structured forums are demonstrative of what people are generally reading and some of the truths and values that they take from these presentations. Within this context readers openly identify with, question, learn from and challenge the characters that they meet. These interpretations of disability provide presumably honest discussion and access to the ways in which disability is being both presented and interpreted by readers, allowing, for a differential but influential kind of analysis.

The interpretation of literature approached by the masses is frequently disparaged by experts as inconsequential and irrelevant. By taking the exploration of novels to the people, we are provided with increasingly insightful information about factors which shape readers’ perspectives and understandings. Using widely read novels and readers’ comments about them offers a challenge to traditional literary authority through the inclusion of popular interpretation as an additional and valid perspective. We are able to see what people are reading in the mainstream and how they are reading that information and their resulting ability to form and shape societal understandings of disability.

Using the discussion of OBC novels as a sample, both challenges literary authority and also brings questions about the power and influence surrounding readers based on Winfrey’s impact as a cultural figure. While her role in this research does not go beyond her ability to provide me
with a large sample of widely read novels and supplementary reading material, her control of readers’ interpretations must be considered in relation to the analyzed discussion. Looking beyond the televised/web-based book club episodes, this research includes readers’ discussions from a variety of book review and book talk sites, including the OBC website. These readers demonstrate a significant freedom in their discussion including matters far beyond the scope covered by Winfrey and the OBC website. For example, Winfrey is cited as focusing her discussion of novels on the writer’s process, and emotional connections with the books. (Illouz, 2003). While the emotional aspect of reading is widely discussed by readers, her focus on the writing process is rarely brought up in online discussion. By the same token, while disability is mentioned in some of the reading questions, the scope of the discussion of disability found in reader posts far exceeds what might be expected from the direction of the recommended questions. While clearly this cultural icon is a factor in demarking contemporary taste in reading, directing discussion through reading questions and reflective of Winfrey’s personal interests, the overall discussion surrounding the novels spans significantly beyond the program directed discussion both in time and scope.

Books in this context are set forth in a generally friendly and unintimidating environment, inclusive of a wide scope of readers and discussion contributors. Participants show through their comments their level of comfort in putting forth their own views and opinions about the books and their characters. In this often promising illustration, readers show through their discussion of books and recognition of disability, that unlike in the cited study of literature where disability has been ignored, in popular discussion disability and the role of disability can find a voice.

**Readers identify fiction as important to our understandings of difference**
More than any other comments, readers refer to their like or dislike of a character based on their ability to understand, connect with and explore their lives whether similar or different from their own. Further, more frequently than any other aspect of the characters discussed were readers’ comments about the emotional connections that they shared with characters. The most striking aspect of these connections is the shared experiences that readers describe with characters with disabilities. In the disability studies field we frequently speak of the “otherness” of people with disabilities and our societal tendencies to separate “us” from “them”. This clear divide was not so evident in reader’s discussions. In their posts about characters with disabilities, their difference was repeatedly described as something readers shared in or had experienced in their own lives. This sharing of lives was also described as making people with lives different from their own seem less disparate. These examples demonstrate that familiarity seems to breed respect for difference, recognizing commonality and individualizing characters. The well-rounded characters presented such as John Singer, or Trudi Montag, left many readers feeling connected with people with disabilities in a way that they had not been before. Through the sharing of the day-to-day lives of these characters, readers describe finding commonality as much as difference. Ordinary or extraordinary, the very personal feelings of John Singer, the brutal rape of Delores, Trudi trying to stretch her small body to be taller like the other children, or Jewel’s attempts to meet the needs of her family are shared with and among readers. The intimate details of seemingly real-life, including life with a disability are shared openly through the creation of fiction, opening the discussion of private life in a public forum.

Readers describe the ways in which they actively seek different experiences through fiction and the ability to relate these experiences to their own, whether that is the description of a foreign country or region, a rich or poor life. Books are described as entry points into different lives and
in this case into the lives of people with disabilities. Readers indicate that they experience these characters and relate to them as real people. The details of life that are shared in fiction, the private thoughts, embarrassing moments, that in reality we may never share with others, include readers through story. While on the one hand this can be seen as voyeuristic, the flip side of this is the finding of commonality within diversity. Readers share extensive discussion about the concept of a shared humanity. While recognizing that the life of Delores Price, for example, is not their own, people connect with her and find a common ground and an emotional connection with this true to life character.

Characters flaws are also frequently identified as the point of connection with readers. The character of Patty in Franzen’s *Freedom* was identified as representative of some of the more unsavoury characteristics present in us and also demonstrates readers’ love for characters based on both their goodness and their flaws. Chele789 (2011) sums this up noting “I loved them, identified with them, or sometimes thought they were just plain gross!” Lamb’s Delores is likewise seen by readers as heroic, sympathetic, full of self-pity, vulnerable, selfish and unsure. Feeling as if they have shared in the experience presented in the novel, readers describe feeling part of the community and sharing in characters joy and pain. The ability of authors to create this sense of attachment and shared emotion is the mark of the power of the novel. The idea of empathy and its connection with novels has come to light more recently in research (see for example Chiaet, 2013, Oately, 2011, Keen, 2007) highlighting the ability of books to bring difference closer to readers.

Realistic representations of characters with disabilities have the ability to deepen understandings and to integrate and to include rather than to scapegoat (Adelson, 2005). Some examples of novels which celebrate difference and provide more accurate, representative, and visible
presentations of disability to encourage discussion of difference and the role of disability in the future include:

<table>
<thead>
<tr>
<th>Author</th>
<th>Publication</th>
<th>Title</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dunn, Katherine</td>
<td>1989</td>
<td>Geek Love</td>
</tr>
<tr>
<td>Evison, Jonathan</td>
<td>2012</td>
<td>The Revised Fundamentals of Caregiving</td>
</tr>
<tr>
<td>Henderson, Emma</td>
<td>2010</td>
<td>Grace Williams Says It Loud</td>
</tr>
<tr>
<td>Itani, Francis</td>
<td>2003</td>
<td>Deafening</td>
</tr>
<tr>
<td>Lethem, Jonathan</td>
<td>2000</td>
<td>Motherless Brooklyn</td>
</tr>
<tr>
<td>Nussbaum, Susan</td>
<td>2013</td>
<td>Good Kings Bad Kings</td>
</tr>
<tr>
<td>Picoult, Jodi</td>
<td>2010</td>
<td>House Rules</td>
</tr>
<tr>
<td>Wood, Patricia</td>
<td>2007</td>
<td>Lottery</td>
</tr>
</tbody>
</table>

Looking at the strong emotional connections that readers describe in relation to characters with disabilities, it is evident that fictitious presentations of disability have the power to have profound effects on readers. Realistic representations have the ability to deepen understandings of disability and the societal role of disability, encouraging new ways of thinking, and the potential for progressive attitudes and actions towards people with disabilities.

**Talking about books is demonstrated to bring a new dynamic to reading about disability giving an additional layer of information and a reported sense of collective responsibility**

Readers’ discussions demonstrate that people are interested in disability in productive ways. Though they may not always know why or how to gain insight into disability issues, or have even chosen the novel in which disability is presented, their comments demonstrate more than a morbid curiosity about disability and disability issues. The question becomes, then, where does this take us? While this can be viewed as the creation of spectacle or misplaced curiosity, it can
also be regarded as an interest in difference and an attempt to understand different lives. While this research upholds the representation of cultural stereotypes and tropes in the presentation of many of the peripheral characters with disabilities, the discussion of major characters frequently challenge these long held assumptions about both a lack of conversation about characters with disabilities as well as a recognition of the role of disability in society.

In the cultural study of disability we accept that readers consume stereotypical presentations of disability and the flat portrayal of these characters as cultural knowledge. While many readers do uphold such contentions, an additional faction of these readers do not accept the simple, clichéd presentations of disability that are written and question the creation of these characters. Through not only reading about these issues, but readers’ willingness to dig deeper and to query the typecasts put before them and to bring forth these issues in a public forum demonstrates their interest in and concerns about such presentations. While peripheral characters with disabilities are more readily identifiable as stock, and stereotypical characters and metaphors upholding ableist perspectives than those in more prominent roles, this kind of depiction is not wholly accepted by readers. Those who post comments consistently question presentations and demand more of authors in terms of these flat illustrations and the inclusion of disability as a part of stock characters. Through their discussion readers repeatedly do not accept disability as a reason for evil behaviour and readily raise concerns about the lack of exploration of malevolent characters, their backgrounds and the reasons for their behaviour. Flat or unexplored presentations, as demonstrated by many readers’ comments were not accepted as realistic regarding the characters they were said to portray.

Bringing forth further discussion, readers also frequently describe the ways in which they view disability as a wider social issue based on their interpretation. While not only being fused with
other significant social issues some of which include race, gender, socio-economic status, and social mobility, disability was identified by many as holding a place within this scope of societal concerns. Once again the public dialogue surrounding these issues brings them from the solitary practice of reading to a public discussion forum with the ability to reach wider audiences and encourage greater social action in real life related to issues brought forth by fiction. Readers repeatedly noted that they did not enjoy reading deliberately political books, or novels that appeared to serve a political purpose, but that they frequently learned from and appreciated stories which caused them to recognize social issues in less direct ways. Readers wanted to discuss characters that make them think about their own prejudices, the idea of being disabled in a world that does not tolerate difference, about the experience of being different and the role of subjugation. All of these observations are noted to make readers reflect on their own behaviour and complicity and once again to discuss this complicity openly. Referencing society’s role in the treatment and acceptance of disability, readers discuss being challenged in their responses to disability, forced to identify the role of ignorance and fear related to disability and to learn new lessons for living through broadened minds more open to difference. Through these presentations and the ensuing discussion, disability and disability issues enter the consciousness of readers where they question the role and treatment of disability on a wider social level.

**Concluding Remarks**

The most significant remaining question after completing this analysis has been whether or not, while bringing disability into the consciousness of readers and creating dialogue about disability in a widespread forum, works of fiction written about characters with disabilities by non-disabled authors provide appropriate material for the pursuit of social change in the area of disability. Of
the 54 novels discussed in this selection, only one author self-identifies as a person with a
disability or has a visibly identifiable disability. This has led me to consider the issue of the
appropriation of disability experiences in these novels. I cannot claim to know if a presentation
of disability in a fictitious context outside of my own experience is realistic or how important
that realism is to the overall impact of the characterization. There is not a single experience of
disability, nor perhaps even a common thread that classifies this group as a single entity. I am
troubled, however, that the characters with disabilities described are not frequently written by
authors with disabilities. This being said, I also respect artistic freedom and the use of
imagination in the creation of representative fiction including the role of free speech in what
PEN Canada (2014) identifies as necessary in open and democratic societies. The question of
artistic freedom and ethics in writing has long been argued in relation to cultural appropriation
and most certainly in the area of disability (see for example Mills, 2000). The creation of fiction
is argued by Young and Haley (2012) while representing real things, insiders and their cultures,
as not an act of appropriation because cultures do not own subject matters but that they are part
of the public domain. They argue that anyone may write about their experiences or what falls
within the realm of their imagination. Wally Lamb writes as a woman and is praised for his
insight, while WP Kinsella has been strongly criticized for writing from the point of view of
Aboriginal people in works such as his collection of short stories Dance me Outside, but has also
been the recipient of many awards for his works including an honorary Doctorate from the
University of Victoria in 1991, The Order of British Columbia (2005) and the George Woodcock
Lifetime Achievement Award (2009). Male, British medical law professor Alexander McCall
Smith writes from the perspective of Precious Ramotswe, a female detective in Botswana, in The
No. 1 Ladies’ Detective Agency (1999). While the specific experiences described by these
authors may lack the insight of an insider, they do not take away opportunity for an insider to produce a similar work from a more experienced standpoint.

Young and Brunk (2012) identify cultural appropriation as harmful in two cases, firstly, when a violation of property rights occurs and, secondly, when such an appropriation attacks the viability of cultures and their members including through the threat of assimilation, discrimination, poverty or lack of opportunity. Looking to the premises of disability studies and particularly critical disability studies, several tenets challenge the writing of disabled characters by non-disabled authors. Goodley (2011) notes that it is “Fundamentally important that disabled people revise as well as deconstruct dominant modes of cultural production in ways that give voice to their potentialities (163)”.

The cultural model of disability identifies popular culture as a source which re-enforces the devalued place of disability in society. Disability, identified as an opportunistic device used in storytelling, is said to uphold dominant ideas about the able/disabled body divide and to maintain the notion of the demonized disabled body in order to maintain the domination of the able bodied. The creation of these fictitious characters can be seen in some ways as appropriated and exploited by able-bodied writers. Meeting Young and Brunk’s (2012) criteria of harm, the promotion of the hatred of, pity for, fetishization or patronization of people with disabilities does occur both in novels and in their interpretations by readers, causing a selection of them to fall into the category of harmful appropriation. While readers’ comments in some ways reflect these offensive realities, these creations have also been shown to serve many of the goals of disability studies. Presentations of characters such as Trudi and Delores, challenge marginalization and promote the importance of diversity, especially in terms of embodiment, not only in their presentation but more so in readers responses to them. Promoting disability awareness Icy was cited numerous times as a spur to assist disabled people in their fight for
equality and the battle for deinstitutionalization. Many other examples, discussed at length through this thesis, have been cited as offering new perspectives on disability, as well as an acknowledgement and respect for difference.

Since its inception, disability studies as a discipline has sought goals of societal transformation, the emancipation and democratization of people with disabilities. Critical theory is based in these same roots. The findings of this analysis of readers’ comments about disability in popular culture novels builds a role for fictional narrative in the formation of public opinion, both positive and negative, as well as the book club as an emergent public sphere. Using this example, while far from Habermas’ original ideas, attitudes, connections and conceptions of social issues are all identified through experiences of reading and the discussion of novels.

I was initially drawn to Habermas’s theory of the public sphere based on the concept of a democratic and participatory space for debate and critical thinking. This vision of an inclusive arena where the public takes charge of decision making in impartial terms paints an ideal picture of a progressive society. The online discussion of the novels selected for Oprah’s Book Club are representative of a new public sphere. The varied groups and individuals and their conversational contributions present a multiplicity of publics and some of their various goals, interests and priorities. From this public arena I have been able to pull and to synthesize a sample of public opinion regarding disability as it is presented in discussion forums.

Popular narrative demonstrates itself not as trivial, as it is often assumed, but as a powerful force in the formation of progressive public discussion related to disability. The open forum dialogue of novels upholds the tenets of disability studies, allowing for discussion of personal, domestic and experiential issues that demark the feminist refrain that “the personal is political.” Looking
to this more inclusive medium of discussion demonstrates both public spheres and a middle brow
approach to reading both literature and genre fiction as an entrance to some of the more
transformative, emancipatory and democratic goals of critical theory and critical disability
studies. This work has shown that popular culture book clubs provide us with an important
source of information. The communal act of discussion related to these reading groups
demonstrates an emergent public sphere which brings together a diversity of people to carry forth
issues that are important to them, expanding the scope of subjects to be discussed. The
discussion of these books brings them to life. Moving this experience from one of isolation to a
discursive exchange, this cultural knowledge holds the ability to bring closer the emancipation
called for by both disability and critical theory scholars alike.

While still acknowledging the binary relations of normalcy and difference and the often
oppressive conditions of society, readers and the presentation of disability in widely read fiction
can work towards a valued reception and presentation of disability in its multiple forms.
Readers’ discussion points to the possibilities for change through the reception and identification
with characters with disabilities, while encouraging and creating new ways of thinking about
disability.
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http://www.amazon.com/review/R1JVRKD49VN8SL/ref=cm_cr_pr_perm?ie=UTF8&ASIN=B004S1WMHG

http://www.amazon.com/review/R2WQZJUB2558F4/ref=cm_cr_pr_perm?ie=UTF8&ASIN=068484477X

http://www.amazon.com/review/R3KGMYH7R798PB/ref=cm_cr_rdp_perm


http://www.amazon.com/review/RVKJEPEH8PGG/ref=cm_cr_pr_perm?ie=UTF8&ASIN=0142000205

http://www.amazon.com/review/R3F8JN2RKX7GAU/ref=cm_cr_rdp_perm?ie=UTF8&ASIN=0140244824


http://www.amazon.com/review/R3OD8M8UE4XB2L/ref=cm_cr_rdp_perm?ie=UTF8&ASIN=068484477X

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Tina Pangourelias. (2000, May 3). If I could give it 10 stars I would!. Message posted to http://www.amazon.com/review/R1J1359OE0X8KO/ref=cm_cr_pr_perm?ie=UTF8&ASIN=067157650X


Tracey. (2006, April 12). Comedy and pain all wrapped into one... Message posted to http://www.amazon.com/review/R2A81YNIXKVTX1/ref=cm_cr_rdp_perm?ie=UTF8&ASIN=0671003755


Tripathi, S. (2004, January 5). The Steinbeck opus, difficult to trudge thru, but worth it!. Message posted to http://www.amazon.com/review/RKE822HIJB10B/ref=cm_cr_rdp_perm?ie=UTF8&ASIN=0142004235


Wildwoodldy. (2000, February 20). Life as it really is. Message posted to http://www.amazon.com/review/R2IX5UCU8PQ8MR/ref=cm_cr_pr_perm?ie=UTF8&ASIN=0671042572


Wisdom Falls between the leaves of truth. (2010, February 15). In the end, one woman rises up; overcomes her odds. Message posted to http://www.amazon.com/review/R4EUSQNBLNS6P/ref=cm_cr_rdp_perm


Wolfensberger, W., National Institute on Mental Retardation, & Canadian Association for the Mentally Retarded. (1972). The principle of normalization in human services. Toronto: Published by National Institute on Mental Retardation through L. Crainford.


## Appendix A: Book Index

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<th>Division of:</th>
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Appendix B: Code Book

CODE BOOK:

Unit of Data Collection: n=Each individual book (novel, short story -excluding self-help, memoir, non-fiction) included in the selections of Oprah’s book club for the duration of the club from 1996-2011

1. General Information
   a. Book ID: ID number as indicated on the book ID list
   b. Coder ID: Individual coder number
   c. Book Title: Title of Novel
   d. Publisher: Name of original publisher
   e. Original Date of Publication: Date of original publication
   f. Year included in Book Club: Club year

2. Author Information
   a. Author name: Last, First
   b. Author currently living? Author living as of November 12, 2010
      1- Yes 0- No
   c. Author Nationality? Indicate country of citizenship and birth (all that apply)
      a. America 1- Yes 0- No
      b. Canada 1- Yes 0- No
      c. Germany 1- Yes 0- No
      d. Nairobi 1- Yes 0- No
      e. South Africa 1- Yes 0- No
      f. Haiti 1- Yes 0- No
      g. Columbia 1- Yes 0- No
h. Other 1- Yes 0- No

d. Author identified in “about the author” as PWD?

About the author is the short description given about the author usually located on the jacket or inside cover. Often accompanied by a photo.

Disability is defined for this research based on the World Health organization definition as having impairments (problem in body function or structure), activity limitations (a difficulty encountered by an individual in executing a task or action), and participation restrictions (a problem experienced by an individual in involvement in life situations)

a. 1- Yes 0- No 2 – Cannot be determined

e. Author visibly identified as PWD in author photo?

If book provides a photo of the author, is a disability visibly identifiable?

a. 1- Yes 0- No 2 – Cannot be determined

f. Is disability present in a character in novel? 1- Yes 0- No  (If “No” stop here)

Disability is defined for this research as a character who is treated in the story as: based on the World Health organization definition, having impairments (problem in body function or structure), activity limitations (a difficulty encountered by an individual in executing a task or action), and participation restrictions (a problem experienced by an individual in involvement in life situations)

4. Other Relevant Information:

a. Geographic location of story? Where most closely resembles where the story takes place (check all that apply)

   1. Urban 1- Yes 0- No
   2. Suburban 1- Yes 0- No
   3. Rural 1- Yes 0- No

b. Region of story: Where most closely resembles the region where the story takes place (check all that apply)

   1. US – West Coast 1- Yes 0- No
   2. US – East Coast 1- Yes 0- No
   3. US – Central 1- Yes 0- No
4. US – South  1- Yes  0- No
5. Canada  1- Yes  0- No
6. Europe  1- Yes  0- No
7. Other  1- Yes  0- No

c. Era of Story: *Describe what most accurately represents the time period in which the story takes place (check all that apply)*

1. Contemporary (1975-present)  1- Yes  0- No
2. Mid 20\(^{th}\) Century (1940-1975)  1- Yes  0- No
3. Early 20\(^{th}\) Century (1900-1939)  1- Yes  0- No
4. Pre-20\(^{th}\) Century  1- Yes  0- No

3. Disability General Variables

a. Character Name: *Name of each character with disability – create separate column for each individual in the novel – complete all info for each character to “Other Relevant Information” Section*

b. Brief Description: *A brief but distinguishing description of each character coded (characters with disability(ies))*

c. Character ID: A unique 4 digit number beginning with 0001 (complete for each character to end of this section 3)

d. Type(s) of disability identified in book  *Indicate all that apply*

1. General Disability (Physical/Mental)  1- Yes  0- No
2. Mobility  1- Yes  0- No
3. Intellectual  1- Yes  0- No
4. Auditory  1- Yes  0- No
5. Vision  1- Yes  0- No
6. Mental Health  1- Yes  0- No
7. Addictions  1- Yes  0- No
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e. Character Role?

*Indicate on scale from 1-5, 1 as most protagonist (the leading character, hero, or heroine) to 5 as most antagonist (the adversary of the hero or protagonist) the perceived role of each character with a disability.*

1------------2---------------3---------------4--------------5  
Protagonist                  Neutral                  Antagonist

f. Age grouping: *Approximate chronological age of character based on descriptions and interactions with others*

1. Child: the character is estimated to be 12 years of age or younger
   1- Yes     0- No

2. Adolescent: the character is estimated to be 13-19 years of age
   1- Yes     0- No

3. Young Adult: the character is estimated to be 20-39 years of age
   1- Yes     0- No

4. Mature Adult: the character is estimated to be 40-64 years of age
   1- Yes     0- No

5. Elderly: the character is estimated to be 65+ years of age
1. Male
2. Female
3. Transgendered
4. Unable to determine

h. Socio-Economic Status of character with disability? An estimate of character’s SES

1. Upper or upper middle class: An individual who is well-to-do or moderately well-to-do. Not dependent on monthly income to live
2. Middle class: An individual who works for a living, has all the necessities and some of the luxuries but is dependent on working for livelihood
3. Working class: An individual who does not have the necessities of life or just barely has the necessities and no luxuries.
4. Unemployed: May be unemployed or on social assistance
5. Unable to determine

i. Character with disability employed? Employment status of character with disability

1. Employed 1- Yes 0- No
2. Unemployed 1- Yes 0- No
3. Child 1- Yes 0- No
4. Slave 1- Yes 0- No
5. Retired 1- Yes 0- No
6. Unable to determine 1- Yes 0- No

j. Main sources of information on person with disability? Main character who provides information about character with disability

1. Individual 1- Yes 0- No
2. Family Member 1- Yes 0- No
3. Friend 1- Yes 0- No
4. Other 1- Yes 0- No

k. Outcome of character with disability? What happens to the character with disability at by end of the story (check all that apply)

1. Institutionalization (hospital, jail) 1- Yes 0- No
2. Death 1- Yes 0- No
3. Overcome (no longer disabled) 1- Yes 0- No
4. Inclusion (accepted as is) 1- Yes 0- No
5. Other 1- Yes 0- No
6. Unable to determine 1- Yes 0- No

5. Social Capital

a. Best Seller Hard Cover? Was the book on the NY Times Best Seller Hardcover List – Available from the Library and Book Trade Almanac

1. Year of Publication 1- Yes 0- No 2- N/A/
2. Club Year 1- Yes 0- No 2- N/A/

b. Sales figures (publication year): where available retrieve from the Library and Book Trade Almanac
c. Sales figures (club year): where available retrieve from the Library and Book Trade Almanac
d. Award Recipient? Has the book been the recipient of the following awards? Information available from awards list.

1. Pulitzer 1- Yes 0- No
2. Man Booker Prize 1- Yes 0- No
3. Giller Prize 1- Yes 0- No
4. National Book Award 1- Yes 0- No
5. National Book Critics Circle Award 1- Yes 0- No
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<td>Author in Bloom’s “Literary Canon”</td>
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<td>l.</td>
<td>Is the Oprah Book Club Logo located on the novel you are using?</td>
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## Appendix C: List of Awards

<table>
<thead>
<tr>
<th>Organization</th>
<th>Book</th>
<th>Author</th>
<th>Ranking</th>
<th>Number of times Author in lists</th>
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<tr>
<td><strong>Modern Library 100 Best Novels (Board)</strong> - selected by the ML Board</td>
<td>Sound and the Fury</td>
<td>Faulkner, William</td>
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<td>The Heart is a Lonely Hunter</td>
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<td><strong>Canadian Readers top 100 of all time</strong> - poll by Indigo books</td>
<td>A Fine Balance</td>
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<td>East of Eden</td>
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<td>I Know this much is True</td>
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<td>The Poisonwood Bible</td>
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<td>100 Years of Solitude</td>
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<td>White Oleander</td>
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<td>The Corrections</td>
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