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#### Novel Conversations: Connecting with disability in three examples of popular fiction

Joanna Rankin, PhD, Instructor, Community Rehabilitation & Disability Studies
Cumming School of Medicine, University of Calgary
joanna.rankin@ucalgary.ca

Abstract: Examining how readers of popular fiction respond to characters with disabilities and characters immersed in the lives of characters with disabilities, this paper serves to contribute to understandings of the meanings that readers ascribe to disability in popular culture using the public sphere of online discussion. Specifically, I study online reader discussion of three characters, namely: Trudi in Ursula Hegi's (1996) Stones from the River, Icy in Gwyn Hyman Rubio's (1998) Icy Sparks and Jewel in Brett Lott's (1991) Jewel. I present findings from my analysis of reader discussion using readers' descriptions of their identified connections with characters with disabilities. While these connections challenge the othering frequently cited in presentations of disability through readers' recognition and appreciation of the well-rounded characters beyond traditional disability tropes, the unmet potential of reader discussion to challenge the status quo is also demonstrated through readers' failure to expand these connections beyond the pages of the novels.

Keywords: Disability, Novels, Public Opinion, Public Sphere, Online Discussion, Book Club

Novel Conversations: Connecting with disability in three examples of popular fiction

Joanna Rankin, PhD, Instructor, Community Rehabilitation & Disability Studies
Cumming School of Medicine, University of Calgary
joanna.rankin@ucalgary.ca

I have loved to read as long as I can remember. Some of my happiest memories of childhood are going to the library, coming home and curling up with my new collection of books, not knowing where to start amidst the selection of new worlds 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 each night. Like many readers, I learn from books, about history, about geography, about lives both similar and different from my own. Characters I come to know, to love and hate, teach me about life, inspire me, and make me laugh and cry. Many novels have touched and even changed my life. I recall the heavy heart I felt reaching the end of Gone with the Wind (Mitchell, 1936), a big, long, indulgent novel. I felt a sadness at not only what happened in the story, but also that Rhett and Scarlett and the world that accompanied Tara would no longer be part of my daily routine. I reminisce about Holden Caulfield, my first literary love, whose outlook and adventures soothed my adolescent soul in *The Catcher in the Rye* (Salinger, 1951), and Sethe, in Morrison's *Beloved* (Morrison, 1998) introduced to me in a second year English course, who haunts me to this day. These stories are windows 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. 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. Reflecting my experience, others describe a connection with novels and characters and the unique shared humanity experienced through reading. Novelist George R.R. Martin (2011) exemplifies this writing that "A reader lives a thousand lives before he dies..."

Purpose

The purpose of this paper is to contribute to understandings of the meanings that readers ascribe to "disability" in popular culture through an examination of how readers of popular fiction respond to characters with disabilities, and characters immersed in the lives of characters with disabilities, using the public sphere of online discussion. Specifically, I study online reader discussion of three characters, each of whom has a disability or is immersed in the life of a character with disability within a work of popular fiction centered on disability, namely: Ursula Hegi's (1996) Stones from the River, Gwyn Hyman Rubio's (1998) Icy Sparks and Brett Lott's (1991) Jewel. To achieve this purpose, I define disability in accordance with the World Health Organization definition as entailing 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) (WHO, 2011). This definition has been used to reflect the medicalized understanding of disability most closely represented by readers and authors. As in lived experience, readers tend to *interpret* representations of disability through a medicalized view, even if the author has not had this intent rather than reflecting the more socially conceived notions of disability common in disability studies.

I provide background for my study beginning with highlighting the impact of popular fiction within popular culture and I follow this with a discussion of disability portrayals in popular fiction in general and how these portrayals may illuminate meanings of disability in public opinion. I then present the theoretical anchoring of my study in terms of Habermas'

examining evidence of reader described connections to characters with disability and characters who are immersed in the lives of characters with disabilities. To focus my study I use a textual analysis, an approach described by McKee (2003) as allowing researchers to come to informed conclusions about the interpretation of text. Accordingly, I gathered and examined data about the ways that people understand the world, how they make sense of the world, and how they fit into the world in which they live (McKee, 2003) and how each of these factors is informed by the characters with disabilities that they discuss. I present findings from my analysis of reader discussion of characters with disabilities, or characters immersed in the lives of characters with disabilities, in the form of links I identified between readers descriptions of their connections with characters and the potential for reader discussion to both uphold and challenge the status quo through the formation of public opinion.

#### **Background**

Recognizing the Impact of Popular Fiction

Fictional presentations hold power to shape public opinion through emotional responses, (Spelman, 1997) closeness to characters (Long, 2003), and empathy (Davis, 2008). The study of literary works of fiction has developed into, and is maintained as, a valued academic discipline (Eagleton, 2003). The roles of emotion and connectivity in the study of fiction though, has been devalued and reflects ascribed low levels of cultural capital (Mazzocco and Green, 2011, Oately, 2011). Bourdieu's cultural capital, Farr (2005) explains is based on "cultural elite sensibilities...that are socially scarce" and the disavowal of mass culture. Looking to the readers of the novels of Oprah's Book Club (OBC) and their interpretations of disability in these novels, challenges the sacred nature of literary elitism and confronts the notion of literary expertise and

widespread disdain for the popular based on the notion of cultural capital. Resistance to this blurring of boundaries is shown through Rooney's (2005) observation that in serious circles "It's just not hip to be comfortable with Oprah's Book Club." (33). This sentiment is upheld by literary author Jonathan Franzen's refusal appear on the Oprah Winfrey show when *The Corrections* (2001) was featured in the club because he felt the novel was "a hard book for that audience" (Schindehette, 84,cited in Rooney, 2008). This is echoed in examples such as the prideful exclamations of independent book sellers advertising with slogans such as "books you won't see on Oprah" (Rooney, 2008, 1).

Culturally esteemed novels are rarely reflective of what the public is reading. While Farr (2005) recognizes that 75% of fiction is bought and read by women, and fiction markets are dominated by female authors, the majority of award winning novels and authors (e.g. Nobel Prize, National Book Award, Pulitzer Prize, Giller Prize) are dominated by men. Since the time of Farr's research, these trends continue. Women author's consistently win significantly fewer major literary prizes than their male counterparts. From 2005-2017 female authors won a total of eighteen of the above listed awards where male authors won thirty-three.

Award	Male	Female
Nobel Prize for	9	4
Literature		
National Book Award	9	4
Pulitzer Prize for	7	5 (no award given in
Literature		2012)
Giller Prize	8	5

(nobelprize.org, nationalbook.org, pulitzer.org, scotiabankgillerprize.ca)

This table shows the number of major award given to male and female authors from 2005-2017

Correspondingly, consideration of what is being read and reacted to by the widespread, pronouncedly female reading audience is minimal. An assumed passive reader stance including

a lack of serious analysis, as well as the idea of "reading for pleasure" continue to be linked to femininity and associated with the non-serious and devalued readers identified by Long in 2003. The popular culture book club and especially the OBC, on which this research is based has been critiqued 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), the resulting discussion of novels as Orwellian groupthink (Farr & Harker, 2008) and as toxic entertainment which contaminates culture (Abt & Mustazza, 1997). I believe these assumptions that entail being highly critical of popular fiction's exploitation of what are considered easy issues, which play on sentiment fall short by failing to appreciate the impact of popular reading and its resulting discussion.

In this study, I move outside these guidelines to examine the devalued voices of popular fiction readers, recognizing the role of popular reading in the context of disability along with scholars who look to the possibilities provided by readers connections with characters, to explore the impact of what Oatley (2011) notes as "...the possibilities, the vicissitudes and the emotions of being human" (196) that accompany the discussion of books. Readers spend hours with characters and settings as they move between reading fiction and living the reality of their own lives. The voices of readers, who have obtained and read a novel then taken time to share their opinions of, and experiences with, the novel, bring a new voice to our understanding of the meaning of novels and uphold Moody's (cited in Cheyne, 2012) observation that "popular narrative is not trivial". This study is a redress to the devaluation of the consumption of popular fiction and is anchored in feminist and cultural scholarship aimed at re-evaluating the significance of the emotional and connective capacity of readers' experiences outside the boundaries of cultural elitism. I seek to elevate and analyze the online voices of readers as they

describe their responses to, and connections with, characters with disabilities and characters immersed in the lives of characters with disabilities.

While reading itself transports us, discussing books adds a layer to the experience of novels in readers' lives. Discussion solidifies the connections experienced between readers and characters (Long, 2003). By collecting data similar to that collected from studies of more traditional book clubs (see for example Long, 2003 or Radway, 1997) the online discussion of novels, offers a rich and temporal source of information regarding the ways in which individuals talk about novels, connect with characters and shape public opinion based on their interactions with characters and scenarios.

# **Disability in Fiction**

A historical review of fiction provides abundant examples of disability from ancient mythology to the present. In fact, presentations of disability in novels have been widely studied and are identified as ubiquitous across cultures and time (Shakespeare, 1997). These presentations have been identified 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, as a narrative prosthesis to propel a story forward (Mitchell & Snyder, 2001); a means of imposing standards of normality, conformity and productivity (Davis, 1995, Keith, 2001); a gendered issue (Fine & Ash, 1988, Morris, 1991); and as a contributing element of social and cultural identity (Mitchell & Snyder, 2002, Thomson 1997a, 1997b), and a reflection of belief systems (Stiker, 1999).

The role of culture in disability research has grown in recent years, and the developing study of disability in fiction demonstrates a broad range of areas of interest, considering topics such as, the continued use of stereotype (Wheatley, 2017), children's literature as a challenge and upholder of societal attitudes (Adomat, 2014), the role of affliction in our literary cultural traditions (Holmes, 2017), questions of inclusion (Murray, 2017), disability and masculinity (Bourrier, 2015), genetics, bio-ethics (Barker, 2013) and bio-politics (Mitchell, 2015), the relationship of race and disability (Jarman, 2017) and the role of disability and rhetoric (Dolmage, 2017). Attention has also been given to extending the exploration of the role of disability in specific genres such as crime fiction (Jakubowicz & Meekosha, 2004), romance and genre fiction more generally (Cheyne, 2011, 2017), science fiction (Allan, 2013, Berube. 2005), comic books and graphic narratives (Foss, Gray, & Whalen, 2016) and young adult fiction (Hughes, 2017). Analysis around specific disabilities portrayed in fiction such as Autism (Rodas, 2016) and blindness (Bolt, 2014, 2005) are interwoven in these writings along with reapproaching traditional literary texts from a disability perspective, such as in Bolt, Rodas & Donaldson's (2012) volume on Jane Eyre, Oswald's (2016) contemporary analysis of The Sound and the Fury, and Hall's (2012) analysis of modern fiction.

#### **Theoretical Framework**

Jürgen Habermas presents a theory of the public sphere based on ideals of public debate. Habermas recognizes the role of citizens in the deliberation of common issues and competing ideas towards the formation of public opinion. Hauser (1999) goes beyond Habermas' more formal conceptions of deliberation to identify the role of everyday discussion or "vernacular". Hauser points to "rhetoric", persuasive communication and eloquence as components of language structure, function and patterns of use, and notes how these constitute powerful tools in

"discourse" and the formation of public opinion. This study takes up Hauser's more day-to-day conception of public sphere as described by Spoel, Harris and Henwood (2014) who write "Where Habermas idealized the salon and tearoom, Hauser privileges street corners, bars, and bowling alleys". I argue that readers' "rhetoric", and "discourse", or what I refer to more simply as their discussion and debate, about characters with disabilities, within an online "public sphere", constitutes an important part of the discussion that shapes public opinion and ultimately, cultural perceptions of disability. I treat readers' discussion and debate as a sample of interactions of the sort identified by Hauser and as constituting the development and proliferation of discussion and debate for which Habermas argues. I analyze this sample for its capacity to shape public opinion in settings which are informal, on-going, and without official rules or boundaries. I argue readers' movement from the private act of reading about, to online public discussion of, disability contributes to the shaping of public opinion of disability. This open forum is a venue for the expression of multiple perspectives, debate and political participation, which are foundations of a public sphere (Calhoun, 1992, Gripsrud, Moe, Molander & Murdock, 2010). I interpret online discussions about disability as part of a public sphere alongside disability studies theory which challenges the devaluation, historical oppression and exclusion of people with disabilities. I use this theory as an abstraction and set of tools rather than an absolute which as a disability scholar shapes how I look at these issues.

#### Methodology

# Design

I used a textual analysis study design to guide my examination of online discussion of disability. Textual analysis entails examining text to gain an understanding of how those who produced the text make sense of phenomena (McKee, 2003). I treat those whose discussion

board posts are about disability as the producers of text. I apply textual analysis to a case comprised of online discussion of characters with disabilities and/or characters immersed in the lives of characters with disabilities in three novels with the aim of understanding how readers make sense of disability and to draw conclusions about some of the ways in which this may contributes to the formation of public opinion about disability.

# **Broader Sample**

The three novels comprising my subsample for this study were selected from a broader sample for a study of disability portrayals, and readers' online discussions of disability portrayals, in novels included in the Oprah's Book Club (OBC) (Rankin, 2014). These novels were part of the popular talk show the Oprah Winfrey Show between 1996 and 2011. Novels from the more recent manifestation of the book club started in 2012 have not been included.

The original OBC recommended a total of 70 books and my broader sample includes 61 novels from the club recommendations which I selected given their inclusion of characters with disabilities and/or characters immersed in the lives of characters with disabilities. Non-fiction and children's books are excluded from the broader sample. The 61 novels were published between 1877 and 2011 and encompass English as well as English language translations, by authors from the United States, Canada, Ireland, Germany, Russia, Haiti, Columbia, South Africa, and Nigeria. Thirty-four novels were authored by women and twenty-seven by men. Twelve authors had won a total of fourteen major awards (Pulitzer, Nobel Prize in Literature, James Tait Black Prize for Fiction, National Book Award, Giller Prize, Boeke Prize, National Book Critics Circle Award and, Hemingway PEN Award). One author in the sample self-identifies as a person with a disability in the author description included within the novel. For the larger project from which this study has been developed, a content analysis was conducted to

quantitatively measure the occurrence and presentation of disability in novels and a textual analysis was used to interpret readers' discussion of disability.

The criteria of including only novels from OBC was developed in light of the cultural influence of OBC reflected in the fact that between 1996 and 2002, not one week passed without at least one OBC recommendations being on the best seller list (Farr, 2005). Corresponding online discussions have been widely available and have afforded me access to present-day, real-time reader discussions of disability in novels as well as a temporal source of discussions by readers who have posted comments over the past 20 years.

#### **Sub-sample**

This study entails an analysis of a case comprised of online discussion of main characters in three novels: Ursula Heigi's (1996) Trudi, in *Stones from the River*, Gwyn Hyman Rubio's (1998) Icy, in *Icy Sparks*, and Brett Lott's (1991) Jewel, in the novel *Jewel*. Discussions of these novels are targeted because within each of the novels, characters with disability, or characters immersed in the lives of characters with disability, are the protagonist and their experience with disability is central to the plot of the novel. Further, the three novels are included given the availability of online reader discussion content for analysis, a web search by book title on the three websites resulted in a minimum of one hundred online comments or posts. I treat the online discussion of disability portrayals in these novels as a sample of a public sphere and I examine readers' texts in terms of how ideas expressed in the texts uphold and/or challenge public opinions about disability. Using online discussion specific to these three novels affords a glimpse into the ways that novels, and the characters within novels, can illuminate and create meanings around disability. Spanning geographic and chronological settings, the lives of Trudi, a "Zwerg", the German word for dwarf, Icy, a child with undiagnosed Tourette's Syndrome, and

Jewel, the mother of six, whose youngest child Brenda Kay has Down Syndrome, have inspired readers' to discuss disability through online posts in ways that both reflect and shape public opinion.

#### **Data collection**

Data in the form of online discussion posts pertaining to characters with disabilities and/or characters immersed in the lives of characters with disabilities from the three novels were collected from three online book discussion mediums, namely the OBC website, Amazon.com and Good Reads, which became a subgroup of Amazon in 2013 (Chandler, 2013). These websites were chosen for their accessibility to readers and the range of formats they encompass. The OBC website provides a small number of posts from readers ranging from in-depth discussion to short reviews. Some posts are in response to guided questions, while other posts are unprompted. By comparison, both Good Reads and Amazon provide access to a large number of posts which contain reader reviews, discussion and interactions. A total of 902 posts from the three websites, "published" between 1997-2013 and ranging in length from a single sentence to just over one single-spaced page, were reviewed.

#### **Data analysis**

Analysis began with reading and reviewing all available posts novel by novel to gain familiarity with the content of the data. The largest number of posts pertained to *Stones from the River* (357), followed by *Jewel* (310) and *Icy Sparks* (235). I initially divided posts into smaller themes for analysis including: 1. Reasons readers' love/hate the book, 2. Ideas that challenge literary authority 3. Expressions of emotional connections with characters, and 4. Discussion of disability and other social issues. My next stage of analysis entailed examining posts for inclusion

of discussion of disability or characters with disabilities. I examined posts in terms of whether readers were discussing peripheral versus main characters and whether readers gave evidence of viewing disability as central to the novel. Disability-focused posts that pertained to main characters and gave evidence of disability as central to the novel comprise my final sample of 402 posts. These posts were drawn from each of my four initial themes although relatively few posts were drawn from the "ideas that challenge literary authority" theme. I cut and pasted my sample of posts into a word document according to their initial theme then conducted an in-depth textual analysis to identify what is in the text and giving it a name or theme (McKee, 2003; Berg, 2004). Themes were chosen to "reflect all relevant aspects of the messages and retain, as much as possible, the exact wording used in the statements (Berg, 2004, p. 268) and I followed the interpretive practices of constant comparison in attempting to uncover patterns (Berg, 2004). I generated three thematic streams including: (1) Connecting with disability in a cruel world, (2) Collective suffering, and (3) Cautionary tales of motherhood.

#### Postings Reviewed

Book	Stones From the	Jewel	Icy Sparks	Total
	River			
Total posts reviewed	357	310	235	902
Posts included in this sample	168	116	118	402

This table shows the number of posts reviewed and included in the sample for each novel

#### **Findings: (Dis) Connections**

Through the online discussion of characters with disabilities and/or characters immersed in the lives of characters with disabilities portrayed in these three novels, readers give evidence of experiencing a variety of connections with Trudi, Icy and Jewel, the protagonists in each

novel. I have presented my findings by quoting reader discussion posts and identifying readers by their user names and the date of their discussion post in parentheses immediately following quotes.

Readers' discussion of disability initially appears encouraging in the acknowledgement of, and respect for, the diversity that characters represent, and readers described connections and empathy with these characters. Beyond the stereotypical tropes that are frequently identified in the literature surrounding characters with disabilities, readers' repeatedly cite the ways in which they feel bonded with Trudi, Icy and Jewel. Readers describe these characters as "flawed", but "good", based on their "humanity" which includes living with or supporting someone living with disability. Characters are upheld for how they "educate" (Caroline Gibson, 2013) and normalize difference (georgia 1 moses, 2001), Readers discuss relating to characters' intense emotional experiences of love, sadness, outrage, shock, disappointment and hope. While this initially appears promising as a foundation for readers' to positively shape public opinion about disability through their experiences with characters, upon further investigation the connections described can be seen to exist consistently in contexts of adversity rather than more general settings, upholding rather than challenging the negativity associated with disability. Specifically readers' identify with characters in terms of 1- connecting with disability in a cruel world, 2- collective suffering, and 3- cautionary tales of motherhood.

# Connecting with Disability in a Cruel World

Readers' frequently reference their connections with characters in terms of characters' historical and social settings of hardship, specifically, Trudi in Nazi Germany, Icy in a small, severe Appalachian village and Jewel in the poor and racially divided, rural Mississippi of the 1940's. Their settings constitute the harsh context within which characters' experiences,

specifically, Trudi's small stature, Icy's "fits and pops" and Jewel's burden of caring for her youngest daughter, play out.

The emotions readers describe demonstrate reader fondness, respect and love for the characters. Readers speak in terms of "falling in love with" the character of Trudi (Christina B. Erickson, 1995) and "absolutely loving everything about her" (Carolyn Seefer, 1997). In relation to Trudi in particular, readers commend the author for bringing the "historical atrocity" of Trudi's context to life through the story (Author and Avid Reader, 2006). Though Trudi's corporeal form is not the object of Nazi scrutiny, her physical difference and identity as an outsider, during this era of conformity and chaos is central to the story and Trudi's environment is fundamental to her devaluation and mistreatment. While readers' debate whether the central theme of the story is about Trudi, or the Holocaust more generally, readers' posts demonstrate a keen recognition of "Trudi's disability, if that's the word for it" (A Customer 1, 1998) as an allegory for the Second World War. Readers identify Trudi as a symbol of the "terrible things that happened to the Jews in Germany during the war" (Chris.collins@iname.com, 1998). Trudi's "bravery" and "humanity" (I love reading and going on vacation with my family, 2012) in contrast to this backdrop is central to how readers discuss their connections with Trudi including feeling that they can locate themselves in her world. A Customer 2 (2001) describes "becoming a part of this time and place" and experiencing a resulting "empathy for the characters and the moral dilemmas they faced".

Similarly, readers describe Icy as a "delightful heroine!" (Sharon Kinman, 2012) who will catch "your heart in the first few pages…" (Lisa Fischbach, 2002). This likeable, funny (L.M. Boilard, 2002), charming, bright, (Kay Mitchell, 2002) and complex, (Bob Artege, 2005) character is one that readers "couldn't help but love" (Ellen Teo, 2012). Icy, is discussed as a

misunderstood child within the harsh, mythologized cultural region of Appalachia in the 1950's which is central to the story. Readers' describe and connect with Icy's painful experience of being different within this context. Scorpiogirl (2001) observes "In the end, this book is not simply about Tourrette's [sic] syndrome. It is about human ignorance, fear and tolerance". Much like the discussion of Trudi, readers' associate Icy's difficult times with her disability with the setting in which she exists.

Readers' describe a sense of knowing Icy and sharing her emotions. A Customer 9x (2002) says "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". The author's ability to put the reader in Icy's place "...makes you cry with Icy's defeats and leaves you elated with her victories." (Brandi Stewart, 2002). In contrast to the unforgiving environmental and social backdrop, readers' consider their own "responses to difference" (Kelly Budd, 2001). Readers express relating to this "sweet child" and brave young woman in the context of the harsh environment that rejects her.

While Jewel is not "loved" in the same way as Trudi and Icy, readers discuss Jewel's parenting authenticity and struggles as powerful and speak admiringly of her ability to love and fight for both her daughter Brenda Kay and her family more generally. "She's human," "strong and forceful" (A customer 3, 1999), and has an "indomitable spirit" (Bearette24, 2000). Jewel's devotion to her family is described as "breathtaking" (<u>Cag4444@mindspring.com</u>, 1999).

Jewel's experience raising Brenda Kay, who has Down Syndrome, plays out in rural Mississippi during the 1940's and 50's. Jewel and her family move from a setting of poverty, racism, misogyny, ignorance, and the hard life of the Southern poor to California to pursue what they perceive as increased open-mindedness, specialized schools and services for Brenda Kay. Readers speak of Jewel's pain and burden associated with managing difference, and disability

specifically, within the divided, racialized context of the South. Negative attitudes towards

Brenda Kay and her difference are conveyed by doctors, friends and community. Jewel's

ultimate deference to her husband, and even Jewel's use of racist language, are discussed in

online posts as reflective of the backwards and intolerant environment which contrasts with

Jewel's deep and unconditional love for Brenda Kay. A reader, Sabel (2007) claims the book is

"realistic" and "accurately reflects the culture and attitudes towards minorities (African
Americans and people with disabilities) of its setting". Readers also describe Jewel's experience

as highlighting the "struggle to gain equality for the Brenda Kay's of our world (A Customer 6,

2000) and advance larger issues of 'compassion, forgiveness, disappointment and acceptance".

# **Collective Suffering**

Readers discuss the characters in terms of readers' own experiences of unhappiness and struggle. Readers discuss Trudi, Icy and Jewel in terms of their difficult experiences with disability and readers link these experiences to their own dealings with sadness, hopelessness, defeat and isolation.

Trudi is shunned by family and community based on her physical difference and <a href="Chris.collins@iname.com">Chris.collins@iname.com</a> (1998) describes Trudi's as "...the story of a girl whose physical differences set her apart from others her own age". Readers' frequently share their own experiences of not fitting in and use this as a basis for their connections with Trudi. Trudi's pain, negation and attempts to fit in are equated with readers' interpretation of universal experiences as A Customer 7 (1998) states: "Trudi is not just a dwarf, she is me. She is anyone who feels uncomfortable in themselves". While A Customer 8, (1999) claims: "Trudi represented our internal shame through her dwarfism..." other readers express being moved by Trudi's experience and aspiring to Trudi's strength. Robert Spencer (1998) for example admires Trudi's

"...power to bind, heal or destroy" and her story "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..."

Like Trudi, Icy's character arouses readers' expressions of connections with Icy's experience of rejection by peers and community. Readers describe identifying with Icy's plight relative to unhappiness in their own lives. Kristine (2001) conveys feeling Icy's "pain and confusion ... I have felt alone, fearful, ashamed, angry, hopeless and confused." Experiences of loneliness, sadness, frustration, and anger were described as familiar "because I was once a kid having to deal with the ridicule of others". (A customer 9, 2001).

Readers' frequently describe their own need to be loved and accepted in a world where they do not fit in. Kerrie (2001) proclaims: "I suffer from the same syndrome that Icy suffers from. The 'I need to be accepted and loved" syndrome". Mauricewms (2001) concludes, "Icy's trials seemed no greater than anyone who doesn't fit within the confines of what our culture deems normal...it matters not what our differences are, we deserve to be accepted for them, included with them".

For her part, Jewel, as the parent of a child with a disability, evokes reader connections related to difficulties of parenting and raising as family in a "tough" situation. Jewel's daughter, Brenda Kay, is identified as the cross the family has to bear. Even before her birth, Brenda Kay is prophesized in the novel as "yo' hardship...yo' test in this world" (42) which resonates with readers. They refer to Jewel's strength "to indure [sic] the heartaches life can bring." They talk of "struggle" and "hanging on for dear life" (suz, 2012) and cast Jewel's experience as a realistic portrait of hardship.

#### **Cautionary Tales of Motherhood**

Readers express strong emotions toward characters through their discussions of motherhood. They empathize with the experience of not having a mother depicted by Trudi and Icy and they also criticize and admire Jewels' devotion to her daughter Brenda Kay. Readers' converge in reinforcing beliefs about the expected role of mothers and their descriptions stand as a "cautionary tale" about the unfortunate fates of mothers of children with a disability. Both Trudi and Icy's mothers die, and Jewel's family and marriage are jeopardized by Jewel's commitment to Brenda Kay.

The absence of Trudi's mother is central to Trudi's character. Near the beginning of the story, Trudi's mother is institutionalized owing to her deteriorating mental health upon the birth of Trudi, her "aberrant" daughter. The immense pain caused by having a child with a disability leads to Trudi's mother taking her own life. Red Haircrow: Writer, Educator and More (2011), a reader, describes the link between Trudi's birth and her mother's mental health stating "Trudi's birth, her dwarfism is yet another trigger into her mother's slow descent into madness." Beverly Diehl (2013) speaks to the perceived injustice of Trudi's life as both a person with dwarfism and as being born to a mother who does not respect the implicit sanctity of this role, saying, "Trudi is a Zwerg, a dwarf...and what makes matters worse, her mother is crazy." The burden of disability which spans two generations in this example, serves as a warning to mothers of the tragedy that can ensue when an adult with a disability (in this case, madness) becomes a mother as well as through the arduous and painful mothering reality of bearing and raising a child with a disability. While Trudi and her father share a close relationship, the departure and psychiatric state of Trudi's mother is far more focal in readers' posts. Readers bond over shared contempt

for mothers who abandon their children and distaste and fear of the combination of motherhood and mental illness.

While Trudi's mother abandons her, Icy's mother dies shortly after Icy's birth and this is quickly followed by the death of Icy's father. Readers discuss the loss of Icy's mother far less than the loss of Trudi's mother as Icy has the benefit of a nurturing relationship with her grandparents. "Orphaned at a very young age, spunky Icy is raised by her loving grandparents" (Irishcoda, 2007). While Icy's segregation and sadness are well documented throughout the novel, readers' counter her unhappiness with the love of her grandparents. Yet readers caution about the hazard of having a child with a disability as they draw connections between Icy's Tourette's and the death of her parent(s), and the subsequent burden of raising Icy faced by Icy's grandparents. This is evidenced in Ashley's (2010) classifying the *Icy Sparks* novel as one of "the most depressing books in the world" about "a girl with no mother, raised by her loving but confused grandparents. A child who's only friend is a 400 pound adult".

The centrality of motherhood in readers' descriptions of their connections to Jewel cast disability most clearly as a "cautionary tale" for mothers in that mothers are warned of immense demands and corresponding difficult decisions of parenting a child with a disability.

bmspoll@epix.net (1999) shares that "Having a retarded daughter is heartbreaking; I know from personal experience." While readers are divided in their support for Jewel's decisions, many identify Jewel as sacrificing the family unit for the good of Brenda Kay. One reader recognizes "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." (A Customer 9c2, 2000). Condemning Jewel, Mary Haunreiter (2000) writes "many mothers like Jewel...place their high needs child first".

Justine Cardello (2000) agrees yet qualifies "Yes, a special child like Brenda Kay needs special attention, but not at the cost of your whole family."

#### **Discussion**

To grasp a culture's understanding of disability, their ideology and values need to be investigated (Eiesland & Sailers, 1998). In this study, I present a sample of cultural understandings in the form of readers' online discussion of disability. Presentations of disability in fiction have been critiqued by disability scholars for taking the form of one-dimensional, dehumanizing and stereotypical representations. Comparatively, the online discussions posts about disability analyzed here challenge one-dimensional portrayals as readers' evidence personal connections with characters with disabilities and disability issues.

Further, these posts demonstrate foundational aspects of a public sphere by incorporating public debate, discussion of issues and competing ideas. In the same way that Habermas and Hauser identify this type of discussion as foundational to the formation of public opinion, discussion from reader posts is formative in the creation of public opinion. Through online discussion posts, readers demonstrate that reading novels can evoke personal transformation (Davis, 2008) as readers describe a bringing together of real and fictional lives toward self-reflection and experiencing multiple subjectivities (Long, 2003). By focusing on visceral connections to characters with disabilities and/or characters immersed in the lives of characters with disabilities, readers identify with traditionally devalued emotional experiences and challenge the conventional assumptions of literary scholarship that the feelings created through the experience of reading are simplistic. Through analysis of discussion posts, I show that visceral connections as part of reading experiences are in fluential in reader understandings of disability and, ultimately, help shape public opinion about disability.

What can initially be interpreted as readers' progressive recognition of disability and their ability to blur the able/disabled divide through their connections with characters is in fact, a bearer of false hope, constrained by the settings of adversity in which characters' lives play out. The connections made, and closeness developed is done so while still re-enforcing the more traditional roles of pity, burden, sadness and overcoming that reader's themselves have escaped, but where characters with disabilities remain. The adverse settings in which Trudi, Icy and Jewel are immersed leave readers without opportunities to recognize or relate to characters in more ordinary contexts and this may diminish the overall power and wider applicability of readers' connections with characters. In the same way that McKee (2003) argues that a Hollywood onscreen kiss between men does not challenge heteronormative expectations if the kiss occurs in an extraordinary circumstance, such as in space or a post-apocalyptic world, reader connections with characters in settings of historical brutality, emotional adversity, or failings to meet societal expectations of motherhood, fall short in contesting the established distance between disability and normativity that would challenge the status quo.

Simpson-Housley and Norcliffe's (1992) argue the importance of what they term "landscape" as they claim that in fictional works, landscape is "more than an ensemble of physical and human components" but rather holds s "a deeper significance closely bound up with attitudes and values" (3). Accordingly, in their discussion of Trudi, Icy and Jewel, readers almost always speak in terms of the adverse physical and social settings in which the characters live. Readers' keen awareness of characters' hostile settings fuels readers' willingness to identify with the humanity of characters with disabilities and discuss their shared outrage at the unjust treatment of the "people" they have come to love. Indeed, characters, bound by the pages

of the novel, offer a safe place to connect with disability as well as to offer judgement surrounding the treatment of people with disabilities in the fictional past.

Readers' own adverse experiences and emotions perpetuate the association between disability and devaluation. Readers describe admiring characters' "strength" and "courage" yet more frequently and expressively identify with characters' "pain" and "suffering". Readers frequently identify the "self-hatred", "discomfort" and "heartache" experienced by Trudi, Icy and Jewel as their point of emotional connection with the characters. When readers describe their own specific incidences of feeling excluded, they discuss their self-proclaimed devaluation as a painful time or a memory, rather than a current reality. The ongoing devaluation and isolation experienced by Icy, Trudi, and Jewel is not frequently identified as an enduring state for readers. Indeed, readers speak of identifying with devaluation from the safety of having moved beyond their experience of devaluation. Yet readers do not address or expect Trudi, Icy and Jewel to follow this same trajectory which suggests readers' more subtle acceptance of connections between suffering and disability. Thus reader connections to Trudi, Icy and Jewel hold power to reinforce links between disability and devaluation.

Analysis of this sample of reader online discussions demonstrate that in spite of reader connections with characters, assumptions about links between disability and devaluation limit the impact of these characters in readers' lives beyond reader engagement with the novels. While the discussion exists in a public sphere with the potential for democratic and progressive exchanges of ideas, this analysis illuminates limits to the transformative potential of reader discussion in its current form. Despite the genuine nature of reader connections to characters, readers' sensemaking of disability experiences are constrained by themes of adversity of characters' setting and as such, fall short in reframing disability in broader, more profound ways.

#### Conclusion

Readers demonstrate the potential power of their voices in the shaping of public opinion through their discussion of disability and their connections with disability in novels. Like Habermas' ideal public sphere, reader online discussion is based on open citizen participation, critical reflection and a location where public opinion can be formed to resolve public issues. (1970, 1971, 1975, 1979, 1989). Through readers' posts, we see, as Hauser (1999) describes, the shaping of public opinion, in this case, in the discussion of disability. While described connections make inroads to disputing one dimensional portrayals and understandings of disability, we can see in readers' own words, the tendencies to re-enforce relationships and connections with disability in negative space and time which in turn re-enforce connections outside of valued, normative circumstances. This failure to understand connections as ordinary leaves us questioning whether these connections bring readers any closer to disability/characters with disabilities at all and whether these connections would be made in other circumstances. We should guery whether readers' would find Trudi so "likeable" if she lived in present-day suburbia, or Icy, "loveable" and "beautiful" if she accepted her own diversity or if Jewel would be so compelling if the family had always lived in California?

Recognizing online discussion as a public sphere and the voice of readers as force in the shaping of public opinion around disability, the online discussion put forth by readers serves as a valuable source of information. This analysis illuminates a definitive pattern of connections with these characters in scenarios of difficulty, isolation and suffering and compels us to question and re-interpret the understandings and power of these bonds relegated to negative space and to further question what would push the relationship between readers and characters with disabilities beyond connections through adversity to create a more fruitful discussion in this

public sphere. While the original book club ran from 1996 -2011, nine years after its conclusion, reader comments continue to be added to the discussions of these novels and their characters. Present-day comments continue to uphold the patterns identified through earlier posts. Recent examples such as Judy's Reviews (2017) identify Tourette syndrome as "tough and frightening". Kiel (2017) exemplifies the continued connections that exist between the cruelty of the world, character likeability and reader sympathy. She notes "I fell in love with Icy and just wanted to jump into the pages, give her a hug, and tell her that I would be her friend". Casey (2015) confirms this once more, noting Trudi as "sad but fascinating" and the novel itself as "horribly sad" but "very rewarding to read". The connections described past and present too often presume the lived experience of disability is associated with pain and suffering. Exemplifying Alexander Pope's (1709) classic recognition "A little learning is a dangerous thing" these interpretations demonstrate readers' regular limited understanding of disability as a social issue. Their general discussions bring forth a potentially distressing correlation between readers' feelings of connectedness to and understanding of disability and their simultaneous beliefs about the inferiority of people with disabilities in comparison to the accepted norm. These types of discussion, highlight the continued need to question public opinion surrounding disability and the implications of such opinions on contemporary issues such as the recent legalization of assisted suicide in Canada, where public opinion has the power to shape high stakes practices.

#### Limitations

This study is limited to my interpretations of the meanings readers ascribe to disability as discerned from reader online discussion posts. I make no claim of conclusiveness of these interpretations nor of the broader influence of reader discussion in the shaping of public opinion about disability. Instead I offer an examination of readers' online discussion as an example of

wider discussion of, and meanings associated with, disability. While a variety of readers posts were analyzed, those cited as evidence in this study pertained to beliefs about disability in the three themes I generated through data analysis. Many discussion posts not included would likely afford a variety of other interpretations. The novels discussed provide a sample for comparison, as reader comments were prolific and exemplify discussion around a diversity of disabilities, as well as representing both the point of view of characters with disabilities themselves and that of the mother of a child with a disability. The analysis also stems to a significant degree from book reviews posted by readers which often do not result in on-going discussion. Instead, my conclusions are limited to reader posts in which meanings readers attach to disability, and shifts in reader opinions may not be evident in included posts. Rather, this analysis is limited to the contents of the moment in time when readers post.

Appendix A List of Books Included in Oprah's Book Club 1996- 2010

	Club Year	Year of Publication	Author	Book
1	1996	1988	Hamilton, Jane	Book of Ruth
2	1996	1996	Mitchard,	The Deep End of the Ocean
3	1996	1977	Morrison, Toni	Song of Solomon
4*	1997	1981	Angelou, Maya	The Heart of a Woman
5*	1997	1997	Cosby, Bill	The Meanest Thing to Say
6*	1997	1997	Cosby, Bill	The Treasure Hunt
7*	1997	1997	Cosby, Bill	The Best Way to Play
8	1997	1993	Gaines, Ernest, J.	A Lesson Before Dying
9	1997	1987	Gibbons, Kaye	Ellen Foster
10	1997	1989	Gibbons, Kaye	A Virtuous Woman
11	1997	1995	Hegi, Ursula	Stones from the River
12	1997	1992	Lamb, Wally	She's Come Undone
13	1997	1995	Morris, Mary	Songs in Ordinary Time
14	1997	1995	Reynolds, Sherri	The Rapture of Canaan
15	1998	1998	Bohalijan, Chris	Midwives
16	1998	1997	Cleage, Pearl	What looks like crazy on an ordinary
17	1998	1994	Danticat, Edwidge	Breath, Eyes, Memory
18	1998	1997	Hoffman, Alice	Here on Earth
19	1998	1998	Lamb, Wally	I know this much is true
20	1998	1995	Letts, Billie	Where the Heart is
21	1998	1997	Morrison, Toni	Paradise
22	1998	1998	Quinland, Anna	Black and Blue
23**	1999	1998	Binchy, Maeve	Tara Road
24**	1999	1999	Clarke, Breena	River Cross My Heart
25	1999	1999	Fitch, Janet	White Oleander
26	1999	1994	Hamilton, Jane	A Map of the World
27	1999	1999	Haynes, Melinda	Mother of Pearl
28	1999	1998	Kingsolver,	The Poisonwood Bible
29	1999	1991	Lott, Bret	Jewel
30	1999	1999	Manasay, A.	Vinegar Hill
31**	1999	1995	Shlink, Bernhard	The Reader
32	1999	1998	Shreve, Anita	The Pilots Wife
33	2000	1999	Allende, Isabel	Daughter of Fortune
34	2000	2000	Berg, Elizabeth	Open House
35	2000	1991		House of Sand and Fog

36**	2000	1999	Miller, Sue	While I was Gone
37	2000	1999	Morgan, Robert	Gap Creek
38	2000	1970	Morrison, Toni	The Bluest Eye
39	2000	2000	O'Dell, Tawni	Back Roads
40	2000	2000	Schwarz,	Drowning Ruth
41	2001	2001	Franzen, Jonathan	The Corrections
42*	2001	1999	<u>Malika Oufkir</u>	Stolen Lives: Twenty Years in a
43	2001	1995	Mistry, Rohinton	A Fine Balance
44	2001	1996	Oates, Joyce	We Were the Mulvaneys
45	2001	1998	Rubio, Gwyn	Icy Sparks
46	2001	2001	Tademy, Lalita	Cane River
47	2002	1997	MacDonald, Ann-	Fall on Your Knees
48	2002	1973	Morrison, Toni	Sula
49	2003	1948	Patton, Alan	Cry the Beloved Country
50	2003	1952	Steinbeck, John	East of Eden
51	2004	1931	Buck, Pearl, S.	The Good Earth
52	2004	1967	Garcia Marquez.	One Hundred Years of Solitude
53	2004	1940	McCullers,	The Heart is a Lonely Hunter
54	2004	1877	Tolstoy, Leo	Anna Karenina
55	2005	1929	Faulkner, William	The Sound and the Fury
56	2005	1932	Faulkner, William	Light in August
57**	2005	1930	Faulkner, William	As I lay dying
58*	2005	2003	Frey, James	A Million Little Pieces
59*	2006	1955	Wiesel, Elie	Night
60	2007	2002	Eugenides, Jeffery	Middlesex
61	2007	2002	Follett, Ken	The Pillars of the Earth
62	2007	1985	Garcia Marquez,	Love in the Time of Cholera
63**	2007	2006	McCarthy,	The Road
64*	2007		Poitier, Sidney	The Measure of a Man: A Spiritual
65*	2008	2005	Tolle, Ekhart	A New Earth
66	2008	2008	Wroblewski,	The Story of Edgar Sawtelle
67**	2009	2008	Akpan, Uwen	Say You're One of Them
68	2010	1861	Dickens, Charles	Great Expectations
69	2010	1859	Dickens, Charles	A Tale of Two Cities
70	2010	2010	Franzen, Jonathan	Freedom
	•		•	

## Appendix B

Novel Summaries ( from <a href="https://www.goodreads.com/">https://www.goodreads.com/</a>)

# Stones from the River – Ursula Heigi (1995)

From the highly acclaimed, award-winning author of *Floating in My Mother's Palm* comes a stunning novel about ordinary people living in extraordinary times.

Trudi Montag is a *Zwerg*—a dwarf—short, undesirable, different, the voice of anyone who has ever tried to fit in. Eventually she learns that being different is a secret that all humans share—from her mother who flees into madness, to her friend Georg whose parents pretend he's a girl, to the Jews Trudy harbors in her cellar.

Ursula Hegi brings us a timeless and unforgettable story in Trudi and a small town, weaving together a profound tapestry of emotional power, humanity, and truth.

# Icy Sparks – Gwynn Hyman Rubio (2001)

Icy Sparks is the sad, funny and transcendent tale of a young girl growing up in the mountains of Eastern Kentucky during the 1950's. Gwyn Hyman Rubio's beautifully written first novel revolves around Icy Sparks, an unforgettable heroine in the tradition of Scout in To Kill a Mockingbird or Will Treed in Cold Sassy Tree. At the age of ten, Icy, a bright, curious child orphaned as a baby but raised by adoring grandparents, begins to have strange experiences. Try as she might, her "secrets"—verbal croaks, groans, and physical spasms—keep afflicting her. As an adult, she will find out she has Tourette's Syndrome, a rare neurological disorder, but for years her behavior is the source of mystery, confusion, and deep humiliation.

Narrated by a grown up Icy, the book chronicles a difficult, but ultimately hilarious and heartwarming journey, from her first spasms to her self-acceptance as a young woman. Curious about life beyond the hills, talented, and energetic, Icy learns to cut through all barriers—physical, mental, and spiritual—in order to find community and acceptance.

# Jewel – Brett Lott (1991)

Jewel and her husband, Leston, have been blessed by a fifth child, a girl they name Brenda Kay. But Brenda Kay, who was born with Down's syndrome, is also a challenge. In this inspirational and deeply moving audiobook, Jewel realizes that Brenda Kay is her special gift from God.

	Reader Discussion Post	Source
1	A Customer 1. (1998, November 24). Amazed at the hostility in these reviews! [Book Review]. Retrieved	Amazon
	from	
	https://www.amazon.com/review/R1OOI01RZ0L51W/ref=cm_cr_rdp_perm?ie=UTF8&ASIN=068484477X	
2	A Customer 2. (2001, March 30). One of my all time favorite books [Book Review]. Retrieved from	Amazon
	https://www.amazon.com/review/R3PYIZZNYPEOHN/ref=cm_cr_rdp_perm/?ie=UTF8&ASIN=068484477X	
3	A Customer 3. (1999, November 28). Loved this book. Retrieved from	Amazon
	https://www.amazon.com/review/R2ACIEBAYY00Z2/ref=cm_cr_rdp_perm?ie=UTF8&ASIN=0671038184	
5	A Customer 6. (2000, March 28). How does he know? [Book Review]. Retrieved from	Amazon
	http://www.amazon.com/review/RTSPXGI5VE9XL/ref=cm_cr_pr_perm?ie=UTF8&ASIN=0671038184	
6	A Customer 7. ((1998, September 30). Definitely one to recommend. [Book Review]. Retrieved from	
	https://www.amazon.de/Stones-River-Ursula-Hegi/product-reviews/0684844729?pageNumber=5	
6	A Customer 8. (1997, June 21). Good, but not excellent [Book Review]. Retrieved from	Amazon
	http://www.amazon.com/review/RQECC3DUS2UCF/ref=cm_cr_rdp_perm?ie=UTF8&ASIN=068484477X	
7	A Customer 9. (2001, June 18). Great Emotions [Book Review]. Retrieved from	Amazon
	http://www.amazon.com/review/RZM5YATQLZTID/ref=cm_cr_rdp_perm?ie=UTF8&ASIN=0142000205	
8	A customer 9c2. (2000, November 14). I thought this was a wonderful book [Book Review]. Retrieved from	Amazon
	http://www.amazon.ca/gp/aw/cr/rRHQJNUTWPWWGR	
10	A Customer 9x. (2002, March 18). Touching [Book Review]. Retrieved from <a href="http://www.amazon.ca/product-">http://www.amazon.ca/product-</a>	Amazon
	reviews/0140280146?pageNumber=4	
14	Ashley. (2010, April 24). Icy Sparks (Oprah's Book Club) [Book Review]. Retrieved from <a href="Lev Sparks"><u>Icy Sparks</u></a>	OBC Website
	(Oprah's Book Club)	
15	Author and Avid Reader. (2006, May 8). An important work, a masterpiece [Book Review]. Retrieved from	Amazon
	http://www.amazon.com/review/R1EHIQVJFN72D8/ref=cm_cr_pr_perm?ie=UTF8&ASIN =068484477X	
17	Bearette24. (2000, July 27). Great Content, horrible writing [Book Review]. Retrieved from	Amazon
	http://www.amazon.com/review/R1RMTDQ971OJ65/ref=cm_cr_pr_perm?ie=UTF8&ASIN=0671042572	
18	Beverly Diehl. (2013, February 11). Stones that'll stay with me. Retrieved from	Amazon
	http://www.amazon.com/review/RYZFTSEQMGF4M/ref=cm_cr_pr_perm?ie=UTF8&ASIN=068484477X	
19	bmspoll@epix.net. (1999, August 17). Lott delicately touches a dozen painful nerves [Book Review].	Amazon
	Retrieved from	
	http://www.amazon.com/review/R3T0JWGD7NKPJO/ref=cm_cr_rdp_perm?ie=UTF8&ASIN=0671038184	

20	Bob Artege. (2005, July 30). One of my favorites [Book Review]. Retrieved from	Amazon
	ttp://www.amazon.com/review/R30J2O0HOB2PGG/ref=cm_cr_pr_perm?ie=UTF8&ASIN =0142000205	
21	Brandi Stewart. (2002, March 11). The strong will endure [Book Review]. Retrieved from	Amazon
	http://www.amazon.com/review/R2DHCTFVB0DNAY/ref=cm_cr_rdp_perm?ie=UTF8&A SIN=0142000205	
22	Cag4444@mindspring.com. (1999, March 31). Contemporary Celtic Fiction [Book Review]. Retrieved from	Amazon
	http://www.amazon.com/review/R6Y01T3PXAI9J/ref=cm cr pr perm?ie=UTF8&ASIN=0671038184	
24	Carolyn Seefer. (1997, August 12). Quite simply, a masterpiece [Book Review]. Retrieved from	Amazon
	ttp://www.amazon.ca/product-reviews/0671577050?pageNumber=24	
25	chris.collins@iname.com. (1998, August 12). Ever wonder how the German's let the Holocaust happen?	Amazon
	[Book Review]. Retrieved from	
	http://www.amazon.com/review/R9L0GR31F9JKY/ref=cm_cr_rdp_perm?ie=UTF8&ASIN =068484477X	
26	Christina B. Erickson. (2005, September 30). Amazing storyteller of a WWII coming of age [Book Review].	Amazon
	Retrieved from	
	https://www.amazon.com/review/RKQO11S37AVMF/ref=cm_cr_rdp_perm?ie=UTF8&ASIN=068484477X	
28	Ellen Teo. (2012, September 24). More than I expected [Book Review]. Retrieved from	Amazon
	http://www.amazon.com/review/R29N9GSQI0WJZL/ref=cm_cr_pr_perm?ie=UTF8&ASIN=B000OZ0NVW	
29	georgia_1_moses. (2001, June 8). Our Discussion Group's thoughts [Book Review]. Retrieved from	Amazon
	https://www.amazon.com/review/R1II7RL2TH3C1U/ref=cm_cr_rdp_perm?ie=UTF8&ASIN=0142000205	
32	I love reading and going on vacation with my family. (2012, March 27). A slow read, but absolutely beautiful.	Amazon
	Retrieved from	
	http://www.amazon.com/review/R3W1MKTAPS4JPZ/ref=cm_cr_rdp_perm?ie=UTF8&ASIN=B003E7EUJI	
33	Irishcoda. (2007, July 11). Icy Sparks (Oprah's Book Club). Retrieved from	Goodreads
	https://www.goodreads.com/review/show/2959647?book_show_action=true&from_review_page=1	
34	Judy's Reviews (2017, June 21). Icy Sparks. Retrieved from	Goodreads
	https://www.goodreads.com/review/show/2032982778?book_show_action=true&from_review_page=1	
35	Justine Cardello. (2000, November 27). Another Oprah Disaster [Book Review]. Retrieved from	Amazon
	https://www.amazon.ca/gp/aw/cr/rR2CSP6LO6CJSBX	
37	Kay Mitchell. (2000, May 14). How different is different? [Book Review]. Retrieved from	Amazon
	http://www.amazon.com/review/R5GBISE8JS6ZM/ref=cm_cr_pr_perm?ie=UTF8&ASIN=068484477X	
38	Kelly Budd. (2001, March 30). A Courageous Story [Book Reivew]. Retrieved from	Amazon
	http://www.amazon.com/review/RC0XRZU5V0H83/ref=cm_cr_pr_perm?ie=UTF8&ASIN=0142000205	

39	Kerrie. (2001). Icy Sparks Discussion Group [Discussion Group]. Retrieved from	OBC Website
	http://www.Oprah.com/Oprahsbookclub/Icy-Sparks-Discussion-Group-Members	
39	Kiel. (2018, February 12). Icy Sparks. Retrieved from	Goodreads
	https://www.goodreads.com/review/show/2266044082?book_show_action=true&from_review_page=1	
40	Kristine. (2001). Icy Sparks Discussion Group [Discussion Group Post]. Retrieved from	OBC Website
	http://www.Oprah.com/Oprahsbookclub/Icy-Sparks-Discussion-Group-Members	
41	L.M. Boilard. (2002, February 3). Enjoyable Characters3 1/2 stars [Book Review]. Retrieved from	Amazon
	http://www.amazon.com/review/R1D9DKXSYEG8BD/ref=cm_cr_pr_perm?ie=UTF8&ASI N=0142000205	
42	Lisa Fischbach. (2002, September 22). Excellent Read [Book Review]. Retrieved from	Amazon
	http://www.amazon.com/review/R2GM1LG9HAABMY/ref=cm_cr_rdp_perm?ie=UTF8&	
	<u>ASIN=067003049X</u>	
43	Loubr. (2013, February 8). Great book [Book Review]. Retrieved from	Amazon
	http://www.amazon.com/review/R346LUXY7DAOJR/ref=cm_cr_rdp_perm?ie=UTF8&ASIN=B005D7	
44	Mary Haunreiter. (2000, February 23). A mother's love for her handicapped child. Retrieved from	Amazon
	http://www.amazon.com/review/RAAUAG2BSPIRK/ref=cm_cr_pr_perm?ie=UTF8&ASIN=0671038184	
45	Mauricewms. (2001, April 11). It crept up on me [Book Review]. Retrieved from	Amazon
	http://www.amazon.com/review/R3G8862T9R2M96/ref=cm_cr_pr_perm?ie=UTF8&ASIN=0142000205	
47	Red Haircrow: Writer, Educator and More. (2011, June 9). Personal Commentary and Review [Book Review].	Amazon
	Retrieved from	
	https://www.amazon.com/review/R1EGWWW8JSUZK3/ref=cm_cr_pr_perm?ie=UTF8&ASIN=068484477X	
48	Robert Spencer. (1998, June 23). A great twentieth century masterpiece [Book Review]. Retrieved from	Amazon
	http://www.amazon.com/review/RJD82WK7A797N/ref=cm_cr_rdp_perm?ie=UTF8&ASIN=068484477X	
49	Sabel. (2007, July 6). It will give you a deeper understanding [Book Review]. Retrieved from	Amazon
	https://www.amazon.com/review/R227RB2GFWWAUO/ref=cm_cr_pr_perm?ie=UTF8&ASIN=0671042572	
50	Scorpiogirl. (2001, July 15). Heartbreaking and hilarious [Book Review]. Retrieved from	Amazon
	http://www.amazon.com/review/RLL4I2H1TDHZO/ref=cm_cr_rdp_perm?ie=UTF8&ASIN=0142000205	
51	Sharon Kinman. (2012, December 25). Icy Sparks [Book Review]. Retrieved from	Amazon
	http://www.amazon.com/review/R2HZAT0I87A037/ref=cm cr rdp perm?ie=UTF8&ASIN=B000P29HZC	
53	suz. (2012, March 3). These jewels didn't sparkle [Book Review]. Retrieved from	Amazon
	http://www.amazon.com/review/R2Q7OE2G1X1PLE/ref=cm_cr_rdp_perm?ie=UTF8&ASIN=B006R9HQ8M	

# **Bibliography**

- Abt, V., & Mustazza, L. (1997). Coming after Oprah: Cultural fallout in the age of the TV talk show. Bowling Green, OH: Bowling Green State University Popular Press.
- Adomat, D.S. (2014). Exploring Issues of Disability in Children's Literature Discussions. *Disability Studies Quarterly* 34(3). 1041-5718
- Allan K. (2013) Disability in Science Fiction. Palgrave Macmillan, New York
- Barker, C. (2013). "The Ancestors Within": Genetics, Biocolonialism, and Medical Ethics in Patricia Grace's *Baby No-Eyes*. *Journal of Literary & Cultural Disability Studies* 7(2), 141-158. Liverpool University Press
- Berg, B. L. (2004). Qualitative research methods for the social sciences (5th ed.). Toronto;: Pearson.
- Bérubé, M. (2005). Disability and Narrative. PMLA, 120(2), 568-576.
- Biklen, D., & Bogdan, R. (1977). Media portrayal of disabled persons: A study in stereotypes. *Interracial Books for Children Bulletin*, 8, 4-9.
- Bourrier, K. (2015). *The measure of manliness: disability and masculinity in the mid-Victorian novel*. University of Michigan Press, Ann Arbor.
- Bolt, D. (2014). The metanarrative of blindness: a re-reading of twentieth-century Anglophone writing. University of Michigan Press; Ann Arbor.
- Bolt, D., Rodas, J.M. and Donaldson, E.J. (2012) *The Madwoman and the Blindman: Jane Eyre, Discourse, Disability*. Ohio State University Press
- Bolt, D. (2005). Looking back at literature: a critical reading of the unseen stare in depictions of people with impaired vision. *Disability & Society*, 20(7)
- Brontë, C., & Nemesvari, R. (1999). *Jane Eyre*. Peterborough, Ont: Broadview Press. (Original work published in 1847).
- Chandler, O. (March 28, 2013). Exciting news about Goodreads: We're joining the amazon family! Retrieved from: <a href="https://www.goodreads.com/blog/show/413-exciting-news-about-goodreads-we-re-joining-the-amazon-family">https://www.goodreads.com/blog/show/413-exciting-news-about-goodreads-we-re-joining-the-amazon-family</a>
- Cheyne, R. (2017). Disability in Genre Fiction. In C. Barker & S. Murray (Eds.), *The Cambridge Companion to Literature and Disability* (Cambridge Companions to Literature, pp. 185-198). Cambridge: Cambridge University Press
- Cheyne, R. (2012). Introduction: Popular Genres and Disability Representation. Journal of Literary and Cultural Disability Studies 6(2). 117-123
- Davis, K. C. (2008). Oprah's book club and the politics of cross-racial empathy. In C. K. Farr, & J. Harker (Eds.), *The Oprah affect: Critical essays on Oprah's book club* (pp. 141-162). Albany, NY: State University of New York Press.
- Davis, L. J. (1995). Enforcing normalcy: Disability, deafness, and the body. New York: Verso.

- de Cervantes Saavedra, M., & Grossman, E. (2005). *Don Quixote* (1st ed.). New York: Ecco. (Original work published in 1605).
- Dolmage, J. (2017). Disability Rhetorics. In C. Barker & S. Murray (Eds.), *The Cambridge Companion to Literature and Disability* (Cambridge Companions to Literature, pp. 212-226). Cambridge: Cambridge University Press.
- Eagleton, T. (2003). After theory. New York: Basic Books.
- Eiesland, N., L., & Sailers, D. A. (Eds.). (1998). *Human disability and the service of god.* Abingdon Press.
- Farr, C. K. (2005). Reading Oprah: How Oprah's book club changed the way America reads. Albany: State University of New York Press.
- Farr, C. K., & Harker, J. (Eds.). (2008). The Oprah affect: Critical essays on Oprah's book club. Albany, NY: State University of New York Press.
- Fine, M., & Asch, A. (1988). Women with disabilities: Essays in psychology, culture, and politics. Philadelphia, PA: Temple University Press.
- Foss, C. Gray, J. & Whalen, Z. (eds). (2016). Disability in Comic Books and Graphic Narratives. Palgrave MacMillan; UK.
- Gartner, A. (1987). Images of the disabled, disabling images. New York: Praeger.
- Habermas, J. (1989). Strukturwandel der öffentlichkeit. the structural transformation of the public sphere: An inquiry into a category of bourgeois society / Jürgen Habermas : (T. Burger, F. Lawrence Trans.). Cambridge, MA: MIT Press
- Habermas, J. (1970). On systematically distorted communication. *Inquiry, 13*, 205-218. Habermas, J. (1971). *Knowledge and human interest* (Jeremy J. Shapiro Trans.). Boston: Beacon.
- Habermas, J. (1975). Legitimation crisis (T. McCarthy Trans.). Boston: Beacon.
- Habermas, J. (1979). *Communication and the evolution of society* (T. McCarthy Trans.). Boston: Beacon.
- Hall, A. (2012). Disability and modern fiction: Faulkner, morrison, coetzee and the nobel prize for literature. New York; Houndmills, Basingstoke, Hampshire;: Palgrave Macmillan.
- Hauser, G. A. (1999). *Vernacular voices: The rhetoric of publics and public spheres* (Pbk ed. ed.). Columbia, S.C.: University of South Carolina Press.
- Hegi, U. (1995). *Stones from the river* (1st Scribner paperback ed.). New York: Simon & Schuster.
- Holmes, M. (2017). Embodying Affliction in Nineteenth-Century Fiction. In C. Barker & S. Murray (Eds.), *The Cambridge Companion to Literature and Disability* (Cambridge Companions to Literature, pp. 62-73). Cambridge: Cambridge University Press.

- Hughes, C. (2017). The "words inside": "Disabled" Voices in Contemporary Literature for Young People. *Journal of Literary & Cultural Disability Studies* 11(2), 187-203. Liverpool University Press.
- Hyman Rubio, G. (1998). Icy sparks. New York: Penguin.
- Jarman, M. (2017). Race and Disability in US Literature. In C. Barker & S. Murray (Eds.), *The Cambridge Companion to Literature and Disability* (Cambridge Companions to Literature, pp. 155-169). Cambridge: Cambridge University Press.
- Keith, L. (2001). Take up thy bed and walk: Death, disability and cure in classic fiction for girls. New York: Routledge.
- Kriegl, L. (1987). The cripple in literature. In A. Gartner, & T. Joe (Eds.), *Images of the disabled, disabling images* (pp. 31-46). New York/London: Praeger.
- Long, E. (2003). *Book clubs: Women and the uses of reading in everyday life*. Chicago, IL: University of Chicago Press.
- Longmore, P. K. (1987). Screening stereotypes: Images of disabled people in television and motion picture. In A. Gartner, & T. Joe (Eds.), *Images of disability, disabling images* (pp. 65-78). New York/London: Praeger.
- Lott, B. (1991). Jewel: A novel. New York: Pocket Books.
- Martin, G. R.R. (2011) A Dance with Dragons. New York: Bantam Books.
- Mazzocco, P. J., & Green, M. C. (2011). Narrative persuasion in legal settings: What's the story? *The Jury Expert*, 23(3), 27-34.
- McKee, A. (2003). Textual analysis: A beginner's guide (1st ed.). Thousand Oaks, Calif;London;: Sage Publications.
- Mitchell, D.T. (2015). The Biopolitics of Disability: Neoliberalism, Ablenationalism, and Peripheral Embodiment. University of Michigan Press, Ann Arbor
- Mitchell, D. T., & Snyder, S. L. (2006). Narrative prosthesis and the materiality of metaphor. In J. Davis (Ed.), *The disability studies reader* (2nd ed., pp. 205-216). New York: Routledge
- Mitchell, D. T., & Snyder, S. L. (2001). Representations and its discontents: The uneasy home of disability in literature and film In G. L. Albrecht, K. D. Seelman & M. Bury (Eds.), *Handbook of disability studies* (pp. 195-218). Thousand Oaks, London, New Dehli: Sage Publications.
- Mitchell, D. T., & Snyder, S. L. (2000). *Narrative prosthesis: Disability and the dependencies of discourse*. Ann Arbor: University of Michigan Press.
- Mitchell, M. (1936). Gone with the wind. London: MacMillan Publishers
- Morris, J. (1991). *Pride against prejudice: Transforming attitudes to disability*. Philadelphia: New Society.
- Morrison, T. (1998). Beloved: A novel. New York: A.A. Knopf.

- Murray, S. (2017). The Ambiguities of Inclusion. In C. Barker & S. Murray (Eds.), *The Cambridge Companion to Literature and Disability* (Cambridge Companions to Literature, pp. 90-103). Cambridge: Cambridge University Press.
- Norden, M. F. (1994). The cinema of isolation: A history of physical disability in the movies. New Brunswick, N.J.: Rutgers University Press.
- Oatley, K. (2011). Such stuff as dreams: The psychology of fiction. Chichester, West Sussex, U.K. ;: Wiley-Blackwell.
- Oswald, D. (2016). Otherwise Undisclosed: Blood, Species, and Benjy Compson's Idiocy. *Journal of Literary & Cultural Disability Studies* 10(3), 287-304. Liverpool University Press
- Radway, J. A. (1997). A feeling for books: The book-of-the-month club, literary taste, and middle-class desire. Chapel Hill: University of North Carolina Press.
- Rankin, J.C. (2014). Chatter that Matters: A new path to progressive understandings of disability through the online discussion of popular novels. (Unpublished doctoral dissertation). York University, Toronto, ON.
- Rodas, J.M. (2016). Narrative Architecture and Autistic Voice in Mary Shelley's *Frankenstein*. In Bradshaw, M (ed) *Disabling Romanticism: Body, Mind, and Text*. Palgrave Macmillan, London, 169-90.
- Rooney, K. (2008). *Reading with Oprah: The book club that changed America* (2nd ed.). Fayetteville: University of Arkansas Press.
- Salinger, J. D. ([c1951]). *The Catcher in the Rye* /. Boston: Little Brown.
- Shakespeare, T. (1997). Cultural representation of disabled people: Dustbins for disavowal? In L. Barton, & M. Oliver (Eds.), *Disability studies : Past, present and future* (pp. 217-233).Leeds: The Disability Press.
- Simpson Housley, P., & Norcliffe, G. B. (1992). No vacant Eden. In American Council of Learned Societies York University., American Council of Learned Societies., G. B. Norcliffe & P.
- Spelman, E., V. (1997). Fruits of sorrow: Framing our attention to suffering. Boston: Beacon.
- Spoel, P., Harris, R., & Henwood, F. (2014). Rhetorics of Health Citizenship: Exploring Vernacular Critiques of Government's Role in Supporting Healthy Living. Journal of Medical Humanities, (2), 131.
- Stiker, H. (1999). *A history of disability*. Ann Arbor: University of Michigan Presssandra. (2000, February 13).
- Thomson, R. G. (1997a). Disabled women as powerful women in Petry, Morrison, and Lorde: Revising black subjectivity. In D. T. Mitchell, & S. L. Snyder (Eds.), *The body and physical difference: Discourses of disability* (pp. 299). Ann Arbor: University of Michigan Press.

- Thomson, R. G. (1997b). Extraordinary bodies: Figuring physical disability in American culture and literature. New York: Columbia University Press.
- Wheatley, E. (2017). Monsters, Saints, and Sinners. In C. Barker & S. Murray (Eds.), *The Cambridge Companion to Literature and Disability* (Cambridge Companions to Literature, pp. 17-31). Cambridge: Cambridge University Press
- World Health Organization (2011). Summary, World Report on Disability. Available from: http://www.who.int/disabilities/world\_report/2011/report/en/