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This study investigated how language used in youth literature communicates theoretical models of disability, and how language used in book reviews and library cataloging compares to the disability language in the books. Using social constructionism and moral, medical, and social models of disability as a theoretical framework, the researcher used discourse analysis to examine 22 award-winning books from the Dolly Gray Award for Children's Literature in Developmental Disabilities and the Schneider Family Book Award, along with library cataloging and book reviews that describe the books. The disability language in all of the texts reflected three major themes: descriptions, feelings, and responses to disability. The books demonstrated a shift from moral or medical theoretical models of disability to a social model of disability. The study has implications for libraries in that librarians have a responsibility to create and maintain library collections that provide accurate and authentic portrayals of disability. Further,

the study suggests that librarians should seek input from people living with disabilities in understanding disability language preferences and information needs.

Representations of Disability in Youth Literature:  
A Discourse Analysis of Award Winning Books

by

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## Representations of Disability in Youth Literature:

### A Discourse Analysis of Award Winning Books

People enter a library for many different reasons. Library patrons may need information on a specific topic for work or school, want to check a favorite webpage or social network, or hope to find a book for their reading enjoyment. Patrons might want to read about people whose life experiences and challenges are similar or different from their own. One library acknowledged this diversity of wants and needs with an invitation to “Find Yourself Here” and stated “No matter what you’re looking for, you can find it at Worthington Libraries!” (“Find Yourself,” 2013).

For the library patron whose life circumstances are outside the mainstream culture, finding one’s self in the library or in the contents of many books on today’s library shelves may be a challenge. For a young person with a disability, this is an exceptional challenge. A limited number of books are available that include a character with a disability, and of those, some may not represent the disability in a way that is authentic to the reader (Blaska, 2004, Cissell, 2001, Dyches, Prater, & Jenson, 2006; Fleisher & Zames, 2001; Leininger, Dyches, Prater, & Heath, 2010; Prater & Dyches, 2008). Since there are many ways that a person can experience disability the challenge often becomes almost insurmountable. When a patron cannot locate an authentic book on a topic of interest, especially when looking for a reflection of one’s own life challenges, what message does this send to the individual with a disability about personal value or status in society?

## **Legislation**

Over time, through the enactment of laws and corresponding public policies and professional practices United States (U.S.) society has changed the way it failed to include individuals with disabilities, and consequently improved views of individuals with disabilities. This shift from an out-of-sight, out-of-mind attitude and approach to life is largely the result of actions by U.S. lawmakers including the enactment of the Rehabilitation Act of 1973, Education of All Handicapped Children Act of 1975, P.L. 94-142, which was later named the Individuals with Disabilities Education Act (IDEA) in 1990, and the Americans with Disabilities Act of 1990 (ADA). These three laws address issues of physical and electronic accessibility, education, employment, and other rights that enable people of all abilities to pursue full lives.

Disability is a natural part of the human experience and in no way diminishes the right of individuals to participate in or contribute to society. Improving educational results for children with disabilities is an essential element of our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities. (IDEA, 2004)

The first two acts affect children and youth in educational settings. While the Rehabilitation Act of 1973 set the stage for inclusion of children with disabilities in various aspects of the educational environment by prohibiting discrimination, it was not until the Education of All Handicapped Children Act of 1975, P.L. 94-142 that education as a fundamental right of all children was established. Subsequently known as the Individuals with Disabilities Education Act (IDEA), the Act and its amendments govern

how states and localities provide early intervention, special education and transition related services to eligible infants, toddlers, children and youth with disabilities.

According to Dow and Mehring (2000):

A key feature of P.L. 94-142 was the right of parents to participate in all aspects of the identification, referral, evaluation, placement, and instructional decisions for their children. This legislation required general and special educators to find ways to make parents partners in the placement process, and guaranteed families the right to due process. (p. 262).

In addition to the laws, educational policies and guidelines exhibit change in the way U.S. society enables individuals with disabilities to pursue full lives. For example, policies include guidelines for writing Individualized Education Programs (IEP) including measurable outcomes-based language describing delivery of free education in the least restrictive environment appropriate. This concept led directly to the approach of mainstreaming children whenever possible with a variety of disabilities into the general classroom.

The introduction of children with varying needs into the classroom and the school library media center brought new challenges and opportunities for teachers and school librarians who served individual needs of children with disabilities who like all students needed access to instructional resources and computer technology (Walling & Karrenbrock, 1993). Books that addressed disability related issues or included characters with disabilities quickly became the medium to “provide a forum to discuss characteristics of people with disabilities, environmental and attitudinal barriers they might experience, and feelings they might have while dealing with these difficulties”

(Prater & Dyches, 2008, x). The response from the children's book publishing community was significant according to a study of books published before and after the implementation of P.L. 94-142. According to Harrill (1993), there were more instances of disabilities represented in the books published after P.L. 94-142 than before, the portrayals of disability in the illustrations and text were more authentic, accuracy of the information presented was improved, and terminology was less technical and more understandable by a wider audience. Books that include individuals with disabilities provided additional information for children with and without disabilities who wanted to understand the disability experience. These new portrayals of individuals with disabilities served to raise new awareness and to bring about change as students, teachers, and librarians discussed the stories, characters and situations represented in the books.

Although one of the primary goals of the ADA was to remove barriers to employment, the law had sweeping effects on other aspects of society's response to disabilities. In addition to following the law, library and information professionals were required to learn about the law to assist patrons with their own information searches about the law, as well as to understand the ramifications, planning, and delivery of new library services (Walling & Irwin, 1995). Libraries addressed access issues, which included not only physical access to the buildings, but also modifications to program plans and pathways to information for people with varying access needs. Libraries also purchased materials in multiple formats and installed assistive and adaptive technology on computer hardware in the library.

While the ADA provided the foundation for necessary changes, changing attitudes takes time. Russell (2009) quotes an unknown author as stating, "Congress

cannot change attitudes with the stroke of a pen” (p. 66). She goes on to discuss the challenges involved in bringing about the societal changes that must follow:

We can have laws that require accommodations, ramps, curb cuts, elevators, and lifts for equal access. These things (although sometimes a challenge to get implemented) are easy to see and fairly easy and clear to implement. Attitudes, however, cannot be changed via the law. This calls for more awareness, education, flexibility, and sensitivity. (p. 66)

### **Library Services and Collection Development**

A preliminary search of articles related to libraries and disability finds that the library and information sciences discipline has an active research agenda regarding services for people with disabilities. Libraries have a long tradition of identifying gaps in service, and numerous resources address some of these needs related to disability. Scholars have written books and articles covering topics such as accessibility to the physical library and digital resources, assistive technology, and sensitivity when helping patrons with disabilities (Dresang, 1977; Roberts & Smith, 2010; Walling & Irwin, 1995; Walling & Karrenbrock, 1993).

In addition to assisting library patrons, one of the primary roles of librarians is to build library collections of information resources. Librarians use professional skills in making materials selections by using various selection tools as well as understanding the needs of their service community. Youth librarians draw upon reviews of books and other resources in specialized trade publications such as *Booklist*, *Horn Book*, *VOYA*, and *School Library Journal*. In addition, they may use other standard collection development tools such as book awards, best book lists, age targeted bibliographies (Price & Rowland,

2010; Lima & Thomas, 2010) or subject themed bibliographies including those that cover disabilities (Baskin & Harris, 1977; Baskin & Harris, 1984; Blaska, 2003; Crosetto, Garcha & Horan, 2009; Dyches & Prater, 2000; Prater & Dyches, 2008; Robertson, 1992; Ward, 2002).

### **Disability in Youth Literature**

Youth literature is one indicator of social change. According to Prater and Dyches (2008), “the manner in which society perceives individuals with disabilities contributes to ways in which they are portrayed in books...if they are perceived as more like than unlike those without disabilities, they will be shown in integrated settings having reciprocal relationships with other characters” (p. xii). Two different studies conducted by Blaska suggest that this change is coming slowly (2004). In the first study, conducted in 1992, she reviewed 500 award-winning or highly recommended books published for children from 1987-1991. The publication dates of these books fall immediately before and around the time of the passing of the ADA. While approximately 20 percent of the general population have some form of a disability (Fleisher & Zames, 2001), only 2 percent of the books reviewed had a character included in the storyline or illustrations (Blaska, 2004). In a separate study conducted in 2000, Blaska examined the reading collections of 40 early childhood programs and found that only 1.4% of the books available for independent reading included disability in the storyline or illustrations (2004). While these percentages are small, these studies demonstrate a commitment on the part of the creators of youth literature to include the disability population in the materials it provides for children. Recent articles also discuss

the prevalence of characters with disabilities in the Newbery Award and Caldecott Award books (Dyches, Prater, & Jenson, 2006, and Leininger, Dyches, Prater, & Heath, 2010).

Several popular children's series contain at least one book that includes a character with a disability such as *The Berenstain Bears and the Wheelchair Commando* (Berenstain & Berenstain, 1993), *Clifford's Big Red Ideas: A Special Friend* (Bridwell, 2002), and *The Baby-Sitters Club: The Truth About Stacey* (Martin, 1986). New titles continue to develop the characterizations of disability in youth literature by moving away from problem novels where disability is the major conflict such as books like *Izzy Willy-Nilly* (Voigt, 1986), where the character must come to terms with an amputation following a car accident. In contrast, in *The London Eye Mystery* (Dowd, 2007), the major conflict is tied to the resolution of the mystery rather than disability and the main character happens to have a disability which gives him an edge in his ability to resolve the plot. Another approach is present in books written by authors who live with disability themselves such as *Accidents of Nature* (Johnson, 2006), which is a story loosely based on events from the author's experience as a girl going to a "special needs" summer camp. Since the author is drawing on her own life experiences, the characters and situation have a high level of authenticity that comes through in the language of the book as developed in the characters, the setting, and the plot.

### **Book Awards**

Over time, the establishment of book awards exhibits a change in the way U. S. society includes and views individuals with disabilities. The purchase of award winning materials is a common practice in libraries and is a way to add reviewed titles considered high quality. The American Library Association gives several awards regularly for youth

materials. The identification of a title as an award winner of a major award such as the Newbery Medal or Caldecott Medal guarantees that the title will see increased visibility in library collections with many libraries purchasing these titles automatically and many indefinitely maintaining presence in libraries. A popular vote taken from a master list of nominated titles determines many state awards. Receiving a nomination for one of these awards can result in increased sales and additional printings of titles in addition to increased visibility for the book and the author and/or illustrator (Hilbun, & Claes, 2010). While it is difficult to obtain exact numbers for the impact of awards on book sales, informal studies (Fein, 1992, and Habash, 2012) and anecdotal evidence from the preliminary study on award impact in this report suggest that book awards do have a positive impact on sales.

However, book awards do not have a reputation for equally representing all sectors of the population. One recent article specifically reviewed representations of disabilities in Caldecott books (Dyches, Prater, & Jenson, 2006), and concluded that at the time of the study “approximately 12% of the students in public schools have a disability...only 4% of Caldecott Medal and Honor Books include a character with a disability. The underrepresentation is even greater than the underrepresentation of female characters in Caldecott award-winning books” (n.p.). In another study, it was determined that similar to the study of Caldecott books, “the representation of characters with disabilities in Newbery books is not proportionate to the current school population of children and adolescents with disabilities” (Leininger, Dyches, Prater, & Heath, 2010, p. 587). Additional points made in the same study include that the characters with disabilities were more often supporting rather than main characters, that in some

instances the author removed the character with a disability from the plot or by death, or provided the character with a miraculous cure. In addition, Leininger et al. were disappointed to observe that the characters with disabilities frequently serve as a means for a character without a disability to grow, rather than the character with the disability experiencing growth and development over the course of the book. Leininger et al. emphasize that parents and school professionals should use care to “choose books that accurately and positively portray characters with disabilities” (p. 594).

Recently created book awards provide recognition and increased visibility of books that represent the diversity of people within the population. Specialized bibliographies include information about these awards (Marks, 2006; Smith, 1994; York, 2005).

**Youth book awards portraying underrepresented cultural groups.** The connection between social legislation and the introduction of complementary youth book awards began with the earliest American Library Association (ALA) youth book awards, the Newbery Medal, which began in 1922, and the Caldecott Medal, which began in 1937. The inception of these awards roughly coincides with the Fair Labor Standards Act of 1938, which included stringent restrictions on child labor. This legislation followed decades of child labor reform activism that ushered in a more contemporary notion of a protected childhood. A changing understanding of childhood led to a changing understanding of the need for high quality children’s books. Responding to the dearth of quality youth literature, members of the ALA created the awards to encourage authors and publishers to create books that met high standards of excellence. Decades later, the Civil Rights Movement forced the nation to consider racial and cultural

diversity. Approximately a decade after key activities in the Civil Rights Movement, librarians Mabel McKissick and Glyndon Greer bemoaned the lack of high quality youth literature that portrayed racial and cultural diversity. The librarians first awarded the Coretta Scott King Award in 1970 at an ALA conference, and ALA officially recognized it 1980 (Smith, 1994). Other awards followed including the Pura Belpré Award that celebrates the Latino culture, the Asian/Pacific American Award for Literature that portrays the Asian/Pacific American heritage, and the American Indian Youth Literature Award that honors books by and about American Indians. Table 1 includes information on each of these awards including the date of inception, the awarding organization, and the goal of the award. In each case, the award honors outstanding youth literature that portrays a previously underrepresented group with the expectation that authors and publishers will create exceptional new books and libraries will add them to library collections.

**Youth book awards portraying disability.** One clear indication that the attitudes within some segments of society about individuals with disabilities are changing is the inception of youth literature awards for books depicting characters with disabilities. Two youth literature awards specifically focus on portrayals of disability, the Dolly Gray Award for Children's Literature in Developmental Disabilities and the Schneider Family Book Award. As illustrated in Figure 1, the Dolly Gray Award for Children's Literature in Developmental Disabilities starting in 2000 and the Schneider Family Book Award starting in 2004 follow roughly a decade after the passage of the ADA and IDEA, and illustrate the connection between social legislation and creation of youth literature awards.

*Dolly Gray Award for Children's Literature in Developmental Disabilities.*

Initiated in 2000, this award is a collaborative project between the Division on Autism and Developmental Disabilities (DADD) of the Council for Exceptional Children (CEC) and Special Needs Project, a distributor of books related to disability issues. Books receive the award biennially in two categories: picture book and juvenile/young adult chapter book. The award honors Dolly Gray, a young woman who experienced living with cerebral palsy. This award recognizes “authors, illustrators, and publishers of high quality fictional children's books that appropriately portray individuals with developmental disabilities” (“Dolly Gray Awards,” 2010).

The award webpage provides additional information on the anticipated impact of the award:

The framers and sponsors of this award believe the Dolly Gray Children’s Literature Award is making a great impact toward the general public’s recognition of the positive societal contributions of individuals with developmental disabilities, greater understanding and acceptance of teachers and school-aged peers of students with developmental disabilities, and encouragement of authors and illustrators to publish quality literature including characters with developmental disabilities. (“Dolly Gray Awards,” 2010).

While it may be that public youth librarians are less familiar with this award since it does not have a specific library organization affiliation, due to its connection with an education organization school librarians may be more familiar with the award and may already be selecting these materials for their collections.

***Schneider Family Book Award.*** Given annually since 2004 by the American Library Association (ALA), the award recognizes books in three categories: young children book, middle school book, and teen book. The award, named for the family of Dr. Katherine Schneider, honors “an author or illustrator for a book that embodies an artistic expression of the disability experience for child and adolescent audiences” (“Schneider Family,” 2011).

According to Dr. Katherine Schneider, the founder of the award carrying her family name, “the disability experience in these wonderful children’s books is a part of a character’s full life, not the focus of the life” (“Schneider Family,” 2011). The award criteria allows for the character with a disability to be either the protagonist or a secondary character. Dr. Schneider provided the definition of disability used in the evaluation process. From the manual, “Dr. Schneider has intentionally allowed for a broad interpretation by her wording, the book ‘must portray some aspect of living with a disability, whether the disability is physical, mental, or emotional’” (“Schneider Family,” 2007). The Schneider Family Book Award may not be as familiar as other ALA awards as noted by its absence in several recent textbooks in their descriptions of youth literature awards (Kiefer, 2010; Nilsen & Donelson, 2009; Norton, 2007; Tunnell, 2008). However, the Schneider Family Book Award was recommended in one recent children’s literature textbook (Vardell, 2008), suggesting that it will gain in familiarity with time.

### **Evaluating Portrayals of Disability**

Historically, representations of characters with disabilities have relied on stereotypes such as the “cheerful/noble cripple” such as Tiny Tim from Charles Dickens’ *A Christmas Carol*, or the pitiable or angry characters such as Clara from Johanna Spyri’s

*Heidi*, or Colin from Frances Hodgson Burnett's *The Secret Garden*. In all of these texts, the character with a disability makes either a remarkable recovery within the context of the book, or as in Tiny Tim's case, the promise of good health with a bright future.

Biklen and Bogdan (1977) defined ten common stereotypes found in books and media portraying characters with a disability: pitiable and pathetic; object of violence; sinister or evil, atmosphere; "Super Crip;" laughable, own worst enemy; burden, non-sexual; and incapable of fully participating in everyday life. These stereotypes do not represent the reality that young people living with disabilities actually face. Readers need contemporary books with authentic representations to balance the stereotypical images represented in the historical texts. A similar concept to Biklen and Bogdan's (1977) atmosphere stereotype is the inclusion of a character with a disability whose primary purpose in the story is to "influence the growth or development of a character without any disability" (Prater & Dyches, 2008, x). As Prater and Dyches further explained, "representing characters with disabilities only as they affect characters without disabilities does not represent the full range of contributions that individuals with disabilities make to our society" (2008, x).

Several authors have developed tools for evaluating youth literature books that represent disability (Blaska, 2003; Derman-Sparks & the ABC Task Force, 1989; Heim, 1994; Myles, Ormsbee, & Downing, 1992; Smith-D'Arezzo, 2003). Participants in the Circle of Inclusion Project at the University of Kansas (2002) identified nine points for evaluation including reviewing the illustrations, story line, lifestyles of characters, relationships between characters, effects on reader's self-image, author or illustrator's

background, author's perspective, loaded words, and copyright date compared to target age of reader.

Each of the two literature awards that honor youth books representing disability have evaluation criteria used by reviewing committee members. The webpage for the Dolly Gray Award for Children's Literature in Developmental Disabilities states, "the greatest weighting will be given to sensitive portrayal of character(s) with developmental disabilities. The literary quality of the text and the quality of the illustrations are also considered" ("Dolly Gray Awards," 2010). In addition to this overall criterion, the review committee considers the following points: portrayal of characters; social interactions; exemplary practices; sibling relationships; point of view; literary quality; and illustrations ("Dolly Gray Awards," 2010). As stated in the manual, the criteria used for evaluating books under consideration for the Schneider Family Book Award originated with the Linda Lucas Walling Collection in South Carolina. The criteria for the Schneider Family Book Award emphasize the importance of the literary quality and states that "first of all, the material should meet the basic criteria for the high quality children's literature" ("Schneider Family," 2011). This is a different emphasis from the Dolly Gray Award for Children's Literature in Developmental Disabilities with the greatest weight given to the sensitive portrayal of the characters with developmental disabilities followed by literary quality. Additionally, the Schneider Family Book Award review committee considers aspects of the stories including interest, hiding disability, sympathy and sentimentality, accurate representation of disability, realistic characters, and social interactions. In addition to these criteria, additional information is provided for evaluating picture books that address the need for those books to also meet high

quality standards as well as being adapted towards an individual child's specific needs related to their own "cognition, perception, vision, hearing and/or tactile kinesthetic skills" ("Schneider Family," 2011).

### **Purpose of Study**

As evidenced in their evaluation criteria, both the Schneider Family Book Award and the Dolly Gray Award for Children's Literature in Developmental Disabilities have as their aim providing authentic examples of representations of disability within high quality children's literature. An analysis of language, or discourse, of books offers a means to learn how the discourse of disability is included in these books to create these positive and authentic portrayals as articulated in the award criteria.

This study examines the hypothetical statement that the creation of young adult book awards devoted to authentic representation of disability in the context of high quality literature positively changes the discourse of disability as language communicates theoretical models of disability. The researcher investigated two related questions: how language communicates theoretical models of disability in contemporary youth literature, and how language used in book reviews and library cataloging supports or conflicts with the way language communicates models of disability in contemporary youth literature. Discourse analysis illuminates themes in the books that lead to an understanding of how language describes aspects of disability.

Theoretical models of disability offer explanations for character choices and may be part of characterization, plot, theme, or even setting of the books. The appearance of theoretical models of disability in books aids readers in understanding characters and motivations, characters conflicts, or significance of settings and situations. The study

focuses on three theoretical models of disability: moral, medical, and social. Before initiating this study, the expectation was that the study would show that not only is it possible to identify the theoretical models of disability in the books through discourse analysis, but also in some cases the major conflict of the novel might be identified as a conflict in theoretical models of disability between characters. Since the book evaluation criteria used by the two youth book awards that include characters with disability most closely aligns with the social model of disability, there is an expectation that the social model will be the most prevalent theoretical model of disability identified in the books, followed by the medical model and finally the moral model.

Knowing what theoretical models exist in a book will not only lead to a deeper understanding of the book, but it may also help to connect a reader with a book of choice. Since library personnel and patrons use supplementary tools to select and locate books, it is helpful to know how the supplementary tools describe the books. The supplementary tools studied were professional book reviews and catalog information, which includes subject terms and catalog descriptions. The researcher held an expectation that the language that illuminates the theoretical models of disability in the books and the language used in the supplementary materials might not emphasize the same themes of the discourse of disability. Based on preliminary work, an initial assumption was that in the supplementary tools, subject headings may emphasize medical model language more than books, but catalog descriptions and book reviews would use a broader mix of model language.

## Literature Review

A theoretical discussion of how society views individuals with disabilities begins with identification of metatheory, or theory about theory. Scholars through the ages have grappled with attempting to understand how we know what we know, and over time, have formulated ways of thinking about thinking. Determining the nature of reality and methods of investigation is central to this discussion of metatheory. Eloquently explained by Case, “just as a pyramid depends on its foundation to provide stability for the rest of the structure, scholars rely on basic assumptions regarding the nature of reality and the purposes and methods of investigation (2007, p. 142). Case describes various foundational concepts including perspectives, paradigms, and theories that aid in the scholar’s task of research, specifically in information science. Drawing from Thomas Kuhn’s work, Case defines a paradigm as a way to describe “the various points of view that researchers take in their search for explanations (2007, p. 144).

One example of a paradigm for which Case provides a description is constructionism. According to Case, constructionism draws from a variety of theorists that share a common interest in the “importance of language and social interaction in knowledge formation and in establishing social/power relationships” (2007, p. 159). Talja, Tuominen, and Savolainen compare three different approaches in information science: constructivism, collectivism, and constructionism (2005). As opposed to constructivism, which these researchers describe as being concerned with “individual creation of knowledge structures and mental models through experience and observation,” they determined that in constructionism, knowledge is produced in “ongoing conversations” as well as in “discourses that categorize the world and bring

phenomena into sight” (2005, p. 82). In other words, within the constructionist paradigm, people interacting through discourse socially construct knowledge.

### **Foundations of Social Constructionism**

Social constructionism, the paradigm that informs the theoretical framework of this study, is a “bundle of theoretical frameworks” as opposed to a single theory (Tuominen, Talja, & Savolainen, 2005, p. 329). Social constructionism has emerged from research practice in the social and human sciences. Some key scholars that are frequently credited with providing a background for the development of social constructionist research are: Peter Berger and Thomas Luckmann (1966) who focus on the social construction of reality; Mihail Bakhtin (1981) and Michel Foucault (1972) who emphasize discourse analysis; Harold Garfinkel (1984) on ethnomethodology; Harvey Sacks (1996) concerning conversation analysis; and Kenneth Gergen (1985, 1991, 2009) who is well-known for research in social psychology.

Social construction is part of the postmodern tradition, moving away from the rational and ordered approach of the modernist tradition. While modernist scholars are most interested in objective observations of how the world appears and functions, social constructionist scholars shift their focus to discovering knowledge of the world through shared understandings explored through dialogue and discourse. Gergen (2009) describes this move as a response to three major threads. The first thread is a response to the claim of value neutrality of the modernist era that led to a postmodern recognition that understanding of the world comes within a context that is value laden. Critical theories respond to the imbalance of power and oppression of segments of society. Gergen’s second thread is the rise of linguistics as a means to deconstruct literary

messages to unearth their underlying meaning and to challenge uncontested statements of reason. His third thread deals with the response to common acceptance of scientific facts as infallible truth. In the postmodern community of scholars, it became appropriate to question the means of discovering scientific facts as well as to begin to discuss the values and ethics inherent in the scientific realm. Social constructionists and other postmodern theorists assert that people should question accepted knowledge in the world. Gergen (2009) suggests the following questions when approaching traditionally held beliefs: “how did we come to hold these views; why do they seem so very obvious; what do they do for us; who is silenced by such assumptions, and are there reasons to explore alternatives?” (p. 32).

Social constructionism has maintained a strong presence in the humanities and social sciences and in recent years has expanded into other fields of study. A recent search of the online catalog of the William Allen White Library at Emporia State University provided 218 hits when using the search term “social construction\*.” A sampling of the topics represented cover subjects including social construction and difference and inequality, intellectual disability, technology, emotions, abuse, evolution, parenting, race, and sexuality. In a thorough review of current constructionist research, Holstein and Gubrium (2008) bring together accounts of active research agendas in a variety of fields including anthropology, communication, education, management, nursing, psychology, public policy, science and technology, and sociology. They explain that although a variety of approaches are represented, approaches are unified by a “distinctive way of seeing and questioning the social world—a vocabulary, an idiom, a language of interpretation” (p. 5). They further explain that constructionist research

“typically deals with practical workings of *what* is constructed and *how* the construction process unfolds” and it does not lend itself to “dealing with the *why* questions that predominate in more positivistically oriented inquiry” (p. 5).

While social constructionism has spread as a research paradigm, the approach is not without its critics. Some of the more common criticisms of social construction are that it takes a purely relativistic stance and ignores scientific truth in viewing all knowledge as socially constructed, or that it is morally wrong when it claims undesired behaviors are socially constructed (Holstein & Gubrium, 2008). In addition, some scholars are concerned that uncertainty as to the nature of social constructionism has led to a lack of clarity as to the nature of this approach. Stam (2001) answers the question of “what is social constructionism?” by acknowledging that it has been considered “a movement, other times a position, a theory, a theoretical orientation, an approach” (p. 294). Jenkins (2001) expresses concern that the “significant influence of social processes should not blur other important contributions to the dynamics of the self-concept” (p. 358), chiefly the individual’s capacity for thought and evaluation as part of the development of self, separate from social influences.

The following discussion describes how specific disciplines use social constructionist research to investigate issues pertinent to this research project. The three areas covered in more depth are social construction and psychology, social construction and information science, and social construction and disability.

**Social construction in the field of psychology.** One field of study that has adopted the utility of social construction as a means of understanding the world is psychology. Within that discipline, one psychologist known for a life-long exploration of

social constructionism is Kenneth Gergen. For Gergen, social constructionism is a way of looking at the world that asks us to “rethink virtually everything we have been taught about the world and ourselves” (2009, p. 2) and to view the world as being constructed through our social relationships. The invitation that he extends is to look beyond “anything traditionally accepted as true, rational, or right” with the possibility that “as we speak together, listen to new voices, raise questions, ponder alternatives, and play at the edges of common sense, we cross the threshold into new worlds of meaning. The future is ours – together – to create” (2009, p. 5). Gergen identifies his assumptions for social constructionism, which state that society constructs meaning and knowledge through interactions and discourse, and questioning social assumptions moves society to a better future. Gergen’s purpose in pursuing social constructionism as a research agenda is to work towards a betterment of the human condition through reviewing and possibly revising current ways of acting and interacting (2009).

In addition to Gergen’s work, psychology scholars have explored the application of social constructionist methods to the study of critical psychology, discursive psychology, theoretical psychology, therapy, health psychology, and the history of psychology (Gergen & Gergen, 2008). An additional area that makes connections between psychology and the humanities is narrative psychology, such as in the work being done by Dan McAdams (1993, 2006) contributing to the understanding of narrative in personal life. Raskin (2002) suggests that social construction connects to an approach called hermeneutic constructivism as both approaches closely link the way that groups create knowledge through linguistic activity.

**Social construction in the field of information science.** Social constructionism has found application in the field of information science as well as the other social sciences previously referenced. Tuominen, Talja and Savolainen (2005) discuss the usefulness of social constructionist methods when studying information practice stating that these studies can be used to “analyze information, information technology, and information users as conversational constructs produced within the boundaries of specific discourses and epistemic positions” (p.330). They provide examples of research in the field of everyday life information seeking, interactions between librarians and users, collaborative information seeking and retrieval, and even in the design of digital libraries. They further invite the LIS community to consider adopting constructionism as a useful metatheory, stating that “information, information systems, and information needs can all be analyzed as linguistic and conversational constructions, as entities that are produced within existing discourses” (Tuominen, Talja, & Savolainen 2002, p. 281). In another article, they suggest the following applications for research:

...information seeking research focusing on accounts of information practices, analysis of professional and scientific discourses of IS and information technology, design of digital libraries and argumentation visualization systems for mapping literatures, perspectives and debates, and design of collaborative knowledge filtering and synthesis systems. (Talja, Tuominen, Savolainen, 2005, p. 93)

In an effort to clarify how social constructionism applies to information science, Holland (2006) provides the following definition:

Social constructionism in information studies is taken to mean the focus on dialogue and discourse as the essential elements in people describing and producing their experiences. Dialogue and discourse stress the role of language in the building of social reality, which encompasses information practices as seeking, accessing, creating, using and sharing information. All associated experiences, emotions, identities and social worlds are language based, and thus best researched with a dialogue and discourse focus. (p. 92).

Holland acknowledges a strong research tradition for information science in cognitive studies, which he feels has sometimes led to an imbalance since “cognitivism focuses on the individual at the expense of the context and social constructionism focuses on the context at the expense of the individual’s acts” (p.97). He proposes a research agenda that combines the two, which would open up new avenues of understanding for information behavior.

Similar to Raskin’s work in psychology, Capurro (1992) finds a significant connection to hermeneutics in his work in information science. In his understanding of hermeneutics referring to our “being-in-the-world-with-others” (p. 85), he makes a likely connection to the socially constructed reality of the social constructionism paradigm and sees great utility in continuing research in the hermeneutic-rhetorical tradition in this field.

Various scholars have applied the paradigm of social constructionism to their thinking about information science. Although not stated as a social construction, Julien (1999) provides an interesting discussion about the need to re-evaluate the field’s use of the term “user” as it actually represents a construction on the part of the field as to who

is worth studying. She makes the point that as a discipline studying “user” behavior, we are neglecting to consider those non-users of information, and that our construction of the term may be inhibiting our understanding of the people who may not fit our constructed definition, and thereby restricting our research agenda. Although it has been over ten years since she encouraged information science scholars to adopt a new term, the less inclusive term “user” remains in use. Julien’s underlying hope is that a dialogue between the information science professionals and the people served by libraries may lead to a better construction for the term “user” (1999).

Talja (2005) discusses the construction of information technology literacy. In one study, she interviewed scholars who describe themselves in terms of their own competencies in computer usage, their attitude about computer use, their emotional stance regarding computers, etc. She discovered an occasional division between how the scholars self-describe their computer literacy and their actual technological skills. She recommends employing a socio-cultural perspective, which allows for the tie to the individual’s social nature and construction of self.

In another example of socially constructed meanings, Chelton (2001) explores why some librarians see young adults as problems. The library personnel see the young adults in the study as being a problem in the library, not knowledgeable about library resources, rude and not the type of person desired in the library. An important message in this article is the need to develop an awareness of the power of language and discourse, as well as the need to focus attention on the portrayal of individuals or groups. A lack of attention may lead to marginalization of a group, and the service provided to them negatively influenced due to preconceived ideas held by library staff. Chelton views the

understanding of these biases and how the formulation of biases to be of crucial importance to the profession. According to Chelton, “the communicative construction of the mythical ‘ideal user’ within the work setting, as well as the power of the socialization toward this myth that occurs there, should become as important a part of LIS professional education as the construction of an information system” (pp. 10-11).

Rothbauer (2004) investigated the role of voluntary reading by young women who were exploring their sexual identities. While Rothbauer learned that many of the young women in the study had encountered helpful and sympathetic library staff members, it was not always easy for the women to locate the materials that they wished to read at the library. Rothbauer also explored the impact of the reading materials on the young women. Rothbauer suggests that libraries could not only do a better job creating the collections, and in providing access to the materials using current language in the catalog and databases.

In the case of providing services for people with varying disabilities, which is the focus of this study, it is important to remember that like other marginalized groups, the needs of individuals with disabilities are often misunderstood and met with ineffective responses by traditional library services. While libraries regularly address issues of physical access to information resources and service, obstacles that may prevent individuals with disabilities from accessing information that they need or want are likely to be cultural or social obstacles rather than physical.

**Social construction and disability.** Another academic area that includes significant use of social constructionism is disability or disability studies. Goffman (1963) explores the phenomenon of stigma and presents it as a model for understanding

society's response to people who are different from the social norm. According to Goffman, individuals change their normal behaviors when interacting with a person who is "stigmatized" because of a shared societal belief system. This may play out in a variety of ways, both positively and negatively, depending on the cultural understanding of the stigma. In the case of individuals with disabilities, the treatment by those around them will likely influence their understanding of themselves and their place in their society. Although not strictly a work addressing social constructionism, Goffman's work shares an understanding of the social nature of difference and the subsequent societal response.

In a more contemporary study by Crystal, Watanabe, & Chen (1999), researchers provided an opportunity for 5th and 11th graders in the United States and Japan to explore their feelings about disability. Participants viewed an illustration of five children waiting to go swimming, four children were standing and the fifth was sitting in a wheelchair. The participants described their feelings as if they were the person sitting in the wheelchair, and as if they were one of the other children interacting with the person in the wheelchair. The researchers used Goffman's concept of stigma to frame a discussion of the process. The researchers were able to identify more similarities than differences in the response to disability between the two cultures in terms of socialization and expected responses to disability. While this study does relate specifically to social constructionism, the youth in the study exhibited an understanding of socially negotiated expectations.

## **Theoretical Models of Disability**

It is worthwhile to consider various theoretical models used for creating knowledge and related to understandings of disability while continuing the discussion of disability as a social construction. Three of the more pervasive models receive the focus for this discussion: the moral model, the medical model, and the social model. Although these three models developed in different historical eras, all are still in use today. The moral model of disability represents a supernatural worldview in thinking about disability dating back to the ancient world and is the “oldest of all disability models, but, arguably still the most prevalent worldwide” (Goodley, 2011). The medical model of disability has roots in the mid-19th century with the advent of modern medicine and identification of cures and treatments for disabling conditions. The transition from moral to medical models represents a shift from magical thinking to the scientific method (Goodley, 2011). The social model of disability is an outgrowth of the disability rights movement of the late 20th century (Oliver, 1990). The social model represents a paradigm shift in that disability is no longer identified as a personal tragedy as in both the moral and medical models, but instead, as a societal response to individual impairment (Goodley, 2011). Various additional models are in contemporary use such as the political model (Gilson & Depoy, 2000), the psychological model (Avoke, 2002), the functional model, (Smart, 2009) and other scholars question the utility of a single unified model at all (Gabel & Peters, 2004). Goodley (2011) suggests that the new models and approaches align more closely with the social model than the earlier moral or medical models of disability.

**Moral model of disability.** The moral or religious model (Avoke, 2002) is one of the earliest theoretical models of disability. In the moral model, disability results from

a moral choice such as sin or transgression against a spiritual power and often has negative overtones. The individual with a disability, their parents, or their community aggrieved the higher power, and the individual with the disability suffered because of those choices. According to Avoke,

...the use of pejorative labels and the manner in which people with disabilities are treated tends to be considered justified, because disability in the past was so strongly attributed to religious or magical models where evil was *placed* on an individual from the gods. (2002, pp. 770-771)

In these cases, the individual with the disability, family, or community may attempt some form of penance to appease the higher power and possibly return the individual to perceived normalcy. A view that was dominant in India stated that disability was a “retribution for past karmas (actions) from which there can be no reprieve” and further that disability is “an essential characteristic of the individual that has to be endured to pay back for all the sins committed in the past” (Ghai, 2002, p. 91). Goodley (2011) describes the negative effects of a moral model view of disability as “being ostracized from family and community, feeling profound shame, having to hide disability symptoms or the person with a disability” (p. 7).

Alternately, under the moral model the community sees the individual with a disability as blessed by the spiritual power. The individual with a disability experiences closeness or clear communication with the spirit world. The community views the family of the individual with a disability as favored by the spiritual power who has confidence in their capability of caring for a child with special needs (Fadiman, 1998).

In ancient Western civilization, the cause of disability was important when predicting community response. When the community observed a disability resulting from immoral acts, they were less inclined to be supportive of the individual or family. However, if the disability resulted from a heroic deed, such as a war injury, some cities provided support and even a modest pension (DePoy & Gilson, 2004). Questions about worthiness of empathy or support for individuals with disabilities continue as our contemporary society struggles to determine the Americans with Disabilities Act of 1990 (ADA) coverage for those whose actions may have brought about their medical needs such as people with AIDS and pregnant women (Alemzadeh, 2012).

**Medical model of disability.** While the moral model continues to play a role in some cultural traditions and social norms, with the advent of modern medicine the medical model has partially supplanted the moral model (Burch & Sutherland, 2006; Hayes & Hannold, 2007; Llewellyn & Hogan, 2000). In the medical model, the disability represents an aberration from the normal, healthy body. The medical model uses medical terminology to describe disability such as diagnostic language (cerebral palsy, spina bifida) or treatment language (occupational therapy, ankle foot orthotic). Once identified and described, the disability can be treated and possibly cured. This model frequently involves interventions for the individual with disabilities such as treatment or surgery, therapy, assistive devices such as hearing aids, corrective lenses, and prosthetics or other mobility devices, all in an effort to return the person back to a close proximity of a perceived normal state. Closely related to the medical model are rehabilitation and educational models that seek to respond to the perceived limitations with therapeutic treatment, skills training, and educational accommodations.

Critics claim that the medical model devalues the body that is different and sees the ultimate goal as returning that body to as close to average as possible to achieve the greatest value.

Not unexpectedly, the medical model of disability does not bode well for those who are permanently disabled with conditions that cannot be modified or changed by professional intervention. In this view, the individual who cannot be ‘fixed’ by professional intervention so to speak, remains deficient. (Gilson & Depoy, 2000, p. 208)

Members of the disability rights movement respond by identifying value in all bodies regardless of the way that they move or perceive the world, and assert that all individuals are an equal part of making up the diversity that we call human (Smart, J. F., & Smart D. W., 2006).

**Social model of disability.** The social model developed in conjunction with the disability rights movement. In the social model, disability is seen as a reality that society should address openly, since it can affect any member of the population as it is “the one minority that anyone can join at any time” (Shapiro, 1994, p.7). Proponents of the social model acknowledge disability as a difference in body, but not necessarily as a condition needing modification or healing. The social model suggests that body difference alone does not create the disability, but rather the disability comes from the external realities that hamper life activities such as mobility or communication. Many proponents of the social model claim a distinction between *impairment*, defined as individual body limitations, and *disability*, defined as social restrictions or obstructions that impede the individual in carrying out life activities (Goodley, 2011). The social model sees the

challenge not in getting all bodies to meet a specific set of standards for normalcy, but instead to create environments where all bodies are accepted and enabled to carry out life activities. For instance, the concept of universal design in architecture asserts that building design needs to enable optimal facility use by all potential users. Universal design includes choices such as ramps instead of steps, doors wide enough to accommodate wheelchairs and scooters, and signage provided in multiple formats (large print, Braille, etc.) and at a height that will accommodate someone sitting. Retrofitting a building to meet ADA requirements is a challenge, but new construction can consider this from the beginning to ensure maximum accessibility (Shapiro, 1994).

Critics of the social model claim either that it goes too far in separating the physical reality of disability from the social realm, or that it does not go far enough in addressing the needs of those with disabilities (Gabel & Peters, 2004). Morris (1991) argues that the social model does not validate the experience and pain of living with a disabling condition and suggests a reconceptualization of the model to acknowledge this reality and incorporate a sociological understanding of impairment. Due to the relative youth of this model of disability, it is not surprising that a unified viewpoint has not yet emerged as the definitive social model of disability. As mentioned previously, Goodley (2011) sees an eventual evolution of this model as several contemporary approaches use complementary concepts to the social model of disability.

### **Language of Disability**

As expressed in the last section, language has a specific role to play in constructing the discourse of disability. According to Keller, “naming nature is the special business of science. Theories, models, and descriptions are elaborated names. In

these acts of naming, the scientist simultaneously constructs and contains nature” (1985, p. 193). Priestly provides a similar perspective:

When we speak in terms of gender, race, class, age, sexuality or disability we are also contributing to the production of those same social divisions and categories. Moreover, when we name ourselves, or when others name us within such categories, we too are being produced.” (1999, p. 92)

In terms of disability, language is a “powerful tool in the definition of disability culture as well as in advancing an understanding of disabled people as marginalized and devalued by nondisabled dominant groups” (DePoy & Gilson, 2004, p. 83).

**Legal definitions.** Language describes disability in legal definitions used in various pieces of legislation that deal directly with disability. Because the definitions differ depending on the specific law and the elements covered in the law, there can be misunderstandings or misinterpretation of language use based on specific contexts. Two of the significant pieces of disability legislation highlighted previously, Americans with Disabilities Act of 1990 (ADA) and the Individuals with Disabilities Education Act (IDEA), use specific terminology related to disability.

In the language used in the ADA, a person is defined as having a disability if the individual has a “physical or mental impairment that substantially limits one or more of the major life activities of such individual; a record of such an impairment; or being regarded as having such an impairment” (ADA, 1990). As evidenced in this language, there is room in the ADA definition for differences of opinion about who is eligible for provisions under the law. Disability exists on a continuum from a mild to severe impact on an individual. For instance, an individual with a visual impairment might use

corrective lenses that have only a slight correction to someone who is blind and uses a service animal for assistance with navigation. Evaluation would be required to determine which individuals with visual impairment met the ADA definition of disability and qualified for accommodations under the law. To qualify for accommodations under ADA may require an assessment from a medical professional to determine the level of impairment and life limitations, and in some cases, a legal response from the court to determine the appropriate accommodations. The second phrase of the ADA definition, “a record of such an impairment,” addresses the more permanent nature of the disability, in that the condition exists over time. The third phrase of the ADA definition, “or being regarded as having such an impairment” brings into play the social aspect of disability. The total definition provides a broad view of disability in that it includes aspects that are measureable or testable, along with aspects that have no available metrics or assessment and rely on social interaction.

IDEA ensures a free, appropriate public education to children with disabilities in the least restrictive environment. This law defines a child with a disability as meaning one “with mental retardation, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance (referred to in this title as ‘emotional disturbance’), orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities; and who by reason thereof, needs special education and related services.” (IDEA, 2004).

Despite the more specific information provided in this law regarding the definitions of disability covered, aside from a medical diagnosis, it is easy to imagine differing

interpretations of the language of the law. Prior to a child receiving services under IDEA, appropriate personnel will evaluate the child, family and school personnel will meet and discuss recommended accommodations or services, and an Individualized Education Program (IEP) will be written and agreed upon by appropriate parties.

**Medical Terminology.** Medical professionals use standard terminology to describe disability from the medical perspective. Terms change with new medical information or changing understanding of medical conditions. A recent example of changing medical language is the decision to remove the term “Asperger Syndrome” from the upcoming edition of the Diagnostic and Statistical Manual of Mental Disorders-V (DSM-5), which will go into effect in May, 2013 (“DSM,” 2012). Another standard classification tool is the International Classification of Diseases (ICD). From the World Health Organization, the ICD-10 is the current edition of the document, used since 1994. Work is currently underway on the eleventh edition, due out in 2015 (“International Classification,” 2013). The 11th revision of the classification has already started and will continue until 2015.

**Controlled vocabulary.** Library professionals use language to name topics in very specific ways as part of the system of cataloging. If the language selected for the controlled vocabulary of the catalog is not the language with which library patrons are familiar, patrons may have little success in locating the materials desired. As Olson frames it, “library users seeking material on topics outside of a traditional mainstream will meet with frustration in finding nothing, or they will find something but miss important relevant materials” (2001, p. 639). It is important to understand not only the role that language plays in library cataloging, but to recognize the potential challenges

using a controlled system of vocabulary poses for the library user. One challenge of the cataloging system is the process involved in making changes can move very slowly, and not be current in contemporary use of language to describe disability. In addition, people familiar with older terminology may have difficulty finding information cataloged under newer terminology.

**Person first language.** As the views of society changed towards inclusion of individuals with disabilities, it became necessary to reevaluate the language used to describe persons with disabilities. Lee wrote, “one may apply to a person what is implied in the label while ignoring the person himself” (1969, p. 15). This phrase emphasizes the danger in viewing a person as the label given to them by society if that label keeps one from seeing or valuing the person first. This is the core concept behind the approach to language and communication known as “person first” (Blaska, 1993). The key component of the person first language philosophy is to reorder word structure, putting the person first, and the disability second. For instance, instead of referring to the young person as “wheelchair bound,” refer to the “young person who uses a wheelchair,” or instead of the “epileptic,” refer to the “boy who has epilepsy” (Blaska, 1993; Russell, 2008). The concept of person first has become the standard in many legal settings, scholarly communication, educational institutions, and hopefully, in youth literature as well. Both the Americans with Disabilities Act and the Individuals with Disabilities Education Act use person first language in their titles (Russell, 2008).

For the most part, person first language has permeated our conversations and has become the commonplace mode of referring to disability in professional communication. Numerous examples of guidelines for appropriate communication are available such as

style guides for writing (“Style Guide” 2013) and organizational guides for language and interactions (“Respectful Disability Language,” 2013). Guides also caution another category of language to avoid, frequently referred to as victim language, which identifies the person with the disability as a victim, portraying the person with the disability as weak and vulnerable. Examples to avoid are phrases such as “suffering from cerebral palsy,” “confined to a wheelchair,” or “wheelchair bound.” These last two phrases are especially questionable as wheelchair use provides increased mobility and freedom for a person rather than restricting their movements (“Respectful Disability Language,” 2013).

However, the practice of using person-first language when talking about disability is not without its detractors within the disability community. According to DePoy and Gilson, the use of person-first language implies a medical explanation of disability that internalizes the disability as in the “person with the disability.” They further state that rather than exploring other factors that may contribute to the disablement, “the term ‘disabled person’ does not imply the directionality of the disablement. One may be disabled by a legitimate medical-diagnostic, social barrier, or political powerlessness explanation.” (2004, p. 83). This explanation complements the earlier description of the social model of disability where the disablement of the person comes from factors outside of the person themselves.

**Derogatory Language.** Slang or informal language use sometimes signals membership in a cultural group.

Consider the terms used by persons with disabilities, such as “crip” or “wink.”

These terms would be considered derogatory when used by non-disabled people to describe people with disabilities. However, when used by disabled persons

among themselves, the terms not only are “allowed” but also are often symbols of pride and community (Depoy & Gilson, 2004, p. 83).

If used by those outside of the community, the language can seem derogatory, but when used within the community it may serve as a means to embrace and reclaim words that have held negative connotations and power. According to Galinsky, Hugenberg, Groom, and Bodenhausen (2003), “self-labeling diffuses the impact of derisive terms by making the name more commonplace” (p. 231). This approach has been used by a variety of marginalized groups in an effort to reclaim or reappropriate language that has been used negatively towards the group. Disability rights activists and scholars have embraced the power in reappropriating language that carries negative connotations. According to Galvin (2003):

Claiming ownership over a word that was previously used in derogatory ways and investing it with new, more positive meanings not only leads to a new show of strength to those outside the liberatory discourse, it also protects the individuals thus named from being hurt any longer by the negative connotations that may still be inherent in other people’s use of the term. (pp. 90-91)

### **Discourse and Youth Literature**

One means of examining language use is by studying the discourse as presented in texts using a method such as discourse analysis. In this study, the definition of discourse analysis given by Potter and Wetherell (1987) is used. These researchers ...use ‘discourse’ in its most open sense...to cover all forms of spoken interaction, formal and informal, and written texts of all kinds. So when we talk of ‘discourse analysis’ we mean analysis of any of these forms of discourse. (p. 7)

These researchers clarify the role of language further in that “a large part of our activities are performed through language; our talk and writing do not live in some purely conceptual realm, but are mediums for action” (Potter & Wetherell, 1987, p. 9). The concept of construction applies in three ways to an analysis of discourse where accounts of events include building blocks such as language, choice of elements, and an emphasis on “the potent, consequential nature of accounts...in a profound sense, accounts ‘construct’ reality” (Potter & Wetherell, 1987, p. 33-34). Two key questions come forward, “how is participants’ language constructed, and what are the consequences of different types of construction?” (Potter & Wetherell, 1987, p. 55) In order to pursue this approach to research, one must then take the first step:

...the suspension of belief in what one normally takes for granted, as we begin to think about how a practice is constructed and what it assumes rather than seeing it as a mere reflection of an unproblematic reality. The relativity of our own discourse of selves and people is made explicit when other cultures are studied.

(Potter & Wetherell, 1987, p. 104)

In applying these thoughts to research in the disability discourse, one must step back from unquestioned models or ways of seeing disability and view it with fresh eyes.

Another scholar states it this way:

I suspect there is no culture in the world which has not used words to further disable disabled people...no wonder disabled people have struggled all this time not with the actuality of their impairment, not just the history of labeling and segregation, but the representation placed in people’s minds of what constitutes a disabled person. (Slack, 1999, p. 28-29)

By examining the discourse of disability by using discourse analysis, researchers can investigate the nuances of the conveyed message.

Specific examples of using discourse analysis with youth literature include studies of picture books dealing with sexual abuse of children (Lampert & Walsh, 2010), children's books about AIDS (Blumenreich & Siegel, 2006), children's literature that explores other cultures (Stewart, 2008; Ryan, 2006; & Smith, 2006), and a critical analysis of young adult literature (Curwood, 2013). Each of these studies examined an aspect of the social world by exploring the language used in youth literature through discourse analysis.

## Methods

To investigate the social construction of knowledge about disability as expressed in youth literature, the researcher conducted a study of award winning books. The approach to the study of selected texts of books was to view books as data sources, and to use the research method of discourse analysis to conduct an exploratory study of the texts to determine ways language usage constructs the aspects tied to disability. Specifically for this study, the researcher investigated award winning chapter books from the Schneider Family Book Award and the Dolly Gray Award for Children's Literature in Developmental Disabilities (Table 2). The study excludes award-winning picture books from each of the two awards due to a choice made to limit the study to texts only and not add evaluation of illustrations.

Drawing on the approaches to discourse analysis as described by Potter and Wetherell (1987), Wetherell, Taylor, and Yates (2001a), and Corker and French (1999), the study focused on the discourse used in the books to describe and explain the disability experience of the characters. Due to the flexibility and clarity of the description of stages of discourse analysis outlined by Potter and Wetherell, the researcher determined that adopting their method of discourse analysis provided the best fit for this research project. The researcher collected basic demographics of the characters as a foundation including gender, age, type of disability, and major or minor character status. In addition, the researcher examined catalog records for these books in order to understand the ways that the controlled vocabulary of the library catalog and the catalog descriptions describe the disability experience. Professional book reviews for each book were also gathered, and the language of the reviews is included as another facet of the discourse. Finally, the

researcher read and re-read the books, identifying emerging themes tied to disability in the books. The analysis examines the data revealed from the texts and places it in the larger context such as the context of the awards, social context, and legislative context. This chapter outlines the research questions, discusses preliminary studies, and discusses specific actions for each step of the discourse analytic research process.

### **Research Questions**

According to Foss and Waters (2007), research questions can be made more effective by identifying six different elements: the theoretical construct of interest; the recognizability of the theoretical construct; a question that transcends the data set; the connection of the present study to an understanding of the theoretical construct; the potential of the study to surprise the reader; and the potential of the study to produce robust results. Following Foss and Waters guidelines, the research questions evolved from a desire to understand how contemporary youth literature portrays individual disability experience. The researcher investigated the following research questions:

1. How does language communicate theoretical models of disability in contemporary youth literature?
2. How does the language used in book reviews and library cataloging support or conflict with the way language communicates models of disability in contemporary youth literature?

### **Preliminary Studies**

During the planning phase of this project, the researcher conducted three preliminary studies to assess the worthiness of this research project and the identified method of study. The first study involved a preliminary reading of all of the books that

have received the Schneider Family Book Award (24 books awarded 2004-2011), and the Dolly Gray Award for Children's Literature in Developmental Disabilities (10 books awarded 2000-2010). The second preliminary study examined the catalog records retrieved from WorldCat for all of the award books. The third preliminary study reviewed two measures of impact from the designation of books as American Library Association award winners.

**Preliminary readings.** The researcher conducted a preliminary reading of all thirty-four books that had received either youth literature award through 2011 with the intent of determining potential as a data set for this research project. No formal coding occurred during the preliminary reading of the books, but the researcher noted themes for further investigation in the subsequent readings of the texts. As award winning books, multiple reviewers have evaluated the entire group, so as anticipated there were no observable problems with the books or the portrayal of disability.

Based on this reading, it was determined that one potential and unique direction for the study would be an analysis of the books in terms of inclusion of differing theoretical models of disability. Other themes that emerged from the initial readings included the various functions of language used to represent disability, character roles and relationships between characters with disabilities and those not demonstrating disabilities, and stereotyped representations in characters, setting, or plot. These observations led to sixteen preliminary questions in five preliminary coding categories (Table 3). Additionally, it was determined that using discourse analysis for this study was a reasonable approach.

**Catalog records.** The second preliminary study involved collecting and examining the catalog records for all thirty-four award books that had received either the Schneider Family Book Award or the Dolly Gray Award for Children's Literature in Developmental Disabilities. The researcher identified and tabulated forty-four unique subject terms that represent disability. Autism spectrum was the most common specific condition encountered. Some of the catalog descriptions contained dated terminology with negative connotations. In addition, some catalog descriptions did not use person first language. The catalog descriptions occasionally suggested the theoretical models of disability included in the books.

This limited review of the catalog records did provide some interesting points for consideration. First, the lack of any mention of disability in the subject terms of four books that received an award for representation of disability was curious. Without subject terms or keywords in the book description, it may be difficult for a patron to locate those books when doing a keyword or subject search tied to disability. Second, the distribution of subject terms showed that some disabilities occur in the books more frequently than others do. This led to a comparison of the distribution of disabilities in the study set of books to the occurrence of the varying disabilities in the general population. Third, the preliminary study showed the utility of language as a means to investigate the catalog records. From this initial review of the catalog records, it was determined that catalog information would complement the books, and would prove to serve as a valuable facet to the research project.

**Award impact.** The third preliminary study considered the impact of receiving book awards on the likely availability of the books in libraries. The researcher used two

measures to assess the impact of the awards: holdings listed in the WorldCat database of libraries, and sales ranking on Amazon.com. The 2011 American Library Association Youth Media Awards ceremony took place on January 10, 2011. With each award announcement, the researcher recorded baseline numbers for each measure and repeated recording measurements daily for one month.

The researcher discovered that winning any of the youth media awards led to a significant spike in sales ranking for a book regardless of its popularity beforehand. For books that were less popular before winning an award, the library holdings data suggests an enhanced initial wave of adoption activity, followed by a steady climb with higher percentage gains. While this data set was determined not to be necessary for the final research project, it was a valuable tool in the preliminary planning to assess the worthiness of a study focused on award winning books.

### **Discourse Analysis**

Potter and Wetherell (1987) identify ten stages in the analysis of discourse: research questions, sample selection, collection of records and documents, interviews, transcription, coding, analysis, validation, report, and application. They suggest that these stages are not “clear sequential steps but phases which merge together in an order which may vary considerably” (p. 160), and the authors further identify these stages as a “springboard rather than a template” (p. 175). Using the springboard suggestion as a guide, the interview stage was not included as part of this study. The following paragraphs include further information on each of the stages as outlined by Potter and Wetherell as well as a discussion of the application in this research project.

**Research Questions.** The research questions should focus on the discourse or as Potter and Wetherell (1987) state, “participants’ discourse or social texts are approached in *their own right* and not as a secondary route to things ‘beyond’ the text like attitudes, events or cognitive processes” (p. 160). The researcher wrote the research questions with an emphasis on the language, “how does the language communicate theoretical models of disability...,” and focused on the creation of the discourse and possible benefits from its study.

**Sample Selection.** Part of the process of performing discourse analysis is reading and rereading significant amounts of text. “There is a danger here of getting bogged down in too much data and not being able to let the linguistic detail emerge from the mountains of text” (Potter & Wetherell, 1987, p. 161). To respond to this concern, the researcher selected a sub-set of award winning youth literature, excluding the award winners from the picture book category.

To answer the research questions, the researcher used award winning books from the Schneider Family Book Award and the Dolly Gray Award for Children's Literature in Developmental Disabilities (Appendix A). These two awards complement each other well due to their slightly different emphases and backgrounds. As mentioned previously, the Schneider Family Book Award joins other youth media awards given by the American Library Association, and is familiar to school and public librarians who select materials for library collections. Youth books that include a character with any disability are eligible for this award. The Dolly Gray Award for Children's Literature in Developmental Disabilities is narrower in its eligibility criteria, focusing specifically on developmental disabilities. As this award is a collaborative effort between the Division

on Autism and Developmental Disabilities (DADD) of the Council for Exceptional Children (CEC) and Special Needs Project (a distributor of books related to disability issues), it may reach a slightly different audience.

The different emphases of the two awards are further evident in the fact that no titles have received both awards. There have been books that have been on both review lists. For example, *Marcelo in the Real World* was on the 2010 Dolly Gray Award for Children's Literature in Developmental Disabilities review list and won the Schneider Family Book Award for the same year. This suggests that it is possible in the future that a book receive both awards.

Excluded from review for this study were any of the books that are primarily picture book format, leaving six books from the Dolly Gray Award for Children's Literature in Developmental Disabilities, and 16 books from the Schneider Family Book Award for a total of 22 books. All books received awards since 2000, and books from the 2011 awards are included.

In addition to the books, professional book reviews for a given book from established review sources such as *Booklist*, *School Library Journal*, *Hornbook*, *Kirkus Reviews*, and *VOYA* are part of the data set for the study (Appendix B). These items added to the richness of the discourse by providing another facet for exploration.

The last element in the data set is the standard cataloging for the books (Appendix C). The points of interest in the cataloging information are the description of the book as well as the subject terms used to describe the book. Although contemporary library users may be more likely to conduct keyword searches than subject searches in an online public

access catalog (OPAC), keyword searches will include the subject terms, catalog descriptions, as well as other text in the catalog record.

Since this was an exploratory study into the representations of disability in a specific selection of youth literature, the researcher used a larger sample than might be suggested by the guidelines set forth by Potter and Wetherell (1987). The researcher considered using a subset of the award winning books, but determined that drawing from the entire group of award winning chapter books would enhance the richness of the study. The researcher determined that a manageable amount of data was attainable by focusing on the words and phrases that specifically addressed disability and setting aside the remaining text.

**Collection of Records and Documents.** It is common for discourse analysis to use “records and documents of interaction, as opposed to material garnered from the researcher’s own dealings with participants...one of the most important advantages of collecting naturalistic records and documents is the almost complete absence of researcher influence on the data” (Potter & Wetherell, 1987, p. 162). The researcher used published documents for this study, including books, book reviews, and cataloging information.

**Books.** The first phase of the data collection began with an initial quick reading of all of the 22 books. The primary goals for the first reading were to gain an understanding of the style of the book, the disability represented, and to make general notes of themes that might merit further study. Also within the first reading, the researcher informally evaluated the books using the Circle of Inclusion guidelines (2002).

Following the second reading of the books, the researcher evaluated the books using the two award criteria as well as the Biklen and Bogdan (1977) list of stereotypes.

During the second reading of each of the books, words and phrases that referred to disability were marked. Types of information included in these notes were information about the specific disability, description of symptoms or manifestations of the disability, feelings about the disability, and responses to the disability such as medical treatment, accommodations, or adjustments to the educational setting. The researcher made notes in the margins of the books indicating preliminary categories of information.

**Reviews.** In addition to reading each book, the researcher created a file of published book reviews for each title. As mentioned previously, the researcher used standard review sources such as *Booklist*, *School Library Journal*, *Hornbook*, *Kirkus Reviews*, and *VOYA*. The number of book reviews located per book ranged from two to 11, with an average of 5.7 book reviews per book. The researcher identified and gathered the book reviews, and marked the reviews in a similar fashion to the books. The researcher identified examples of how the review authors used language to construct disability in the reviews.

**Catalog subject terms and descriptions.** The third data element was the cataloging information for each of the award winning books. The researcher referred to both the Library of Congress online catalog and the WorldCat online database to acquire the catalog information. Once the cataloging information was gathered, the researcher read and marked the catalog documents in the same fashion as the books and reviews, identifying the words or phrases selected to describe disability in either the subject terms or the item descriptions.

**Transcription.** Potter and Wetherell (1987) state that a “good transcript is essential for a form of analysis which involves repeated readings of sections of data, and the process of transcription itself can be helpful in forcing the transcriber to closely read a body of discourse” (p. 165). Since it is a very time-intensive process, they recommend making decisions regarding the level of detail needed in the transcription. Although this research project did not involve transcription of interviews or personal interactions, the process of transferring the passages from the books, book reviews, and catalog information into the database was a form of transcription and a valuable step in the research process.

Following the identification of passages from the books that included reference to disability, the researcher typed the entire passages into a database (Microsoft Office Access 2007). In addition to the passages, the researcher entered the margin notes along with information about some of the specific language categories of interest such as person first language and/or derogatory language. The researcher also noted the speaker (character or story narrator), page number of the passage, and any suggestion of the disability model represented. The researcher followed a similar process in entering the information referencing disability from the book reviews, catalog descriptions, and subject headings.

**Coding.** Coding is a preliminary tool to analysis, with a goal “not to find results but to squeeze an unwieldy body of discourse into manageable chunks” (Potter & Wetherell, 1987, p. 167). In some instances, “the phenomenon of interest may not become clear until some analysis has taken place and a number of attempts at theoretical

interpretation of the data. In these cases the process will be a cyclical one of moving between analysis and coding” (p. 167).

Following the quick reading and the initial identification of themes and examples, a second reading of all of the books took place, capturing additional information related to the disability discourse found in the data set. The second reading began the intentional coding phase of the research process. During this phase, careful attention was given to the identification and gathering of examples of all significant instances of the use of language that describes the disability experience in the books. The researcher did not filter the instances included through any theoretical lens during this phase, but included the wide range of ways that disability was included in the books such as mention of diagnosis, description of disability, interactions between characters related to disability, feelings about disability, and treatments or accommodations in response to disability. According to Potter and Wetherell (1987),

...it is important to stress that as coding has the pragmatic rather than analytic goal of collecting together instances for examination it should be done as inclusively as possible...thus all borderline cases, and instances which seem initially only vaguely related, should be included. (p. 167)

As mentioned above, the coding and analysis activities may overlap, with movement back and forth between the research activities as new themes and understandings emerge. In preparing for the book reading, the researcher considered some potential themes such as the socially constructed nature of disability, categorization and/or stereotypes regarding disability, different ways of talking about disability, and uses of enabling or

disabling language by characters or in descriptive text. The researcher used categories and related questions as preliminary points for coding (Table 3).

The researcher entered the words, phrases, and researcher's notes about language use and themes in a database (Microsoft Office Access 2007). Following the entry of the words and phrases along with the notes on language use and themes into the database, the researcher printed out all of the key information from the books and cut the sections apart into paper slips for manual sorting. The researcher divided the paper slips with the words and phrases into three broad categories: *descriptions* of disability; *feelings* about the disability; and *responses* to the disability. The researcher further divided the three broad categories into thirty-six sub-categories (Table 4).

The researcher developed the list of coding terms over the course of processing several books. The researcher modified, merged, deleted, or created codes to respond to the reality emerging from the information in the books. In some cases, a category that started as an outlier in a book and placed in the *other* category became one of the coded categories when the same theme reoccurred with more frequency in subsequent books. Following the initial processing of the books, the researcher finalized the codes and performed a subsequent evaluation of the books to include new codes and to correct any errors or changes in the initial coding.

Following the completed coding of the books, the researcher coded the book reviews and catalog information with the same group of thematic codes. The researcher entered the codes for the books, book reviews, and catalog information into a database (Microsoft Office Access 2007).

To investigate the importance of specific language categories the researcher looked at notes from the original readings. Building on previously identified categories, additional specific language categories were established (Table 5). Using the additional language categories, the researcher evaluated the books to apply codes for these specific instances. Table 6 illustrates a sample page of text with both thematic and specific language codes identified. Following the completed coding of the books, the researcher coded the book reviews and catalog information with the specific language codes.

**Analysis.** The analysis stage involved reviewing the data, looking for pattern and function. The pattern may emerge as variability and/or consistency, both are valid and worthy of study. Potter and Wetherell (1987) stress that this phase of the process relies upon “a broad theoretical framework, which focuses attention on the constructive and functional dimensions of discourse, coupled with the reader’s skill in identifying significant patterns of consistency and variation” (p. 169).

The coding phase and the analysis phase of the research occurred in a cyclic fashion, with movement back and forth between the two activities. Themes emerged from the coding activities, initial analysis of the meanings led to additional thoughts and this encouraged a return to the data for verification or new understandings. To ease the organization and manipulation of data after the researcher entered all of the coded data in to the database, the researcher copied all basic information and codes from the books, book reviews, and catalog information to an electronic spreadsheet (Microsoft Office Excel 2007). The researcher used an original interactive web tool to provide a visual display of the placement of different elements in the books (Figures 2, 3, and 4). The web tool provided a means to examine which codes emerged as visual patterns showing

occurrence or connection. The researcher checked emerging themes from the visual displays from the web tool against numeric counts of incidence of occurrence in the data, and the researcher modified the codes as needed.

**Validation.** Potter and Wetherell (1987) address the concern that discourse analysis may not appear as clearly defined as some other research methods, and therefore may seem to produce less trustworthy results. For instance, one approach used for validation in other coded research methods is to use multiple coders and compare results. Potter and Wetherell do not see coding as the final stage in discourse analysis, and instead identify other means to validate the results of the research. These researchers state, “this does not mean that the reader has to take the conclusions of the kind of analysis on trust, however, because there are several stages of validation” (p. 169). They describe the stages of validation as coherence, participant’s orientation, creation of new problems, and fruitfulness.

**Coherence.** Coherence refers to the connection of themes within the data set. Potter and Wetherell (1987) stress that coherence does not require that the data all presents a unified theme, for example, “cases that lie outside the explanatory framework of a theory are almost always more informative than those that lie within, and often dredge up important problems” (p. 170). During the coding process of this research project, the researcher identified outliers in the passages drawn from the books. The outliers did not fit any of the existing codes, and the researcher adjusted the existing codes to include new codes, merge existing codes, or change names of codes to reflect new meaning. The researcher finalized the codes during the book coding; the researcher did not make any additional changes to the codes while coding the book reviews or

catalog information. The three broad emergent themes in the coded materials, description of disability, feelings about disability, and responses to disability, retained their usefulness in representing all of the documents used in this research project.

***Participant's orientation.*** Understanding the participant's orientation is a key to understanding their part in the discourse. For this research project, the "participants" are the texts including the books, book reviews, and the catalog information. Each text in the study represents the viewpoint or orientation of its author, and many author voices are included in this research project. While the texts have connections, various authors have written them with individual purposes. The book authors created works to entertain and inform, the book review authors created reviews to guide decisions about reading or acquiring the reviewed titles, and the catalog authors created subject headings and book descriptions to guide users to the books. With different purposes, it is important to consider the various authors' purposes when describing and analyzing the discourse.

***Creation of new problems.*** Rather than seeing research as an end in itself, Potter and Wetherell (1987) hope that discourse analysis will lead to new questions and problems. These researchers state, "the existence of new problems, and solutions, provides further confirmation that linguistic resources are being used as hypothesized" (p. 171). This research project provided new information about the portrayals of disability in youth literature, and it served as a springboard for additional questions that may lead to additional research activities, for example, to investigate historical portrayals of disability or history of language.

***Fruitfulness.*** Potter and Wetherell's (1987) final element of validation is fruitfulness. According to these researchers, discourse analysis is not only a research

exercise; it should produce new explanations that expand our knowledge of the social world. This research project applied theoretical models of disability to a study of youth literature as an avenue to understand aspects of character development and plot elements. Identifying the theoretical models of disability in this way opens the possibility for discussion of other instances of clash of theoretical models leading to interpersonal conflict.

**Report.** For Potter and Wetherell (1987), the final report is “more than a presentation of the research findings, it constitutes part of the confirmation and validation procedures itself” (p. 172). They stress that the report should include enough examples of the data so that the reader may see the connections and reasoning process for themselves. “Discourse analysis involves fluid movement between the different stages, with coding, analysis, validation and writing each leading back to earlier phases and ultimately to the talk and writing which were the original point of departure” (p. 174). The report for this research project includes a sample of a coded text passage, all of the thematic and specific language codes along with examples from the texts, as well as other accounts of the research process.

**Application.** Potter and Wetherell (1987) express their feelings about the worth of producing valuable work through scholarship in this way, “we feel that researchers should pay considerable more attention to the practical use of their work over and above the amassing of research findings and the furtherance of careers” (p. 174). They encourage the popularization and open exchange of ideas as the appropriate continuance to the research process, especially when it can involve dialogue with the very people who have been the topic of the research. They acknowledge and respond to the concern that

discourse analysis does not have a practical application by saying that “It is important to remember that virtually the entirety of anyone’s understanding of the social world is mediated by discourse in the form of conversations, newspapers, novels, TV stories and so on” (p. 174). The researcher for this research project is sharing the results through this report, but will also be publicizing the results of this work through one or more articles and presentations. Of particular interest to the researcher are opportunities to share the results of this research project with library practitioners who follow book awards, read book reviews, and ultimately select books to add to library collections.

### **Assumptions**

The researcher initiated this project with several assumptions in mind. Based on a preliminary review of the award books for the data set, the assumption was that the socially constructed nature of disability would be present in the literature. The researcher also assumed that different theoretical models of disability would be included in the language of the text, sometimes in the same book, and might provide a way to discuss the perspectives of the different characters. The researcher began with the assumptions that the publication timeframe of the books was significant in that all of the publication dates for the books followed the passage of significant pieces of disability legislation, and would reflect a subsequent societal change in the portrayals of disability.

Due to their selection as youth literature award books that present disability, the researcher assumed that the books would be worthy of study for this project, and would be a valid means of understanding more about the social nature of disability. In addition, due to their recognition as literary award winners, the researcher assumed that these books might have a higher rate of inclusion and increased visibility in school or public

library collections, and so might have increased usage by young people. Finally, in the spirit of Dow and Mehring (2001), the researcher hoped that these books would reach a wider audience than people personally connected with disability, but might connect to all interested information seekers regardless of their role with disability issues.

### **Researcher Bias**

According to an approach put forth by Moore, Beazley, and Maelzer (1998), it is important to consider not only the theoretical model of disability when structuring research, but also to find significant ways to add validity to the research project by including people on the research team or advisory board that have a personal lived experience with disability. In this case, the researcher is drawing on personal experience with disability as a mother of a son with disabilities in addition to serving as a librarian involved in library collection development, provision of resources, and services to people with disabilities. In order to validate the project further, the researcher requested feedback from colleagues who experience disability personally as well as have knowledge of youth literature. The researcher has also served as a member of the review board for the Dolly Gray Award for Children's Literature in Developmental Disabilities, and so is personally familiar with that evaluation process.

## **Findings and Analysis**

The researcher read the selected books multiple times, recorded information about literary elements and theoretical models of disability present in the books, compared the books to existing evaluation criteria including evaluation for inclusion of stereotypes, and identified and refined emergent codes for both disability themes and specific disability language use. The researcher applied the same thematic and specific language codes to the supporting documents including the controlled vocabulary subject headings, catalog descriptions, and professional book reviews.

### **General Characteristics of the Books**

Twenty-two books were included in the study set (Table 2), six (6/22, 27%) that received the Dolly Gray Award for Children's Literature in Developmental Disabilities, and sixteen (16/22, 73%) that received the Schneider Family Book Award. The Dolly Gray Award for Children's Literature in Developmental Disabilities winners received awards biennially from 2000 through 2010, and the Schneider Family Book Award winners received awards annually from 2004 through 2011. The publication dates of the books run from 1997 through 2010. Generally, the Dolly Gray Award for Children's Literature in Developmental Disabilities considers books published in the previous two years and the Schneider Family Book Award considers books published in the previous year. However, the first year of the Dolly Gray Award for Children's Literature in Developmental Disabilities considered more years of publication, which explains the earlier publication date of one of the titles.

Because the Dolly Gray Award for Children's Literature in Developmental Disabilities focuses specifically on books including a character with a developmental

disability, this feature has the potential to skew the entire study set somewhat to an overrepresentation of the category of developmental disability population. However, this potential imbalance is somewhat offset by the fact that there are significantly fewer books from the Dolly Gray Award for Children's Literature in Developmental Disabilities group. There are 29 instances of a major character with one or more disabilities. Using the categories from Individuals with Disabilities Education Act (IDEA), there are four (4/29, 14%) cases of specific learning disabilities, two (2/29, 7%) cases of speech or language impairments, four (4/29, 14%) cases of intellectual disability, three (3/29, 10%) cases of emotional disturbance, three (3/29, 10%) cases of hearing impairments, three (3/29, 10%) cases of orthopedic impairments, three (3/29, 10%) cases of other health impairments, one (1/29, 3%) case of visual impairment, one (1/29, 3%) case of multiple disabilities, and five (5/29, 17%) cases of autism. While this breakdown of categories (Table 7) does not replicate the recent range of disability categories for students receiving services named in IDEA, it does show a representative sample of the major categories of disabilities.

The 22 books in this study include 59 major characters or character groups. In seven instances, the character group *parents* represent two to four parents who represented the same primary role and model of disability. The ages of major characters represented a range from 1-year-old through adult (Table 8). The protagonists with disabilities range in age from 11-years-old to 18-years-old for the majority of the books. Two (2/22, 9%) books follow the protagonist as they enter adulthood. Fifteen (15/22, 68%) books have a protagonist that has a disability, six (6/22, 27%) books have a protagonist that does not have a disability, and one (1/22, 5%) book has a protagonist that

has a fantasy disability in that he is invisible (Table 8). Twenty (20/22, 90%) of the books use a first person point of view and two (2/22, 9%) books use a third person point of view. Of the first person point of view books, 14 (14/20, 70%) books use the perspective of a character with a disability and six (6/20, 30%) books use the perspective of a character without a disability. One (1/2, 50%) of the third person point of view books uses the perspective of a protagonist with a disability; one (1/2, 50%) uses the perspective of a protagonist without a disability.

The books include eight different categories of theoretical models of disability among the 59 major characters or character groups (Table 8). Forty (40/59, 68%) characters or character groups acted in accordance with the same theoretical model of disability throughout the book. Of the characters that acted in accordance with the same theoretical model, one (1/40, 2.5%) character acted in accordance to the moral model, three (3/40, 7.5%) characters acted in accordance to the medical model, and 36 (36/40, 90.0%) characters acted in accordance to the social model. Ten (10/59, 17%) characters acted in accordance to a mix of theoretical models of disability with eight (8/10, 80%) characters acting in accordance to a mix of medical and social models, and two (2/10, 20%) characters acting in accordance to a mix of moral and medical models. None of the characters acted in accordance to a mix of moral and social models. Six (6/59, 10%) characters transitioned from one theoretical model of disability to another during the course of the book with five (5/6, 83%) characters transitioning from the moral model to the social model, and one (1/6, 17%) character transitioning from the medical model to the social model. It is interesting to note that all of the characters that transitioned from one model to another moved to a social model, and none moved from social to another

model. In three cases (3/59, 5%), there was inadequate information to assign a theoretical model of disability to the major character.

### **Book Summaries**

During the book readings, the researcher identified basic literary elements and theoretical models of disability. The following book discussions include a plot summary, major characters, theoretical model(s) of disability held by major characters when identifiable, family relationships, and point of view for each book in the study set.

*After Ever After* (Sonnenblick, 2010). Jeffrey and Tad are best friends who forged a friendship based on their respective battles against cancer and their struggles with impairment caused by the treatments. Jeffrey now walks with a limp and has difficulty processing information, while Tad uses a wheelchair for mobility. They support each other through not only their shared medical experiences, but also the normal social angst that accompanies adolescence. When Tad's cancer returns and eventually takes his life, Jeffrey must find the strength to move forward and carry on without his friend.

Jeffrey is the first person narrator and protagonist of the book, Tad serves as a supportive character. While both boys are fully developed and show a wide range of responses to other characters and situations, Jeffrey goes through the most dramatic growth and change over the course of the book while Tad remains fairly static. Jeffrey and Tad each live with both of their parents who are supportive of them throughout their medical treatments. Jeffrey has an older brother who is away for most of the story, but who communicates periodically via written communication. Tad has a younger sister who he refers to as the "Emergency Replacement Child" which is a reference to the fact

that she was born around the time of his first cancer diagnosis and he suspects that his parents questioned his life expectancy.

This book has a heavy emphasis on the medical model of disability as the characters focus on efforts to treat and cure the boys' cancer and to remediate the after effects. However, there is also an underlying social model in the perspective of both of the boys as they try to focus on the more mundane aspects of their lives such as succeeding in school, meeting girls, and having a social life. Tension exists between the perspectives of Jeffrey's parents as his mother wants to make sure that he is given accommodations to respond to his learning challenges while his father feels that the accommodations only serve to hold him back by not forcing him to face his challenges.

An interesting point in this book is the author's note at the beginning of the book referencing a child he had known who battled cancer whom he refers to as "the bravest kid who ever set foot in my classroom" and commends the child for "showing by shining example that in the battle against cancer, fighting IS winning" (Sonnenblick, 2010, n.p.). These comments show the perspective of the author and likely influence the development of the characters in the story.

*Anything But Typical* (Baskin, 2009). Typical of a person with a diagnosis on the autism spectrum, Jason has difficulty with social interactions. His communication flourishes when he writes, and he enjoys interacting with other writers in an online community. He explores disability issues by creating a character that may have the opportunity of a cure through a medical procedure. Through the online community, he receives feedback on his story and develops a friendship with one particular young writer online. While he has enjoyed becoming virtual friends, he becomes anxious over the

prospect of meeting her in person at a writer's conference. Accompanied by his mother, he attends the conference, meets his friend, and is relieved to learn that although he had difficulty relating to her in person, she accepts him and will continue to support him and his writing endeavors.

Jason is the first person narrator and protagonist of the story. He shows a wide range of responses to other characters and situations and goes through significant growth and development over the course of the story. He lives with both of his parents as well as with his younger brother.

All of the members of Jason's family are supportive and work to help him identify accommodations that he can make to ease his way through social interactions. Jason and his parents all work from the social model perspective, accepting Jason as he is and working to adapt the situations that cannot be changed.

*Becoming Naomi León (Ryan, 2004)*. Life with their great-grandmother, Gram, is comfortably predictable for Naomi and her younger brother Owen until their mother, Skyla, and her current boyfriend arrives with plans to take them with her on her next adventure. The children are uncomfortable with the plans, especially when it becomes clear that Owen may not be included. Skyla does not fully accept Owen who has medical issues affecting his stance, gait, and voice, leading his doctors to refer to him affectionately as a "Funny Looking Kid." In order to thwart Skyla's plan to remove Naomi for her own selfish reasons, Gram and the children take a hurried trek to Mexico where the children reconnect with their father who accepts them both with open arms.

As the protagonist, Naomi is a fully developed character and shows a wide range of responses to other characters and situations. Owen is a supporting character who is not

as clearly developed, but does show a wide range of responses to other characters and situations and some growth over the course of the book. After their mother abandoned the children at an early age, the children live with their great-grandmother. By the end of the book, a renewed relationship with their father looks promising.

The parental figures in the story take conflicting approaches to Owen's disability. Gram pursues medical treatment for Owen but accepts him and follows a social model, while Skyla rejected Owen as a burden once as a young child and repeats her rejection of him upon her return. Skyla seems to be working from a mix of moral and medical models, as she would like for Naomi and Owen to be "fixed." When that is not possible, Skyla sees the children as a burden that she does not want. Naomi has communication issues connected to her early trauma from her mother's neglect and rejection, but works through those during the course of the book, coming to accept herself and claim her inner strength. Naomi does learn to trust Owen's capabilities, transitioning to a social model in thinking of Owen's disability.

***The Curious Incident of the Dog in the Night-Time (Haddon, 2003).***

Christopher happened upon an intriguing mystery when he discovered a dead dog in his neighbor's yard. Using his logical capabilities, he identifies clues that ultimately lead him to the resolution of the mystery as well as uncovering some unexpected bits of information about himself and his family. As part of the process, he has to overcome social inhibitions tied to his place on the autism spectrum.

The author wrote the book as Christopher's first person account framed as a writing assignment given to him to help him to process the events that took place. He displays a wide range of responses to other characters and situations and experiences

growth and development over the course of the story. Christopher lives with his dad with the understanding that his mom died some time previously. However, during his investigation he discovers that his mom's death was a ruse created by his dad to cover the fact that she left the two of them. Towards the end of the story, Christopher reunites with his mother.

Throughout the book, Christopher sees himself as a capable young man who understands his limits, and solves problems based on his strengths. Both of his parents focus on his limitations, his mom came to the point of not being able to overlook them any longer prior to her departure. While inadequate information is given to identify the specific disability models that influence the parents in the story, Christopher seems to be working under a social model where he clearly understands the accommodations that he needs to thrive and succeed, and he is learning how to let others know of his needs.

*Five Flavors of Dumb (John, 2010).* Up until recently, Piper has done her best to fade into the background at her high school, but everything changes when she finds herself managing a hot new teen rock band. The irony of this move does not escape Piper, as she cannot hear. Since her dad lost his job, money has been tight in the family, so much so that Piper's parents raided her college fund to pay for her younger sister's cochlear implant surgery. Piper has decided that if she can turn the band into a marketable entity, she can recoup some of the lost funds and still follow her dream of attending Gallaudet University after high school graduation. The band is reasonably successful, and her parents understand the efforts that she is putting into her future and agree by the end of the book to support Piper in her educational endeavors. In addition to

supporting her financially, her dad, who was the only holdout in the family, finally begins to learn sign language in another sign of evolving support for Piper.

Piper narrates the story in a first person voice and is the protagonist of the book. She experiences a wide range of responses to other characters and situations, and has significant growth and development over the course of the book. She lives with her parents and two younger siblings, a brother and a sister.

Piper holds a social model, in that the primary obstacle to her success is the inability of others to communicate with her via sign language. She is a good lip reader and is fluent in sign language, and several characters do initiate sign language instruction as a means of improving their communication. Her parents exhibit a mix of models. They have a primarily medical model approach concerning Piper's young sister in that they invested the family's limited funds in a cochlear implant surgery to improve her hearing. With Piper, they exhausted the current medical options and so moved to a social model when contemplating her current and future situation. By the end of the book, her father's show of support in learning sign language pushes his viewpoint toward the social model.

*Hurt Go Happy (Rorby, 2006)*. Joey feels isolated from most social interaction due to her hearing loss, which resulted from childhood abuse by her father. Joey, who is limited in her communication with those whose lips she can read easily, is interested in learning sign language. Her mother is vehemently opposed to Joey's sign language usage. When Joey meets a neighbor with a chimpanzee who signs, Joey's world opens up and eventually her mother accepts Joey's new mode of communication. New

complications arise when the signing chimpanzee moves to an abusive testing facility and Joey has to intervene.

Told in third person through Joey's eyes, the story unfolds to show her development and growth as a complex character with a wide range of responses to other characters and situations. Joey lives with her mother, stepfather, and younger brother.

One of the key plot elements arises from the conflict of models of disability followed by Joey and her mother. Joey adopts a social model early on in the story, desiring to learn sign language to minimize the impact of her hearing loss. In contrast, her mother is staunchly opposed to Joey's desires, presumably because of the shame and guilt over the origin of the hearing loss. In this regard, the mother is working from a perspective of the moral model, as she blames herself for not protecting Joey from the abusive father, and seeks to minimize notice of Joey's hearing loss to keep people from asking how it occurred. Only after confrontations with numerous characters assuring her that the best thing for Joey would be to learn sign language does the mother move slowly toward a social model perspective.

***Jerk, California (Friesen, 2008).*** Emotionally rejected by his abusive stepfather, Sam experiences guilt and shame over his Tourette syndrome manifestations, which include uncontrolled muscle twitches and vocal outbursts. After graduating from high school and getting kicked out of his house, Sam finds refuge with a local quirky character, George, who knew Sam's father and encourages him to rethink what he has heard about his disreputable past. Joined by Naomi on a cross-country journey of self-discovery, Sam claims his given name, Jack, and learns the truth about his father and the genetic thread of Tourette syndrome that has affected multiple family members.

Sam/Jack is the first person narrator and protagonist of the story. He experiences a wide range of responses to other characters and situations and goes through significant growth and development over the course of the novel. He begins the story living with his mother, stepfather, and younger brother but moves out shortly after graduation to live with George who serves as his boss and mentor. Following George's death, Sam/Jack inherits the farm and brings his mother and brother to live with him there.

The moral model of disability guides Sam/Jack as he experiences shame and guilt over his Tourette syndrome manifestations. His stepfather, who has influenced Sam/Jack's self-image, also holds this view. Although his mother does not seem to hold the same viewpoint, she is too withdrawn from the situation to effect a change in Sam/Jack. George and Naomi both hold more of a social model perspective, and over the course of the book, influence Sam/Jack to rethink his viewpoint and adopt a social model perspective as well.

*The London Eye Mystery (Dowd, 2007)*. When his cousin Salim gets on the London Eye Ferris wheel but does not get back off, it is up to Ted and his sister Kat to solve the mystery of Salim's disappearance. Ted's "brain runs on different operating system" which proves to be a great asset as he looks at problems in a unique manner, finds the clues that were missed by others, and solves the missing person mystery (Dowd, 2007, p.31).

Ted is a fully developed character who grows over the course of the book. He experiences a wide range of responses to other characters and situations, within the limits of his position on the autism spectrum. He lives with both parents who both encourage

and support him, and an older sister with whom he has a typical sibling relationship that includes normal annoyances as well as complex feelings tied to Ted's disability.

The social model guides all of the characters in this book with Ted's unique way of thinking ultimately seen as a benefit in resolving the plot issues. This book is unusual in the study set in that Ted's disability turns out to be an advantage in the resolution of the conflict. Another model that emphasizes capability, such as the capability approach (Mitra, 2006), might be an appropriate choice to discuss this set of characters.

*A Mango Shaped Space* (Mass, 2003). For years, Mia has hidden her unusual ability to see colors associated with letters, numbers, and sounds. When she is 13, she realizes that her sensory experiences are making it difficult for her to succeed in her schoolwork and finally admits to her parents what she has experienced. Their immediate response is to diagnose and treat Mia's condition, and consultations occur with various professionals before a neurologist diagnoses Mia with synesthesia. As the family learns, synesthesia is a crossing over of sensory input in the brain. While her parents remain focused on finding a cure, Mia explores the more interesting aspects of her condition, ultimately accommodating for the troublesome attributes of synesthesia and embracing the beauty it brings to her life.

Mia is the first person narrator and protagonist of the story. She experiences a wide range of responses to other characters and situations and significant growth over the course of the book. Mia lives with her parents, an older sister, and a younger brother.

This book is similar to another book in the study set, *My Thirteenth Winter*, in that the primary focus of the book is on diagnosing and describing an unusual condition.

Although synesthesia does affect Mia's learning and academic success, it is not officially

a disability but rather a mild condition more akin to color blindness. However, two models of disability are appropriate to discuss in terms of this book. For the majority of the book, the medical model guides Mia and her parents as they are all seeking a cure for Mia's unusual condition. Once Mia learns more about it, she switches to a social model, even going so far as to identify the benefits and advantages of synesthesia. By the end of the book, her parents also accept her condition and begin to acknowledge the positive attributes of synesthesia.

*Marcelo in the Real World (Stork, 2009).* After years of attending a private school for students with varying abilities, Marcelo's father challenges Marcelo to get a taste of the "real world" by spending the summer working in his law firm (Stork, 2009, p. 20). Marcelo, who is high functioning on the autism spectrum, lacks confidence that this will be a positive experience, but finally agrees to the challenge with the promise that he will be able to return to his beloved private school in the fall. During the summer, he increased his understanding of social interactions and used his logical capability to solve a troubling mystery related to one of the legal clients represented by the firm. As he approached the fall, he had gained enough confidence in his abilities to not only plan a move to the public high school for his senior year but also to develop a plan for his future that included additional education and a professional career.

Marcelo is both the protagonist and the first person narrator for the story. He experiences a wide range of responses to other characters and situations and undergoes significant growth and development. He lives with both of his parents, and has an older sister that lives elsewhere. While both of his parents are supportive, his mother tends to

be slightly more protective while his father feels that the appropriate path for Marcelo involves additional challenges.

Neither Marcelo nor his father truly identifies Marcelo as “disabled,” instead seeing the possibility of him living a normal life in the “real world” with only minor accommodations. In this manner, the social model of disability guides each of them throughout the book. While his mother also primarily works within the social model, she sees more challenges ahead for Marcelo and tends to worry a bit more about him moving too quickly towards independence.

*Me and Rupert Goody (O’Connor, 1999).* Jennalee was perfectly content with her lot in life until Rupert Goody, an unfamiliar young man who seems to process information slowly, arrived unexpectedly at Uncle Beau’s store. Jennalee frequented Uncle Beau’s store to escape her irritating siblings, and was accustomed to being Uncle Beau’s chosen assistant. When Rupert arrives with the news that he is Uncle Beau’s son, Jennalee is angry and worries about her place in Uncle Beau’s affection. Jennalee initially sees Rupert as an annoyance and rival and although they are not related, she takes on the role of a younger sibling who is feeling neglected and acting out to gain Uncle Beau’s attention. In addition, Jennalee questions Rupert’s capability in taking on tasks around the store due to his unspecified cognitive limitations. In time, Jennalee comes to accept Rupert, and realizes that there is room for both of them in the store and in Uncle Beau’s heart.

Told from Jennalee’s first person point of view as the protagonist, she guides the action of the story and expresses a wide range of responses to other characters and situations and character development and growth. On the other hand, although Rupert

does display a variety of responses to other characters and situations, he is a static character who changes little over the course of the book. The author does not clearly define Rupert's disability, and other characters describe him in informal terms such as "a mite slow" (O'Connor, 1999, p. 38) or "half-wit" (O'Connor, 1999, p. 13). Rupert's role is primarily as the antagonist to Jennalee, and serves primarily as a means for her character to grow. Rupert is an only child, raised primarily in foster homes after his mother died when he was a baby. Jennalee lives at home with her parents and siblings, but spends most of her time interacting with Uncle Beau and Rupert.

Two of the three disability models studied are present in this book. Rupert's cognitive issues appear to have been present throughout his life and no account of attempting to diagnose the issue or respond educationally or therapeutically is included in the book. Jennalee views Rupert as a burden, which brings her more in line with a moral model of disability throughout most of the book. By the end of the book, she accepts Rupert as he is and is generally supportive of adjusting his duties and responsibilities to match his limitations, which would indicate a transition in her thinking to more of a social model approach. Uncle Beau accepts Rupert as he is throughout the book, holding a primarily social model throughout.

*My Thirteenth Winter* (Abeel, 2003). The only non-fiction book in the study set, this book is a memoir written by Samantha (Sam) Abeel who received a diagnosis of a learning disability, dyscalculia, when she was thirteen years old. She shares her frustration prior to the diagnosis when she feels anxious about her inability to master mathematical concepts. Her story continues as she describes her ongoing challenges in

balancing her creative strengths and limitations throughout the rest of her educational journey.

Sam is a fully developed character who displays a wide range of responses to other characters and situations and experiences significant growth over the course of the book. Sam lives with both parents who support her throughout the book, as well as a rarely mentioned younger brother.

The major focus of the book is diagnosing and treating Sam's condition, which aligns her with the medical model of disability. While she does acknowledge her strengths as a writer, she remains heavily focused on the process of determining what is "wrong" with her and finding ways to respond to her learning challenges. By the end of the book, she has graduated from college and is beginning her adult life, and comes to a level of acceptance of her situation. There is also a thread of the moral model as she experiences a mix of shame and depression over her perceived limitations. In addition, on occasion she perceives herself as special, almost like a chosen one. This appears to be a response to feeling disconnected to her peers, and has ties to the moral model of disability.

*Reaching for Sun (Zimmer, 2007)*. Josie has difficulty communicating and moving due to cerebral palsy. Her mom encourages her to participate in therapy to address her issues and gain as much mobility as possible. However, Josie is tired of trying to change who she is and ends up skipping scheduled therapy sessions to devote more time to her one friend, Jordan, and her interest in plants. She feels most accepted when she and her grandmother visit the residents at the local nursing home. The nursing home residents relate to Josie whose challenges are much like theirs. After Josie's

grandmother has a stroke, her mobility and communication deteriorate and Josie looks within herself to find the strength to be supportive and helpful.

Josie is the first person protagonist in this novel written in verse. The sparse text effectively portrays Josie's wide range of responses to other characters and situations as well as her growth and development. Josie lives with her mother and grandmother, while her father left when she was very young. Josie's mother is supportive, but is frequently unavailable due to school and work responsibilities. Josie's grandmother takes the role of the primary adult influence prior to her stroke, after that event Josie and her mother become caregivers for the grandmother.

Josie's mom mainly follows the medical model in the sense that she is regularly trying to nudge Josie into therapeutic treatment in order to help her meet her full potential. Both Josie and her grandmother function more in the social model where they identify adjustments and accommodations that are available for Josie to carry out various tasks such as learning to knit and work with plants. Josie's friend Jordan also works from the social model as he focuses most on Josie's capabilities rather than her limitations.

***Rules (Lord, 2006).*** Catherine assumes a fair amount of responsibility for insuring that her younger brother, David, survives each day without having a major melt down. To this end, she has created a series of rules of living to help him navigate life. Unfortunately, David's behavior is rather unpredictable as he has a diagnosis on the autism spectrum, and he often has trouble remembering or following the rules that Catherine has established for him. Although she generally has a good relationship with David, it isn't until she develops a friendship with another young man, Jason, who has mobility and communication challenges, that she finally realizes she has created David's

rules in response to her own embarrassment. Once she accepts this fact, she is able to move towards fully accepting both David and Jason.

As the protagonist, Catherine is a fully developed character who experiences a wide range of responses to other characters and situations and growth. David and Jason are both characters with disabilities and function in supporting roles in the story. They each exhibit a range of responses to other characters and situations, but neither character grows significantly over the course of the book. Catherine and David live with both parents, who although are somewhat distracted at times, are supportive of David and acknowledge that Catherine occasionally is probably asked to do more than her share of caring for David. Jason lives with a supportive family including his mother, father, and an older brother.

The social model is the primary model displayed in this book. Even though David and Jason receive therapy to improve mobility and communication, there is no discussion of any attempt to try to cure either boy. Catherine feels burdened at times by having to watch over David, and at times feels embarrassed by acknowledging either David or Jason in public, which has elements of the moral model, but the acceptance of both characters overrides the burden.

*Small Steps (Sachar, 2006)*. Armpit is a young man with a juvenile criminal record who is trying to clean up his act. He befriends a younger local girl, Ginny, who has cerebral palsy and accompanies her to a pop concert where they meet the star of the show, Kaira DeLeon. Armpit develops a relationship with Kaira and travels as her guest to another event. Armpit exposes Kaira's manager of inappropriate use of funds but due

to a physical assault, Kaira must place her career on hold. Armpit returns home satisfied that his life is heading in a good direction.

Armpit is protagonist of the story, told in third person through his perspective. Armpit exhibits a wide range of responses to other characters and situations, and has notable growth over the course of the book. Ginny has limited development and range of responses to other characters and situations. Her primary function in the course of the book is as device to support Armpit's growth. Ginny lives alone with her mother as her father deserted them when she was younger.

The portrayal of Ginny is somewhat stereotypical as pitiable and pathetic. She is dependent on Armpit for protection and support. When other characters encounter Ginny, they show fear, ignorance, or disgust, including professionals that should have more familiarity with disability as part of their professional training. An example of professionals showing inauthentic responses is the time that paramedics did not recognize Ginny having a seizure but instead thought that Armpit had given her an overdose of illegal drugs. There are also odd moments featuring disability such as when Armpit apologizes to Ginny for using the accessible parking decal, implying that Ginny would regard using it as a sign of weakness and a lack of capability. These elements support the role of disability as a stereotype rather than a realistic portrayal, and the book includes inadequate information to identify Ginny's specific theoretical model of disability. Armpit seems to hold somewhat of a social model tempered by stereotypes.

*A Small White Scar* (Nuzum, 2006). While they were young, twins Will and Denny were inseparable. Will encouraged his brother to grow and learn, even when Denny's cognitive issues kept him from reaching the same level of success as Will. After

their mother died, Will's father made Will the person most often responsible for Denny, a task that Will despised. In an effort to rid himself of the burden of caring for his brother, Will ran away to follow his own rodeo dream, but Denny followed leading to a major fight between the boys. When Will gets hurt while riding, their roles reverse, and Denny shows that he is capable of taking on an adult role and caring for Will.

As a supporting character, Denny shows less development than Will, who is the protagonist. Denny shows growth over the course of the book, and experiences a wide range of responses to other characters and situations. The two boys live with their father on the family ranch, but much of the action of the story takes place away from the ranch as the boys have set off on their own adventure.

Somewhat surprising for the historical period of the 1930s, his mother (who died before the action of the story takes place) and his father view Denny as reasonably capable. Denny and his parents seem to come from a social model perspective that encourages Denny to be as responsible as possible within his limitations. Alternately, the doctor who attended the birth of the twins felt that Denny should live in an institution. Although not explicitly stated in the book, from the description of Denny's condition, it would appear that he has Down syndrome. Similar to the doctor, Will focuses on Denny's limitations, and sees him as a burden throughout the book, only coming to acceptance of his worth in the concluding pages.

*So B. It* (Weeks, 2004). Heidi lives with questions about her past that her mother, Sophia, cannot answer due to her cognitive limitations. An unexpected clue is unearthed in the form of a camera with undeveloped film, which provides the name of a residential institution where Sophia might have lived. Leaving Sophia in the care of

Bernadette, their neighbor with agoraphobia, Heidi takes a solo cross-country trek seeking answers. She discovers that not only did her mother live in the institution, but her father still does and her grandfather is the director of the institution.

As the protagonist, Heidi is a well-developed character and experiences significant growth over the course of the book, primarily because of her independent quest to learn of her personal history. As a supporting character, Sophia shows a range of responses to other characters and situations but not extensive growth or development.

Both Heidi and Bernadette show a social model approach to disability as they accept Sophia as she is. Both Heidi and Bernadette encourage Sophia to work within her limitations and learn new skills. Although Heidi challenges Bernadette to move beyond her agoraphobic comfort zone, ultimately Heidi accepts Bernadette's limitations. Heidi encourages Bernadette to strengthen her capabilities. Both Heidi and Bernadette follow the social model throughout the book.

*Tending to Grace (Fusco, 2004)*. Communication is difficult for Cornelia, who frequently stays silent rather than struggle to fight the stutter that regularly impairs her speech. After Cornelia's mother abandons her at her Great Aunt Agatha's home so that her mother can pursue her own interests with her current boyfriend, Cornelia all but stops talking completely. Slowly Agatha nudges her towards speech while Cornelia challenges Agatha to confront her own inability to read. By the time Cornelia's mother returns late in the story, Cornelia has developed the strength to stand up for her own needs, and has found her voice to express them.

Cornelia tells the story in first person as the protagonist and displays a wide range of responses to other characters and situations as she develops and grows through the

story. Agatha goes through transformative growth as well as she comes to terms with some of the difficulties surrounding her life. Through the majority of the story, Cornelia lives with her Great Aunt Agatha, her mother abandoning her to follow her own dreams.

There seems to be some level of moral model perspective for Cornelia as she responds to the emotional pain of being abandoned by her mother by communicating less and less with the world until all speech becomes a source of pain and shame. Curiously, when her speech is getting in the way of her desires such as getting a library card, Cornelia does not adopt any sort of an accommodation like writing out her needs on paper, but instead her communication difficulties stop her from satisfying her wishes. Agatha seems to come from a social model perspective, encouraging Cornelia to stand up for herself and find her voice to let others know what she needs. By the end of the book, Cornelia has healed significantly from the emotional damage inflicted by her mother, and has moved to more of a social model perspective where she will not allow her speech challenges to hamper her continued growth.

*Things Not Seen (Clements, 2002).* Bobby wakes up one morning with the shocking realization that he is now invisible. Shortly after his parents come to terms with this new reality, they end up in the hospital after a car accident. Bobby learns to adopt new techniques for making his way in the world without a visible body, and becomes friends with a girl who is blind, Alicia, along the way. Alicia is fairly recently blind, following her own unexpected morning surprise of waking up with no vision. Alicia becomes a supportive ally on Bobby's quest for a cure for his condition. Along with their scientist dads, the two teens figure out the mystery of Bobby's invisibility and are able to reverse the condition.

As the protagonist, Bobby is a fully developed character and experiences a wide range of responses to other characters and situations as well as growth through the story. Alicia is also developed as a support character, displaying a variety of emotions as well as some growth as a character. Both characters live with both of their parents and neither have siblings. Alicia's mom is somewhat overbearing, not quite adjusted to allowing Alicia to move about independently.

Bobby's invisibility functions as a temporary disability, and guides all of the characters into a medical model of disability as they search for a cure. Bobby reverses his condition and regains his visible body. However, Alicia does not find a cure and retains her blindness. In Alicia's case, the characters have adopted a social model, providing accommodations in her transportation and communication to allow her to traverse her life activities as independently as possible. As mentioned before, her mother is not quite ready to let Alicia interact with the world independently and although there are glimpses into a future that will focus more on her ability/capability that is not quite the current scenario.

***Tru Confessions (Tashjian, 1997).*** Tru experiences guilt over the fact that her twin, Eddie, received a brain injury from a birth trauma involving a temporary lack of oxygen. She is obsessed with trying to find a cure for Eddie and she goes to great lengths to research his condition, raise public awareness, and plan a future professional life where she will continue her quest. Unbeknownst to Tru, her mom befriends her in an online forum and urges her to accept Eddie's condition as permanent and to focus her efforts on accepting Eddie as he is and being the best she can be as well.

Tru is the first person protagonist, and in that role is well developed and displays a wide range of responses to other characters and situations. She grows as a character and moves towards acceptance of the possibilities for both Eddie and her future lives. As a character, Eddie is minimally developed, and remains a static character over the course of the book. Eddie experiences a wide range of responses to other characters and situations. The twins live with their mom as their dad left the family when the twins were very young.

Through most of the book, Tru is working from a medical model perspective as she works to find a cure for Eddie. Although portrayed as unhappy about his differences at times, most of the book portrays Eddie as content and generally happy with himself. Both Eddie and Mom take a mostly social model approach to Eddie's disability, a position that Tru eventually shares by the end of the book.

*Under the Wolf, Under the Dog (Rapp, 2004).* Steve has had an unusually tragic year with his mother's death following a long fight with cancer, his brother's suicide, and his father's incapacitating depression. Not surprisingly, these events take a toll on Steve's mental health and he finds himself as a temporary institutional resident after dealing reasonably with his situation was no longer possible. During a short time frame, he finds that he has committed more than one minor crime as well as injuring and eventually losing sight in one eye. While this does not make for an upbeat story, it does end on a surprisingly positive note as Steve and his father begin to put their lives back together and find that they can count on each other for support.

Steve is the first person narrator and protagonist of the story. He displays a wide range of responses to other characters and situations and experiences growth and

development over the course of the story. For the duration of the story Steve is in residence at a residential juvenile mental health facility, but has flashback sequences that take place while he is living at home prior to, during, and after the deaths of his mother and brother.

While there are medical and therapeutic interventions for Steve's mental health and vision issues, the social model is actually a better representation of the guiding force behind the perspectives of both Steve and his father. Even with the dark aspects of the story and the asocial and dangerous choices that Steve makes, there is not a sense of shame or blame tied to his mental health issues.

*Waiting for Normal* (Connor, 2008). Addie dreams of living a "normal" life where she can focus on being part of a family and going to school rather than managing a household. She serves as the de facto caregiver for her mother, who seems to have a condition similar to bipolar disorder and is incapable of keeping track of basic life responsibilities. Addie feels that she lacks the "love of learning," a phrase that she learned from her rather irresponsible mother, but her stepfather reminds her that she has dyslexia and is a very bright girl who only needs minor accommodations to succeed. Addie makes the best of her situation, making friends with local business people and requesting minor adjustments at school. By the end of the book, her mother has given up custody of Addie and has allowed her stepfather to adopt her and reunite her with her younger sisters, a move that will create a more "normal" family environment.

Addie is a fully developed character who grows throughout the book. Addie experiences a wide range of responses to other characters and situations. She lives with

her mother and has a relationship with her stepfather and two younger siblings who live elsewhere.

Except for her mother who seems to focus solely on Addie's limitations, the other key characters in the book seem to function from a social model perspective. Addie's disability (dyslexia) is apparent, but is not the driving force of plot. Once Addie receives minor accommodations at school (extra time to learn music aurally rather than reading the music, tag board bookmark to assist in reading) her learning issues become less apparent. By the end of the book, Addie accepts that she is very capable, and that she should not take on the responsibility for her mother.

### **Evaluation Criteria**

All books in the study set are award-winning books and met evaluation criteria that included high literary quality. With that assumption in mind, the researcher reviewed each book using four different evaluation tools to identify how the books met or did not meet the criteria. The four tools used were the evaluation criteria for the Dolly Gray Award for Children's Literature in Developmental Disabilities ("Dolly Gray Awards," 2012), Schneider Family Book Award ("Schneider Family," 2011), Circle of Inclusion Project criteria (2002), and the list of stereotypes created by Biklen and Bogdan (1977). Table 9 identifies where the books did not meet the criteria for the four tools. For the first three tools, instances listed on the table reflect unmet criteria. For the fourth tool, the listed stereotypes are present in the book.

In the Dolly Gray Award for Children's Literature in Developmental Disabilities criteria, the most common criterion not met was minimal development for a primary character with a disability identified in eight books. This criterion signifies a major

character with a disability that did not experience significant growth or development whether the character was the protagonist, antagonist, or a supporting character. The researcher identified single instances of two other criteria in two separate books, in one, the plot was overly complex and in another, there was uneven literary quality.

In the Schneider Family Book Award criteria, the most common criterion not met was absence of others with disabilities, identified in six books. The criterion identifies characters with disabilities interacting with other characters that have disabilities as well as those without disabilities. This criterion implies that multiple characters with disabilities are included in the book. Since the evaluation tool applies to youth literature, the criteria further suggests that the major character with a disability should be a child or youth and two books did not meet this criterion and are listed, as character with disability is an adult. Two books included the criterion plays on sympathy & sentimentality. Two other criteria, character with disability does not solve own problems and character tries to hide disability were identified one time each in two separate books.

In the Circle of Inclusion Project criteria, the most common criterion not met was mild derogatory language, identified in 11 books. In all cases, the derogatory language connects to disability and falls into one of three categories: spoken by a character without a disability about a character with a disability, spoken by a character with a disability about another character with a disability, or spoken in a self-referential statement by a character with a disability. It should be noted that the instances were mild in all cases, and generally provided more authentic characterizations than if the derogatory language had been omitted. One book included two additional criteria, sophisticated subject matter and character with disability not a positive role model.

The book study set included six of the 10 stereotypes identified by Biklen and Bogdan (1977). The most common stereotype identified was *burden*, noted in six books. Six books included the stereotypes *non-sexual* and *atmosphere*. Four books included the stereotype *own worst enemy*, one book included the stereotype *pitiable & pathetic*, and one book included *limited participation in everyday life*.

### **Codes of Disability Information**

**Thematic codes.** During the book reading process, the researcher highlighted passages in the books that dealt with the disability experience. Four thousand, eight hundred and ninety (4,890) passages were highlighted which included phrases, sentences, and multi-sentence short passages. The researcher made notes regarding the content of the passages. The researcher identified emergent themes and then refined them into a set of thematic codes, which fell into three broad categories: description, feelings, and responses (Table 4).

The category of description refers to information about the disability itself and is divided into nine sub-categories or codes such as diagnosis, physical appearance, mobility, communication, and thought processes. Description codes applied to the largest group of passages from the book, accounting for 2,183/4,890, 44.6% of the total passages from the books. Within the description codes, the most commonly used codes are communication (616/2,183, 28%), physical appearance (376/2,183, 17%), and thought processes (330/2,183, 15%). Also worth noting is that although it was fifth on the occurrence list, the code diagnosis (198/2,183, 9%) was present in every book, and is the only code that received that distinction.

The category of feelings refers to feelings about the disability from either the character with a disability or another character and contains nine sub-categories. The feelings category had the fewest passages (1,120/4,890, 22.0%) of the total passages from the books. The feelings statements were predominantly negative feelings such as blame, burden, anger, and social isolation with few positive feelings such as acceptance. Within the feelings codes, the top code was value with (217/1120, 19%). Although the value category it includes either positive or negative statements about value, the negative statements within the category (201/217, 93% of value statements) outnumbered the positive statements (16/217, 7% of value statements). The next highest code was a positive statement of acceptance (158/1120, 14%). The third highest ranking in the feelings category was a tie between three primarily negative codes. The three codes are fear/anxiety (131/1120, 12%), blame/shame/guilt (132/1120, 12%), and burden with (134/1120, 12%). A significant finding from the feelings category was the proportion of negative feelings about disability (941/1120, 84%) as compared to the positive feelings about disability (179/1120, 16%).

The category of responses was the middle group with (1,587/4,890 or 32.5% of the total passages from the books. The responses were divided into 18 sub-categories including professional responses such as medical treatment or therapy, accommodations such as educational adjustments or assistive technology, or interpersonal responses such as self-advocacy or social learning. The most frequently used code for the responses category was education (225/1,587, 14%). This code includes educational testing, accommodations, and teacher responses. The next two highest codes involve social

interactions with social learning coming in second (145/1,587, 9%) and social accommodation (143/1,587, 9%) following closely behind.

**Language Codes.** The researcher created the language codes through an iterative process of identifying specific language usage and assigning emergent categories and then checking and refining the codes (Table 5). The researcher identified 1,237 entries and assigned ten specific language codes. The most commonly used category of specific disability language is medical (702/1,237, 57%). These entries reflect diagnostic language or disability related medical treatment. Although other instances of medical language occurred in the books, medical language not specifically tied to disability was not part of this count.

The second highest code was derogatory language (233/1,237, 19%). A subdivision of this code was provided to show the variety of usage of derogatory language to bully or tease others with a hurtful intent (171/233, 73%), to identify members of the community by playful teasing or using group specific language (11/233, 5%), or to belittle oneself with self-deprecating language (51/233, 22%). It is worth noting that the speaker and context of the word usage was critical to determine the desired impact. One book in particular, *After Ever After*, made the most common use of derogatory language used within a community for playful teasing. In this book, one of the two characters that have undergone cancer treatment has a sharp wit, and uses the playful teasing form of derogatory language to encourage the other character. The same character responded very negatively when other characters used similar derogatory comments to him or the other character that had undergone cancer treatments.

The third highest code was informal disability language (78/1,237, 6%). This form of language usage moves away from the formal medical language that is most often in use and serves to allow for personalized descriptions of individual experiences of disability such as “differently wired brain” in reference to a character with autism.

One code, which is noteworthy due to surprisingly low usage, was person first language (11/1,237, 0.9%). On initial review, this may seem to suggest a lack of contemporary or sensitive language usage, but it is important to note that this construction of language primarily connects a person with a disability, frequently making use of diagnostic language such as “the girl with cerebral palsy.” This construction serves to establish the connection between a person and a disability themed characteristic and so might occur only infrequently in the course of a novel. In the same way that an author might specify other identifying characteristics such as a character’s hair color on rare occasions, an author might establish a disability themed characteristic early in the story and then only reference it tangentially as it affected the plot or character interactions. Another point that could influence the low usage of person first language is the fact that sixteen of the books tell the story from the perspective of a protagonist with a disability, fifteen of those books tell the story from the first person point of view. The authors of the books might have decided that it did not have an authentic sound for a character to use person first language when describing themselves in their own voice as part of the establishment of their character.

### **Stereotypes**

Biklen and Bogdan (1977) defined 10 common stereotypes found in books and media portraying characters with a disability: pitiable and pathetic, object of violence,

sinister or evil, atmosphere, Super Crip, laughable, own worst enemy, burden, non-sexual, and incapable of fully participating in everyday life. From reading the study set of books, the researcher identified six of Biklen and Bogdan's ten stereotypes in the books: burden, non-sexual, atmosphere, own worst enemy, pitiable and pathetic, and limited participation in everyday life. Four of the stereotypes were not present in the books: object of violence, sinister or evil, Super Crip, and laughable. The most common stereotypes identified were burden, non-sexual, and atmosphere, which were present in six books. Four books included the stereotype own worst enemy, and one book each included the stereotypes pitiable & pathetic and limited participation in everyday life. Of the six stereotypes identified, two had clear connections to specific thematic codes. The first of these was burden, which tied to two different thematic codes, and the second was non-sexual which tied to one thematic code. The researcher did not specifically code the books for stereotypes in the initial readings; rather the researcher defined the thematic codes from the emergent themes from the books and then compared to the stereotypes to find any direct connections. The researcher conducted a further examination of the two stereotypes with significant connections to thematic codes.

**Burden stereotype.** Two of the thematic codes illuminate specific aspects of the stereotype burden (Table 10). One thematic code connected to the burden stereotype is the burden thematic code. The passages identified as fitting under the burden thematic code illustrate two aspects of burden. In the first case, characters view disability as a personal burden on members of the family, and in the second case, characters view disability as a financial burden. Almost half of the books in the study set indicated some form of burden on members of the family due to disability, and a third of the books in the

study set indicated a financial burden tied to disability. Examples of personal burden include staying home to care for a child with a disability as in *Things Not Seen*, or feeling a personal responsibility to care for a sibling as in *A Small White Scar*. Examples of financial burden include selling family property to support the character with a disability as in *Reaching for Sun* or *Tending to Grace*, or using the college fund of one character to support a medical treatment for a sibling such as in *Five Flavors of Dumb*. Another thematic code that showed a reasonable connection to the burden stereotype was expectation gap, used to indicate a differing expectation among characters related to disability. One book that showed a high incidence of expectation gap was *Rules*, where the older sibling objects to her parents' request to watch her younger brother who has autism. Another book that has a large number of passages assigned to this thematic code is *After Ever After* where the older brother feels a responsibility towards his younger brother's health and disability issues.

**Non-sexual stereotype.** One thematic code, romance, directly connects to the stereotype of non-sexual. Seven books (7/22, 32%) from the study set show passages that are tied to the thematic code romance, which means that the remaining 15 books (15/22, 68%) do not have any passages that are tied to romance (Table 11). A review of the notes from the readings of the books showed that an additional four books included a romantic element not tied directly to disability language and so did not show up in the coded passages for romance. The researcher decided that the age of the major character with a disability was an important point for analysis, and set the age 13 as a dividing line under which romance might be less likely to occur as a thematic code in reference to a character with a disability. Seven major characters were age 12 or under, only one of

which had any passages labeled as romance tied to them. Of the two adult characters with disabilities, neither had any mention of romance in the course of the story, one had a past romantic relationship that pre-dated the story and was referenced in the book but was not framed in disability language so did not show up as one of the coded passages. The researcher compared mention of romance in either the thematic passages or the notes from the readings to the types of disability represented in the characters, and no clear pattern emerged. There was a slightly stronger indication of the non-sexual stereotype in books that received the Dolly Gray Award for Children's Literature in Developmental Disabilities. Since there are only six books from this set, the sample is considered too small from which to draw any clear conclusions, but it does show a potential skew that deserves further study and attention.

### **Theoretical Models**

The researcher identified the best fitting thematic and specific language codes for each theoretical model of disability. The researcher assigned models of disability to each book based on the predominant model assigned to the major characters during the reading process. Next, the researcher reviewed the thematic and specific language groups to find the best fit to the theoretical models of disability represented in the books.

Each of the following tables (Tables 12, 13, 14) lists the categories of model patterns (single model, mixed models, transitioning models) that were predominant in the books. Each table has the books ordered to follow a consistent structure with the transitioning models listed first, followed by the mixed models, single models and/or models that were not represented. The researcher reviewed the codes to identify those that best fit each model, and in some cases, multiple codes combine to create the optimal

connection. The tables show the three codes or grouped codes that exhibit the best fit for each of the three models of disability. The numbers represent the number of instances for each code or grouped codes, followed by an average tied to the model group.

**Moral model of disability.** The moral model (Table 12) shows the best fit for thematic codes which are blame/shame/guilt, social isolation, and low self-esteem. It is noteworthy that all of the codes for the moral model table come from the feelings category of thematic codes, which may reflect a character's value judgments connected to the moral model. The first two groups of books (moral model to social model transition, moral/medical model mix) include seven books (7/22, 32%). Each of the seven books contains a significant inclusion of the moral model for one or more of the major characters. The next two groups (model mix or transition with zero moral model inclusion, social model only) include 15 books (15/22, 68%). Each of the 15 books contains no significant inclusion of the moral model for any of the major characters. While the pairing of the codes to the model is not a perfect fit, the descending averages show a connection to the moral model with a higher number of average instances per code tied to the book groups including the moral model. Some outliers have potential explanations such as *Rules*, which has a high number of blame/shame/guilt code instances. In *Rules*, the character that experienced blame/shame/guilt feelings actually experienced guilt over her self-consciousness about others' opinions about her brother and at times did not acknowledge her relationship to the characters with disabilities. This does not describe the expected feelings that would reflect blame, shame, or guilt directly about the disability. Another instance of a high number of blame/shame/guilt feelings is in *Reaching for Sun* where the character experiences guilt over lying about skipping her

physical and occupational therapy sessions. Again, this is a deviance from the expected pattern for this code.

**Medical model of disability.** The medical model table (Table 13) shows the best-fit codes, which are search for cause/cure, a group of four codes from the response category and tied to medical responses, and medical language, which is one of the specific language codes. The first code and the code group all come from the response category. The medical model table is the only one of the three model tables that includes a code from the specific language codes. The first three groups of books (medical to social transition, moral/medical mix or medical social mix, some minimal medical model) include nine books (9/22, 41%). Each of the nine books contains a significant inclusion of the medical model for one or more of the major characters. The next two groups (no medical model but some moral to social transitions, social model only) include 13 books (13/22, 59%). Each of the 13 books contains no significant inclusion of the medical model for any of the major characters. Again, while the pairing of the codes to the model is not a perfect fit, the descending averages show a connection to the medical model with a higher number of average instances per code tied to the book groups including the medical model. There are possible explanations for some of the outliers in this group as well. In the case of the high number of search for cause/cure in *Hurt Go Happy*, the cause of the disability is hidden due to shame and feelings of guilt, but other characters are concerned enough to ask about it. This is a difference from the expected response for this code, which would be that one of the characters is actively searching for a cure for the disability. In the case of the high number of search for cause/cure in *Anything But Typical*, the character searching for a cure is actually a

fictional character in a story within the story of the book. The protagonist has created a character facing the possibility of a surgery that would reverse the effects of his disability.

**Social model of disability.** The social model table (Table 14) shows the best-fit codes, which are acceptance, future plans, and accommodation, a group of two codes from the responses category including social accommodation and assistive technology. The first code comes from the feelings category, and the second code and the code group come from the response category. The medical model table is the only one of the three model tables that includes a code from the specific language codes. The first three groups of books (moral to social transition or medical to social transition, model mixes, and social model only) include 21 books (21/22, 95%). Each of the 21 books contains a significant inclusion of the social model for one or more of the major characters. The last group (moral/medical mix) includes one book (1/22, 5%). The single book contains no significant inclusion of the social model for any of the major characters. Again, while the pairing of the codes to the model is not a perfect fit, the descending averages show a connection to the social model with a higher number of average instances per code tied to the book groups including the social model. Because of the high number of books that contained the social model at some level, this was a difficult group to identify the best-fit codes. The top group of books does show the highest numbers of instances within the codes, which suggests that the codes could work as indicators for the existence of the social model in the books. The top group of books reflects more internal model conflict in the characters as compared to the next group, which focuses on more external model

conflict. The internal model conflict is chiefly the impetus for the transition from one model to another as part of the story.

### **Coded Text Comparisons**

After the thematic coding and the specific language coding on the books was completed, the same code sets were applied to the supplementary texts which included the controlled vocabulary catalog subject headings, the catalog book descriptions, and the professional book reviews. The goal was to determine how closely aligned the supplementary texts were with the themes and language used in the books.

The supplementary text coding comparison for the thematic codes showed the most striking difference between the breakdown of the codes in the books and in the catalog subject headings (Table 15). The books had a somewhat balanced distribution of coded book passages with almost half of the passages falling under description (2,183/4,890, 44.6%), just under one quarter falling under feelings (1,120/4,890, 22.9%), and about one third falling under responses (1,587/4,890, 32.5%). In comparison, all of the subject terms fell under description (62/62, 100%) with the majority falling under the sub-category code of diagnosis (60/62, 96.8%). The comparison between the books and the thematic codes for the catalog book descriptions and book reviews showed more similarities in the code distribution. Catalog descriptions and book reviews also had as their strongest category description with a majority of the catalog description codes (21/33, 63.6%) and book review codes (275/449, 61.2%) falling under that category. Unlike the subject terms, both of the other types of supplemental texts included entries in both of the other categories. Of interest is the fact that the second highest occurring thematic code for the catalog descriptions is the response code of search for a cause/cure.

The researcher previously noted the presence of this code as an indicator of the medical model. Considering all of these aspects of the supplemental texts, it is apparent that the catalog descriptions and the book reviews may provide a more nuanced representation of the book than the catalog subject headings. The subject terms primarily focus on the diagnosis of the disability that is included in the book rather than feelings or responses to the disability.

While an imbalance is also present when looking at the comparison between the specific language codes between the books and the supplemental texts, the differences are not quite as stark as they are in the thematic coding (Table 16). Medical language is the highest percentage in all categories including books (702/1237, 56.8%), subject terms (68/81, 84.0%), catalog descriptions (17/29, 58.6%), and book reviews (191/271, 70.0%). Of note is the fact that the subject terms are much more closely in line with the other categories in terms of a balanced distribution than in the thematic codes. The other codes that show up in the subject term codes are educational (11/81, 14.0%) and legal (2/81, 2.5%). This is the strongest showing for these terms in any of the text types in this comparison. This suggests that disability related legislation such as Individuals with Disabilities Education Act (IDEA) and Americans with Disabilities Act of 1990 (ADA) might have had an impact in the evolution of the subject terminology. Derogatory language is the second most common category in the books (233/1,237, 18.8%). In contrast, it is completely absent from the subject terms and only minimally included in catalog descriptions (1/29, 3.5%) and book reviews (3/271, 1.1%). Since the derogatory language occurs in either dialogue between characters or internal monologue, this would help to explain the imbalance of representation among the different text types. Another

noteworthy item is the relatively strong showing in the catalog descriptions of informal disability language (5/29, 17.2%), older style disability language (3/29, 10.3%), victim language (1/29, 3.5%), and person first language (2/29, 6.7%). In each of these categories, the catalog description provides the highest percentage of any of the supplementary text types included in this study. Especially interesting is the strength of both the older style disability language, which would indicate antiquated or dated terms for disability along with the person first language, which is a more contemporary approach to structuring language to talk about disability. This phenomenon would require further inquiry to determine the source of this imbalance, but some possible explanations could be the change in language over time that corresponds to age of the catalog descriptions or differences in the knowledge of disability language held by different catalogers who wrote these specific descriptions. A more extensive review of catalog descriptions for disability themed books might offer more insight into the extent of these language uses. One last specific language category worth mentioning is victim language which has a larger percentage in both the catalog descriptions (1/29, 3.5%) and the book reviews (7/271, 2.6%) than in the books (13/1,237, 1.1%). Victim language most often portrays the person with a disability as more vulnerable than the rest of the population. The books that receive the youth literature awards generally provide very positive role models in their characters with disabilities, so victim language may not support the desired characterizations. The portrayal of a character as a victim was one of the Biklen and Bogdan (1977) stereotypes not included in the books in this study set.

## **Conclusions and Recommendations**

The purpose of this study was to determine how society views individuals with disabilities through an investigation of language used in contemporary youth literature, book reviews and library cataloging. In particular, the researcher designed the project to investigate books published after the passage of Individuals with Disabilities Education Act (IDEA), and the Americans with Disabilities Act of 1990 (ADA). To achieve this goal, the researcher studied 22 award-winning books of the Dolly Gray Award for Children's Literature in Developmental Disabilities or the Schneider Family Book Award. The researcher used discourse analysis (Potter & Wetherell, 1987) for the research project, which includes multiple readings of the study set of documents, coding for the emergent themes, and analyzing the results.

### **Summary of Findings**

Societal views of disability are understandable in terms of three theoretical models of disability: moral, medical, and social. The researcher found that specific words or phrases from the books point to these theoretical models of disability, but not as clearly as anticipated. After the initial round of coding, the researcher discovered that only 10% of all identified disability themed passages had a clear connection to a specific theoretical model. The researcher recognizes that identification of theoretical models of disability is a more nuanced process, which requires an examination of the sum total of the character's thoughts, speech, and actions related to disability. The researcher discovered that certain thematic and language codes have connections to specific theoretical models of disability and are useful in validating conclusions drawn from reading notes.

The books show a preponderance of characters either holding or moving toward the social model. Of the 59 characters or character groups identified, the social model guides a majority (44/59, 75%) of the characters by the end of the story, and a smaller group has a medical/social model mix (6/59, 10%). That leaves only 15% with no social model component (9/59, 15%), which is comprised of small numbers of exclusively medical model (3/59, 5%), medical/moral model mix (2/59, 3%), exclusively moral model (1/59, 2%), and three characters that do not fit any of the three theoretical models (3/59, 5%). Furthermore, all model transitions end with the character moving to the social model, as there are no transitions ending in either the medical or the moral model. The pattern is even clearer when only the protagonists are considered, since most of the protagonists (20/22, 91%) are either in the social model or transitioning to it by the end of the book.

Looking at the books individually, eight (8/22, 36%) books reveal all characters exclusively in the social model throughout the book, whereas there were no books solely rooted in the medical or moral model in the same way. These eight books include a major character with a disability wherein the disability is just a part of life as opposed to the central conflict. One example from this set of books is *The London Eye Mystery* wherein the protagonist's disability serves as the key to resolving the conflict. These are books about coming to terms with disability as a normal part of life and not morality tales or the wonders offered by medical science.

Subject terms, catalog book descriptions and book reviews show differing language use from the books they describe. Since characters reveal models of disability through extended storytelling, the researcher did not categorize the supplementary texts

by models of disability as such. The specific language codes are not dependent on characters, and are identifiable in the supplementary texts. Some of the specific language codes have connections to individual theoretical models, and help to illuminate theoretical model inclusion in the supplementary texts. For the subject terms, the language is very limited in type with a sole focus being on medical diagnostic terms. An attempt to glean any model information on the books through the subject terms is not possible. Catalog book descriptions focus on the medical diagnosis although more variety of other types of language is present. A clear indication of the models seen in the books is elusive. The clearest sense of disability models can be determined from the book reviews.

### **Responses to Research Questions**

The researcher investigated two research questions in this research project. Both questions focus on the way that language communicates theoretical models of disability. The first question focuses on the way that language communicates the models in books, and the second question focuses on the way that language communicates the models in book reviews and library cataloging and whether or not the language in the book reviews and cataloging supports or conflicts with the language in the books. The two research questions led to the following responses.

#### **Question One Issue: Theoretical Models of Disability in Youth Literature.**

**Response 1: In contemporary youth literature, language regarding feelings about and responses to a disability predict specific theoretical models of disability, while description is not a predictor.** The language themes coded for in the entire set of quote passages fall into three broad categories: those that include description of the

disability, feelings about the disability, and responses to the disability. The researcher found that the description category is not very useful in determining the model of disability held by characters in the books. All of the thematic codes that act as indicators of theoretical models of disability are from the feelings and response categories. Different characters interpret the same descriptions of disability using different models. For example, in *Becoming Naomi León*, there is a conflict in how the major characters view Owen, who has multiple disabilities. Naomi and Gram see him as a valuable part of the family who happens to have some medical needs connected to his disability, while Owen's mother, Skyla, views him with disgust and abandons him, as she does not see him as an important part of her life. The description of Owen is the same to all of the other three characters; the difference is in their feelings about Owen and their response to him.

**Response 2: In contemporary youth literature, use of derogatory language may be present in books using moral, medical, or social theoretical models of disability.** Derogatory language is a common specific language type, the second most prevalent after medical language. An expectation is that books in the social model will have less derogatory language but instead it is present there as well. However, the derogatory language that is included in the books is not overly harsh (such as crazy, dimwit, and twitchy), and primarily supports the creation of authentic characters. It is interesting to note that the derogatory language played multiple roles. The most common use is when a character without a disability was teasing or bullying a character with a disability. In contrast, derogatory language builds community through playful teasing among multiple characters with disabilities, or in efforts to reappropriate negatively

charged language (Galinsky et al., 2003). Derogatory language also appears when a character with a disability expresses anger or frustration with themselves or with their situation. The use of derogatory language seems to contribute less to building meaning about specific disability models and more meaning about the universality of its occurrence in the lives of characters with disabilities in an authentic portrayal.

**Response 3: In contemporary youth literature, feelings of blame, shame, guilt, social isolation, low self-esteem and attempts to hide the disability are indicative of the theoretical moral model of disability.** Goodley (2011) describes the negative effects of a moral model view of disability as “being ostracized from family and community, feeling profound shame, having to hide disability symptoms or the person with a disability” (p. 7). Four thematic codes have the best correlation with the moral model. Three of these are from the feelings category, namely: blame/shame/guilt, social isolation, and low self-esteem. The other thematic code is from the response category, namely: hiding the disability from others. There are fewer books to consider since the moral model is the least prevalent. Nevertheless, the five books that feature a moral to social model conversion have the highest average count for all four of these codes. On the other end of the spectrum, the eight books that are solely social model have the lowest count averages of these codes. It is noteworthy that three out of four of these codes come from the feelings category of thematic codes, which may reflect a character’s value judgments. As stated earlier the researcher did not designate codes in a blind mechanical fashion, which allows for consideration of outliers. For instance, *Rules*, which is a strictly social model book, has a high blame/shame/guilt code count. However, the character that experiences blame/shame/guilt feelings actually experiences guilt over her

self-consciousness about others' opinions about her brother and the times she does not acknowledge her relationship to the characters with disabilities. These are not feelings of blame, shame, or guilt directly indicated about the disability itself.

**Response 4: In contemporary youth literature, the responses of searching for a cure or seeking medical treatment are indicative of the theoretical medical model of disability.** The researcher uses five thematic codes indicated in the response category to predict the theoretical model referred to as medical model. These include search for cause/cure, and a group of four codes aggregated dealing with medical responses – seeking diagnosis, treatment, therapy, and counseling. The specific language category of medical language also correlates with the medical model being present. As with the moral model, no books are exclusively medical model, but there are two with a medical to social transition and five more with a medical/social or medical/moral mix. These seven books have the highest average code counts for all of the themes and language types mentioned above.

Again, the codes counts alone do not tell the entire story. The book *Hurt Go Happy* contains no medical model but has a high search for cause/cure code count. In this case, the cause of the disability is hidden due to shame and feelings of guilt, but other characters are concerned enough to ask about it. This is a difference from the expected response for this code, which is likely to be that one of the characters is actively searching for a cure for the disability. Another book with a high count of search for cause/cure codes is the solely social model book *Anything But Typical*. The character searching for a cure is actually a fictional character in a story within the story of the book.

In this case, the character in the story within a story actually rejects the cure as offered, moving to self-acceptance and social model.

**Response 5: In contemporary youth literature, feelings of acceptance, making future plans, use of assistive technology and social accommodation are indicative of the theoretical social model of disability.** The theoretical model referred to as social model of disability represents a special challenge because all books except one contains the social model tied to at least one character. As a result, there is no balanced pair of book sets with and without the social model. What occurs instead is that certain thematic codes tend to indicate books wherein the social model mixes with other models or a character transitions from another model to the social model. The codes that correlate well here are the feeling category of acceptance, the response category of making future plans, and an aggregate of the two response code categories of social accommodation and assistive technology. There are seven books wherein a character transitions from the medical or moral model to the social and this group has the highest average counts on these thematic codes. These are books likely to include an internal model conflict. In six books, the social model mixes in with other models and these have the next highest average count for these codes. The eight books that were solely social model have the lowest average counts for these codes. Therefore, the presence of these codes indicates models in conflict with social model as part of the mix. Books that are strictly social model are conspicuous in scoring low in all code count categories tied with models of disability.

**Response 6: In contemporary youth literature that portrays disability, plots and conflict have a strong connection to theoretical models of disability.** In many of

the books, the theoretical models of disability play a major role in the plot as one of the characters goes through a transition from one model of disability to another. One example of this type of role transition takes place in *Hurt Go Happy* as primarily the moral model first guides Joey's mom as she tries to keep Joey from learning American Sign Language in an effort to hide her hearing loss. Eventually she learns to accept Joey's desire to learn to sign and transitions to more of a social model. In another example, in the book *Tru Confessions*, Tru is clearly working from a medical model perspective as she works diligently to try to find a cure for her brother who has brain damage due to birth trauma. Over the course of the book, Tru learns to accept her brother for who he is and moves gradually into a social model perspective. There were some positive examples of inclusion of disability that were secondary to the plot as in *The London Eye Mystery* wherein Ted's uniquely wired brain serves as the means to solve the mystery. In this case, the disability is an advantage in resolving the major conflict in the book.

#### **Question Two Issues: Language Usage in Book Reviews and Library Cataloging**

**Response 7: In cataloging contemporary youth literature, catalog subject terms are almost exclusively diagnosis-based and provide limited insight to many important disability issues.** Language related to disability as seen in the catalog subject terms consists of 97% of the single thematic code for description of the diagnosis (60/62, 97%). A library user can successfully search catalog subject terms for books containing a specific medical condition such as cerebral palsy or blindness. However, the books using a medical term can vary widely as far as using outdated stereotypes or the disability model represented. A reader who cares less about the specific condition of a main character but instead wants books with a social model framework about a character

adapting to a disabling condition of some broad type will have difficulties using subject terms to locate what they seek.

**Response 8: In cataloging contemporary youth literature, the catalog book descriptions are heavily diagnosis-based, but contain a wider range of language than the subject terms. Catalog descriptions include a mix of antiquated and current usage.** Catalog descriptions also have as their strongest thematic code category description (21/33, 63.6%). However, there are significant numbers of feelings and response type codes. A user of this material will have more varied information to consider. A major difference with the books themselves is the lack of derogatory language in the catalog descriptions. Derogatory language is common in the books to create authentic experience for the characters, but a user of the catalog description might not be expecting this. Curiously, the catalog descriptions contain more antiquated and victim language than the books but at the same time also more person-first language than the books. This mix of usage likely reflects the mix of understanding of disability issues among the many disparate authors of these descriptions.

**Response 9: In contemporary youth literature, books and book reviews include similar usage of language of disability.** The researcher identified 36 thematic codes to categorize the topics describing disability in the books. None of the supplementary texts (book reviews, subject headings, catalog descriptions) uses all of the thematic codes. As illustrated in Table 14, of the supplementary texts the book reviews use the widest diversity of thematic codes (30/36, 83%), followed by catalog descriptions (11/36, 31%), and finally subject headings (2/36, 6%). The wide diversity of codes in the book reviews most closely mirrors the diversity of language used in the books to describe

disability. The pattern of diversity among the different texts is similar in the specific language codes (Table 15). The researcher identified ten specific language codes in the books and none of the supplementary texts uses all of the language codes. Once again, the book reviews use the most specific language codes (9/10, 90%), followed by catalog descriptions (6/10, 60%), and finally subject headings (3/10, 30%). Diversity of language in book reviews more closely reflects the language in the books and as such, the book reviews provide the best avenue for the potential reader to locate books that match their interests. The biggest discrepancy with the books in terms of disability language is the lack of derogatory language that is nearly absent in the book reviews but used significantly in the books in a natural way to aid in character development.

### **Implications and Recommendations**

The researcher developed the following implications and recommendations from the review of findings and responses to the research questions. In the tradition of social constructionism (Gergen, 2009), the researcher asserts possible explanations for the views currently held about individuals with disabilities and suggests alternatives. The following statements are possible explanations for how language in contemporary youth literature influences societal views of individuals with disabilities.

**Theoretical models of disability guide readers' expectations.** The authors of the various texts in this research project (books, book reviews, subject headings, catalog descriptions) likely bring a conscious or unconscious theoretical model of disability with them when creating or describing a character with a disability. Additionally, readers bring a conscious or unconscious theoretical model of disability with them when encountering books or supplementary texts that include a character with a disability. The

accepted theoretical model of disability (or mix of models) that a reader embraces is likely to be similar to one of three models: moral model, medical model, or social model. Based on books read, the reader may modify a previously accepted model of disability. Model expectation may certainly influence the reader's reaction to books.

Viewed through the perspective of a moral or medical model of disability, none of the books in this study set has a "happy ending." There are no characters cured of a disability through either modern medicine or the grace or appeasement of higher powers. There are very few cases of the underlying disabling condition improving significantly. While circumstances of some characters with disabilities improve, the improvement is occurs largely through increased coping skills and accommodation, and not by becoming "less autistic" or "less blind." One curious exception to this rule was the protagonist in *Things Not Seen* who identified a successful "cure" from the fantasy disability of "invisibility." In contrast, the character with the real disability in the same book remains blind. This limited fantasy example makes clear the realistic prospects of "cure" for those individuals experiencing actual real world disabilities.

**As presented in a limited set of award winning youth literature, the prevalent view of disability is in transition from moral and/or medical models of disability to a social model of disability.** Taken as a body, the books in this research project represent snapshots of high quality portrayals of disability in youth literature for roughly the 2000-2010 decade. The books reflect a society following the passage of the Individuals with Disabilities Education Act (IDEA), and the Americans with Disabilities Act of 1990 (ADA), and well into a transition to a social model of disability. The only books with unchanging and uniform models held by all characters are those that are social

representing about a third of the books, suggesting that the book authors accept this as a logical end. Model conflicts and model transitions are also common but the social model is always in the mix and always the objective in all model transitions. This suggests a possible shift in the theoretical lens through which contemporary society views individuals with disabilities. The classic moral model with the cosmological implications of disability as resulting from sin is not present in the study set of books, but the model still survives as a remnant through the feelings of shame, blame, guilt, and a desire to hide that would have been part and parcel of the fully moral approach (Goodley, 2011). The medical model, responsible for the view that modern medicine must cure an individual with a disability to be acceptable in society is still important but not an end in itself (Hayes, & Hannold, 2007). This is clear from the lack of any books in this study wherein the character with a disability experiences a cure and only a few significantly benefit from modern medicine. In this regard, the study set of books may be ahead of general society in a transition to a social model world. Since the study set reflects exemplary portrayals of disability, the suggestion is that the social model is the preferred approach and one that society may adopt more widely in future.

**Libraries play an active role in the social construction of disability.**

According to Priestly (1999),

when we speak in terms of gender, race, class, age, sexuality or disability we are also contributing to the production of those same social divisions and categories. Moreover, when we name ourselves, or when others name us within such categories, we too are being produced. (p. 92)

When librarians make selection choices that include or exclude materials that represent disability, and when they describe those same materials, they are participating in the process of the social construction of disability. DePoy and Gilson (2004) further describe the importance of language as a “powerful tool in the definition of disability culture as well as in advancing an understanding of disabled people as marginalized and devalued by nondisabled dominant groups” (p. 83). When understood in this light, the role of the library as an active participant in the discourse of disability should not be understated, nor the responsibility taken lightly. As Gergen describes, “the future is ours – together – to create” (2009, p. 5).

**Recommendation 1.** *Librarians must maintain library collections that provide accurate and authentic portrayals of disability that reflect current thinking in disability theory.* Librarians must understand contemporary thinking in terms of disability such as theoretical models including the social model of disability or other appropriate models that follow. Understanding contemporary theoretical models of disability helps to inform the decisions involved in library materials selection. The resources selected should avoid stereotypes (Biklen & Bogdan, 1977), represent a diversity of disability experiences (Blaska, 2003), and approach disability from varying theoretical models of disability (DePoy & Gilson, 2011). Award winning books that feature disability are a good option to meet these criteria as a review board has already vetted them. An example from this study set that serves as an exemplary model for this recommendation is *The London Eye Mystery* (Dowd, 2007). In this book, Dowd creates a character with a disability that has authentic characteristics for his specific diagnosis, major characters in the book appear to

hold the social model of disability, and the disability factors as an advantage in resolving the plot.

In addition to selecting library materials, librarians must regularly review collections to determine currency and accuracy of resources that portray disability. Librarians must address disability issues in library selection policies, and include regular review of older materials that may contain stereotypical or antiquated representations of disability. Librarians actively participate in the discourse of disability by making materials and information available and accessible for use.

**Recommendation 2.** *Librarians must be educated as to the strengths, limitations, and impact of book reviews and library cataloging on individuals with disabilities.* Reading or viewing books or other materials has an impact on societies' views of individuals with disabilities. Librarians use professional tools such as book reviews and cataloging information when selecting or accessing resources. Library users may use some of the same tools when selecting a book, or they may go straight to the online catalog and search by subject or keyword to find a book on a topic of their interest. This study determined that the language used in the professional tools does not provide a clear or accurate picture of the portrayals of disability in youth literature. Specifically, the subject headings in library cataloging focus on the diagnosis of the disability present in the books, while excluding the feelings or responses that the characters have regarding the disability. Using a keyword search that includes the catalog descriptions will provide a more nuanced understanding of the book and may aid the librarian or library user in locating desired information.

In addition to the type of terms used in the subject headings or catalog descriptions, another consideration is that the language used may not reflect current usage of disability themed terminology. Catalog descriptions and book reviews included some dated language. Book reviews provided the most variety in language and delivered the closest replication to the feelings and responses to disability that were present in the books. Both librarians and library users may choose to use these tools to gain a clearer understanding of books including portrayals of disability, and must understand their strengths and limitations in describing these books.

**Recommendation 3.** *Librarians must include patron accessible contemporary tools for locating and recommending books representing disability.* According to Olson (2001), traditional cataloging may not effectively represent topics that fall outside of the mainstream. Librarians may find that library users benefit from non-traditional resources when locating and selecting materials. Social media offers enticing options that may assist the location process including web sites that allows individuals to describe and review books. Software is available to allow library users to add descriptions (social tags) and reviews to materials in the library catalog. Rothbauer (2004) echoes the need for contemporary language to aid library users locate materials as online catalog subject headings may not use language that is intuitive to library users.

**Recommendation 4.** *Librarians must seek input from individuals living with disabilities on library collections and locating and accessing information.* As Chelton (2001) discussed, library personnel may make assumptions about groups of people that may not hold true at an individual level. These assumptions lead to marginalization of a group of people, and the library service that they receive may be impacted. This point

applies to the varied interests and access needs for individuals with disabilities. Librarians must find ways to gain input from individuals with disabilities to learn of information needs as well as access needs. Options include hiring staff members who live with disabilities to better replicate the community served, creating an advisory board including individuals with varying abilities, and providing means for individuals with disabilities to make their needs known to library personnel such as public forums or surveys. Julien (1999) articulates the importance of considering the needs of not only current library users, but also those individuals who do not use the library. By seeking input from individuals with disabilities, librarians may begin to understand why some individuals with disabilities are not using the library and consider preferred alternatives to resources, services, and access. Library personnel should avoid making assumptions about members of the community of persons with disabilities concerning what they would like to read or access, as the library personnel may not understand the impact that the information encounters have on individual readers. In the words of Helen Keller (1902), "In a word, literature is my Utopia. Here I am not dis-franchised. No barrier of the sense shuts me out from the sweet, gracious discourse of my book-friends. They talk to me without embarrassment or awkwardness" (p. 105). Through discourse with individuals with disabilities, libraries can meet their potential to enable people of all abilities to find themselves in the library collection and fulfill their information needs on the library shelves.

### **Future Research**

One of the results of this study was to illumine the numerous options for continued work in this area. Some of the possibilities fall under the broad areas of

additional studies of books that portray disabilities, authors and/or illustrators of books portraying characters with disabilities, cataloging related to disability, creating new tools to evaluate literature portraying disability, using theoretical models of disability to evaluate literature, involving participants to examine the impact of disability themed literature on perceptions of disability, and applying critical theory to a study of youth literature that portrays disability.

While other researchers have conducted research projects examining portrayals of disability in literature, there are some possibilities to supplement the existing studies. One possibility is to apply the code set created for this study to a larger book set by conducting a retrospective research project that examines disability portrayals throughout a longer history. This research project is limited to a small set of award winning books, which have publication dates between 1997 and 2010. It is likely to be fruitful to expand the study to include books that have publication dates prior to the 1990 passage of the Americans with Disabilities Act (ADA). While other studies have looked at inclusion of disabilities in award winning books of long-standing awards such as the Newbery and Caldecott (Leininger, Dyches, Prater, & Heath, 2010, and Dyches, Prater, & Jenson, 2006), the studies primarily focus on determining inclusion and types of disabilities represented. An additional study can determine if the models of disability included in older books reflected different understandings of disability at different points in history.

Another possibility that can add to the understanding of the authenticity of the portrayals of disabilities is to compare fiction books with autobiographical works or memoirs that portray characters and people who live with a disability. While a comparison to evaluation criteria demonstrates that the books in this study meet a high

standard for the creation of authentic and believable characters, it might be interesting to compare fictional characters to stories of real people who live with a disability. In light of this research project, looking at the way that language portrays disability in fiction compared to language describing disability in books describing real people who live with disabilities might highlight similarities and differences in the ways that language functions in these two forms of literature. A researcher can apply the set of codes created for this research project to an examination of fictional and autobiographical accounts to illuminate the role that language plays in the social construction of disability in that the author's perspective on disability might play a role in the language selected to describe disability.

Other categories of books that can benefit from additional work in understanding the portrayal of disability in youth books are non-award winning fiction youth books, picture books, and non-fiction youth books. Many books in library collections have not received any awards, and indeed, including the entire set of award winning books identified in this study would not likely satisfy all anticipated user needs for this topic. Instead, libraries include many books that have not received this type of recognition, but have been determined to be good selections for the library based on the library's selection policy. Reviewing titles that receive positive reviews or using random selections from library collections would give a broader picture of the representation of disability in youth literature. As mentioned previously, this research project specifically excludes picture books, but picture books can provide rich material to review for representation of disability. Earlier studies focus on the portrayal of disability in one of the major awards given for picture books, the Caldecott Medal (Dyches, Prater, & Jenson, 2006).

Illustrated books combine the additional layer of visual information to the information provided in the text. Non-fiction or information books provide yet another glimpse into the broad portrayal of disability in youth books that may be in library collections. While the purpose of information books is to inform, many of the same evaluation criteria apply, including such elements as how a character with a disability is included in all aspects of life, contemporary language use to describe disability, and accurate information about living with a disability. In addition, many information books provide pathways to additional resources that provide further information about disability. The examination of non-award winning fiction youth books, picture books, and non-fiction youth books can expand the knowledge of disability portrayals in youth books.

Although not a focus of this research project, participants in the Circle of Inclusion Project at the University of Kansas (2002) identified two points for evaluation of books related to authors and/or illustrators: author or illustrator's background, and author's perspective. Future research could determine if individual authors and/or illustrators have identified backgrounds, experience, or interest in disabilities that led them to create books that portray characters with disabilities.

Additional research projects investigating cataloging for disability themed books and materials have potential for yielding new understandings of how language represents and describes disability themed books and materials. Possible areas for examination include the history of catalog subject headings describing disability, expanding the study of language usage in catalog book descriptions for disability themed materials, and comparing language use in subject headings with user created social tags that describe disability themed books and materials. One possible approach is to look at the history of

subject headings use to describe disability themed materials. As terminology changes over time to describe disability in legal, medical, and educational realms, subject terms change to describe library materials (Olson 2001). Once a researcher understands the chronology of subject term changes, the researcher can compare the subject headings to the literature of the same era to get an understanding of how books and cataloging reflect changes in language. Investigating contemporary language use in the description of disability themed books and materials, a researcher can compare the controlled vocabulary of subject headings the more informal vocabulary employed in user created descriptors or “social tags.” Some web based social media sites and commercial online booksellers allow users of the sites to describe and review books in their own words and terminology. Some public libraries also allow user created descriptors for books and materials. A researcher can compare these social tags and user created descriptions to catalog subject headings and book descriptions to develop an understanding of the different language choices made by different user groups.

Several evaluation tools were included in this research project. A future study could investigate the utility of each of the current evaluation tools with the goal of creating a unified, streamlined tool that one could incorporate when making disability themed book selections whether for library, home, or classroom use.

This study is limited in scope by comparing documents to three frequently used theoretical models of disability. It is fruitful to investigate other theoretical models of disability in terms of their usefulness for examining portrayals of disability in youth literature such as the capability approach (Mitra, 2006), the Explanatory Legitimacy Theory (DePoy & Gilson, 2004), or new models that have yet to be described. A

researcher can expand this study to include other models to determine which additional models will serve well to understand the characters in the books. Theoretical models of disability provide a useful additional tool for evaluating youth literature portrayals of disability. With additional studies, the approach used in this study can be refined and the codes streamlined for increased effectiveness. The theoretical models provide a connection to the disability community and current disability scholarship thinking to verify that the evaluation criteria stay relevant.

This study focuses exclusively on the representation of disability within texts and does not involve any direct participant involvement. Another possibility for additional research involves participant responses to disability themed literature. One option is to acquire individual responses to literature through interviews or written responses. A possible study design involves reading or hearing a book about disability and includes a pre-test and post-test using an instrument for assessing perceptions and/or feelings about disability.

Lastly, this study was exploratory in nature, and did not approach the topic from a critical discourse analytic perspective. Future research on the topic of representations of disability in youth literature may select to use critical theories to identify muted voices in the disability community or issues of power involved in this arena. Ultimately, the goal will be to locate all voices in the library collection.

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Table 1

*Youth Literature Award Information*

Award	Distribution	Awarding organization	Goal of the award
American Indian Youth Literature Award <sup>a</sup>	Biennially since 2006	American Indian Library Association (AILA)	Awarded to identify and honor the very best writing and illustrations by and about American Indians
Asian/Pacific American Award for Literature <sup>b</sup>	Annually since 2001	Asian/Pacific American Libraries Association (APALA)	Awarded to honor and recognize individual work about Asian/Pacific Americans and their heritage, based on literary and artistic merit
Caldecott Medal <sup>c</sup>	Annually since 1937	Association for Library Service to Children (ALSC), a division of the American Library Association (ALA)	Awarded to the artist of the most distinguished American picture book for children
Coretta Scott King Book Award <sup>d</sup>	Annually since 1970 (under ALA auspices since 1980)	Ethnic & Multicultural Information Exchange Round Table (EMIERT), a round table of the American Library Association (ALA)	Awarded to recognize outstanding books for young adults and children by African American authors and illustrators that reflect the African American experience
Dolly Gray Award <sup>e</sup>	Biennially since 2000	Division on Autism and Developmental Disabilities (DADD) of the Council for Exceptional Children (CEC) and Special Needs Project	Awarded to recognize authors, illustrators, and publishers of high quality fictional children's books that appropriately portray individuals with developmental disabilities
Newbery Medal <sup>f</sup>	Annually since 1922	Association for Library Service to Children (ALSC), a division of the American Library Association (ALA)	Awarded to the author of the most distinguished contribution to American literature for children
Pura Belpré Award <sup>g</sup>	Biennially from 1996-2008, annually since 2008	Association of Library Service to Children (ALSC) and the National Association to Promote Library and Information Services to Latinos and the Spanish-Speaking (REFORMA)	Awarded to a Latino/Latina writer and illustrator whose work best portrays, affirms, and celebrates the Latino cultural experience in an outstanding work of literature for children and youth
Schneider Family Book Award <sup>h</sup>	Annually since 2004	American Library Association (ALA)	Awarded to an author or illustrator for a book that embodies an artistic expression of the disability experience for child and adolescent audiences

<sup>a</sup>Adapted from American Indian Youth Services Literature Award. (2010). *American Indian Library Association*. Retrieved from <http://www.ailanet.org/activities/youthlitaward.htm>

<sup>b</sup>Adapted from Asian/Pacific American Award for Literature. (2010). *Asian/Pacific American Librarians Association*. Retrieved from <http://www.apalaweb.org/awards/literature-awards/>

<sup>c</sup>Adapted from Caldecott Medal Home Page. (2011). *Association for Library Service to Children*. Retrieved from <http://www.ala.org/ala/mgrps/divs/alsc/awardsgrants/bookmedia/caldecottmedal/caldecottmedal.cfm>

<sup>d</sup>Adapted from Coretta Scott King Awards. (2011). *American Library Association*. Retrieved from <http://www.ala.org/ala/mgrps/rts/emiert/ckbookawards/index.cfm>

<sup>e</sup>Adapted from Dolly Gray Awards for Children's Literature in Developmental Disabilities. (2010). *Council for Exceptional Children*. Retrieved from <http://www.daddcec.org/Awards/DollyGrayAwards.aspx>

<sup>f</sup>Adapted from Newbery Medal Home Page. (2011). *Association for Library Service to Children*. Retrieved from <http://www.ala.org/ala/mgrps/divs/alsc/awardsgrants/bookmedia/newberymedal/newberymedal.cfm>

<sup>g</sup>Adapted from Pura Belpré Home Page. (2011). *Association for Library Service to Children*. Retrieved from <http://www.ala.org/ala/mgrps/divs/alsc/awardsgrants/bookmedia/belpremedal/index.cfm>

<sup>h</sup>Adapted from Schneider Family Book Award. (2011). *American Library Association*. Retrieved from <http://www.ala.org/ala/awardsgrants/awardsrecords/schneideraward/schneiderfamily.cfm>

Table 2

*Book and Award Information*

Book title	Book code	Publication year	Award	Award year
After Ever After	Afte	2010	Schneider	2011
Anything but Typical	Anyt	2009	Schneider	2010
Becoming Naomi Leon	Beco	2004	Schneider	2005
The Curious Incident of the Dog in the Night-time	Curi	2003	Dolly Gray	2004
Five Flavors of Dumb	Five	2010	Schneider	2011
Hurt Go Happy	Hurt	2006	Schneider	2008
Jerk, California	Jerk	2008	Schneider	2009
The London Eye Mystery	Lond	2007	Dolly Gray	2010
A Mango Shaped Space	Mang	2003	Schneider	2004
Marcelo in the Real World	Marc	2009	Schneider	2010
Me and Rupert Goody	MeAn	1999	Dolly Gray	2002
My Thirteenth Winter: A Memoir	MyTh	2003	Schneider	2005
Reaching for Sun	Reac	2007	Schneider	2008
Rules	Rule	2006	Schneider	2007
Small Steps	SmSt	2006	Schneider	2007
A Small White Scar	SmWh	2006	Dolly Gray	2008
So B. It	SoBI	2004	Dolly Gray	2006
Tending to Grace	Tend	2004	Schneider	2006
Things Not Seen	Thin	2002	Schneider	2004
Tru Confessions	TruC	1997	Dolly Gray	2000
Under the Wolf, Under the Dog	Unde	2004	Schneider	2006
Waiting for Normal	Wait	2008	Schneider	2009

*Note.* In the award column, “Schneider” refers to the Schneider Family Book Award, and “Dolly Gray” refers to the Dolly Gray Award for Children’s Literature in Developmental Disabilities.

Table 3

*Preliminary Codes and Related Questions*

Category	Questions
Models of Disability	What models of disability are present in the books, reviews, and cataloging?
	Are multiple models represented within the same book?
Exemplary Practices for Inclusion	Are issues of physical and/or electronic accessibility directly or indirectly addressed?
	Are issues of inclusion in education indirectly or directly addressed?
	Are issues of employment indirectly or directly addressed?
	Are other rights that enable people of all abilities to pursue full lives indirectly or directly addressed?
	Is a shift from old to new language pertaining to disability and related issues indirectly or directly addressed?
Characters	What disabilities are represented among the characters?
	What roles are played by the characters with disabilities?
	Which character holds which model?
	What are the relationships of the characters who express models of disability?
	Do characters change the model over the course of the book?
Plot	How do the theoretical models of disability impact the plot of the books?
Language	Do the books use person first language?
	If they do not use person first language, how does this impact the representations of character, plot, theme, etc.?
	Do the books use slang or negatively charged language to describe disability?

Table 4

*Thematic code definitions and examples: Descriptions, Feelings, Responses*

Code	Total count	% of total	Definition/Example
Description Category	2,183 (total)	44.6% (total)	description of the disability using explicit diagnostic language or attributes that result from the disability
Communication (DCO)	616	12.6%	<p>impact of disability on communication such as use of sign language, stuttering, etc:</p> <p>“She turned away. I couldn't lip-read anymore, and her words became indistinct--a really obnoxious thing to do to someone who's hard of hearing.” – Five, pg. 22.</p>
Physical Appearance (DP)	376	7.7%	<p>description of physical appearance, actions, movements, etc. as impacted by the disability:</p> <p>“Owen started racing through his second-grade homework like a horse on a tear. People were usually fooled by his looks and thought he was low in school due to being born with his head tilted to one side and scrunched down next to his shoulder.” – Beco, pg. 4.</p>
Thought Process (DT)	330	6.7%	<p>atypical ways of thinking such as would be common in characters who would be described on the autism spectrum:</p> <p>“My mother is a different story. That is an expression, since she herself is not really a story.” – Anyt, pg. 17.</p>
Sensory Experience (DS)	275	5.6%	<p>disability related impact on the senses outside of communication:</p> <p>“And when I am in a new place, because I see everything, it is like when a computer is doing too many things at the same time and the central processor unit is blocked up and there isn't any space left to think about other things.” – Curi, pg. 143.</p>
Diagnosis (DD)	198	4.0%	<p>explicit diagnosis or descriptive words or phrases that describe the nature of the disability:</p> <p>“She had been born with cerebral palsy. A few neighborhood kids called her spaz, and retard, but most treated her with respect because she was a friend of Armpit's, and because she was willing to answer their questions.” – SmSt, pg. 20.</p>
Learning Difference (DL)	179	3.7%	<p>impact of disability on learning such as learning disabilities:</p> <p>“No matter how hard I try, I can never keep up in math class, and trying to learn Spanish will be even worse. The problem is clear to me. It has to do with my colors.” – Mang, pg. 28.</p>

Mobility (DM)	113	2.3%	references to impact that disability has on mobility such as gait or use of mobility devices:  "Tad used to walk at least part of every day until partway through sixth grade. Then all of a sudden, he just gave up and started spending all of his time in a wheelchair." – Afte, pg 80.
Other (DO)	93	1.9%	references to other forms of disability represented in the book but not attributed to the primary character with disability:  "...she saw Harley coming along the sidewalk in his motorized wheelchair. Harley wasn't his real name; it was the nickname some kids had given him. He was in the eighth grade and had cerebral palsy." – Hurt, pg 41.
Challenges (DCH)	3	0.1%	other challenges tied to the disability but not connected to communication, mobility, or learning:  "My mother asks me to hang Eddie's sheets on the line outside. (A few times a year he still wets the bed.)" – TruC, pg. 132.

Code	Total count	% of total	Definition/Example
Feelings Category	1,120 (total)	22.9% (total)	feelings about the disability that are shared by the character with the disability, other characters in the book, or the narrator
Value (FD)	217	4.4%	references to valuing or devaluing the character with the disability by others around them:  "Either you can't read or you're just stupid. Which is it?" – MeAn, pg. 39.
Acceptance (FA)	158	3.2%	references to acceptance of the character with a disability by others or self-acceptance, also includes comforting:  "I twitch hard. 'You look like your father,' he says. 'It's the twitch.' Mr. Malley waggles his head. 'It's the eyes. And the square jaw. Your father was a handsome fellow.'" – Jerk, pg. 143.
Fear/Anxiety (FF)	131	2.7%	includes feelings of fear, anxiety, worry, stress:  "I realize that there is something wrong with me--something so wrong that it makes my mom afraid. I am afraid, too." – MyTh, pg. 18.
Blame/Shame/ Guilt (FS)	132	2.7%	includes feelings of blame, shame, guilt:  "When she asks me what happened I blurt: 'I've been skipping the clinic all week.' My hand covers my mouth." – Reac, pg. 132.

Burden (FB)	134	2.7%	perceptions of being burdened by the disability including financial burden and disappointment:  "Beside me, David holds his hands over his ears. 'Did David do something to upset you?' Mom asks. Unbelievable! I look up to the rearview mirror. 'You were supposed to watch him! You promised!'" – Rule, pg. 178.
Anger/ Frustration (FM)	117	2.4%	includes feelings of anger or frustration:  "Except before I stop to think, I hear myself asking, 'How long have you been blind?' Right away her smile freezes and she gets this half-confused look on her face, and she starts to turn red. I can't tell if she's mad or embarrassed." – Thin, pg. 77.
Self-Esteem (FSE)	86	1.8%	references to feelings of self-worth and includes feelings of sadness, failure, depression:  "He is looking at himself in the full-length mirror, sobbing. 'I don't want to be different,' he says. 'I want to be the same. Same as everybody else.'" – TruC, pg. 111.
Social Isolation (FSI)	85	1.7%	references to instances where the character with the disability feels isolated from others whether by their choice or through the actions of others:  "I tell her how they just don't understand, how they don't get it, how they don't know what it's like for me, how I am socially forgotten." – MyTh, pg. 174.
Other (FO)	60	1.2%	includes other feelings such as thoughts of suicide or death, feelings tied to religion, comparisons of differing disabilities:  "At this point I had pretty much decided that I was going to kill myself." – Unde, pg. 229.

Code	Total count	% of total	Definition/Example
Responses Category	1,587 (total)	32.5% (total)	Responses to disability by the character with the disability or by other characters
Education (RE)	225	4.6%	includes educational accommodations, testing and/or evaluations, teacher response:  "I fix my eyes on a spot on the floor while I struggle to find the words to explain why going to a regular high school would not be right for me." – Marc, pg. 8.

Social Learning (RSL)	145	3.0%	<p>references to the intentional instruction in social skills as a response to a lack of expected social reactions:</p> <p>“That's where I keep all the rules I'm teaching David so if my someday-he'll-wake-up-a-regular-brother wish doesn't ever come true, at least he'll know how the world works, and I won't have to keep explaining things.” – Rule, pg. 9.</p>
Social accommodation (RLL)	143	2.9%	<p>references to disability related accommodation on the part of other characters outside of legally required accommodations, includes characters learning sign language to communicate more effectively with another character:</p> <p>“Even though I was overwhelmed that Dad was learning sign language, I still wanted to say no...I stopped at the doorway. ‘Thank you for learning to sign,’ I said.” – Five, pg. 242.</p>
Capability (RC)	131	2.7%	<p>references to the perception of capability of the character with the disability by themselves or other characters:</p> <p>“Sometimes I think there's more in that brain of yours, Ted, than in the rest of ours put together. If brains alone could bring Salim back, yours would do it.” – Lond, pg. 199.</p>
Search for a Cure/Cause (RSC)	126	2.6%	<p>references to the quest for information about the cause of the disability (beyond the diagnosis) or the quest for a cure whether realistic or not:</p> <p>“That's how I'll cure Eddie, uncovering some amazing new therapy through my meticulous research. Win the Nobel Prize while helping out my brother.” – TruC, pg. 11.</p>
Medical— Treatment (RMM)	125	2.6%	<p>medical response to the disability such as prescriptions, medical appointments, surgery, etc.:</p> <p>"He still has doctor appointments every three months to see what can be done for him. Another one a week from today. Maybe you should consider coming along to see what this child is up against." – Beco, pg. 104.</p>
Medical— Diagnosis (RMD)	107	2.2%	<p>procedures leading to a diagnosis such as evaluations by medical personnel, medical testing, etc.:</p> <p>“Then my syndrome was diagnosed by the doctors. 'Why does he have to get all the interesting diseases?' she moaned to Mum and Dad.” – Lond, pg. 78.</p>
Medical— Counseling (RMC)	75	1.5%	<p>counseling provided by professional counselors in either clinical or school setting:</p> <p>“Almost spill my guts to a stupid shrink who won't stop saying my name and only listens because Mom gives him money.” – Jerk, pg. 48.</p>

Future Plans (RFP)	73	1.5%	<p>references to the future plans of the character with the disability, or comparing those plans with those of the other characters:</p> <p>“‘There's one thing that would get me to sell some of it off,’ she says after taking a loud finishing slurp of her tea, putting the cup back into the pack, and standing up. ‘Sendin' you to college. Bo's right. You read better than anyone, Cornelia...’” – Tend, pg. 166.</p>
Medical—Therapy (RMT)	70	1.4%	<p>medical therapy related to disability such as physical, occupational, or speech therapies:</p> <p>“Just like the plants, I dream of being back outside for long summer days, not stuck in occupational therapy twice a week, speech therapy three times a week...” – Reac, pg. 45.</p>
Other (RO)	68	1.4%	<p>references to other responses to disability such as seeking out resources, investigating legal requirements, etc.:</p> <p>“Apparently, Joey's deafness was considered a handicap by the parking police, because Pam had been permitted to park her van right outside the door.” – Hurt, pg. 240.</p>
Using disability as an advantage (RU)	67	1.4%	<p>references to times when characters intentionally use their own disability or that of another character as an advantage:</p> <p>“‘The thing is,’ I tell them, aware of the quiver in my voice, ‘my colors help me a lot too. I'm the best speller in my class, and I can remember history really well too. Phone numbers, names, everything. Well, except for math and foreign languages...’” – Mang, pg. 90.</p>
Assistive Technology (RA)	55	1.1%	<p>adaptive technology tied to disability such as communication devices, computer modifications:</p> <p>“That's because I talk to Alicia a lot. We talk on the phone, and we do instant messaging. She's got a text-to-speech translator on her PC, so whatever I type into a message window, her PC says out loud. She types a lot faster than I do. And we just talk.” – Thin, pg. 113.</p>
Self-Advocacy (RS)	45	0.9%	<p>references to efforts on the part of the character with the disability to advocate for their own legal, social, or educational needs:</p> <p>“‘I'm seventeen,’ I blurt out. ‘Meaning?’ Aurora inquires. ‘It should be Marcelo's decision.’ I gather up all my strength and lift my eyes to look first at Aurora and then at Dr. Malone.” – Marc, pg. 8.</p>
Expectation Gap (RG)	36	0.7%	<p>differing expectations between characters tied to disability issues, most commonly refers to expectations that siblings will have responsibility for sibling with disability:</p> <p>“She's right. It is different and here's how: Everyone expects a tiny bit from him and a huge lot from me.” – Rule, pg. 61.</p>
Romantic Issues	35	0.7%	<p>references to romantic thoughts or relationships for the</p>

(RR)			<p>person with the disability:</p> <p>“My mom tells me I will find a girlfriend one day, just like everyone else. I will find someone who sees how ‘special’ I am. I know no girl will ever like me. No matter what I do, no matter how hard I try.” – Anyt, pg. 7.</p>
Raising Awareness (RI)	33	0.7%	<p>references to efforts to raise community awareness of the disability or the character with the disability:</p> <p>“There isn't a kid in the grade who hasn't eaten spaghetti at the church hall's annual Alper Family ‘Fun-Raiser’ Dinner, or gotten dragged to a high school jazz band concert in my honor, or -- God help me -- bought a Save Jeffrey T-shirt.” – Afte, pg. 1.</p>
Hide (RH)	28	0.6%	<p>disability is hidden from view or knowledge of others either by the character with the disability or another character:</p> <p>“She stands and throws the core into the corn. ‘You hide who you are, you live half a life. You speak up, then you can be who you was meant to be.’” – Tend, pg. 79.</p>

Table 5

*Specific language code definitions and examples*

Language type	Total count	% of total	Definition/Example
Medical (LM)	702	56.8%	addresses specific medical information tied to disability <sup>a</sup>  "Cognitive disorder" – Marc, pg. 55. "deaf" – Curi, pg. 39.
Derogatory language	233	18.8%	Words or phrases with a negative connotation about disability
[from others] (LO)	[171]	[13.8%]	teasing or bullying a character with a disability by a non-disabled character  "half-wit" – MeAn, pg. 13. "spazz . . . retard" – SmSt, pg. 20.
[from other character with disability] (LW)	[11]	[0.9%]	friendly insults from one character with a disability to another character with a disability  "we're kind of like honorary speds" – Afte, pg. 17. "You might be a math-tard now" – Afte, pg. 46.
[from self] (LS)	[51]	[4.1%]	self-deprecating statements made by character with a disability  "A twitchy six-foot raisin" – Jerk, pg. 52. "the creature" – Jerk, pg. 85.
Informal disability language (LN)	78	6.3%	describes the disability or the disability experience in less than formal language but not meant to be negative or derogatory  "different operating system" – Lond, pg. 269. "bum brain" – SoBl, pg. 5.
Educational (LT)	72	5.8%	words or phrases that are specifically tied to disability related education practices  "IEP" – Anyt, pg. 58. "special education" – MyTh, pg. 20.
Euphemistic terms for disability (LE)	49	4.0%	euphemisms for disability, or a character with a disability  "special needs" – TruC, pg. 9. "special angel" – TruC, pg. 11.

Referring to the “normal world” from point of view of person with the disability (LG)	45	3.6%	words or phrases that describe the non-disabled perspective  “neurotypical” – Anyt, pg. 1. “hearing world” – Hurt, pg. 73.
Older style disability language (LA)	23	1.9%	outdated words or phrases used to describe disability-- these could be a product of older publication dates, lack of knowledge about current language usage, effort to create realistic character language, or authentic language use for the historic period that is portrayed  “Feebleminded” – SmWh, pg. 31. “mentally handicapped” – TruC, pg. 32.
Victim Language (LV)	13	1.1%	words or phrases that present the character with a disability as a victim of their condition and frequently brings about pitying responses from others  “broken inside” – Reac, pg. 140. “damaged child . . . Elliot suffered” – SoBI, pg. 216. “wheelchair bound” – Afte, pg. 229.
Legal (LL)	11	0.9%	words or phrases that specifically address legal issues related to disability  “restaurants that accommodate wheelchairs” – Rule, pg. 69. “Americans with Disabilities Act” – Thin, pg. 177.
Person First Language (LP)	11	0.9%	words or phrases that are specifically selected or arranged to refer to the person before the disability  “hiring practices for persons with disabilities” – Thin, pg. 178. “she has cerebral palsy” – SmSt, pg. 63

<sup>a</sup> Omitted from this category are more generic medical terms that include but are not specifically tied to disability such as therapy, medication, etc.

Table 6

*Text sample with thematic and specific language codes*

Text	Thematic code	Language code
On the way to the cafeteria, I peek inside Eddie's classroom.		
He's in one of the other sixth-grade classes, down the hall from mine.		
We're in different classes because we're twins, not because of Eddie's <b><i>disability.</i></b>	RE	LM
Our school has the <b><i>special-needs kids</i></b> in regular classrooms with a resource person to help them keep up.	RE	LE
The school board calls it " <b><i>inclusion.</i></b> "	RE	LT
As far as I'm concerned, the more Eddie gets included, the better.	RE	
From the hall, I watch everyone in Eddie's classroom working on different things.		
Eddie sits at the computer, rocking back and forth in his seat.	DP	
The screen is filled with five or six planets and a few shooting stars.		
Mrs. Bell comes over and kneels next to him, speaking gently.		
One of my favorite things to do is to watch Eddie when he doesn't know I'm there.		
Sure, it's spying, but I don't think he'd mind.		
It's kind of comforting to see him out in the world, without Mom, without me.	FB	
I suppose I watch him for my benefit more than his.	FB	
I still never like to leave him alone for too long.	FB	

*Note.* This text comprises two consecutive paragraphs from the book *Tru Confessions*, p. 23. Words italicized and in bold indicate words identified for specific language codes. Thematic codes refer to the whole sentence. Sentences with no indication of either code type were not included in the data set.

Table 7

*Comparison of disability frequency between books and students receiving services through Individuals with Disabilities Education Act (IDEA)*

<b>Type of Disability</b>	<b>U.S. Students receiving services through IDEA [2009-2010]</b>	<b>Represented in Dolly Gray and Schneider award winning books [2000-2011]</b>
Specific Learning Disabilities	37%	14%
Speech or Language Impairments	22%	7%
Intellectual Disability	7%	14%
Emotional Disturbance	6%	10%
Hearing Impairments	1%	10%
Orthopedic Impairments	1%	10%
Other Health Impairments	11%	10%
Visual Impairments	<1%	3%
Multiple Disabilities	2%	3%
Deaf-Blindness	<1%	0
Autism	6%	17%
Traumatic Brain Injury	<1%	0
Developmental Delay	6%	0

*Note.* “Schneider” refers to the Schneider Family Book Award, and “Dolly Gray” refers to the Dolly Gray Award for Children’s Literature in Developmental Disabilities. Information about students receiving services through IDEA adapted from U.S. Department of Education, National Center for Education Statistics (2012). Digest of Education Statistics, 2011 (NCES 2012-001). Table 46.

Table 8

*Character information*

Book code	Character name	Age	Disability	Role	POV	Models
Afte	Jeffrey	~ 13	Learning issues from cancer	Pro	1 <sup>st</sup>	Md/S
	Tad (friend)	~ 13	Mobility issues from cancer	Sup	---	Md/S
	Parents	Adult	---	Sup	---	Md
Anyt	Jason	12	Autism	Pro	1 <sup>st</sup>	S
	Parents	Adult	---	Sup	---	S
Beco	Naomi	11	Selective mutism	Pro	1 <sup>st</sup>	S
	Owen (sibling)	8	Unspecified physical issues	Sup	---	S
	Gram (grandma)	Adult	---	Sup	---	S
	Sklya (mom)	Adult	---	Ant	---	M/Md
Curi	Christopher	15	Asperger's	Pro	1 <sup>st</sup>	S
Five	Piper	18	Deaf	Pro	1 <sup>st</sup>	S
	Grace (sibling)	1	Deaf	Sup	---	---
	Parents	Adult	---	Sup	---	Md/S
Hurt	Joey	13-20	Deaf	Pro	3 <sup>rd</sup>	S
	Charlie	Adult	---	Sup	---	S
	Mom	Adult	---	Ant	---	M→S
Jerk	Sam/Jack	17	Tourette's	Pro	1 <sup>st</sup>	M→S
	Bill (stepdad)	Adult	---	Ant	---	M
	George (mentor)	Adult	---	Sup	---	S
	Naomi (friend)	~ 17	---	Sup	---	S
Lond	Ted	12	Autism Spectrum (Asperger's)	Pro	1 <sup>st</sup>	S
	Kat (sibling)	14	---	Sup	---	S
Mang	Mia	13	Synesthesia	Pro	1 <sup>st</sup>	Md→S
	Parents	Adult	---	Sup	---	Md→S
Marc	Marcelo	17	Asperger's	Pro	1 <sup>st</sup>	S
	Parents	Adult	---	Sup	---	S
MeAn	Jennalee	11	---	Pro	1 <sup>st</sup>	M→S
	Rupert (rival)	Adult	Unspecified cognitive	Ant	---	S
	Uncle Beau	Adult	---	Sup	---	S
MyTh	Samantha	5-25	Dyscalculia	Pro	1 <sup>st</sup>	M/Md
Reac	Josie	13	Cerebral Palsy	Pro	1 <sup>st</sup>	S
	Mom	Adult	---	Ant	---	Md
	Grandma	Adult	Stroke related issues	Sup	---	S
	Jordan (friend)	12	---	Sup	---	S
Rule	Catherine	12	---	Pro	1 <sup>st</sup>	S
	David (sibling-C)	8	Autism	Ant	---	S
	Jason (friend-D)	14	Unspecified mobility & communication issues	Sup	---	S
SmSt	Armpit	17	---	Pro	3 <sup>rd</sup>	S

	Ginny (friend)	10	Cerebral Palsy	Sup	---	---
SmWh	Will	15	---	Pro	1 <sup>st</sup>	M→S
	Denny (twin)	15	Unspecified cognitive	Ant	---	S
	Parents	Adult	---	Sup	---	S
SoBl	Heidi	12	---	Pro	1 <sup>st</sup>	S
	So B. It (mom)	Adult	Unspecified cognitive	Sup	---	---
	Bernadette (friend)	Adult	---	Sup	---	S
Tend	Cornelia	14	Communication/Stuttering	Pro	1 <sup>st</sup>	M→S
	Agatha (aunt)	Adult	---	Sup	---	S
Thin	Bobby	15	Invisible (fantasy disability)	Pro	1 <sup>st</sup>	Md/S
	Alicia (friend)	~16	Blind (real disability)	Sup	---	Md/S
	Parents	Adult	---	Sup	---	Md/S
TruC	Tru	12	---	Pro	1 <sup>st</sup>	Md→S
	Eddie (twin)	12	Brain Damage	Sup	---	S
	Mom	Adult	---	Sup	---	S
Unde	Steve	17	Mental health/blind one eye	Pro	1 <sup>st</sup>	S
	Dad	Adult	Mental health	Sup	---	S
Wait	Addie	~11	Learning disability	Pro	1 <sup>st</sup>	S
	Mom	Adult	---	Ant	---	Md
	Stepdad	Adult	---	Sup	---	S
	Soula (friend)	Adult	---	Sup	---	S

*Note.* In Age column, ~ represents approximate age inferred by other textual clues. In Role column, “Ant” = antagonist, “Pro” = protagonist, and “Sup” = supporting character. In POV column, “POV” = point of view, “1<sup>st</sup>” = first person, and “3<sup>rd</sup>” = third person. In Models column, “M” = moral model of disability, “Md” = medical model of disability, “S” = social model of disability, two codes with a slash indicate a mix of models, two codes with an arrow indicates a transition from one model to another, and dashes indicate inadequate information to assign a theoretical model of disability to this character.

Table 9

*Comparison of books compared to evaluation criteria and stereotype lists*

	Dolly Gray	Schneider	Circle of Inclusion	Stereotypes
Afte	---	---	Mild derogatory language	Burden
Anyt	---	Absence of others with disabilities	Mild derogatory language	---
Beco	Minimal development for primary character with disability	Minimal development for primary character with disability	Mild derogatory language	---
Curi	---	---	Mild derogatory language	Non-sexual
Five	---	---	---	Burden
Hurt	Plot overly complex	Plot overly complex	---	Non-sexual
Jerk	---	---	Mild derogatory language	Own worst enemy
Lond	---	Absence of others with disabilities	Mild derogatory language	---
Mang	---	---	Mild derogatory language	---
Marc	---	---	Mild derogatory language	---
MeAn	Minimal development for primary character with disability	Minimal development for primary character with disability, absence of others with disabilities, character with disability is an adult	Mild derogatory language	Atmosphere, Non-sexual, Burden
MyTh	Uneven literary quality	Plays on sympathy & sentimentality	---	Own worst enemy, Non-sexual
Reac	---	---	---	---
Rule	Minimal development for primary characters with disability	Minimal development for primary characters with disability	Minimal development for primary characters with disability	Burden, Atmosphere

SmSt	Minimal development for primary character with disability	Plays on sympathy & sentimentality, Absence of others with disabilities	Minimal development for primary character with disability, Mild derogatory language	Atmosphere, Pitiabile & Pathetic
SmWh	Minimal development for primary character with disability	Absence of others with disabilities	Minimal development for primary character with disability	Burden, Atmosphere, Violence, Non-sexual
SoBI	Minimal development for primary character with disability	Character with disability an adult	Minimal development for primary character with disability	Limited participation in everyday life
Tend	---	Absence of others with disabilities	---	Own worst enemy, Non-sexual
Thin	Minimal development for primary character with disability	Absence of others with disabilities	Minimal development for primary character with disability	Atmosphere
TruC	Minimal development for primary character with disability	Minimal development for primary character with disability, character with disability does not solve own problems	Minimal development for primary character with disability, Mild derogatory language	Atmosphere
Unde	---	---	Sophisticated subject matter, character with disability not positive role model	Own worst enemy
Wait	---	Character with disability tries to hide disability	---	Burden

*Note.* “Dolly Gray” refers to the Dolly Gray Award for Children’s Literature in Developmental Disabilities, “Schneider” refers to the Schneider Family Book Award, and “Circle of Inclusion” refers to the Circle of Inclusion Project at the University of Kansas.

Table 10

*Burden stereotype*

Book code	Passages indicating burden on family members due to disability	Passages indicating significant financial sacrifice due to disability	Passages related to not wanting or being able to live up to others expectations
SmWh	39 (23.8%)	0	0
Rule	27 (9.2%)	0	16 (5.5%)
Wait	22 (33.8%)	0	0
TruC	10 (6.4%)	0	0
Jerk	7 (2.1%)	2 (0.6%)	0
Five	5 (1.7%)	4 (1.3%)	0
Thin	3 (1.8%)	1 (0.6%)	1 (0.6%)
Marc	0	3 (0.9%)	0
Afte	0	3 (0.9%)	15 (4.3%)
Anyt	2 (0.7%)	0	0
Reac	2 (2.8%)	1 (1.4%)	0
Beco			0
Unde	0	1 (0.6%)	0
Tend	0	1 (0.5%)	0
MyTh	0	0	3 (0.9%)
Hurt	0	0	1 (0.2%)
Curi	0	0	0
Lond	0	0	0
Mang	0	0	0
MeAn	0	0	0
SmSt	0	0	0
SoBl	0	0	0

Table 11

*Non-sexual stereotype*

Book code	Romantic Issues (RR)	Other mentions of romantic issues for disabled character	Age of disabled character	Type of disability
MyTh	0	No	5-25	Dyscalculia
Hurt	0	No	13-20	Deaf
SmWh	0	No	15	Unspecified (Down's?)
Curi	0	No	15	Asperger's
Tend	0	No	14	Communication/Stutter
Thin	0	Yes	15/~16	Invisible/Blind
Unde	0	Yes	17	Mental health/Blind 1 eye
Reac	0	Yes	13-14	Cerebral Palsy
Mang	1 (0.2%)	Yes	13	Synesthesia
Five	1 (0.3%)	Yes	18/1	Deaf/Deaf
Rule	2 (0.7%)	Yes	8/14-15	Autism/Cerebral Palsy?
Marc	4 (1.2%)	Yes	17	Asperger's
Jerk	5 (1.5%)	Yes	17	Tourette's
Anyt	10 (3.5%)	Yes	12	Autism
Afte	12 (3.4%)	Yes	~13/~13	Learning/Mobility
SoBl	0	Yes (much earlier)	Adult	Unspecified cognitive
MeAn	0	No	Adult	Unspecified cognitive
TruC	0	No	12	Brain Damage
Lond	0	No	12	Autism Spectrum (Asp)
Wait	0	No	~11	Learning disability
SmSt	0	No	10	Cerebral Palsy
Beco	0	No	~7	Unspecified physical

Note. Top section (above dark line) includes all instances of RR (including one character under 13) and all youth characters 13 and over. Middle section includes adult characters. Lower section includes youth characters under 13. In Age of disabled character column, ~ represents approximate age inferred by other textual clues.

Table 12

*Moral model*

Model pattern	Book code	Blame, shame or guilt (FS)	Social isolation (FSI)	Low self-esteem (FSE)
Moral to Social transition for a major character	Hurt	26	11	4
	Jerk	15	8	15
	MeAn	12	0	1
	SmWh	5	0	0
	Tend	11	7	11
		Avg. 13.8	Avg. 5.2	Avg. 6.2
Moral/Medical mix	MyTh	4	20	20
	Beco	1	0	2
		Avg. 2.5	Avg. 10.0	Avg. 9.0
No Moral Model at all, some other sort of model mix or transition	Reac	12	3	0
	Mang	5	4	5
	TruC	8	1	4
	Thin	1	9	4
	Afte	1	3	0
	Five	3	8	1
	Wait	0	0	0
		Avg. 4.3	Avg. 4.7	Avg. 2.0
Social Model only for all characters	Anyt	0	3	2
	Curi	0	0	0
	Rule	20	4	4
	Unde	0	0	13
	SoBI	8	0	0
	SmSt	0	0	0
	Marc	0	3	0
	Lond	0	1	0
		Avg. 3.5	Avg. 1.4	Avg. 2.4

Table 13

*Medical model*

Model Pattern	Book Code	Search For Cause/Cure (RSC)	Medical (RMD + RMM + RMT + RMC)	Medical Language (LM)			
Medical to Social transition for a char	Mang	15	Avg. 65	Avg. 48			
	TruC	16	15.5	32.5			
Major character with a Medical/Moral or Medical/Social Model mix	Thin	19	Avg. 10.2	1	Avg. 21.6	36	Avg. 72.0
	Afte	0		83		125	
	Five	26		0		70	
	MyTh	3		4		124	
	Beco	3		20		5	
Some minimal Medical Model	Wait	0	Avg. 0	Avg. 0	3	Avg. 3.5	
	Reac	0	0	5.5	4	3.5	
No Medical Model at all, but some Moral to Social transitions	Hurt	15	Avg. 3.6	5	Avg. 7.6	80	Avg. 24.6
	Jerk	3		26		30	
	MeAn	0		1		0	
	SmWh	0		4		0	
	Tend	0		2		13	
Social Model only for all characters	Anyt	16	Avg. 3.3	11	Avg. 15.8	33	Avg. 18.6
	Curi	0		9		9	
	Rule	6		20		2	
	Unde	2		37		23	
	SoBI	1		6		0	
	SmSt	1		16		21	
	Marc	0		23		51	
	Lond	0		4		10	

Table 14

*Social model*

Model pattern	Book code	Acceptance (FA)	Future Plans (RFP)	Social accommodation (RLL)
Moral to Social transition or Medical to Social transition for a major character	Hurt	6	13	111
	Jerk	16	1	0
	Mang	8	0	0
	MeAn	11	0	0
	SmWh	11	12	0
	Tend	2	5	0
	TruC	15	4	0
Model mixes within or between characters with some Social	Afte	7	1	1
	Beco	7	2	0
	Five	0	11	47
	Reac	4	3	0
	Thin	10	8	21
	Wait	0	0	0
Social Model only for all characters	Anyt	17	0	0
	Curi	5	6	0
	Rule	8	0	18
	Unde	1	0	0
	SoBl	5	0	0
	SmSt	5	0	0
	Marc	10	6	0
	Lond	0	1	0
Moral/Medical	MyTh	10	0	0

Table 15

*Comparison of thematic codes across source types*

Code	In Books	Subject Terms	Catalog Descriptions	Book Reviews
Description Category	2,183 [44.6%]	62 [100%]	21 [63.6%]	275 [61.2%]
Communication	616 [12.6%]	2 3.2%	1 [3.0%]	14 [3.1%]
Physical Appearance	376 [7.7%]	0 [0%]	0 [0%]	3 [0.7%]
Thought Process	330 [6.7%]	0 [0%]	1 [3.0%]	31 [6.9%]
Sensory Experience	275 [5.6%]	0 [0%]	0 [0%]	4 [0.9%]
Diagnosis	198 [4.0%]	60 [96.8%]	19 [57.6%]	187 [41.6%]
Learning Difference	179 [3.7%]	0 [0%]	0 [0%]	30 [6.7%]
Mobility	113 [2.3%]	0 [0%]	0 [0%]	6 [1.3%]
Other	93 [1.9%]	0 [0%]	0 [0%]	0 [0%]
Challenges	3 [0.1%]	0 [0%]	0 [0%]	0 [0%]

Code	In Books	Subject Terms	Catalog Descriptions	Book Reviews
Feelings Category	1,120 [22.9%]	0 [0%]	6 [18.2%]	65 [14.5%]
Value	217 [4.4%]	0 [0%]	0 [0%]	7 [1.6%]
Acceptance	158 [3.2%]	0 [0%]	0 [0%]	12 [2.7%]
Burden	134 [2.7%]	0 [0%]	1 [3.0%]	14 [3.1%]
Blame/Shame/Guilt	132 [2.7%]	0 [0%]	0 [0%]	8 [1.8%]
Fear/Anxiety	131 [2.7%]	0 [0%]	1 [6.0%]	5 [1.1%]
Anger/Frustration	117 [2.4%]	0 [0%]	2 [6.0%]	4 [0.9%]
Self-Esteem	86 [1.8%]	0 [0%]	0 [0%]	5 [1.1%]
Social Isolation	85 [1.7%]	0 [0%]	1 [3.0%]	10 [2.2%]
Other	60 [1.2%]	0 [0%]	0 [0%]	0 [0%]

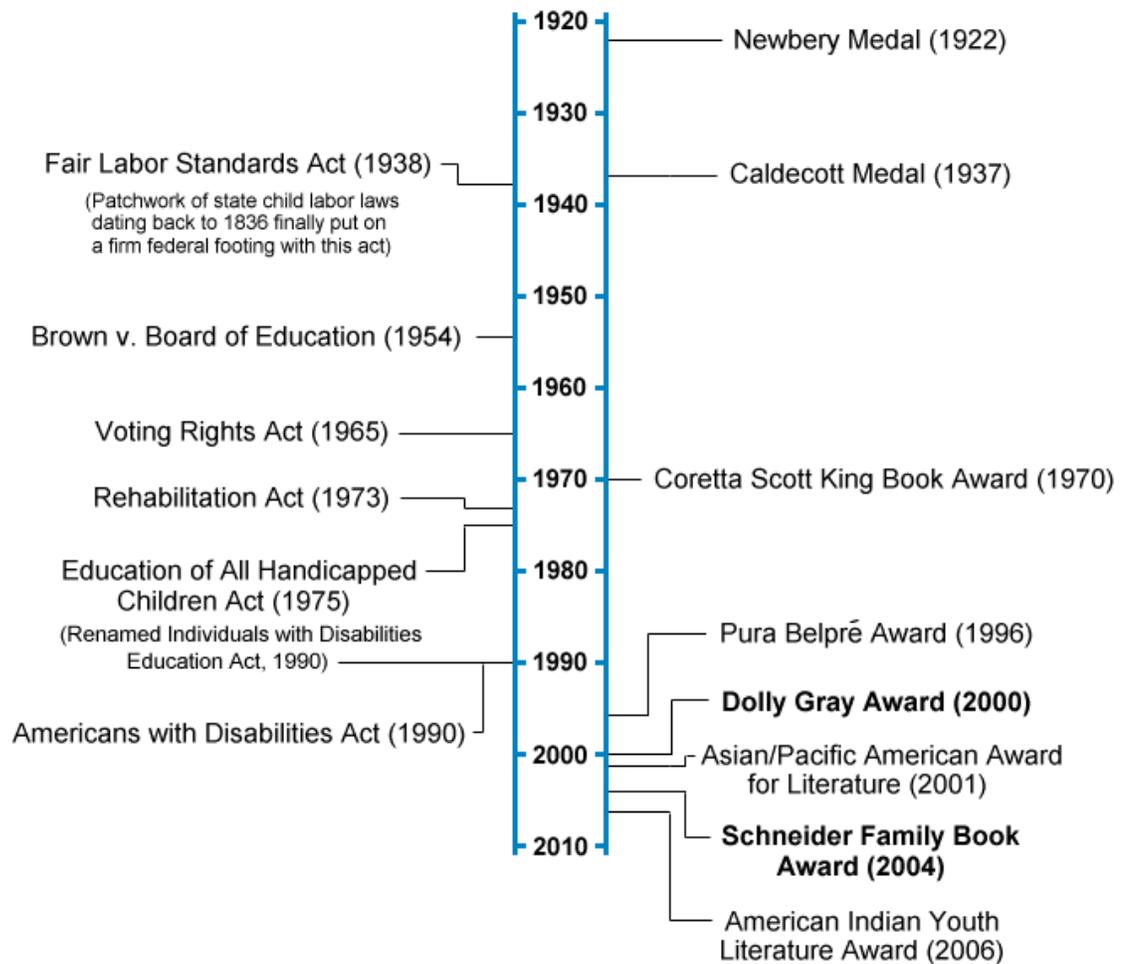
Code	In Books	Subject Terms	Catalog Descriptions	Book Reviews
Responses Category	1,587 [32.5%]	0 [0%]	6 [18.2%]	109 [24.3%]
Education	225 [4.6%]	0 [0%]	0 [0%]	12 [2.7%]
Social Learning	145 [3.0%]	0 [0%]	0 [0%]	10 [2.2%]
Social accommodation	143 [2.9%]	0 [0%]	1 [3.0%]	8 [1.8%]
Capability	131 [2.7%]	0 [0%]	1 [3.0%]	21 [4.7%]

Search for a Cure/Cause	126 [2.6%]	0 [0%]	3 [9.0%]	11 [2.4%]
Medical--Treatment	125 [2.6%]	0 [0%]	0 [0%]	14 [3.1%]
Medical--Diagnosis	107 [2.2%]	0 [0%]	0 [0%]	3 [0.7%]
Medical--Counseling	75 [1.5%]	0 [0%]	0 [0%]	1 [0.2%]
Future Plans	73 [1.5%]	0 [0%]	0 [0%]	6 [1.3%]
Medical--Therapy	70 [1.4%]	0 [0%]	0 [0%]	2 [0.4%]
Other	68 [1.4%]	0 [0%]	0 [0%]	5 [1.1%]
Using disability as an advantage	67 [1.4%]	0 [0%]	0 [0%]	1 [0.2%]
Assistive Technology	55 [1.1%]	0 [0%]	0 [0%]	0 [0%]
Self-Advocacy	45 [0.9%]	0 [0%]	0 [0%]	0 [0%]
Expectation Gap	36 [0.7%]	0 [0%]	0 [0%]	0 [0%]
Romantic Issues	35 [0.7%]	0 [0%]	0 [0%]	3 [0.7%]
Raising Awareness	33 [0.7%]	0 [0%]	0 [0%]	4 [0.9%]
Hide	28 [0.6%]	0 [0%]	1 [3.0%]	8 [1.8%]

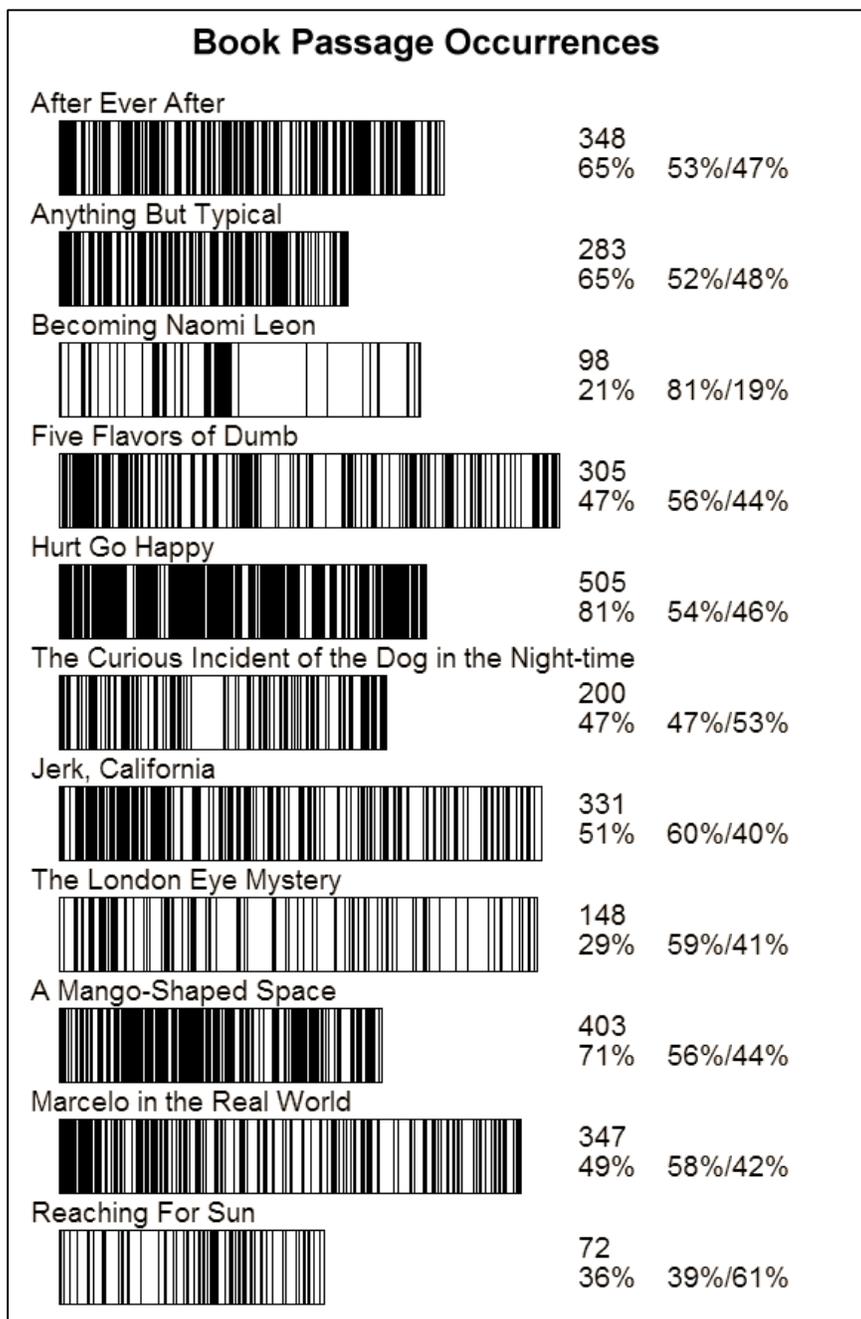
Table 16

*Comparison of specific language types across source types*

Language type	Percent of total			
	In Books	Subject Terms	Catalog Descriptions	Book Reviews
Medical	702 [56.8%]	68 [84.0%]	17 [58.6%]	191 [70.0%]
Derogatory language	233 [18.8%]	0 [0%]	1 [3.5%]	3 [1.1%]
	171 [13.8%]	0 [0%]	0 [0%]	3 [1.1%]
	11 [0.9%]	0 [0%]	0 [0%]	0 [0%]
	51 [4.1%]	0 [0%]	1 [3.5%]	0 [0%]
Informal disability language	78 [6.3%]	0 [0%]	5 [17.2%]	19 [7.0%]
Educational	72 [5.8%]	11 [14.0%]	0 [0%]	9 [3.3%]
Euphemistic terms for disability	49 [4.0%]	0 [0%]	0 [0%]	11 [4.1%]
Referring to the “normal world” from point of view of person with the disability	45 [3.6%]	0 [0%]	0 [0%]	14 [5.2%]
Older style disability language	23 [1.9%]	0 [0%]	3 [10.3%]	11 [4.1%]
Victim Language	13 [1.1%]	0 [0%]	1 [3.5%]	7 [2.6%]
Legal	11 [0.9%]	2 [2.5%]	0 [0%]	0 [0%]
Person First Language	11 [0.9%]	0 [0%]	2 [6.7%]	6 [2.2%]



*Figure 1.* Timeline of youth literature awards and relevant legislation.



*Figure 2.* Web tool showing all thematic code passages for sub-set of books. Variables represent total number of passages, percentage of book pages including one or more passages, percent of passages lying before and after the midpoint of the book.

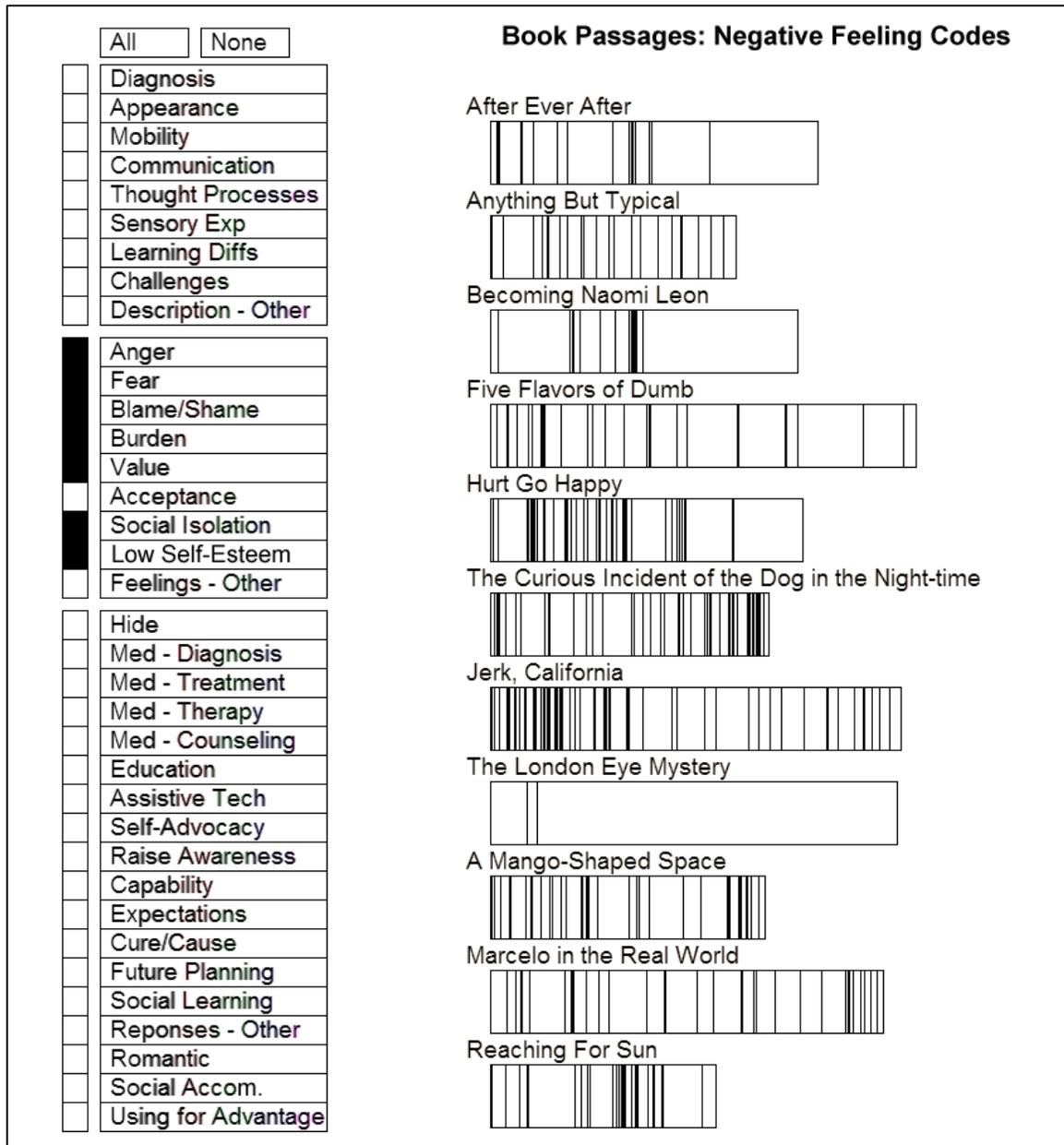


Figure 3. Web tool showing negative feelings passages for sub-set of books.

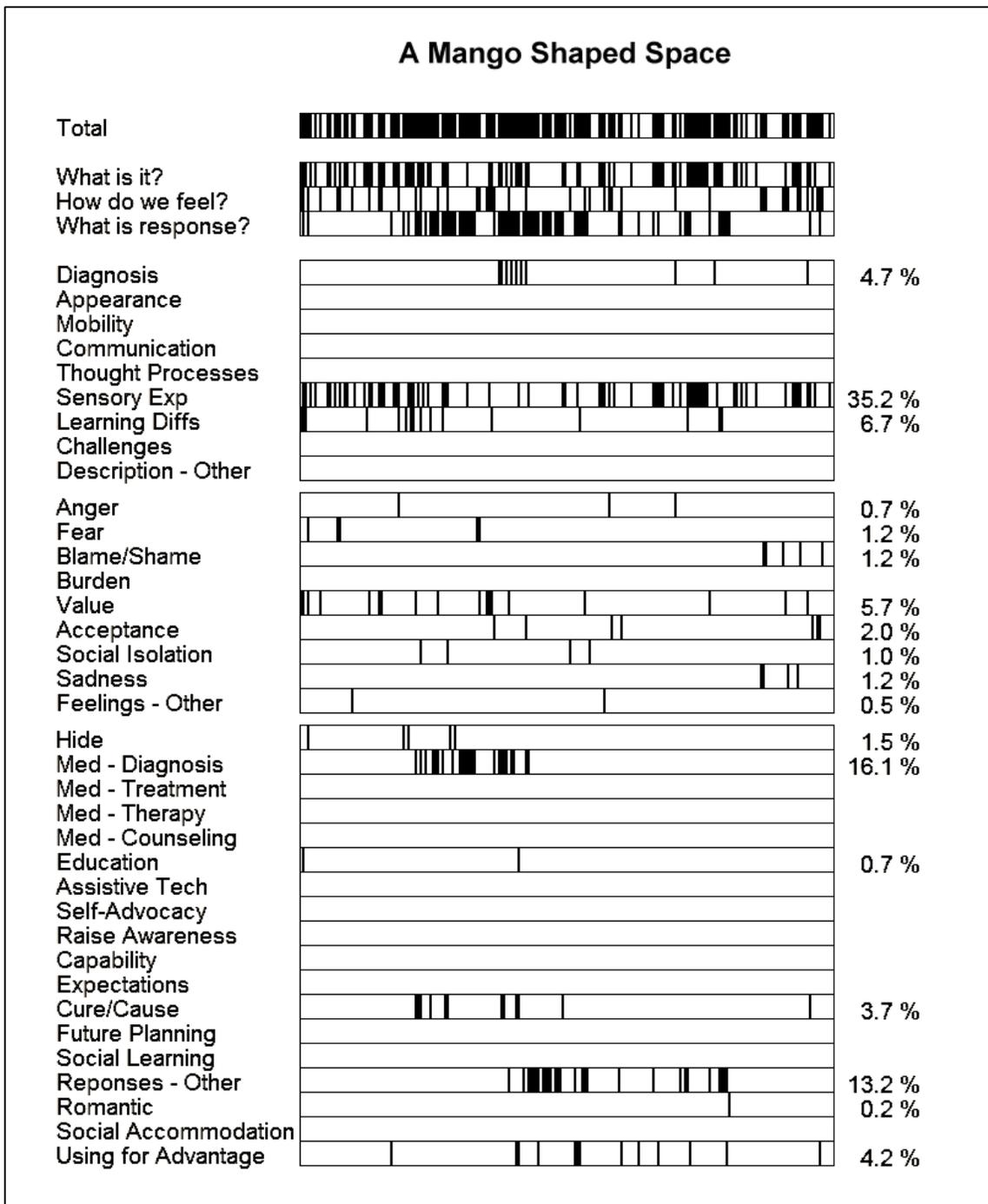


Figure 4. Web tool showing break down of all codes for a single book. Variables represent the percent of the codes within this book.

## Appendix A

### Award Winning Youth Literature Books

- Abeel, S. (2003). *My thirteenth winter: A memoir*. New York, NY: Orchard Books.
- Baskin, N. R. (2009). *Anything but typical*. New York, NY: Simon & Schuster Books for Young Readers.
- Clements, A. (2002). *Things not seen*. New York, NY: Philomel Books.
- Connor, L. (2008). *Waiting for normal*. New York, NY: Katherine Tegen Books.
- Dowd, S. (2007). *The London Eye mystery*. New York, NY: David Fickling Books.
- Friesen, J. (2008). *Jerk, California*. New York, NY: Speak.
- Fusco, K. N. (2004). *Tending to Grace*. New York, NY: Alfred A. Knopf.
- Haddon, M. (2003). *The curious incident of the dog in the night-time*. New York, NY: Vintage Books.
- John, A. (2010). *Five flavors of dumb*. New York, NY: Dial.
- Lord, C. (2006). *Rules*. New York, NY: Scholastic Press.
- Mass, W. (2003). *A mango shaped space*. New York, NY: Little, Brown & Company.
- Nuzum, K. A. (2006). *A small white scar*. New York, NY: Joanna Cotler Books.
- O'Connor, B. (1999). *Me and Rupert Goody*. New York, NY: Frances Foster Books.
- Rapp, A. (2004). *Under the wolf, under the dog*. Cambridge, MA: Candlewick Press.
- Rorby, G. (2006). *Hurt go happy*. New York, NY: Starscape.
- Ryan, P. M. (2004). *Becoming Naomi León*. New York, NY: Scholastic Press.
- Sachar, L. (2006). *Small steps*. New York, NY: Delacorte Press.
- Sonnenblick, J. (2010). *After ever after*. New York, NY: Scholastic.

Stork, F. X. (2009). *Marcelo in the real world*. New York, NY: Arthur A. Levine Books.

Tashjian, J. (1997). *Tru confessions*. New York, NY: Henry Holt.

Weeks, S. (2004). *So B. It*. New York, NY: Laura Geringer Books.

Zimmer, T. V. (2007). *Reaching for Sun*. New York, NY: Bloomsbury Children's Books.

## Appendix B

### Book Reviews

#### ***After Ever After***

Chipman, I. (2009). [Review of the book *After ever after*, by J. Sonnenblick]. *Booklist*, 106(8), 39.

Clark, T. (2010). [Review of the book *After ever after*, by J. Sonnenblick]. *School Library Journal*, 56(1), 114.

Gross, C. E. (2010). [Review of the book *After ever after*, by J. Sonnenblick]. *Horn Book Magazine*, 86(2), 73-74.

Kennedy, M. (2010). [Review of the book *After ever after*, by J. Sonnenblick]. *Journal Of Adolescent & Adult Literacy*, 54(4), 299-301. doi:10.1598/JAAL.54.4.9

[Review of the book *After ever after*, by J. Sonnenblick]. (2010). *Kirkus Reviews*, 78(1), 48.

[Review of the book *After ever after*, by J. Sonnenblick]. (2010). *Publishers Weekly*, 257(1), 48.

#### ***Anything But Typical***

3 views on autism. (2009). [Review of the book *Anything but typical*, by N. R. Baskin]. *Instructor*, 118(5), 16.

Chipman, I. (2009). [Review of the book *Anything but typical*, by N. R. Baskin]. *Booklist*, 105(11), 40.

[Review of the book *Anything but typical*, by N. R. Baskin]. (2009). *Kirkus Reviews*, 77(3), 169.

[Review of the book *Anything but typical*, by N. R. Baskin]. (2009). *Publishers Weekly*, 256(6), 48-50.

S. D., L. L. (2009). [Review of the book *Anything but typical*, by N. R. Baskin]. *Horn Book Magazine*, 85(3), 289.

Smith-D'Arezzo, W. (2009). [Review of the book *Anything but typical*, by N. R. Baskin]. *School Library Journal*, 55(3), 141.

### ***Becoming Naomi León***

Blasingame, J., & Carlile, S. (2005). Y en Español. [Review of the book *Becoming Naomi León*, by P. M. Ryan]. *Journal Of Adolescent & Adult Literacy*, 49(3), 248.

Heppermann, C. M. (2004). [Review of the book *Becoming Naomi León*, by P. M. Ryan]. *Horn Book Magazine*, 80(5), 598.

Isaacs, K. T. (2005). [Review of the book *Becoming Naomi León*, by P. M. Ryan]. *School Library Journal*, 51(3), 69.

Morrison, S. (2004). [Review of the book *Becoming Naomi León*, by P. M. Ryan]. *School Library Journal*, 50(9), 216-217.

[Review of the book *Becoming Naomi León*, by P. M. Ryan]. (2004). *Kirkus Reviews*, 72(17), 873.

[Review of the book *Becoming Naomi León*, by P. M. Ryan]. (2004). *Publishers Weekly*, 251(37), 79.

Rochman, H. (2004). [Review of the book *Becoming Naomi León*, by P. M. Ryan]. *Booklist*, 101(2), 245.

### ***The Curious Incident of the Dog in the Night-time***

Gropman, J., Woodcock, S., Jones, T. E., Toth, L., Charnizon, M., Grabarek, D., & Larkins, J. (2003). [Review of the book *The curious incident of the dog in night-time*, by M. Haddon]. *School Library Journal*, 49(10), 207-208.

Huntley, K. (2003). [Review of the book *The curious incident of the dog in night-time*, by M. Haddon]. *Booklist*, 99(15), 1376.

[Review of the book *The curious incident of the dog in night-time*, by M. Haddon]. (2003). *Kirkus Reviews*, 71(8), 557.

[Review of the book *The curious incident of the dog in night-time*, by M. Haddon]. (2004). *School Library Journal*, 5064.

Zaleski, J. (2003). [Review of the book *The curious incident of the dog in night-time*, by M. Haddon]. *Publishers Weekly*, 250(14), 42.

### ***Five Flavors of Dumb***

Pattee, A. S. (2010). [Review of the book *Five flavors of dumb*, by A. John]. *School Library Journal*, 56(12), 116.

[Review of the book *Five flavors of dumb*, by A. John]. (2010). *Kirkus Reviews*, 78(20), 1060.

[Review of the book *Five flavors of dumb*, by A. John]. (2010). *Publishers Weekly*, 257(42), 50-51.

### ***Hurt Go Happy***

MacMillan, K. (2006). [Review of the book *Hurt go happy*, by G. Rorby]. *School Library Journal*, 52(10), 168.

[Review of the book *Hurt go happy*, by G. Rorby]. (2007). *Library Media Connection*, 25(5), 77-78.

### ***Jerk, California***

Booth, H. (2008). [Review of the book *Jerk, California*, by J. Friesen]. *Booklist*, 105(1), 91.

Korson, S. (2009). [Review of the book *Jerk, California*, by J. Friesen]. *Library Media Connection*, 27(4), 75.

Murphy, N. G. (2008). [Review of the book *Jerk, California*, by J. Friesen]a. *School Library Journal*, 54(12), 124.

[Review of the book *Jerk, California*, by J. Friesen]. (2008). *Kirkus Reviews*, 76(16), 219.

### ***The London Eye Mystery***

Augusta, C. (2008). [Review of the book *The London Eye mystery*, by S. Dowd]. *School Library Journal*, 54(2), 113.

Cooper, I. (2008). [Review of the book *The London Eye mystery*, by S. Dowd]. *Book Links*, 17(4), 11.

Cooper, I. (2008). [Review of the book *The London Eye mystery*, by S. Dowd]. *Booklist*, 104(9/10), 78.

Kids & YA. (2008). [Review of the book *The London Eye mystery*, by S. Dowd]. *Kirkus Reviews*, 76(4), 14.

M. V., P. P. (2008). [Review of the book *The London Eye mystery*, by S. Dowd]. *Horn Book Magazine*, 84(3), 311.

[Review of the book *The London Eye mystery*, by S. Dowd]. (2007). *Kirkus Reviews*, 75(24), 1294.

[Review of the book *The London Eye mystery*, by S. Dowd]. (2008). *Kirkus Reviews*, 76(22), 12.

[Review of the book *The London Eye mystery*, by S. Dowd]. (2008). *Library Media Connection*, 26(6), 69.

[Review of the book *The London Eye mystery*, by S. Dowd]. (2008). *School Library Journal*, 54(54).

[Review of the book *The London Eye mystery*, by S. Dowd]. (2007). *Publishers Weekly*, 254(48), 70-71.

Schneider, D. (2011). The best school novel I've ever read. [Review of the book *The London Eye mystery*, by S. Dowd]. *Book Links*, 20(3), 4-7.

### ***A Mango-shaped Space***

Brabander, J. M. (2003). [Review of the book *A mango-shaped space*, by W. Mass]. *Horn Book Magazine*, 79(4), 463.

Carton, D. (2003). [Review of the book *A mango-shaped space*, by W. Mass]. *Booklist*, 99(15), 1390.

Jones, T. E., Toth, L., Charnizon, M., Grabarek, D., Larkins, J., & Mitnick, E. (2003). [Review of the book *A mango-shaped space*, by W. Mass]. *School Library Journal*, 49(3), 237.

[Review of the book *A mango-shaped space*, by W. Mass]. (2003). *Kirkus Reviews*, 71(5), 392.

Roback, D., Brown, J. M., Bean, J., & Zaleski, J. (2003). [Review of the book *A mango-shaped space*, by W. Mass]. *Publishers Weekly*, 250(15), 71.

### ***Marcelo in the Real World***

3 views on autism. (2009). [Review of the book *Marcelo in the real world*, by F. X. Stork]. *Instructor*, 118(5), 16.

Blasingame, J. (2010). [Review of the book *Marcelo in the real world*, by F. X. Stork]. *Journal Of Adolescent & Adult Literacy*, 54(1), 73-74.

Cooper, I. (2009). [Review of the book *Marcelo in the real world*, by F. X. Stork].

*Booklist*, 105(15), 38.

J., H. H. (2009). [Review of the book *Marcelo in the real world*, by F. X. Stork]. *Horn*

*Book Magazine*, 85(2), 204.

Odean, K. (2009). Feeling different. [Review of the book *Marcelo in the real world*, by

F. X. Stork]. *Teacher Librarian*, 36(5), 60.

[Review of the book *Marcelo in the real world*, by F. X. Stork]. (2009). *Kirkus Reviews*,

77(2), 97.

[Review of the book *Marcelo in the real world*, by F. X. Stork]. (2009). *Library Media*

*Connection*, 27(6), 74.

[Review of the book *Marcelo in the real world*, by F. X. Stork]. (2009). *Publishers*

*Weekly*, 256(1), 51.

Smith-D'Arezzo, W. (2009). [Review of the book *Marcelo in the real world*, by F. X.

Stork]. *School Library Journal*, 55(3), 156.

### ***Me and Rupert Goody***

Flynn, K. (1999). [Review of the book *Me and Rupert Goody*, by B. O'Connor]. *Horn*

*Book Magazine*, 75(5), 615.

[Review of the book *Me and Rupert Goody*, by B. O'Connor]. (1999, October 15). *Kirkus*

*Reviews*, 67, 1649.

Roback, D., & Brown, J. M. (1999). Forecasts: Children's Books. [Review of the book

*Me and Rupert Goody*, by B. O'Connor]. *Publishers Weekly*, 246(50), 84.

Steinberg, R. (1999). Grades 5 & Up: Fiction. [Review of the book *Me and Rupert*

*Goody*, by B. O'Connor]. *School Library Journal*, 45(10), 156.

Townsend-Hudson, S. (1999, November 1). [Review of the book *Me and Rupert Goody*, by B. O'Connor]. *Booklist*, 96(5), 530.

### ***My Thirteenth Winter***

Cummins, J. (2004). [Review of the book *My thirteenth winter: A memoir*, by S. Abeel]. *Booklist*, 100(12), 1050.

Menaldi-Scanlan, N., Jones, T. E., Toth, L., Charnizon, M., Grabarek, D., & Larkins, J. (2004). [Review of the book *My thirteenth winter: A memoir*, by S. Abeel]. *School Library Journal*, 50(3), 224.

[Review of the book *My thirteenth winter: A memoir*, by S. Abeel]. (2003). *Kirkus Reviews*, 71(20), 1267.

Roback, D., Brown, J. M., Bean, J., & Zaleski, J. (2003). [Review of the book *My thirteenth winter: A memoir*, by S. Abeel]. *Publishers Weekly*, 250(49), 63.

### ***Reaching for Sun***

Brown, N. (2007). [Review of the book *Reaching for sun*, by T. V. Zimmer]. *School Library Journal*, 53(3), 222.

Glantz, S. (2007). [Review of the book *Reaching for sun*, by T. V. Zimmer]. *Library Media Connection*, 25(6), 75.

Heppermann, C. M. (2007). [Review of the book *Reaching for sun*, by T. V. Zimmer]. *Horn Book Magazine*, 83(2), 207-208.

O'Malley, A. (2007). [Review of the book *Reaching for sun*, by T. V. Zimmer]. *Booklist*, 103(9/10), 106.

[Review of the book *Reaching for sun*, by T. V. Zimmer]. (2007). *Kirkus Reviews*, 75(2), 83.

**Rules**

Burns, C. (2006). [Review of the book *Rules*, by C. Lord]. *School Library Journal*, 52(4), 142.

Dobrez, C. (2006). [Review of the book *Rules*, by C. Lord]. *Booklist*, 102(12), 98-99.

[Review of the book *Rules*, by C. Lord]. (2006). *Kirkus Reviews*, 74(5), 234.

[Review of the book *Rules*, by C. Lord]. (2006). *Library Media Connection*, 25(2), 70.

[Review of the book *Rules*, by C. Lord]. (2006). *Publishers Weekly*, 253(16), 188.

Trierweiler, H. (2007). Best books on friendship for tweens. [Review of the book *Rules*, by C. Lord]. *Instructor*, 117(1), 75.

**Small Steps**

Burns, C. (2006). [Review of the book *Small steps*, by L. Sachar]. *School Library Journal*, 52(1), 143.

Gallagher, G. (2006). [Review of the book *Small steps*, by L. Sachar]. *Library Media Connection*, 24(6), 66.

Mattson, J. (2006). [Review of the book *Small steps*, by L. Sachar]. *Booklist*, 102(9/10), 101.

Smith, R. (2006). [Review of the book *Small steps*, by L. Sachar]. *Horn Book Magazine*, 82(1), 87-89.

[Review of the book *Small steps*, by L. Sachar]. (2005). *Kirkus Reviews*, 73(23), 1279.

[Review of the book *Small steps*, by L. Sachar]. (2005). *Publishers Weekly*, 252(45), 70.

**A Small White Scar**

Odean, K. (2007). The importance of siblings. [Review of the book *A small white scar*, by K. A. Nuzum]. *Teacher Librarian*, 34(3), 22.

Phelan, C. (2006). [Review of the book *A small white scar*, by K. A. Nuzum]. *Booklist*, 102(22), 75-76.

[Review of the book *A small white scar*, by K. A. Nuzum]. (2006). *Kirkus Reviews*, 74(12), 636.

Rohrlick, P. (2006, July). [Review of the book *A small white scar*, by K. A. Nuzum]. *Kliatt*, 40(4), 12.

Smith-D'Arezzo, W. (2006). [Review of the book *A small white scar*, by K. A. Nuzum]. *School Library Journal*, 52(8), 126-127.

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### ***So B. It***

Carton, D. (2004). [Review of the book *So B. It*, by S. Weeks]. *Book Links*, 14(1), 17-18.

Carton, D. (2004). [Review of the book *So B. It*, by S. Weeks]. *Booklist*, 100(19/20), 1731.

Flynn, K. (2004). [Review of the book *So B. It*, by S. Weeks]. *Horn Book Magazine*, 80(4), 462.

[Review of the book *So B. It*, by S. Weeks]. (2004). *Kirkus Reviews*, 72(10), 499.

[Review of the book *So B. It*, by S. Weeks]. (2004). *Publishers Weekly*, 251(22), 75.

Salvadore, M. B. (2004). [Review of the book *So B. It*, by S. Weeks]. *School Library Journal*, 50(7), 114.

### ***Tending to Grace***

Hunter, S. W., & Mandell, P. (2004). [Review of the book *Tending to Grace*, by K. N. Fusco]. *School Library Journal*, 50(5), 148.

[Review of the book *Tending to Grace*, by K. N. Fusco]. (2004). *Kirkus Reviews*, 72(8), 393.

[Review of the book *Tending to Grace*, by K. N. Fusco]. (2004). *Library Media Connection*, 23(3), 70.

[Review of the book *Tending to Grace*, by K. N. Fusco]. (2004). *Publishers Weekly*, 251(27), 56-57.

Rochman, H. (2004). [Review of the book *Tending to Grace*, by K. N. Fusco]. *Booklist*, 100(22), 1924.

### ***Things Not Seen***

Davidson, S. L. (2002). [Review of the book *Things not seen*, by A. Clements]. *School Library Journal*, 48(3), 226.

Decker, C. (2002). [Review of the book *Things not seen*, by A. Clements]. *Book Report*, 21(2), 52.

Jung, M. (2003). [Review of the book *Things not seen*, by A. Clements]. *Journal Of Adolescent & Adult Literacy*, 47(3), 271.

Pricola, J., & Rodman, B. (2002). Noteworthy. [Review of the book *Things not seen*, by A. Clements]. *Teacher Magazine*, 13(8), 49.

[Review of the book *Things not seen*, by A. Clements]. (2002). *Kirkus Reviews*, 70(3), 178.

Roback, D., Brown, J. M., Britton, J., & Zaleski, J. (2002). [Review of the book *Things not seen*, by A. Clements]. *Publishers Weekly*, 249(4), 291.

Rochman, H. (2002). [Review of the book *Things not seen*, by A. Clements]. *Booklist*, 98(16), 1412.

Sutton, R. (2002). [Review of the book *Things not seen*, by A. Clements]. *Horn Book Magazine*, 78(2), 210.

### ***Tru Confessions***

Burke, L. T. (2000). [Review of the book *Tru confessions*, by J. Tashjian]. *Reading Today*, 18(1), 32.

Brown, J. M., & Roback, D. (1997). Forecasts: Children's books. [Review of the book *Tru confessions*, by J. Tashjian]. *Publishers Weekly*, 244(43), 77.

Dollisch, P. A. (1997). Grades 5 & up: Fiction. [Review of the book *Tru confessions*, by J. Tashjian]. *School Library Journal*, 43(12), 131.

Estes, S. (1998). Books for middle readers: Fiction. [Review of the book *Tru confessions*, by J. Tashjian]. *Booklist*, 94(9/10), 816.

MacGregor, A. (2008, May). [Review of the book *Tru confessions*, by J. Tashjian]. *Kliatt*, 42(3), 24.

### ***Under the Wolf, Under the Dog***

Adam, R. (2005). [Review of the book *Under the wolf, under the dog*, by A. Rapp]. *Library Media Connection*, 23(6), 69.

Burkam, A. L. (2005). [Review of the book *Under the wolf, under the dog*, by A. Rapp]. *Horn Book Magazine*, 81(1), 98.

Dobrez, C. (2004). [Review of the book *Under the wolf, under the dog*, by A. Rapp]. *Booklist*, 101(6), 585.

Fiction reprints. (2007). [Review of the book *Under the wolf, under the dog*, by A. Rapp]. *Publishers Weekly*, 254(25), 58.

Jones, T. E., Toth, L., Charnizon, M., Grabarek, D., Larkins, J., & Goldsmith, F. (2004).

[Review of the book *Under the wolf, under the dog*, by A. Rapp]. *School Library Journal*, 50(10), 176.

[Review of the book *Under the wolf, under the dog*, by A. Rapp]. (2004). *Kirkus*

*Reviews*, 72(18), 918.

### ***Waiting for Normal***

C. M., H. H. (2008). [Review of the book *Waiting for normal*, by L. Connor]. *Horn Book*

*Magazine*, 84(2), 215-216.

Cooper, I. (2008). [Review of the book *Waiting for normal*, by L. Connor]. *Booklist*,

104(15), 50-51.

Curriculum connection. (2008, April). [Review of the book *Waiting for normal*, by L.

Connor]. *School Library Journal*, (54), 53-53.

[Review of the book *Waiting for normal*, by L. Connor]. (2007). *Kirkus Reviews*, 75(24),

1293.

[Review of the book *Waiting for normal*, by L. Connor]. (2008). *Publishers Weekly*,

255(7), 155.

Schultz, J. (2008). [Review of the book *Waiting for normal*, by L. Connor]. *School*

*Library Journal*, 54(2), 112.

## Appendix C

### Catalog Information

#### *After Ever After*

LC Online Catalog. (n.d.). [Catalog record of the book *After ever after*, by J.

Sonnenblick]. *Library of Congress*. Retrieved from

<http://lcn.loc.gov/2009010430>

WorldCat. (n.d.). [Catalog record of the book *After ever after*, by J. Sonnenblick]. *OCLC*.

Retrieved from <http://www.worldcat.org/oclc/317383417>

#### *Anything But Typical*

LC Online Catalog. (n.d.). [Catalog record of the book *Anything but typical*, by N. R.

Baskin]. *Library of Congress*. Retrieved from <http://lcn.loc.gov/2008020994>

WorldCat. (n.d.). [Catalog record of the book *Anything but typical*, by N. R. Baskin].

*OCLC*. Retrieved from <http://www.worldcat.org/oclc/232655890>

#### *Becoming Naomi León*

LC Online Catalog. (n.d.). [Catalog record of the book *Becoming Naomi León*, by P. M.

Ryan]. *Library of Congress*. Retrieved from <http://lcn.loc.gov/2004000346>

WorldCat. (n.d.). [Catalog record of the book *Becoming Naomi León*, by P. M. Ryan].

*OCLC*. Retrieved from <http://www.worldcat.org/oclc/54415069>

#### *The Curious Incident of the Dog in the Night-time*

LC Online Catalog. (n.d.). [Catalog record of the book *The curious incident of the dog in*

*night-time*, by M. Haddon]. *Library of Congress*. Retrieved from

<http://lcn.loc.gov/2002031355>

WorldCat. (n.d.). [Catalog record of the book *The curious incident of the dog in night-time*, by M. Haddon]. *OCLC*. Retrieved from <http://www.worldcat.org/oclc/50604879>

### ***Five Flavors of Dumb***

LC Online Catalog. (n.d.). [Catalog record of the book *Five flavors of dumb*, by A. John]. *Library of Congress*. Retrieved from <http://lcn.loc.gov/2009044449>

WorldCat. (n.d.). [Catalog record of the book *Five flavors of dumb*, by A. John]. *OCLC*. Retrieved from <http://www.worldcat.org/oclc/482550376>

### ***Hurt Go Happy***

LC Online Catalog. (n.d.). [Catalog record of the book *Hurt go happy*, by G. Rorby]. *Library of Congress*. Retrieved from <http://lcn.loc.gov/2006045203>

WorldCat. (n.d.). [Catalog record of the book *Hurt go happy*, by G. Rorby]. *OCLC*. Retrieved from <http://www.worldcat.org/oclc/70597573>

### ***Jerk, California***

LC Online Catalog. (n.d.). [Catalog record of the book *Jerk, California*, by J. Friesen]. *Library of Congress*. Retrieved from <http://lcn.loc.gov/2008007922>

WorldCat. (n.d.). [Catalog record of the book *Jerk, California*, by J. Friesen]. *OCLC*. Retrieved from <http://www.worldcat.org/oclc/216938818>

### ***The London Eye Mystery***

LC Online Catalog. (n.d.). [Catalog record of the book *The London Eye mystery*, by S. Dowd]. *Library of Congress*. Retrieved from <http://lcn.loc.gov/2007015119>

WorldCat. (n.d.). [Catalog record of the book *The London Eye mystery*, by S. Dowd]. *OCLC*. Retrieved from <http://www.worldcat.org/oclc/125401031>

***A Mango-shaped Space***

LC Online Catalog. (n.d.). [Catalog record of the book *A mango-shaped space*, by W. Mass]. *Library of Congress*. Retrieved from <http://lcn.loc.gov/2002072989>

WorldCat. (n.d.). [Catalog record of the book *A mango-shaped space*, by W. Mass]. *OCLC*. Retrieved from <http://www.worldcat.org/oclc/50803170>

***Marcelo in the Real World***

LC Online Catalog. (n.d.). [Catalog record of the book *Marcelo in the real world*, by F. X. Stork]. *Library of Congress*. Retrieved from <http://lcn.loc.gov/2008014729>

WorldCat. (n.d.). [Catalog record of the book *Marcelo in the real world*, by F. X. Stork]. *OCLC*. Retrieved from <http://www.worldcat.org/oclc/228676541>

***Me and Rupert Goody***

LC Online Catalog. (n.d.). [Catalog record of the book *Me and Rupert Goody*, by B. O'Connor]. *Library of Congress*. Retrieved from <http://lcn.loc.gov/98030235>

WorldCat. (n.d.). [Catalog record of the book *Me and Rupert Goody*, by B. O'Connor]. *OCLC*. Retrieved from <http://www.worldcat.org/oclc/39516004>

***My Thirteenth Winter***

LC Online Catalog. (n.d.). [Catalog record of the book *My thirteenth winter: A memoir*, by S. Abeel]. *Library of Congress*. Retrieved from

<http://lcn.loc.gov/2003040465>

WorldCat. (n.d.). [Catalog record of the book *My thirteenth winter: A memoir*, by S. Abeel]. *OCLC*. Retrieved from <http://www.worldcat.org/oclc/51536704>

***Reaching for Sun***

LC Online Catalog. (n.d.). [Catalog record of the book *Reaching for sun*, by T. V. Zimmer]. *Library of Congress*. Retrieved from <http://lcn.loc.gov/2006013197>

WorldCat. (n.d.). [Catalog record of the book *Reaching for sun*, by T. V. Zimmer]. *OCLC*. Retrieved from <http://www.worldcat.org/oclc/69671842>

### ***Rules***

LC Online Catalog. (n.d.). [Catalog record of the book *Rules*, by C. Lord]. *Library of Congress*. Retrieved from <http://lcn.loc.gov/2005017519>

WorldCat. (n.d.). [Catalog record of the book *Rules*, by C. Lord]. *OCLC*. Retrieved from <http://www.worldcat.org/oclc/61109244>

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