Disabilities in Children’s and Adolescents’ Literature

Beth, Jayme, and Cristal

Abstract

The goal of our project was to evaluate and develop criteria for children and adolescent literature dealing with the topic of disabilities. We did this project at the request of a local elementary school. For our project, we: 1) developed a criteria to evaluate books based upon a review of literature; 2) read and reviewed recommended books grades 1-8; 3) conducted focus groups with children grades 1-8 to determine how they select books and their thoughts of the word, “disability”; 4) selected books based upon an analysis of our data for read alouds grades 1-8; 5) interpreted the data and wrote final criteria for book selection and provided recommended book reviews for teachers at the elementary school. Our research is trustworthy: we triangulated our data, sought multiple perspectives, practiced self-reflectivity, and incorporated themes from the literature on the power of literature and criteria for selecting children and adolescent literature. Our research illustrates a very real need for effective children and adolescent literature to be infused into the classroom. Not all books on disability send appropriate messages or engage the general student population. Teachers need to know their students and take care in the selection of books. The criteria and recommended reading lists our project produced will assist teachers in this pursuit.
Background

Critical Question:

Our original critical question was How do we evaluate the classroom libraries of the local elementary school for themes of diversity based upon criteria that would most benefit the development of the children’s global and personal identities? After further reflection however, the principal of the school requested we narrow the scope of the study to include only texts with primary characters living with cognitive or invisible disabilities. Thus our critical question’s focus shifted to How can children’s and adolescent’s literature help identity and acceptance of cognitive and invisible disabilities. Early into the reading of our sample texts we recognized that there were a limited number of books available that focused on these specific types of disabilities, so we expanded our selection to books that also included characters living with more outwardly recognizable disabilities. The evolution of our critical question finally evolved to: How can children’s and adolescent’s literature develop identity and acceptance of disabilities?

Setting:

The setting of our study was a local elementary school which consists of grades one through eight. The grades are divided into levels; each level contains two grades, creating four classroom levels. They work with a place based and experiential learning philosophy throughout all grades. There is a community-centered curriculum, meaning students learn from their surroundings and use their environment as a learning tool.
Most schools focus on Reading, Writing, and Arithmetic but this school focuses on these six R’s: “reduce, reuse, recycle, relevance, rigor, and relationships.” The first three fall under the stewardship goals of the school and the latter three are addressed in the citizenship goals of the school. The school believes in the importance of helping students understand learning is enjoyable. Developing skills to learn independently through experiences and hands on education is emphasized throughout all grade levels.

Their school is embedded in the community and students work closely with the people in their town. As children grow within this learning community they think critically and create their own individual voices.

When we developed our critical question for our action research project we took into consideration this experiential learning and place based philosophy of the school. Specifically, we wanted to introduce books that would be relevant and interesting to future readers in this context.

**Study Design:**

Our study included six primary phases:

1. **Literature Review:** Our team did an extensive literature review covering four primary themes.
   - The literary elements of exemplary children’s and adolescent’s literature
   - The role of literature in personal identity and increased acceptance of others
   - The role of disability in children’s and adolescents’ literature
   - Award winning book lists
2. Criteria and Sample texts: Based on our literature reviews, we developed initial criteria to use when reading our sample texts then we proceeded to read 42 sample texts for grades 1 through 8. As we read more books we adapted our criteria as we saw fit, using our literature reviews to help guide us.

3. Focus Groups: We visited the FGCS, and held small focus groups sessions for all 4 levels. In these groups, we discussed with students how they select books to read and asked them their thoughts about the word “disability”. We also had our sample books on hand; along with some popular children’s books in different categories to determine which books they felt more drawn to and why.

4. Data Analysis: After completing our focus groups, we integrated the data we collected with the original literature reviews to create our first Analytic Memo.

5. Read Alouds: Based on our Analytic Memo we selected three books we felt exemplified excellence in all areas of our criteria and conducted read alouds for levels 1, 2, and 4 at the elementary school.

6. Final Data Interpretation: Our final analysis of our study included: analyzing the read aloud data and drafting and revising four synthesis statements; creating a poster, presentation, and paper summing up our findings; and finishing a final criteria and book review list presented to the teachers and administration at the elementary school.

Results

Synthesis Statement One: The Importance of Reliability

In children’s and youth literature, the reader’s ability to relate to the story is an important literary element. When children are able to find similarities between aspects
of their lives and the story they are reading they become more interested in the book. This connection encourages readers to stay engaged with the book and continue reading it, which increases the amount of knowledge learned.

Dyches, Prater, and Jenson shed light on this concept in their article, *Portrayal of Disabilities in Caldecott Books* (2006) as they believe that “young readers may have difficulty relating to characters with disabilities portrayed in these books because they are unlike people with disabilities with whom they interact at school or in the community” (p.13). We can understand from this statement that the authors believe it is important for students to find the books they are reading relatable. If it is difficult for students to relate to characters, they may not be interested in the book, which could lead them to dismiss the book and the messages that could be learned along with it.

In our own data collection, we found that this quality of relatability, was present in the younger grades, but became increasingly important in book choice with the increasing age of the reader. These tables reflect the data we collected about relatability in our focus group discussions. We found that older students strongly prefer characters more like themselves, while younger students are more evenly split between liking characters similar and different to them:

| Preferred Reading about Characters like themselves |
|------------------------|--------|--------|--------|--------|
| Level 1    | Level 2 | Level 3 | Level 4 |
| 11         | 1       | 4       | 5       |
Preferred Reading about Characters different from themselves

<table>
<thead>
<tr>
<th>Level 1</th>
<th>Level 2</th>
<th>Level 3</th>
<th>Level 4</th>
</tr>
</thead>
<tbody>
<tr>
<td>16</td>
<td>4</td>
<td>1</td>
<td>0</td>
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We read aloud the book *Waiting for no one* written by Beverley Brenna in a level four read aloud at FGCS. This book is told from the perspective of the main character, an eighteen year old girl, who lives with Asperger's syndrome. We read the first chapter of the book and then asked the students to write their immediate thoughts and opinions about the book.

One specific student states, “I would like to read that book cuz its what I was feeling like when I was younger [:)] and I would like to see how she feels.” This statement shows how this student could relate to this character, catching her interest and encouraging her to continue reading.

Another student wrote, “It seems like a interesting story of a girl’s struggle with a mental disability. I would like to read it because my mother works with S.P.E.D. and other programs with children that have disabilities.” This demonstrates how this particular student found a connection between this book and some aspect of her own life. Even though she may not directly relate with the main character she still finds the book interesting because of some familiar aspect of the book.

Information gathered from our literature review, we found that all students benefit from seeing characters like themselves in literature, including children with disabilities.
Additionally, children without disabilities will benefit from reading books with characters that are disabled as a way to have a better understanding and acceptance in real world experiences (Wopperer, 2011). Since a primary purpose of introducing this type of literature to students is for them to gain understanding of those living with disabilities, finding the main character relatable is not always going happen. Therefore, we wonder if the reader has to find a connection with a main character in order to glean benefits from the reading, or is having a connection with the setting and/or supporting characters enough?

**Synthesis Statement Two: Realistic Characters versus Realistic Fiction**

Our second synthesis statement stems from the fact that the vast majority of the sample texts we read were Realistic Fiction. Thirty six of the forty two books we read and reviewed were within this literary genre. As the literature reviews stress the importance of depicting characters living with disabilities realistically, it makes sense that most of these books have been written in the context of realistic fiction.

**Genres of Sample Texts**

<table>
<thead>
<tr>
<th>Realistic Fiction</th>
<th>Historical Fiction</th>
<th>Fantasy / SciFi</th>
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</thead>
<tbody>
<tr>
<td>36</td>
<td>1</td>
<td>5</td>
</tr>
</tbody>
</table>

The article *Culture or Disability? Examining Deaf Characters in Children’s Book Illustrations*, written by Debbie Golos (2012), Annie Moses, and Kimberly Wolbers states this idea directly when they assert that “because images and words for young children are powerful it is critical for picture books to portray positive and accurate
images and information about deafness and deaf people in both text and illustrations.”

Although this specifically refers to deaf individuals, we can confidently apply this concept to all disabilities utilizing the same motives. Young students need to be able to see and learn about the truth in order to accept it.

Dyches and her colleagues (2006) draw our attention to why realistic portrayals of characters with disabilities are important in the education of young students. They state that “since schools in the United States are serving increasingly diverse student populations, there is a great need for more authors to write picture books that accurately portray children who experience a wide variety of life experiences, including disabilities.” Since students are diverse and there are many disabilities existing throughout the United States there must be a creation of children’s books portraying characters realistically from all backgrounds. This can lead to an increased understanding of real disabilities and the struggles that accompany those who face them. The idea that disabilities do not define people, but are simply one aspect of them is also important to demonstrate. Therefore bibliotherapy or the use of literature to guide and teach students can be very effective when characters are realistically depicted.

Harper and Brand (2010) state that teachers are “urged to select a variety of genres and cultures for read-alouds rather than using a single book to represent a particular culture,” because it allows students to see a realistic representation of the world rather than a bias one. While this quote specifically mentions culture, this also directly applies to exposure to characters living with disability.

While realistic fiction supports the concept of realistic representation of characters living with disability, both within our focus group discussions and our read
aloud data, we found that students were drawn to other genres at least as much, if not more than realistic fiction. For example, when we read the realistic fiction book *Waiting for No One* to the level four class, immediately following we asked for their responses and opinions of this book. Here are some of their written replies to our question:

- “The book sounds a little interesting but I don't know if I would choose it to read myself. I’m more into science fiction historical fiction and fantasy...”
- “The book sounds good altogether... I just tend to read science fiction the most.”
- “The book sounded good but I don’t think I would read it because I like more mystery and action and adventure books not so much life stories.”

Evidently these particular students, who were not alone in the class with regards to their opinions of the book, were disinterested in the book because it was not their favorite genre. They preferred to read books within other genres that enticed them to continue reading.

More evidence about genre preferences outside of realistic fiction within the student population at FGCS comes from the level two focus group discussion. We asked the students their favorite author or series of books and the majority of their responses were outside the genre of realistic fiction. Here is a list of their responses:

- Magic tree house
- Mystery/adventure of edward
- Full metal alchemist
- Percy Jackson, inkheart
- Rick and Cornelia folk
- Catwings and unicorns
- Pokemon series, Diary of a wimpy kid
- Bone, diary of a wimpy kid, big nate

The genres of these books are: fantasy (Magic Tree House, Catwings and Unicorns), Mystery and Adventure are stated, Science Fiction (Percy Jackson), Graphic novels (Pokemon, Bone, Big Nate, and Fullmetal Alchemist), and only one realistic fiction book is mentioned (Diary of a wimpy kid). This particular realistic fiction book contains many elements of a graphic novel. Students pick these genres of books for pleasure, therefore if children's books about disabilities existed in these genres children might be more enticed to read them.

Referring back to our literature reviews however, we would like to point out that if books about disabilities were written in different genres than realistic fiction, primary characters would need to be portrayed with a disability as accurately as possible. Portraying a character as heroic or overcoming of their disability takes away from the acceptance and understanding of disabilities.

Taking this into deeper consideration, we think that what is important to keep realistic is the experience of the character living with a disability, in the sense that the symptoms, challenges, and ability to compensate are realistic. Having a realistic setting, context, or even a traditional novel format seems less important. In fact, having alternative texts that are science fiction, action/adventure, or graphic novels might entice readers to choose these texts when they might not have based on their own genre preferences.
Two important questions arise from this. How do we find existing texts that depict characters living with disability in genres other than realistic fiction? And, would the desired outcomes be reached with less, equal, or greater efficacy using science fiction, action/adventure, or graphic novels as they are with realistic fiction?

**Synthesis Statement Three: Social understanding and acceptance of disability**

A primary goal of providing texts about disabilities is to help students better relate with other people in society who are experiencing life differently than they do, specifically those living with disabilities. In order to accomplish this, students need to first have an understanding of what disability is and is not. This leads to our third synthesis statement about social understanding and acceptance of disability.

From our literature reviews we gained an idea that bibliotherapy, or reading books about a certain subject in order to gain knowledge, can specifically help students gain a better understanding about disabilities when reading appropriate books. For example, Gavigan and Kurtts (2008) surmises that “examining disabilities through children’s and young adult literature provides a new perspective on understanding and acceptance of individual differences and the importance of being sensitive to those issues that are part of the lives of individuals with disabilities.” This statement is the opinion of the authors but reveals how reading children’s books containing characters with disabilities can expose children to new concepts and help encourage them to accept or at least be sensitive to the lifestyle of others different from them. The authors are not saying children will automatically befriend those with disabilities after reading a picture book concerning disabilities but they do confidently believe books can be a gateway into creating social acceptance and understanding of disabilities.
Dyches and her colleagues (2006) looked specifically into Caldecott award winning books and found that books that included “accurate depictions of characters with disabilities have potential to shape children’s socialization with those who may be unlike themselves, and such books may help children with disabilities to normalize their situation.” Not only can nondisabled readers gain a better understanding about those different from them by reading books about disabilities, but also students with disabilities can relate to characters. This may help them feel like they are not alone with regards to challenges they may face.

Wopperer (2011) also emphasized the importance of introducing these texts to students, stating, “If children and young adults are exposed to books that portray characters with disabilities, they can learn about their own feelings towards their peers with disabilities, reflect on similarities between themselves and the characters with the disability, and become aware of the everyday life of a child with a disability.” Developing compassionate understanding for others begins through exposure to differences thus taking the stigma out of what disability means to the reader.

During our small focus group sessions, we asked students, grades 1-8, to share their first thoughts about the word “disability”. We were surprised to find that out of 26 student responses, seven of them were strikingly negative. While many students answered with specific conditions, or mentioned specific people within their social circles living with a disability, a few mentioned death, criminal behavior, and drug addiction.

How students react to the word “disability”

<table>
<thead>
<tr>
<th>Not sure/ I</th>
<th>Someone can’t do</th>
<th>Death</th>
<th>Illness</th>
<th>Specific disabilities</th>
<th>Other</th>
</tr>
</thead>
</table>
Quotes from students’ response to the word disability include:

- “Somebody who can’t do this, it is very hard for them, or it hurts them.”
- “My grandma that died.”
- “My mommy, because she has a disability with her eyes, and it makes it hard to see”
- “Ways that the person who has a disability that is going to good into the world”
- “What does it mean?”
- “Dad side of the family who are drug addicts and are in jail.”
- “I think mental disabilities.”

These reactions reinforced the importance our project because many of them were negative. We know the word “disability” has a negative connotation throughout modern society but we believe that if we help students understand the lives of people with disabilities, the word will become less stigmatized. Social acceptance and understanding of disabilities may be achieved through exposure to books; therefore we want to expand children’s knowledge through bibliotherapy.

Although we believe exposure to characters living with disabilities will transform students’ perception of not only the word disability but also those people with disabilities, we believe further study should be conducted in this area to see if social acceptance and understanding of those living with disabilities can occur.

**Synthesis Statement Four: Direct identification of disability in text**
In reading our sample texts, we found that 31 of the 42 books directly identify a character's disability either in the title, on the cover, or in the text of the story. Because our study was directed elsewhere, we didn’t have ample time to address how the direct identification of disability impacts a student’s choice in books; however, in our focus groups, students often did not choose the books that displayed a disability on the cover.

The literature reviews we conducted did not address this point specifically but mentioned a notion about implicit representation of a disability within schools. The article From Spaceman to the ADDed Touch: Using Juvenile Literature to Teach about Attention Deficit Hyperactivity Disorder, written by Prater, Johnstun, and Munk explains “most of the books demonstrate what school is like for students with ADHD” the authors are stating that the book simply describes a typical day for a student with ADHD. We gleaned from this example that many books don’t specifically identify a disability for the reader but do describe other aspects from the character’s life.

During our small focus groups, we asked students' if they were interested in reading various books, and why or why not. One of the books presented was “Rolling Along: The Story of Taylor and his Wheelchair”, written by James Heelan, students' which depicts Taylor on the front cover in his wheelchair. Students did not express much interest in this book, and gave the following feedback:

- boring
- looks like disabilities
- nothing draws my attention
- looks too easy because it’s a picture book
- I don’t like realistic fiction
This synthesis statement opens to many new questions that deserve more study. Are students less likely to select books that have explicit identification of a disability on the cover? Is a story that does not directly identify the character’s disability more likely to be enjoyed by readers? Is there a difference in the rate of the desired outcomes of personal and global development from reading books that specifically identify a disability versus books with characters whose disabilities are not labeled?

Final Criteria and Book Reviews

The final culmination of our action research project was the creation of criteria and a book review list that we will share with the elementary teachers to assist them in building their own classroom libraries. As we read our sample text we agreed upon what aspects of the books we read were wanted and what were unwanted. We made these judgments off of what we learned throughout our literature reviews, our focus groups discussions of how children pick books, and our own personal opinions of the books. The criteria has expanded, condensed, and evolved throughout our project but we finally came up with a list of final compact criteria for teachers, parents, and students to consider while they are choosing books about disabilities.

Criteria for Books with Primary Characters Living with Disability

Basic Literary Quality:

- Is the setting realistic and relatable to the reader?
- Illustration quality
- Are characters well developed and relatable to the reader?
• Is the book interesting to readers?
  o enticing cover art?
  o intriguing plot?
  o a genre students want to read?

• Does the book support the values you wish to communicate to the reader (tolerance, inclusiveness, compassion, empathy)?

• How well developed are main characters?

• Will main characters engage students in the reading?

Characters living with disabilities:

• Is a main character living with a disability?

• Do the illustrations depict characters living with disabilities as passive or active in the story’s plot?

• How is the character living with a disability portrayed?
  Desired Portrayal:
  • Realistic
  • Empowered
  • Stereotypes are broken
  • Is the character described with traits outside their particular disability?

Undesirable Portrayal:

• Depressed or constantly happy

• Pathetic or piteous

• Unrealistically heroic or superhuman (overcoming all odds of their disability)

• Being “cured” of their disability
• Ignorant or unintelligent

Elements for Personal Identity Development

• Does the book encourage acceptance of and respect for differences in peers?
• Is the evolution of relationships between characters with and without disabilities positive?
• Are characters living with disability positive role models for readers also living with disability?
• Are the characters who are not disabled positive role models for readers learning about persons living with disabilities?

Other elements to consider

• Is a specific disability identified in the book, or are characters exhibiting qualities of a specific disability without it being openly stated?
  ○ Characters developed in ways that don’t necessarily identify a specific disability can make them more relatable to readers, but books with specifics can be a good tool for educating readers about the experiences of others living with distinct conditions. Keep the goal in mind when selecting a text in this manner.
• Does the book contain loaded words like “lazy”, “slow”, “stupid”, or “suffering from”?
• If there are loaded words, do the perspectives of characters using such words change over the course of the book?
  ○ Having loaded words is acceptable as long as the plot shifts to eliminate these descriptors about characters living with disability.
• Are lessons in this book explored rather than preached?

• Does the book strike a positive emotional chord?

Now we would like to explore a few specific examples from our criteria, along with accompanying books we felt demonstrated excellence in children’s literature about disability.

The first criterion pertains to if the book is interesting to the reader or not? The book So. B. It. written by Sarah Weeks is an excellent example of how a book can interest readers. During our focus group time we found that students were interested in this book because of its title, the cover picture, and the description on the back. When one of our team members read this book, she was enthralled by its plot and could not wait to find out the meaning of the title. The main character, a seven year old girl, is taken care of by an agoraphobic neighbor because her mother has a severe cognitive disability. There is adventure, excitement, and comical twists throughout the book. Due to all these reasons we believe any reader would be interested in this book.

Our second criterion we wish to talk about deals with if the character living with a disability is portrayed positively? In the text Mrs. Gorski, I think I have the Wiggle Fidgets, written by Barbara Esham and illustrated by Mike Gordon we can see that David’s behavior is distracting to his class, and his teacher, Mrs. Gorski, schedules a parent-teacher meeting to discuss it. When David overhears his parents saying that he has the Wiggle Fidgets, David sets out to find solutions to the trouble he’s having in school. This book does a great job of empowering the main character as he develops tactics to accommodate his Wiggle Fidgets in the classroom.
Another very important element of our criteria asks if the book encourages acceptance of and respect for differences in peers? An excellent example of this is the book *Sixth Grade Can Really Kill You* written by Barthe DeClements. This is a story about a girl named Helen, who has a difficulty reading, and to prevent her from being held back or put in the Special Education classroom, Helen’s mother has her memorize what she will be required to read. Later, Helen is given the option to decide for herself if she wants to enter the Special Education classroom for assistance in reading. Helen is hesitant at first, but soon learns that the students in there are no different from herself and her peers, who adore Helen, see that even though she’s in Special Ed, she is still the same girl she always has been.

Supporting our first synthesis statement is the concept of whether or not characters are well developed and relatable to the reader. *First Star I See* by Jaye Andras Caffrey does an excellent job of developing the main character, Paige, who has Inattentive ADHD. Paige wants to win a writing contest so that she can meet her favorite actress, but she struggles to actually write the paper as she is often caught up in her daydreams. This is a something that many of us can relate to.

We also felt that if an emotional chord was struck within a reader then the book would be more meaningful him or her. The book *Mockingbird* by Kathryn Erksine, struck an emotional chord for one of our team members because the main character who has low spectrum Autism deals with the death of her older brother from a school shooting. While reading this book our researcher thought of her two brothers and how much they mean to her. Unfortunately, we can all be emotionally struck by the school shooting incident. Our researcher laughed, cried, and felt excited to journey through this book;
therefore we are confident that young students would feel emotionally tied to this book as well.

Connecting back to our synthesis statement two we would like to demonstrate an excellent example of a book that portrays a character with disabilities realistically. *Andy and his Yellow Frisbee* written by Mary Thompson is a picture book that discusses a typical interaction between a nondisabled student and a student with Autism. The story tells an experience a girl has with Andy and his yellow frisbee on the playground. The girl tries to interact with Andy, who is autistic, but she realizes that their relationship as friends cannot begin suddenly but that it may take time. This book accurately portrays how interactions with people with disabilities do not always work out the way we intend them to but this does not mean we should give up on making friends with all kinds of people.

Our personal identities have morphed and grown throughout this project; we all gained perspective:

**Beth:** While I supported the direction of this study from the beginning, I was deeply troubled by the existing negative response to the word disability found in our focus groups. This enforced for me how vital it is that we expose our students to diverse populations, such as those living with disability, through carefully selected literature.

**Jayme:** Throughout our research I learned about different disabilities and the daily challenges people who live with disabilities face. I also found there is a strong need for children to be exposed to and given the opportunity to read and learn about disabilities.
at a young age. We also considered becoming authors of children’s books about disabilities considering how much this research has impacted us.

Cristal: While conducting our research, I learned that there is a need for children’s books that have characters with disabilities that not only describe the characters as having said disability, but the character is seen as more than having a disability and is part of a bigger story in various genres then just realistic fiction. In addition, there is a need for our children in our society to have a better understanding of what “disability” means.

**Project Literature Base**


Linter, T. Using “Exceptional” Children’s Literature to Promote Character Education in Elementary Social Studies Classrooms. The Social Studies 102:5, 200-203.


