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Disabilities in Middle-Grade Literature

A Senior Honors Thesis

Submitted in Partial Fulfillment of the Requirements
for Graduation in the Honors College

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students a model example of an Honors senior thesis project.*

The term “disability” has had many connotations, specific to different times throughout our history. Not too long ago people were scared of the word and often treated people with disabilities as problems that needed a cure (Brantlinger 3). This stereotype was both reflected and perpetuated in our school systems, our news reports, our educational theories, and our literature. Since then, our society has made great strides toward acceptance of diversity and those who have disabilities by enacting laws for inclusive education, as well as including characters with disabilities in T.V. shows and movies, and writing novels which include a character with a disability. While this progress makes many people happy, it is not enough. Those with disabilities are not accurately nor fairly represented in our society, specifically in our literature and media.

It is clear that the media is a powerful force that helps drive the beliefs of our communities and society as a whole. It has the power to be a great help to those in need of reaching others, or detrimental to the reputation of any person. While we have seen an increase in the representation of people with disabilities in the media, the way in which they are portrayed is often inaccurate, and therefore detrimental to the way most people view others with disabilities.

A representative from the *Chicago Lighthouse*, a non-profit organization for people with disabilities, references two different portrayals in the media which perpetuate the stereotypes of those with disabilities. These portrayals include “victim/ helplessness” and “inspirational/heroic” in which the characters which have disabilities look as if they are in desperate need of charity, or in which the disability is the focus and the character overcomes the disability to be the hero, respectively (“Media and People”). Unfortunately these are not the only portrayals that are getting attention. According to Paul Hunt, there are 10 commonly recurring stereotypes of people

with disabilities that show up in our media and literature. Among them are the two previously mentioned as well as “evil”, “atmosphere [background characters]”, and “laughable” (Hunt 2). These are devastating titles to have to associate oneself with.

These stereotypes and assumptions about those who have disabilities come from the long-standing fallacies of earlier times (Hunt 2). So though we have been progressive in integrating those with disabilities into society—starting campaigns for the advocacy of using person first language and also integrating new educational laws—we have not reflected this kind of inclusive progress in our literature, or our television shows and movies. Instead, we continue to showcase or make a spectacle of the disability rather than the person. For those with disabilities, it is not so much about the amount of representation they are getting in the media, but the accuracy of that representation. There needs to be more quality than quantity (Brown 1). If the media was able to accomplish representing characters of television shows and movies accurately, the world would be exposed to realistic experiences of those with disabilities (Brown 3). The same can be applied to the complexity and identity of characters in fictional literature. These realistic experiences would help extinguish the inaccurate stereotypes that live on in today’s media and affect the perceptions about those living with a disability.

From an education perspective, it is important that we begin to enact change within our schools. Incorporating and granting exposure to disabilities is an easy way to enlighten the next generation of what is happening with their peers and many others in society. This could be done in a number of different ways, however books would be a great way to empower those with disabilities and extinguish the stereotypes that are occurring in our present media.

The best part about reading a book is connecting with the characters and making the adventure they are having your own. The goal for most teachers is to find that one book with which a student connects and actually enjoys reading. The printed text is one of our greatest tools for learning, communication of ideas, and emotional understanding. As thus, it is undoubtedly important that middle school students learn to read and digest texts. As education has progressed through the decade it has come to be known that students learn and retain more when they are able to make personal connections to the content (Goodman 24). As a result we are beginning to see more choice on the part of the students, especially in literature. Students are able to choose books from the shelves on which to base their assignments, and undoubtedly they will choose books which interest them.

When choosing a book we often look for characters that remind us of ourselves. That is not to say that we can't enjoy a book that has characters that seem nothing like us. However, we always find some way to connect with the way the character is struggling or feeling.

Unfortunately students that have disabilities do not always have the opportunity to find a book with a character that has similar struggles to themselves. Having a disability substantially affects a person's life activities in ways that are untouched by living without a disability. These struggles, as well as triumphs are important to emphasize in literature. Students living with a disability have the right to find books in which the main character's life resembles their own.

Author and scholar Beverly Brenna interviewed a fellow children's author, Jean Little, who specializes in writing books which have a protagonist who has a disability. Jean Little is a former special education teacher who also acknowledged the need for more literature for young readers who are living with disabilities. She defines the low number of books currently available as a matter of social injustice (Brenna 3). Similar to the fighting that was done to overcome

injustice on the basis of race and gender, students with disabilities need advocates who are willing to make the change. Of the 33 books that received a Newberry Award from 2010 to present, only five of these books had a character with a disability anywhere in the book (American Library Association). Of the five books mentioned, three of them have protagonists who have a disability. These numbers indicate a gap in literature for young readers.

It is important to note that having more literature whose main character has a disability, would not only benefit those students who have disabilities, but would also serve as a way to expose others to life with a disability. It has the power to increase understanding among students and develop mutually respectful relationships.

I would be remiss if I did not acknowledge the many authors who have featured characters who have a disability, especially in the last decade. In fact, an article encouraging teachers to diversify their classroom libraries has a long list of books in which there is a character who is disabled. However, many of the books are outdated and reflect an old society and focus on disability (Kaiser 5). For instance, Evan Jacob's novel *Screaming Quietly* is about a boy who has autism. His brother tries to keep him and his condition a secret throughout the novel, and it depicts the boy as being a nuisance to the social life of his family (Jacob). It shows the terrors that he can have and describes his special needs at school, but it never gets around to the actual boy and how he functions with his disability. This novel was written in 2013, but reflects values which are dated and inaccurate to others who have autism. Therefore, we need to be critical of the literature already made available as it has the potential to produce negative results, such as the perpetuation of false stereotypes. Kaiser's article also notes that publishing houses for books that have a character with a disability are often hidden from the main stream

and go out of print rather quickly (2). In short, rarely will you see any of these books in the display case at a Barnes and Noble.

In addition to being critical about how the disability is presented in the book, we have to be aware of the focus of the novel as well. Brenna discusses that many books let the disability be the single trait that defines the character. It is different than a trait such as the race, gender, or age of the character (Brenna 4). The disability becomes the focus, the driving element of the novel. This kind of writing does not let the reader connect with the character, but rather with the disability. Therefore, readers without a disability might feel pity for the character rather than a personal connection. This takes the emphasis off of accepting diversity, producing the opposite of the desired effect. This is what can be called an “issues book,” or a “problem novel” (Brenna 8). Instead characters need to be created like real people with a multiplicity of traits so that a variety of readers can make connections to the character(s).

For both educational and societal purposes, it is important that more authors write novels for young readers that have realistic portrayals of people with disabilities. There is a very clear gap in children’s literature regarding this topic. As a result, I have decided to construct a novel for both educational and recreational use that I hope will begin to mend the gap and encourage diversity. The title of my work is *The Altura*. *Altura* translates to “tall one”, and it is the name of the roller coaster where the climax of the novel will take place. The main character of my novel is a 12 year-old seventh grade boy who has bipolar disorder. He will grapple with the mood swings, mania, and depression, in addition to moving schools, making new friends, and experiencing middle school puberty. In order to make my novel different from the pre-existing literature, I conducted my own analysis of the current texts.

I have read many novels with a protagonist who has a disability, both from the last few years and reaching back into the previous decade. I have acquired knowledge from those books, learning from the good and the bad, which will be used in crafting my own. The literature that I showcase in the article were books which truly had an impact on the writing of my novel. I have included novels from 1986, 2003, and 2015. It is clear from their content, how much change our society has seen over time. They represent amputation (physical disability), Asperger's Syndrome, and deafness. The authors of these novels were truly inspirational. My analysis of them follow in chronological order:

Izzy, Willy Nilly By: Cynthia Voigt

This novel was first published in 1986 and clearly reflects society at the time of its publication. Voigt brings a different perspective to disabilities in literature. In this novel, the main character, Izzy, does not begin life with a disability. In fact she has already lived a good portion of her life without being labeled as disabled. She is a sophomore in high school when she is a terrible car accident with a drunk driver. Izzy is badly injured and one of her legs has to be amputated.

Though this book is clearly focused on the struggle of recovery and learning to go through life with a disability, it also shares focus with raising awareness to drunk drivers and high school parties. A large portion of the novel is about Izzy regretting her decision to attend the party and wishing that she could go back and change her mind. The mood of most of the novel is devastating.

Of the three notable books during my research, this one was the least progressive in presenting the disability, most likely due to its early publication date. The awareness was more

about how having a disability can make a person feel, rather than how it affects their life experiences and actions. It is also important to note that because Izzy does not start life with a disability, there is a longer adjustment period for her. She has not yet come to terms with having the disability or making it part of who she is. Voigt voices this when Izzy tells the readers, “It used to be, before, that when I woke up in the morning everything was fresh, and there were new chances every morning” (Voigt 56). It shows the devastation that labels can bring to those who have disabilities. Izzy is relatively optimistic about the injury until she is made to feel invisible by her friends when they visit her in the hospital as they talk over her bed as if she isn’t there (Voigt 45). Further Izzy is shown to spiral into depression when she thinks about who she has become calling herself “crippled, amputated, handicapped, and deformed” (Voigt 50). In this way for most of the novel the disability is what defines the character. In this sense the novel is left unresolved.

The most important element of this novel was the awareness to the thoughts, feelings, and doubts that those living with a disability may feel often but not outwardly show. It helped the reader to become reflective on their treatment of those with disabilities. However, it still places the reader apart from those with disabilities instead of allowing them to make a personal connection with the character. Overall, it evokes the feeling of pity.

The Curious Incident of the Dog in the Nighttime By: *Mark Haddon* (2003)

The writing of this novel was unlike anything else I have ever read. The voice of the character tells a realistic story of life with autism, and is a tremendous breakthrough for its release in 2003. This novel is about a young boy, Christopher, who has Asperger’s Syndrome,

and therefore faces challenges each day that many people take for granted. It is a humorous novel in which this young boy sets out to find the person who murdered a neighborhood dog. Along the way he discovers a lot about himself, his past, and his abilities to overcome what he thought was impossible. What I found to be the most inspiring thing about this novel was the complexity of the main character. If we replaced the main character by someone without a disability, the plot could stand on its own, but the lessons and the triumphs experienced by the character would not be as profound (Brown 2).

This is how we can be sure that this is not simply an “issues book” (Brenna 10). I admire the style in which this book was written. The label of the disability is never mentioned or acknowledged by any character in the book. This was also an effective tool in separating the disability from the identity of the character. I believe it is necessary that the book be told in first person, as it shows how Christopher’s thoughts and actions are affected by his disability, but also shows readers that many of his processes are the same as someone without a disability. For instance, Christopher goes to the candy shop after school to spend the money he earns. This is a typical middle-school activity, it is simply affected by his disability because he will only visit one candy shop and he won’t buy yellow candy because he detests the color. Still Haddon is able to keep the focus on what the character is doing (going to the candy store) rather than on the disability. In essence, the book separates the disability from the character and reveals a complex person.

One of my favorite parts of the book is when Christopher is talking about the other kids he goes to school with. The main character attends a school for students with “special needs.” He says quite plainly that “All the other children at my school are stupid” (Haddon 43). This not only shows the honesty and innocence with which the main character thinks, but also that

Christopher does not acknowledge that he would also be considered a child of “special needs,” since he attends the school. It is such a profound line because it reveals that the disability is part of who Christopher is. His disability does not define him, it is merely part of his identity. He does not accept or internalize the stereotype of being “special needs” simply because he has the label of Asperger’s Syndrome.

This sense of identity and separation of disability from the person is what I am looking to emulate in my own book. I will also stylistically be borrowing some ideas from the author. Because my book is on a mental illness, I think it is necessary to allow the character to lead the plot by his emotions and actions. Therefore, I will be putting my book in first person. The main character is portrayed to be writing the novel as the reader is reading it. For my novel, this style choice also makes sense. The protagonist in my novel will be writing the novel at the suggestion of his therapist to write his thoughts and feelings as a form of reflections and behavior therapy, a common coping technique for children and young adults who have bipolar disorder.

Lastly, I think that it is important to mention that Haddon has a realistic ending to the novel. It is not a happily ever after ending where all the conflict are completely made right. In fact, it is a very broken resolution, but it is entirely realistic. He stays clear of the stigma that the disability needs to be cured or that the protagonist needs to come out the hero. Instead, the conflict is resolved as an ongoing healing process at the end of the novel. It is the type of ending that makes the reader wonder how the characters would be managing today.

El Deafo By: Cece Bell (2015)

This novel was the recipient of the 2015 Newberry Honor award (American Library Association). It is a graphic novel about a young girl who loses her hearing due to meningitis.

The graphics in the novel were very telling to the thoughts of the main character, Cece. They were effective because they depicted how things often sound garbled to Cece. This made it easier for the reader to empathize with how Cece was feeling throughout the novel. Similarly, the novel raised awareness for the different elements of being deaf.

In chapter three, Cece learns from her teacher how to read lips and what to look for. As a result Cece tells the reader some of the things that make it hard for her to read lips like exaggerated mouth movements, shouting, the dark, and group discussions (Bell 32). She also mentions how she needs to look for visual, context, and gestural cues in order to distinguish words which may look the same on lips, such as “pear” and “bear” (Bell 30). Bell also has her character emphasize how labels hurt her feelings more than anything. There is a rather large conflict in the book when one of Cece’s friends keeps referring to her as the “deaf friend” and “poor thing” (Bell 101). The labels ruin the friendship that they have. Cece is showing that she does not want her disability to define who she is, but wants it just to be accepted as part of herself. In this way, Cece’s friend tries to make her being deaf an issue rather than focus on who Cece really is as a person.

Bell also raises awareness for one of the largest paradoxes of living with a disability: Enjoying when someone is being kind and including, but always wondering whether that’s because they want to be with the person or whether it’s because others feel pitiful about your condition. Cece expresses this when the neighborhood kids ask her to participate in their kickball game, “But I think they’ve been told to be nice to the deaf kid” (Bell 118). This is meant to provoke readers thinking about their interactions with those who have a disability.

While I think that the interactions and exposure of experiences are authentic throughout the novel, this book is definitely focused on the disability, rather than the character. All the

events of the novel surround the disability. This novel is based on the true story of Cece Bell's childhood, therefore the feelings and events are authentic. It stands to reason that the book focuses so much on the disability because of the way that it impacted so many life events. I admire the way that Bell is able to promote awareness for interactions between those without disabilities and those who may have a hearing impairment, but I dislike the way that the main character has to become a superhero, El Deafo, to make friends and find her identity within the childhood community. The stereotype mentioned earlier about superhero's needing to overcome their disability to live a normal life is touched upon in this novel. Instead of encouraging others to accept the identity of a person who is deaf, many parts of the novel evoke the feeling of pity. It is only after she identifies with being a super hero that she begins to live a life of friends and integration into the classroom.

The goal for my novel is to raise the amount of awareness that Bell is able to bring to the deaf community and focus that awareness on bipolar disorder. However, I do not want the disability to be mentioned and risk losing my readers to emotions of pity for the character. I feel that those who are not deaf would have a hard time connecting with Cece in the novel because it is so focused on her being deaf rather than realistic experiences of a young girl. I want the experiences in my novel to be authentic and realistic for most readers. Those same experiences, and actions of the character are then highlighted by the disability. Because Bipolar disorder is a mental illness, it may be indistinguishable to many readers if not mentioned by name in the novel. While I wish to keep the name for his disability out of the text, I will use terms such as mania and depression to distinguish that the character does in fact have bipolar disorder.

While I did not do a full literature analysis on the novel *Wonder*, published in 2012 by R.J. Palacio, I felt that it was necessary to touch on it because of its highly acclaimed fame at this time, for both the novel itself and the film adaptation. It is different from the other books on disability because it does not focus on just one part of the story, but instead details the life of each person who is affected by the young character's disability. While I think that this is a powerful way to connect to a variety of readers across all age groups, it is not the goal of my novel. I am creating my novel in order to reach a very specific age group (12-16 year olds) and raise awareness for a specific mental illness. While I think that many people will be able to connect with my book, it will have its most powerful impact on my targeted readers. It is my hope that the readers of my novel will find themselves within the character with the disability, and relate to the protagonist rather than placing their position as one of the other characters, which is what Palacio's book may have the tendency to produce. This is why the book did not make my critical source list for the construction of my own novel.

As I scoured the library looking for books labeled as disability awareness, and exhausting search engines, these were the notable titles that contributed most to my piece. I noticed as I was doing this search that there were very few books about characters whose disability was a mental illness. I found a few, but in most of them the character was not the protagonist and therefore also not the child in the book. I was looking for books which were considered children's or young adult literature since I believe this is where the gap is occurring, and also where the most societal change is likely to take place. *The Curious Incident of the Dog in the Nighttime*, whose main character is assumed to have Asperger's syndrome was the closest thing to a book on mental illness.

Most people with mental illness are often reluctant to share how they feel (NIHM). This would make it very difficult to accurately portray a person with this type of disability as a character in a book. While struggles of those in a wheel chair might be easy to assume, those with mental illness deal with much more beneath the surface. However, I considered the many struggles and emotions felt by a middle school student who may be living with a mental illness. I find that the gap in literature is too great to ignore. I took a look at the article earlier mentioned for use of teachers diversifying their library and noted that as of 2009 there were only about five novels in existence that center around a character with a mental disability (Kaiser 4). It could be argued that mental illness is separate from a disability and therefore, does not belong in this research. However, a disability is anything that significantly affects a person's life on a day to day basis. Mental illnesses can most certainly fall into this definition and must be considered in literature for this age group. Therefore, I began my research on pediatric bipolar disorder in order to develop my thirteen-year-old, seventh grade protagonist in my novel, *The Altura*.

In order to make my character as realistic as possible, not only did I spend my time reading articles about the disorder, but I also spent countless hours watching documentaries and interviews of both children and adults with bipolar disorder. I want my experiences, thoughts and feelings to be authentic so that students dealing with bipolar disorder on a daily basis can connect with my character. On the other hand, my protagonist is simply a middle school child dealing with normal middle school things, such as a big move to a new town, high emotions driven by puberty, and the popularity struggle. My hope is that readers from many different points of view are able to find a little piece of themselves in my novel.

As previously mentioned, the protagonist of my novel, Samson Weisinger, will be writing this novel from a first person perspective. It is the alternative to an emotional journal that

his therapist has encouraged him to start writing. At the conclusion of this article, I have included the first chapter to the prospective novel. I chose to use the first chapter as a way of introducing my protagonist and my mother. It reveals the way that he thinks and acts. It gives a good sense of how he interprets living with bipolar disorder. I wanted the readers to be captured by his odd sense of emotion and storytelling. I wanted it to be clear from the first chapter that my character is living with bipolar disorder, but I did not want to mention the disability. I believe this will be the easiest way to separate the disability from the character and evoke a sense of connectedness instead of awareness among my readers. Further the first chapter sets up both the past as well as the present conflict, and beginning of the plot.

As I continue to write my novel, my characters will become increasingly more complex. I chose to start the novel with my protagonist in a manic state, since it is the point where most children with pediatric bipolar disorder start their day (“Bipolar Disorder in Children”). Samson is clearly excited to move in with his grandmother whom he mentions is the only person he loves more than himself. He will be even more excited when he discovers his grandmother’s is right down the road from a new amusement park with one of the largest roller coasters in the world, The Altura, which is where the title of the book comes from.

I decided to include this roller coaster because during periods of mania, those with bipolar disorder like to take risks and get their adrenaline rushing. Naturally, an amusement park is a perfect fit for such activities. It is also an area that is highly relatable to my target group of readers. This roller coaster also becomes important because it will be the place that the main character takes a very big risk that could cost him his life at the climax of the novel, which is another component of bipolar disorder.

One of the important elements of my novel is to distinguish for readers the difference between the depressive state of someone with bipolar disorder and the feeling of sadness. Samson's grandmother is going to die at some point in the novel. As it would any middle school child, this will make Samson very sad. This emotion, however is going to look very different from Samson's depressive state which is brought on by stress from missing so much school work in preparation for the funeral. This way, there is a clear distinction of sadness and depression and the triggers for each.

Children who have bipolar disorder go through cycles of mania and depression much more often than adults with bipolar disorder. In fact some kids go through a cycle of both in the span of two days ("Bipolar Disorder in Children"). The changes in mood can be effected and triggered by many things, the most popular one being any kind of stress placed on the child (Life Issues). It is also been proven in most cases that depression takes up a lot more time of the child's life than the mania stages (Stebbins, 117). The knowledge of these aspects of bipolar disorder in children contribute to the events, actions, and feelings portrayed in the novel.

The other struggle that will occur throughout the novel is making and keeping friends. I thought this was an authentic struggle for all middle school students, it is only heightened by Samson's disability. When Samson first moves to his new school, he is in a state of mania and instantly popular for his funny, risky behaviors. However, after he isolates himself from his friends and says some things that he doesn't mean, his popularity is extinguished. His friends notice he is not the same, and don't want to be around him anymore. The rotation of cliques and friend groups is another authentic experience of middle school students.

Lastly, an important character named Otto is introduced. He is the school nerd of sorts, who doesn't have many friends. However, he really understand Samson in a way no other friend

has. Although Samson is resistant to the friendship at first, because of what it will do to his reputation, he gradually becomes closer with Otto. It is Otto's supportive relationship that helps Samson escape suicide. It shows the power of support from peers to those who have bipolar disorder, while teaching an important life lesson of friendship and appearances to all readers. It is revealed late in the book that Otto's mother also has bipolar disorder, again without mentioning the name of the disease, which is why Otto understands Samson so well. This goes to show that you never know who might have similar experiences.

Otto serves as Samson's emotional support throughout the novel. While emotional support is an obvious choice for any struggling teen, it is especially important for those with bipolar disorder. This, along with the therapy that Samson receives, and is the purpose for his writing of the story, is representative of treatment plans recommended for people with bipolar disorder (NIHM). Lastly, it should be noted that it is often difficult for bipolar disorder to be diagnosed right away, which delays medication usage and other medical treatment plans (Life Issues). Therefore, Samson will use these alternative treatment plans throughout the novel, which turn out to be highly effective in the end.

The ending of the novel will be realistic but happy, while playing on the humor of the creation of an "epic middle school novel" that is set up in the first chapter. It is my hope that my novel can touch many middle school readers. I want teachers to be able to use it as a way to add diversity to their classrooms, and I want students to be able to make connections to the text in authentic ways.

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