

REPRESENTATION & CONSTRUCTION OF DISABILITY IN YOUNG ADULT

LITERATURE

by

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Abstract

Young adult literature shows how different people groups interact with each other within a culture. Many young readers are exposed to injustice and prejudice for the first time in the books they read. Because of this, it is important for educators to incorporate inclusive literature in their classroom. They should be aware of the diversity of their student population and should choose books that accurately depict the lives of those in minoritized groups. One aspect of diversity that is commonly overlooked is ability and disability. The goal of this study is to find out how disabilities are portrayed in young adult literature, what challenges characters with disabilities face, and how they overcome these challenges. This two-semester project works toward a greater understanding of ability and disability in young adult literature through a critical content analysis of two young adult novels using a Critical Disability Theory framework. The focus of this content analysis is on how the main character shows agency and independence, how they advocate for others, how they view themselves and their disability, and how other characters view the main character and their disability.

Keywords: disabilities, young adult literature, critical content analysis, characters with disabilities, representation of disabilities, Critical Disability Theory, CDT, critical theory

Introduction

Literature is a powerful tool in society because it gives people the ability to momentarily step into the lives of others and experience a world different from their own. Not only do we get a glimpse of another life, but we also can apply literature to our own lives. This is the concept of mirrors and windows—using books as mirrors, to see yourself, and as windows, to see others. Unfortunately, characters with disabilities are under-represented in literature, and because of this, children with disabilities have a hard time using books as mirrors to visualize their own lives as an important part of society. Likewise, students who are able-bodied are not given the opportunity to see into the lives of those who have disabilities. The under-representation of characters with disabilities is a disservice to all students, both able-bodied and disabled. It is the responsibility of educators to find pieces of literature that represent all aspects of ability to include in their classroom. The goal of this research project is to find young adult literature that depicts the life of someone who is disabled, whether it be a physical or developmental disability, and analyze how their disability is portrayed. The research questions for this study are the following: How are disabilities portrayed in young adult literature? What challenges do characters with disabilities face in young adult literature? How do the characters overcome these challenges?

Review of Literature

Books as Mirrors and Windows

In the article “Mirrors, Windows, and Sliding Glass Doors,” Rudine Sims Bishop emphasizes the point that children use books to see into the lives of others or to reflect on their own lives. Unfortunately, minoritized groups, whether it be race, ethnicity, religion, or disability, are underrepresented in literature. “When children cannot find themselves reflected in the books

they read, or when the images they see are distorted, negative, or laughable, they learn a powerful lesson about how they are devalued in the society of which they are a part” (Bishop, 2015, p. 1). In the same way, children from majority groups are unable to see the world from other perspectives and understand a world outside of their own (Bishop, 2015). “Teachers play a crucial role in selecting children’s literature for their classroom libraries that not only represents their students’ identities but also reaches to encompass identities beyond those embodied in a classroom space” (Kleekamp, 2018, p.1). Both mirror books and window books are equally important to have in the classroom because students come from many different backgrounds and can understand themselves and each other more through diverse literature.

Analyzing Representation

More and more literary scholars are beginning to realize the importance of the publication of books that are inclusive to all groups. As research continues to be done in this field, there is now more “critical awareness of how disability experiences have either been misrepresented in or absent from children’s literature in the past” (Kleekamp, 2018, p. 2). Misrepresentation is not an issue that should be overlooked because it blurs the vision of readers who are using these books as mirrors or windows. Just because a book includes a character from a minoritized group does not mean that the book portrays them in a positive way. “High-quality inclusive children’s literature features characters with agency and multidimensional lives who happen to carry disability labels” (Kleekamp, 2018, p.1). The purpose of these stories is not to shy away from the obstacles that people with disabilities face; it is to show how the lives of these people are not defined by their disability (Kleekamp, 2018).

Theoretical Framework

Critical disability theory (CDT) was introduced into the field of disability studies by Tonette Rocco in 2005 and was modelled after critical race theory. The first principle of CDT is that disabled people have a unique voice and complex experience (Rocco, 2005). This point emphasizes that people with disabilities should not be labelled by their condition because they are so much more than their disability. The next principle is that disability should be viewed as part of a continuum of human variation (Rocco, 2005). The question of being disabled does not have a yes or no answer; it is a spectrum based on ability. Another principle of CDT is that disability is socially constructed (Rocco, 2005). This means that the concept of disability only exists because of a society's attitude toward people who are different and are not considered normal. From these social norms comes ableism. CDT emphasizes the fact that ableism is invisible (Rocco, 2005). Ableism is more than just prejudice; it is prejudice by able-bodied and able-minded people toward people with disabilities (Myers & Bernasi, 2008). The final principle of CDT is that disabled people have a right to self-determination (Rocco, 2005). Self-determination is the right for people with disabilities to be independent and make their own decisions about their life. The purpose of using the critical disability theory for this critical content analysis is to have lens through which educators can view works of literature and evaluate their portrayal of characters with disabilities.

Methods

For this study, we chose to use the method of a critical content analysis to analyze the representation of disabilities in young adult literature. "Critical content analysis involves bringing a critical lens to an analysis of a text or group of texts in an effort to explore the possible underlying messages within those texts, particularly as related to issues of power"

(Short, 2016, p. 6). A critical content analysis differs from a regular content analysis in that a critical content analysis prioritizes a critical lens as a frame for the study, not just as part of interpreting findings or citing scholarship in a literature review (Short, 2016, p. 5). For this study, the critical disability theory will act as the critical lens.

One of the first steps in conducting a critical content analysis is selecting books to analyze. Using a smaller number of texts is more useful for an in-depth analysis (Short, 2016), so I narrowed my search to two novels suitable for high-school readers. I wanted the books to be recently published and also award-winning so that they were reputable within the literacy studies community. Based on all of this criterion, I selected *The Running Dream* by Wendelin Van Draanen and *Marcelo in the Real World* by Francisco X. Stork. Both of these books are winners of the Schneider Family Book Award, which is an award specific to literature that portrays the experience of disabled characters. They were both published around ten years ago, and they are categorized as suitable for middle and high school readers on Scholastic.

Table 1
Summary of novels used for critical content analysis

Title	Author	Year of Publication	Protagonist	Disability	Plot Summary
<i>The Running Dream</i>	Wendelin Van Draanen	2012	Jessica Carlisle	Physical (amputee)	Jessica Carlisle is an amazing runner, but a bus accident after a track meet causes her to lose her leg. Jessica has to learn to walk and run again on a prosthetic leg. Along the way, she gets closer to Rosa, a girl in her math class who has cerebral palsy. This new friendship helps Jessica see how blessed she is to be able to walk and run again, and she wants Rosa to see

					what it feels like to cross a finish line.
<i>Marcelo in the Real World</i>	Francisco X. Stork	2009	Marcelo Sandoval	Developmental (similar to Asperger's Syndrome)	Marcelo sees the world differently than other people, but his dad refuses to believe that his son is different. Arturo forces his son to spend the summer working in the mailroom at his law firm. Marcelo learns about the real world from his coworkers, Jasmine and Wendell. He is exposed to the injustice of the justice system and fights to make it right.

After selecting books, the next step was to begin reading each book twice—once as a quick read for content and the second time as a deeper analysis (Short, 2016). It is important for researchers to get an overall sense of the book, its content, and its theme before diving into the analysis. “Much of critical content analysis involves an efferent stance, so we first want to ‘live within’ the experience of that text as a reader—to experience the whole before we start analyzing the parts. Our focus initially is not a critical reading, but a personal response” (Short, 2016, p. 8). The second reading involved annotating the text in relation to CDT and the research questions, which will be important for the final analysis. I chose to use a color-coded system; each color represented one of the four major themes of the novels. The four questions I chose to ask during coding are the following: how the main character shows agency and independence, how the main character advocates and cares for others, how the main character views themselves and their disability, and how other characters view the main character and their disability. Each of these four themes were underlined in the books, flagged with sticky notes on the pages, and were entered into a spreadsheet to organize the data.

Findings

Introduction

The goal of this critical content analysis is to find out how disabilities are portrayed in young adult literature, what challenges characters with disabilities face, and how they overcome these challenges. In order to do that, I examined both of the selected novels with four common themes—how the main character shows agency and independence, how the main character advocates and cares for others, how the main character views themselves and their disability, and how other characters view the main character and their disability. The following sub-sections reveal my findings about each theme within both novels.

How the Main Character Shows Agency and Independence

The Running Dream by Wendelin Van Draanen

When a character has agency, it means that they have the freedom to make their own choices and take control over their situation. In Jessica Carlisle's life, she takes control over her recovery when she loses her leg in a bus accident. Jessica is resistant to receiving help for basic tasks, such as getting into her house, walking upstairs, and going to the restroom. She is used to doing all of these things on her own, but now that her leg has been amputated, she can no longer do everything she used to be able to do. The first example of Jessica's agency is when she walks from her hospital bed to the bathroom by herself. She says to her mother, "I'm sick of bedpans. 'Hand me the crutches.' I growl at my mother. She's unsure. I haven't done so well with the physical therapist. 'Hand them to me!' She does, and I swing my legs over the edge of the bed. Carefully. Slowly. It takes a little doing, but I stand, supported by the crutches. I'm already panting" (Draanen, 2012, p. 14). This situation is an example of agency because Jessica is determined to find a way to do everyday tasks without help from anyone else. Even though

Jessica still needs assistance from her mom and the nurses, she wants to do things on her own like she could before the accident. Jessica shows agency again when she gets home from the hospital and decides to take the stairs instead of using the ramp that can accommodate her wheelchair. “‘I can do steps you know. I don’t need a ramp.’ I don’t mean to, but I sound angry... She’s worried. She wants me to use the wheelchair. I ignore her concerns as I hobble forward” (Draanen, 2012, p. 48). Jessica does not want any special treatment or accommodations at home. She wants to go into her house by using the stairs like she normally would.

When Jessica is finally able to go back to school, her best friend Fiona volunteers to wheel her to all of her classes. At first, Jessica is grateful for the help, since she does not have the arm strength to roll herself across campus, but once she encounters her first ramp at school, she realizes how much she misses being able to fling herself over the railings and into the classroom. She thinks to herself “I can no longer catapult. Or swing. Or slide. I can only roll. Something about this makes me grab the wheels and push. ‘Careful,’ Fiona says. ‘Don’t get your fingers caught.’ ‘Just let me do it,’ I tell her” (Draanen, 2012, p. 96). Jessica doesn’t want to rely on someone else to help her move around the school. She wants to be able to move on her own, so she takes control of steering the wheelchair up the ramp to her classroom.

Later in the book, Jessica decides to train for a ten-mile race, which she will not only run on her new prosthetic leg built specifically for running, but will also push her friend Rosa in her wheelchair. She begins training for the race on her own by putting bags of potting soil onto the wheelchair to add weight. She sets small goals for herself to keep herself going. “*A little farther, I tell myself. Then you can turn around. I coax myself with milestones: Just to the end of the block. Just to the stop sign. Just to the next bend. My arms are tired of holding the handles. I want to let go. I want to stop. But I press on*” (Draanen, 2012, p. 285). Jessica pushes herself to

get stronger so that she can eventually push Rosa in a race. She challenges herself and never gives up, even when she wants to. When she tells her track coach Kyro about her plan, he is in shock and questions her. She responds by saying “Look, I’m going to do it. I’m asking you to help me” (Draanen, 2012, p. 301). Jessica is determined to get Rosa across the finish line, no matter how hard it will be for her. Everyone is telling her that she can give up if she needs to, but she won’t. She’s going to do it, no matter what anyone tells her. Once Jessica puts her mind to something, there is no stopping her.

Marcelo in the Real World by *Francisco X. Stork*

As previously stated, agency is when a character takes control of a situation and makes decisions for themselves. Marcelo shows agency by standing up to his father and other people in the law firm. Arturo, Marcelo’s father, does not think that Marcelo is mature enough to make decisions for himself. He wants his son to go to a regular high school instead of Paterson, a school for kids with special-needs. Marcelo has attended Paterson for his whole life, and he does not want to switch schools. He tells his mother, “I’m seventeen. It should be Marcelo’s decision. I should be allowed to finish the last year of high school at Paterson, where I’ve always been” (Stork, 2009, p. 8). Marcelo is normally not one to speak his mind, but here, he stands up for himself and says what he wants. Marcelo and Arturo make a deal—if Marcelo succeeds at working in the mail room of Arturo’s law firm for the summer, he can choose where he goes to school. Marcelo is reluctant to give up his summer job as a stable man at Paterson but decides that it will be better for him in the long run. He says “Marcelo will work at the law firm... Call [Harry] tonight. He will need to find a new stable man for the summer. Whoever it is must be told that it is only a summer job” (Stork, 2009, p. 34). Even though Marcelo does not want to

work at the law firm with his dad, he decides to do it for the summer so that he can go back to Paterson in the fall.

When Marcelo starts working at the law firm, he has to learn how to do many things, including how to interact with others. He is not comfortable talking to strangers, but in this job, he has to. When someone comes in the mail room and asks him to help bind documents, he is confused but still tries to help. He thinks to himself “I don’t know what ‘tabbed’ means and I don’t know how to bind, but I can make copies, so I say, ‘I can make the copies. I can start.’” Even though Marcelo’s colleague is rude to him and thinks he is incompetent, he still offers assistance and goes out of his comfort zone. Another coworker that is rude to Marcelo is Wendell, Arturo’s business partner’s son. Wendell is a rich college student who preys on the women at the law firm. He asks Marcelo to set him up with Jasmine, the other mail room worker. At first, Marcelo avoids giving Wendell answer, but he finally decides to stand up for himself and for his friend Jasmine. “‘No. I look into Wendell’s face when I say this and see his eyes widen with surprise. ‘Pardon?’ ‘No. I will not ask Jasmine to go’” (Stork, 2009, p. 126). Marcelo is afraid to say no to Wendell, but he does it anyway. Wendell takes his plan a step further by asking Arturo to let Marcelo work with him instead of in the mailroom with Jasmine. When Arturo asks Marcelo about this, Marcelo raises his voice at his father, which is something he does not normally do (Stork, 2009, p. 155). He is getting better at speaking his mind and standing up for himself.

Marcelo’s biggest challenge comes when he discovers a picture among a pile of files for a lawsuit. The picture of a girl with an injured face was put in the trash pile, but Marcelo feels that it could be an important part of the Vidromek case. He begins to search for information about her, without telling anyone except for Jasmine. When he gets caught with the picture, he

does not want to lie, but he also does not want to be honest about what he has found. “‘What’s that?’ I answer Juliet’s question truthfully: ‘A picture.’ Then I say something that comes as a surprise to me. ‘I found it under the desk. It belongs to Robert Steely.’ The deception works. Juliet does not ask to see it” (Stork, 2009, p. 178). It is not in Marcelo’s character to lie, but he does in order to continue his search for information about the girl in the picture. He has improved his ability to think fast and make split-second decisions.

When he has finally gathered enough information, he decides to come forward to Jerry Garcia, a competing lawyer who has been representing Ixtel, the girl in the picture. He tells Jerry, “I found a memo from the head of quality control to the president of Vidromek, telling him that the windshields were defective” (Stork, 2009, p. 281). Marcelo has thought through all of the repercussions of his action. This is Marcelo’s biggest demonstration of agency because he knows that telling Jerry Garcia about the document will affect his father and the entire company, yet he still decides to tell Jerry because he wants to do the right thing.

How the Main Character Advocates and Cares for Others

The Running Dream by Wendelin Van Draanen

When Jessica goes back to school, her math teacher Ms. Rucker makes her sit in the back of the class with Rosa, her classmate who has cerebral palsy. At first, this is hard for Jessica because she is worried that people see her as “special-needs” (Draanen, 2012, p. 106). However, after spending time with Rosa for math tutoring, Jessica and Rosa become close friends, and Jessica encourages others to befriend Rosa as well. The first time Jessica stands up for Rosa is when Ms. Rucker gives her the option to return to her normal seat. She decides to stay in the back with Rosa and compliments her on her math skills in front of the teacher and the whole class. She says, “‘Rosa’s a math genius, you know’” (Draanen, 2012, p. 176). Jessica makes this

same claim to her friends Fiona and Gavin when they ask about her new friend. “‘Who’s Rosa?’ Gavin asks. ‘She’s a freshman,’ I tell him. ‘She’s got cerebral palsy,’ Fiona whispers. ‘She’s my friend and a math genius,’ I tell them both, and give Fiona a scolding look. ‘She’s been great to me through this whole thing’” (Draanen, 2012, p. 234). When Fiona identifies Rosa by her condition, Jessica stands up for Rosa because now she sees her as more than the girl with cerebral palsy.

When Jessica told her mom about her new friend, she did not mention that Rosa has cerebral palsy. When Jessica’s mom learns about Rosa’s condition, she asks Jessica why she did not tell her about it. To explain why, Jessica recalls a note that Rosa wrote to her. “‘She asked me, *If you could change one thing what would it be?* ... When I asked her the same thing, she said’ –I turn the note—‘*That people would see me, not my condition*’” (Draanen, 2012, p. 247). Jessica realizes the reason why she never said anything—she wants Rosa to be known for more than just her condition. Before the accident, Jessica never really knew Rosa, but now, she knows Rosa beyond her condition.

The biggest way that Jessica advocates for Rosa is by running in the River Run Race with her. Since the accident, Jessica has gotten a lot of attention from the local news, so her first race on her prosthetic running leg is a huge deal for the whole town. However, Jessica does not want this race to be all about her; she wants people to see Rosa. When a news reporter asks her about the race, she turns the attention away from her and back toward Rosa.

“‘Look,’ I tell her, ‘this is not about me. I’m doing this for Rosa. And yeah, at first I just wanted her to experience a run—to cross a finish line and hear people cheering for her — because that’s something she wanted. But you know what? Her biggest wish isn’t to cross a finish line or have people cheer for her. It’s to have people see her instead of her

condition. That's all anybody with a disability wants. Don't sum up a person based on what you see, or what you don't understand; get to know them'" (Draanen, 2012, p. 306).

Jessica makes a powerful statement about people with disabilities. She advocates for Rosa by sharing her message about wanting to be seen and gives her the opportunity to be seen by pushing her through the race and over the finish line.

Marcelo in the Real World by *Francisco X. Stork*

When Marcelo is forced to work alongside Wendell in the law firm, he is given the task of going through all the files for the Vidromek case. While doing so, Marcelo discovers a picture in the bottom of a box labelled "trash." Marcelo quickly realizes that the girl in the picture must have been hurt by the shattering of the Vidromek windshields. He is immediately affected by the picture and cannot forget what he has seen.

"I look at it for only a fraction of a second and immediately put the picture face down on the desk. I close my eyes but the image of what I saw remains. It is possible to simply put the picture back in the envelope and walk away. I know that if I look at the picture again, the image will affect me like a burn. Yet I have to look. I am drawn to it... I turn the picture over slowly. I focus on the eyes of the girl. She is my age, maybe a year younger, but it is hard to tell. Her eyes remind me of someone. Eyes that I have seen before. Half of her face is intact but the other side is missing" (Stork, 2009, p. 153).

Marcelo has mixed emotions about finding the picture—it is hard to look at, yet he cannot keep himself from looking. He describes the feeling to Jasmine by saying, "It was like I wanted to fight the people who hurt her. But then I realized that might include my father. It was confusing" (Stork, 2009, p. 165). Marcelo feels sympathy and compassion for the girl in the picture, which

forces him to continue his search for answers. He wants to fight for her, but is confused about how his father may be involved.

Marcelo feels connected to Ixtel because of his father's involvement in her situation. He thinks to himself, "I feel connected to her through my father's actions. I feel an obligation to right my father's wrong. But why? Shouldn't my father's welfare come first? His welfare is my welfare. How does one weigh love for a parent against the urge to help someone in need?" (Stork, 2009, p. 252). Marcelo wants to right his father's wrongs, but he feels guilty for going against his father to do what he thinks is right. When Wendell finds out that Marcelo confided in Jerry Garcia, he is furious because Marcelo betrayed both of their fathers. Marcelo explains to Wendell why he did it: "I found the picture of the girl that Jerry Garcia is the lawyer for. Her name is Ixtel" (Stork, 2009, p. 286). Marcelo is motivated to do the right thing and stand up for Ixtel, even though it means going against his father's business.

When Marcelo and Ixtel finally meet each other for the first time, she is so grateful to him. She tells him, "You ever have anyone do something so good for you that you feel bad because there is no way to thank them? You say the words 'thank you,' but they don't seem enough. That's how I feel. But anyway, I'll say it. Thank you" (Stork, 2009, p. 296). Without Marcelo's help, Ixtel would have never gotten justice for what happened to her. Because of Marcelo, Ixtel received compensation for facial reconstruction surgery. When Marcelo got to see Ixtel face-to-face, he knew he made the right decision in fighting for her.

How the Main Character Views Themselves and Their Disability

The Running Dream by Wendelin Van Draanen

The book begins with a stream of Jessica's thoughts as she lies in her hospital bed after her accident. "My life is over. Behind the morphine dreams is the nightmare of reality. A reality I

can't face. I cry myself back to sleep, wishing, pleading, praying that I'll wake up from this, but the same nightmare always awaits me...My hopes, my dreams, my life...it's over" (Draanen, 2012, p. 3). Without her leg, Jessica cannot run, which is her worst nightmare as a runner. When people come to visit her in the hospital, they tell her to get well soon, but Jessica doesn't believe this is something she can overcome. She thinks to herself, "I'm not sick. I'm crippled. Disabled. A gimp" (Draanen, 2012, p. 18). This is the first time that Jessica identifies as being disabled, and it is not said in a positive way. Jessica sees her disability as a burden and is ashamed of it. When her friends take her to the doctor for a check up on her prosthetic leg, she is embarrassed to be seen without her leg. "Off come the leg and the liner. Off come the socks and the nylon. Suddenly I'm feeling very self-conscious. Naked... And all of a sudden I'm mortified. Why in the world did I let them come back here? Fiona's fine, but Gavin? I'm desperate to get this over with. To cover up. To get out of here" (Draanen, 2012, p. 252). Jessica feels vulnerable with her leg exposed to her friends. She is embarrassed of her leg and wants to cover it up. When she hears that there is a delay with the shipment of her new flex foot, it reminds Jessica that she is made up of pieces and parts. "But there's a part on back order. A *part on back order*. Somehow I've almost blocked from my mind that I'm an assemblage of nuts and bolts and carbon graphite" (Draanen, 2012, p. 267). Jessica feels like a machine that can be assembled and taken apart. No matter how hard she tries to forget, she will always need to have a prosthetic body part.

Jessica's interaction with Rosa helps her to realize just how lucky she is to eventually be able to walk again. "I suddenly really get that I am lucky. I'll never do a fifty-five flat in the 400 again, but I will stand on my own again. This wheelchair won't be with me every day of my life" (Draanen, 2012, p. 107). Rosa will never have the opportunity to walk on her own. She will always be confined to her wheelchair. Jessica's wheelchair is just a temporary solution until she

gets her prosthetic leg. When she finally gets a prosthetic leg that fits her, she works hard to learn how to walk again. “I’ve worked hard on my gait; on learning how to adapt. And watching myself in the mirror now, I see that part of my problem was the tools I was using. The old leg was clunky compared to this one. With my new ‘flex foot’ my gait looks smooth, my stride confident. I feel almost normal” (Draanen, 2012, p. 270). With her new leg, Jessica finally starts to feel normal again, and she is able to stand up for herself when people make comments about her leg. She no longer sees herself as disabled, which is apparent when she tells her track coach, ““Hey! I’m able-bodied”” (Draanen, 2012, p. 300). Jessica does not let her condition define her anymore.

At the end of the novel, Jessica has gotten much more comfortable with her disability. She even switches between her walking leg and her running leg in the middle of the track. “I’m getting good at the switch. It only takes me about ten seconds now. And I’m more comfortable with the leg; more comfortable with people’s curiosity” (Draanen, 2012, p. 278). Jessica is not ashamed of her prosthetic leg because it gives her the ability to run, which is the most important thing in her life. After finishing the River Run Race with Rosa, she reflects on how far she has come since her accident. “That wasn’t a finish line for me. Eight months ago it was a herculean effort to walk myself and my IV stand to the bathroom. Today I ran my friend ten miles across her first finish line. Eight months ago I couldn’t do anything. This race has made me believe that there’s nothing I can’t do. This is my new starting line.” (Draanen, 2012, p. 312). Jessica has re-learned how to walk and run on her new leg, and now she feels unstoppable.

Marcelo in the Real World by *Francisco X. Stork*

At the beginning of the novel, Marcelo is set on continuing his education at Paterson. He truly believes that the best place for him to be is at a school for special-needs kids. His father, on

the other hand, wants him to go to Oak Ridge, a normal high school. Marcelo thinks to himself, “Arturo needs to be convinced that the best way for me to be like everyone else is to continue at Paterson, where I can learn at my own pace, where I am learning to make decisions and becoming responsible and independent, all the things he wants me to be” (Stork, 2009, p. 11). Marcelo wants to go to a school where he can be around other kids like him. He needs to convince his father that Paterson is the best school for him. He tells his father, “I do not want to go to Oak Ridge next year. A regular high school is not for Marcelo. I do not fit in” (Stork, 2009, p. 33). Marcelo knows that he is different and does not fit in with other kids, which is why he wants to stay at Paterson. However, after spending the summer at his father’s law firm, Marcelo realizes that he is able to do things he never thought he could do. He thinks, “There are times when I wonder whether I ever belonged at Paterson. Here I am functioning in the real world, having conversations with people, detecting what is on their minds, imagining what they must be feeling, in a way that many autistic kids are never able to do” (Stork, 2009, p. 185). Marcelo has really come out of his shell at the law firm. He has done things that most kids at Paterson could not do.

The novel does not explicitly say what condition Marcelo has, but he does describe it a few times. When he explains to his father why he cannot work at the law firm, he says, “There are so many things I still have difficulties with. I cannot walk by myself in a strange place without a map. I get flustered when I am asked to do more than one thing at once. People say words I do not understand or their facial expressions are incomprehensible. They expect responses from me I cannot give” (Stork, 2009, p. 23). Even though Marcelo has difficulties with things, he does not think he is abnormal. He thinks that at the law firm, he will have to pretend to be normal, in Arturo’s sense of the word. His thoughts are “This is an impossible task, as far as I

can tell, especially since it is very difficult for me to feel that I am *not* normal. Why can't others think and see the world the way I see it?" (Stork, 2009, p. 23). Marcelo knows that he is different, but that does not mean he is not normal. In fact, he wishes that more people could think like him. When Jasmine asks him about his condition, these are his thoughts:

"Explanations about my condition are based on the assumption that there is something wrong with the way I am, and at Paterson I have learned through the years that it is not helpful to view myself or the other kids there that way. I view myself as different in the way I think, talk, and act, but not as someone who is abnormal or ill. But how do I explain the differences to people? It is easier to say that Asperger's syndrome best describes my differences. It makes people comfortable to have a scientific-sounding term. But actually, I feel dishonest when I say I have AS because the negative effects of my differences on my life are so slight compared to other kids who have AS or other forms of autism and truly suffer" (Stork, 2009, p. 55).

Marcelo tells people that his condition is closest to Asperger's syndrome, although he does not share the same characteristics that other people with Asperger's have. He feels guilty about labelling himself as something that he is not, but he has to give people some kind of explanation that they can try to understand.

The only time in the novel that Marcelo questions whether or not something is wrong with him is during his conversation with Wendell about sexual attraction. Marcelo does not view women in the same way that Wendell does, which is actually a good thing because Wendell is a womanizer. However, Marcelo looks up to Wendell, so their conversation makes him doubt himself. When recalling the conversation, he tells Jasmine, "I never thought there was anything wrong with how I felt. But, maybe there is something wrong with me. Maybe I will never feel

that someone is beautiful” (Stork, 2009, p. 113). Because Marcelo does not view women in the same way that Wendell does, he thinks that something might be wrong with him, but after he spends more time with Wendell, he realizes that Wendell is not a good role-model. Marcelo knows that he is different, but that does not mean that he is sick or disabled or abnormal.

How Other Characters View the Main Character and Their Disability

The Running Dream by Wendelin Van Draanen

After Jessica’s accident, it takes a while for her parents and her sister Kaylee to adjust to their new reality. Jessica’s father wants to take control of the situation. “He sounds like he knows what he’s talking about. But really he’s a self-employed handyman. And I’m not something he can fix” (Draanen, 2012, p. 13). Jessica’s dad views her as something he can fix or put back together, but there is nothing he can do to get her leg back. Her sister Kaylee and Kaylee’s friends do everything they can to avoid Jessica. “Kaylee’s friends are trying hard not to look at my leg, and I can’t help looking at theirs. None of us seem to have anything to say...They move aside as I crutch past them, and in a flurry of whispers they escape up the stairs to Kaylee’s room” (Draanen, 2012, p. 50). They do not want to address the elephant in the room—Jessica’s leg. Instead of being friendly to Jessica or pretending like everything is normal, they run away to Kaylee’s room to talk about Jessica. After a while, they stop hanging out at Kaylee’s house, most likely to avoid Jessica. Jessica’s mom is the only one in the family that stays strong through the entire recovery process. When Jessica walks on her prosthetic leg for the first time, her mom is amazed. “She’s blinking at me. It’s like she’s just discovered her daughter is Wonder Woman, and for a moment I feel like I am” (Draanen, 2012, p. 75). Jessica’s mom is the only one in her family that can see beyond Jessica’s condition and recognize how strong Jessica is.

When Jessica returns to school, people treat her differently. “Everywhere I go, I feel like the elephant in the room. A lot of people do say hi and welcome me back, but a lot more don’t” (Draanen, 2012, p. 99). People feel awkward around Jessica or choose to ignore her. They do not want to address her because they are unable to treat her the same way that they used to. Even her teachers treat her differently. Jessica’s math teacher, Ms. Rucker, tells her to sit with Rosa, a student with cerebral palsy, which makes Jessica upset. She thinks to herself, “Yes, I’m missing a leg but the rest of me is...well it’s normal. Do people think I’m special-needs now? Is that how they see me?” (Draanen, 2012, p. 106). Not everyone sees Jessica as special needs. Her best friend Fiona remains at her side through it all. She pushes Jessica around in the wheelchair when she comes back to school and tells her “Just be a queen for a day” (Draanen, 2012, p. 90). Fiona is a great friend to Jessica because she has adapted to Jessica’s condition and is willing to do anything to help her best friend.

Before Gavin Vance became Jessica’s friend, he only saw her situation as an opportunity to write a good article for the school newspaper. When the track team puts together a fundraiser for Jessica’s running leg, Gavin shows up. “Before I can even think to yell, Hey! You need my permission to do that! Gavin has already taken some shots and is running back across the street. And in a flash he’s inside his car and driving away” (Draanen, 2012, p. 195). Jessica feels like Gavin only sees her as a headline, not as a human being with feelings. However, when the article he wrote about Jessica comes out in the town paper, she is stunned. He wrote “Jessica Carlisle may have lost her leg, but she has not lost her spirit. Last Thursday she was back at the track, cheering from the sidelines as her teammates battled Langston High in a dual league meet. Next year she’d like to be back on the track. Running” (Draanen, 2012, p. 199). Even though Gavin

did not speak to Jessica at the fundraiser, he still contributed to the effort by writing an article for the whole town to see. He sees that Jessica is a girl full of spirit and hope.

Becoming a part of the track team after the accident was difficult for Jessica. After Jessica and Gavin begin dating, Gavin's ex-girlfriend Merryl treats her horribly. Merryl says to Jessica, "He's only going out with you because he feels sorry for you. You're, like, his community service project" (Draanen, 2012, p. 313). Merryl is the only member of the track team who has not moved on from Jessica's accident and does not treat her normally. Jessica is also challenged by Vanessa, a runner from a rival high school. She says "So why is she here? If she knows she's a distraction to everyone, why is she here?" (Draanen, 2012, p. 173). Vanessa thinks that if someone can't run, they shouldn't be on the track, even if it is to support their team. The comments from Merryl and Vanessa really hurt Jessica because she desperately wants to be a part of the track team again.

Thankfully, the track team, led by Coach Kyro, wants to do everything they can to help Jessica run again. They had a secret meeting about their plan before they told Jessica about it. Coach Kyro told her, "So we had a team meeting yesterday and formed the Help Jessica Run campaign. Every runner volunteered for at least one of four committees...Our goal is to buy you a running leg so you can get back on the track and compete on the team your senior year" (Draanen, 2012, p. 144). Jessica was one of the team's strongest runners, and her teammates believe that she can get back to running with them again. When she gets her first prosthetic leg, they were so excited to see it, but they quickly realized that life with a prosthetic limb is not as glamorous as they might have thought. The girls were horrified at the sight of her pipe leg, and the boys were fascinated with it. Jessica thought, "I tell myself that the guys being wowed and the girls being revolted is better than the other way around, but both extremes are a little much"

(Draanen, 2012, p. 190). This makes Jessica feel self-conscious about her leg, but after getting her permanent leg, she feels more confident.

When the track team raises enough money for her running leg, Jessica is surprised by what it looks like. “I see that the strange yellow pattern is writing. Signatures. Comments. Things my teammates have written. *Run, Jessica! We love you, Jessica! Run like the wind. You’re amazing! Believe! Race me! Welcome back, Jessica! It’s a bird, it’s a plane, no it’s Jessica Carlisle!* I can’t read anymore because I’m sobbing” (Draanen, 2012, p. 273). The team customized her leg with encouraging messages they had all written for Jessica, which shows how they view her and her disability. Everyone that knows Jessica knows that she is strong, resilient, and a great runner.

Marcelo in the Real World by *Francisco X. Stork*

The reason why Marcelo has to work at a law firm for the summer is because his father thinks he needs to be exposed to the real world instead of living in a bubble at Paterson. Arturo does not acknowledge that his son has a disability. He tells Marcelo, “All these years, it wasn’t really necessary for you to go to Paterson. You don’t really belong there. I know you realize this yourself. There’s nothing wrong with you. You just move at a different speed than other kids your age. But in order for you to grow and not get stuck, you need to be in a normal environment. It is time” (Stork, 2009, p. 20). Arturo does not think that Marcelo belongs at a school for special-needs kids because he does not think anything is wrong with his son. At one point, Arturo tells Marcelo, “You’re not disabled” (Stork, 2009, p. 40), which is true when only looking at his physical appearance. He believes that forcing Marcelo to work at the law firm will help him grow up and be more normal, but there is no way to change Marcelo developmentally.

When working at the law firm, Marcelo hears from his co-workers that his father has acknowledged the fact that he is different. Jasmine tells him, “Your father said you had some kind of cognitive disorder” (Stork, 2009, p. 54), which surprises Marcelo because he has never heard his father admit that anything is different about him. Unfortunately, his father’s words to his co-workers makes them look down upon him before even meeting him. When Jasmine takes Marcelo on his first mail run, she asks him, “You can read, right?” (Stork, 2009, p. 51). Marcelo thinks this is some kind of joke; he does not pick up on the fact that she thinks he is slow. However, when a secretary almost calls him retarded, Marcelo does pick up on it, and he is very confused. He thinks to himself, “So Beth somehow expected me to be retarded or slow or something... But where did she get the expectation that I was retarded? Who put it there in the first place?” (Stork, 2009, p. 77). Beth must have heard from another co-worker, maybe from Arturo, that Marcelo is retarded. This means that people at the law firm are talking badly about Marcelo and are making assumptions about him because he is different.

Stephen and Wendell Holmes are two men at the law firm that are extremely rude to Marcelo. Stephen Holmes is Arturo’s business partner at the law firm. When Marcelo comes into the office, Stephen calls him “Gump,” which confuses Marcelo and makes him remember a story from years before: “I remember that Gump is what Stephen Holmes calls me ever since I hit tennis balls with Wendell at the summer barbecue. ‘Your son is a regular Forrest Gump,’ Stephen Holmes said to Arturo after Wendell and I were done. ‘What exactly do you mean by that?’ Arturo responded. I remember how all the people sitting on the patio suddenly stopped talking.” (Stork, 2009, p. 65). Marcelo does not understand that being compared to Forrest Gump is not a compliment. Stephen Holmes thinks Marcelo is slow and treats him badly, and his son Wendell treats him the same way.

Wendell uses Marcelo to get to Jasmine, and when Marcelo refuses to help him, Wendell lashes out. He says, “I took you for this innocent moron while all along you want Jasmine. I cannot believe Jasmine prefers...” (Stork, 2009, p. 264). Marcelo is able to fill in the blanks here and finally sees that Wendell is not a true friend to him. When Wendell finds out that Marcelo gave information to Jerry Garcia, he says, “You are one misguided retard. What world do you live in? You are an idiot. An imbecile.” (Stork, 2009, p. 285). This statement could have upset Marcelo, but it actually makes him smile because Wendell is treating him exactly how he would treat anyone else.

Jasmine is the one person in the novel that accepts Marcelo for who he is and treats him with respect. When they first meet, she is very clear that he was not her first pick to be working with her in the mail room, but she quickly shows him the ropes and leaves him to his work. When Beth, one of the secretaries, comes in with documents that need to be copied, tabbed, and bound, Jasmine shows Marcelo how to do it and then lets him do it on his own, even if it means they will not finish in time (Stork, 2009, p. 79). As the story progresses, Jasmine begins to open up to Marcelo about her life, and she even takes him on a trip to her hometown in Vermont. At the end of the novel, Marcelo decides that instead of going to Paterson in the fall, he will go to Oak Ridge to finish high school. Then he will go to nursing school in Vermont, where he can be close to Jasmine and her family. When he tells Jasmine his plan, she tells him, “You will always be welcome there” (Stork, 2009, p 312), and she kisses him on the cheek. Jasmine is able to see beyond Marcelo’s condition and loves him for who he is.

Discussion

Introduction

As a future educator, it is important to incorporate diverse books into my classroom. Diversity includes all aspects of humanity, including ability and disability, which is commonly overlooked by many. This research project was created in order to find young adult novels with characters who have disabilities. Not only did I want to find these books; I also wanted to evaluate their portrayal of these disabilities. Using the method of critical content analysis, I examined the depiction of disability in two young adult novels, *The Running Dream* by Wendelin Van Draanen (2012) and *Marcelo in the Real World* by Francisco X. Stork (2009). I found that in each of the books, the main characters are not defined by their disability. Even though some negative aspects of having disabilities are included in both novels, the focus remains on how the main character overcomes adversity, becomes independent, and advocates for others. The principles of critical disability theory (CDT) are used in the following subsections to show the significance of the findings.

How the Main Character Shows Agency and Independence

In the books that I chose to analyze, the main characters show agency in different ways. In *The Running Dream* (Draanen, 2012), Jessica's independence is mostly physical, since her disability is due to an amputation. Jessica pushes herself to do things on her own, like going up the stairs, taking a shower, and navigating to class. She also has to persevere through learning to walk and run again. Marcelo's agency is also physical in some aspects in *Marcelo in the Real World* (Stork, 2009). He is challenged physically when he had to copy, tab, and bind files without any instruction. He also has to navigate through the city to Jerry Garcia's office by himself with only a map (Draanen, 2012, p. 183). These things are difficult for him not because

he is physically disabled but because he is developmentally challenged and has trouble doing tasks that most people could easily complete. In both of these character's lives, they show agency in a physical sense.

Jessica and Marcelo also show agency mentally because they are forced to make decisions on their own that impact the story and potentially the rest of their lives. In Jessica's situation, she has to decide that she wanted to run again, and she had to train intensely to complete the River Run race with Rosa. Learning to walk and run again is a conscious effort that Jessica has to continually give in order to get back to where she was before the accident. Also, her friendship with Rosa shows agency because she decides not to follow what is socially acceptable in school and instead decides to befriend an outcast. Marcelo's mental agency is shown through his relationship with his father. It would be easier for Marcelo to do what his father tells him to do without putting up a fight, but he makes the choice to stick up for himself again and again. In the end of both novels, the main characters do things they never thought they could accomplish—Jessica with the River Run race and Marcelo with his law firm job and future in Vermont.

Independence is one of the main tenants of CDT. According to CDT, self-determination is "control over one's life based on the choice of acceptable options that minimize reliance on others making decisions and in performing everyday activities" (Rocco, 2005, p.5). I interpret this definition of self-determination to include the key components of independence and agency because taking control and making decisions are steps to becoming independent and show that a character has agency. One thing that I did notice in both of the books is that the main characters were not entirely independent. They both had to rely on other people at times. Jessica had to depend on Fiona at school, and Marcelo had to depend on Jasmine at work. I wish I could have

seen these characters accomplish their goals without needing a supporting character to help get them there.

How the Main Character Advocates and Cares for Others

One of the common themes between the books *The Running Dream* (Draanen, 2012) and *Marcelo in the Real World* (Stork, 2009) is that when the main character comes in contact with someone in need, they cannot stop themselves from helping. Both Jessica and Marcelo have an abundance of compassion, and despite their own unique circumstances, they still want to help others. This is not something that I was expecting to see in the books but was very glad to find. Not only were the main characters their own heroes at times; they were also the heroes for someone else.

In *The Running Dream* (Draanen, 2012), Jessica advocates for Rosa, a girl in her math class with cerebral palsy. Rosa goes unnoticed by the rest of the students, and even Jessica ignores her until Ms. Rucker makes her sit at Rosa's table. At first, Jessica is reluctant to get math tutoring from Rosa, but once she does, their friendship immediately begins to flourish. When Jessica talks about running, Rosa wishes she could relate to the feeling of having wind blow through her hair or crossing a finish line. This makes Jessica determined to make those dreams a reality for Rosa. Not only that, but she also wants other people to get to know Rosa and see beyond her disability. She dedicates her first race since her accident to Rosa and pushes her across the finish line, with the whole town watching and cheering them both on.

In *Marcelo in the Real World* (Stork, 2009), Marcelo finds a picture of a girl who had been injured by Vidromek's malfunctioning windshields. Her picture ended up in the trash pile, but when Marcelo saw it, he knew he could not leave it there. Even though his search for information on the girl meant possibly hurting his dad's business, Marcelo still continues his

quest because he wants to do the right thing no matter what. He receives backlash from his co-workers, his boss, and even his father, yet he still stands firm in his decision to find justice for Ixtel.

Advocating and caring for others fits into one of the principles of CDT— “disability has a unique voice and complex experience” (Rocco, 2005, p. 4). The “complex experience” refers to the disability, but a “unique voice” means the character should not be defined by their disability. Characters with disabilities should have a voice and be heard rather than ignored. In both *The Running Dream* (Draanen, 2012) and *Marcelo in the Real World* (Stork, 2009), the protagonists fought to make their voices heard, despite all physical and developmental setbacks, in order to advocate for the people they care about.

How the Main Character Views Themselves and Their Disability

The main characters of the books that I analyzed are very different. Marcelo was born with a developmental disability, but Jessica became disabled during her teenage years from a bus accident. Because of this, they view their disabilities differently. When Jessica finds out her leg was amputated, she feels like her life is over. At the beginning of the novel, she plays the victim. She is upset that school life goes on without her (Draanen, 2012, p.82). The track team still goes to meets, her friends still go to class, and the bus accident becomes old news after a few days. Meanwhile, Jessica has to deal with the aftermath of the accident for the rest of her life. Over time, Jessica comes to terms with her new normal and does not let her disability stop her from running or doing things she did before. The reason why Jessica struggled to transition is because, in her mind, she went from one end of the dichotomy to the other—from able-bodied to disabled. However, Jessica soon realizes that ability is not a dichotomy; it is a spectrum (Rocco, 2005). Just because she lost a leg does not mean she is completely useless and incapable of everything.

This concept of an ability spectrum, which is a part of CDT, is something that Jessica wrestled with throughout the novel.

In contrast, Marcelo does not view himself as a victim or as disabled. He knows that he is different, but that does not mean there is something wrong with him. After a conversation with his father at the beginning of the book, Marcelo thinks to himself, “Arturo is basically asking me to pretend that I am normal, according to his definition, for three months. This is an impossible task, as far as I can tell, especially since it is very difficult for me to feel that I am *not* normal” (Stork, 2009, p. 23). In this thought, Marcelo is referring to one of the main principles of CDT. There is no such thing as being normal or disabled; these are social constructs (Rocco, 2005). Marcelo is right in the fact that his father has his own definition of normal. He has a positive self-image, which is an important aspect of diverse books (Myers & Bernasi, 2008). Teaching books with characters that have disabilities and view themselves in a positive way can help students form positive self-image for themselves and teach them that they have intrinsic value.

How Other Characters View the Main Character and Their Disability

In both *The Running Dream* (Draanen, 2012) and *Marcelo in the Real World* (Stork, 2009), the main characters receive both positive and negative treatment from other characters. When Jessica goes back to school, the track team welcomes her back with a party and posters all over school, but some of her teammates are rude to her. They are eager to help fundraise to get her running leg but are also disturbed by the leg itself. Jessica says, “I get mobbed by my teammates, and of course they all want to see my leg. Until they do. The girls try not to show it, but they are horrified” (Draanen, 2012, p. 190). Jessica needs to feel accepted by her peers so that she can be less self-conscious about her leg. Even though everyone is not able to get past the outward appearance of Jessica’s leg, her best friends, Fiona and Gavin, can see beyond it. Gavin

tells Jessica, “I want to be around you because you inspire me! You’re amazing” (Draanen, 2012, p. 287). Before they were friends, Jessica thought Gavin only saw her as a headline for a news story, but now she knows that he is a true friend who not only sees beyond her leg but is also inspired by her.

In the same way, Marcelo gets mixed reviews from his new colleagues at the law firm. The secretaries think he is incapable of doing office work for them. Marcelo thinks to himself, “Juliet is looking at me as if I were an idiot. I probably am in her eyes. She has told me so before” (Stork, 2009, p. 173). He has also been told by multiple people at the law firm that he is stupid or retarded. His father’s business partner compares him to Forrest Gump, which is definitely not a compliment. These are all examples of ableism, prejudice by able-bodied and able-minded people toward people with disabilities (Myers & Bernasi, 2008). CDT argues that ableism is invisible to the average person but is painfully felt by the one being discriminated against (Rocco, 2005). Jasmine is only person in the office that respects Marcelo for his differences and does not act superior to him. Marcelo describes their relationship by saying, “She looks at me in a new way. It is a serious and tender look I’ve never seen before” (Stork, 2009, p. 312). One thing remains true for both *The Running Dream* (Draanen, 2012) and *Marcelo in the Real World* (Stork, 2009)—the people who are closest to the main character view them more positively because true friends can see beyond a disability.

Conclusion

There are a few main points to take away from the discussion when relating it back to the research questions. In the books *The Running Dream* (Draanen, 2012) and *Marcelo in the Real World* (Stork, 2009), characters with disabilities are portrayed as multidimensional human beings who are capable of accomplishing things that most people would consider impossible for people

with disabilities. They face challenges that come with their disability as well as challenges from other characters. The main characters, Jessica and Marcelo, overcome these challenges by making decisions on their own that not only impact their lives but also the lives of other people that they care about. Jessica and Marcelo are both courageous individuals who are motivated to do the right thing, even if they are the only ones doing so.

Conclusion and Future Implications

The purpose of this study is to find out how disabilities are portrayed in young adult literature, what challenges characters with disabilities face, and how they overcome these challenges.

Importance of the Study

On a personal level, conducting this study was important to me as a future high school English teacher. English teachers, along with all other teachers, need to include more diverse literature in their classrooms. On a professional level, many studies have already been conducted about diversity in children's and young adult literature, but most of those focus on racial diversity. There have not been very many studies devoted solely to disability, which makes this study even more important. According to Rudine Sims Bishop's concept of mirrors, students need diverse literature in order to see themselves represented. When children cannot find characters that are similar to them, or when those characters are treated or portrayed in a negative way, students take this personally and realize how society views people like them (Bishop, 2015). Bishop also states that having books serve as windows also important. If students "only see reflections of themselves, they will grow up with an exaggerated sense of their own importance in the world—a dangerous ethnocentrism" (Bishop, 2015, p. 1). Having books act as both mirrors and windows help students recognize and appreciate their similarities and

differences, and it is the job of educators to find books for their classroom that can accomplish this.

Lessons Learned

Reflecting on the findings of this content analysis, I believe that all of the original research questions have been adequately answered. From the two novels, I was able to see how both physical and developmental disabilities were portrayed. I also read about what challenges characters with disabilities faced and how they were able to overcome those challenges. Only reading two novels was a limitation of this study, but I did this in order to complete a more in-depth analysis of each novel. From this study, I learned just how important diverse literature truly is. I am certain that I will have students in my classroom who have disabilities, some that cannot be physically seen, so it is extremely important to incorporate literature that portrays these characters as strong, confident individuals who are not limited by their disabilities.

Future Implications

This critical content analysis is an important development for the educational community. There have been many studies about diverse literature in terms of racial diversity, but only a few studies focus on disability. From this research, I can recommend to other teachers two books that portray characters with disabilities, *The Running Dream* by Wendelin Van Draanen (2012) and *Marcelo in the Real World* by Francisco X. Stork (2009), and I can share Myers and Bersani's strategies for analyzing books. I intend to share the results of this study, including the principles of Critical Disability Theory, to other education majors at East Carolina University and in my professional learning community. I hope that from this study, other educators will realize the significance of incorporating inclusive literature into their classrooms and will join the movement of increasing diverse books in classrooms across the country.

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