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## A Study of Autism in Children's Literature

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A Study of Autism in Children's Literature

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## Introduction

Whether we realize it or not, we all have a desire to see ourselves represented in the literature we read. We like to read about characters who endure similar struggles as us, have similar cultures to us, and look and act like us. This allows us to easily relate to and connect with characters, further enveloping us into the story world as well as helping to shape our views of the real world. Imagine that you are a child and want to read about other children like you, but all of the books that you find have only adult characters. Now pretend that you can find books about children, but all of them paint children in a negative light or portray them incorrectly. How would you feel, and would you want to read books like this?

Fortunately, there are many books with child protagonists, but we cannot say the same about protagonists who have disabilities. Autism spectrum disorder (ASD) is a developmental disability that can cause social, behavioral, and communication challenges for people who are diagnosed (“Data & Statistics”). Michael Bérubé, professor of literature at Pennsylvania State University, makes an important claim about autism in his book *The Secret Life of Stories*: “it is a truism in the intellectual disability community that when you have met one person with autism, you have met...exactly one person with autism. The range of behaviors and possible positions on the autism spectrum are simply too bewilderingly diverse to admit of generalization” (Bérubé 50). Autism is considered to be on a spectrum because the abilities of people who have autism vary significantly and every individual’s strengths and weaknesses are different. Asperger’s Syndrome was previously a separate diagnosis, but in 2013 it became part of the umbrella diagnosis of ASD (“What is Asperger’s Syndrome”). Instead of using the term “Asperger’s”, people who have autism are now frequently categorized using terms such as “high-functioning” and “low-functioning” based on their ability. For example, those who once had Asperger’s are

now referred to as having high-functioning autism. However, these terms present their own issues because the division between them is unclear: for example, a “high-functioning” person with autism may live independently but be unable to cross the street by themselves, while a person deemed “low-functioning” may not speak but communicate by writing and have a high IQ (Loftis 9).

The term “autism” was first described as a medical developmental disorder in DSM V separate from Schizophrenia in 1980, which is surprisingly recent (Zeldovich). Now 1 in 59 children in the United States are diagnosed with an autism spectrum disorder (“Data & Statistics”). After the categorization in 1980, a great deal of literature about children with autism was published. As I dove into this literature I began to wonder: how do these authors portray autism? Furthermore, for whom is children’s literature about autism written? Is it intended for children who have autism spectrum disorder, or for neurotypical children to learn about children who have autism?

My study of autism within texts for young people uses the concepts introduced in disability studies. Scholars of disability representation have emphasized that literary narratives often marginalize characters with disabilities. Rosemarie Garland Thomson argues in *Extraordinary Bodies* that characters who have a disability in literature are “on the margins of fiction as uncomplicated figures or exotic aliens...main characters almost never have physical disabilities” (Thomson 9). In this instance, Thomson refers to physical disabilities. Yet I have found during my study that this translates to disabilities such as autism spectrum disorder, even though people with ASD often do not have a physical characteristic that sets them apart from others (“Data & Statistics”). And although my study has proven that protagonists who have ASD

do exist in literature, they can be seen as “exotic aliens” in their own narratives, especially in literature about siblings who have autism.

I will also explore the concept that characters who have disabilities in literature are seen merely as metaphors. Michelle Resene connects this idea to Tiny Tim, the young disabled boy in the novel *A Christmas Carol* that represents innocence and purity (Resene 95). I have discovered that some of the characters in the literature that I have researched are presented as metaphors or used as plot devices to communicate a broader theme to the reader (Loftis 12).

Finally, I will explore the “overcoming” narrative that is prevalent in disability studies. Often disability is portrayed as a negative aspect of life or a burden, and the stories about disability end with the protagonist finding some way to “overcome” his or her disability. This is all part of the “cure culture” that is objectionable to disability theorists. Stuart Murray, author of *Representing Autism*, claims that this overcoming narrative theme is “so dominant in the representation of disability that it almost seems that there is no alternative” (Murray xvi). For example, the 2012 novel *Wonder* by R.J. Palacio ends with protagonist Auggie Pullman, a boy with a severe facial deformity, receiving an award, accompanied by the cheers of all the people in school who used to make fun of and avoid him. Now that Auggie has survived his first year of public school and “overcome” his disability, he is rewarded. However, this part of the text could also be interpreted as the neurotypical students learning to think differently; Auggie cannot change the way he looks, but perhaps everyone else can change the way they see. In my thesis, I will explore ways in which themes of “overcoming” disability are present in novels about autism.

In my research, I also explored theorists who focused on autism literature specifically in order to find prevalent themes. Murray argues that any disability (autism included) is

“traditionally seen in terms of a lack or an absence” (Murray xvi). I will explore how this idea manifests itself in the literature that I have read, and even in popular culture and organizations. For example, when we consider autism advocacy, we likely think of Autism Speaks, which is a large autism organization that funds research for the causes and treatment of ASD, as well as spreads awareness about the disease. Despite its positive theme, there is a great deal of backlash toward the organization, mainly because of its logo—a puzzle piece. A puzzle piece typically indicates that something is missing; in a way, this representation indicates that Autism Speaks believes that people who have autism (the people for whom the organization is advocating) are not complete people, essentially “treated more like a puzzle than a person” (Loftis 4). Author and educator Amy McCoy interprets the puzzle to be a positive metaphor: she defines it as, “you’re hard to figure out, but we’re going to figure it out together.” She claims that she has never been offended by its meaning. However, according to some theorists the puzzle piece also might indicate that there is a single solution to autism, rather than that autism is a multi-faceted disability in a different form for every person. In this thesis, I explore whether this “absence” idea is present in children’s literature, and discover whether children who read these books and grow up in the culture advocated by Autism Speaks will subconsciously develop the idea that people who have autism are not complete people.

In my thesis, I would also like to explore person-first language. According to the Employer Assistance and Resource Network on Disability Inclusion, person-first language “conveys respect by emphasizing the fact that people with disabilities are first and foremost that—people” (“People-First Language”). This means that instead of identifying a person as “an autistic person”, they should be identified as “a person with autism.” McCoy reveals that she only uses person-first language both in her books and in her daily life. Despite pushes for person-



first language for people who have disabilities such as autism, many people with disabilities (particularly young people) “are choosing to use ‘identity-first’ language such as ‘autistic’ or ‘disabled’” (“People-first Language”). McCoy also admits that she has noticed this identity-first language used among people who have autism in an autism Facebook group. I want to discover whether person-first language is used in the books that I have studied in order to determine whether only person-first language is acceptable or whether it can be interchangeable with identity-first language.

According to fiction author Katherine May, disability as a metaphor is prevalent in autism literature as well as disability literature, which the Autism Speaks puzzle piece only makes more evident. She argues that “recent research, engaging with autistic people as partners rather than simply observing them, suggests that we have badly misunderstood the interior life of autism...these cold, naive characters are nothing more than literary tropes” (May). She also points out that the people who have autism in literature usually exhibit characteristics that are the opposite of what society values, such as a lack of empathy, no sense of humor, and an inability to touch or love (May).

Sonya Freeman Loftis argues that the way we perceive, interpret, and write about people who have autism creates a “looping effect” in which “the thing defined (autistic people) is potentially susceptible to shifting cultural definitions and labels (the cultural conception of what it means to be autistic)” (Loftis 13). This means that because we think that people who have autism are one way, they become that way, both in our minds and in real life. In my research, I hope to discover whether these works of literature judge and observe people with autism rather than allowing them to explain their own experiences (May).

Many autism experts claim that people who are severely affected by autism spectrum disorder are understudied and therefore less prevalent in medical literature and research (Stedman et al.). This means that the full picture of autism is presented inadequately to the public, and there is a bias toward the people with autism who have fewer limitations (Stedman et al.). Although this research refers to medical literature, it also applies to children's literature, which favors the stories of children that have less severe autism (perhaps because it is easier to tell someone's story if they are able to speak). Robert Rozema emphasizes this belief: "Young adult literature has only known *one* child with autism: the hyper-functioning, hyper-verbal savant with Asperger syndrome" (Rozema 27). Because a single story of autism is presented in texts for children, they cannot fully understand autism. Readers might never understand that there are many people with autism spectrum disorder that will never speak, walk, or exhibit behaviors in the same ways as the people with ASD that they read about in literature (Rozema 29).

There are also ideas about the Theory of Mind and mind-blindness discussed in medical and children's literature that have been criticized. Loftis discusses in *Imaging Autism* that the Theory of Mind is dehumanizing for people who are on the autism spectrum, because "such ideas propose that people with autism do not understand that other people have minds, thoughts, and feelings and that we are frequently unaware that those minds, thoughts, and feelings may work differently from our own... You cannot say that a person with autism does not have feelings just because they act in a different way than you" (Loftis 9). Not only does the Theory of Mind claim that people who have autism do not understand others, the term "mind-blind" is often applied to people who have autism, indicating that the Theory of Mind was not developed or lost in these people. In fact, a young adult novel about a teenager with autism that I did not choose to read for this thesis is titled *Mindblind*, only emphasizing this characterization.

The “overcoming” narrative that is prevalent in disability literature is also present in autism literature. Phrases such as “we are battling autism”, “our child was stolen by autism”, and “she is trapped behind the wall of autism” are commonly used, characterizing autism as a dreaded state for the people who are diagnosed (Loftis 15). Yet in reality, autism is not a disease, and should not be treated as such. People who are diagnosed with autism deserve to be accepted for who they are rather than wish that they did not have autism.

My thesis work is divided into two sections: the first section (entitled “To Kill a Negative Autism Representation”) will examine protagonists who have autism spectrum disorder. I will explore their similarities and differences, discuss what authors do well, and identify any problematic areas that may exist, such as those that I have addressed previously. My thesis will examine questions of autism as alien and exotic, autism as a metaphor or literary trope, a lack of severe autism representation, autism as a burden to others, autism as something that must be overcome, and autism as an absence.

In considering the characteristics of protagonists with autism, Chapter One surveys a number of important children’s literature texts in order to explore autism representation in contemporary literature. The chapter begins with an examination of *Mockingbird* by Kathryn Erskine. This novel tells its story through the first-person perspective of Caitlin, a fifth-grader who is on the autism spectrum. In the story, Caitlin simultaneously overcomes both her disorder and her older brother’s death. I will explore the “overcoming” autism narrative in this novel. *Planet Earth is Blue*, a 2019 novel written by Nicole Panteleakos, is the only book in my study about a child with ASD who cannot speak. Through this, I seek to learn about severe autism and discover why it is not well-represented in children’s literature. In 2007’s *The London Eye Mystery* by Siobhan Dowd, siblings Ted and Kat have to solve the mystery of their lost cousin

Salim. The novel emphasizes that Ted's brain "runs on a different operating system", yet not always as a positive attribute (Dowd). Through *The London Eye Mystery*, I will explore literary tropes of autism as a metaphor and autism as exotic. Finally, I will address a graphic novel called *Melting Down: A Comic for Kids with Asperger's Disorder and Challenging Behavior*. Written in 2013, its disguised intent was to educate parents about autism, but in reality, it is meant to convince readers to send their children to a residential school for children to "correct" challenging behavior. I will analyze autism as a metaphor in this graphic novel. By analyzing the construction of the protagonists in these five novels, the chapter will offer an overview of the tendencies that shape central characters in contemporary autism children's fiction and consider whether the center of the story can be occupied by a fully developed personality.

The second chapter of my thesis (entitled "How to Say 'Unethical Representation' Out Loud") will delve into books about the siblings of children who have autism. I have found that these novels are often less about autism and the child who has autism and more about celebrating the sibling who has to "deal" with autism. While some of these novels are powerful, the "overcoming" narrative is present and autism is often seen as a burden and something to eliminate or ignore. I will discuss these themes in *Little Big Sister*, a novel written by Amy B. McCoy in 2016 that is based on a true story about nine-year old Katie feeling as though she has to act as the older sister to her older brother Mikey, who has autism. *How to Say I Love You Out Loud* by Karole Cozzo is a 2015 young adult romance novel about high schooler Jordyn, who is in despair when she finds out that her brother Phillip, who has autism, is going to attend high school with her. In this novel, I will also investigate autism as a burden to others (specifically in sibling relationships). *Rules*, a 2006 novel by Cynthia Lord, chronicles the story of Catherine, a twelve-year-old who wants to become best friends with the new girl next door—and who

desperately wants her younger brother David (who has autism) to stay away. She constructs a list of rules for David to follow so that he can act normally in their everyday life. I will use this novel to explore the “overcoming” autism narrative. I will also explore similar ideas in *Same but Different: Life on the Autism Express*, which is a novel based on a true story about a girl named Callie and her twin brother Charlie, who has autism. Although Callie loves and tries to protect Charlie, it is evident that she also resents her brother. I specifically found this novel important to include due to the lack of representation of African American characters with ASD. By drawing together this archive of representations of sibling relationships, I hope to explore how the siblings of children with autism view autism from their own perspective.

My goal in this thesis is to investigate the ethical implications of representations of autism and whether the representations treat characters with dignity, avoiding the pitfalls that disability and autism literature has identified. Studying a range of texts will allow me to compare the different methods of autism portrayal, whether through the first-person perspective, third person perspective, or the perspective of siblings. I hope to determine whether one of these perspectives is preferable to another and provides a better representation of autism. Studying both protagonists and siblings in stories about autism will allow me to conclude which novels should be presented to children in academic settings and which communicate themes that present problematic views of autism. I hope to discover that some children’s literature novels present a positive and authentic representation of children who have autism and thus are appropriate materials to use in a classroom.

## Chapter One: To Kill a *Mockingbird* Negative Autism Protagonist Representation

In this chapter, I identify works of children's literature with protagonists who have autism and investigate the authors, as well as their reasons and goals for writing these novels. Then I commend and critique the autism representation in each novel and ultimately decide which of them: 1) takes an ethical approach to portraying autism, 2) describes characters with autism authentically, 3) places characters with autism at the center of narratives, and 4) appeals to audiences of both children with autism and neurotypical children, allowing them to connect to and understand the character with autism. Likewise, I will determine which of the novels portray children with autism in a derogatory way, creating characters who are metaphors or objects of pity, making an effort to "overcome" their autism rather than accept themselves for who they are. Finally, I explore whether they appeal to audiences who do not have autism as a sort of "survival guide" in dealing or coping with people who have autism.

### **Mockingbird**

First, I will investigate the "overcoming" autism narrative in *Mockingbird* in order to determine whether the protagonist is a character who embraces her autism or is forced to change herself in order to fit into society. Author Kathryn Erskine has a close emotional connection to the 2007 shootings at Virginia Tech upon which she bases the novel (she makes protagonist Caitlin's older brother Devon the victim of a school shooting). Her purpose for writing *Mockingbird* was to "understand how community and family— particularly families with special-needs children—dealt with this violent event, and how our lives might be different if we understood each other better" (Erskine). Erskine hopes that through early intervention of intellectual disability, society can avoid violence. She also cites her own daughter's autism as a reason for writing *Mockingbird*, admitting that when she received her diagnosis it "explained a

lot. I do believe there's much we can do to help those on the autism spectrum learn about and understand our world. At the same time, I think we can learn much of value from people who see the world differently" (Erskine).

*Mockingbird* is told through the first-person perspective of fifth grader and main character Caitlin, and this gives readers the opportunity to see inside Caitlin's head and understand why she acts the way she does. Throughout the novel, we experience Caitlin's ups and downs as she overcomes life on the autism spectrum without her brother to help her. Caitlin exhibits a few classic ASD tendencies, such as a lack of expressive emotions ("I wonder what she means [when she says that the funeral must have been very difficult]. We sat in church. It was not very difficult"), a tendency to take everything literally ("Her door is always open...Actually it's almost always closed. But if you knock then she remembers to open it"), and difficulty with social skills ("I can't [have empathy] because it didn't happen to ME. I don't have bandages or a purple scratched-up face so how am I supposed to know how it feels?") (Erskine 7, 12, & 122). Yet Erskine does not simply present these representations; she also allows readers to experience Caitlin's side of the story. For example, while the students in Caitlin's class assume that Caitlin moved Rachel's seat into the corner of the classroom to be mean to her, we as readers know that she was doing this to be *nice*, because this is what she herself would have wanted if she had a scratched-up face (Erskine 120). Caitlin thinks that she is practicing empathy, so she is confused when Rachel bursts into tears and her classmates chastise her.

As I have discussed in the introduction, the Theory of Mind proposes that "people with autism do not understand that other people have minds, thoughts, and feelings" (Loftis 9). Although some of Caitlin's actions in *Mockingbird* may appear unemotional to the people in her life, readers learn that while Caitlin struggles with emotions, she tries her best to understand

them. Thus, she battles against the stereotypes that the Theory of Mind introduces. For example, she points out, “You shouldn’t smile when you do something bad because a smile is supposed to mean you’re being nice. I wish people would follow the Facial Expressions like they’re supposed to” (Erskine 29). People who do not have autism are usually easily able to tell what a smile means, because we take into account not only facial expressions but also body language, tone, and more. This makes the discrepancy between happy smiles and smirks easy to distinguish. Erskine makes an important point through this Caitlin quote: although this may be easy for us to understand, it is not so easy for Caitlin.

Caitlin clarifies what is difficult to understand about our world if you do not possess innate social skills: she remarks, “Devon says you can’t moan or scream or shake your hands up and down or rock or get under a table or spin around over and over in public. Actually you can’t do most things over and over in public because that’s not normal unless it’s something like clapping or laughing but you have to do it only at the right times and places and Devon always tells me. Now I don’t know anymore” (Erskine 27) Most of us never think about whether it is the right time to clap or laugh, because we can follow the social cues of the environment around us, see what other people are doing, and pull on our background knowledge to quickly decide what to do in nearly every situation. Yet Erskine spells out for us why this is difficult for Caitlin—she has developed a schema that she cannot complete any actions over and over in public, other than the exceptions that her older brother Devon has made for her. Now that her brother has passed away, Caitlin does not have anyone to help her aside from her guidance counselor Mrs. Brook because her father has never understood her the way that Devon did.

*Mockingbird* also indicates that everybody who has autism is different, which is a quality that represents Erskine’s ethical approach to representing autism. Instead of portraying a “single



story” of autism, Erskine teaches readers that autism is a multifaceted disorder that is different for every person who has it. As referenced in my introduction, when you meet a person who has autism, you have only met “one person with autism” (Bérubé 50). There is a boy at Caitlin’s school named William H. who also has autism and works with Mrs. Brook. And although Caitlin understands what it is like to be treated differently, she still has a negative opinion of William and does not think he is anything like her. When the other kids in her class say that she has autism, Caitlin retaliates with “William eats DIRT and SCREAMS when he gets mad! I AM NOT AUTISTIC!” (Erskine 176) Mrs. Brook points out the problems with Caitlin’s outburst; she tells Caitlin that William H. is her friend, that he is talented at soccer, and that “We all fall on the spectrum of behavior somewhere...it’s a line and we’re all on it. Some of us are farther along the line than others” (Erskine 178). This teaches both Caitlin and readers about the autism spectrum, which many of us disregard or do not fully understand. Erskine hints to readers that although Caitlin’s disorder (which is now known to be on the autism spectrum) is not the same as William H.’s, both Caitlin and William deserve to be treated with the same kindness and respect. Erskine’s inclusion of William H. is yet another reason why *Mockingbird* is successful in its autism representation—it indicates to readers that although we are learning about Caitlin’s journey, no one else is the same as Caitlin. Erskine depicts this scene without belittling William H. or labelling him as low-functioning.

Through *Mockingbird*, we see directly into Caitlin’s life, as well as her thoughts and observations. This allows us to make conclusions about who she is and why she makes the decisions she makes. While at first readers might be confused as to why Caitlin’s sentences include random capitalizations such as “Dad says to Look At The Person”, we later receive an explanation for this pattern (“[The word heart] doesn’t look right that way. How can any word be

more special than Heart?") (Erskine 5 & 63). Erskine presents autism ethically because she places Caitlin at the center of the narrative and the novel shows readers not only how others perceive Caitlin, but also how Caitlin perceives herself and her world through the first-person perspective. Erskine portrays a child with autism who is working to understand the people around her, but who struggles because the people around her do not work to understand her. Only when Caitlin works together with others (such as her new friend Michael, her nemesis Josh, Mrs. Brook, her father, and the other students in her class) does she receive the "closure" that she longs for from her brother's death.

While I thoroughly enjoyed *Mockingbird*, I did identify a problem in its autism representation. There is one point toward the end of the novel in which Erskine has Caitlin "overcome" her autism and find empathy for her brother. As Caitlin is looking at Devon's Eagle Scout project, she begins to think about her brother and the time that was taken away from his life and suddenly begins to cry, proclaiming to her father that she finally "gets it" (Erskine 218). *"I'm not crying for me! I pull my head out from under the sofa cushion and Look At The Person. I'm crying for Devon! I'm crying because I feel bad for HIM! Isn't that empathy? I'm feeling for HIM instead of me!"* (Erskine 219). She releases two of her autism characteristics (she gets out from under the sofa cushion, where she likes to hide, and makes eye contact with her father, which she hates to do) and experiences what she believes must be empathy, after all she has learned from Mrs. Brook. However, I argue that this section is used as a device used to wrap up the novel rather than to portray Caitlin for who she is. By the end of the novel, Caitlin has achieved so-called "closure" because she has found empathy for her brother and for others. As a result, she starts adding colors to her drawings even though for the rest of the novel she only drew in black and white (Erskine 232). This is clearly a metaphor: Caitlin adds color to her

drawing and simultaneously adds color and happiness to her life, now that she has let go of some of her autism characteristics. It should not be necessary that Caitlin has to “overcome” all of these parts of who she is in order for the novel to end properly. As in most children’s and young adult literature, there is pressure to convert to the classic narrative form and provide a “happy ending” with a sense of closure about the novel and its characters. Erskine follows this format with *Mockingbird*. However, it should be okay that Caitlin is not like everybody else at the end of the novel. It should be okay that she does not always finish her pictures, that she does not like to color them in, and that she does not display her feelings in the same way as others, and the novel should not have to end with Caitlin changing herself to fit these criteria. I argue that these are not faulty characteristics that Caitlin should have to rise above and instead are some of her defining characteristics—and there is nothing “wrong” with them!

### **Planet Earth is Blue**

Although William H. is a preverbal character who has autism in *Mockingbird*, he is infrequently mentioned in the novel and readers do not have the opportunity to get to know him. Protagonists with low-functioning autism in literature appear infrequently, despite the fact that as many as 40% of children with autism are nonverbal (“Understanding Nonverbal Autism”). The 2019 novel *Planet Earth is Blue* depicts a preverbal child with autism as the protagonist, so it was important to include in this study.

*Planet Earth is Blue* is especially interesting because autism is not protagonist Nova’s main “obstacle”: she is also a foster child who is constantly shipped from home to home (and in many of the homes the foster parents do not understand Nova’s condition) and has now been separated from her older sister, Bridget. Nova is represented as a multi-faceted character, and her autism is only one of the many aspects of her life that readers come to know.

Author Nicole Panteleakos has an extensive background working with people who have autism, which is likely what inspired her to write this novel; she was an instructor in a school for children with autism, volunteered at an autism center's afterschool program, and worked at a weekend social program for students on the spectrum (Panteleakos). Panteleakos claims that a common misconception about autism that she has encountered is that "people who are nonverbal are...unable to understand what is being said to them, which is why a lot of adults in Nova's life have addressed her in loud voices with short, basic sentences" (Panteleakos). We soon discover in *Planet Earth is Blue* that Nova is perfectly capable of understanding what is said to her, including offensive remarks about her disorder.

The novel takes place in 1986, at a time in which nonverbal people had limited access to resources that would allow them to communicate with others (Panteleakos). Nowadays, we might meet a nonverbal person with autism who uses a tablet or device that speaks for them. Panteleakos hopes that with this novel, she can show readers that Nova is capable of complex thoughts, despite the fact that she cannot voice them. By including sections that depict Nova's voice, Panteleakos provides an ethic portrayal of autism that centers around Nova's experience rather than the experiences of the other characters with which she interacts.

Although Nova's story is told in third person, at the beginning of each chapter there is a letter that Nova writes to Bridget. Nova cannot read or write at her grade level, but she can comprehend at her grade level, and these letters allow her to express herself in ways that she cannot verbally. These sections of each chapter are extremely important, because they reveal a great deal to us about Nova. We grow to understand the close relationship that she shares with her sister and their passion about space travel and the *Challenger* launch that the two girls are supposed to watch together. Nova's letters to Bridget are especially fascinating because to others

they are indecipherable—her foster parents can tell that she is trying to write something, but it looks like a bunch of squiggles to them. However, Panteleakos gives readers the power to see into Nova’s mind and read the letters fluently, which no one in Nova’s life (not even Bridget) can fully do. Even though Nova does not speak, she is perfectly capable of having complex thoughts, proving that characterizing her as “low-functioning” presents problems (Loftis 9). Through this experience, Panteleakos also provides us a complete picture of Nova’s character in a way that does not conflict with Nova’s abilities in her world. In *Planet Earth is Blue* we are able to experience Nova’s story from the third and first-person perspectives in two formats (prose and letters) and both of these perspectives revolve around Nova, which aids in providing an ethical and well-rounded representation of her autism.

Panteleakos allows readers to empathize with Nova and understand her situation in *Planet Earth is Blue* because she educates readers about the history of disability in America. In her author’s note, she tells readers that “By the 1960s, ‘retarded’ was used as both a diagnostic term and as an insult, and the two uses continued to overlap for over forty years” (Panteleakos 227). The novel shows us the effects that this word has on Nova; she is terrified of testing of any sort (even at home with her foster parents, whom she trusts) because she always receives the same evaluation from every school: “Cannot read. Does not speak. Severely mentally retarded” (Panteleakos 4). Even Nova’s social worker, a professional responsible for Nova’s well-being whom Nova should be able to trust, refers to Nova as “retarded” and does not realize that even though Nova cannot talk, she can still understand what is said.

In a pivotal moment of the novel that both reveals a lack of knowledge and respect for children who have autism and uncovers the complexities of a character’s life with autism, Nova’s general education teacher teaches the students about the *Challenger* launch. After every

question that Mr. O'Reilly asks, Nova's hand shoots in the air because she knows everything about space travel. However, even though her teacher sees her frantic waving and hears her loud, excited noises as she tries to get his attention, he continuously calls on other students (many of whom do not even know the right answers) (Panteleakos 96). Eventually, when Nova's aid asks her to calm down, Nova gives up trying and her teacher continues the lesson: "She knew all the answers. // But nobody asked her" (Panteleakos 98). While her classmates and her teacher might perceive Nova's outbursts as random and nonsensical, we readers know the truth—for some reason, most likely because of Mr. O'Reilly's own discomfort and lack of knowledge about disability, he excludes Nova from participating in the general education classroom when he should really be facilitating her inclusion. This scene shows readers one of the many struggles that Nova endures being constantly surrounded by people who do not understand her capabilities. People such as her teacher judge her before getting to know her, and with the exception of her current foster family, she does not have the opportunity to demonstrate her knowledge in a form other than a test or evaluation. We as readers see how difficult it would be to not have your voice heard, so we can empathize with Nova just like we can with Caitlin.

*Planet Earth is Blue* ends with Nova's foster parents telling her that they want to adopt her, and Nova answering "oh-kay", even though she is typically unable to speak complete words (Panteleakos 218). The ending is powerful because it does not "resolve" her autism; even though Nova's family learns that she can read some words, her autism is not "cured" and she never changes who she is. Loftis elaborates on autism cure culture in *Imagining Autism*: "While some [people with autism] desire a cure, others feel that autism is central to their personal identity and are offended by the very idea of it (11). Even though Nova's foster parents work to help her improve her reading and speaking skills, they do not view her autism negatively like Nova's

social worker or try to cure her. Yet I wonder how young readers might perceive the biggest surprise of the novel, which occurs just before the novel ends, in juxtaposition with Nova's autism.

Throughout the novel, Nova writes letters to Bridget under the impression that even though her sister is gone right now, she will return by the time that the *Challenger* launches so that they can watch it together. Nova anticipates that Bridget will walk through the door of her classroom on the day of the launch, but when this does not happen and the *Challenger* crashes, Nova runs out of her school in a frenzy to Bridget's memorial on the side of the road. Nova comes to the realization that Bridget is never coming back because she died in a car accident (Panteleakos). Nova experiences post-traumatic stress from being in the car accident as well. She does not understand that Bridget is dead and will not come back to her until the very end of the novel. This moment compares to the recognition of loss in *Mockingbird*, because Caitlin has little to no reaction to Devon's death until the end of the novel, when she "discovers empathy" and cries for her brother, which is similar to Nova's realization.

These novels rely on death and grief to convey to audiences that people with autism handle their emotions differently than most people. Both characters do not truly acknowledge their loss until the end of the novel as a sense of "closure" to both their grieving and the novel. I wonder if this idea could be problematic for students reading *Planet Earth is Blue*; they might think that Nova's inability to understand what happened to her sister until the end of the novel is a reflection of her autism. Perhaps Nova will therefore no longer be perceived as smart, because she was not able to put together the information about her sister despite seeing her memorial and being in the car crash that killed her. I worry that students associate this climactic part of the novel as a characteristic of all children who have autism, when this is more likely a characteristic

of any child who has experienced a traumatic event. While Nova discovering the death of her sister was certainly the climax of the novel, I wonder if this was a good way to represent a child who has autism. It seems as though it was used as more of a literary device to add drama to the end of the story than to convey information about Nova, just as Caitlin expressing empathy and crying for her brother was a way to wrap up *Mockingbird* and allow her to “overcome” her autism.

### **The London Eye Mystery**

Next, I will examine autism as exotic in Siobhan Dowd’s 2007 young adult novel *The London Eye Mystery* in order to determine if this presents an ethical or discriminatory presentation of autism. Authors can treat autism as strange in an ethical way if they demonstrate to readers why this is untrue, but they can also present it as discriminatory if they do not present the protagonist’s views about being portrayed this way by others so that readers understand and empathize with them. I argue that Dowd is an ethical author because she does not present her protagonist with autism as an exotic alien or a spectacle (Thomson 9). Even though her protagonist elicits negative responses from the other characters because of his disability, Dowd presents Ted’s viewpoints and beliefs, so we have a method of counteracting the opinions of the other characters (Thomson 9).

Dowd passed away the year that the novel was published, which means that we have very little information about her intentions in writing a novel about a child with autism or her knowledge about children who have autism (Dowd). *The London Eye Mystery* follows the story of English teenager Ted, whose cousin Salim has gone missing on the London Eye Ferris wheel during a family trip to London. He works with his older sister Kat in an investigation separate from the police in order to discover what happened to Salim. Ted’s autistic tendencies are



eventually what lead them to solve the mystery (Dowd). Ted constantly struggles to be understood and to have his voice heard, and while this may be in part because he is a child, it is mainly because he is on the autism spectrum. Michelle Resene reinforces this autism representation in her article “A ‘Curious Incident’: Representations of Autism in Children’s Detective Fiction” when she argues that “readers see how most adults in the narrative underestimate [Ted’s] intelligence and agency and why this is unfair. Ideally, this will disrupt readers’ notions of able-bodied superiority and instead lead them to question why people with disabilities are denied power and agency in our society” (Resene 96). We see that Ted is perceived negatively by his family, but through the narrative we come to empathize with Ted and perceive him in a positive light.

Dowd makes two interesting choices in her portrayal of autism: first, she never labels it as “autism”. When Ted and his family refer to his autism, they consistently call it his “syndrome” and his sister Kat calls it “what Ted’s got” (Dowd 30 & 36). Autism is never referenced in the novel, and Ted’s disorder remains an ambiguous part of his identity that his family is aware of but does not want to name. This categorization of autism makes autism appear to be exotic to both Ted’s family and readers. Even Ted refers to his own condition in these vague terms, which indicates to readers that perhaps he and his family are so ashamed of Ted’s autism that they do not even want to say it aloud, much like the wizards in Hogwarts refuse to speak the name of the evil villain “Voldemort.”

Dowd also includes the same bare-bones description of autism at least four times throughout the novel, including on the back cover. The description is that Ted’s brain “runs on a different operating system than other people’s” (Dowd 31). This exact phrase is rampant throughout the novel and is both how Ted describes himself and how other people describe him.

I argue that this is another way in which Ted appears strange or exotic to readers. This phrase indicates that everybody else other than Ted operates in the same exact way and that Ted's brain is akin to a machine, which is dehumanizing and untrue. The phrase alienates Ted from the rest of his family and the rest of the world. It is as if it becomes his motto to live by; he has accepted that he is different from everybody else, and that being different is not necessarily good. The lack of other phrases and explanations to describe what autism is to readers makes Ted and other people who have his "syndrome" appear alien.

However, there is one moment in the novel in which Ted has the opportunity to explain his autism to his cousin Salim: "It's this thing in my brain...it's not that I'm sick...or stupid...but I'm not normal either...It's like the brain is a computer...But mine works on a different operating system from other people's. And my wiring's different too...It means I am very good at thinking about facts and how things work and the doctors say I am at the *high-functioning end of the spectrum*" (Dowd 37). Even though autism is described once again as a "different operating system", Ted adds his own anecdotes regarding how he thinks about autism. He also reveals to Salim that he has high-functioning autism but does not elaborate, meaning that Ted might not know exactly what this means himself. Because Ted's family is not intent on learning more about autism or referring to it by name, Ted is left in the dark about a great deal of his condition (and perhaps an entire community that shares his same condition). Thus, autism is foreign even to Ted, who has it.

Fortunately, Resene argues that Dowd presents Ted's autism as an advantage by the end of the novel— "rather than claiming to have 'overcome' or 'cured' his autism... [Ted] views his autistic characteristics as partially responsible for his success" (95-96). Yet even though Ted eventually comes to appreciate his disorder, he reveals to Salim at the beginning of the novel that

he does not like having autism: “Mr. Shepherd says if I learn how to be like other people, even just on the outside, not inside, then I’ll make more friends...I don’t like being different. I don’t like being in my brain. Sometimes it’s like a big empty space where I’m all on my own. And there’s nothing else, just me” (Dowd 39). Readers learn early on in the novel that because Ted has been categorized as different by everyone in his life, he is taught that he is the one who has the problem. Ted’s teacher thinks that he needs to change who he is and act like everybody else so that he can make more friends, when perhaps Ted’s classmates need to change and be more accepting of those that are different from them. Ted has been conditioned to believe that his autism is an issue that he needs to work to solve and try not to mention, so of course he does not have pride in his identity.

Although Ted is portrayed as exotic and strange, Dowd shows readers that although the other people in Ted’s life may see him that way, he is not that different from everybody else, and the aspects of him that make him different are not negative. Dowd proves this by making Ted the one who eventually discovers what has happened to Salim and leads his family to Salim’s location, saving the day. This shows the family and readers that while Ted may be different, this difference is what led him to solve the mystery that even the police officers could not. Resene claims that “Rather than making adjustments to help the reader solve the mystery more easily...Dowd makes demands on readers to adjust their thought processes to fit the narrative. They are expected to watch for weather-related narrative sign posts in order to determine what elements of the plot are important, to focus on material evidence instead of having access to suspects’ suspicious responses and behaviors, and to listen carefully to Ted’s weather-related theories about geostationary satellites and the Coriolis Effect and apply these based on an understanding of Ted’s individual metonymic connections. In other words, readers must learn to

think like ‘weather detectives’ to think like Ted, if they are to have any hope of being successful at solving the novel’s core mystery” (Dowd 93). Therefore, instead of a child with autism being forced to think like neurotypical children (as is frequently the case) in order to be successful, neurotypical children are forced to think like a child with autism in order to be successful.

Even though the readers appreciate Ted’s extraordinary brain and acknowledge that it can help to solve the mystery, his family does not and ignores him when he tries to provide his thoughts and input about the situation. Even though his sister Kat works with him to solve the mystery, she eventually runs off without him despite his protests and tells him, “I’m sorry, Ted. You’re really good at thinking, but you’re no good at doing. If you come with me, you won’t be any use” (Dowd 188). Kat sees Ted’s foreign operating system as a great ally to help her discover what happened to Salim, but she uses him as a resource rather than a partner. Despite the fact that the readers respect Ted, his family still has no respect for him.

When Ted announces to his family that he has discovered what happened to Salim, he is completely brushed aside and ignored. His mother “[pats his] head as if [he’s] said nothing” and his father tells him that “now isn’t the time” (Dowd 252 & 256). Only when he finally conveys the information to his sister (who also refuses to listen at first) and she runs down the stairs to tell their parents do they listen. Toward the end, Ted reveals a significant insight: “When I talk to people about something I’ve found out, they don’t listen. When Kat does, everybody listens” (Dowd 305). This quote is extremely important in emphasizing Ted’s alienation from the rest of his family. Not only does his family not take him as seriously as they do Kat because of his disorder, but he also does not convey the same feelings and expressions as Kat, so they are undermined and forgotten. Because Ted does not shout and use the same sense of urgency as Kat, his family listens to his sister and not him. This section is especially important because it is

at the very end of the novel. Ted's family clearly does not exhibit any sort of story arc of understanding his cognitive difference in *The London Eye Mystery*. Although the family is grateful that Ted's unique brain was able to help find Salim, nothing changed to move this family dynamic forward regarding Ted's disorder. His family will always think of him as exotic, because they believe that it is this weirdness that led him to find Salim. They cannot see Ted as a person separate from his condition (even though they often try to forget about it)—he and autism are always connected, and he IS autism.

However, what does change is our relationship to Ted. At first, we adopt the outlook that Ted is unusual, because at the beginning of the novel we are not used to his differences and pick up on the attitudes of his family. Yet through experiencing the novel through Ted's perspective readers soon no longer view Ted as exotic, instead valuing his way of seeing the world and even adopting it themselves in order to understand the end of the mystery. The readers form a positive relationship with Ted and accept him for who he is, and this means that Dowd portrays him ethically to readers, even if his family continues to see him in a discriminatory way. Ted is a powerful main character who proves that he can solve the mystery of Salim even though everybody undermines and doubts his abilities. Readers can understand and empathize with Ted and see that he is not exotic, even though he may have characteristics that make him different.

### **Melting Down**

In *Melting Down: A Comic for Kids with Asperger's Disorder and Challenging Behavior*, I will examine autism as a metaphor in order to determine if this representation can still be ethical. I will ultimately argue that *Melting Down* presents a derogatory portrayal of autism because the character with autism is created with an ulterior motive to advertise to audiences, not to connect with audiences.

The story begins with an introduction from Jim Balestrieri, the CEO of Oconomowoc Residential Programs. He claims that “In an ideal situation, this companion children’s book will be used therapeutically, to communicate directly with these amazing children, and to help support the work ORP and companies like ours are doing” (Krukar et al. v). Balestrieri directly claims that this novel is intended for an audience of children who have autism (and the title of the comic indicates the same: “A Comic *for* Kids”). However, the title of the comic is startling, because a meltdown is characteristically negative. The novel indicates that someone or something will be “melting down” (and it ultimately ends up being the protagonist who has autism, Benjamin).

On the cover of the novel, Benjamin sits against a tree with his back to readers, looking at a train puzzle that has pieces missing. This echoes the Autism Speaks puzzle piece metaphor of absence; therefore, the title page indicates not only that children who have autism are “melting down” or have meltdowns, but also that they are missing pieces or are not fully there. Although Balestrieri tells us that this graphic novel is for children who have autism, it is clearly made for parents who are trying to manage their children and find a way to “deal” with their issues.

One of the positive aspects of this graphic novel is that the illustrations allow us to step inside of Benjamin’s world with him. For example, Benjamin is passionate about trains, so not only is there a train on the front cover, there is also a train track on the first pages of the novel that weaves its way from the gutter into one of the panels and back out (Krukar et al. 1). The first page is a light, calm shade of blue, indicating that Ben is happiest and most relaxed when he is playing with his trains, just as he is in the very first panel (Krukar et al. 1). A variety of neatly stacked train parts and tracks surround Benjamin, and his bedspread also has trains on it. Two small speech bubbles call Benjamin’s name in the panel, but all we focus on is the large picture

of Benjamin and his trains. We can relate to Benjamin—he is in his own world, and we are right there with him. Benjamin is not trying to ignore his father, but he is so invested in his trains that he can hardly hear him, and the size of the speech bubbles indicates this to us. The pictures in *Melting Down* allow us to step into Benjamin’s world and see why he acts the way he does and better understand him as a protagonist so that parents can better relate Benjamin to their own child.

This happens multiple times throughout the novel, such as in another panel in which all of the other students in class are laughing at Benjamin (Krukar et al. 20). In the second panel on the page Benjamin begins to excitedly talk to the girl next to him about history, but he does not realize that he is supposed to be paying attention to his teacher while she explains a lesson. One of the other students comments, “What a loser” and the next panel shows a bright yellow background (a stark difference from the other panels on the page) with “HAHAHAHA” etched obnoxiously in black. All of the students look toward Benjamin and laugh, the teacher looks on and says nothing, and Benjamin’s face is large and forlorn in the left-hand corner of the panel. Readers understand why he made this outburst; the first caption on the page reads “[I] was eager to put my new social skills to the test. I was going to try to make a friend!” (Krukar et al. 20). The combination of this caption and the images that follow allow us to step into Benjamin’s world and see that he meant well but was misunderstood because he has autism and thinks differently. This page also shows us that it is not always the child who has autism that is in the wrong. Often the other general education students (and even the teachers) who are not accepting are to blame.

The combination of captions and illustrations help readers to understand what Benjamin is going through. Benjamin often has violent outbursts when his routine changes or someone

does something he does not like, such as when his father makes him pancakes for breakfast when his mother is supposed to make him French toast. Even if we can understand the reasons behind his actions, Benjamin is violent to the point where it is unsafe for him to be around his classmates and siblings. Benjamin is sent to Genesee Lake School, a residential school where professionals help Benjamin to understand his feelings and keep his actions safe and under control. During one outburst, Benjamin's aid asks him to take some time to cool down: Benjamin's subsequent speech bubble reads, "With no one threatening punishment, yelling at me, or holding my arms down, my feeling of rage passed quickly. I was left feeling drained, exhausted, and most of all confused" (Krukar et al. 34). The illustration shows a sound wave that is loud and out of control with orange in the background slowly decreasing into a calm, steady wavelength with blue in the background (Krukar et al. 34). This is a powerful representation of Benjamin's meltdown fading away—we are in tune with Benjamin's emotions and see why he reacts the way he does, and we also see that this method of taking a break from the situation works well for him. Although he gets distressed when people are yelling at him, if he is spoken to calmly and not touched, he can calm down much faster and have a better handle on his emotions.

Although the novel ultimately appears to ethically represent autism because we are able to see Benjamin's perspective shine through, *Melting Down* has ulterior motives. Jim Balestrieri, the author of the introduction, is the CEO of the residential program that Benjamin attends in the novel. In "A Note About This Book", it blatantly states "Those who do resemble [Benjamin] face challenges that have made it difficult to benefit from education in the public school system. At Genesee Lake School, we strive to build relationships with the children in our care so that they learn new skills that will lead to a successful return to their home, school, and community"



(Krukar et al. vii). Clearly, the purpose of this novel is not to have children who have autism see themselves reflected in a graphic novel, as the title and Balistreri's introduction might indicate. Rather, the novel is intended for parents of children who have autism in order to convince them to send their child to one of the companies' residential schools. Thus, it is difficult to take any part of this graphic novel seriously or to see this initial "understanding" of Benjamin as anything more than a means to an end. The authors want parents to read this graphic novel so that they will be swallowed into the company and Balestrieri will earn money.

Before Benjamin attends Genesee Lake School, his life is practically falling apart. Nobody can understand him, and he ends up stabbing himself and another student with scissors in a dispute over paint in art class. However, once Benjamin's parents decide to send him to the residential school, Benjamin's life immediately begins to change for the better. He adapts to the new schedule, makes friends, and eventually returns home and receives his high-school diploma. *Melting Down* is not for or about children who have autism, although it may seem so on the surface. This novel is a disturbing metaphor—it is an advertisement for Genesee Lake School and Balistreri's other residential schools. Using Benjamin's story, *Melting Down* is meant to convince readers that if the program works for Benjamin, then perhaps it will work for your child with autism, too. This is incredibly unethical, and this book about autism should not be used in schools.

## **Conclusion**

There are a variety of risks associated with incorrectly representing protagonists with autism to youth. Children who have autism might become discouraged and will no longer want to read books with autism characters, because they do not see themselves portrayed positively. Furthermore, children who do not have autism will develop the wrong idea about children with

autism (whether this is that they are exotic or weird, they are a problem, they must overcome their autism, and more) and this will develop even more stigma surrounding autism rather than clarify it. In order to ethically represent autism in children's literature, it is important to consult children with autism and adults who have experiences with these children, give the character with autism a voice that allows readers to empathize and connect with them, make the character with autism the center of the novel or the narrator, and give the character goals, hopes, and dreams that do not require them to "overcome" their autism in order to be successful. These novels should present protagonists with autism who both empower other children with autism and inspire neurotypical children to be a friend.

## Chapter Two: How to Say “Unethical Sibling Representation” Out Loud

In this chapter, I address sibling relationships in children’s novels about autism and explore scenarios in which the sibling of a child with autism is the protagonist of the novel. These texts are beneficial when they are relatable to children with autism and their families, and children read about experiences and struggles that they can recognize in their own lives. They are also ethical when the sibling in the novel struggles to understand their sibling with autism but ultimately comes to some place of acceptance or empathy. Novels are often ethical when the protagonist has a connection with their sibling with autism and shares moments with them throughout the novel (whether these moments are good or bad). It is important that readers do not see the child with autism in a negative light, even if the protagonist describes them negatively. Finally, they advance education when the author of the novel has a desire to educate readers about what it means to have autism and facilitate inclusion of different abilities. However, these novels can tread into more unethical waters when the protagonist centers the story around themselves and how they overcame the difficulties of “dealing” with their sibling with autism. Narratives like this can convince readers that children with autism are a burden or a problem for their siblings and the other people in their life to solve, and this dehumanizes them.

### **Little Big Sister**

When author Amy B. McCoy wrote the elementary-level novel *Little Big Sister*, she created characters that are inspired by her own two children, Matthew, who has autism, and Kathryn, who is neurotypical. I argue that although autism is occasionally presented as a burden on the sibling, overall this novel advances autism literature by presenting an ethical view of autism. This argument is based upon my interpretations of the text as well as an interview that I conducted of McCoy.

McCoy is a former elementary school teacher and has a blog called *Dancing in the Rain* that she began in 2013 about her children, and many of the concepts in the blog reflect the novel's ideas. In a blog post, McCoy remarks, "It is happening right before my eyes—Kathryn is surpassing Matthew. In every way—physically, socially, emotionally, academically—she is light-years ahead of him. She has become his 'little big sister' which must be a confusing place for a seven-year old." She admits that, "I want to make sure we are celebrating Kathryn's accomplishments but I don't know how to do this without feeling we are leaving Matthew behind. Meanwhile, we celebrate Matthew's accomplishments so easily" (McCoy). McCoy admits that she does not have all of the answers about parenting a child who has autism and does not know what is right in every situation. This blog helped to inspire her novel, as she even references the "little big sister" idea that later becomes her novel's title.

McCoy remarks that the purpose of her blog was, among other reasons, "to help people (including my own friends and family) 'get it' better about what life is like for families who are raising a child with autism or any disability" (McCoy). Yet instead of speaking from her own perspective as she does in *Dancing in the Rain*, McCoy wrote *Little Big Sister* from the perspective of her daughter, who is the sibling of her child with autism. She remarks, "Once I realized that my daughter's friends also desired to 'get it' better- I came up with the idea for the book" (McCoy). I selected this novel to be a part of this study because it is self-published and was the winner of the 2017 Next Generation Indie Book Awards for Children's Fiction. It has also circulated widely among elementary schools, and McCoy's website states that *Little Big Sister* is "suitable for classroom use"; it offers a reading guide for students to use in order to connect with the book. Because of this, I wanted to determine whether the disability representation in the novel is positive.

Because *Little Big Sister* is based upon McCoy's own children, I asked her if she allowed her daughter to contribute to the writing process, given that the novel was from her perspective. McCoy shares, "Kathryn gave me content ideas by sharing with me what occurred at school – both what she observed with her own classmates and with her brother. When something would happen at home with my son, we would look at each other and ask, 'should that go in the book?' and we'd decide together" (McCoy). Through directly consulting a sibling of a child with autism and incorporating her daughter's thoughts and ideas into the story, McCoy is able to paint a more realistic story.

*Little Big Sister* is narrated by nine-year-old protagonist Katie, whose older brother Mikey has autism. In the novel, we see a glimpse into Katie's life as Mikey's "little big sister." When Katie tries to call for her mother, she cannot come right away: it is always "in a minute", because she is constantly preoccupied with Mikey (McCoy 2). When Katie wants to go to the mall, Mikey has to come along and throws a temper tantrum after he is forced to leave the computer store, cutting the shopping trip short (McCoy 35). Katie reveals to readers how it feels to have a brother with autism: "No one knows what it's like for me. What it's like to have this brother who is so annoying. I know other kids have siblings who irritate them. Big brothers who wrestle them or little sisters who copy them all the time. It's different for me. My brother is a big brother who acts like a little brother. Even though he is older than me, he seems a lot younger" (McCoy 13). Katie is also honest with readers about the embarrassment that she feels when she is in public with her brother: "I noticed some teenagers, pointing and staring at us. I really wanted to disappear" (McCoy 35). As much as Katie loves her brother and is aware that the teenagers are being disrespectful, she cannot help feeling as though her brother causes others to ostracize her with his outbursts. This is relatable for any children who understand what it feels

like to have a sibling that acts differently than the rest of the world expects them to. Katie struggles to live with a brother with whom she cannot have the same relationship that her peers can with their siblings.

Although Katie is honest about the difficulties of living with her brother and is open about what she sometimes dislikes about him, the narrative demonstrates ways in which Katie embraces her brother for who he is. She remarks, “That’s [a] good thing about Michael. He always cheers people on, even if they don’t want to be cheered on, like me” (McCoy 10). As she watches her brother have a meltdown, she “[wishes] [she] could hug him to make him feel better but also [wishes] he would just stop screaming. I hate when I feel that way—like I love him and hate him at the same time” (McCoy 43). Katie is a down-to-earth character who openly discusses her feelings with readers, so they are able to understand why it is difficult for her to be Mikey’s sister sometimes. Yet readers do not perceive Mikey negatively, because Katie makes sure they are aware that he sees the world differently than other people and his actions are out of his control. She also shows readers the ways in which Mikey’s differences make him great (such as when he cheers for others), which some authors who write about autism fail to mention.

One implication of having a sibling as the central character in a text about autism is that they will paint their own reality, not the reality of their sibling with autism. In *Little Big Sister*, Katie has relevant experiences to which children who have a sibling with autism can often relate and sympathize. For example, Katie invites her friend Mia to her house and becomes frustrated when her friend does not understand Mikey. When Mikey shrieks with delight after receiving an email from a friend, Mia says to Katie, “Does [Mikey] always make those noises? Your house is loud!” (McCoy 48) Katie does not say anything directly to Mia, because once again she feels embarrassed by Mikey, but she responds to readers, “I’ve seen [Mia’s] brother and sister at the

playground, and they make a lot of noise. But deep down, I know what she meant, and it hurt my feelings. Michael's happy sounds are so different from most other kids' sounds of happiness" (McCoy 49). Children who have siblings with autism often feel nervous about their friends interacting with their sibling and feel defensive when friends are not understanding or accepting. Katie's brother may be different from Mia's siblings, but Katie recognizes that this does not mean his sounds are bad. *Little Big Sister* does not present a derogatory treatment of children with autism, because Katie acknowledges that Mia's comment was unfair to Mikey and hurtful to her. We do not experience Mikey's perspective in this scene because Katie is the central character; however, a great deal of Katie's experiences, such as this one, directly connect to her brother.

*Little Big Sister* tackles not only autism, but also how to educate friends and peers about all different abilities, thus taking on a pedagogical perspective. McCoy's reason behind writing *Little Big Sister* was so that she and her daughter could help others "'get it' better," and this is reflected in the novel. When Katie becomes frustrated about the way that people treat her brother, she and her two friends decide to create a presentation for their class about how to treat people who have different abilities. They tell other students that "people with disabilities have feelings, too," they instruct them to "please [not] point or stare," and instruct, "when talking to a student who has special needs, please use your *regular* voice," (McCoy 107 & 116). Katie not only recognizes her brother's strengths and accepts him for who he is in *Little Big Sister*, but she also advocates for him and other children who have different abilities in order to educate her peers about inclusion. This pedagogical moment in the text confirms Katie's understanding of her brother's autism, thus centralizing Mikey in the novel as a positive figure.

Katie is a powerful protagonist and sister that inspires other children who have siblings with autism to embrace, accept, and advocate. *Little Big Sister* also provides a pedagogical perspective that allows children to learn not only about what it means to have autism, but also how we should treat all people who are different than us, making it a great text for elementary schools to use. Children can relate to Katie's struggles as well as learn from and understand her moments of frustration, yet ultimately see that she loves to be Mikey's "little big sister." She says to her mother, "I never thought I would say this, but I'm glad Mikey is my brother" (McCoy 135). The novel ends with a list that Katie creates called "What's RIGHT with Mikey" and lists his strengths, such as how he is a great reader and makes others smile (McCoy 136). Her brother may not be like all other brothers, but she sure does love him. Katie acknowledges that too often, people focus on what is *wrong* with people who have disabilities and not what is *right* with them, and she fights to alter that stereotype. For these reasons, I argue that *Little Big Sister* is a powerful novel that has an ethical representation of a child's experience with a sibling who has autism. This text can also teach children to accept and be kind to people of all different abilities.

### **How to Say I Love You Out Loud**

I will investigate autism as a burden on the sibling in the young adult novel *How to Say I Love You Out Loud* by Karole Cozzo. Unlike *Little Big Sister*, this novel provides an unethical autism portrayal because of the flawed protagonist's dehumanization of autism, her lack of understanding about autism, and the absence of any connection to her sibling with autism. This is not to say that the text should not have been written, because the protagonist displays many real human reactions; instead, I argue that it is not a good text to teach children about autism.

This is Cozzo's debut novel, and she was inspired to write it because of her experience working with students with different abilities and their families. She was interested especially in



exploring the sibling dynamic in these families, because “many kids are forced to be mature from such a young age, and at times their needs are going to have to come second because there might be someone with more pressing or immediate needs” (Cozzo). Cozzo has published other books on Swoon Reads, a website that contains free romance books for teenagers. Similar to her other books, *How to Say I Love You Out Loud* is mainly a romance novel, but a large part of it also incorporates the protagonist’s sibling with autism.

*How to Say I Love You Out Loud* is a first-person novel narrated by Jordyn Michaelson, who is just beginning her senior year when she comes to find out that her younger brother Phillip’s special education school has shut down, so he needs to attend her school until Jordyn’s parents can find a new school for him. Unlike Katie’s descriptions of Mikey, Jordyn’s descriptions of her brother with autism are all negative. For example, she remarks, “Phillip does everything to stay in his private little world—as distant as possible from the rest of us” (Cozzo 22). Katie, a more powerful protagonist, would likely have phrased this in a more positive way that indicates understanding; perhaps she would have said that her brother likes to have space sometimes because that is what his brain needs, but he still loves his family. Jordyn dehumanizes her brother with this quote, because she makes him appear to want nothing to do with people, even though Jordyn should know that as a child with autism he struggles to express his emotions. She already seems to be an unreliable narrator; and because the novel is told from her first-person perspective, we only receive biased information and descriptions of Phillip from her.

Later there is another clear example of Jordyn’s lack of understanding about Phillip and autism. Jordyn whines, “Phillip is so damn oblivious to the damage he causes. It’s Phillip’s world and he can’t see beyond it to how *his* world sometimes really messes up other people’s worlds” (Cozzo 100). Jordyn refers to Phillip’s actions as “damage,” which dehumanizes him

and reduces him to a problem. While nine-year-old Katie can understand the reasoning behind her brother's actions and realizes that he never tries to be selfish, seventeen-year-old Jordyn cannot comprehend that Phillip is not out to destroy her life. Even though Jordyn reveals to readers that she spent a summer working at a special needs camp, readers discover that she has little to no understanding of and acceptance toward different abilities. She exhibits no empathy toward her brother and essentially sees everything that he does as a direct attack on her. Jordyn claims that Phillip is selfish because it's his world "and he can't see beyond it," but Jordyn cannot see beyond her own world either. Although her parents' reasoning for sending Phillip to her school is reasonable, she is furious because all she cares about is how she will be affected. She does not consider the position of her parents, let alone Phillip—they are likely unhappy with the situation as well, but they know Phillip must attend school so that he does not fall behind. She complains to them, "Why can't he just stay at home till he can go somewhere else?" (Cozzo 38) When her parents assure her that this change should only last until November, she shouts, "By November, my life will be over! Thanks" (Cozzo 38). Clearly Jordyn views Phillip more as a burden that will ruin her school social life than a person with thoughts and feelings.

During this argument with her parents, Jordyn narrates to readers, "It's not fair. I cannot deal with Phillip at school. I can't take the whispers and stares, having them turned in *my* direction once everyone realizes what Phillip's last name is" (Cozzo 35). Jordyn is not actually worried about Phillip being made fun of at her school; rather, she is concerned with herself and the negative attention that she might receive if people were to find out that they were siblings. Once again, Jordyn demonstrates that she is selfish and does not see Phillip as her equal. She would prefer that he stay home and receive no education than he attend her school, where he might occasionally pass her in the hallway but would never have a class with her. Cozzo creates

Jordyn as a selfish character so that she can have a character development arc as the story goes on, but ultimately this arc is unsuccessful, making Jordyn a flawed protagonist.

Jordyn is so obsessed with popularity and the social hierarchy at her school that she decides without any hesitation that the solution is to pretend she does not know Phillip. In fact, readers discover that ever since Jordyn began attending her new school, she never told anybody about Phillip, including her best friend, Erin. Instead, she came up with lies about why Erin could never come over to her house. Now that Phillip must attend her school, Jordyn decides that instead of being honest with herself and her peers and standing up for her brother, she must ignore his existence at her school. This only further dehumanizes Phillip, because it shows that Jordyn is ashamed of him; even though Katie was sometimes embarrassed by Mikey's actions, she was never ashamed of him. *How to Say I Love You Out Loud* depicts Phillip's autism as a problem. Because of this, children with autism cannot look to this novel for powerful characters as researcher Carol Ann Moore claims they should be able to: she says, "The literature should provide role models for the disabled who read the material" (277). Jordyn is far from a role model, and her negative depictions of Phillip do not allow us to see him as a role model either.

When Jordyn passes Phillip in the hallway on the first day of school, he has a panic attack because of the loud fire alarm and begins to yell. His aid tries to help him calm down, but Jordyn knows he needs to put his headphones on in order to feel relaxed again. However, instead of rushing over to help, she helplessly watches the scene unfold: "I don't know why I don't push my way through the crowd and rush to help my brother, as I'm the one person there who knows what he needs" (Cozzo 49). Only when the students disperse for class and nobody can see her does Jordyn go over to Phillip and place his headphones over his ears. We are asked to be critical of Jordyn in this section of the text because even though she could have helped Phillip much

sooner, she allows him to continue to be in pain and his aid continue to struggle for a solution because she is so mortified that somebody could see her and associate her with her brother. Jordyn judges her brother for who he is, and now we know that because of this, she assumes that everyone will judge her for who she is if people know that they are related.

Jordyn prioritizes her popularity over her brother so much so that she allows students to make ignorant comments about people with different abilities (namely Phillip) and does not correct them. For example, “Erin...innocently wondered aloud at lunch if [Phillip] was ‘crazy, or maybe retarded, or what?’” (Cozzo 52) Due to Jordyn’s extensive knowledge of disability, even if Phillip was not her brother she should have interjected and told Erin that the “r-word” is derogatory and explained that having a different ability does not make you crazy. Even if she could not open up about Phillip, at the very least she should have educated her friend—Erin was not well-informed, and if she knew that the word was offensive she would not continue to use it.

When Phillip has a meltdown at school, the other people at Jordyn’s school refer to it as “hilarious” (Cozzo 65) and one student claims, “That kid was out of control. He didn’t think twice about attacking the person who was trying to work with him” (Cozzo 66). Jordyn is frustrated by the lack of respect for her brother: “They don’t know him at all. Yet they assume he is crazy, violent. Likening him to a possible criminal, a possible murderer” (Cozzo 67). However, she still refuses to come forward to defend him (or any children with different abilities, for that matter) because she cares so much about what her ignorant and immature student body thinks about her, and the text does not critique her for this concern because the novel is a first-person narrative. Jordyn understands that Phillip was trying to escape his aid, not attack him, and she acknowledges that everyone’s perceptions are flawed, but she does not try to tell anyone this for fear of losing popularity.

When Jordyn is at a bonfire with her friends, the rumors about Phillip only get worse, and Jordyn has to run away from the crowd. She reflects, “He’s still a person. He’s not a joke to share around a bonfire. // My life is not a laughing matter” (Cozzo 68). Yet claiming that Phillip is “still a person” is not quite a positive description. Rather, it seems to indicate that even though Jordyn’s brother is nothing short of a nuisance in her life, he is “still a person.” Not only this, she says that *her* life is not a laughing matter, once again making Phillip’s autism about her. She does not want to defend Phillip for his own sake and the sake of all of those with different abilities as much as she wants to defend herself. Everyone is laughing about her brother, and she is related to her brother, so she decides that everyone is laughing at her. Sadly, this is ultimately what she cares about, not Phillip.

*How to Say I Love You Out Loud* places the sibling at the center of the narrative, which casts the child with autism to the wayside. Phillip becomes an object and an obstacle in the novel, and he is used as nothing short of an aid in the story arc. Disability theorist Scott Pollard emphasizes this as one of the “pitfalls of disability fiction” when he discusses the “second fiddle phenomenon”: “The character with an impairment is neither the central character within the narrative nor fully developed, merely serving to bring the central character/s to a better understanding of themselves or disability” (264). Phillip fits Pollard’s pitfall in *How to Say I Love You Out Loud*, because he helps Jordyn come to some conclusion about disability without ever connecting with her or being a fully developed character. This is another reason why I argue that this novel presents a negative representation of a protagonist’s experience with a sibling who has autism.

Jordyn decides to talk about Phillip with her crush, Alex, when he notices that she is upset and questions her. Alex tells her, “For the record, our friends out there, they’re not bad

people, right? If they knew he was your brother, they wouldn't be talking like that in front of you" (Cozzo 71). Instead of correcting Alex and telling him that they should not talk like that at all, Jordyn is fixed on Alex keeping her secret: she demands, "You're not going to tell anyone, are you?" (Cozzo 77) Jordyn lacks the perspective that if other people make judgements about her because of Phillip, then they are in the wrong, not her. Jordyn decides that rather than revealing the truth that Phillip is her brother and stopping the untrue and offensive rumors, she should continue to conceal her life and pretend that her brother does not exist when they are at school. At least Alex has some perspective about Jordyn's choice, as he remarks, "It's a shame you never gave anyone a chance here. Kinda sucks you chose to handle it that way" (Cozzo 76). Furthermore, when Erin eventually finds out the truth, she tells Jordyn, "Phillip being your brother wouldn't have made me see you any differently. But I sure see you differently now" (Cozzo 141).

As the novel progresses, Jordyn continues to make poor decisions and hold negative beliefs about her brother's autism. When her mother gets excited because Phillip has been invited to a special needs ball, Jordyn accuses her of being selfish for wanting to go to something Phillip would hate, when in reality her mother wanted Phillip to receive the recognition that Jordyn has received her entire life (Cozzo 104). Eventually Jordyn turns everyone against her because of her negative perceptions of Phillip: her mother, Erin, and even Alex. We as readers are meant to be sympathetic towards her as others criticize her, because as we have been following her story we "understand what she is going through."

However, what is most critical about the autism representation in *How to Say I Love You Out Loud* is the way that the author wraps up the novel. Jordyn decides to enroll in a speech competition, and she gives an elaborate speech in front of a large audience about her brother: "I

love you, Phillip, and I'm proud of you. You are ten times stronger than I'll ever be. You are not weird, crazy, retarded, or psycho. You are strong, brave, funny, and resilient...I love you, and tonight, for you, I take that feeling beyond the privacy of our home or the quiet confines of my heart. I'm going to work on loving you out loud" (Cozzo 189). Jordyn expresses a love for Phillip in front of a crowd that she never expressed privately to readers, which makes it seem exaggerated. Disability theorist Carol Ann Moore elaborates on this in "Portrayals of the Disabled in Books and Basals" when she claims that "characters with disabilities should not always be illustrated as the recipients of charitable acts by the non-disabled" (277). In this scene, Jordyn conducts the charitable that Moore describes because she uses her voice to speak for Phillip because Phillip is unable to speak for himself.

Given that Jordyn spends the majority of the novel complaining about and pretending she does not know Phillip (she even admits in the speech: "I've done worse than reduce Phillip to a robot; I've reduced him to a problem), it does not seem realistic that she makes this sudden turnaround. And even though Jordyn claims to now be "loving [Phillip] out loud," she delivers this speech to a group of strangers and refuses to show the tape of her speech to anyone except for her mother, as a sort of apology. Despite this speech, Jordyn keeps her feelings about Phillip under wraps. Even at the end of the novel after Jordyn has accepted Phillip, she still makes his autism all about her through giving a speech in which she receives all of the recognition, not Phillip. She claims that she loves him even though she never connects with him throughout the course of the novel.

The ends with Jordyn and Alex locked in a loving embrace after having kissed and confessed their feelings for one another. Phillip is nowhere to be found. This novel does not promote positive views of autism, because Jordyn teaches a philosophy that siblings with

different abilities are an embarrassment and they will in turn make you an embarrassment. Jordyn is a weak protagonist, and while the novel may be an enticing romance for young adults, it is not one to be used to consult autism. Jordyn consistently belittles Phillip, turns him into a problem, and makes his autism all about her. There is never a true moment of connection between the siblings, even after Jordyn delivers her speech and claims to accept and love Phillip for who he is. Rather, this moment reflects the “means of testing or enhancing [the protagonist’s] moral standing” and is a form of literary representation of disability that critic Ato Quayson cautions against (36). Instead of a fully-defined character, Phillip is a literary trope used to help Jordyn’s morals shift and develop. Because of this, *How to Say I Love You Out Loud* would be especially derogatory if a child with autism were to read it.

## **Rules**

I will investigate overcoming autism in *Rules* by Cynthia Lord in order to conclude that the novel depicts an ethical autism sibling relationship. *Rules* is Lord’s debut novel and received the Newbery Honor book award. It is about a twelve-year-old named Catherine whose younger brother David has autism and whose entire family “revolves around his disability” (Lord). Catherine wants to help David to be “normal,” so she spends her time constructing a list of different rules for him to follow. Before the first chapter begins, readers see a list of some of David’s rules scrawled in Catherine’s handwriting, such as “If someone says ‘hi,’ you say ‘hi’ back” (Lord). A lot of Catherine’s rules teach David general manners like this one, but others teach social cues such as, “Sometimes people laugh when they like you. But sometimes they laugh to hurt you” (Lord). This is not a rule to follow so much an idea that Catherine wants David to keep in mind; because David has autism and struggles to read facial expressions and social situations, he does not understand when their neighbor Ryan is teasing him.



Catherine's has justification for creating David's rules: "If my some-day-he'll-wake-up-a-regular-brother wish doesn't ever come true, at least he'll know how the world works, and I won't have to keep explaining things" (Lord 9). Even though David loves the rules, Catherine clearly wants David to "overcome" his autism, because the purpose of the rules is to help him see the world just like everybody else does (and most importantly, like she does) (Lord 4). Murray identifies this 'overcoming' narrative in *Representing Autism* and questions, "The dominant arc of most disability narratives is a movement from the representation of an impairment to the overcoming of the difficulties that are seen to come from it" (xvi). *Rules* appears to follow this trajectory, because Catherine directly states that she wishes that David did not have autism, and constructs her list of rules a way to "fix" her brother and make him as close to "normal" as possible.

Yet unlike Jordyn in *How to Say I Love You Out Loud*, Catherine has a close connection to her brother. Although she struggles to understand him and desperately wants to change him, she still works to understand his world as she helps him understand her own. Not only does Catherine create and teach David his rules, but she also engages in activities that David likes. The two siblings often speak in lines from their favorite book series, *Frog and Toad*, and this makes it easier for David to communicate. According to Catherine, "Mom says David'll never learn to talk right if we keep letting him borrow words" (Lord 57). Still, Catherine knows that her and David's *Frog and Toad* conversations are a lot more than David "borrowing words." At the end of the novel she claims, "Tomorrow I'm going to tell Mom she has a point about David needing his own words, but other things matter too. Like sharing something small and special, just my brother and me" (Lord 200). Even though at the beginning of the novel Catherine attempts to normalize David through the creation of her rules and wishes that he did not have

autism, it is evident that she cares a great deal about David and shares a special relationship with him. Conversely, Jordyn never shares a single moment with Phillip in *How to Say I Love You Out Loud*—her brother is merely a nuisance and a burden to her, and because she has no connection with him readers never form one, either. Phillip is alien to readers because they never have the opportunity to learn about him except through Jordan, but many of the scenes in *Rules* are centered around interactions between Catherine and David, so readers get to know David well.

Catherine uses a variety of figurative language to describe David and his autism. For example, she remarks, “Talking to David can be like a treasure hunt. You have to look underneath the words to figure out what he’s trying to say” (Lord 38). She creates a positive comparison, because a treasure hunt may be difficult but is still intriguing and exciting. With this language, Catherine also indicates to readers that she works hard to interact with her brother and understand what he is communicating to her, something Jordyn never does. Later in the novel, Catherine uses a more negative simile to describe David: “How can his outside look so normal and his inside be so broken? Like an apple, red perfect on the outside, but mushy brown at first bite” (Lord 110). Catherine refers to David as “broken,” which is dehumanizing, and she essentially describes David’s autism as negative. Her description of David directly relates to Murray’s description of autism: “The autistic body, unlike most physically impaired bodies, does not often signal its disabled status. It can however, suddenly display...an obvious behavioral difference” (“Autism and the Contemporary” 29). Throughout the novel Catherine hopes to help David overcome his autism and be as “normal” on the inside as he looks on the outside, which is a limitation of *Rules*.

*Rules* shows us many sides of Catherine: even though she is a sister, she is also a daughter and a friend, and it is tricky for her to play all of these roles at the same time. Catherine's parents often ask her to babysit David, and even though they take David to the video store, they refuse to take Catherine to the places that she would like to go. As Catherine phrases it, "Everyone expects a tiny bit from him and a huge lot from me" (Lord 61). Unfortunately, Catherine's parents do not always listen to her and her needs, and in one scene her mother even tells her, "[David] needs more from me. Stop overreacting" (Lord 111). *Rules* provides an important autism representation, because many siblings of children with autism can relate to this lack of attention from their parents. *Little Big Sister* begins with a scene in which Katie tries to get her mother's attention but knows that her mother will never be there for her right when she needs her. *Rules* is reminiscent of this idea, and for this reason it can help autism siblings see themselves reflected in the books that they read. It is not easy to constantly have your needs placed second, and Catherine eventually tells her parents, "Maybe he *does* need you more than me, but that doesn't mean I don't need anything at all" (Lord 187).

Although Catherine longs for a life of normalcy, she also wants to protect her brother: she says, "I feel like I'm ripping in half. One half wanting to run away and be a regular person with my friends, but the other half is scared to leave David because he can't make it on his own" (Lord 119). Unlike Jordyn, Catherine feels compassion for her brother and wants to protect him. Even though she wishes she could have a brother "who'd give back as much as he took, who I could joke with, even fight with," Catherine stands up for David when Ryan makes fun of him in front of her new friend Kristi, proving that she chooses her brother over popularity; Jordyn makes the opposite choice. While Jordyn pretends that her brother does not exist for the majority of *How to Say I Love You Out Loud*, Catherine tries to help her brother navigate life as a child on

the autism spectrum. Ultimately, Catherine accepts that she will always feel “pulled between the regular world of school and friends, and David’s world where none of the same things matter” (Lord 135). She exists in both of these worlds rather than putting her friends and her social life over her brother the way that Jordyn does.

The novel ends with a heartfelt scene between the two siblings; David breaks one of Catherine’s rules and puts a toy in the fish tank, but instead of getting angry at him she laughs. In this scene, it becomes clear to readers that even though Catherine has spent a great deal of time trying to “fix” David and wishing that he could fit into society’s mold, she accepts that he cannot follow every single rule, and that is okay. Catherine learns to let go of her worries and allows this moment with David to “be enough” (Lord 200). This is a powerful end to the novel, because it demonstrates that Catherine loves her brother for exactly who he is, and they experience a beautiful moment together. In *How to Say I Love You Out Loud*, the novel ends with a passionate embrace between Jordyn and her crush. While *Rules* attempts to show the evolution of a sibling relationship, *How to Say I Love You* is far more focused on a romantic one that does not involve the child with autism at all.

*Rules* portrays autism as something that needs to be overcome in multiple instances. Catherine creates a list of rules to normalize her brother, she describes him as “broken,” she wishes that he did not have autism, and she even draws a picture of her family in which she has a pretend neuro-typical older brother instead of David (Lord 140). Yet I think that these moments were important to the story, because they displayed Catherine’s human and very real feelings and frustrations. We are asked to sympathize with Catherine through these feelings and at the same time see her flaws. While centering her in the narrative provides us her views rather than David’s, we also experience David’s actions and can form our own opinion of him. And even

though Catherine sometimes has negative feelings, she still maintains a close connection to her brother and always wants the best for him. The novel is about the relationship between Catherine and David, and their relationship may not be perfect, but it is certainly special. Catherine eventually learns to embrace David for his differences, which is reflected in the final fish tank scene. For these reasons, I argue that this novel presents an ethical representation of autism.

### **Same but Different: Life on the Autism Express**

Told from two different perspectives, the novel *Same but Different* by Holly, Ryan, and RJ Peete presents an ethical representation of autism because although the sibling with autism is occasionally a burden for the other sibling, the same is true in the reverse. Not only does *Same but Different* examine Callie's perspective about her twin brother Charlie, who has autism, we also get to hear Charlie's perspective. I investigated whether centering the voice of a person with autism helps shift the depiction of the sibling relationship. Because the authors expose readers to two sides of the story, a more ethical representation of autism arises—the child who has autism has the opportunity to speak, rather than the sibling constantly speaking on behalf of them.

Similar to *Little Big Sister*, *Same but Different* is based upon the real-life experiences of two siblings with autism: Ryan and RJ. They collaborated with their mother to create this book, as well as a picture book called *My Brother Charlie* intended for a younger audience. Their mother Holly writes that, "Our hope is that by sharing our journey, as well as experiences from the many awesomely resilient autism families we have encountered over the years, we will open a sorely needed dialogue about navigating the nuances of autism and adolescence" (Peete et al.). Holly also adds that "as the mom of a black son, the anxieties are compounded," because society perceives black males as threatening, and due to RJ's autism, his actions can often be unpredictable (Peete et al.). This book takes an important step toward increasing diversity in

children's literature about autism and providing an outlet for children with autism, their siblings, and their parents.

Unlike the other novels that are explored in this chapter, this novel is intended for children with autism to read, enjoy, and see themselves reflected in their reading. RJ emphasizes this himself, including a special dedication: "To a kid with autism: I want you to know how special and valuable you are. Never let anyone tell you different. You have a voice" (Peete et al.). The family describes their journey as "The Autism Express," putting a positive spin on autism that combats the idea that autism is something negative or something to overcome (Peete et al.). Rather, the family works together, loves one another, and enjoys the bumpy ride.

*Same but Different* begins with Callie's perspective as she reveals that she is "a little more than excited and relieved about not being in the same grade as Charlie. No more cringing when my "has-trouble-talking" brother is forced to speak out loud in class. No more volunteering to be his partner for class projects because no one else wants to. No more being known as 'Charlie's sister.' I can finally be me" (Peete et al. 2). This emphasizes the trope of autism as a burden, because as much as Callie loves Charlie, she is thrilled to finally be rid of him in school. Yet shortly after this we turn to Charlie's chapter, and he claims that "I'm cool with the no Callie [in school] part. That girl is always trying to jump into my business. Always telling me that she's my eyes and ears for when I need help 'figuring it out.' Well, guess what. I can 'figure it out' without *her*" (Peete et al. 3). This is an ethical representation of autism, because we view the perspective of the child with autism as well as the sibling. We see that as it turns out, both siblings are relieved to be through with one another! Callie explains to readers why Charlie is so difficult to deal with in school, but Charlie also explains how frustrating Callie can be. They both bother one another, much like all siblings do at times; Callie's feelings of frustration are not

one-sided. This sharing of perspective convinces readers not to automatically empathize with the sibling who does not have autism, because Callie is not the only one in charge of the story. Callie and Charlie share this narrative, so they both control how they are represented.

Callie and Charlie's story is told in a variety of short stories about their experiences as siblings navigating the world together. As the siblings get older, Callie struggles with knowing when she should "step in or hang back" when it comes to Charlie (Peete et al. 8). Because Charlie is uncomfortable with speaking in school, he is dependent on Callie and wants her to explain how he works to his teachers, which becomes stressful for Callie; she must "step in." Yet later, Charlie is angry when Callie tries to stop him from hanging out with two freshman boys that he does not realize are taking advantage of him. Callie is forced to "hang back" even when she knows that something bad will happen to her brother. She complains, "*Why me?* Why do I have to be born the twin of a brother like you? Why do I have to be the strong one? Why can't I have it my way all the time, like you get?" (Peete et al. 34) Children who have siblings with autism can likely relate to Callie's human struggles and the feeling that their sibling gets to have everything.

Meanwhile, readers learn about Charlie's feelings: he asks, "Why me?" and "Why don't they get me?" (Peete et al. 38 & 39) Callie thinks that it is all about Charlie, but Charlie expresses how frustrating it is to be forced to do what he does not want to do, such as hang out with Callie's friends, wear gross-smelling deodorant, and go to the mall. Charlie also questions, "Why do people say I'm *autistic*? I hate that word," when Callie claims, "a word is just a word, and what does it really matter?" (Peete et al. 45 & 46) This demonstrates a way in which Callie is not accepting of Charlie's autism—she cannot understand what it is like to be Charlie, so she does not see why the word "autistic" is such a big deal to him. Eventually, Charlie expresses that

“autism *does* suck. It’s because of sucky autism that I can’t [do] whatever I want like every other teenager I know” (Peete et al. 147). Charlie develops a negative outlook on autism because he begins to feel burdened by his own ability.

*Same but Different* emphasizes, as the title indicates, the many ways that Callie and Charlie are different. They cannot read each other’s minds, so they do not understand the struggles that the other endures and do not empathize with one another. As the reader, we are able to see both sides and understand that nobody is “right.” Despite the siblings’ differences, the three authors demonstrate the special twin sibling connect that Charlie and Callie share. They have a secret door knock, and Callie helps Charlie create lists to stay organized with everything that he needs to do. Callie reflects, “Why do I know exactly what you like and what you hate, without having to ask? Why am I the one who can pick out the best birthday gifts, and know you will love my presents more than anything?” (Peete et al. 40) Charlie similarly reflects, “As much as Callie gets on my nerves, I’ll admit she understands me the best of anyone” (Peete et al. 48). The siblings sometimes become frustrated with one another, just as all siblings do. Their lives are a little bit different because of Charlie’s autism, but this does not mean that Charlie’s autism is a burden, even though Charlie is frustrated with the label.

The novel ends with Charlie going on a date and to the dance with Callie’s best friend, Jillian. Although Callie is embarrassed with how Charlie acts in front of Jillian, she ultimately realizes that Jillian likes Charlie for exactly who he is and embraces his differences. Callie writes an email to Charlie about how humiliated she felt as she watched him with Jillian, but she deletes it because “I know that’s got to be hard. I know you can’t help it. I know you weren’t doing any of this to me” (Peete et al. 173). Callie reaches a stage of understanding, acknowledging that this is who Charlie is and that she cannot be angry for it. Callie recognizes this much faster than



Jordyn, who refuses to even acknowledge that her brother Phillip exists, let alone accept him for who he is. Charlie does not fully accept his autism, but it is clear that the people around him do: Jillian tells him, “Don’t apologize for being you” (Peete et al. 171).

*Same but Different* showcases a sibling relationship that is far from perfect, but this is not *because* of Charlie’s autism. The twins become frustrated with one another for different reasons, but they also love and support one another. Although both siblings sometimes treat autism as a burden throughout the novel, they never convince the reader that autism is a burden. Rather, this novel shows readers two perspectives: what it is like to have autism and what it is like to live with someone who has autism. *Same but Different* accomplishes its goal to spread awareness about autism as readers learn about autism in a variety of ways.

## **Conclusion**

Texts like those addressed in this chapter can still treat autism ethically even if the character with autism is not the central focus, so long as we experience enough of the character in the novel and at least some positive aspects of the character are developed. The character cannot be built solely upon the sibling’s opinions, and the novel must focus upon more than a couple of interactions between the siblings that tell us about the character with autism’s thoughts, actions, and behaviors. The role of pedagogy to these sibling narratives is important, because it allows us to teach neurotypical children about what it means to have autism. Yet these novels can become unethical representations of autism when other factors (such as romance or other subsets of the main character’s life) prevail over the representation of the sibling with autism. The sibling relationship need not be settled to be ethical; that is, siblings may never fully get along. However, it is important for the audience to be able to separate the sibling with autism from the protagonist’s feelings about the sibling with autism.

## Conclusion

In this study, I have highlighted eight books about characters who have autism, identified the standards needed for these texts to be ethical, and concluded whether or not each text presented a constructive representation of autism and a positive educational impact based on the standards. The standards that I used to evaluate the books are based upon an accumulation of studies that I read from a variety of disability and autism theory researchers. The standards that I have developed for texts in which the character with autism is the protagonist include:

1. The character with autism should be placed at the center of the text's narrative.
2. The text should appeal to people who have autism as well as people who do not have autism. The text should *not* appeal to audiences who do not have autism as a sort of "survival guide" to deal with people who have autism.
3. The reader should be able to connect and empathize with the character who has autism at some point in the text.
4. The character with autism must not make efforts to "overcome" their autism, and if they do make these efforts, they should come to realize that they need not overcome their autism (although coping mechanisms can be used).
5. The character with autism should not be treated by the text as an object of pity.
6. The text should not convince the reader that the character's autism must be "cured." Autism should not be treated as a disease.
7. The text must not convince the reader that the character who has autism is exotic or unusual, even if the characters in the text believe this to be true.
8. The character with autism must not be used as a metaphor, literary trope, or plot device in the text.
9. Autism should not be treated as an absence or lack of something in the text.
10. The character with autism may have negative thoughts about their autism, so long as they do not convince the reader that autism is negative.

I have also identified standards that should be regarded in literature about protagonists with siblings who have autism. The standards are as follows:

1. The text should not center the child's autism around the sibling protagonist. The text should not be a means to describe how the protagonist "deals" with their sibling's autism.
2. The text should provide opportunities for the reader to get to know the child with autism.

3. The reader should not view the child with autism in a negative light because of their autism even if the protagonist does. If the protagonist sees their sibling in a negative light, they should eventually come to some place of acceptance or empathy.
4. The siblings depicted in the text should have a connection and share moments with one another throughout the text (whether these moments are good or bad).
5. The text should educate children who do not have autism about what it means to have autism and how to facilitate inclusion of different abilities, thus taking on a pedagogical perspective. However, the novel should also appeal to children who have autism.
6. The text should not convince readers that children with autism are a burden or problem for the other people in their life (including the sibling), but the protagonist should be allowed to have human reactions to their sibling with autism.
7. The text and the protagonist's perspective should not dehumanize the character with autism.

Although there is a great deal of children's literature about autism that exists today, I have noticed a lack of diversity in the literature. The majority of children's autism literature features a male as the character with autism; only two out of the eight books in my study feature a female as the character with autism. In the books that depict sibling relationships, the sibling of the character who has autism is almost always a female (this was true in all four of the books that I studied). This aligns with research, because a study conducted in 2017 claimed that there are about 4.2 boys with autism for every girl (Zeliadt). Furthermore, girls frequently receive diagnoses later in life in comparison to boys, so this could also explain the lack of children's literature about autism featuring girls (Zeliadt).

This discrepancy between male and female diagnoses could be because (1) people primarily think of autism as affecting boys and (2) autism may look different in girls than boys; for example, "girls may have fewer restrictive interests and repetitive behaviors than boys do, and may have more socially acceptable types of interests. They are also more likely than boys to mask their autism features by copying their peers" (Zeliadt). Because of these diagnostic biases, less females than males are diagnosed with autism, and therefore males are predominant in

children's literature about autism. If I were to continue this study, I would focus on females depicted in autism literature, and I would widen my study to encompass adult literature as well. I would like to compare children's and adult literature about females with autism as well as research whether females believe that they are ethically represented in literature. I also wonder if the lack of literature about females with autism will be present in all literature.

Because all of the texts that I studied depict and describe autism in different ways, I have been unable to conclude whether identity-first phrases such "autistic person" are significantly prevalent. Because many people who have autism use identity-first language, I cannot conclude that the term "autistic" is unethical; however, for the purposes of this study I have used only person-first language. I believe that it is acceptable to use "autistic person" and "person with autism" interchangeably in literature, so long as the identity-first language is not used derogatorily. I would be interested to learn more about these terms and why we are taught to use person-first language when some people with autism prefer identity-first language.

I have chosen not to use the terms "high-functioning" and "low-functioning" as standards to categorize people on the autism spectrum in this thesis, because research shows these terms "do not reflect how much support [people with autism] need" (Chawla). For example, a person with autism may be labeled "high-functioning" because they have a high IQ score, but they may struggle with daily living skills such as brushing their teeth, tying their shoelaces, or taking the bus (Chawla). The authors in my book seemed to argue against these defining terms as well, such as when Mrs. Brook explains the autism spectrum to Caitlin in *Mockingbird* and when Ted refers to "the high-functioning end of the spectrum" in italics, as though he does not seem to identify with the term in *The London Eye Mystery* (Dowd 37). I hope that in the future, these terms eventually cycle out of autism characterization, because even though I used them at the

beginning of my study, I have come to see the downsides of this terminology. Not only can these terms be considered offensive and labeling to people who have autism, but they also do not explain a great deal about the person who has autism and lead us to make conclusions about them that may not be accurate.

I have concluded that although people with autism have a voice in literature, books about people with autism are most often written by people who do not have autism but have some connection to autism (typically through their family or profession). If I were to continue this study I would like to research autism literature written by people who have autism, such as *The Reason I Jump* by Naoki Higashida, which I referenced when I created this thesis. It is possible that this perspective may provide me with a completely different set of standards about what people with autism believe of current literature.

In this thesis, I originally proposed to include a third chapter in which I described the integration of books about autism into classrooms. This would have helped me to expand on the pedagogical approach that some of the texts (especially those about siblings such as *Little Big Sister*) took. I would have used this chapter to explore two lessons that featured books about characters with autism that I observed or taught in my student teaching placements.

Unfortunately, due to school closures associated with COVID-19 this chapter had to be omitted. This is the most significant flaw in my study, as implementing what I learned in my research would have helped me to develop and receive feedback on autism resources in the classroom.

The first lesson that I would have described in the chapter took place in December of 2019 in a kindergarten class at Coventry Grammar School. A special education teacher came into the classroom and read a picture book called *I See Things Differently: A First Look at Autism* by Pat Thomas to the students and asked them questions. The purpose of this lesson was to educate

the students about one of the students in their class that had autism. I found that *I See Things Differently* presented a positive and age-appropriate representation of autism for the kindergarteners, as well as opened up the floor for them to discuss their friend with autism. Here are a few quotes from the kindergarteners that I recorded after they listened to the book (I have substituted the name “Taylor” for the student with autism).

- “Sometimes I say ‘hi [Taylor]’ and she doesn’t say anything”
- “I’ve seen her jump up and down” (a student describing Taylor)
- “Some people may suck their thumb; some people rock back and forth” (a student discussing what some people do when they feel overwhelmed)
- “When tons of people talk and I can’t concentrate that good I cover my ears” (a student relating to Taylor and discussing what they do when they feel overwhelmed)
- “Why is [Taylor’s] chair there and not somewhere else?” “It makes her feel comfortable.”
- “When somebody doesn’t speak” (a student’s definition of autism)

I argue that this lesson was a success because it allowed students to learn more about autism, as well as learn more about how they can be a friend to Taylor. The kindergarteners made connections to Taylor and discussed what they like to do when they feel overwhelmed or scared. The students realized that everyone does things in a different way, and even though Taylor learns differently than them, that is okay. This lesson presented autism in an ethical way for students, and in the third chapter, I would have provided pedagogical standards for autism literature.

The second lesson that I planned to include in the third chapter was one that I designed myself around the picture book *A Friend Like Simon* by Gaynor Kate. This lesson was to be taught to my fourth-grade classroom at Bowers School in Manchester. In the lesson, I would have read aloud *A Friend Like Simon* to my students and stopped to ask them questions throughout the book, as my students were accustomed to doing this with their teacher. In the lesson, I planned to ask my students some of these questions:

- “Have you ever met somebody that had a different ability than you? Did this person’s differences confuse you or make you feel uncomfortable?”

- “Why did Simon react this way? Make a prediction.”
- “Turn and talk to your partner: revisit your prediction from the beginning of the story. Now that you have more information about Simon, is your prediction the same? Why or why not?”
- “What do you think it means to have a different ability?”
- “What do you think it means to have autism?”
- “How do you know that Simon has a different ability from the rest of the students in the class?”
- “What does Matthew realize about Simon?”
- “What is the theme of the story?”
- “What is *inclusion*? How can you practice inclusion in school?”

After the group discussion and read aloud, I planned an activity in which the students filled out a KHW (Know/How I Know/Want to Know) chart about autism in assigned partner groups. Here is an example of what this chart might have looked like:

What I Know About Autism	How I Know (reference the text)	What I Still Want to Know About Autism

At the end of the lesson, I would have evaluated whether the exercise was successful based on the pedagogical standards that I would have identified. This section of my thesis would have been significant, because it would have allowed me to draw conclusions about how to present autism ethically to students in classrooms. For example, I opted to teach my students about autism by calling it a “different ability” rather than a “disability.” However, I fear that my lesson may have presented autism unethically because I asked the students to reference *A Friend Like Simon* to teach them about what it means to have autism, even though if you meet a person

with autism, “you have met...exactly one person with autism (Bérubé 50). In teaching this lesson in the future I must assure my students that even though they are learning about Simon’s autism, not every person with autism will be just like Simon.

As a future teacher, I would like to find strategies to introduce all different abilities into the classroom through a variety of texts so that I can facilitate acceptance and inclusion among my students. Furthermore, I would like my students to experience diversity in literature and learn about people who have different abilities at a young age. I hope that one day I can teach this lesson to my students, draw conclusions about the lesson’s autism representation, and add to this study of autism in children’s literature.

My thesis research was successful because it allowed me to synthesize all that I learned from the children’s texts about autism that I studied, as well as the autism and disability scholarship that allowed me to create a list of ethical representation standards. I hope that in the future I can continue and evolve this study through researching female representation in autism literature, autism literature written by people who have autism, and autism pedagogy in the elementary-school classroom.

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