

## *Original Paper*

# The Struggle is Real: Advocacy, Activism, and Agency in Young Adult Protagonists with Autism

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### ***Abstract***

*While there is much research behind adolescent protagonists developing advocacy, activism, and agency in young adult literature in order to change the trajectory of their lives, fewer studies have examined adolescent protagonists with autism under similar circumstances. The image of the semi-comic, socially tragic autistic teenager is portrayed in the media more often than one who advocates for himself, takes action to be independent, and develops as an agent of change. This paper examines six award-winning young adult novels whose protagonists emerge as young people developing independence despite dealing with the challenges living with autism brings. How they exert this autonomy helps illustrate the multitude of ways in which teens handle frustration, challenges, and helplessness while managing a disability. Readers not only engage with teenagers facing obstacles, but also have the opportunity to develop a better understanding of their peers, a deeper sense of empathy, and empowerment to make changes in their own lives.*

### ***Keywords***

*autism spectrum disorder, young adult literature, self-advocacy, inclusion literature*

## **1. Introduction**

More children than ever before are being diagnosed with an Autism Spectrum Disorder (ASD) with one in 68 children being diagnosed in 2010 and that rate remaining stable through 2012 (CDC, 2015, 2016). In the last two decades, research focusing on children with ASD has become a popular area of study (Jang, et al.) with professional journals, documentaries, news reports, parenting guides and parent autobiographies filling our bookshelves, the internet, and our airwaves. Clearly, autism is at the forefront of discussion and debate in both the scientific and popular literature (Murray, 2010). For the general public, much of their learning about autism comes from the popular press or visual media, in particular,

fictional accounts through books and movies. As public awareness and curiosity about autism has increased, so has the number of characters with autism in Young Adult Literature (YAL) (Irwin, Goldsmith, & Applegate, 2015). YAL depicts a range of teen characters with diverse experiences across the range of the autism spectrum, largely reflecting research on actual teens (Irwin et al., 2015). Mark Haddon's *The Curious Incident of the Dog in the Night-Time* (subsequently referred to as *Curious Incident*), is probably the best known novel with a protagonist on the autism spectrum. It became a worldwide best-seller in 2003, and has since sold over 10 million copies, has been translated into 44 languages and has won 17 literary awards (Clinton, 2014). Intended for both an adult and young adult audience, *Curious Incident* has been adopted on to many secondary school recommended reading lists and is therefore becoming an ASD cultural reference point for young people. Perhaps one of the most telling indicators of the novel's popularity as a school requirement is the abundance of published study guides and summaries (www.bookrags.com; www.thebestnotes.com; SparkNotes Literature Guides; Gradesaver Classic Notes; Insight Study Guides; Cambridge Wizard English Guides; Bookclub-in-a-Box and more). The sheer number of art projects and videos created by students and posted to the Internet attest to the novel's reach and influence on young adults. *Curious Incident* has brought international attention to a single 15 year-old character with ASD and started a rising wave of novels written from the perspective of a young person with ASD (Robinson, 2012).

The way autism is portrayed in YAL can have significant influence on young people's beliefs about autism. This literature provides readers a chance to experience vicariously what it means to live with autism, and to see a little of themselves in characters "whose lives are parallel to their own and who struggle with similar conflicts and issues" (Miller, 2013, p. 28). "Teens can meet peers with ASD in books as well as in life. Since high-functioning characters with autism are predominantly mainstreamed, they appear at school and have classmates who can get to know them" (Irwin et al., 2015, p. 14). According to Bucher and Manning (2014), the characters featured in young adult literature are undergoing changes and turmoil that reflect authentic issues that adolescents are experiencing in life. Themes that readers encounter in adolescent literature include asserting independence, coming of age, accepting responsibilities, developing empathy, and filial and romantic relationships. While not universal, self-advocacy, agency, and activism are also common themes that arise in young adult literature.

YAL has the power to bring to light common experiences, emotions, and dilemmas while also promoting respect for differences. Starting with *Curious Incident* as a reference point, we will explore how characters with ASD in this book and others are presented in YAL. More specifically, we will address the following research questions:

- 1) How are protagonists with autism portrayed in YAL?
- 2) How do these protagonists express advocacy, agency and activism?

## 2. Method

### 2.1 Selection Criteria

The selection criteria for books included in this review were that the book must: (a) be a fictional account written after 2000; (b) be an award winner in the area of Young Adult Literature (award winners are more popular and more likely to appear on recommended reading lists, and have reviews about their contents published); (c) have a protagonist that is a young person with ASD and the story is told from that person's point of view; and (d) the young person with ASD shows agency, advocacy and/or activism. Eight books (with six characters) met the selection criteria (see Table 1).

**Table 1. Books Included in Analysis**

Book Title	Author, Publisher	Character	Year Published	Awards
<i>The Curious Incident of the Dog in the Nighttime</i>	Mark Haddon New York: Vintage a Division of Penguin Random House	Christopher	2003	-Costa Book of the Year (2003), -Guardian Children's Fiction Prize (2003), -Waverton Good Read Award (2004), -Whitbread Award for Novel and Book of the Year (2003), -McKitterick Prize (2004), -Los Angeles Times Book Prize (2003), -Exclusive Books Boeke Prize (2004), -ALA Alex Award (2004), -Zilveren Zoen (2004), -Commonwealth Writers' Prize for Best First Book Overall (2004)
<i>Wild Orchid</i> <sup>1</sup>	Beverley Brenna	Taylor	2005	-Young Adult Book Award by the
<i>Waiting for No One</i>	Markham,		2010	Canadian Library Association (Wild
<i>White Bicycle</i>	Ontario: Red Deer Press		2012	Orchid) -Dolly Gray Children's Literature Award Winner (Waiting for No One) -Michael L. Printz Award, Honor Book 2013 (White Bicycle)
<i>The London Eye</i>	Siobhan Dowd	Ted	2008	-Bisto Book of the Year, Bisto Merit

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<i>Mystery</i>	New York: Yearling			Awards, -Cybils Award for Middle Grade Fiction (2008) -School Library Journal Best Book of the Year -Kirkus Review's Best Children's Book Award
<i>Marcelo in the Real World</i>	Francisco Stork New York: Arthur A. Levine	Marcelo	2010	-Schneider Family Book Award for Teen Book (2010), -James Cook Book Award (2011) -YALSA Best Book for Young Adults - Publisher's Weekly Best Book of the Year
<i>Mockingbird</i>	Kathryn Erskine New York: Philomela a Division of Penguin Random House	Caitlin	2012	-National Book Award for Young People's Literature (2010), -International Reading Association Award - ALA Best Fiction for Young Adults - Dolly Gray Children's Literature Award
<i>Colin Fischer</i>	Ashley Miller and Zack Stentz  New York: Razorbill a Division of Penguin Random House	Colin	2013	-ABA Young Adult Honor Award (2013)

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8 books, 6 different characters with autism spectrum disorders (CWA).

<sup>1</sup> In *Waiting for No One*, *Wild Orchid*, and *The White Bicycle*, the same character, Taylor, has Asperger's Syndrome.

Case study methodology was used wherein each protagonist with ASD was considered a case. We described the characters according to diagnostic hallmarks (e.g., communication and social interaction difficulties, sensory sensitivity, resistance to change in the environment or routines, intense interests) as defined by the Individuals with Disabilities Education Act of 2004 (IDEA, 2004). Each character was then examined to determine how and when agency, activism, and advocacy were exercised in their lives.

### 3. Results

#### 3.1 Case Studies: The Characters

##### 3.1.1 The Detectives

**Christopher**, in *The Curious Incident of the Dog in the Nighttime*, is a 15 year-old only child, who lives with his dad in Swindon, England. As Christopher investigates the death of a neighbor's dog, he discovers that his father lied about his mother's death. His mother is still alive, but left the family because the marriage was strained and she had difficulty dealing with Christopher's behavior. Christopher no longer trusts his dishonest father, and runs away, seeking his mother in London. The solo journey to London tests many of Christopher's greatest fears such as noises, crowds, being away from home, and interrupting his known schedule and environment.

Christopher has very concrete ideas such as, "you can't trust people who lie", and he doesn't like novels because they are "lies about things that did not happen and they make me feel shaky and scared" (p. 20). Christopher likes symmetry and for things to be in order; he has a keen eye for patterns. He likes the color red, and hates the colors yellow and brown. He likes to know exactly what time it is, likes prime numbers, math puzzles and riddles. He is good with numbers and memorizing facts. He hopes to be an astronaut one day and likes Sherlock Holmes mysteries because there is a puzzle to be solved through observation and logic.

Christopher has difficulty with idioms and figurative language such as "catch you later", or "being an apple in someone's eye". He doesn't like words that can mean two different things. He does not care for metaphors because they are lies; similes are acceptable because they are words stating one thing looks "like" another and that is not hard to visualize (i.e., it really did look like the man had two mice hiding in his nostrils) (p. 17). Christopher often finds jokes difficult to understand; he has difficulty reading body language, does not look at people's faces, says he cannot tell what others are thinking, and assumes that others feel the same way he does.

Christopher is sensitive to sound, touch, crowds and too much information, such as someone asking too many questions too fast, or too much going on in the environment. He hums and groans to block out noise, and closes his eyes when too much information is coming in. Although the book never specifically states Christopher's disability, it is presumed he has Asperger's Syndrome (AS). He is in the 10<sup>th</sup> grade at a separate school for students with disabilities. Most of the students have intellectual and/or physical

disabilities and work on life skills and arts and crafts. Christopher, on the other hand, is quite intelligent and will be the first person from his school to take advanced math.

**Agency.** Readers are able to see Christopher grow throughout the novel as he is forced to make difficult decisions, expand his limited comfort zone, find ways to cope independently, and act upon beliefs that may not correspond to information the adults in his life provide. Discovering his father betrayed his trust and lied to him, Christopher is jarred into action by taking control of his own life and making the decision to run away. Prior to this, the navigation of his life was primarily in the hands of his father and school teacher. There are glimmers of agency prior to the betrayal, such as his personal philosophy that he explains as, "...I decide for myself what I am going to do and what I am not going to do" (p. 30), and his commitment to the canine murder mystery: "I decided that I was going to find out who killed Wellington even though Father had told me to stay out of other people's business" (p. 28). However, most of Christopher's life illustrates a heavy reliance on others and is in stark contrast to the agency Christopher must develop in a matter of hours as he is faced with decision after decision on his journey to find his mother.

Once he makes the decision to be with his mother, Christopher's actions and thoughts demonstrate a continuing sense of agency. One clear example of this is when he says, "I decided that I couldn't go home again" (p. 129). Another very telling example of Christopher's newly formed agency is his formulation of a plan that includes many obstacles that he is almost certain to face. This is not a journey of the unknown so much as it is a journey into what Christopher knows will be fraught with hardship, but forges ahead with anyway. This is the sense of control and agency that Christopher develops throughout the novel. It is evident that Christopher himself acknowledges the growth and development through action and intervention that he undergoes, when he closes the story with, "And I know I can do this because I went to London on my own, and because I solved the mystery of Who Killed Wellington? and I found my mother and I was brave and I wrote a book and that means I can do anything" (p. 221).

**Ted**, in *The London Eye Mystery*, is a 12 year-old boy with AS who just finished his first year of secondary school. He lives in London with both parents and an older sister. Ted's father is a demolition expert; his sister, Kat, is a typical teenager—very socially oriented, concerned about appearance, knows teen culture, and is adept at sneaking and lying to their parents. Kat doesn't have much time for Ted and finds him annoying, but she does love him and says he has a good brain. During the summer, Ted's cousin comes to visit for a few days and disappears. Ted investigates the mysterious disappearance with his sister. Similar to Christopher, he takes a train alone for the first time; a difficult task because it is new and he has difficulty with crowds. Ted systematically makes observations, develops theories and tracks events to figure out where his cousin may be. Ultimately, Ted's analytic mind saves his cousin's life.

Like Christopher, Ted is good at remembering facts and recites them frequently. Ted wants to be a meteorologist and is especially interested in weather, which he talks about at length, if allowed. His

routines include listening to the weather report during the day and the shipping forecast at night before he goes to sleep. He is also good at math and skilled at deductive reasoning. Ted understands how different he is from his peers and says, “I know I’m a weirdo. My brain runs on a different operating system from other people’s. I see things they don’t and sometimes they see things I don’t” (p. 31). Although Ted is good at remembering facts, he forgets everyday things like his school gym bag. Ted states, “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” (p. 39).

Ted describes himself as clumsy and he does not like athletic activities. He wears his school uniform even on weekends and summer break and when anxious, “my hand shakes itself out”. He tilts his head to the side, looks beyond, rather than directly at people, and seems expressionless. Ted is sensitive to noise, especially people talking loudly. He has difficulty understanding idioms and why they are used; yet he has memorized a few such as *laughing one’s head off*, *up your street*, *talking up a storm*, and *driving someone bananas*. Ted is not good at lying, and has a hard time understanding when other people are not telling the truth. Ted has learned if others look straight at you, then you could become friends; and when you are talking, if the muscles in people’s faces are not doing anything, it means they are bored. “Mr. Shepherd says if I learn how to be like other people, not just on the outside, but on the inside, then I’ll make more friends” (p. 38). Ted has no friends his age. He claims his mum, dad, and Mr. Shepherd as his only friends.

**Agency.** Ted’s powerful analytic mind and keen attention to details that others dismiss as insignificant enable him to solve the mystery of his cousin’s disappearance. What is most significant, however, is that Ted does so by choice, displaying agency. Ted sees the need, realizes that his way of thinking can serve a purpose in the situation, and becomes an agent of change out of necessity. “This is how having a funny brain that runs on a different operating system from other people’s helped me to figure out what had happened” (p. 4).

Ted also possesses another quality that others find annoying, but was crucial in serving his investigative skills in this situation: being relentless in the pursuit of the truth. No matter what the circumstances were, whether it was the appropriate time or not, whether it made him seem tactless or insensitive to others’ feelings, Ted continued to pursue the truth and dig for facts. When the family is sitting in silence pondering the gravity of his cousin’s disappearance, Ted breaks the silence by trying to present his theories. After being shushed, he refuses to give up and presents his ideas to his sister Kat, ultimately recruiting her to share in this agency. However, even Kat tries to surrender to frustration on several instances. Even after Kat tries to literally and figuratively trash all of Ted’s theories, he presses on. “I picked up a pen... I was eager to see if we could eliminate all the theories...” (p. 143).

When he forces the issue with his mother, he is rebuffed in no uncertain terms. Instead of arguing or giving up, Ted communicates his unwavering agency by purposely shattering a crystal glass on the floor.

This vivid illustration of his agency continues throughout the novel as Ted resists his natural urges and fears to speak to strangers, travel alone, and even wins the respect of a police investigator who says, “If only some of my officers had half your brains, Ted” (p. 156).

**Colin Fischer**, who has AS, is 14 years old when the story begins on his first day of high school in the novel also named *Colin Fischer*. He lives with his parents, who work in the space industry, and a younger brother, Danny, in the San Fernando Valley of California. Danny is not at all kind to Colin; he is jealous of the attention Colin gets and relishes when Colin makes mistakes. In describing himself to a teacher, Colin stated, “I’m diagnosed as high functioning, but I still have poor social skills and sensory integration issues that give me serious deficits in areas of physical coordination” (p. 39). Colin avoids eye contact, often doesn’t notice facial expressions, and when he does, he has difficulty understanding them. To assist in reading emotions, he refers to facial expression cards, which he keeps in his notebook. In fact, the tagline of the novel is “solving a mystery one facial expression at a time”. Colin has a flat, robotic tone of voice and flat affect. Like Christopher and Ted, he interprets language literally and has difficulty with figurative language/idioms. Colin is brutally honest and says what he observes. Disruption to his structure and routines is devastatingly distressing. Like Christopher, Colin does not like fiction because it is too far removed from reality; inferences make him uncomfortable because he likes certainty. Like Christopher and Ted, Colin likes Sherlock Holmes and solving a mystery is part of the novel’s plot. Colin loves Star Trek’s Mr. Spock and Commander Data, has a keen eye for details, and also likes math.

Like the other characters, Colin doesn’t like to be touched. He is sensitive to fabrics and clothing, and is very sensitive to smells, which he says he can “taste”. He has food preferences and will only eat crunchy foods. Like Christopher, Colin has color preferences and does not like the color blue. Colin often suffers from sensory overload. On the first day of high school, Colin shrieks with terror at the hallway noise. Colin uses his notebook to record events at school including the movements of various groups—the nerds, popular girls, goths, and jocks. He watches his classmates “with the detached interest of an anthropologist”. One person in particular that Colin watches is Wayne, a school bully who put Colin’s head in the toilet on the first day of school. Ironically, this bully becomes his friend as Colin tries to solve the mystery of who brought a gun to school. Motivated by finding the truth, Colin and Wayne join forces to investigate.

**Activism and Agency.** By teaming up with his tormentor, Colin begins to step beyond his comfortable routines, leading to deeper involvement in real life and a real mystery. His parents, at one point in the novel, reminisce nostalgically about what life was like when Colin was not independent, making decisions for himself, and befriending unsavory characters. Yet the injustice that is unfolding right in front of him is more than Colin can ignore. In fact, ignoring it and giving in to a sense of helplessness are not options for him. “Wayne Connelly is innocent, and I will prove it. The game is afoot” (p. 86). Colin is wired for activism when it comes to analyzing the evidence, finding the answers, and seeking the truth.

Even though he is somewhat removed from the investigation after he is questioned by the police, he refuses to stop himself from taking action to exonerate Wayne. This activism moves him to look beyond past wrongs to ensure that the boy isn't wrongfully accused and punished. For Colin, the search for the truth is more important than personal feelings of discomfort.

Colin also displays agency as he works to ensure the wrong person is not punished. The interventions that Colin utilizes in his quest for the truth are not always purposeful, but ultimately work. "I just figured out the truth. The rest...happened" (p. 201), he says after his parents commend him for his agency in saving an innocent boy. Colin's acute sense of justice makes it easy for him to make what others would consider difficult decisions. And in the end, the most difficult decision for Colin is not lending a helping hand to absolve an innocent boy, but literally offering a helping hand to the same boy getting on to the trampoline. The agency he applies to the mystery has an unexpected effect on his own response to the world.

### 3.1.2 The Relentless

**Taylor in *Wild Orchid*, *Waiting for No One*, and *The White Bicycle*** is an 18 year-old girl with AS who has just finished high school. By the third book, she is 19, and has completed her first year of taking classes at a university and has a job. Taylor lives with her mother in Saskatchewan, Canada and is an only child. Taylor's father lives in Wyoming with his girlfriend, who Taylor likes. Taylor does not like the men her mother dates. Taylor remembers her parents fighting and believes they broke up because of her. Taylor's mother gets both exasperated with, and worried about Taylor. In return, Taylor gets frustrated with her mother. Taylor is extremely focused on her resume, and works toward adding to it in a concrete, repetitive manner. Her main goal is employment so that she can be independent, which is a theme throughout the three books.

As a child, Taylor lined up her toys and had difficulty when things changed or did not go her way. She had meltdowns that involved hitting, kicking, and biting others. Kids teased her and called her names. As a teen, Taylor still had difficulty with eye contact and preferred structured routines. Taylor is good at sorting things, is a talented artist, and reads very well. She describes herself as a follower of rules. She has a photographic memory, especially when it comes to plants and animals and can identify them by their scientific names. She carries on long monologues about gerbils, flowers and other things in nature. Taylor is actively working on learning to take the perspective of others, and on becoming more self-aware.

Taylor was diagnosed with AS at age 11 (grade 6). She interprets language literally and often does not understand questions and expressions such as *not my cup of tea* and *take your mind off it*. She doesn't understand why people say things they don't mean. Taylor also likes to count things, including the number of words people say and the number of steps she takes. She feels comforted with doing things a certain number of times. She experiences anxiety and obsessively cleans when stressed; she also has the urge to swear when feeling anxious. Taylor is sensitive to noise, light, bright colors, and being wet. Like

the other characters, she is sensitive to smells and doesn't like being touched. When overwhelmed, feelings suddenly explode in her head until all she can see is white. Over time, however, Taylor has learned strategies to make the white go away. She is sensitive to certain fabrics and wears the same worn denim dress daily because it is comfortable. She does not like the color yellow because it makes her sneeze, and she likes foods that are white.

**Agency and Advocacy.** The first novel is centered on a summer away from home and out of Taylor's comfort zone. Not only is Taylor in a new environment, surrounded by unfamiliar people, but she must also take it upon herself to advocate for her goal of becoming an adult. Her mother, with whom she has a strained and sometimes forced relationship, treats her like a child, despite Taylor's repeated hopes of independence. While her mother refuses to recognize Taylor's transition to adulthood, Taylor champions for her independence by making clear-cut decisions for herself. "She (her mother) went out of my room and banged the door. It's not good to bang doors. It's hard on the hinges. It's good I locked the door, because now nobody will bang it again" (p. 9). While locking the door is a simple, somewhat juvenile solution, Taylor is asserting her independence. By the middle of the book, Taylor's self-advocacy has moved from locking doors to running away. "You don't know anything about what's possible or necessary and just because you're my mother you think you can be the boss of me and you aren't... I'll just run away again and keep running until I'm so far away..." (p. 142).

Part of Taylor's relentless advocacy for her own independence includes having a boyfriend. While she may be somewhat naive about what this entails, she knows that engaging in an adult relationship will prove to others that she is no longer a child. She zealously pursues any and all leads in this arena, finding that these kinds of relationships are as confusing as they are difficult to cultivate. Instead of doggedly pursuing this, she shows her growth by saying, "I'm not sure if he is my boyfriend, and if he is, I'm not sure I like it" (p. 70). By the close of the first novel, Taylor is no longer self-advocating for romantic relationships to prove her independence, but is acting like an adult instead. When she is forced to resign from her job to move home with her mother, she doesn't take the easy way out by having her mother speak with her boss and co-workers. "I got this job by myself, and I will take care of quitting... Remember, you're not the boss of me" (p. 146).

In the third book, *The White Bicycle*, Taylor and her mother fly to France to spend the summer with her mother's new boyfriend and his sons. Taylor agrees to the trip because she will be a personal care assistant for one of the sons who has cerebral palsy. She sees this job as a resume-builder to increase her employability because "being employable means something great: being independent" (p. 25). Taylor continues the classic adolescent quest for differentiation from her mother. First, she rescues an old woman from drowning and wants to continue seeing the woman. Taylor's mother will not give her a ride to the woman's home and tells Taylor she cannot go. Taylor defies her mother and researches how to take a bus to the city where the old woman lives, stating, "this is what a smart person would do if she wants to

go to Cassis (the city) and her mother will not drive her” (p. 120). In thinking about the relationship with her mother Taylor asks herself, “who has responsibility for my existence?” and “how can I be free if I don't make any decisions for myself?” (p. 125). Taylor is afraid of going against her mother's wishes, and is also afraid of taking the bus in a foreign country. Despite her fears, she takes initiative and successfully maneuvers the bus system, and develops a friendship with the old woman.

Taylor again demonstrates agency when she overhears that her job as a personal care assistant was just a ruse to get her to go along on the trip. Taylor asserts to her mother, “lies and deception. You have ruined my resume!... You have given me a summer with an empty resume, and now I will never get a full-time job, and I will be stuck with you until you die and I am living alone” (p. 156). Taylor continues by reciting her good qualities as an employee, such as being dependable and responsible, and tells her mother and the boyfriend that she will not continue to help the young man unless “it is a real job and it is called *personal care assistant*” (p. 157). Later, when calmer heads prevail, Taylor tells her mother that she is going to make her own choices. “From now on, I am an adult and I will be making choices about myself. That is something I have control over... If I am going to be independent we both have to keep on choosing for ourselves and not the other person”.

**Caitlin in *Mockingbird***, is a 10 year-old girl in the 5<sup>th</sup> grade who has been diagnosed with AS. Caitlin has many dysfunctional behaviors similar to descriptions of Taylor's behavior in her younger years. Like Taylor, Caitlin is a good reader and an excellent artist. Caitlin's brother was her social interpreter and told her specific things to do in social situations. Unfortunately, Caitlin's brother was killed in a school shooting on the “the day our life fell apart”. Caitlin's mother died when she was only three years old. As a result, the family is comprised of only Caitlin and her father, who is greatly incapacitated by grief. Throughout the book, Caitlin seeks “closure” believing it is a tangible thing. She finally finds closure by working with her father to complete a wooden chest that her brother had begun before his death. Caitlin's relentless quest for closure is similar to Taylor's quest for employment and independence.

Caitlin is uncomfortable looking people in eye. When she is nervous or unsure of what to do she flaps her hands, sucks on her sleeve, or hums. The sounds of some words hurt her ears, and she interprets idioms literally. She has difficulty with change, difficulty with directions, and dislikes certain shades of yellow and green, and all shades of pink. Like Taylor, Caitlin wears the same thing day after day because her skin is sensitive; she can't wear clothes that touch her skin too much. Caitlin refuses to work with other children in the classroom. She hates recess because sounds and lights make it hard for her to breathe; when someone shouts, Caitlin shakes. Therefore, Caitlin walks around the playground with the counselor during recess. The counselor points out how other kids interact with each other and works with Caitlin on adapting to changes in routine, and behaviors that will help her to fit in better with kids her own age. Caitlin has only one friend, a younger child whose mother was also a victim of the school shooting. Although Caitlin thinks she does not have emotions, she has a list of skills she does well, including

manners. Caitlin reminds a bully at school when he doesn't mind his manners.

**Agency and Advocacy.** Coping with life after her brother's sudden and tragic death has been a struggle for Caitlin, but has also propelled her down the path toward agency and advocacy. Caitlin's life has never been easy, but she is in an especially tenuous place at the opening of the book. Her mother has been gone from her life due to cancer and is only a distant memory to Caitlin. Her brother Devon, served as her anchor and advocate as she attempted to navigate the confusing world of friends, enemies, and everyone in between. After her brother's tragic death, she could no longer rely on him to serve as her advocate. Her father, unable to cope with his grief, also has difficulty trying to truly help his daughter. Instead, Caitlin must fill those roles for herself and learn how to become both agent and advocate while seeking closure. The most powerful way Caitlin develops self-advocacy is through her memory of the varied lessons her brother taught her as they were growing up. She honors his memory by continually referring to things Devon said in the past and being attentive to his voice that now exists in her head. These tips that Devon imparted to her were more than just behavioral suggestions about fitting in with her peers, but larger than life lessons that shaped her into an advocate for herself as well as others who are in need. "It's not about the dog! It's about people! You shouldn't hurt innocent people Scout. That's what is mean" (p. 80).

Caitlin searches for the intangible feeling of closure as she takes what she's learned from Devon and uses it as an agent of change in order to help herself, her father, her new friend Michael, and eventually, the entire community. While she cannot dispel the cloud of grief her father is battling, she helps him face Devon's death by asking for his help in completing Devon's Eagle Scout project and bringing the light back into their home. "I go back in to put his shade up so the sun pours in and makes his room warm and bright and I can see dust particles in the beams of light that maybe are part of Devon or maybe not but they make Devon's room look happy again... I leave Devon's door open" (p. 168).

Advocating for herself and for her father may be difficult, but for Caitlin, empathy is a characteristic she continues to work on. Her ability to advocate for her young friend, Michael, is the consummate example of the next step of her growth. She is only able to advocate for a friend after she has felt empathy for him. "Michael looks up at me with his Bambi eyes. In them I see sadness and I think it's fear or maybe it's confusion. I also see friendship. And I think there's a look that means I need to do something to help. To answer the question. I think it's the look I gave Devon. A lot" (p. 209). In the end, Caitlin is able to parlay the successful advocacy for herself, her father, and Michael into closure for the entire community.

### 3.1.3 The Moral Poet

**Marcelo Sandoval** in *Marcelo in the Real World* is a 17 year-old with AS who lives with his father, an attorney, and his mother, a nurse. He is close with his sister who lives away while attending Yale. Marcelo is bilingual, learning Spanish from his grandmother and he talks about himself in the third person. The family represents a successful minority family with Marcelo experiencing advantages of his

upper middle class upbringing such as attending an expensive private school for students with disabilities. Like Christopher in *Curious Incident*, Marcelo is higher in cognitive functioning than most of the students at the school and he has an important role taking care of the ponies used for the therapeutic horseback riding program. Marcelo wants to continue his last year of high school at the special school, but his father wants him to leave the protective environment and attend a *regular* public school for his senior year. To prepare for the *real world*, Marcelo's father arranges for him to work in his law firm during the summer.

In describing his AS, Marcelo says, "I feel dishonest when I say I have AS because the negative effects of my differences on my life are so slight compared to other kids who have AS or other forms of autism and truly suffer" (p. 55). He later adds, "I always feel like I'm doing the people who have these conditions a disservice when I use the term, because then people say, 'Oh, that doesn't seem so bad'" (p. 56). Marcelo has been part of a study that is using MRI technology to study the workings of his brain. His father doesn't like it when Marcelo sees the research doctor. He states that there is nothing wrong with his son; he wants to focus on Marcelo being independent, self-sufficient, and learning about competition in the real world.

Marcelo is very introspective and intensely interested in religion and morality. He is childlike in demeanor, but tall and strong. He finds comfort in schedules and makes a daily time schedule down to the minute. He likes to be organized and keeps a notebook of rules and questions. Marcelo isolates himself when possible, has difficulty when asked to do more than one thing at a time, and cannot navigate his surroundings without a map. He has difficulty with facial expressions and figures of speech. He has learned some small talk, but like Ted in *London Eye Mystery*, prefers *big talk*, which is talk about important things. Marcelo doesn't like to be touched, and like Ted, Caitlin, and Taylor, wears the same type of clothes every day—a short sleeve white shirt changing to long sleeves in winter. He opens and closes his fists when upset. Marcelo's co-worker and potential love interest says that Marcelo has the heart of a poet.

**Agency, Activism, and Advocacy.** Like Christopher, in *Curious Incident*, this story begins with Marcelo existing in a familiar routine where he feels comfortable and able to handle the day-to-day stressors with strategies he has been taught or has developed on his own. The first example of agency is presented early on when Marcelo makes the decision to temporarily give up this safe world for the possibility of pursuing his dream of working full-time with the ponies after the summer. He accepts the opportunity in what is his first step toward self-advocacy, knowing that, "...after three months, it will be over, and I can be who I am" (p. 23). His summer job envelops him in unfamiliar, uncomfortable, and sometimes upsetting experiences that project Marcelo toward developing a spirit of activism that not only conflicts with his father's views, but also allows him to see beyond his world by helping someone he doesn't know.

Like many activists, Marcelo endures internal struggles that revolve around loyalty to his family, to himself, to those around him, and to his “pervasive interests” (p. 56). Doing the right thing is something Marcelo is comfortable with and understands, as it is black and white in the world he has existed in thus far. However, doing the right thing in “the *real world*, as his father calls it, is quite another thing. By going against his father in the pursuit of justice for a young girl who was harmed by a malfunctioning windshield, Marcelo flexes his newly developed spirit of activism. As the attorney for the windshield company, Marcelo’s father must come to terms with all that his son has learned and the culmination of this learning that manifests itself in Marcelo’s stance in the real world.

#### **4. Discussion**

##### *4.1 Agency and Advocacy within the Family, School or Community*

Of the six characters, three characters exhibited agency within their families. Interestingly, these three characters (Christopher, Taylor, & Caitlin) were only children in a single-parent family. The single-parents’ struggles with adult relationships played a prominent role in the storyline of these books and may have prompted the protagonists to assert their independence and detach themselves from the problems of their parents. Christopher’s mother ran away leaving his father angry, confused, and keeping the truth from his son. Christopher reacted strongly to his father’s “lie” and ran away from home. Caitlin’s father was immobilized by the grief of recently losing his son, and his wife’s some years prior. Caitlin searched for and found a way to bring closure to the situation to ease the pain of her father and others in the community. Taylor’s mother had several unsuccessful dating relationships. Taylor’s pursuit of a job, which she saw as a stepping stone towards independence, at times conflicted with her mother’s plans to relocate for several months to be near her latest boyfriend. The protagonists from single parent homes made life more difficult for an overstressed parent who was just barely hanging on. At the same time, they asserted themselves in an effort to take control over their own lives and make their own decisions. The protagonists’ needs for stability and structure was disrupted by outside influences, thus requiring them to advocate for themselves within the family to maintain equilibrium. However, separation and differentiation from one’s parent is a typical adolescent developmental task and a common theme in adolescent literature; it is not specific to those on the autism spectrum. The other three characters were from two-parent homes and had siblings. Interestingly, these characters expressed their agency and advocacy in school or the community, rather than at home. Ted solved the mystery of his missing cousin by finding him in a building ready for demolition. Marcelo went against his father’s best interests to provide assistance for victims of a faulty windshield. Taylor saves an older woman from drowning and becomes her friend and ally. Colin solves the mystery of who brought a gun to school and exonerates a student who had bullied him for years. Caitlin brings closure for her father and the community in relation to a school shooting.

#### 4.2 Agency and Advocacy Related to Characteristics of Autism

**Talents and Intense Interests.** The novels portray youth with ASD as having islands of genius. Of the four male characters, three were portrayed as interested in math, space and weather, with an intense interest in Sherlock Holmes making them natural detectives due to their analytical skills (Christopher, Ted, & Colin). Similarly, Marcelo investigated to find the truth about his father's law firm. All four of the male characters had an unwavering need to find the truth. Like Caitlin and her intense desire to find closure, this need drove the storyline.

Christopher counted prime numbers when afraid; Taylor counted the number of words people said. Taylor was interested in science; especially plants and animals, in particular gerbils. She was also a good artist, as was Caitlin. Caitlin and Marcelo loved reading; Marcelo had a particular interest in reading and discussing religious texts. While not everyone with ASD is especially skilled at math or deductive reasoning, the authors of the YAL included in this review did not go too far by portraying any of the characters as autistic savants, which represent less than 10% of the autistic population (Edelson, n.d.). However, the characters in this review were verbal and had special interests that were more intense than the interests of their peers. Their special interests were used in the plot to help the protagonists overcome obstacles and to assert themselves in dilemmas that highlight typical teenage identity issues (Robinson, 2012). These YAL protagonists had more in common with typical peers of this age than they had differences.

**Language and Communication.** All six characters were verbal, but were described as having difficulty with social communication. Telling the truth was a major plot theme in four books, *Curious Incident*, *London Eye*, *Colin Fisher* and *Marcelo in the Real World*. All of the characters were portrayed as misunderstanding idioms, which was used to provide light-hearted comedy. The protagonists' difficulty with figurative language was used heavily in all of the books to paint a picture of a quirky, highly intelligent individual, who understood language and had a complete vocabulary, but was very literal in interpretation and frequently made social faux pas. This underscores the similarities these characters have with their adolescent peers who are often embarrassed by their own social missteps. Well-written first-person descriptions may influence young people's beliefs by promoting awareness and empathy of what a young person with ASD experiences (Miller, 2013). Despite social challenges, especially when the characters interacted with those outside of the family and/or comfort zone, the figurative language barrier did not keep them from advocating for their cause or taking action to meet their goals.

**Sensory Sensitivity.** The novels describe sensory sensitivity from a first-person perspective quite well. The characters described how sights and sounds made their heads spin, or feel full; made them feel sick, or made it hard to breathe; all symptoms of anxiety. All characters were highly sensitive to sound, touch, and/or texture. This could provide information to peers as to why youth with ASD become agitated (e.g., meltdowns, tantrums) and/or non-responsive (withdrawing into themselves, self-stimulatory behavior) in

situations where there is an overabundance of sensory stimulation. Armed with this information, peers may be more understanding, accepting, and supportive of their classmates with ASD.

As the protagonists moved into uncharted territory, they were forced to support themselves through the use of learned coping strategies and calming techniques. Caitlin called one of her strategies stuffed-animaling. When things would get blurry because of too much stimulation, she would blur all the colors and shapes together so they “change into fuzzy and warm instead of sharp and cold... If you take the monkey bars and the people and blur them together they get soft and fluffy and kind, just like a stuffed animal” (pp. 27-28). Taylor would consciously push her anger down through her feet and out into the floor. Christopher recited prime numbers in his head, Marcelo searched for his internal music, and Colin bounced on a trampoline. Several characters relied on deep breathing and pressing their palms together. Our protagonists provide examples of digging deep and using self-regulatory strategies to approach situations that were markedly uncomfortable. Similar to typically-developing adolescents, our protagonists were faced with situations where they demonstrated independence and advocated for themselves. Our characters showed the reader that perseverance and keeping an eye on the prize is worth even extreme effort and discomfort. They endured great physical anxiety and pain to achieve their objectives that included finding the truth, healing a community, seeking justice, and solving a mystery in the nick of time to save a life.

## **5. Conclusion**

The books reviewed provided positive images and may challenge ablism/disabling attitudes (Beckett Ellison, Barrett, & Shah, 2010). For the protagonists in this review, their skills were valuable and helped others. The characters with disabilities are portrayed as an interesting curio, quirky geniuses, who are sensitive to sounds, light, and are thrown off by changes in routine or in the environment. Readers do get an insider’s view into why sensory stimulation and changes are upsetting. Most of the characters discuss how they learned to deal with the challenges. The insider’s view also includes glimpses into how students are teased for their differences, which may promote empathy in the young people reading the books.

Empathy is not the only thing readers may garner from these books. Young adults may also learn the importance of activism—not only as a way to elicit change in their schools and communities, but also in their own lives. Like their peers in the novels, readers may begin seeing themselves as potential agents of change as reflected in the actions and words of their peers with autism. Young adults may learn to take the perspective of a student with ASD, and can advocate for students they encounter. Just as important as advocacy is, the idea of more empathy leading to more acceptance is a powerful one. While each of these books has its unique characters and its own plot, the common thread of agency, activism, and advocacy is a strong message for all young people.

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