

The Real Deal: Teen Characters with Autism in YA Novels

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The Real Deal: Teen Characters with Autism in YA Novels

By Marilyn Irwin, Annette Y. Goldsmith, and Rachel Applegate

Abstract

Between 2012 and 2014, the U.S. Centers for Disease Control revised their estimate of the prevalence of autism spectrum disorder (ASD) from one in eighty-eight children¹ in the United States to one in sixty-eight children.² With this large number of youth with ASD in our communities, it is critical that accurate information be presented in YA literature, fiction as well as nonfiction, to increase understanding of the disorder. What is real in the depiction of autism in YA novels? Based on analysis of fifty-eight YA novels that include a young adult character with ASD, a portrait has been drawn of how they are treated, who their friends are, and where they go to school. The data from the novels were contrasted with current research involving actual youth with ASD to assess the accuracy of the fictional portrayals. Findings indicate that the depiction of educational placement and the behavior of others toward the characters in the books was a reasonable reflection of real life as shown in the research; however, fewer friendships were found in the novels than studies of actual adolescents with ASD indicate.

Introduction

The U.S. Centers for Disease Control and Prevention (CDC) considers “ASD [autism spectrum disorder] an important public health concern” and reports that “more people than ever before are being diagnosed with an ASD.”³ Although the reason for the increase is unclear, research published in 2012 estimated the prevalence of ASD to be one in eighty-eight children in the

United States.⁴ In 2014 that rate was increased to one in sixty-eight.⁵ The CDC provides the following definition of autism spectrum disorder:

Autism spectrum disorder (ASD) is a developmental disability that can cause significant social, communication and behavioral challenges. There is often nothing about how people with ASD look that sets them apart from other people, but people with ASD may communicate, interact, behave, and learn in ways that are different from most other people. The learning, thinking, and problem-solving abilities of people with ASD can range from gifted to severely challenged. Some people with ASD need a lot of help in their daily lives; others need less.

A diagnosis of ASD now includes several conditions that used to be diagnosed separately: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger syndrome. These conditions are now all called autism spectrum disorder.⁶

The American Psychiatric Association publishes the *Diagnostic and Statistical Manual of Mental Disorders*, the tool most commonly used by professionals to define the criteria for diagnosing a psychosocial disorder. An updated version, commonly referred to as *DSM-5*, was published in 2013. The new edition combines the different types of ASD under the heading 299.00 Autism Spectrum Disorder.⁷ The full *DSM-5* criteria may be found at the CDC website: <http://www.cdc.gov/ncbddd/autism/hcp-dsm.html>.⁸

Individually, together, and in collaboration with others, Mary Anne Prater and Tina Taylor Dyches have written extensively in the area of children's literature and developmental disabilities, an umbrella term that includes autism spectrum disorder.⁹ Their work covers the full age range of youth literature, including young adult materials, and focuses on the objective

coverage of the disabilities and potential educational usefulness of the materials, as well as listing the titles of the works identified. How the fictional teens compare to actual youth with disabilities is not in their purview.

Much has also been written about the role of fiction for youth that includes people with disabilities.¹⁰ Ayala provides four cogent reasons for making the materials available for students:

1. Because of the issues raised, the materials can help children “understand and cope with difficult decisions they must face in an increasingly complex society.”
2. The “relevant, authentic publications” can be used to draw students to reading.
3. The books can portray people with disabilities “who are increasingly reflected in our society.”
4. People with disabilities can be provided with an entertaining reflection of self.¹¹

In 2003 the award-winning and best-selling book *The Curious Incident of the Dog in the Night-Time* by Mark Haddon was published.¹² Told in the first-person voice of fifteen-year-old Christopher, the reader learns that the narrator is very smart but has some behavior issues. It is also revealed that he attends a special school, has no friends, and is often called names. Although this is just one fictional representation of a teen with ASD, the portrayal of Christopher received so much attention that readers without previous knowledge of autism might consider it normative of all individuals on the spectrum. This raises the question of how teens with ASD are portrayed in other young adult novels and how that compares with what research tells us about real life.

What the Research Says

In 1986 Madeleine Will—then the Assistant Secretary for the Office of Special Education and Rehabilitative Services in the U.S. Department of Education—called for increased placement of

students with mild and moderate disabilities into regular education classrooms.¹³ This began the Regular Education Initiative, which has resulted in a growing number of special education students spending at least part of their day in classrooms with their non-disabled peers. Ann Christy Dybvik reports that during the 2000–2001 school year, approximately 40% of children with autism spent at least 40% of their school day in a regular classroom, and this increased dramatically since the beginning of separately recorded autism data in 1992–93.¹⁴

A 2014 report from the U.S. Department of Education states that 39% of students with autism spent 80% or more of the day in a regular class, over 18% stayed 40–79% of the day, and nearly 34% were included less than 40%. Slightly over 9% were listed as having educational placements in other environments defined to include a “separate school, residential facility, homebound/hospital environment, correctional facilities, and parentally placed in private schools.”¹⁵ The report also states that over 6% of students with autism ages fourteen through twenty-one dropped out of school for the 2010–11 school year.¹⁶

Because a deficit in social skills is one of the characteristics of ASD,¹⁷ individuals with the disability have difficulty making peer friends; however, research indicates that friendships are present.¹⁸ For example, an average of two best friends was found for all participants with ASD in the research by Bauminger and Kasari.¹⁹ Most of the research has been conducted with samples of high-functioning young adults with ASD.²⁰

Inappropriate behaviors and bullying are a concern of many educators and parents. A study of mothers of children with Asperger syndrome found the following:

The overall prevalence rate reported by mothers of peer victimization was 94%. Mothers reported that almost three-quarters of their children had been hit by peers or siblings in the past year and 75% had been emotionally bullied. On the more severe end of peer

victimization, 10% of the children were attacked by a gang in the past year and 15% were victims of nonsexual assaults to the genitals.²¹

This research raises the following questions about how characters with ASD are handled in young adult novels compared to what is present in real life. Specifically, where are the teens educated, do they have any friends, how are they treated by their peers, and how does this relate to the reality found in the research on adolescents with ASD?

Methodology

One hundred young adult novels published between 1968 and 2013 were identified where an individual of any age was labeled as having ASD. Each of the novels included in the study was independently read, coded, and analyzed by two of the three researchers. Using a form that was developed for the study, manifest coding of pertinent content was independently recorded by each of two readers for every title. Manifest coding was utilized in an effort to minimize subjectivity of the coding. For example, when ethnicity was not explicitly stated, it was coded as “unknown.” Some interpretation was required when the information was not stated unambiguously, such as whether a character was to be coded as having mild, moderate, or severe functional abilities. After each reader completed the coding, the individual coding sheets were compared to ensure the quality of the coding and reach agreement on how the data should be entered, particularly when distinct wording was not provided. Final coding represented the consensus of both readers.

This research includes quantified summaries of the situations depicted in the books and represented by the coding. For example, males represented 57% of protagonists with autism. Also, three-quarters of characters with autism were described as having a splinter-savant ability

such as excelling in mathematics, memory, or art. This quantification guided the narrative sections of the research analysis. Filtering by codes identified specific portrayals that illustrate particular dynamics such as educational placement, while the researchers' extensive narrative notes provide rich contextual information. The unit of analysis is the portrayal of each character with ASD in a book. When a character appears in more than one book, the portrayals are counted separately; hence there are more portrayals than books.

Results and Discussion

Fifty-eight out of the one hundred novels contain a young adult ages eleven to nineteen with ASD, and two identified individuals are present in two of the books; therefore, there are sixty character portrayals. The character with ASD in the other forty-two books was either younger than eleven or older than nineteen. Of the sixty portrayals, thirty-four who are able to interact independently with few ASD-related limitations were coded as mild. Sixteen, coded as moderate, have a few functional issues requiring some assistance. The ten coded as severe exhibit numerous ASD-related characteristics and intellectual disabilities requiring full-time assistance.

Schooling

Table 1 compares the educational placements of the characters in the books with data from the U.S. Department of Education about students served by the Individuals with Disabilities Education Act (IDEA). Although many of the characters are shown to have multiple types of educational placements, twenty-two of the young adult characters in the novels studied are included full-time in regular education classrooms, and three of that group are supported by an aide for most of the story. An additional five are pulled out for some special education, totaling 45% of the characters spending all or some of their day in regular classrooms with their non-

disabled peers. Colin Fischer, in the novel of the same name,²² is an example of a character who at various times is in regular classes with and without an aide, and is pulled out for special classes. Additionally, three of the characters attend or have graduated from college. Though it is unusual for a teen to have graduated from college, Nathaniel from *Mindblind* is an unusual character.²³ He is a genius who completes his BA at age fourteen and is taking a gap year during the timeframe of the novel. In thirteen cases, insufficient information is provided to determine where they are being educated, and six are not attending school.

Table 1: Educational Placement

	U.S. Department of Education (percent of students served under IDEA)	Characters with Autism (percent of 60 characters)
Regular education at least 40% of day	57.2	45
Separate environments	9.1	13
Dropped out/Not attending school	6.3	1
Full time special education	N.A.	.5
University	N.A.	.5

Three of the characters are homeschooled, three are placed in special education full-time, and five attend a special school for students with disabilities. These eleven individuals have limited opportunities to interact with their non-disabled peers in educational settings. For

example, Kiara Thornton-Delgado in Lyn Miller-Lachmann's *Rogue*, is being homeschooled because she has been expelled for assaulting a student who mistreated her at her regular school.²⁴

There is more opportunity for the characters with autism to interact with peers when they are together at school, but fewer such opportunities are offered in the books than in real life. Surprisingly, more characters with autism are sequestered in separate environments than are their real-life counterparts.

Friends

Most of the friendship research on actual teens with ASD has focused on high-functioning individuals. This closely matches the functional level of the majority of characters in the novels; however, it means that few comparisons between reality and portrayals can be made with those with moderate and severe ASD-related limitations.

According to Bauminger and Kasari, teens with autism have at least two best friends,²⁵ but fewer friends were common in the books analyzed. Table 2 summarizes the types of friends present—or not—for the characters with ASD. Forty-two of the characters in the novels have at least one peer friend who does not also have a disability. Though some of the character portrayals in the books do have multiple friends—Nathaniel in Jennifer Roy's *Mindblind* has a number of friends including the neighbor he has known since they were both four years old²⁶—that is not the norm. In sixteen books the characters begin as friendless, and friendships develop throughout the story. *Here's How I See It—Here's How It Is*, by Heather Henson, provides a good illustration of this type of relationship: Junebug is at first annoyed by the friendless Trace and his ASD behaviors but eventually finds him to be a steadfast friend.²⁷ The friendships that characters with autism make are primarily with neurotypical people (those not on the autism spectrum), and these friendships are mostly initiated during the timeframe of the novel. Since the

need for the character with autism to be able to function “in the real world” is a frequent theme in the books, like Marcelo in Francisco X. Stork’s *Marcelo in the Real World*,²⁸ the overall picture drawn of these friendships is quite hopeful. Many characters had no previous friends prior to those that are newly established. It is more rare for the character with autism to have a friend with a disability. Friends who also have disabilities are present in eleven books; they are the singular friend in only one book, Justin R. Smith’s *Eye of a Fly*, in which Ernest gets to know a young woman with a brain injury.²⁹

Table 2: Friendships (N=60)

Types of friends	Frequency
Friend without disability	42
Friend with disability	11 ^a
Adult friends	18 ^b
No friends	8
Began as friendless, but developed	16

^aone is only friend

^bfour are only friends

The character with ASD has friends who are adults in eighteen books, in one case being another individual with ASD. The presence of so many neurotypical adult friends suggests that high-functioning teens with ASD in these books are well-equipped to relate to adults on their own level. Teen sleuth Verity from the *Duchess and Bones* series by Alexandra Eden is in fact acknowledged to be considerably brighter than her adult partner, the retired policeman, Bones, which is a running joke in the books.³⁰ On the other hand, it is problematic when the teens’ only

friends are the adults who are paid to support them. Four of the adult companions are the only friends the character has. Eight characters appear to have no friends. In three cases, there was insufficient information provided to determine whether friendships are present.

Most young adults, whether in real life or in young adult fiction, demonstrate some type of romantic interest in members of the same or opposite sex. This interest is rarely found in the novels studied. In *Mindblind*, Nathaniel is one of the exceptions.³¹ He would like to have a relationship with Jessa, but is unclear how to go about establishing one. Marcelo does end up involved with a young woman in *Marcelo in the Real World*, but he is clueless about her affection for him.³² More often, as in *Orange Clouds Blue Sky* by J. Hale Turner,³³ there is no mention of any interest in establishing a relationship. When Starr attends the prom with her older sister, she dances with her female friend and is more interested in the food being served than in the young men who are also in attendance.

Negative Behaviors of Peers toward Individuals with ASD

The research that describes how high-functioning teens are bullied by their peers indicates that these behaviors are very common.³⁴ Since the figures in table 3 are frequency counts, they could not be quantified as a percentage. Though the frequency of negative behaviors by peers could not be compared directly with the very high percentage of victimization reported by mothers of actual high-functioning children with autism (94%), almost every character portrayal was subjected to such behaviors to a greater or lesser degree. It is therefore safe to say that in this regard, art does reflect life.

Table 3: Behavior of Peers Toward Characters with Autism (N=60)

Behavior	Number
Looked down on	8
Objects of ridicule	43
Bullied or shoved	16
Abused	5
No negative behaviors	12
Treated as equals	47

In the study, forty-three of the characters with ASD are objects of ridicule by their peers. The characters are frequently laughed at or called names such as freak, retard, and geek. For example, in *The Half-Life of Planets* by Emily Franklin and Brendan Halpin, Hank reports that some fellow students “are given to calling me a number of creative variations on ‘homosexual.’”³⁵

Sixteen of the characters were coded as being bullied or shoved by their peers. In *Unlocked* by Karen Kingsbury, Holden is kicked in the shins by members of his school’s football team.³⁶ Typical of the treatment often meted out to “nerds,” the resident bully shoves Colin’s head into the toilet on his first day of high school.³⁷ In *Game as Ned* by Tim Pegler, Ned is punched on a couple of occasions by a classmate,³⁸ one of five abused individuals in the study whose injuries result in severe physical or emotional harm.

The behaviors toward eight of the characters indicate that they are looked down on. One of the self-important teen girls in *Orange Clouds Blue Sky* makes it clear that she does not think it is appropriate for Starr to attend the prom.³⁹ No negative behaviors by peers are present in twelve of the sixty character portrayals. Indeed, forty-seven of the portrayals show others

treating those with autism as equals. Yet even these relationships are at times accompanied by behaviors that are negative.

It quickly became apparent in these books that teen characters with ASD could expect poor treatment from many quarters: family, acquaintances, teachers, and even bystanders on the street. The twelve novels that do not show these behaviors may not be realistic, but can give readers hope that more positive interactions are possible. So, too, can those novels in which the characters with ASD are treated as equals by friends and family. Examples include friends Amber and Ricky in Matthew Quick's *Sorta Like a Rock Star*, and cousins Ted and Salim in *The London Eye Mystery* by Siobhan Dowd.⁴⁰

Conclusions

The young adult novels in this content analysis largely reflect the true picture of what life is like for teens with ASD. By comparing the character portrayals of high-functioning individuals with the research documenting the lives of real teens, it is possible to discern similarities in two areas: how the teens are educated and how they are treated by others. In other words, what appears in these books seems to be consistent with reality: there are primarily mainstreamed educational placements, and teens with ASD face many instances of poor treatment. On the other hand, friendships for these teens overall are less common in the books than in real life.

What do these findings mean for actual young adults and the librarians who serve them? Ayala's four reasons for the importance of fiction that includes characters with disabilities⁴¹ provide a point of departure:

1. *Understanding and coping with difficult decisions.* Many of the books provide nuanced depictions of how peers with autism are/should be treated. Though there is a great deal of

name-calling and poor treatment in the books, there are also true friends and even strangers who intervene. Young adults have to grapple with issues such as bullying, and the various scenarios in the books can be a catalyst for discussion or private reflection. YA librarians can include titles in anti-bullying displays, discussions, and pathfinders. Examples: Beth Goobie's *The Lottery*, Tim Pegler's *Game as Ned*, and Ashley Edward Miller and Zack Stentz's *Colin Fischer*.⁴²

2. *Relevant and authentic.* Almost all of these books depict autism in an accurate way. In addition to doing the background research, often the author has some kind of personal connection with ASD, whether as a parent, sibling, teacher, therapist, or person with autism. Many of the books go on to make autism real through strong characterization. How to negotiate friendships and romantic relationships is of keen interest to teens whether or not a disability is concerned, and raising the discussion with these books provides an opportunity to think of peers with autism as people they would want as friends . . . or perhaps more. Examples: Emily Franklin and Brenda Halpin's *The Half-Life of Planets*, Nora Raleigh Baskin's *Anything but Typical*, and Francisco X. Stork's *Marcelo in the Real World*.⁴³
3. *Presence of people with disabilities in our society.* With rates as high as one in sixty-eight children, 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; if homeschooled, they have neighbors. Characters with autism belong in YA novels, as elsewhere. Examples: Deirdre Sullivan's *Prim Improper*, Siobhan Dowd's *The London Eye Mystery*, and Lyn Miller-Lachmann's *Rogue*.⁴⁴

4. *An entertaining reflection of self.* The portraits of characters with ASD can be very compelling and make for rich reading; many of the books are award winners. Of course, it is important to have both mirrors and windows; that is, to see oneself reflected in the literature (mirrors) and learn about the lives of others too (windows). YA librarians who facilitate a writing group could consider writing fan fiction in the voice of a favorite character with ASD. Examples: Jennifer Roy's *Mindblind*, Sarah Dooley's *Livvie Owen Lived Here*, and Beverley Brenna's Wild Orchid trilogy (*Wild Orchid*, *Waiting for No One*, and *The White Bicycle*).⁴⁵

Mark Haddon's *The Curious Incident of the Dog in the Night-Time*⁴⁶ brought international attention to a single teen character with ASD, but there are many more characters in YA literature. The books studied offer the real deal: teen characters with diverse experiences across the full range of ASD, largely reflecting the research on actual teens.

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