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The Real Deal 2*: How Autism Is Described in YA Novels

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Abstract

Autism spectrum disorder (ASD) is often considered one of the invisible disabilities. Youth at the higher end of the spectrum may seem to have quirky behaviors, but otherwise appear to be like everyone else. Those with more severe ASD are commonly misunderstood and thought to simply have disciplinary issues. This study examined 100 young adult novels published between 1968 and 2013 inclusive in which a character was labeled as having ASD to determine how the authors described the disability in each of the books. Those descriptors were then aligned with the diagnostic criteria for autism spectrum disorder found in the fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders*. A total of 7,921 descriptors appear across the 100 books studied, and 6,094 (77%) of them map on to the first two *DSM-5* diagnostic criteria categories. "Having unique obsessions" was the most frequently appearing descriptor present in the books. In 1,827 (23%) instances, the descriptors did not fit within the diagnostic criteria, indicating that the criteria may miss some elements of the ASD experience that authors themselves deem important.

Introduction

Autism spectrum disorder (ASD) is a neurological disability that is typically diagnosed around age five and affects as many as one in sixty-eight American children.ⁱ Although it is a formally recognized condition defined for medical and psychiatric personnel by the

fifth edition of the *Diagnostic and Statistical Manual of Mental Disorders* (*DSM-5*), ii knowledge of this condition among "neurotypical" people would predominantly come from personal encounters and also depictions in culture. One of the most important sources of cultural depiction is literature written for teens.

Literature Review

This study reviewed the descriptions of persons with ASD in young adult novels and examined how and where they matched and did not match clinical terminology and diagnostic criteria. *DSM-5* was taken as the benchmark, even though it was published in 2013, after all of the novels. *DSM-5*'s premise is that while diagnostic language and conceptualizations of disorders may change, the disorders themselves—clusters of human behaviors—do not change. Witness numerous attempts to diagnose literary and historical figures by *DSM-5* criteria (try googling Shakespeare and *DSM-5*). The disputed inclusion and then exclusion of homosexuality as a disorder represents a significant deliberate effort to make the manual conform to what is believed to be true.

How accurate is the depiction of ASD in young adult literature? What does and does not match? And what areas of the ASD experience are reflected in the depictions that are not seen in the *DSM-5*? When librarians interact with patrons—parents, teens, friends—one primary concern with the use of literature about conditions is its veracity. Is an engaging story conveying an accurate depiction of the subject?

The U.S. Centers for Disease Control and Prevention (CDC) considers "ASD an important public health concern" and reports that "more people than ever before are being diagnosed with an ASD." 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. In 2014 that rate was increased to one in sixty-eight.

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." The full *DSM-5* criteria may be found at the CDC website, http://www.cdc.gov/ncbddd/autism/hcp-dsm.html. "ii

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. Viii The result of this initiative has been an increased number of students with ASD who are educated outside of segregated special education classrooms and more exposure of teens who do not have disabilities to their peers with autism. Young adult literature can therefore act as a mirror and a window: a way for youth with ASD to see depictions of people like themselves (the mirror) and a way for their peers without the disability to gain deeper understanding of those around them (the window). In the content of the peers without the disability to gain deeper understanding of those around them (the window).

Autism spectrum disorder is often considered one of the invisible disabilities. Youth at the higher end of the spectrum may seem to have quirky behaviors, but otherwise appear

to be like everyone else. Those with more severe ASD can often be misunderstood and even thought to merely have disciplinary issues. It is therefore important that young adult literature have an accurate depiction of individuals with autism if it is to provide an honest mirror and window for youth. The research question of this study is: What is the correspondence between fictional depictions of the ASD experience in young adult literature and the accepted diagnostic criteria employed by the *DSM-5*? This is addressed in three parts:

- Accuracy (correspondence of depictions to *DSM-5*)
- Depictions that map to *DSM-5* criteria
- Depictions that are not captured by *DSM-5* criteria

Mary Anne Prater and Tina Taylor Dyches have—individually, together, and in collaboration with others—written extensively in the area of children's literature and developmental disabilities, an umbrella term that includes autism spectrum disorder. Their work covers the full age range of youth literature, including young adult materials, and focuses on the objective coverage of the disabilities, potential educational usefulness of the materials, and listing the titles identified. Much has also been written about the role of fiction for youth that includes people with disabilities. xi This body of work generally focused on whether there was a positive or negative representation of the disabilities, but the authors did not address the specific terms used to describe the disabilities in the novels. Positive and negative representations are only one aspect of literary portrayals of autism. What if a positive depiction is an inaccurate stereotype, leading to unrealistic expectations, such as imagining that all autistic individuals can do advanced math as the main character in the movie Rain Man can? What if a negative one inaccurately conveys that autism is associated with violence toward others? Literature scholars need to move beyond simplistic studies of the portrayal of autism in young adult literature to consider these deeper issues and their potential effects on readers.

Methodology

This study examined 100 young adult novels published between 1968 and 2013 to begin to build a more complex understanding of the portrayal of autism in literature for teens. The first step was to define a body of source material. Using standard selection journals and numerous disability-related books and articles (see *Autism in Young Adult Novels*^{xii} for a detailed description of that process), the researchers examined over 500 potential titles published from 1960 to 2013. From that candidate list, 100 young adult novels that included a character specifically labeled with ASD were identified. For this study, this selection criterion (explicit diagnosis) added consistency to the selection. For the purposes of the research question, which is interested in accurately depicted ASD experiences, explicit diagnosis creates a better starting point than non-explicit characterizations.

In the 100 books, the researchers identified 7,921 individual descriptors: words or phrases applied to characters that described their behaviors. The primary *DSM-5* diagnostic criteria for autism spectrum disorder reads: "A. Persistent deficits in social communication and social interaction" and "B. Restricted, repetitive patterns of behavior,

interests, or activities."^{xiii} A number of examples are given as illustrative information. Under "A. Deficits in social communication and social interaction," *DSM-5* provides three illustrative areas:

- "1. Deficits in social-emotional reciprocity . . .
- 2. Deficits in nonverbal communicative behaviors used for social interaction . . .
- 3. Deficits in developing, maintaining, and understanding relationships. . . . "

For "B. Restricted, repetitive patterns of behavior, interest, or activities," four examples are listed:

- "1. Stereotyped or repetitive motor movements, use of objects, or speech . . .
- 2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior . . .
- 3. Highly restricted, fixated interests that are abnormal in intensity or focus . . .
- 4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment. . . . "xiv"

Taking this diagnostic language, each of the researchers independently mapped each descriptor on to a particular *DSM-5* subsection or to "other" when the match was deemed insufficient. In initial coding, the researchers achieved 70% match (inter-coder reliability), and discussion resolved the remaining non-matches. This level of initial matching between two independent coders is appropriate for an exploratory study, particularly when the corpus is fiction, which by its nature strives for distinctiveness in tone and style.^{xv}

The resulting data set consists of 6,094 descriptors coded by *DSM-5* category, originating novel, role of character (protagonist/secondary), and functional limitation level (mild, moderate, severe, or not specified). Preliminary analysis showed that the age of the character did not vary enough to warrant separate analysis. The 1,827 descriptors not fitting into *DSM-5* categories were coded as "other" and independently analyzed.

Results

The analysis of depictions provides data to test each part of the research question: accuracy, common elements of ASD found in both the novels and *DSM-5*, and elements of ASD not captured by *DSM-5*.

Accuracy

The depictions in the novels appear to be largely accurate, when defining "accurate" as reflecting the language of the *DSM-5*. There are 2,420 instances where descriptive words or phrases fit under "A. Deficits in social communication and social interaction" (30% of all descriptive instances, and 40% of DSM-mappable instances). Table 1 summarizes the number of instances in which various descriptors fit within each illustrative example

under the *DSM-5* criteria of "A. Deficits in social communication and social interaction" and the total number of books in which those descriptors were found.

Table 1: Descriptors showing "A. Deficits in social communication and social interaction"

Illustrative Examples	Number of	Number
	Instances	of Books
1. "Deficits in social-emotional reciprocity"	1,688	100
2. "Deficits in nonverbal communicative behaviors used for social	585	89
interaction"		
3. "Deficits in developing, maintaining, and understanding	147	50
relationships"		

Examples of descriptors that align with the first *DSM-5* criteria are as follows:

- A.1. Deficits in social-emotional reciprocity, such as saying something inappropriate, can be found in *Marcelo in the Real World*. When his rabbi asks whether he learned about sex at school, rather than simply saying yes, Marcelo responds, "Sexual intercourse is how humans procreate. The erect penis of the man goes into the vagina of the woman." xvi
- A.2. Deficits in nonverbal communicative behaviors, such as having difficulty interpreting body language: In *The Half-Life of Planets*, the narrator, Hank, says, "Allie tells me there are signs everywhere in the way people act, in the tone of their voice, in the way they hold their head, and I can't read the signs."xvii
- A.3. Deficits in . . . relationships, such as not understanding sharing/taking turns/difficulty making friends: From *The Same Difference*: "Friends share their toys, she told me. Friends do nice things for each other, she said. None of it made sense at the time." xviii

Descriptors of the *DSM-5* diagnostic criteria "B. Restricted, repetitive patterns of behavior, interests, or activities" appear 3,674 times in the 100 books studied (46% of all instances; 60% of *DSM-5*-mappable instances). The number of instances that a descriptor fit this criteria and the total number of books where those descriptors are found is summarized in table 2.

Table 2: Descriptors showing "B. Restricted, repetitive patterns of behavior, interests, or activities"

Illustrative Examples	Number of	Number
	Instances	of Books
1. "Stereotyped or repetitive motor movements, use of objects, or speech"	941	84
2. "Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior"	872	88
3. "Highly restricted, fixated interests that are abnormal in intensity or focus"	996	60
4. "Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment"	865	92

Examples of descriptors that align with the second *DSM-5* diagnostic criteria are as follows:

- B.1. Stereotyped or repetitive motor movement, such as Jason, who "flaps his hands, like when he is excited or just before he is going to say something," in *Anything but Typical*. xix
- B.2. Insistence on sameness, such as lack of flexibility or being rule-bound: In *Rules*, Catherine says, "He might not understand some things, but David loves rules." xx
- B.3. Fixated interests, such as unusual obsessions: Taylor Jane has a unique obsession with gerbils in *The White Bicycle*. When she becomes angry with her mother, she responds, "'Walnut was the first of my series of gerbils!' I say, trying to hold on to the words before everything goes white. 'After Walnut came June, and after June came Charlotte, and after Charlotte came Hammy. And last fall, before I turned nineteen, I got my fifth gerbil, Harold Pinter.' ""xxi
- B.4. Hyper- or hyporeactivity to sensory input, such as sensitivity to touch: In *House Rules*, Jacob's mother says, "I reach out to comfort him but stop myself—a light touch can set Jacob off. He doesn't like handshakes or pats on the back or someone ruffling his hair." xxiii

Frequently Seen Behaviors

The issue of "social-emotional reciprocity" is the most common deficit represented in the area of "A. Deficits in social communication and social interaction," with 1,688 instances found in all 100 books studied (21% of all instances; 70% of "A" instances). Table 3 lists the five most common descriptors found and their frequency under the first *DSM-5* diagnostic criteria.

Table 3: Five most frequently used descriptors showing "A. Deficits in social communication and social interaction"

Illustrative Examples	Descriptors (Number of Uses)
1. "Deficits in social-emotional reciprocity"	Is literal (274)
	Says inappropriate things (260)
	Doesn't respond to others (201)
	Doesn't talk much (143)
	Locked in own world (81)
2. "Deficits in nonverbal communicative	Lacks eye contact (205)
behaviors used for social interaction"	Stares (101)
	Difficulty reading facial expressions (75)
	Blank facial expression (40)
	Doesn't understand body language (29)
3. "Deficits in developing, maintaining, and	Lacks social skills (80)
understanding relationships"	Doesn't play with others (20)
	Has no concept of personal space (11)
	Doesn't like interacting with people (7)
	Has difficulty making friends (7)

In the area of "B. Restricted, repetitive patterns of behavior, interests, or activities," the issue of "highly restricted, fixated interests" was the most common, with 996 instances found in 80 of the 100 books studied (13% of all instances; 27% of "B" instances). Table 4 lists the five most common descriptors found and their frequency under the second *DSM-5* diagnostic criteria.

Table 4: Five most frequently used descriptors showing "B. Restricted, repetitive patterns of behavior, interests, or activities"

Illustrative Examples	Descriptors (Number of Uses)
5. "Stereotyped or repetitive motor	Repetitive behaviors (296)
movements, use of objects, or speech"	Rocks back and forth (186)
	Flaps arms/hands (171)
	Echolalia (107)
	Repetitive use of objects (57)
6. "Insistence on sameness, inflexible	Likes order/routine (327)
adherence to routines, or ritualized patterns	Precise (217)
of verbal or nonverbal behavior"	Rule-bound (107)
	Likes specific foods/drinks (48)
	Likes consistency of numbers (24)
7. "Highly restricted, fixated interests that are	Has a unique obsession (689)
abnormal in intensity or focus"	Perseverates on topics of interest (76)
	Is logical (29)
	Notices details (19)
	Focused (19)
8. "Hyper- or hyporeactivity to sensory input	Doesn't like to be touched/hugged (228)
or unusual interest in sensory aspects of the	Sensitive to sound/noise (211)
environment"	Sensitive to smell (66)
	Is a clean freak (47)
	Sensitive to feel of clothing (42)

When comparing primary characters to secondary characters, protagonists were more likely to be described as having an insistence on sameness—inflexibility, rules, and rituals. Secondary characters were more often (than primary characters) described as having incorrect nonverbal behavior, repetitive motor movements, and repetitive speech.

Repetitive motor behaviors are also much more likely to be used to describe characters with severe functional limitations. Authors use language about lack of speech reciprocity, fixated interests, inflexibility, and sensory overload far more often when the character has only mild or moderate functional limitations. Characters with severe functional limitations were described frequently as displaying repetitive motions and also lacking speech reciprocity.

Uncaptured Elements: "Other"

There were 1,827 of the 7,921 descriptors that the coders did not see as mapping onto established *DSM-5* categories (23%). These same behaviors, not described by *DSM-5*, appeared across many different books. For example, different authors saw lack of coordination as a telling or characteristic behavior for individuals with ASD, yet *DSM-5* does not include that in the diagnostic criteria. These descriptors were perhaps used for dramatic reasons or to reflect common behaviors exhibited also by those who do not have ASD. Alternatively, they could reflect inaccurate stereotypes of people with ASD. The *DSM-5* criteria focus on disability and problems, the "medical model" of psychiatry. For example, *DSM-5* does not provide "honesty" as a criterion, yet this is another common descriptor that was found. The researchers coded these as "other" and then examined them for patterns.

There appear to be two distinct patterns in the "other" behaviors: strong splinter skills (positive) and acting-out behaviors and strategies to minimize them (negative). Tables 5 and 6 show the number of instances where the five most common descriptors are found in these two areas.

Table 5: Five most frequently used descriptors of splinter skills

Splinter Skill	Number of	
	instances	
Excellent memory	135	
Mathematically inclined	103	
Musically inclined	23	
Artistically inclined	18	
Precocious/intelligent	16	

Table 6: Five most frequently used descriptors of acting-out behaviors or strategies to minimize those activities

Behaviors or Strategies	Number of
	Instances
Screams	198
Meltdowns/tantrums	189
Uses calming strategies	185
Hurts others (bites, scratches, hits)	81
Self-injurious behavior	59

Discussion

Previous research has included some of the elements here. For example, Dyches, Prater, and Cramer studied two years' worth of children's books (reading level at picture-book age through ages 7–12) that had the keywords "mental retardation" or "autism." Only 12 books were identified, and they showed a great variety of depictions. This compares with the present study where within a larger (100 books) and more focused (autism only) corpus, distinct trends emerged. In a master's thesis, Weaver identified 42 picture books

depicting autism or Asperger's syndrome (the two were analyzed separately), but of these, 20 were nonfiction. xxiv

The previous study based on this corpus (100 young adult novels) compared depictions to reality in terms of research on the prevalence of particular broad attributes. For example, in these novels 43% of protagonists with autism are female, while in CDC data only 18% of people with ASD diagnoses are female. This was a relatively simple comparison. Data from the books that seemed realistic—such as characters with mild functional limitations primarily being depicted in educational settings alongside peers without disabilities, and those with severe limitations being depicted as in special schools—illustrate the difficulty in comparison with reality. There is little national-level information on schooling prevalence for children with autism.

The purpose of this study was to go beyond the smaller scale of the previous studies to examine the details and nuances of character depiction. Novels, as a reading experience, soar or fail in terms of the richness of their style, characterization, and world-building. Windows and mirrors are foggy or clear depending on writing skill and what can be called the veracity or lived truthfulness of the scenarios authors depict. This is not precisely or statistically describable by means of the usual techniques of research validity, yet there is value in seeing how these micro-scale depictions reflect what the scientific community, as expressed in the *DSM-5*, has collaboratively determined to be an accurate portrayal of this spectrum of disorders.

The depictions of individuals with ASD provided in the young adult novels studied are for the most part consistent with the criteria provided in the *DSM-5*. These rich portrayals of characters, settings, and conflicts can show readers of all ages aspects of the ASD experience in a relatable and non-threatening way with an honest portrayal of reality.

In addition, this body of literature shows descriptions that go beyond the medical, problem-based mind-set of *DSM-5*. The authors of these novels see both strengths and challenges in the ASD experience. *DSM-5* would not, cannot, label "honesty" as a disorder, but several different authors depicted relentless honesty or candor as typical of a character with autism. While this is a positive portrayal, it is unclear whether or not it is accurate to suggest that people with ASD tend to be any more or any less honest than people who do not have ASD. On the other side, problems in controlling behavior are prevalent in these novels. Screaming, meltdowns, and biting others are behaviors that the authors decided were important to depict in the lives of these characters, but again, without strong supporting data, it is unclear how often people with ASD display these behaviors.

Conclusion

It would be wonderful if it were possible to compare prevalence of particular behaviors in these novels with prevalence of those characteristics in the real lives of people with autism spectrum disorder. However, medical and psychiatric research on ASD has been more concerned with etiology and treatment effectiveness than with prevalence of particular characteristics. Identifying and preventing the causes of autism and testing the efficacies of therapies are the primary focus of research funding and publication. Parents

can consult physicians, psychiatrists, and therapists for factual and scientific understanding and practical steps for their own particular situations. Previous literary studies were more limited, both in the number of books considered and in the depth of analysis.

Teens confronting ASD in themselves or others are left with a gap about "what is *normal*." Repetitive behaviors, meltdowns . . . and honesty? The depiction of autism in young adult literature is a vital resource to show siblings, classmates, and those on the spectrum themselves a rich portrayal of the potentials and challenges of this life with autism spectrum disorder. This study highlights the depth of detail available for adolescent readers with respect to people with ASD and suggests that this literature can help those with and without the disorder to better understand it.

Notes

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