Fictional Narratives about Individuals with Autism Spectrum Disorder: Focus Group Analysis and Insight

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Fictional Narratives about Individuals with Autism Spectrum Disorder: Focus Group Analysis and Insight

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──────────── Abstract ────────────

Given the CDC's report of a 30% increase in autism spectrum disorder (ASD) diagnoses over the past two years, it is important to increase awareness and educate teachers and students in both general and special education classrooms. One way to bridge the gap between students with and without ASD is to use authentic narrative fiction as a teaching tool. The goal of this study was to identify aspects of stories with characters with ASD that contribute to authentic and accurate depictions. Insights were elicited from focus groups that included insiders, individuals or family members with ASD, and educators who work with students with ASD. The participants read, reviewed, and discussed fictional narratives that highlighted a character with ASD. Various themes emerged from the focus groups regarding views on authentic and accurate ASD depictions. Discussion and suggestions are presented for future use of narrative fiction in raising awareness in educational settings.

**Fictional Narratives about Individuals with Autism Spectrum Disorder:
Focus Group Analysis and Insight**

In the past two years, there has been a 30% increase in autism spectrum disorder (ASD) diagnoses throughout the country with 1 in 68 children now being diagnosed (CDC, 2014). These numbers indicate that, on average, every classroom in America could have a child with a diagnosed autism spectrum disorder in attendance. Recent changes to the Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (DSM-5) now refer to all previously identified types of autism (i.e., Asperger's, Autistic Disorder, PDD-NOS) as Autism Spectrum Disorder (ASD; American Psychological Association, 2013). Given this type of increase, it is not just special education classrooms that are being impacted; many children with autism are educated in the general education classroom (Yell & Katsiyannis, 2003). It is imperative for educators to find ways to teach their students with and without ASD about this unique disorder. As such, narrative fiction can be an avenue for understanding others; however, the books that are chosen need to be accurate and authentic. The purpose of this research was to obtain insights about what constitutes a 'good book' about ASD. In the following research study, we describe our work with focus groups and argue how this is a compelling way in which to identify authentic literature that in turn could be used to educate students about ASD.

Autism Spectrum Disorder in Educational Settings

Autism Spectrum Disorder is characterized by deficits in social communication and the presence of atypical, repetitive behaviors (American Psychological Association, 2013). In educational settings, children with ASD struggle with limited theory of mind, or in other words, the ability to take another person's perspective and see the world from his/her point of view. This impacts not only their social relationships, but also impacts the quality of their writing (Williams, Goldstein, & Minshew, 2006). Many children with ASD also have motor difficulties that impact their writing. Students with ASD demonstrate decreased rates of reading improvement, difficulties with reading comprehension, and difficulty with word, story and sentence recall (Chiang & Lin, 2007). It has also been suggested that students with ASD process auditory

and linguistic information at a slower rate than their peers (Cashin & Barker, 2009).

Given these areas of difficulty, it is also important to note children with ASD have unique strengths that can be of benefit to them and their classmates. For example, some students with ASD have enhanced visual processing which can help them excel at visual tasks that require high levels of memorization (Kunda & Goel, 2011). Students with ASD can be very detail oriented and may have a deep understanding of specific topic areas (Happé & Frith, 2006). They may also have an increased interest and understanding of computers and technology (Wei et al., 2012). When capitalized upon, these strengths can help students with ASD excel in the classroom and bridge the gap between peers with and without ASD.

Narrative Fiction & ASD

A possible way to bridge the gap between students with and without ASD is to use narrative fiction as a teaching tool (Kelley, Cardon, & Nichols, 2014). Recent research on neuroimaging (Speer, Reynolds, Swallow, & Zacks, 2009) concludes that when participants read narratives, they "activate specific visual, motor, and conceptual features of activities while reading about analogous changes in activities in the context of a narrative" (p. 995). In other words, when someone reads a story and envisions what happens in the story, what happens in the brain, and the thinking that goes on in the brain, is similar to actually experiencing the phenomenon. Similarly, empirical studies (e.g., Djikic, Oatley, Zoeterman, & Peterson, 2009) of fiction literature suggest how fiction can elicit emotional simulation that transforms a person. "Engaging in the simulation experiences of fiction literature can facilitate the understanding of others who are different from ourselves and can augment our capacity for empathy and social inference" (Mar & Oatley, 2008, p. 173). Narrative fiction can help children become more informed about disabilities and to be more empathetic to those with disabilities (Adomat, 2014). Moreover, educators could act as a conduit to help people in society reconsider discursive practices that might marginalize and perpetuate exclusionary practices and policies toward people with ASD (Lester, 2011).

Although fictional narrative could be used as an instrument to help educators understand the phenomenon and experience of ASD, it is essential to carefully examine children's and young adult fiction using a critical analysis

(Kelley, 2006; Kelley & Darragh, 2010), in order to select books that accurately portray individuals with ASD. As mentioned above, fictional stories can help people understand others; however, inaccurate information is problematic, since readers are more apt to believe false claims when they are unfamiliar with a given topic (Wheeler, Green, & Brock, 1999) or read it multiple times (Henkel & Mattson, 2011). "People are credulous creatures who find it very easy to believe and very difficult to doubt" (Gilbert, 1991, p.117). As such, it is imperative to present fictional stories that are accurate and authentic. Only a few studies evaluate literature about characters with developmental disabilities (e.g., Dyches & Prater, 2005; Larson, Whitin, & Vultaggio, 2010); however, none of these studies include insiders, or a group who share a common element such as culture or disability. If we truly want to bridge understanding, it is essential to elicit the voices of family members and individuals with ASD (Mousourou, Santos, & Gaffney, 2011).

For purposes of this research, we elicited information from individuals and family members of individuals with ASD, and educators who work with individuals with ASD, to determine which current fictional narratives portray individuals with ASD that are 1) authentic and engaging, and 2) have the potential to help educators and their students understand the complexities of ASD.

Method

Data collection occurred in two phases. Phase one included book selection and analysis and phase two involved focus groups of insiders and educators. Focus groups were utilized to facilitate interaction among participants to produce a robust discussion around the narrative fiction books for the purpose of data collection (McLafferty, 2004). The focus groups were semi- structured and facilitated by a moderator.

During phase one, researchers searched websites and articles about autism, library indexes, Amazon, and Google for narrative fiction books about autism. To be considered for selection, the books had to be realistic fiction, currently in print, have a main character with autism between the ages of 2-18, and be intended for an audience of K-12th grade. Of the 166 books identified, 58 books met the above criteria and were selected for further review.

Four reviewers analyzed the remaining 58 narrative fiction books. Two of the four reviewers were Speech Language Pathologists with expertise in ASD

and two were scholars of children's literature who were familiar with students and family members with ASD. A content analysis of the 58 books was conducted by all four reviewers to analyze the accuracy, in other words, was all of the information in the book correct and based on substantial current research, the disability discourse of the books, as well as the literary qualities. Scoring rubrics were created and focused on the aforementioned categories. The 58 books were analyzed using the scoring rubric (See Appendix A) for accuracy (Mitchell, 2002) and disability discourse: a) avoidance of stereotypic language, b) avoidance of deficit language, c) inclusion of a people first model, and d) avoidance of heroic storylines (Larson, Whitin, & Vultaggio, 2010). Under literary quality, the following topics were analyzed: a) memorable, b) quality prose, c) encourage readers to draw their own conclusions, d) characters work through problems, and e) avoids didacticism (Tunnell, Jacobs, Young, & Bryan, 2012). While the term memorable is subjective, the scoring rubric used in this study defined memorable as, "This book is going to stick with me. I will passionately recommend it to others."

After aggregating the scoring rubrics for the 58 narrative fiction books, the top four picture books and top eight chapter books identified as authentic, engaging, as well as exhibiting literary quality were selected for the focus groups (See Children's Literature Examined). Accurate was defined as, "the information about ASDs in this book is correct," while authentic was defined as, "this story is believable and feels like a true portrayal of ASDs." After the books were selected, the focus groups were formed and participants gave their informed consent to be studied. Members for the focus groups were recruited from local school districts, autism support groups, and local autism agencies and grouped according to "educator" or "insider" group based on location. There were four insider groups with each group consisting of two to five members for a total of thirteen insiders altogether. There were two educator groups with each group consisting of three to four members for a total of seven educators. The focus group participants were e-mailed instructions to read the books and fill out the scoring rubric given the categories and definitions as described above. Table 1 provides "Insider" group demographics and Table 2 provides "Educator" demographics. Those in the insider group indicated their relationship to a person with ASD and results indicated that ten were mothers of individuals with ASD, one of which was also a person with ASD herself, one was a father, and three were grandmothers. The age range for the individuals

with ASD was 2 to 34. Participants had lived with a person who had a diagnosis of ASD from 6 months to 17 years with the average length of time being seven years. They were asked to fill out an initial questionnaire before they began reading the books. Books were randomly assigned to their group and mailed to their homes with instructions. Instructions indicated they were to start reading the books only after they had completed the initial questionnaire. Insiders were from urban, suburban, and rural areas in the same school districts as the teachers, or in neighboring school districts. Educators were from two different school districts in the Pacific Northwest, one district is urban and the other is suburban.

Focus groups were conducted in school district conference rooms, hotel conference rooms, and university classrooms. The focus group sessions lasted approximately 1.5 hours. The script containing details and instructions for each focus group is outlined in Appendix B. Participants gave written consent to have the sessions recorded for transcription purposes and were assured that confidentiality would be maintained. They were then given three minutes to jot down any thoughts or concerns they had about the books. Participants were then told they would be discussing the books for approximately 20 minutes per book. The primary researchers attended the sessions, but did not participate in the discussion. Participants were asked to complete final questionnaires at the completion of the focus groups.

Results

Various themes emerged from the focus groups with regard to the authenticity of the narrative fiction books that were reviewed (e.g., overrepresentation of high functioning ASD, bullying, sensory issues). There were also themes about the focus groups themselves (differences in experienced versus emergent caregivers of individuals with ASD and the initiation of support groups). Lastly, focus groups discussed the benefits of chapter books when juxtaposed to picture books. Based on the overall ranking of the books, focus groups tended to like books in which characters were multidimensional and showed the everyday struggles of ASD as well as the positive attributes of a character.

Chapter Books Offer More Insight

To begin with, insider and educator focus groups indicated the chapter books were better than the picture books in that they were more insightful and

Table 1: *Demographic Information of Insider Focus Group Participation*

Insider Participants	Participants Relationship	Gender of self/ family member with ASD	Age of Diagnosis	Years of Experience with ASD	Severity of ASD
1	Mother	Male	2	12	Moderate
2	Self, mother	Female, Male	34, 9	4, 8	Mild, mild
3	Grandparent	Male	4	2	Severe
4	Father	Male	4	5	Moderate
5	Mother	Male	23	17	Moderate
6	Grandparent	Female	9	3	Moderate
7	Mother	Male	14	12	Severe
8	Mother	Male	11	4	Mild/
9	Mother	Male	4	14	Mild
10	Mother	Male	16	9	Mild
11	Mother	Male	4	2	Moderate
12	Mother	Male	2	4	Mild
13	Mother	Male	10	6	Mild
			10.43	7.29	

provided more in depth explanations of the characters and their autism; however, both insider and educator focus groups indicated the characters with autism were very one-dimensional and they expressed an interest in seeing more multi-dimensional characters represented in the books. Specifically, they wanted to see more 'normal' characters (i.e., average IQ's, not attending an ivy league school at 16, etc.) with autism represented as opposed to presenting only the quirky aspects of the characters with autism. Several focus group members reported that sensory issues were over-represented and at times seemed inauthentic. For example, one of the educators stated, "they did talk a lot about

the sensory" and a caregiver pointed out, "there was (sic) a lot of the things in there about he didn't want to be touched or hugged by his, even by his parents," and yet another caregiver noted one image in particular of a child in *Ian's Walk* (Lears & Ritz, 1998), "standing under the fan and, you know, watching it go around." The overabundance of sensory concerns in *Ian's Walk* was highlighted further:

> Ian's walk was my least favorite because it didn't seem as realistic to me I guess. Not with all the things you hear about. Back to the noise discussion. Lights, noise, smells, sensory overload. (Response to *Ian's Walk*)

> I would have liked if they would have done more explaining of why he was doing those things through the sisters' eyes, but I thought they should say why he's lying on the pavement, etcetera. Why he likes the bricks and not the flowers. (Response to *Ian's Walk*)

With regard to some of the characters with autism appearing to one-dimensional, another insider focus group member stated:

Table 2: *Demographic of Educators*

Educator Participant	Years working with students with ASD	Approximate number of students with ASD taught
1	30+	50
2	9	8
3	4.5	30-40 (35)
4	16	100
5	30	30
6	1	3
7	14	100
Average	12.42	58.25
Total	104.5	326

> I didn't like this one very much, I loved the idea of it, but I was trying to read it from the perspective of someone who doesn't know anything about autism, and it came across as someone who is weird, and I only like him because he had an outburst against someone I didn't like. But then it was like, now I think he is okay. Too much information was implied. Almost there, but on a personal level, too much implied. Weird and quirky instead of acceptable or nice parts. I get defensive automatically. (Response to *A Friend Like Simon*)

Teachers Lack of Knowledge about ASD

In addition to some of the characters seeming one dimensional, both insider and educator focus groups were frustrated with the limited understanding of ASD that was exhibited by some of the educators in the books.

> I agree that the teachers seem to have no experience and no training at all. Which for that grade, they should certainly be more aware. (Insider response to *Jackson Whole Wyoming*).

> I just kept getting mad and more mad about the teachers. Do you not realize what is wrong with this child? Don't you think it was unrealistic that the teachers were all insensitive? (Insider response to *Jackson Whole Wyoming)*

While the above quotes indicate their frustrations with the way educators were portrayed, the insider and educator focus groups were also quick to recognize when an educator was supportive in the books, as well. For example, in the book *Mockingbird* (Erskine, 2010*)*, Caitlyn had a very positive relationship with several educators:

> I liked the art teacher in here, too, the art teacher had so much . . . it seemed like he just had an instinct of understanding of her, you know, and realized that 'okay she's just an awesome drawer, but she has limitations that she can't color and that's okay right now', you know, when she goes to middle school, maybe we'll work on that. (Insider response)

> I also thought it was very interesting how the school counselor tried to work with her and just, she was, you know, the school counselor was trying to direct her. Well look at those people. She's like what am I

supposed to be seeing, you know, and what am I supposed to be looking at, so it's just, you know, the detail of how some people on the spectrum have to learn what facial expression means. (Educator response)

Overrepresentation of Higher Functioning ASD & Bullying

Focus group participants also indicated the higher functioning aspect of ASD was overly represented in the books. Specific comments from insiders included things like, "Two books hit on Asperger's kids who are much higher functioning," and "she was on the very, very high end of Asperger's." As an example, the book *Mindblind* (Roy, 2010*)* refers to a child who has a sensational intellect and attends MIT at the age of 16.

Similarly, the focus group participants noted a trend toward bullying of high functioning characters in the chapter books; meaning that the child with autism was bullied at some point in the book. One caregiver in particular pointed out a scenario from the *Reinvention of Edison Thomas* (Houtman, 2010):

> This kid was on his own, 100% on his own, and so he was falling on his face and he was trying to get up and he had to deal with bullies, you know, in particular Mitch who had really been, who he thought was his friend.

Another insider appreciated how the response to bullying was represented in *Jackson Whole Wyoming* (Clark, 2005):

> Yes, you'll have bullies but you'll have some of the kids who say knock it off and leave him alone. You have kids who will stand up for them. The kids are really good that stand up for our kids even though they may not play with them. They do interact some, schoolwork projects. But it drove me nuts that the teachers had no idea throughout the book.

In addition to the overrepresentation of Asperger's or higher functioning autism, focus group participants pointed out the unrealistic nature of some of the books with regard to the level of functioning and the savant or heroic aspects presented in the story:

> I felt Mark, he was a really likeable character but he was I would say a savant in a lot of ways. . . just had a lot of really extremely, I mean his

maturity, his ability to kind of transcend the experience of the typical peer and also articulate was to me questionably unrealistic, and in the rubric [they] use the word heroic. Was a character shown in a heroic-light? And I would say certainly yes, in fact they called him a hero several times when he saved the child, and so in that regard, I just, I haven't personally seen a lot of that, where you have this person with ASD who's saving other kids in like a hero situation and making decisions that ultimately saved lives and having the ability, the communication skills to not only think that through, but then articulate it. (Insider response to *Colder Than Ice*)

Experienced vs. Emergent Insiders

In our focus groups, it appears the more experience a focus group member had (i.e., years living with or working with someone with ASD), the more critical their review of the narrative fiction. For example, insiders (e.g., family members) with more experience were more introspective, while emergent insiders enjoyed more familiar storylines and the familiarity trumped the literary quality of the book. Several family members appreciated the elements in the books where characters with ASD were accepted for who they were as opposed to focusing on some aspect of the child that needed to be 'fixed'. While analysis of these examples is limited by our small focus groups, the differences expressed by experienced insiders and emergent insiders should be explored further. A caregiver of a child who was recently diagnosed initially really liked the book, *A Friend Like Simon* (Gaynor, 2009):

> I have already shown it to my son's friend's mom. This gave me words for how to explain it to a kid who didn't have [autism]. . . . I'm fairly new to the whole autism thing, and I am at the very beginning of this, but I already recognize how complex this is. So I don't know how accurate, when you read it, the more general they make it, easier for a broader range of ASD.

After hearing other insider respondents in the focus group talk about too many stereotypical quirks ("weird and quirky instead of acceptable"), this particular caregiver started to view the picture book with more criticism, "I like what you said, about focusing on the quirks, hadn't thought of that." During the initial reading, the emergent insider liked the book, because it connected to her life

despite the seemingly stereotypical behaviors depicted in the book. Along the same lines, Tunnel, Jacobs, Young and Bryan (2012) argue that reader's taste in books are not necessarily based on the literary merit of the book. "The positive feelings a reader has about a book are the same whether they come from a quality book or one of low literary merit" (p. 13). That being said, we noticed more experienced insiders were less likely to become attached to a book about autism just because it was a topic in which they connected. Rather they were able to resist immediate attachment to a book and consider the literary merits of the book.

Focus Groups Sparked Support Groups

Indirect themes that were not directly related to the narrative fiction books emerged in the focus groups as the groups became a sort of quasi-support group for the participants. Specifically, insider participants felt that educators, in general, were "set in their ways" and very "black and white" in how they approached children with ASD. Further, some insiders indicated the teachers of their children don't have a good understanding of children with ASD. It was also interesting to note several participants in the insider focus groups had children attending the same school districts, yet the services their children were receiving in the same school district were vastly different. So while narrative fiction can help readers learn about autism, focus groups with participants who have things in common may also be surprisingly helpful.

> I can't say my understanding of autism was modified. I no doubt gleaned info that I can't think of at this moment. However, I was surprised by the comments by "Heather" and her experience with professional staff, parents and other students at ABC Elementary. My grandson is also in the ABC District and we (my son, daughter-in-law and I) have felt that we have been well served. (Insider response)

Comments about specific districts or community services led to further discussions about the lack of community support and resources that some focus groups members experienced. As an example:

> My participation in the focus group didn't modify my understanding of autism, but it certainly increased my awareness of the need for more help for ASD kids in the public school system and the need for more

help for these kids through private insurance programs. (Insider response)

Equally important to the focus group participants, although not a direct target of this research project, was that several participants in the insider groups met others with whom they felt an affinity, so much so that they exchanged information about community resources, as well as contact information so they could continue the conversations and give moral support to each other.

Discussion

During the focus groups, information from 'insiders' and 'educators' was collected to provide insight into which aspects of current fictional narratives portray individuals with an ASD in an authentic and engaging manner. In addition, it was important to determine which narratives had the potential to help educators and their students understand the complexities of ASD. Two of the identified themes, a) chapter books are more insightful and, b) avoidance of overrepresentation of higher functioning ASD and bullying, can help guide educators when choosing narrative fiction. In addition, utilizing focus groups to help determine which books have the potential to help educators is an important tool and should be considered when identifying books that may be beneficial in educational settings. After concluding the focus groups, the books identified as both authentic and engaging were: *Rules* (Lord, 2006), *Mockingbird* (Erskine, 2010), and *Anything but Typical* (Baskin, 2009).

Educators can learn some helpful lessons from the focus group insights. First, autism is so much more than sensory anecdotes. While sensory needs are one aspect of autism, they are different for every child and manifest in different ways across different contexts. Understanding an individual child's sensory needs is imperative to helping them thrive in the classroom. Second, the spectrum of ASD is often underrepresented and doesn't accurately reflect the day to day experiences of students on the spectrum. Understanding the entire spectrum and teaching students in educational settings to understand the complexities of the spectrum is an invaluable lesson and one that should be taught in every classroom. Third, educators that take the time to understand a student with ASD can play a large role in their educational success. The supportive educator, who understood the complexities of autism, took the time to build a connection with the student and was able to influence their social and academic performance.

Recommendations for Future Authors

To help educators inform their students about ASD, fictional narratives should limit the sensationalism that is often present. In other words, not every child with ASD is going to win the science fair or attend college as a young teenager. When books highlight the extremes and the rarities of persons with ASD (Hughes, Hunt-Barron, Wagner, & Evering, 2014), it may make it difficult for teachers and students to understand what 'regular' ASD may look like. It is important that narrative fiction offers a view into the spectrum of autism as opposed to the outliers of autism.

Along those lines, it would be beneficial for narrative fiction books about ASD to highlight more of the day-to-day challenges faced by many families. Cynthia Lord's (2006) book *Rules* does a nice job of emphasizing some of the everyday struggles, including meltdowns, therapy appointments, and neighbors that don't understand, but in general, the other books overlooked this key element that provides clues into the authentic lives of many on the spectrum.

The focus on sensory struggles was another theme that seemed to get an inordinate amount of attention. While sensory issues are important to highlight, they are only one element of a child's autism (Kelley, Cardon, & Nichols, 2014). Often overlooked were the communication struggles children with ASD face. Specifically, narrative fiction focusing more on the different types of communication struggles faced by children with ASD (i.e., initiation, reciprocity, understanding non-literal language, etc.), as opposed to over emphasis on non-verbal or highly echolalic children, would be beneficial. For example, one mother insider commented, "My sense of *Waiting for Benjamin* as a children's book is it introduces the siblings' experience, however I don't think it pictured ASD beyond the stereotypic behaviors."

In addition, the majority of the characters in the books represented the higher end of the autism spectrum. This was particularly evident in the chapter books. Only one chapter book, *Rules* by Cynthia Lord (2006), really addressed an individual who would not be considered "high functioning". Several of the picture books depicted children who struggled more with their autism, for example *Ian's Walk* by Laurie Lears (1998), in general, the focus was on the social and sensory struggles of children who were able to verbally communicate.

Focus Group Benefits

The focus groups offered compelling insights into the authentic and engaging nature of the selected narrative fiction books. Oftentimes, literary experts who may or may not be topic matter experts choose books for educational purposes. Using focus groups to assist with book selection, particularly as it relates to special topics such as ASD, should be considered. Focus groups that include subject matter experts can provide insights that may be otherwise overlooked, increasing the potential benefit of the books to inform and educate the reader.

One of the unexpected benefits of the focus groups were the families' abilities to connect with each other. Very quickly, the groups became a safe place to share stories and to swap therapy ideas. In addition, families were desperate to learn about service options in the area. In the Inland Northwest, there is no central place for families to learn about different resources that are options for their children; the focus groups served that purpose. Families exchanged numbers and planned to continue the conversation about services and autism supports outside of the focus groups. In the future, it may be beneficial for families to join "book clubs" with other families who are in similar situations, as the books serve as a jumping off point for discussions around the disability that can then lead to support and guidance.

Limitations

One of the limitations we discovered involves the literary quality of the books. Books that may not have been of the highest literary quality may have been ranked as a favorite by focus group members because they were more memorable to insiders. In other words, because the topic was of interest, the overall rankings of the books may have been high, even though the literary quality of the books may not have been as high. Finally, as is apt to happen with volunteers, some of the participants who had committed to attend the focus groups, weren't able to attend at the last minute, thereby limiting the number of participants in the overall study. For example, there were approximately five participants invited for each focus group; however, in some cases, only two participants attended the session.

Future Directions

Since we conducted our original search, there has been an influx of

new autism literature. It is imperative we conduct another search to determine if there are new narrative fiction books that meet the criteria and may therefore be good teaching tools in the classroom. It would be beneficial to conduct new focus groups as we continue the search for chapter books and picture books with high levels of accuracy, authenticity, and literary quality.

Conclusion

Focus groups are an effective way to elicit the voices of insiders and educators of a specific group, in this case individuals with autism. The focus groups provided insight as to which books felt authentic and why, as well as which aspects of autism seemed to be missing from the books. Thus, books that portray an array of symptoms and severity levels, particularly delving further into the social communication struggles faced by individuals with ASD, are needed to further develop narrative fiction books surrounding this important topic.

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Appendix A

Name of Reviewer:_____

Title:_____

Author:_____ Publication Year:_____

1. Accuracy: Is the information about ASDs accurate in this book?					
1	**2**	**3**	**4**	**5**	**6**
Based on my knowledge about ASDs, the information about ASDs seems outdated and/or incorrect.		Based on my knowledge about ASDs, most of the information about ASDs is correct.		Based on my knowledge about ASDs, the information about ASDs in this book is correct.	
Comments					

2. Authenticity: Does this story portray an authentic depiction of ASDs?					
1	**2**	**3**	**4**	**5**	**6**
Based on my experience with ASDs, this story is implausible and doesn't feel like a true portrayal of ASDs.		Based on my experience with ASDs, this story is mostly believable and somewhat feels like a true portrayal of ASDs.		Based on my experience with ASDs, this story is believable and feels like a true portrayal of ASDs.	
Comments					

3. Avoids Stereotypes: Does the story avoid stereotyped and oversimplified information?

1	2	3	4	5	6
The information is stereotypical and oversimplified.		Most of the information avoids stereotypes and provides some specific information, but some information is too generalized.		The information avoids stereotypes and provides specific information.	

Comments

4. Avoids Deficit Model: Does the story avoid describing an individual as handicapped with deficits and deficiencies?

1	2	3	4	5	6
The characters are described as having a handicap and/or have deficits without being refuted.		Usually the description of characters avoids a deficit model, but a few times the character is presented in a generalized way.		Characters are multidimensional and described by individual qualities and differences. Any negative descriptions are countered with thought-provoking multi-dimensional statements.	

Comments

5. People First: Does the story use the "People First" model? (A "child with autism" and not an "autistic child".)

1	2	3	4	5	6
The story uses the features of the disability to portray the character.		The story uses the features of the disability to portray the character; however, the book was published in the UK.		The "people first" model is always followed.	

Comments

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6. Heroic Storyline: Does the story avoid the heroic storyline?

1	2	3	4	5	6
The character with an ASD is not accepted until he/she does something heroic.		The talents of the character with an ASD are not mentioned and/or the character is not presented as a hero.		The talents of the character with an ASD are described, but these talents do not make him/her a hero.	

Comments

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7. A Classic: Is the book memorable and recommendable?

1	2	3	4	5	6
I've already forgotten parts of this book. I will have a hard time recommending this book to others.		When prompted, I will remember the storyline. I will recommend this book to others.		This book is going to stick with me. I will passionately recommend it to others.	

Comments

8. Clear Writing: Does the author present facts and feelings clearly in writing?

1	2	3	4	5	6
The writing was contrived and/ or confusing at times. It was not a smooth read.		For the most part, the writing was enjoyable to read and the prose had only a few hiccups.		I whizzed through this book, because the prose was seamless and interesting.	

Comments

9. Encourages Inference: Will readers draw their own conclusions without being told precisely what to think?

1	2	3	4	5	6
The characters' thoughts and behaviors were told bluntly.		At times the descriptions allowed me to draw my own conclusions, but other times the conclusions were directly stated.		The characters' behaviors and actions were described in a way that I could infer what they were thinking or doing.	

Comments

10. Insights: Does the author show the characters working through their problems?

1	2	3	4	5	6
The characters' problems were easily resolved and the insights seemed too tidy and/or unrealistic when considering the age and ability of the character.		The characters worked through some of their problems, but other problems were resolved quickly. Insights lacked adequate reflection and/or were not exactly appropriate for the age and ability of the character.		The author showed the characters working through their problems. Unexpected insights surfaced naturally and appropriately as the characters learned about their situation. Insights were appropriate for the age and ability of the character.	

Comments

11. Didactic: Does the author avoid didacticism? (Didacticism is writing that pretends to be a story but actually is a lesson.)

1	2	3	4	5	6
The book seemed like a lesson. "Correct" behaviors, attitudes, and beliefs were directly stated without providing other perspectives.		Mostly the story came first, but the "lesson of the story" was presented too quickly and too tidy.		The story came first and the lesson was inferred through the character dealing with conflict and achieving insights.	

Comments

Please note: The scoring rubric is a compilation of direct quotes from various resources (Mitchell, 2002; Larson, Whitin & Vultaggio, 2010; Tunnell, et al 2010) and compiled into one rubric. Quotations and citations were not indicated on the rubric, so as not to distract readers when reviewing the books.

Appendix B

Focus Group Script

Thank you everyone for participating in the focus group session today. We appreciate your willingness, your time, and your effort helping us evaluate these books which have characters with autism. As we mentioned before, the goal of this research is to select accurate and authentic literature that can be shared with children to help them understand autism. The scoring rubrics you already completed for each book and the discussions we will have today will help us identify some good books.

As mentioned in the consent form, this focus group discussion will be audiotaped, so the discussion can be transcribed. Your name and any identifying information will not be included in the transcriptions. You may refuse to answer any questions during the focus group session and you may withdraw from the study at any time.

Before we begin discussing the books as a whole group, we would like you to take a few minutes to gather your thoughts about the books. We have provided paper, pens, and pencils, so that you can jot down your thoughts.

First, we would like you to rank order the three (3) books from your favorite book to your least favorite book. Next, think about what you especially liked about each book and any concerns you might have about each book. Please feel free to jot down simple notes so that you can refer to them during the discussion. You will have three minutes to write your notes. (Give the participants three minutes to write their notes.)

During the discussion, we might jot down notes, or we will ask follow-up questions. However, for the most part, we will not participate in the group discussion. We encourage you to engage in conversation and to voice your opinions about the books. There may be times that you disagree and that is okay. By having straightforward conversations, we will be able to understand these books from different perspectives.

To begin, we would like a volunteer to select a book for discussion. We will

spend about 20 minutes discussing that book before going on to another book. Who would like to begin?

(Moderators will keep time. After 20 minutes, the moderator will guide the group to discuss another book. This will be repeated until all of the books have been discussed.)

Thank you for your candid remarks about the books. Your comments and insights have been very beneficial.

The last part of this research study is to complete a final questionnaire. You may complete it now or take it home and mail it to us. (A self-addressed envelope with be provided.) If you prefer to complete the questionnaire on a word processor, we will email the questionnaire to you and you can email the completed form back to us.

Thank you for participating in this research study. We truly value your time and effort.

Possible probing questions (Krueger & Casey, 2000, p. 110)

- Would you explain further?
- Would you give me an example of what you mean?
- Would you say more?
- Tell us more.
- Say more.
- Is there anything else?
- Please describe what you mean.
- I don't understand.

About the Authors

Teresa A. Cardon, PhD., CCC-SLP, BCBA-D has worked with diverse individuals on the autism spectrum for over two decades. Dr. Cardon has published her research on autism in peer-reviewed journals and presents at conferences both nationally and internationally. Dr. Cardon has conducted behavior analytic research on video modeling to support skill acquisition in young children with autism. In addition to researching narrative fiction and autism, Dr. Cardon is conducting research on clinical aspects of Speech Language Pathologist's and Board Certified Behavior Analyst's. She is also researching pre-service teacher outcomes for special education students who take courses in Autism Studies.

Jane Kelley, Ed.D. is an Associate Professor at Washington State University. She teaches pre-service teachers in the Teacher Education Program and graduate students in the Language, Literacy and Technology (LLT) Program. She was an elementary teacher for 10 years and now teaches children's literature and literacy methods courses for educators. Her research and scholarly activities are grounded in critical multicultural analysis which involves examination of ideology of power in children's literature and the dissemination of this theory and pedagogy.