

AUTISTIC ADOLESCENTS' VIEWS ON AUTISM IN CHILDREN'S BOOKS

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ABSTRACT

The following study was based on the limited research that has involved autistic voices about their portrayals in media, in particular, children's books, and was meant to expand the research that has already been done. We interviewed four autistic adolescents about their experiences with reading books about autism, and then asked them to create their own hypothetical story featuring an autistic character. These ideas are meant to influence authors and how they think about the future portrayals of autism they will create. Participants were also informed of current themes frequently seen in children's books that already exist, and asked to comment on them. These presented themes included agency, modes of communication, bullying, and superheroes and superpowers. Participants shared an overall desire for books and portrayals of autism to be realistic and respectful. They shared a preference for showing autism as a difference rather than a disability, while still showing it as something that comes with both strengths and weaknesses. Additionally, while split on whether authors should be autistic themselves, all participants shared the value of books being accessible to all audiences, including autistic and non-autistic readers. These findings are discussed throughout the paper and are meant to shed light on the conversation about what portrayals are appropriate and not, this time involving autistic voices.

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INTRODUCTION

According to current prevalence estimates (Maenner et al., 2023), 1 in 36 children in the United States is diagnosed with autism. Nationwide, the rate of autism diagnoses is increasing, as are conversations about disabilities and peoples' visibility of them. Along with the increased rate in diagnoses is the increased rate at which children's books portraying at least one autistic character are being published (Venker & Lorang, 2023). As more books are being published, it is important that they present a positive and desired image because it is possible these books may be the first time non-autistic children experience disabilities and people with them (Dyches, Prater, & Cramer, 2001). Similarly, and perhaps more importantly, autistic children see themselves in these stories, and use them to begin understanding how they fit into the world around them (Bishop, 1990; Webber, 2024a; Pennell et al., 2017; Webber, 2024b). Assessing the quality of autistic portrayals is especially important because while some of the authors are autistic themselves, many are not. Additionally, while hiring sensitivity readers is becoming increasingly common, it is not done consistently enough for all books to be "checked" (corbin, 2024) prior to publication.

Therefore, it is fundamental that people represented in the books are included in the conversation because without them, books can unintentionally be inaccurate, and potentially even harmful, to how autistic people are regarded in the real world, let alone how they regard themselves. When books portray autism or any other disability, there is a risk of being inaccurate and possibly harmful to the community they represent. Autistic authors are similarly challenged by this task because even though they have the same disability by name, all autistic people experience it differently (Webber et al., 2024; Barrio et al., 2021). As is commonly said: if you've met one autistic person, you have still only met one autistic person. The characteristics,

qualities, and preferences are unique to each individual, even if there are similarities between them (Donaldson et al., 2017). Given this, even if an autistic author writes a children's book with an autistic character, autistic children and adolescents reading it may not identify with it or appreciate the representation because it is not necessarily their experience. By finding out how autistic people want to be represented in books, it informs the public's understanding of what media to produce, how to consume it, how to use it as an educational and therapeutic tool, and particularly how to navigate interactions with autistic people and how they may interpret them.

Although children's books about autism are commonly used as a way to increase understanding and acceptance (Lian et al., 2020), many of these books contain messages that may undermine the development of positive self-perception and peer relationships (Venker & Lorang, 2023). Children's books about autism commonly portray stereotypical depictions of autism, highlight a lack of agency (i.e., decision making) in the autistic character, and emphasize negative peer interactions, like teasing and bullying (Venker & Lorang, 2023; Lemoine & Schneider, 2020; Azano et al., 2017; Dyches et al., 2001). An ongoing content analysis in the Michigan State University Lingo Lab is identifying numerous instances of teasing, verbal and physical bullying, exclusion, and negative expressions about autistic characters.

Given these concerns, many (presumably non-autistic) researchers have created lists of recommendations for how to assess the quality of children's books about autism (Gaffney & Wilkins, 2016; Prince & Hayden, 2022). However, this research rarely includes autistic people in the discussion, which is problematic. This leads to potentially harmful promotion of certain books and representations that may seem appropriate to non-autistic researchers and readers but are not acceptable to members of the autistic community. One way to find out and prevent unintentional harm—and maximize the positive effect of children's books—is to include autistic

voices in the research. In recent years, this has become more understood, and researchers such as Anders Nordahl-Hansen and Stian Orm, as well as others, have included autistic voices in their studies on autistic representation in media formats like film and television. Through their research, they have found what autistic and non-autistic people think would make disability representation better (i.e., using autistic actors in the roles of autistic characters, having autistic producers, bouncing ideas off of autistic community members, etc.) (Orm et al., 2023). A more thorough discussion of this research is included later.

We have long known that reading books to children of all abilities enhances not only their language, but also their understanding and processing of the world. Book reading removes an immediate need to process and respond, as children can read and learn in a less intimidating environment and learn how to respond before they're in a situation where they have to react right away (Lemoine & Schneider, 2021). Portraying autistic characters in children's books, especially as their visibility in daily life is increasing, provides an accessible way for children of all abilities to be presented with a reality that may or may not be their own (Lemoine & Schneider, 2021; Webber et al., 2024a; Webber et al., 2024b). In fact, a study in the United Kingdom conducted by Best and colleagues (2020) reported that in a study of over 58,000 people ages 9-18, 39.8% of participants were interested in having more books represent characters like them, and 47.3% were interested in having more opportunities to read about people with different life experiences (Best et al., 2020; Webber et al., 2024b). Varied representations help them learn how to accept and interact with people who do experience that reality as their own.

Most research typically done with disabilities looks at what people with a specific diagnosis can and cannot do, what their typical profile looks like, and their developmental trajectories. On the other hand, research often does not consider what their opinions are, even on

the matters that concern them the most (Orm et al., 2023; Webber et al., 2024a; Webber et al., 2024b). On top of this, autistic children are frequently excluded from qualitative, participation-based studies (Cascio et al., 2020). Asking autistic individuals what they think about their representations is another small step toward not only general inclusion and accessibility, but appropriate inclusion and accessibility. Therefore, this study sought to answer the following questions:

- 1) What do autistic adolescents think about representations of autism in children's books, including stereotypes, agency, communication, and bullying?**
- 2) What ideas do autistic adolescents have about how children's books can be used more effectively, including what future portrayals do they want to see exist?**

Portrayals of Autism in Film and Television

Autism is becoming more visible in all forms of media, but television and film, rather than books, have been described as the most significant source of autism representations. Not only is it the most frequent place to see autism represented, but TV and film are viewed as the “most significant source of information” that the public has access to (Nordahl-Hansen, Tøndevold, et al., 2017). Some examples of autistic representations in TV and film are the characters Sheldon in *The Big Bang Theory*, Raymond in *Rain Man*, and Zen in *Chocolate*. Researchers have investigated autistic perspectives about these portrayals. Nordahl-Hansen, Tøndevold, & Fletcher-Watson (2017) found that most mass media representations of autism rely on stereotypes and use “savant skills” to make it clear that the character is autistic (Nordahl-Hansen, Tøndevold, et al., 2017). Savant skills are those which are particularly more impressive than in the general population as well as an individual's overall ability (Howlin et al., 2009). Currently, due to a still-limited number of films and TV shows portraying autism, a very

narrow view is represented. The view, including an over-use of savant skills, promotes stereotypical understandings of autism and autistic individuals, perhaps skewing the access to and awareness of autism the general public has (Nordahl-Hansen, Tøndevold, et al., 2017).

As a result of relying so heavily on stereotypes, autistic representations in the media have been highly controversial and therefore debated among the general population, researchers, and especially the autism community (Nordahl-Hansen, Øien, et al., 2017). As discussed, the frequent portrayal of savant skills is not representative of the real-life autistic population and may lead to harmful perpetuations of stereotypes. However, Nordal-Hansen, Øien, et al., (2017) propose that these media presentations can actually be beneficial when in the hands of educators who know how to use the films to teach about autism (Nordal-Hansen, Øien, et al., 2017). They should not be taken as the only way to learn about autism, but they can be incredibly beneficial in presenting initial exposures to autistic characteristics. Additionally, while they are beneficial, they should also not be taken as the “only way to be autistic,” and the best way to become acquainted with autism is to interact with autistic individuals in daily life (Nordal-Hansen, Øien, et al., 2017).

Now that there are more autistic representations in media, researchers are starting to ask how people perceive them and what would make them better. One recent study asked autistic people, friends and family of autistic people, and people with no immediate connection to the autistic community their opinions. Generally, autistic people recommend casting autistic actors, using autistic writers, including a more diverse autistic population in the characters, and “making autism incidental and not central to the plot” (Orm et al., 2023). One reason autistic individuals are calling for more inclusion in mass media production is that typically, while they are represented, they are still not often included in the process themselves, whether that be as actors,

producers, or writers (Orm et al., 2023). As stated, autistic visibility is increasing in film and TV and researchers have not let that slip by unstudied. This literature on film-based representations provides a helpful model for investigating autistic perspectives about portrayals in children's books.

Autistic Representation in Children's Books

Children's books about autism are sought out by parents and family members of autistic children, as well as by classroom teachers to provide opportunities for learning about autism by autistic and non-autistic children alike (Barrio et al., 2021). Classroom teachers, especially, use books portraying autism as a way to inspire conversations about autism and inclusion. While harmful representations can still support positive conversations about what *not* to do or believe when interacting with autistic peers, it can be very helpful for children to be shown what *to* do and how *to* act with their peers to promote inclusion and positive interactions between students. One way to do this is to step away from a reliance on stereotypes. Instead, teaching and representing autism as an overarching disability with multiple characteristics that vary between people in their presentation can teach without stereotyping every autistic person into the same box. One particular tip given by a study is to "select a variety of books that highlight these differences... reading several different books will help point out that not all children with autism have the same characteristics and abilities" (Sigmon et al., 2016). Promoting positive portrayals and autism as perhaps more of an umbrella term of characteristics rather than meaning one way of behaving, thinking, and/or functioning points children in a better, more inclusive direction.

Windows and Mirrors

Children's books are commonly described as providing "mirrors" and "windows" for their readers. A mirror refers to the idea that children see themselves in the literature, and a

window refers to the idea that children can see and learn about others through the characters in the books (Lemoine & Schneider, 2021, Bishop, 1990). Mirrors are also used to describe children seeing who they want to be or could be, even if the culture around them sees them as less (Bishop, 1990). For example, children with disabilities can see themselves depicted in the story as strong, capable, included, etc., when classmates or other people might limit their abilities or participation in real life. Representations in books also have the ability to show autistic children the valuable roles they have in society and help them to understand what those roles can look like (Webber et al., 2024a; Webber et al., 2024b). Conversely, relying on stereotypes to depict autism can limit the diversity of mirrors and windows, as children learn to see autism in one specific way.

Books give subtle messages about who and what we value in our society. When children cannot find themselves in books, or when they see themselves presented only as laughable stereotypes, they learn a powerful lesson about how much they are undervalued in the society in which they are a part. (Bishop, 1990)

Windows, as opposed to mirrors, are how readers learn about the world and other people around them — including similarities and differences. Stories teach people, particularly children, about cultural values and give them an opportunity to digest the information through others before having to implement social rules and expectations in their everyday life (Bishop, 1990). Based on prior research, important areas in literature are stereotypes, representation of differences and abilities, and agency.

Stereotypes in Children's Books

One of the most common criticisms of books portraying autism focuses on their use of stereotypes (Pennell et al., 2017). Autism is diagnosed based on the presence of various

characteristics, particularly having to do with social, emotional, and communicative functions. Challenges arise in toeing the line between representing autistic characteristics and relying on stereotypes, whether harmful or not. Current research shows that representing a wide range of characteristics, as well as depicting them “through dialogue and inner thoughts of the person with ASD,” and not relying on only one or two specific characteristics, leads to more appropriate representation and decreases the threat of stereotyping characters into one way to be autistic (Barrio et al., 2021). In a study completed by Webber and colleagues (2024), an autistic participant shared that he sees autistic representations as focusing on the stereotyped aspects of characters’ day-to-day lives, rather than on the “more nuanced, everyday aspects” (Webber et al., 2024b). Stereotypes are, it seems, relied on in media to emphasize the fact that a character has a particular disability, rather than representing them as a person first, navigating life as someone with a disability.

Types of Representation

Children’s books about autism sometimes describe autistic “differences” or “abilities” in ways that may be problematic. Though this is not the case for all books, some present autistic characters in ways that may be negatively perceived. Frequent portrayals animalize the autistic character, frame them as being from another planet, describe them as having “‘extreme’ reactions” (i.e., violence, screaming and shouting, throwing tantrums), engaging in self-harm, and as being particularly distinct from the rest of the population (Lemoine & Schneider, 2020; Webber et al., 2024b). For example, in one book a peer calls an autistic boy an alien and says he should go to his own planet (Mueller, 2012). In another book, people say negative things about a young Temple Grandin: “She’ll never be normal;” “Her brain’s not quite right;” “You must send her away” (Mosca, 2017). Surprisingly, this is the case even for books about autism that are

specifically recommended for educators to use (IRIS Center, 2024). Describing the behaviors of autistic children in this way promotes the extreme actions and responses that can be characteristics of autistic individuals. However, they are not representative of every autistic person, nor do autistic people have only these characteristics. This can be harmful to autistic children, as it edges them into a box of what autism is “supposed” to look like according to other children reading these types of books. These representations focus on differences alone, not allowing autistic people to see themselves included or accepted as just another person in the classroom, event, or conversation.

Other portrayals of autistic characters present them as the superhero (or as having superpowers), as a teacher, or as needing to change before they are accepted. The superhero and superpower trope has the intention of helping autistic children “feel better” about their disabilities, but focuses almost entirely on the differences they exhibit, rather than promoting inclusion. All of these representations require the autistic character to change in some way over the course of the book. In the story *Leah’s Voice*, Leah is the autistic character and her sister’s friend, Abby, doesn’t like how Leah acts. She is put-off and frustrated by Leah’s limited verbal output and unexpected reactions, until Leah wins a national art award. After reading about the award in the local paper, Abby comes over to Leah’s house and apologizes, saying she realized she needs to be nice to Leah (DeMonia & Turchan, 2012; Venker & Lorang, 2023).

Similarly, in *Will You Be My Friend*, a story by Grant Harrison based on his own experiences, the main character, Grant, has difficulty feeling like he fits in with his peers. A new student joins the classroom and befriends Grant. They perform together at the talent show, but it isn’t until the performance that they become accepted by the rest of the class, described as “they were in awe when they saw Grant—the kid without friends who fidgets all the time—sitting

behind a shiny new drum set” (Harrison & Xalti, 2022). The story ends with the class cheering for Grant and his new friend, while “Grant shed tears of joy because this was the first time he felt like people finally saw him as someone more than just the kid who fidgets” (Harrison & Xalti, 2022). In these stories, the autistic characters teach their peers that they are worthy of acceptance and friendship by showing a skill, rather than being accepted as they are in the first place. This highlights the belief that autistic people have to prove themselves as a superhero before they can be respected as a person.

Agency in Children’s Books

Agency considers the number and kind of decisions autistic characters can make, specifically for themselves, and is represented in positive and negative ways (Venker & Lorang, 2023; Azano et al., 2017). In some books, such as *A Day with No Words*, or *It Was Supposed to be Sunny*, the characters display more agency over their lives and others’. In *A Day with No Words*, the mother and son both use alternative and augmentative communication (AAC) devices and the son is shown making decisions about what activities to do next. He orders his own food, and when he is made fun of for being non-speaking at the park, his mother stands up for him using her own device. In *It Was Supposed to be Sunny*, the main character, Laila, shows agency when her birthday party plans go off course and she tells herself, “I have been through this before and I can do it again” (Cotterill, 2021). After reminding herself of her ability to adapt to unexpected challenges, Laila comes up with new ideas for how to celebrate her birthday. She has some help from her mom, but the new ideas are completely her own, portraying positive agency in this story and showing children reading the books that they are able, allowed, and encouraged to make their own decisions.

On the other hand, books such as *Ian's Walk* depict autistic characters as having limited agency. Portraying them as unable to make decisions for themselves may present to autistic and non-autistic readers alike that autistic individuals cannot have any control over their lives and must rely on others (Venker & Lorang, 2023). In *Ian's Walk*, Ian's non-autistic sister begrudgingly takes him on an outing with her to the park after being told by their mother, "you'll need to watch him closely the whole time. Are you sure you want to do that" (Lears, 1998, p. 2)? Typically, when autistic characters are given less agency, the non-autistic characters are presented as a protector or mediator in their lives (Azano et al., 2017). Because autistic children can be considered to be "in danger" or "at risk" because of challenges understanding the weight of various situations, this has the tendency to become synonymous with 'unable to make good decisions for themselves' (Azano et al., 2017). Rather than promoting the independence of autistic individuals, negative portrayals of agency promote a belief that autistic people need to be taken care of in order to remain safe, secure, and live a happy life (Venker & Lorang, 2023; Azano et al., 2017).

Inclusion of Autistic Voices in Research

Historically, autism, along with other disabilities, has been pushed to the outskirts of society, with autistic individuals being institutionalized and invisible to the public eye (Cascio et al., 2020). Even in the field of research, autistic individuals have been excluded, their input and perspectives frequently not included in any part of the study (Cascio et al., 2020). However, in recent years, the tides have begun to shift and people with disabilities are much more visible in general society as well as in research (Cascio et al., 2020, Leadbitter et al., 2021). Initially, while the focus of research had shifted to include autism and autistic people, they were still solely the subjects of research studies. Even more recently, research has included a push to include people

with autism in every part of the research, not just as participants in the study (Donaldson et al., 2017). This involves including them in the study development, data collection process, and the analyzing and writing of the results. This ensures that the research is as accessible and appropriate as possible.

An example given by Donaldson and colleagues (2017) speaks to language preferences of the autistic community. In many spaces, the terms “low functioning” or “high functioning” are used to refer to the ability-levels of autistic individuals, but generally, the autistic community is tending to move away from this language (Donaldson et al., 2017). Additionally, an important point made by Orm and colleagues (2023) is that while autistic people have commonly been left out of study development and out of discussions about their representations, they are still the ones who are most affected by the representations and have to live with the effects, whether positive and educational or negative and stigmatized (Orm et al., 2023). Including autistic self-advocates in research ensures that the research is important to the community being studied as opposed to solely non-autistic researchers deciding what is important to learn about (Leadbitter et al., 2021).

This type of approach has been implemented in autism research as “autistic adults have fought to be included in research as both research participants and research partners, making the case that the disability rights motto ‘nothing about us without us’ applies just as much to research as it does to any other realm” (Nicolaidis et al., 2019). Ethical research cannot be conducted without remaining person-centered. In order to remain person centered, the population being studied must be respected as people first and the relationship between the participant and researcher must be prioritized and protected (Cascio et al., 2020).

Research done solely by neurotypical researchers can put an othering lens on participants, making them subjects only, rather than colleagues and people. It reinforces the historical perspective of people with disabilities, treating them as less-than and using them rather than including them. Neurotypical researchers, as a result of being neurotypical and supported by academic institutions, have significant “power, privilege, and potential biases” (Nicolaidis et al., 2019) that influence how they design studies, ask questions, and analyze the findings. Including autistic adults in the development of studies researching autism helps to break down the barriers between researchers and participants and allows for autistic people to enter research spaces in new ways (Nicolaidis et al., 2019). By giving autistic people a voice in research, they and the researchers collaborate and therefore distance themselves from one person being the “expert” in the field, over the other (Donaldson et al., 2017). This leads to a more productive relationship and a promotion of autistic people’s beliefs and attitudes.

As previously stated, the participant-researcher relationship must be protected, especially in the midst of these power dynamics. Studies become more accessible when created with input from autistic individuals as they have particular insight to avoiding “imprecise language, confusing terms, or ableist assumptions” (Nicolaidis et al., 2019). Even working in the field of autism, neurotypical researchers can be unaware of these issues that cause inaccessibility and possible harm to the participants and the studies themselves. An additional benefit of including autistic people in their own research field is to highlight and understand their priorities for themselves and the autistic community rather than continue along the priorities of non-autistic researchers (Leadbitter et al., 2021).

Regard to AASPIRE Guidelines

Although it has been around since the 1940s, the participatory research model has become helpful in understanding and promoting the need for autistic voices to be included in research. The participatory research model refers to the inclusion of community members, not just university or academic researchers (Nicolaidis et al., 2019). Not only are community members willingly participating in research as the subjects, but they are working hand-in-hand with the researchers to develop the study (Nicolaidis et al., 2019). The Academic Autism Spectrum Partnership in Research and Education (AASPIRE) has been at the forefront of advocating for inclusion of autistic people in the whole research study process and uses participatory research in their approach. They promote conversations and interactions between “academic researchers, autistic adults, family members, disability services providers, and healthcare providers” as a way to work towards more inclusive research (Nicolaidis et al., 2019).

In order to successfully include autistic adults in study development, AASPIRE has created a list of ways to implement the participatory research model. The list includes making clear goals for the partnership and stating the roles of the partners so that they know exactly what is expected of them and their involvement. Additionally, the team must make sure there is beneficial communication and “power-sharing,” as well as a continual commitment to ensuring trust between all partners. Lastly, it is encouraged that results are disseminated together as a team, that there is “community capacitation,” and that the community partners are properly compensated (Nicolaidis et al., 2019).

How Neurodivergent Teenagers Feel About Neurodivergent Book Characters

Although many observations about children’s books have been made by non-autistic people, to the researchers’ knowledge there is limited research investigating what autistic people

themselves think about these books. One exception is a study by Webber and colleagues (2024), which asked neurodivergent teenagers about their perceptions of neurodivergence in young adult fiction (Webber et al., 2024). In their study, they completed 16 1:1 interviews with teenagers who have diagnoses of autism, ADHD, dyslexia, and dyspraxia (Webber et al., 2024). Prior to the interviews, three neurodivergent individuals were asked to review the interview guide and make edits and suggestions on what questions they thought should be included and/or prioritized (Webber et al., 2024). No books were read in the course of the interviews, but the questions relied on participants' previous reading of fiction that represented neurodivergence. Results were categorized into two sections: the benefits of neurodivergent representation, and the potential harms of neurodivergent representation (Webber et al., 2024). Students spoke to the benefits and stated that it is helpful to see people with similar (dis)abilities living full lives, being present in society, and use the representation as a way to better understand themselves and help their neurotypical peers understand what their daily lives are like (Webber et al., 2024). Speaking to the harm done by some representations, one participant commented that she would rather not be represented at all than have an inaccurate image presented to the world (Webber et al., 2024). The findings of this study emphasized the importance of continuing conversations about representation in books, both with neurodivergent and neurotypical people alike. With that should, and must, come an increased visibility of books with a variety of representations, particularly those which are presented with input from neurodiverse people (Webber et al., 2024).

THE STUDY

The goal of this study was to investigate autistic adolescents' views about autism in children's books and understand what they want others to know about autism through these books. Participants were asked about their experiences reading (or having read to them) children's books about autism. In addition, they were asked about specific themes and ways that current autistic characters are portrayed. To the authors' knowledge, this was the first study to gather autistic adolescents' views about children's picture books using a semi-structured interview and identifying specific portrayals. For that reason, we conceptualized this as a pilot study where we interviewed four participants, that will pave the way for future investigations of this kind.

This study was needed in the field of autism research as it amplified the voices of autistic people and considered their opinions in research. Asking their opinions, rather than promoting non-autistic views about books that feature autism, is an area where little research has been done thus far. Children's books portraying autism and autistic characters have been published with increasing frequency, rated, sorted into categories of "good" and "bad" with varying results, and qualitatively analyzed for their primary messages (Lemoine & Schneider, 2020; Azano et al., 2017; Sigmon et al., 2016; Dyches et al., 2001). However, rarely have autistic children and adolescents themselves been asked their opinions of these books. Could books considered "good" actually be promoting harmful beliefs about autism? Could some of the "bad" books actually have something beneficial in them? This was especially important because as the current literature mentioned, children learn quite a bit through these books, more than is perhaps realized. Non-autistic children learn how to understand and process autism, as well as interact with autistic peers, while autistic children learn how to understand themselves and their role in

their communities. By conducting this study and asking these questions, it began the process of including autistic people in the conversation about their own portrayals and promoted a more accurately inclusive use of these books.

Population Rationale

Book recommendations are often asked for by parents, grandparents, guardians, and teachers. Teachers, especially, want to supply their classrooms and students with enjoyable, educational, and easily digestible picture books for students to read during free time. Children's picture books are also frequently used in teaching moments with the whole class to facilitate conversations about diversity, acceptance of others, and at times, as introductions to understanding people with different abilities (Sigmon et al., 2016). Similarly, they can be used to help facilitate conversations with autistic children about the real world, their place in it, and potentially even the dangers they may encounter and how to respond, while remaining in a safe place with trusted adults (Bishop, 1990). They are similarly a trusted resource for other adults looking to purchase appropriate and helpful books for their children at home (Barrio et al., 2021). Although the target ages for children's books are younger than adolescents, we selected this population particularly due to the comprehension requirements of the interview study. The participants were required to understand common themes in books about autism, the researchers' questions, and to form their own opinions of the themes. Younger children were less likely to be able to share their insights than adolescents, and adolescents similarly have more "life experience" to base their answers off of. They have likely been in more situations than younger children where they experience others treating them certain ways because of their autism—another reason why the researchers selected them as the target population for this study.

Lastly, while we considered asking autistic adults about their perspectives, they were even further from the target age of the books being used. While they have the most awareness of autism and how it impacts how they navigate the world, they are the farthest from the population being read to or reading children's books. We needed to find the balance for this study between participants who could understand the themes, questions, and provide insights, but who were also still close to the target age for the stories. Therefore, adolescents were best suited for speaking to how these books may be interpreted by children and those being read the stories. We also recognize that while autistic adults may not represent autistic children or adolescents' lived experience, even within these different age categories, there is significant variability in lived experience. For example, white autistic children may not represent all autistic children, and the same is true of autistic people of different races and ethnicities.

METHODS

Four participants, three male and one female, between the ages of 14 and 16 with a medical diagnosis of autism were recruited. When referred to individually from here on, they will be referred to as F14 (female, 14), M14-1 (male, 14), M14-2 (male, 14), and M16 (male, 16). Participants were invited to join the study regardless of their use of verbal speech or augmentative or alternative communication (AAC), though all four participants used verbal speech. Additionally, they were required to have at least a 5th grade reading level, per parent report. The purpose of this inclusionary criterion was to ensure that participants had the language comprehension skills needed to understand the interview questions and the expressive communication skills required to answer them. In addition, the adolescents were required to be able to understand the book themes presented to them and form opinions about what was being portrayed and how. This was necessary because, as our autistic consultant on this project, Drew, pointed out, participants' thoughts had to be original without needing researcher explanations to avoid bias. If participants did not understand the themes, it would have been difficult for them to answer the questions that followed. If this had been the case, the researchers could not have explained the books further because their deeper explanations may have influenced the interpretation the participants then had, which would have influenced the answers they gave and made them less original and potentially representative of a non-autistic point of view.

As a step towards more participatory research, this thesis study included a community partner, an autistic self-advocate, Drew Shaw. While collaborating on this project, we ensured trust between us during our communications so that he felt welcome to share his input. We made clear what his role in this project would look like so that we both understood the expectations placed on the work each of us did. Drew was asked to review the initial study proposal, the

methods, particularly the interview portion, and answered any other questions as they came up. He provided incredibly thoughtful and helpful feedback that gave new perspectives not previously considered. Lastly, at the end of the study and his participation in it, Drew was compensated for his time.

Recruitment

This study was prospectively reviewed and approved by Michigan State University's IRB. Following IRB approval, participants were recruited from late November to early December. A description of the study and its inclusionary criteria was shared with local speech-language pathologists, families, autism groups, and on social media. Families who contacted the lab with interest were provided with further details about the study. Participants' caregivers provided consent to answer screening questions about their child to ensure they met inclusionary criteria. After criteria were met and families confirmed their willingness to participate, a time was set up for them to come to the Oyer Speech and Hearing building on Michigan State University's campus for an in-person interview. The participants and their caregivers then provided informed verbal assent and written consent, respectively, at the start of their interview. They were compensated for their time with a \$25 gift card.

Background Information

During the study, participants' parents were asked to complete a paper form detailing background information about the reading habits in the home. See Appendix A for the questionnaire presented to the participants' families. The form also included demographic information such as age, sex, race, ethnicity, socioeconomic status, and other speech and language services the participant receives. The data gathered from these documents will be analyzed in future research, but are included in Table 1.

Table 1: Answers from the Background Information Survey completed by participants' parents

Participant ID	Race/Ethnicity	Parent Education	SLP Services Your Child Received/s
F14 (Female, 14)	White/Caucasian	Bachelor's Degree	Private speech ages 8-14
M14-1 (Male, 14)	White/Caucasian	High School Diploma	In School
M14-2 (Male, 14)	White/Caucasian	High School Diploma	Current: Consult Speech on IEP Past: School and private speech from age 2
M16 (Male, 16)	White/Caucasian	High School Diploma Some College	Previously received speech

Table 2: Answers from the Background Information Survey completed by participants' parents

Participant ID	Did You Read with Your Child When They Were Little (+ genre)?	Do You Read Together Now (+ genre)?	Do the Books Include Autistic Characters?	Do They Spark Conversations with Your Child?	What Messages/Portrayals Do You Hope For?
F14	Yes, Fiction	Yes, Fiction	Yes	Sometimes	"To know that she's not alone"
M14-1	Yes, Fiction	No	No	N/A	"Any"
M14-2	Yes, 50/50 Fiction and Nonfiction	No	No	N/A	NR
M16	No, Fiction	No	Unsure	NR	NR

Table 3: Answers from the Background Information Survey completed by participants' parents

Participant ID	Do You Look for Specific Themes/Portrayals?	Any Portrayals You Try to Avoid?	Any Specific Books You/Your Child Particularly Enjoyed?
F14	Yes, "positive views on neurodiversity"	"Ableism, artificial distinctions between levels of autism"	"Counting by 7s," "Can You See Me," and "Cassandra in Reverse"
M14-1	No	N/A	N/A
M14-2	No	NR	N/A
M16	NR	NR	NR

Interview

The completed study involved semi-structured interviews that lasted between 25 and 40 minutes and were recorded for coding purposes. I conducted three of the four interviews, and another trained graduate student lab member conducted the fourth due to co-occurring interviews. One 5-minute break was offered halfway through, with the allowance for more breaks as requested by the participant. Participants chose whether they preferred to have their parent(s) in the interview room with them, which three of the four did. Parents were generally quiet and allowed their children to speak openly, but at times did add in some contextual information to help their child think through the questions or qualify their answers. Their comments were welcomed as they did not overpower the time that the participants had to share and did not appear to influence the content of participant answers. For example, one parent helped with recall of specific book titles when the participant could not remember them. This parent also reminded her daughter of the book her daughter is writing, which does feature autistic characters, and asked if she would like to describe the story. Another parent shared information about the beliefs about autism with which he and his spouse raised their children to explain an answer his son gave in the interview.

Each interview began with background questions to get to know the individual and their reading habits (see Appendix B). Next, participants were asked generally about their experiences with children's picture books, or young adult fiction or graphic novels, about autism. Questions covered their thoughts and opinions of autism portrayals in books, the settings in which these books are presented, and the populations who have access to the books. Next, participants were asked to describe a story they would want to tell about an autistic character, particularly how they would, or would not, use themes such as agency/decision making, characteristics of autism,

communication (characters' use of AAC), and bullying, and how they would want autism to be perceived based on their story. We raised the topic of bullying with our autistic participants because bullying of autistic children is frequently portrayed in children's books. Lastly, the interviewer described some of the major themes that commonly occur in children's books about autism.

These themes included the same list as were included in the hypothetical book the participants were asked about, with the addition of the superpower trope. No specific examples from books were used, but each theme was described with as much detail as possible while minimizing unintentional researcher bias. For example, when asking about portrayals of agency, the question was phrased as "in some books, the autistic character makes decisions to solve problems in the story. In other books, the non-autistic characters make the decisions to solve problems. What do you think about decision-making in children's books about autism?" The questions were opinion based, and there was space for follow-up questions as well as general probes, which allowed for greater information to be gathered from each participant. As with any study, this interview was not entirely free of bias, especially as follow-up questions were asked spontaneously based on participant responses. To minimize bias, follow-up questions were kept to a minimum to both maintain similarity of the interviews for all four participants, as well as remain as on-track from the original intent of the interview as possible. Of the interviewers, one was non-autistic, and one was neurodivergent, and we both brought different perspectives, understandings of, and experiences with autism. Additionally, we acknowledge that the position of this research team was that showing instances of autistic agency, varied modes of communication, and limited use of autistic stereotypes is important for children's book portrayals of autism and the messages they share with audiences. Additionally, prior to the

interviews, it was our assumption that portrayals of bullying would be negatively perceived by autistic readers. This set of beliefs may have unintentionally influenced the questions we asked and the ways in which we asked them. See Appendix B for the full interview guide.

Qualitative Coding

Interview data, including occasional parent comments during the interviews, was coded and analyzed using the template analysis method (Brooks et al, 2015). This method is frequently used with data collected from interviews or surveys and “emphasizes the use of hierarchical coding” and structure in analysis (Brooks et al., 2015). The template analysis method requires the “development of a coding template, usually on the basis of a subset of data, which is then applied to further data, revised and refined” (Brooks et al., 2015). The flexibility of this method allows for themes to emerge and be loosely formed from the start. This included main themes that were based on the data gathered in the interviews as well as themes that were created to specifically answer the study’s research questions through use of *a priori* codes.

To implement this analytical method, three members of the Lingo Lab first finalized the transcripts. One was a neurodivergent first-year Ph.D. student in Michigan State University’s department of Communicative Sciences and Disorders. Another was an autistic community research assistant in the Lingo Lab, and the third was a non-autistic, second-year master’s student in Michigan State University’s department of Communicative Sciences and Disorders. All three researchers individually listened to the interview recordings, read through them, and then began to apply the template analysis method, without seeing the codes placed by the other two. This process included six steps: reading through the data collected in the interviews, preliminary coding, organizing the emerging themes, defining the first template, applying the

template to more data, and finalizing the template in order to include the full data set in it (Brooks et al., 2015).

Step one was simply to read through the data in order to get an idea of what was said in the interviews and what kind of information was gathered from the participants. Next was preliminary coding of the data. Fifty-four preliminary themes/codes were created based on important, frequently occurring data found in the transcripts. In this stage, pre-determined themes such as respect and portrayals (current and future) were applied, and new themes were created, even when based on a small portion of the data. The flexibility of template analysis allowed for multiple themes to be created, edited, and sometimes even eliminated based on how the rest of the data developed (Brooks et al., 2015). After we read two transcripts and created the initial codes, the three of us met via Zoom to go through them slowly, and discussed what codes we created and applied to each line. After this meeting, we continued to apply the template to the final two interview transcripts.

Two coders, the first-year Ph.D. student as well as the second-year master's student, met to complete step three, which involved organizing the preliminary themes from step two into groups and defining how they intersected and related to each other (Brooks et al., 2015). This step led to a hierarchy of ideas in which the themes were clustered within each other, and broader themes led to narrower (Brooks et al., 2015). The broader themes housed narrower themes and allowed for greater organization and understanding of the intersection of the data and how each theme is now connected. For example, a preliminary theme of "interactions with non-autistic individuals" fell under the broader theme of "respect" in step three. In step four, the same researchers met, where the initial coding template was formed based on the organization from step three. The thematic clusters formed the basis of the template into which the rest of the data

was sorted. In this stage, definitions of each theme were created as a way to guide the analysis and placement of the rest of the data more clearly into these themes. These definitions also indicated if new themes needed to be created to capture new data that arose throughout analysis (Brooks et al., 2015).

This led to step five, where the rest of the data was analyzed and placed within the preliminary template. As previously stated, when there were data points that did not fit within the first template, themes were modified, and more were created to include new data due to the flexibility of the template analysis method. Some themes include up to four or more subthemes to capture the important aspects of the information provided by the study participants (Brooks et al., 2015). In between steps five and six, the second-year master's student met with a committee member who is an expert in using Template Analysis Method to discuss the thematic clusters and preliminary template. This allowed for someone external to the coding and thematic analysis process to check the codes to make sure they made sense and were appropriate based on the steps we had followed thus far.

Finally, in step six, the template was finalized with the themes, and was then applied to the full data set to complete the analysis (Brooks et al., 2015).

RESULTS

We observed four primary themes across participant answers: portrayals of autism, both current and future; benefits and drawbacks of different audiences; people's understanding of autism; and respect in how autism is talked about and portrayed.

Portrayals of Autism: Current and Future

The bulk of the interview questions focused on participants' views on portrayals of autism that exist in current, published, children's books, specifically having to do with the subthemes that are developed further below. They were also asked to explain the portrayals they hope to see exist in the future, based on a hypothetical story they would create themselves to portray autism.

Agency

When thinking about current portrayals of decision making in children's books, specifically who makes the decisions (i.e., the autistic character or the non-autistic character), participants overall shared the opinion that portrayals should be balanced, with both the autistic and non-autistic characters contributing to decision making. For example, M14-1 stated, "...you're making your own decisions, good for you," and he was supportive of people making decisions for themselves (M14-1). F14 brought up the challenges with showing decision making while also making it equitable, and said, "I feel like sometimes having the non-autistic characters making decisions gives the impression that the autistic character can't make their own decisions, which is a problem, but it [sic] sometimes also making decisions is hard, so, chronic indecisiveness" (F14). Additionally, she stated, "...it needs to be made clear that the autistic characters can make their own decisions and be in control of their own lives and don't need to have someone holding their hand the whole way" (F14). M14-2 provided another perspective

and said, “I feel like they should make some decisions and not some others, and they should make some mistakes and not be perfect, but not just make clearly stupid mistakes all the time...it should be balanced” (M14-2). Lastly, M16 prioritized the respect with which the author portrayed agency, and shared, “As long as, like, it’s handled with care I honestly don’t mind” (M16).

Participants also shared important insights as to what portrayals they think should exist in the future. F14 stated that in her hypothetical book, both the autistic and non-autistic characters would make the decisions that best suited them. In the same vein, M16 stated that in his story, “...everyone would make their own decisions” (M16). M14-2, however, was more split on how he would show varied decision making and peoples’ abilities within that. Similar to what F14 shared about current portrayals, M14-2 shared that in his hypothetical story, he “...would have the autistic character try, but they could end up being split on decisions and not really sure which one to go with. So they might need some help with some decisions” (M14-2). For M14-1, he was focused on showing that autistic characters could make their own decisions and said, “The autistic character would make them” (M14-1).

Bullying

Participants made numerous statements in support of portraying instances of bullying. For example, M14-1 pointed out that books that show bullying are realistic, “Because it happens all the time” (M14-1). He went on to share, “I mean, we should show the truth and get out there, be like ‘This is why we should end the bullying and teasing about this’” (M14-1). F14 was also in support of including portrayals of bullying because “It highlights the problems with not accepting the autistic characters and encourages ... people to accept them” (F14).

While two participants were in support of showing bullying, two participants considered both negatives and positives of showing portrayals of autistic children being bullied. These concerns included that it "...might encourage others to do it," but it is also "...something that would happen in real life, so to say, 'oh it never happens' would be just plain out false" (M16). M14-2 shared, "...it might encourage some kids to do it if it's done in bad faith, but if it's done in a good way to show ... that the bullies were clearly in the wrong, then it can be good" (M14-2).

For hypothetical portrayals, participants shared their ideas about how to appropriately portray bullying of autistic children. M16 suggested that bullying, if present, should be central to the story. He said, "Make it, like, the main focus if you want, put it in, don't just have it as a side detail like 'oh he gets bullied'" (M16). Additionally, M14-2 shared that bullying should continue to be in children's books and he would include it in his own hypothetical story. His autistic character "...might experience people telling them bad things, ...excluding them because they're autistic, or people believing that they're wrong" (M14-2).

Communication Modes

Participants were generally in support of varied communication styles being shown in books featuring autism. When asked about current portrayals, M16 was in support of showing varied communication because, "...you know, not everyone communicates the same way, even neurotypical people" (M16). He said that "...as long as it's handled with respect," different modes could and should be presented (M16). M14-2 was also in support of books that show different modes of communication because it is realistic. He said, "Well, different people speak differently. Like, some people can't speak, so they have to use other ways" (M14-2). Similarly, M14-1 focused on the reality of varied communication in the real world and said, "I think books

should show that. Because of the different ways of communication autistic kids use” (M14-1). Additionally, F14 mentioned that different communication modes should be portrayed because it is the reality that autistic people use different ways of communicating. She also talked about how others should respond to it, and how books can show non-autistic people having the “...patience to accommodate and figure out what works” for the autistic character (F14).

When asked how they would portray communication differences in their hypothetical stories, participants talked about a variety of different ways to communicate. One participant mentioned the challenges autistic people sometimes experience with spoken communication and mentioned alternative communication modes that his hypothetical character may access more easily. M14-1 shared that he would portray characters using “...sign language, because autistic kids don’t like to talk much” (M14-1). The other three participants prioritized speech, but emphasized how it might still look different for autistic people. F14 considered showing the process of being able to communicate in the midst of finding speech challenging to access and said she would portray communication by “All the normal ways [talking], but also, like, having to find other ways of communicating. Like, if you go nonverbal and you can’t talk, you have to figure out other ways ... like texting, writing” (F14). Another participant, M14-2, said he would portray communication differences realistically and respectfully, and his characters “...would communicate by talking, sometimes being a bit forgettable ... but not speaking like they don’t really know how to” (M14-2). Lastly, M16 said that his characters would communicate through “Talking... Just normal banter” (M16).

Superpowers and Notable Talents

Participants were then asked about their thoughts on superpowers and notable talents and their opinions were split. Two were in support of showing autism as a superpower or showing

autistic characters with notable talents. F14 said that she thinks "... it's a good way to highlight how... autism isn't always a bad thing. Like, being able to recognize patterns quickly is really helpful for... math" (F14). M14-1 believed that notable talents would be good to show. He said, "I mean, I think that's good. I mean, like, show your talents like and go out there and be you" (M14-1).

On the other hand, the other two participants were less convinced of the benefit of using superpowers and notable talents to portray autism. M14-2 said, "I feel like if the superpowers are a theme and it's like a superhero book, then it should be there, but if it's not, it shouldn't be there" (M14-1). Finally, M16 was also against using superpowers because "...it's not a fair representation because autism is not ... a talent that you get or that you're born with ... it's more that your brain thinks in a certain way that allows you to do more things" (M16). He went on to say, "Like ... your brain works differently, so in exchange ... you might be worse at some stuff, but you're better at some stuff. At least theoretically, of course. Sometimes it's more take than give and sometimes it's more give than take. After all, it's a spectrum" (M16).

Experiences

Participants were asked about what kinds of experiences their hypothetical character would go through, and they described various experiences, including both potentially positive and negative experiences. Some potentially negative experiences that the autistic character might experience included "...sad feelings...because kids bully them all the time," "being excluded ... because they're autistic," and "...dealing with teachers and social situations and ... anxiety when it's not warranted" (M14-1; M14-2; F14). F14 also mentioned that her hypothetical autistic character might experience situations where they are, "...trying to make eye contact and not ... able to focus on it" (F14). Participants also reflected on positive experiences that their character

might go through, such as “...people accepting them and thinking they’re ok for however characters treat them” (M14-2). M16 talked about possibly including a complex riddle in his story that only the autistic character can fully understand and solve, showing positive aspects of “thinking differently” than the non-autistic characters. He said, “Maybe at one point it’s like a dead end and like the riddle is just way too cryptic, at least for the neurotypical characters. But for whatever reason the autistic character is able to like piece it together even if it’s like not how the original riddle was meant to be interpreted” (M16).

Portrayal

Participants shared ideas about how they would want autism to be portrayed in their hypothetical stories. Generally, answers described showing autism “As something that’s neither a positive nor a negative, it’s just a difference” (M16). M16 also brought up stimming and fidgeting behaviors; he explained that character would “...do stuff that might seem a little odd to neurotypical characters, but for the autistic character it’s just how they cope with the world” (M16). Additionally, M14-2 brought up frustrations that some current portrayals portray autistic characters “...as being stupid and can’t do anything and will end up being a failure” (M14-2). To combat this, M14-2 said that in his portrayal, he “...would like [the autistic character] to struggle with something and...they could be intelligent or not, that they...can have the chance as long as they try” (M14-2).

Hypothetical-Story Take-Aways

We also asked the participants how they wanted to characterize autism in a hypothetical story and what they wanted readers, both autistic and non-autistic, to understand about autism from it. Overall, their responses indicated that they wanted people to have realistic takeaways about the “ups and downs” of autism and being autistic. Specifically, M16 shared that he wanted

people to learn “...that sometimes [autism] has its downs, sometimes it has its ups, not in terms of like how you would think, but more like it has its own challenges but it also has its own benefits” (M16). Similarly, F14 shared that she wanted people to understand “...that autism isn’t the problem. It just doesn’t mesh with the way things are set up” (F14). M14-2 wanted readers to take away “...that there’s nothing to be scared of, nothing to be ashamed of, and that it’s totally normal, and doesn’t really affect that much” (M14-2). Additionally, he wanted the overall message to be “...more encouraging than discouraging” about what it is like to be autistic (M14-2).

One Participant’s Story

After her daughter answered all of the questions about a hypothetical book, F14’s mother mentioned that F14 was actually writing a book featuring autistic characters. After this information was shared, we asked about the specific portrayals that she has already thought about and started to create on paper. F14 described her book as a fantasy that follows twin sisters separated at birth. When describing the twins, F14 said, “...the more I developed their personalities, the more they do seem like the opposite ends of my specific autism” (F14). One twin, Ember, “...codeswitches really hard, like, she has a really strict military discipline, but only when what she’s doing is directly related to the military that she’s in” (F14). The other twin, Luna, “...always wants to have a plan before she does anything, and can’t talk to people” (F14). When asked to clarify what she meant by the fact that Luna can’t talk to people, F14 said, “...she doesn’t really have much experience with talking to people, so just pretty much avoids having to talk to people” (F14). The full details of the story were still being worked out at the time of this interview, but one of the main conflicts F14 mentioned was “...they find each other by chance and have to work together to overcome their challenges” such as the lack of planning and limited

desire to talk to others (F14). Finally, when asked about whether she is framing their characteristics as positives, negatives, or both, this participant said, “I’m showing ... that they can be strengths ... or weaknesses depending on the situation” (F14).

Audience

Reading Habits

Participants also answered questions about their typical reading habits for us to better understand their relationship with books. Participants’ reading habits ranged from reading as often as possible, to only reading when required for school assignments. M14-2 described his preference for not reading as “I’m not the best reader... it’s a bit much for me.” He said a big part of understanding and connecting with characters is “seeing them” but he “can’t really do that with reading” (M14-2). F14 and M14-1 reflected on reading as something that they enjoy but just don’t have enough free time to do very much anymore. In addition to talking about the frequency of their reading, three of the four participants also mentioned their favorite genres, including fantasy, sci-fi, mystery, and adventure. After participants were asked about their general reading habits, they were asked specifically about whether they had read or heard of books that featured autism or autistic characters. F14 was the only participant to answer yes and give specific examples of these books, including the Asperkids series, “To Shape a Dragon’s Breath,” “Sisterhood of the Spectrum,” and “Can You See Me?” She explained that she read these books based on recommendations from her mother, who used other books, such as the AsperKids series, to spark conversations with F14 about navigating the world as an autistic individual. Participants’ reading habits are characterized in Table 2.

Table 4: Participants' self-reported reading habits

Participant ID	Reading Frequency	Reason for Frequency	Preferred Genre	Specific Books Portraying ASD
F14	Every day	School and fun	Fantasy, Sci-Fi	Asper Kids, To Shape a Dragon's Breath
M14-1	4-5 times per month	Primarily school, some fun	Mystery, Adventure	N/A
M14-2	Rarely	School only	None	N/A
M16	Rarely	School only	Fantasy	N/A

Use of Autism Media

Participants also shared their thoughts on where books about autism should be available for access, how they should be used as an educational tool, and how they should be formatted. They shared that books about autism are important to “get out there” to portray autism and introduce others to it. M14-1, M14-2, and M16 thought books about autism should be especially available in libraries and schools because “...that’s where children are kind of away from their parents so their parents can’t, like, make them biased in any way” about the content in the book (M14-2). They also pointed out the benefit of libraries and that families “...don’t have the risk of buying a book that they might not like. And that takes that barrier down to them getting it” (M14-2). F14 stated that books portraying autism should be available “wherever,” and that the important part was that the messages were exposed to others.

Participants stated that books portraying autism could also offer important opportunities for educators to introduce their students to new experiences. M14-2 said, “...well, [teachers] can read it out to the students and just suggest it as an idea of what to read. You know, ‘Hey, this is something new and it’s something someone else is experiencing that might be interesting.’” Another participant, M14-1, said books could be used “...just to set an example of what the real world is like out there.”

When asked about the format that the participants would use for their hypothetical story and the format of those that already exist, they had different thoughts on what they would prefer. F14, M14-1, and M16 shared that their story would be best suited for “a regular book” without pictures. M14-2 had shared that simply reading “...is a bit much...” and he doesn’t “...really get into liking the characters, like part of that is seeing them...but [he] can’t really do that with reading” (M14-2). Given this, he decided that he imagined his hypothetical stories in video format because, in his opinion, “...autism is something you experience, not something you can really see,” and the video would be helpful in “...showing how the characters are struggling with some problems and how they react to certain things,” rather than having to rely on visualizing what the character is going through (M14-2).

Autistic Audience

Despite three of the four participants not having been exposed to books about autism prior to this study, they were asked about the potential benefits of autistic people reading books about autism, or those where autistic characters are portrayed. We asked about both positives and negatives of having an autistic audience. Participants said that reading books with autistic characters might have positive outcomes for autistic people, such as helping them “...learn that there are other people out there who are experiencing the same things” (F14). Similarly, M16 shared that, “[autistic readers] might have an idea, like, a better grasp of like what challenges they face compared to other people without, and what they are better at than people without.” M14-2 identified books to be helpful in teaching autistic readers “...that it’s ok for them and that they’re not stupid,” while M14-1 shared that some books could help “...teach them about why they have autism” (M14-2, M14-1).

Participants also mentioned potential negative aspects of reading books about autism to autistic individuals, or of autistic people reading the books on their own, including concern about the accuracy of the portrayals that autistic people would be exposed to and how inaccurate and incomplete portrayals could be harmful. F14 brought up the spectrum aspect of autism and shared that "...if you see the side of [autism] that is similar to you but, like, [the book] really stresses techniques that don't work for you...you don't learn other techniques that would work for you" (F14). She pointed out that it could be harmful for autistic readers to think there is only one way to exist, or only certain ways to cope, as an autistic person (F14). M14-2 expressed concern that "The characters might be portrayed badly, or the book might not be helpful" (M14-2). M16's concern lay with "...where the author is coming from," and what they show about autism in their book. M16 said that the impact of the book depends on whether "...they're [the author] like 'oh it's a spectrum it should be celebrated,'" or "...if the author's coming from like 'oh it's a disorder we need to cure it' perspective." M16 further explained that if it is the former opinion of the author, "...then yeah, it's not a bad thing," but if it is the latter, "...then yeah that could be really damaging" (M16). One participant did not share any potential concerns about autistic people reading books about autism, and often focused throughout his interview on the benefit of just "getting the message out there" (M14-1).

Non-Autistic Audience

Another important potential audience for books about autism are non-autistic individuals. The participants were asked to share their opinions on potential positives and negatives of these book for a non-autistic audience. When they shared about positives, they commonly focused on the benefits of using these books to teach non-autistic people "...about what that experience is like and just educating other kids about their peers that could have autism" (F14). M14-1 focused

on the fact that these books can show others, especially children, that "...it's not a bad thing to have autism" and M14-2 offered that these books may help non-autistic people "...understand that [autistic people] struggle with things and know that they're not bad, and it's not a bad thing to be autistic" (M14-1, M14-2). M14-2 also shared that books could show non-autistic readers that "It's nothing to bully someone over and that it's ok for people to be autistic, and it's nothing to be scared of" (M14-2).

Proposed drawbacks of non-autistic individuals as an audience for children's books about autism primarily focused on concerns about potential inaccuracies of autistic portrayals. Possible drawbacks also focused on the readers' ability to consume the messages, including factors such as their own understanding or trusted adults' interpretations of the content. According to F14, "If [the book] only shows one side of [autism]. And 'cus it's a spectrum, and then if you only learn one side of it," it can be misleading. M14-2 was concerned that "Some children might not understand, or their parents might tell them that the books are wrong," and how that could influence how portrayals are received. Once again, M16 brought up the perspective of the author, and how they play a big role in influencing the use of books portraying autism. He considered both positives and negatives in his answer, and said, "It could give them like an understanding of like, depending on the book, like either if it's a good portrayal like 'oh, they just think differently than us' but if it's a bad portrayal then it's 'oh they're different from us they need to be cured'" (M16).

Understanding of Autism

General

Throughout the course of the interviews, the participants talked about their own personal understanding of autism. Though they were never directly asked what they think and understand

about autism, each participant expressed their thoughts through their answers, particularly when talking about their ideas for future portrayals and how they would show that their character is autistic. Participants did not report being influenced by books about autism, but many indicated that they were influenced by their parents, families, and the world around them. F14 shared that while growing up, she read books featuring autistic characters, or books directly about autism with her mother, and this sparked conversations for them about what it means to be autistic in this world and how to come to a place where she accepts her autism. All four participants shared their impressions of what autism means to them. F14 stated, “It’s just a different way of thinking that just, society isn’t made for” (F14). When talking about what messages M14-1 wants others to understand about autism, he said he wants people to understand, “...how people get autism and what are the effects of it.” Similar to F14, M14-2 talked about autism as a difference, and stated that to him, it is “Something that doesn’t really make you super smart or something that makes you super dumb. Just something that makes you struggle with some things and just makes you think differently and be different” (M14-2). Lastly, M16 shared a similar sentiment to F14 and M14-2 and said, “It’s not a disorder, it’s a difference in thinking... sure, it can have its good things, but it can also have its bad things. Everything’s like that in the end” (M16). The four participants each had somewhat similar understandings of autism based on their own experiences of living with it in the real world. They ranged from wanting to understand how people “get” autism to wanting people to understand that there is nothing wrong with being autistic, it is simply a difference in how they navigate different life-situations.

Autistic Characteristics

Over the course of the interviews, participants shared their understanding of characteristics of autism – whether they were based on their personal characteristics or others

they have learned are typically present in the autistic community. These characteristics were expressed in participants' comments about their own presentation as well as answers to questions pertaining to portrayals of autism that should be included in books. Some characteristics participants mentioned included "invisible" autistic characteristics, such as a sense of perfectionism; only being able to work towards something knowing it would turn out as planned; difficulty paying attention while also experiencing hyper-fixations; difficulty making or maintaining eye contact; feeling forgetful; and experiencing demand avoidance and indecision. Other "invisible" autistic characteristics included going into situations feeling underprepared and having a strong internal discipline to get things done. Participants also mentioned physical characteristics like making tongue clicks, feeling the texture of objects, general fidgeting, and stimming (e.g., arm flapping).

Other characteristics brought up by participants included thinking and acting "outside the box" when perceived by non-autistic people, and finding speech difficult to access consistently and needing other ways to communicate. Specifically, M14-1 stated, "...autistic kids usually don't like to talk much, they like to like [sic] talk in a weird way" (M14-1). In a similar statement, M14-2 shared, "...some people can't speak, so they have to use other ways. Or if they have a hard time figuring out how to say stuff, or like get them speaking" (M14-2). Additionally, when talking about augmentative and alternative communication (AAC) modalities shown in books, F14 mentioned, "It's a good way of demonstrating even if you're non-verbal and unable to talk, you can still communicate" (F14). In terms of general autistic characteristics F14 also pointed out traits in relation to direct interactions with others. She mentioned difficulty understanding social interactions such as "...dealing with teachers and adults who don't want to listen to what they're (autistic people) experiencing," understanding when to "...ask questions

and when it's okay to be talking about yourself' and personal interests, challenges in understanding types of language such as metaphors, and finally, anxiety when conversing with non-autistic individuals (F14).

Personal Acceptance

The participants showed their personal acceptance of being autistic themselves, how they developed that acceptance, and the need for non-autistic people to also come to an acceptance of others' autism by how they talked about autism and their experiences with it. While talking about the impact books can, and perhaps should, have, M16 stated that "Ultimately, it's up to the individual to... figure out how they feel about autism" (M16). Another sentiment expressed about the impact books can have was that portraying autism positively can help autistic readers understand "...that they're just different and there's nothing to be ashamed of" despite what their peers and general society might tell them (M14-2).

Though they were not the primary participants, there were several points when parents offered relevant comments. One parent shared that, in raising their kids, he and his wife did not buy into the "...puzzle piece type mentality," and wanted to "...look for balanced portrayals..." Therefore, they "...don't think we pushed a lot of autistic literature when they were younger, we tried to just give them the basic... childhood stuff. Because it's not something wrong with them, it's just who they are." These parents indicated that they taught and demonstrated a personal acceptance of autism to their autistic children from the very beginning, helping their children to develop a similar mentality. All four participants, as well as some of their parents, frequently expressed the importance of accepting themselves and members of the autistic community for who they are, and how this is important to display in literature geared towards autistic and non-autistic audiences.

Respect

Another recurring theme across the four interviews was respect. This respect related to how autism is discussed and treated by others, how non-autistic people interact with autistic people, and authors' approaches to writing autistic characters.

Differences in Attitudes About Autism

As seen in the "Understanding of Autism" theme, each participant had a specific understanding of autism and what it meant to them. F14, M14-2, and M16 shared similar sentiments such as that autism is "just a difference" that has its "good and bad things" and makes people "be different," but there is nothing wrong with being autistic. M14-1 focused on characteristics of autism in his understanding, primarily pointing out the challenges with speech autistic people sometimes have, particularly in their comfort and personal access to it. The participants also talked about how books may be interpreted and used by non-autistic people due to their different understandings and beliefs about autism.

One participant expressed concern that some parents or caregivers would not approve of, or appropriately use, children's books portraying autism, furthering a more harmful message about autism. Specifically, M14-2 stated, "...their parents might tell them that the ... books are wrong, and that autistic people are bad and it's bad to be autistic" (M14-2). This concern of how others might respond to or use the books also led the participant to share comments about respect in the ways autism is portrayed, and whether such portrayals show autism as a difference in how people think ("good portrayal") or as a difference that needs to be cured ("bad portrayal") (M16).

Non-Autistic Interactions

The idea of respect was also commonly mentioned in the context of interactions between autistic and non-autistic people. Participants talked about these interactions across most of the

questions, but the topic was raised primarily when questions were asked about portrayals of bullying. When asked about bullying, participants overall expressed positive opinions about the inclusion of these kinds of instances. Participants explained that bullying is a typical occurrence for autistic students and should therefore be shown, with care, in books with autistic characters. In another answer, F14 brought up a potentially frequent experience of non-autistic "...teachers and adults who don't want to listen to what they're [autistic students] experiencing, and why that's a problem and trying to navigate social relations" (F14).

Authorship

Participants were asked directly about who they thought should author books about autism—whether authors should be autistic, or if it did not matter to them. This exemplifies the varied experience and understanding of autism that each person within the autism community has. When asked about whether authors portraying autism in their stories should be autistic themselves, two participants disagreed, and stated "I feel like the people that write the experience of having autism should be autistic, like because you can't really experience autism if you haven't really, so you don't really know what it's like" (M14-2). On the other hand, the other two participants did not express as strong feelings on the topic. The two who did not respond as adamantly against authors being non-autistic were more focused on the fact that autism portrayals were getting published and thought that "...whoever writes the book is just doing the right thing by getting the book out there and just showing people what the world is like" (M14-1).

They believed that it was the right thing to increase people's awareness of autism through children's books, regardless of whether the author was autistic. M16 suggested that "...the books written by autistic people are intrinsically going to have a better understanding of what autism is,

because you kind of need to be autistic to fully understand what autism means, at least to you” (M16). The other two participants were not as convinced as these participants were of the effectiveness of authors simply doing research on autism. They pointed out that to them, it seems challenging to accurately write and portray something, in particular, a whole-life experience that the author has not actually experienced themselves. M14-2 said, “What you can do is see and hear but not really understand” (M14-2). Their answers varied, but were all supported with strong reasons as to why they held the opinion they did. Even by researching information about autism and what autistic people encounter, half of this study’s participants shared that it is not enough. For them, “...people that haven’t really experienced autism shouldn’t really make books about it, about the experience, because they didn’t experience it” (M14-2).

DISCUSSION

During the course of the interviews, participants did not have the same opinions for every question asked. They all had different understandings and opinions about autism because they have lived different lives with autism affecting them in different ways. Overall, however, participants wanted children's books to represent real experiences of autistic children, even if the reality isn't the most positive portrayal, and to do so respectfully. Their responses indicated that to them, presenting autism as having its positives and negatives is the best way to educate others on what it is like to be autistic, rather than sugar-coating different experiences.

As mentioned in the introduction, sensitivity readers are not always included in the assessment of books, or other media-based portrayals of autism. The demand for sensitivity readers is increasing, but as the need grows, the resources may have to be stretched if there are not enough sensitivity readers to go around for all projects. However, this study raised the possibility of including adolescents, and maybe even children, in the conversation. The results of the conducted interviews show that adolescents are extremely thoughtful in how they approach their own autism, how written portrayals are shown to the world, and how they hope, and don't hope, these portrayals could be used. Despite adolescents likely not being as old as the "typical" demographic of sensitivity readers, they have still experienced years of being autistic in the world and developing their opinions about what they want others to see, learn, and understand about what it is like. In future publications of both media showing, and research about, autism, perhaps adolescents and children should play a role in assessing the accuracy and appropriateness of the content.

That said, regardless of whether autistic adolescents, and/or children, are included as sensitivity readers, they still have plenty of insight to give to various portrayals of autism, both

present and future. Based on this pilot study, we experienced the value of having autistic adolescents as study participants rather than subjects, and asking them to share their thoughts and ideas about how autism is and should be portrayed. Based on the data collected in this study, we anticipate the increased potential of children's books portraying autism in their ability to show appropriate and respectful portrayals and how they will be used to educate both autistic and non-autistic people about autism and peoples' experience with it. As non-autistic researchers, asking autistic people about specific portrayals in children's books is the only way to really understand how they view various portrayals and how to use the books to their greatest extent.

Specifically, according to our participants, considerations for future authors of books about autism to weigh include an ability to portray differences in a realistic, but respectful way, as our participants hope that the book will be presented to a wide audience of both autistic and non-autistic children, families, and individuals to read and learn from. It is an important task, too, as readers will learn from the books they read, no matter whether the portrayal shows positive or negative ideas about autism, autistic people, and how to interact with them. Participants shared concerns that representations, while important, can still be harmful to both autistic and non-autistic people, depending on how the author portrays them. However, they also shared that autism is not always all positives, and negative aspects of autism can and should be portrayed. This is an important line to toe by portraying potentially "negative" aspects of autism, while not portraying autism as a negative. In giving ideas about ways to help ensure that future books toe this line appropriately, some participants proposed that only autistic people write books about autism because only they truly know and understand what autism is like at its core. Regardless of who writes the books, all participants agreed that increasing awareness about autism through

books and other media is important to improving acceptance and inclusion of autistic people in the world.

Participants did not talk about the concepts of windows and mirrors in those exact terms in their interviews, but they addressed the same idea when talking about benefits and drawbacks of different possible audiences for books featuring autism. Their considerations of reading to autistic children included that the audience could learn that they are not alone, or could feel that they are alone, depending on the way the author portrays aspects of the character's experience (i.e., the book acts as a mirror). Then, when the participants talked about reading books showing autism to non-autistic children, the audience would be able to understand more about their autistic peers and learn about autism in a more removed sense than learning about it for the first time when met with an autistic peer (i.e., the book acts as a window into someone else's lived experiences).

In terms of content, a reliance strictly on stereotypes, as mentioned by the four participants in this study, would give a skewed vision of what it is like to be autistic. Specific characteristics are a part of autism, yes, but they are not always all present, nor does every autistic person experience it in the same way. As one participant stated, to represent autism appropriately, authors should "try to show both sides of the theoretical autism coin" and show that "it's okay to have autism but there's also things that are going to be different" (M16). F14 already demonstrated this by creating two characters with the same DNA that have different characteristics, but are still both autistic. If the whole "coin" is shown, parents, teachers, and children can all get a better idea of what it is like to be autistic, rather than learn autism to mean one specific characteristic or set of characteristics. This aligns with research published prior to this study, and mentioned in the introduction, that cited concerns of only ever relying on one or

two characteristics in every portrayal of autism, which forces a complex experience into a small box of what it can be.

As an example of showing varied “sides” of autism, bullying, while not a positive portrayal necessarily, is, according to the participants, appropriate to include due to the reality of bullying in everyday life for many autistic children. Some even decided that they would put it in their hypothetical stories as an educational opportunity, rather than leave it out as a way to place rose-colored glasses over the experience of autistic children. This response was especially surprising to us as researchers because we had not anticipated the participants supporting portrayals of bullying in stories. Their explanations of why they would want to include it all made sense, but as it was an unexpected answer, it made us all the more grateful that we asked about bullying specifically. This demonstrated the importance of including and asking the represented groups because, had we not asked, the recommendations some of our team may have made as non-autistic researchers would likely have been biased to not include bullying because it is a more negative experience of many autistic children. These interviews, and our participants, showed that we would have been wrong, at least according to these four, and emphasized the need for continuing this conversation and for including autistic people in research about their own portrayals.

Additionally, it was eye-opening to learn how aware each participant was of how many autistic people use other modes of communication and why they might use them (i.e., autistic burnout, finding speech difficult to access/preferring different modes, etc.). Perhaps it should not have been as surprising, but it demonstrated how far-reaching their knowledge and opinions were on different portrayals, and showed that they considered the entire autistic community rather than just themselves when answering our questions. Again, this emphasizes the validity and necessity

of including autistic voices in research, as well as the work still to be done in learning more about how they view portrayals of autism.

Overall, participants agreed that books can play a role in “normalizing” exposure to autism and giving people a basis on which to form their opinions. They shared thoughts on the benefits of portraying autism in ways that are meant to enlighten others on the reality of autism as best they can without putting autism into a specific box (by only showing “one side” of the spectrum or “coin”). The participants in this study recommend that future portrayals offer a wide variety of characteristics, show characters to be capable of more than the world around them may think they are, and that they can be independent to live their lives as is best for them. Reflections on current portrayals in children’s books led participants to suggest that it is important to represent autism and autistic people in stories, but to do so in a way that educates others, rather than one that diminishes or exaggerates their lived experiences. Everyone, including those within the autism community, have different experiences with autism, which shapes their understandings of, and interactions with, others. The participants agreed that the primary takeaways they hope people get from current and future books that will be published, are that autism is just another way some people experience life that comes with its ups and downs, just as any other non-autistic person’s life has too.

Another point made by the participants was that interactions between autistic and non-autistic people can be full of challenges, but books can play a role in demonstrating both the truth of how interactions go, while also showing the possibilities of what they could, and perhaps should, be. By showing adults acting with patience and taking the time to try to understand what the autistic person is saying to them, as well as varied bullying experiences, participants want books to have the opportunity to teach different types of interactions that promote respect,

inclusion, and understanding of autistic peers, students, and friends. By keeping respect of autistic people first and foremost, representations will become more well-rounded and perhaps more representative of their daily lives.

Limitations and Future Directions

This study was one of the first to interview autistic adolescents about representations of autism in children's books. The prior studies conducted by Webber and colleagues, both of which were published in 2024, looked at neurodiversity representation in picture books, and interviewed neurodivergent teenagers ages 14-17. They asked questions about neurodiversity representation using similar themes to what we picked out for this study, but this was the first that we are aware of that focused specifically on autism in both our recruitment and interview questions, as well as asked about a hypothetical book participants would create. Additionally, our study asked about specific themes noticed across children's books, such as agency, modes of communication, bullying, and superpowers/notable talents, which differs from the Webber studies because theirs focused on whether each participant felt "seen" and accurately represented in current portrayals.

While our study offered important insights, there is still research and work to be done. Autistic voices must continue to be included in this conversation, and while four participants were a manageable size for this study, interviewing approximately 12-20 adolescents in the future will help in improving representations of neurodiversity in children's books. Additionally, in part due to the limited participant number, there was limited diversity within the interviewees. All four used speech to communicate and identified as white/Caucasian. Future studies should strive to include more diverse participants, particularly in terms of race, ethnicity, socioeconomic status, and modes of communication participants use. Including participants who communicate

in alternative ways may provide new perspectives not reached in this study. Additionally, this study did not distinguish between fictional stories and autobiographical stories featuring autistic characters. Asking about these differences specifically could shed more light on whether authors of these books should be autistic or not, and the kinds of stories they tell. Lastly, this study did not ask about additional diagnoses participants may have that impact their daily lives and navigation of the world around them. Future studies might consider including this information to better contextualize and understand participant responses.

Findings emphasize the importance of accessibility and continued publishing of books portraying autism. While all four participants agreed that it is important to portray peoples' differences in books, only one of the four adolescents has read books about autism. While another participant has seen movies and other media with similar portrayals, still three of the four have not personally seen portrayals in books. This points to the, though increasing, still limited existence of books and their accessibility. It is the hope that as more research is done and more information is understood about what portrayals of autism to include and how to write them, more books will be published and become commonplace for autistic and non-autistic people alike to read and learn from.

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APPENDIX A: BACKGROUND INFORMATION SURVEY

- How old is your child?
- Is your child: M F Other _____
- Please check all that apply:
 - White/Caucasian
 - African American
 - Hispanic of Latino
 - Asian
 - Native American
 - Native Hawaiian or Pacific Islander
 - Other: _____
- Years of formal education you have completed: _____
- Please list all speech and language services your child receives (in school, private, etc.):
- Do you read books with your child now?
- Do you tend to read more fiction/narrative books/stories or nonfiction with your child?
- Do any of the books include autistic characters?
 - What are the titles?
 - Do they ever spark conversations for you and your child(ren)?
 - What messages do you want to give your child about autism through these books?
- Do you look for specific themes/portrayals in books to present to your child?
 - What themes/portrayals?
 - Any themes/portrayals you try to avoid? If so, what are they?
- Would you be interested in being contacted about future studies in our lab about similar topics?

APPENDIX B: INTERVIEW GUIDE

- Thank you so much for being here today. We want to know what young autistic people think about children's books about autism (or books with autistic characters). We think it is important to hear what you have to say because you have the unique point of view to help us better understand the content of these books and how best to use them.
- In a minute I'm going to ask you some questions. Please know that there is no right or wrong answer, we just want to know what YOU think. We will take a 5-minute break about halfway through the questions, but if you want to take another break at any time, just ask. Does that sound ok? Do you have any questions?
- First, we'd like to talk about reading. We know that not everyone likes to read in their free time. It's ok if you don't, and it's ok if you do! Remember, there is no right or wrong answer.
 - What are your experiences with reading?
 - In general, how often do you read?
 - What kind of books do you read?
 - What types of characters do you like?
- Have you read any books about autism (or books with autistic characters) or had them read to you?
 - If yes:
 - Tell me more about that.
 - Which book/s have you read?
 - What led you to read (or listen to) these books?
 - Did someone give you the book?
 - Did you see the book somewhere? Where?
 - When and where did you read them?
 - What did you think of these books?
 - Was there anything you particularly liked?
 - Was there anything you particularly didn't like?
 - If no:
 - Have you heard about any books about autism?
 - If yes:
 - How did you hear about them?
 - What have you heard about them?
 - Do you want to read them? Why or why not?
 - If no: ok!
- As you might know, there are a lot of picture books about autism (or books with autistic characters) that are written for young children (preschool to early elementary school age). Have you ever read any children's picture books about autism (or books that include autistic characters) or had them read to you?
 - If yes:
 - Tell me more about that.
 - Which book/s have you read?
 - What led you to read (or listen to) these books?
 - When and where did you read them?
 - What did you think of these books?

- Was there anything you particularly liked?
 - Was there anything you particularly didn't like?
 - If no: Ok.
- One possible audience for picture books about autism is young non-autistic children.
 - What are the benefits (good things) of reading picture books about autism to young non-autistic children?
 - What are the drawbacks (bad things)?
- Another possible audience for picture books about autism is autistic children.
 - What are the benefits (good things) of reading picture books about autism to young non-autistic children?
 - What are the drawbacks (bad things)?
- If you wanted to tell a story about autism in a children's book, what kind of story would you want to tell?
 - What might the autistic character (or characters) be like?
 - What kinds of things might they experience?
 - How might you show decision making? (would the autistic character make them or would someone else?)
 - How might the characters communicate?
 - Different books portray autism (show characteristics of autism) in different ways. How would you want autism to be portrayed?
 - Where would you want your story to be visible (homes, schools, libraries)?
 - How would you want this story to be told (picture book, short videos)?
 - What would you want people to understand or learn about autism from your book?
- People have read many children's books featuring autism, and have noticed that there are a lot of different ways people write autistic characters in these books. I want to know what you think about some of these common themes.
- In some books, the autistic character makes decisions to solve problems in the story. In other books, the non-autistic characters make the decisions to solve problems.
 - What do you think about decision-making in children's books about autism?
- Some books feature autistic characters with superpowers or notable talents, like amazing memory or remarkable intelligence.
 - What do you think about the focus on superpowers/notable talents?
- Some books feature autistic characters who use speech to communicate, and some feature autistic characters who use AAC (augmentative and alternative modes of communication, like tablets, picture cards, or sign language).
 - What do you think about the different forms of communication autistic characters might be shown to use?
- Some books show autistic characters being teased or bullied by non-autistic peers. Sometimes the non-autistic peers stop teasing and bullying the autistic character by the end of the story.
 - What do you think about showing autistic characters who are teased or bullied?
- Some books about autism are written by autistic authors, and some are written by non-autistic authors.
 - Do you have any thoughts or opinions about who writes books about autism?

- One place that children might encounter picture books about autism is at school, in their classrooms. Is there anything you think educators should know about how to best use these books in their classrooms?
- That is the end of our questions. Is there anything else you would like us to know?