

Content Analysis: Representation of Down syndrome in Children's Literature

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ABSTRACT

As the Down syndrome community expands, the importance of seeing representation of children with Down syndrome in juvenile literature is even more crucial. Children need to see themselves and others different from them represented in literature. Specifically, children with Down syndrome need to see themselves represented as more than their disability. The purpose of this study is to analyze the representation of Down syndrome in children's literature, and to understand the audience each novel was written for, the racial and gender identities of the children represented and their multidimensionality, and whom the voice of the story belongs to. This study analyzes 10 children's books published from 2007-2020 to discover the representation of Down syndrome in recent juvenile literature in comparison to the early 2000s. Further, this study looks into the publishing industry and questions whether the Big 5 publishing companies are gatekeeping a community of authors.

Keywords: Down syndrome, juvenile literature, inclusivity, identity, representation, disability, people first language, personal voice

INTRODUCTION

Down syndrome or Trisomy 21 is one of the most common chromosomal disorders in the world, with an increase of about 30% in the United States between 1979 and 2003. Additionally, the life expectancy of children with Down syndrome has also increased, from 10 years old in 1960, to about 47 years old as of 2007 (CDC, 2020). Due to the commonality of Down syndrome, it is even more important that there is inclusive literature for members of the community to see themselves represented and portrayed accurately. Furthermore, it is important that people with Down syndrome see themselves portrayed as more than their disability.

My younger brother was born with Down syndrome in 2007, and while there are now more children's books portraying children with Down syndrome, that was not always the case. I remember my mom struggling to find books to read to him at bedtime, or for my sister and me to read to help us learn and understand what life with our brother may be like. Yet, while there are now more children's books depicting characters with Down syndrome, the struggle does continue with age. Again, now that my brother is 13, finding stories that portray a character with Down syndrome without making it about their disability is difficult to find. However, with further research discussing the topic of representation of children with Down syndrome in juvenile literature, I hope to bring face towards the small amount of available literature.

LITERATURE REVIEW

Impact of Children's Literature

The accessibility to children's literature is important for early childhood development and for children's understanding of societal norms and cultural values surrounding them. Thus, the words used in literature for children are powerful and shape how children perceive people and their environment. Many scholars have looked at the representation of diversity in children's books and how it affects the self-image that children grow up with, as it is "shaped in some degree by exposure to images found in written texts, illustrations, and films" (Hurley, 2005). Therefore, it is evident that the representation of diversity in children's books is impactful on a child's identity, growth, and their perception of the world. However, as Nina Christensen highlights, "there is a tendency to welcome a book representing a disabled person simply because the need for such books is evident." Further explaining that it is important to critically analyze the available books due to the fact that the representation of the characters are often related to the historical period and social setting of the author - which, therefore, may portray harmful attitudes and convey a negative image of the character (Christensen, 2001).

Inclusive children's literature (in the case of this study ages 3-6) not only acts as a mirror for some to see themselves represented in a novel, but simultaneously, it acts as a window into a different world for a child to experience or understand the life of someone else (Kleekamp & Zapata, 2019), or to learn that other people can be the heroes of stories as well. In their research, Kleekamp and Zapata provide a selection of criteria for teachers to pull from when creating diverse libraries for their students that portray humanizing representations of characters who may have disabilities. Their guiding questions include; "How is the life of the character with a disability presented as multidimensional? Whose voice is represented and emphasized in the telling of this story? How are readers positioned to think and feel about the character with a disability? What steps has the author taken to create and present authentic relationships?" (2019).

Likewise, in *Only Time Will Tell: A Content Analysis of Juvenile and Young Adult Literature on Characters with Disabilities and Whether Character Portrayals Have Improved Over Time*, Caitlin Wilson, highlights that historically, books that portrayed characters with disabilities only focused on physical disabilities such as blindness, and orthopedic disabilities (paralyzation, amputations). Wilson's research analyzed the portrayals of characters with disabilities in books published between 1980-1990 and 2000-2010, through content and literary quality. Wilson states, "The subject of disabilities was often seen as a taboo subject, and in many cases people felt uncomfortable discussing it. Literature on disabilities often did not treat characters in a respectful sense" (Wilson, 2012). However, in 1990 when the Americans with Disabilities Act (ADA) became law, enforcing "people with disabilities have the same rights as everyone else" (ADA, 2021), there was a shift in focus, and more stories were written portraying characters with learning disabilities. Through her study, she found that, "characters in more recent novels are more realistic, and are seen in a more positive light" (Wilson, 2012). Noting this change amongst literary content and the recognition of mental disabilities alongside physical disabilities was a critical development for inclusive writing in children's literature.

Similarly, Dyches & Prater, et al. (2001) conducted a study on the characterization of mental disabilities and autism (MD/A) in children's books. Specifically, in one section they delved into the relationships surrounding characters with MD/A. Of the 12 books they acquired for their study, they noted that friendship was a minor theme, and if friendship was depicted it was between a character with MD/A and special needs, never someone without MD/A or non-disabled (2001). This is notable in comparison to Wilson's (2012) study because it falls in line with her analysis of the shift overtime towards positive portrayals of character with disabilities. Further, Dyches & Prater, et al. concluded that in their study there was an overrepresentation of boys portrayed with MD/A, deeming it problematic because it could lead to a stereotype that girls do not have or are mildly affected mental disabilities (2001). Thus, while inclusivity of disability is important, it is still equally important to make sure there isn't a disparity between racial, ethnic, and gender identities represented.

Further, many articles discuss the portrayal of people with different developmental disabilities in juvenile literature. For instance, in the article *Same but Different: Characters with Developmental Disabilities in Current Juvenile Literature*, researchers reviewed the 2018 recipients of the Dolly Gray Award¹ and found that 3 of the 38 books in their study, portrayed children with Down syndrome. However, based on their criteria they found that one of their books represented a character with Down syndrome unrealistically. Emphasizing, that the portrayal of a young character with Down syndrome seeking adventure in Yellowstone National Park by himself while interacting with strangers to be "unrealistic and unwise" (Taylor, et al., 2018). This highlights how the authors should be aware of their audience, and the importance of understanding how a young reader may interpret a story as realistic, which may warrant undesired actions from the readers such as avoiding stranger danger, and wandering off by themselves.

Additionally, Price, et al. (2016), researched inclusive learning environments for children with disabilities, ensuring that their classrooms provided a diverse selection of books including characters with and without disabilities. However, there is a limited selection of books available that portray children with disabilities. Stating, "While many teachers and family members look to community libraries as a resource for books, finding quality materials that feature characters with disabilities can be challenging" (Price, 2016).

Similarly, in 2005, Kalke-Klita conducted an investigation on the *Inclusion of Characters with Down syndrome in Children's Picture Books*, and she found that "research concerning picture books that include characters with DS was practically non-existent." Through her analysis of the picture books, she states that there is a decline in stereotypical assumptions being portrayed and "people with DS are now seen as capable of conducting more independent, satisfying lives instead of needing constant care" (Kalke-Klita, 2005). Furthermore, she comments that a

¹ Dolly Gray Children's Literature Award - In collaboration with Brigham Young University, the Division on Autism and Developmental Disabilities (DADD) sponsor the award which is to recognize "effective, enlighten portrayals of individuals with developmental disabilities in children's books (DGA, 2021)."

“purpose for using books containing a character with DS arises when there is a student in the class or school population who has this chromosomal anomaly. However, this is a very sensitive issue, and decisions must be made dependent on the individual situation” (Kalke-Klita, 2005). This serves as an important reminder that singling out an individual as a representative of a larger group is a form of discrimination, so it is important to gain consent from the family prior. However, many readers feel understood when they see themselves, or other children with similar challenges represented in literature, emphasizing the importance of inclusive children’s literature inside and outside the classroom.

People First Language

The inclusion of respectful language use in children’s books is also important for a child’s development and understanding of societal norms. Children who grow up reading and hearing the proper and respectful way to refer to people who have a disability, will grow up understanding and accepting of those who may be different from them. Likewise, children with disabilities also have the right to read stories portraying characters with disabilities with language that isn’t hurtful and insulting. This is why the use of People/Person First Language (PFL) in children’s books, and everyday language is crucial. While the notion of naming a person before their diagnosis (e.g. person with Down syndrome) seems like a common and respectful thing to do, it has not always been the norm.

PFL is a linguistic device that replaces premodified nouns with postmodified nouns. In other words, PFL allows people to describe what a person “has” versus asserting what a person “is.” Emphasizing, that they are a person first. For example, ‘person with a disability’ versus ‘a disabled person’ and ‘person who is blind’ versus ‘the blind.’ It is important to study the language people use to describe others because it can negatively or positively effect the social attitudes people convey (Guth & Murphy, 1998). In 2006, the DOC enacted the *People First Respectful Language Modernization Act* which is to “require the use of respectful language when referring to people with disabilities in all new and revised District laws, regulations, rules, and publications and all internet publications” (ODR, 2006). This prompted many organizations to rename themselves such as *The American Association on Mental Retardation* changing to *American Association on Intellectual and Developmental Disabilities* - which is their fourth name (Halmari, 2011). Halmari further discussed that “these [linguistic] principles are reflections of changes in society, where an every attempt is being made to create a more polite or sensitive world for all of its members.” Moreover, Halmari also highlighted that while the government and other agencies changing their names to reflect a “more compassionate world, or a more sentimental view of humanity.” She critiques the effort stating, “They are laudable and altruistic, yet they are also prescriptive and based on the potentially naïve Whorfian notion that if we can fix the language, we can fix the world” (Halmari, 2011). In other words, while the adoption of new words into our lexicon is beneficial, that does not inherently solve the problem surrounding society’s negative mindset. Thus, the goal of PFL is to make sure people with disabilities are treated with respect and to create positive portrayals to replace the insensitive portrayals that history has provided. Further, this is now why it is expected of authors to use PFL when portraying characters with disabilities, especially authors with a target audience of children. The incorporation of PFL alongside powerful stories will help instill new societal norms and acceptance in children, and it will uplift children who have a disability to see characters spoken about respectfully. Likewise, this will help to destroy the stereotypes and discrimination placed on people with disabilities.

Research Questions

For my research questions, I chose to use two of the guiding questions mentioned in Kleekamp and Zapata’s research:

1. Are the characters multidimensional outside of their disability?
2. Whose voice is represented and emphasized in the telling of this story?

Alongside my own inquiries about the stories:

3. Who is the intended audience for the book?
4. Is the language used in the story a positive representation of characters with Down syndrome?
5. What race and gender identities are represented in the books?
6. Does the publishing industry gate keep books depicting children with Down syndrome?

METHODS

For this study, I used a textual analysis method on the selected texts. Meaning, I looked at the author's word choice, intended audience, and the relationship depicted between characters to illuminate underlying commentary towards the representation of children with Down syndrome in society and literature. From this analysis, I was able

to gather qualitative data on the language use and descriptive qualities used throughout each book. This allowed me to compare my observations from each analysis in order to understand how characters with Down syndrome are represented in children's literature. I took notes on each book and created a loose code to follow while gathering data. For instance, when observing and annotating for the language use in the selected books, if I came across an instance of positive language describing a character, I marked it and labeled it *P*. Similarly, if I came across a moment of People First Language, I marked it with *PFL*. It was a very simple coding process, but in the end, it provided visual insight as to where I found the instance in context with the rest of the book, not just if the book showed use of positive/negative language, or PFL. From annotations following the language use, I was able to use it as qualitative data to understand how authors are representing children with Down syndrome. Further, by annotating of characteristics such as the race and gender of the main character represented with Down syndrome, and the intended audience - I was able to quantify the results and see the numerical value each group represented, to find if there was any outliers in the selected texts.

Book Selection

The books collected for this study were chosen based on the following requirements: (a) portraying a character with Down syndrome, (b) being published after 2007 (with the exception of 3 books in my prior possession), (c) was published with the intended audience being children. I conducted a Google search to create a list of books I wanted to analyze and obtain for my study based on reviews from Goodreads, Barnes and Noble, and Amazon reviews. Many of the books for this study, were personally acquired through Amazon.

I will be utilizing the books in my prior possession that were published before 2007, *The Best Worst Brother* (2005), *My Friend Isabelle* (2003), and *We'll Paint The Octopus Red* (1998) as tools for comparison between the data to record significant changes in the portrayal of characters with Down syndrome.

RESULTS & DISCUSSION

The results regarding the reviewed books are broken up into categories based upon the guiding & research questions, and compared to other books in this study. Therefore, information regarding one specific book may be found in different locations. A synopsis for each book, as well as an abbreviation key for the books used in the study can be found in the Appendix A. While publishing information can be found in Appendix B.

Multidimensional Characters

As described in Kleepkamp and Zapata's (2019) research, it is important for characters with disabilities to be represented as more than their disability. This provides readers with an opportunity to relate to the characters as a person, not just a person with a disability. Further, if the reader is also a person with a disability, it allows them to find more similarities they may share with the portrayed character. The multidimensionality of characters in literature is important, no matter the abilities given to them. In my study, 12 of the 13 books (92%) portray characters multidimensionally. It should be noted that *You're All Kinds of Wonderful* [YAKOW] does not contain a main character. Instead, YAKOW directly addresses the reader, and its main goal in the story is to emphasize the importance of embracing and loving yourself to the reader. However, YAKOW doesn't portray any major narration development to include it as multidimensional.

Yet, in my research I noted different levels of character multidimensionality in the books. For instance, in *Super Socks* [SS], the main character is Molly and her little sister, Katie, has Down syndrome. Since Molly is the main character in SS, this limited how much of Katie's character we saw. So, while the book depicted Katie's interests in mismatched socks, her love for ice-cream, and how her favorite color is "the whole rainbow," those interests feel very surface-level considering the fact that SS is about a young boy bullying Molly about her mismatched socks, until he meets Katie and that teaches him to be kind and accept others. So, in this instance, as lovable as Katie's character is, she was used as a teaching tool for the young bully.

In *We'll Paint The Octopus Red* [WPTOR], which was published in 1998, Emma is talking about her new baby brother, who she hasn't met yet. Through this conversation with her dad she is sharing all the things she wants to do with Isaac such as going on trips, reading and playing kickball. That is until her father tells her that Isaac was born with Down syndrome, which immediately deters Emma. However, her dad explains that she can still do everything she mentioned with Isaac, but she will just have to do it at Isaac's pace. From this, Emma again accepts and regains confidence in the dream. What is interesting about the character dimensionality in WPTOR is that we are learning about characteristics, interests, and activities future Isaac may hold, but not currently, as he is only a few hours old.

Whereas, in *My Friend Has Down syndrome* [MFHDS] the character dimensionality of Sarah, who has Down syndrome, develops from sharing jokes with her friend and both having glasses, to stating that Sarah wants to be a sugar plum fairy in the nutcracker ballet this year, and in the future Sarah wants to work at the children's hospital because she likes to help people. MFHDS is different from SS and WPTOR because it explains why the character has these interests giving the reader a further understanding into the character, instead of a surface glance.

Similarly, another great representation of multidimensional characters is from author Silke Schnee's works, *The Prince Who Was Just Himself* [TPWWJH] and *Prince Noah and the School Pirates* [PNSP]. In these works, Schnee did not provide any diagnostic labels for the representation of Noah, a child with Down syndrome. Instead, she focuses on introducing his character to the reader, and then diving into a story. Thus, making a story portraying a child with Down syndrome without making it the main story, or a foretelling characteristic of her character. Instead, it is just a boy who saves the kingdom from a bad knight with kindness (TPWWJH) and a boy who works as part of a team to defeat pirates with their own mastered skills (PNSP). This emphasizes that characters with Down syndrome can be portrayed without a diagnostic label.

These observations show that there has been progress in representing characters multidimensionally. Since, WPTOR was published in 1998, MFHDS in 2010, and PNSP in 2016, seeing a change in the multidimensionality of a character makes sense as there has been a positive societal shift in acceptance surrounding disabilities. However, SS being published in 2020 was seemingly a step-back in the world of character multidimensionality, as Katie's character was used to teach a lesson of kindness and acceptance, not for the reader to relate to. While children's books depicting "lessons learned" is normal (and not all are bad), it should not be at a character with a disability's expense.

Represented Voice

The voice a story is told through is key to how someone interprets a story, and it also ties into how a character's dimensionality is portrayed. More often than not, characters with disabilities are represented through the point of view of a friend or family member. In my research, I found that 2 of the 13 books (15%) tell their story through the voice of the main character with Down syndrome. The two books, *Metaphase* [MP], and *Hannah's Down Syndrome Superpowers* [HDSS], allow readers to interpret the story through the eyes of the person with Down syndrome, and how they think and feel for themselves. MP is a comic book that utilizes narration-text boxes to show that Ollie is the person narrating the story and providing context into his life growing up, before the subsequent story comes to life. While dialogues and scenes are depicted between Ollie's superhero dad and villains, it is still evident in the story that Ollie is the main character, and these scenes are used as plot devices. Similarly, in HDSS, Hannah provides information about how her Down syndrome abilities affect her emotionally and physically. As a result, learning about Down syndrome from the account of a child with Down syndrome, adds personal depth to the story and shows children the similarities they share with one another. Likewise, it makes the book feel less like an informational brochure.

In contrast, the remaining 11 books were told either from the voice of a friend (15%), a family member (30%), or a third person narrator (38%). As mentioned before, WPTOR and SS were told from the voice of siblings, as well as *The Best Worst Brother* [TBWB]. Interestingly, the books being told from the voice of the sibling have a common theme following lessons learned. The lesson taught in WPTOR was acceptance, in SS it was kindness, and in TBWB it was patience. This may relate to the fact that a relationship between siblings is different than that between friends, but also it relates to who the target audience is meant to be. Whereas, stories that were narrated by a third person such as *Prince Noah and the School Pirates* [PNSP] took a more imaginative route, and was able to present the thoughts and actions of other characters to the reader as well. This shows that the represented voice of the book ties in more with a more specific target audience, not just children as a whole.

Intended Audience

Another aspect of interest was understanding the intended audience for each book. Through my analyses, I found that the target audience is often dependent upon the voice of the story. While all of these books have a primary target audience of children with Down syndrome, there is an underlying secondary audience as well. So, from my observations I was able to form 3 categories of secondary target audiences: (1) siblings (31%), (2) educators & students (31%), (3) anyone (38%). Since category 3 seems like a broad audience, let me explain; the books that fall into category 3 do not appear to have a specific secondary target audience. Instead, the stories are applicable and inclusive for everyone to enjoy and relate to. For instance, YAKOW, is a book about embracing yourself and while the artwork may depict a child with Down syndrome, the words in the story can be applicable to any reader. Similarly, PNSP, is a fairytale and while its main character, Noah, has Down syndrome there are other children with and without developmental challenges as well such as "children who couldn't see well," and "children who had trouble

walking.” However, while the story featured so many different abilities, it wasn’t the main focus of the story. Instead, it focused on what each child does best (math, singing, wood-shop), and how they used their best skills as a team to defeat pirates. Making, PNSP’s target audience appropriate for any child, while also instilling an appreciation for children developmental challenges.

Further, to explain and rejoin the conversation regarding *We’ll Paint The Octopus Red* [WPTOR], *Super Socks* [SS], and *The Best Worst Brother* [TBWB], in the represented voices section, I found that when siblings are the voice of the story, the audience of the story is also meant to be siblings (category 1). For instance, while a child with Down syndrome would view WPTOR as a story about how they are loved by their family, and the activities they will be included in no matter what. A sibling would interpret the story directly from Emma’s point of view, of learning, understanding, and accepting that their new sibling is going to shape their lifestyle in a new, exciting, and different way, but that it won’t change how you love them. Thus, WPTOR, can act as a lifestyle-transitional book for a child expecting a sibling with Down syndrome.

Then for category 2, there’s educators and students. The books that fell into this section were *Eli, Included* [EI], *My Friend Has Down Syndrome* [MFHDS], *What’s Inside You is Inside Me, Too: My Chromosomes Make Me Unique* [MCMU], and *Hannah’s Down Syndrome Superpowers* [HDSS]. These books provided information for their audience regarding chromosomes, and other facts about their friends with Down syndrome. Sometimes the books even included “Helpful Hints” or “Did you know?” text bubbles throughout the story. Making them great educational tools for learning about and accepting each others differences. For example, in MFHDS there is a text bubble that prompts: “Did you know? Many adults with Down syndrome have jobs, in all sorts of areas.” Similarly, one of the bubbles inserted in HDSS included a section teaching sign language (Image 1), and provided the audience with simple signs to learn to give them opportunities to communicate with their friends better.

So, while understanding that all of these books can show children with Down syndrome that they are being portrayed in children’s literature, there should also be an understanding that providing a classroom, student, or child with only books that fit one secondary audience can be harmful. For example, if a child with Down syndrome only had access to category 2 books, with a secondary audience meant for educators and students, the child may only see themselves represented as a tool for learning about acceptance and chromosomes. This is why having access to more literature options is important because having access to more options means having access to more audiences, and different types of story narratives.

Positive Language

It is evident - and was expected - from these books that “People First Language” has become normalized in published works when writing about characters who have a disability of any kind. All 13 books selected for this study utilized PFL and positive portrayals throughout their stories. Specifically, in *HDSS* (Yarborough, 2019), positive language is taken further past people first language, but also includes anti-ableism language. In Yarborough’s book, when describing the developmental effects of Down syndrome, instead of labeling it as a disability, Hannah describes it as “My Down syndrome abilities.” Furthermore, every ability she lists has a positive connotation, even when describing things that could be potentially dangerous or disheartening, including:

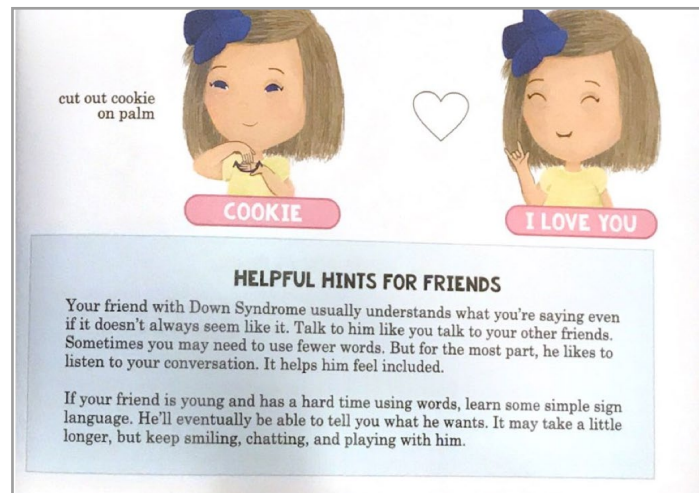


Image 1: Hannah’s Down syndrome Superpowers, by Lori Leigh Yarborough. PT

Table 1: Positive Language Use in Hannah's Down syndrome Superpowers

| Superpower (ability) | Meaning |
|----------------------------|---|
| Fun Friend | Hannah is just like every other friend you may have |
| Terrific Truster | Hannah trusts everyone she meets, so her friends should help to teach her about stranger danger |
| Super Sensory Controller | Describes the abilities seekers and avoiders may have |
| Super Sidekicks | Normalizes receiving help from therapists, is a great tool, and it builds Hannah's super-team |
| Stupendous Stubborn-Streak | Describes how Hannah's friends and family may find this power to be frustrating, but that it is important to find out WHY your friend is upset and help them express their feelings |
| Medical Matters | Describes that "superpowers come with positives and negatives" and that your friend with Down syndrome may have many doctors |

These are just some of Hannah's super Down syndrome abilities listed in the book. The language utilized in HDSS encourages children to describe each other with positive abilities, instead of negating them as problems, or issues. Specifically, the wording of "Medical Matters" is impactful, because it apprehends people from describing a child with Down syndrome (or any disability) as having "issues," as can be derived from statements such as "medical issues" or "defects."

Likewise, *Eli, Included* [EI] also utilized language that works to normalize the use of orthopedic braces. EI, follows Eli to his first day of school. When his teacher is introducing him to the class a student asks "what's on his feet?" Prompting his teacher to respond, explaining that they are orthopedic braces and that they work the same way as braces do for teeth. This comparison helps the students to understand the function of the braces, and gets rid of any stigma surrounding the use of orthopedic braces.

The use of positive language in children's books allows for every reader to see new characters they may relate in a positive light, no one wants to relate to the "bad guy" in a story, especially children. Further, positive language allows for stigmas surrounding people with Down syndrome (or any other mental/physical disability) to be lifted, and changed. Seeing that all of the books in this study portray this quality, highlights that a change in the verbal representation of people with Down syndrome has changed.

Represented Identities

Another inquiry I had about children's books portraying characters with Down syndrome, was if there was any disparities among race and gender. Down syndrome is a genetic condition, when an extra chromosome is attached to chromosome 21. Therefore, since it's not connected to sex chromosomes, nor is it "limited to" a specific race, I expected to see a widespread representation among the children's books. In regards to main character gender, I found that 5 of the 13 books (38%) portrayed girls with Down syndrome; 6 of the 13 (46%) portrayed boys with Down syndrome; and 2 of the 13 (15%) portrayed both boys and girls, as there was no specified main character. These results were expected, and from them it shows that there are no assumptions being made that only one gender can have or is represented with Down syndrome.

However, of the 13 books gathered for this study 11 (85%) portrayed white children with Down syndrome as the main characters, while again, 2 books (15%) didn't portray a main character, thus allowing a more flexible and diverse representation of characters. *You're All Kinds of Wonderful* [YAKOW] and *What's Inside You is Inside Me, Too: My Chromosomes Make Me Unique* [MCMMU] both represented a diverse group of children throughout

their stories. While MCMMU explicitly states that it is talking about Down syndrome, YAKOW does not, thus making the determination of who is represented and portrayed with Down syndrome in YAKOW difficult to assume, simply because assumptions can be incorrect and harmful.

Yet, while this sample size is small the 11 books published that only depict white children with Down syndrome, should not fully be faulted for a lack of main character representation. To explain, 8 of the 11 (73%) are written by either a parent for their child, or by an author working with a parent to portray their child. Thus, the main character of the stories are based off of real children, so to portray them as anything but themselves would be harmful to them and the message the author are trying to communicate. So, this disparity of represented race in characters with Down syndrome, may be in relation to the author's of the books being related to their main character in real life.

Publishing Industry

Further, while gathering information on the books I selected for this study, I noticed how many of the authors were either parents of a child with down syndrome, someone who has a connection to a person with Down syndrome, or a medical professional. From this information, I then decided to look into who published their book, since most of them left an *about the author* note in the back of their book mentioning why they were prompted to create a story. Through this I noted that 6 authors explicitly mentioned their connection to the story - 5 of the authors are parents to a child with Down syndrome, and 1 (HDSS) worked closely with a parent. Since *The Prince Who Was Just Himself* [TPWWJH] and PNSP are written by the same author, Silke Schnee, that means that 7 of the 13 books (54%) selected for this study were written by or with parents. Some of their statements include:

“After the birth of his son Ollie (who has Down syndrome), Chip realized that comic books lack serious diversity in the area of characters with disabilities”

Metaphase, Chip Reece

“The catalyst for this book was witnessing the effect he [her son Noah] had on many people, despite being categorized as disabled.”

The Prince Who was Just Himself, Silke Schnee

“Becky strives to change the outdated stereotypes of Down syndrome.”

47 Strings: Tessa's Special Code, Becky Carey

The effect of parents taking control of the books depicting their children is both inspirational and wholesome, but it also exposes how they felt about previously published works, and/or the availability of inclusive literature in the publishing industry. For instance, only one of the works in my sample was published by a Big 5 publishing company, whereas 10 of the 13 books (77%) were published by small press companies, and 2 of the 13 books (15%) were published independently (See Appendix B).

The Big 5

“The Big 5” publishing companies include *Penguin Random House, Hachette Livre, HarperCollins, Macmillan Publishers, and Simon & Schuster*. Of these Big 5, only one of them published a book selected in this study. *You're All Kinds of Wonderful* [YAKOW], by Nancy Tillman was published in 2017 by Feiwel & Friends, an imprint company of Macmillan Publishers. While observing an interactive website about *The Big Five US Trade Book Publishers* created by Strauss-Gabel et al., it became very evident how much control they have over the publishing industry due to the sheer amount of imprint companies they own. Collectively, the Big 5 own 47 imprint companies that specialize in the manufacturing and publishing of children's books. Not including the 5 imprint companies that span across Disney-Hyperion ownership, since those include more age-groups. Thus, while the selection of books in this study is narrow, I expected there to be more published through imprint companies of the Big 5 than just YAKOW. Because the Big 5 companies have a lot of sway and persuasion in the industry, on top of having the most recognizable names, their products dominate book stores, and are the first books to pop-up online when conducting a search, due to their status in the industry. This creates a difficult industry to rise in for small press companies, because of how much the Big 5 dominates, which intentionally or unintentionally creates a gatekeeping effect on the publishing of children's books with characters with Down syndrome.

Small Press

Conversely, there is the small press industry. The small press industry refers to publishing companies who bring in annual sales below \$50 million, or when the number of titles published yearly by the company is on average 10 or fewer. However, while they are small they are still impactful, since they can “take more risks than the Big five” (Sullivan, 2021).

The 139 Inspired Series is owned by Lori Leigh Yarborough, author of *Hannah’s Down syndrome Super-powers* (2019), and is “written to help kids, their friends, family, teachers, and others understand their diagnosis, what life is like, how their friends can help out, and how they have the same hopes, dreams and desires, just like other kids” (Yarborough, 2021). Similarly, *Woodbine House - Publisher of the Special-Needs Collection* was created to help inform audiences and promote the accessibility of books depicting children with disabilities.

“Woodbine House was founded in 1985 by the father of a child with Down syndrome who hoped to give other parents access to the type of practical, empathetic information he had struggled to find for himself. Since those pre-Internet days, our mission has grown to encompass publishing accessible, empowering books for families, teachers, and professionals who are seeking guidance and support in helping children and adults with *any* disability achieve their potential.” (Woodbine House, 2021)

Further, Woodbine House employees all have some personal experience with special needs which allows them to connect with parents and professionals through their books in an empathic way.

“Because of how we view our work, our publishing standards are unique. We do not publish any book until we think it offers as much tangible, practical information as our authors are able to provide. And we work very hard to make sure the writing in our books connects with our readers. That’s why it may sometimes take us longer to bring out new books” (Woodbine House, 2021)

This statement provided by Woodbine House makes them a very credible company with well established ethos, since all of their workers also have a connection to the special needs community. In my study, Woodbine House was the most prominent published of the selection; However, it is also the most dated of my selection, while still being popular among the community. WPTOR (1998), MFI (2003), and TBWB (2005), were all released by Woodbine.

While it is great that there are publishing companies specifically created for better accessibility to empower, inform, and guide anyone who is looking for help learning about children and adults with any disability, in the case of this study, Down syndrome. It is evident that other main publishing companies are gatekeeping the accessibility of books representing children with Down syndrome. Which is why these companies needed to be created in the first place. Moreover, coming across these books in a natural way is virtually impossible, unless someone is specifically searching for books about Down syndrome. Thus, making for a more limited audience.

CONCLUSION

This research started with a difficulty to find similar studies on the representation of children with Down syndrome in children’s books. However, through shifting and searching a review of other studies was completed and it was understood that there should be evidence of Person First Language, and positive multidimensional portrayals of children with Down syndrome in books. Further, from my research I found that there is a strong correlation between represented voice and secondary audience. This implication is important because understanding how the book reads, and who the book is voiced by will help an educator, parent, or child interpret their understanding of a character differently. Moreover, it is important to provide readers with more than one perspective of people being represented. Not every book provided to a reader about a child with Down syndrome should be from the perspective of a friend or sibling talking about them, instead they should be given the opportunity to hear from the voice of the child as well. Similarly, my study also showed the prevalence of the multidimensionality characters now possess in recent children’s books. In comparison to earlier words such as *We’ll Paint Octopus Red* (1998) and *The Best Worst Brother* (2005), which represented Isaac first with hypothetical interests provided by his sister, Emma’s dreams (WPTOR), and then represented him as frustrating to communicate with in TBWB - characters in more recent children’s books have become much more understood and portrayed with more personal and specific interests for readers to relate to. Likewise, it is important to recognize that some books chose not to label the child represented in their story. TPWWJH and PNSP both portrayed a young boy with who was understood to be “different,” but never diagnostically labeled him. Instead, they chose to focus on the character himself outside of his diagnosis. This is

very forward thinking, and should be done more in children's books depicting children with Down syndrome, because as said before, a person is more than their disability and label.

Further, my research showed that there was little-to-no racial diversity among my sample of books. From this information, I believe that a more research done with a larger sample size would benefit the study as I don't want to make an over-generalization of the entire population of books published. This would allow researchers, authors, and publishers to understand that there may be a disparity in the representation of characters with Down syndrome in the books published, and can be improved in the future.

From this research children's book portraying characters with Down syndrome seem to continue to instill appreciation towards children with Down syndrome as well as portraying them positively and respectfully. While more books will be created to portray characters with Down syndrome, I hope to see more books come out like PNSP and TBWJH that didn't provide diagnostic labels, and just provide fun stories. There is an undeniable power that these author's hold that will help shape an entire generation of young kids to learn and respect others, and help instill and build confidence and happiness in children who get to see themselves represented positively in literature.

LIMITATIONS & FUTURE RESEARCH

It should be noted, that due to the limited sample of this study, this is not meant to be an all-inclusive examination of all works of juvenile literature depicting characters with Down syndrome. Thus, further study with a larger quantity of books would be beneficial in future research projects.

Further, a second limitation of this study is that the picture books were not judged on their aesthetic beauty. While I observed the racial and gender identities presented in the books, I did not analyze based on the artistic style and aesthetic. Thus, the relationship between illustrations and the words on the page were not analyzed side-by-side, and as art plays an important role in publishing picture books, further study may be beneficial for different results.

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APPENDIX

Appendix A: Information & Synopses

| Title of Book | Author | Abbreviation | Synopsis |
|---|-------------------------------------|--------------|---|
| Super Socks | Connie Bowman | SS | Molly's younger sister Katie has Down syndrome and picks out funky mismatched socks for Molly to wear, everyday. Molly gets teased by Billy at school for having crazy socks, but the socks give her superpowers (kindness and courage). Which teaches a lesson of acceptance to Billy, after he meets Katie. |
| 47 Strings: Tessa's Special Code | Becky Carey | 47 STSC | Was created to explain to Casin, that his little sister Tessa was born with Down syndrome. Shows that individuals with Down syndrome can do many things, and that we are the same, but different. |
| What's Inside You, Is Inside Me, Too: My Chromosomes Make Me Unique | Deslie Quinby and Jeannie Visootsak | MCMMU | Aims to inform the audience about Down syndrome by teaching them about the chromosomal make-up of individuals. |

| Title of Book | Author | Abbreviation | Synopsis |
|------------------------------------|--------------|--------------|--|
| Metaphase | Chip Reece | MP | Ollie has Down syndrome and he wants to be a superhero just like his dad. But his dad worries about Ollie, and due to his congenital heart defect he won't let Ollie be in harms way. Ollie then sees a commercial about a company that promises to give you powers - you just have to provide DNA. Ollie visits the company and provides them with his DNA. But what he doesn't know is that the company is lead by a supervillain, and he just gave his dad's power away. Ollie discovers that he does have powers, and that having Down syndrome gave him an even more unique power, allowing him to beat the villain and save his dad. |
| The Prince Who Was Just Himself | Silke Schnee | TPWWJH | The royal couple announce the arrival of their third son, Prince Noah. While they acknowledge that he is different from his brothers, and there are some things he cannot do, the king and queen know he is special. One day a cruel knight shows up to the palace, but Prince Noah disarms him with compassion - and a loving embrace. Being unique saved the day. |
| Prince Noah and the School Pirates | Silke Schnee | PNSP | Prince Noah goes to school on a ship, and he learns that there are different ships for different people. Boys and girls don't go to school together, and there are ships for people with eye-patches, one leg, and ones who learn a little slower. While he is away at school, a storm pushes the ships into pirate territory and they are all taken prisoner. But the students learn with each of their individual talents that they can work together to escape! At the end of the story, all the children are learning together on one ship. |

| Title of Book | Author | Abbreviation | Synopsis |
|-------------------------------|--------------------------|--------------|--|
| We'll Paint the Octopus Red | Stephanie Stuve-Bodeen | WPTOR | Emma learns that her baby brother Isaac was just born, and she's telling her dad all the activities they can do together. When she finds out that he was born with Down syndrome, she was deterred because he was different, but her dad explains to her that Isaac can still do everything with her, she will just need to be patient and helpful with him and he can do anything. |
| The Best Worst Brother | Stephanie Stuve-Bodeen | TBWB | Emma is finding out that her little brother Isaac has some frustrating moments. She wants to teach him sign language to help him communicate. But she is frustrated that he isn't listening to her or working with her. One day, her family goes to a school open house and Isaac uses sign language to ask her teacher for a cookie. This makes Emma happy because her teaching helped him communicate and she's proud of him - deeming him the best brother. |
| Eli, Included | Michelle Sullivan | EI | Eli has Down syndrome and is headed to his first day of school. The class meets Eli and learns about chromosomes and shares fun facts about himself. Through this the class learns about inclusion and the similarities they share with Eli. |
| You're All Kinds of Wonderful | Nancy Tillman | YAKOW | Story that emphasizes the importance of loving and embracing what makes you unique. |
| My Friend Has Down Syndrome | Amanda Doering Tourville | MFHDS | Carmen tells us about her friend Sarah who has Down syndrome. She shares what activities they like (dancing, joking), what characteristics they share (glasses), and also talks about bullying, and their differences (learning acquisition, medical matters). |
| My Friend Isabelle | Eliza Woloson | MFI | Charlie is describing his friend Isabelle and the similar interests they share (reading, art, dancing) and similar qualities (emotions and independence). Charlie also describes the differences he and Isabelle share (height, vocabulary). |

| Title of Book | Author | Abbreviation | Synopsis |
|------------------------------------|-----------------------|---------------------|--|
| Hannah's Down syndrome Superpowers | Lori Leigh Yarborough | HDSS | Hannah is a superhero princess, who describes and explains all her super-abilities of Down syndrome and how they affect her. |

Appendix B: Publishing Information

| Title of Book | Publisher | Year Published |
|---|---|-----------------------|
| You're All Kinds of Wonderful | Feiwel and Friends New York - Macmillan | 2017 |
| Super Socks | Brandylane Publishers | 2020 |
| 47 Strings: Tessa's Special Code | Little Creek Press and Book Design | 2012 |
| Metaphase | Alterna Comics | 2015 |
| The Prince Who Was Just Himself | Plough Publishing House | 2015 |
| Prince Noah and the School Pirates | Plough Publishing House | 2016 |
| My Friend Has Down Syndrome | Picture Window Books | 2010 |
| My Friend Isabelle | Woodbine House | 2003 |
| We'll Paint the Octopus Red | Woodbine House | 1998 |
| The Best Worst Brother | Woodbine House | 2005 |
| Hannah's Down syndrome Superpowers | 139 Inspired Books | 2019 |
| What's Inside You, Is Inside Me, Too: My Chromosomes Make Me Unique | Delsie Quinby | 2014 |
| Eli, Included | Independent | 2019 |