

July 2021

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Recommended Citation

Meyer, Amber and Genareo, Vince (2021) "“Does Your Arm Hurt?” A Content Analysis of Upper Limb Differences in Children's Books," *Michigan Reading Journal*: Vol. 53 : Iss. 3 , Article 8.

Available at: <https://scholarworks.gvsu.edu/mrj/vol53/iss3/8>

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“Does Your Arm Hurt?” A Content Analysis of Upper Limb Differences in Children’s Books

by Vincent Genareo and Amber Meyer



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Public media attention has created more recognition of, and pride among, people with upper limb differences (or ULDs). The recent spotlight on ULDs has stemmed from 3-D printed prosthetics, adaptive gaming devices, national role models (such as a 2018 Super Bowl commercial), and social media sharing. Though the attention has been largely positive, the widely-reported November 2015 incident of then-presidential candidate Donald Trump mocking a reporter with a physical disability forced social scientists to rethink how physical differences are viewed and, more importantly, how they are lived. Very little educational research has been done on the experiences of people with ULDs, and the information available for teachers, parents, and medical professionals is sparse (James et. al, 2006).

This study addresses this gap in research by analyzing preK-6th grade children’s books representing characters with upper limb differences (ULDs) to support teachers in carefully selecting which books to use in their classrooms. Children have the opportunity to develop self-awareness (Chaudhri & Teale, 2013) and positive self-identity (Hall, 2008; Levin, 2007) through their interaction with books in home and school contexts.

In addition, books can provide children with counternarratives to stereotypes and expand their exposure to other cultures and communities (Thein, Beach, & Parks, 2007). Therefore, having diverse character representation with distinct messages told in children’s books can be beneficial to all children. As such, the research questions for this study were: *What children’s books exist for students with ULDs? What thematic elements are present within these texts? What plot elements facilitate classroom discussions about ULDs and differences?*

Literature Review

Upper Limb Differences

An upper limb difference is defined as missing part, or all of, an arm or hand; missing parts of the legs would be referred to as a lower limb difference. ULDs can be congenital (present at birth) or acquired through illness or accident. We have chosen the term limb *difference*, as is becoming more common (Bae, Canizares, Miller, Waters & Goldfarb, 2018), in contrast to its terminology in medical research (i.e., limb reduction, limb deficiency, limb abnormality), because it better encompasses a range of medical issues and does so in a more positive and inclusive way.

Incidence or diagnoses of ULDs have increased over the previous 20 years. Current estimates put the total number of U.S. children with ULDs at 32,500, total individuals with ULDs at nearly 600,000, and approximately 1,500 born each year (Zuniga, Carson, Peck, Kalina, Srivastava & Peck, 2017; Zuniga, Katsavelis, Peck, Stollberg, Petrykowski, Carson & Fernandez, 2015). Most are congenital (born-with), rather than acquired (occurred after birth). The causes for congenital ULDs are most often unknown (Michielsen, Wijk, & Ketellar, 2010). Whether or not a child needs, or chooses to use, a prosthetic depends on their specific ULD and if it prohibits typical or specialty activities (e.g., playing sports or making music) within their life. There exist many types of prostheses for a variety of conditions and functions, but many children choose not to use prostheses because of their lack of sensation or that prostheses themselves do not fit well or are uncomfortable (Zuniga et al., 2017).

With the rising levels of national awareness of ULDs, some support and connection groups have emerged online. For instance, Reddit, the social media platform, has several subreddits or discussion boards. In school, though, having a ULD may contribute to negative psychological effects on children's self-concept and self-esteem. To illustrate, research has shown that boys with limb differences may exhibit significantly lower self-esteem (Andersson, Gillberg, Fernell, Johansson & Nachemson, 2011), which may influence psychological and social well-being and academic achievement (Michielsen et al., 2010). Children as young as four can identify peers with physical disabilities (Dyson, 2005). There is current evidence that able-bodied students avoid interacting with peers with physical differences (Edwards, Camerson, King & McPherson, 2019), so teachers must be aware of the resources they can provide to aid in peer acceptance. Some current research, though, challenges the social effects of ULDs on children (Bae et al., 2018), suggesting children with ULDs may exceed the ability of the general population in forming peer relationships and maintaining positive emotional states.

As classrooms have become more inclusive of students

with special needs and differences, it is more important that general education teachers understand how to foster acceptance, empathy, and belongingness among their students. In order for acceptance and inclusion to occur, students must first be made aware of their peers (Maich & Belcher, 2012). Educators must understand the available resources and pedagogical strategies that encourage peer acceptance for students with specific disabilities and differences.

Multicultural Literature

Sims Bishop (1990) argued that books serve as mirrors, windows, and sliding glass doors which allow the reader to gain perspectives into a larger human experience as it relates to one's own lived experience. The use of quality, diverse, multicultural books that include characters from traditionally marginalized groups in classrooms can provide an accurate representation of the world and day-to-day lived experiences (Sims Bishop, 1990). In addition, the opportunity for children from marginalized groups to see themselves represented by literature provides role models and affirming personal connections.

It is well-documented that children's books help teachers foster supportive learning environments through representation of exceptional children; this can empower children to accept their own and others' differences and demonstrate respect for and understanding of students with special needs (Blaska, 2004). By selecting and using high quality, multicultural children's literature that includes characters with ULDs, teachers can help illuminate the lived experiences of a marginalized group.

Diversity-focused children's books provide a number of important benefits for students with disabilities and their peers. First, they provide context for understanding experiences of those with disabilities. Boutot (2007) suggests teachers lead discussions from the book that examine socially atypical behaviors of characters with disabilities. This includes the way they may talk, walk, or move. This can help children understand reasons for differences and prepare them for understanding any special equipment they may need.

Children's books can also facilitate the construction of identity for those with differences. As children read books, they often seek those they can relate to; those with whom they identify can help to construct how they view themselves (Ullah, Ali & Naz, 2014). They seek characters representative of themselves and learn from the characters through which they see themselves. Teachers should have classroom resources for their students through which realistic representations are offered (Monoyiou & Symeonidou, 2016).

Diverse representations in children's books can be a resource for promoting peer acceptance within and among diverse groups. These books can illuminate feelings that children with disabilities may have so peers without disabilities can learn empathy as they read a book that expresses emotions caused by positive and negative peer interactions. Children, including those with exceptionalities, can struggle with effectively expressing their emotions (Lukash & Coles, 2002), so books may function as a surrogate for those emotions. Books can also support peers without disabilities to examine their own feelings toward students with disabilities and give them a greater understanding of their similarities and differences (Ullah et al., 2014). This acceptance can be nurtured by teachers through deliberate conversations about diversity in the books.

However, quality children's books representing characters with disabilities have been historically absent from classroom resources, in part due to the lack of published books in this area (Beckett, Ellison, Barrett & Shah, 2010). Further complicating the issue is that disability-focused children's books often reproduce stereotypes, negative portrayals, or oppressive terms or attitudes of characters with disabilities (Monoyiou & Symeonidou, 2016). Teachers must be adept at identifying relevant and bias-free texts for their classroom.

Suggestions for identifying quality children's books include looking for stereotypes, loaded words, tokenism, messages sent about lifestyles of characters with disabilities, the authors' and illustrators' backgrounds, copyright date, and overall book quality (Derman-Sparks, 2016). Additionally, Lintner (2011)

recommends that teachers should consider the following questions when selecting a children's book featuring characters with disabilities: (a) How are individuals portrayed? Sad, heroic, realistic? (b) How are relationships with nondisabled peers portrayed? (c) Are characters portrayed in a variety of settings? (d) Does the book encourage acceptance and respect? In this study, we expanded on these questions through the use of Nasatir & Horn's (2003) framework for analyzing children with special needs through illustrations, storylines, authors, and presentations of exceptionalities with the specific focus on children's books that represent characters with upper limb differences.

Methodology

Positionality

As educational researchers, we both hold an interest in exploring themes within preK-6th grade children's books representing characters with ULDs. Genereo is an educational assessment and program evaluator. As a parent of a toddler with a congenital upper limb difference, he started this inquiry as a means to discover children's books that would allow his son to positively see himself within the literature. Meyer's research focus is on inclusive literacy methods. As a teacher educator, she holds a strong belief in the power of the texts that are selected to engage, motivate, and interest children in reading.

Data Sources

We identified and coded 24 books in this study. Children's books used in this study were identified from six sources, all of which were professional organizations specializing in working with children with ULDs, as well as algorithmic suggestions from national online bookstores. Three of the professional organizations were Limbs 4 Kids, Lucky Fin Project, and One Little Fin Blog.

Data Analysis

We conducted content analysis to examine themes within preK-6th grade children's books ($n = 24$) representing characters with ULDs. We used Nasatir & Horn's (2003) framework for analyzing children with special needs through illustrations, storylines, authors,

and presentations of exceptionalities. We modified the framework to adapt to the types of characters in the book (people and animals) and for use with books specific to ULDs; it was initially developed for analyzing content of books spanning across all types of differences. Examples of the modification included a category created to examine if, or how, prostheses were presented in the text or illustrations and specific look-for examples were created specific to ULDs, such as samples of loaded words taken from the books themselves.

Once we agreed on an appropriate framework, we independently coded the books. After coding was completed, we met to check for interrater agreement (percent agreement) and reliability by coding two of each other's books and crosschecking their findings. Scoring reliability was computed (Cohen's $k = .84$; 89.1% agreement) and found *almost perfect agreement*, as defined by Leedy & Ormrod (1997). Once final agreement was completed for all books, we analyzed findings to determine the content and appropriateness of the texts. The findings were descriptively analyzed using the instrument, by examining frequencies of codes (such as Tokenism, Type of Role, Loaded Words, Author's Background), and by analyzing how these codes presented through explicit or implicit messages and illustrations.

Findings

Results suggest a recent emergence of books featuring characters with ULDs. The books spanned genres, but most were biographical and intended to teach students about ULDs. Most books featuring characters with ULDs were intended for pre-K children. Nearly all books displayed tokenism in their presentation of characters. Stereotypes and loaded words were also present, but were most often used to teach and typically resolved within the storyline. There were also potentially problematic elements presented in the books.

What Children's Books Exist for Students with ULDs?

The 24 children's books that feature children with ULDs were published between 1991 and 2018. Most

books were published in 2017 ($n = 7$). In contrast, the second highest number of books published in other years (2008 and 2012) was 3. Between 1991 and 2018, the majority of published books representing characters with ULDs were appropriate for early childhood and early elementary levels. Three books were identified as being appropriate for children in upper elementary grades. There were three different genres represented in the books: fiction ($n = 13$), biographies ($n=8$), and autobiography ($n=2$). In preparation for this study, adolescent literature was also searched; no fictional adolescent literature was found featuring characters with ULD and these few books tended to be biographies or autobiographies.

What Thematic Elements are Present Within These Texts?

The types of characters with ULDs in the books varied. The character with ULDs was typically the main protagonist in the book or a supporting character used to teach the main character about ULDs. There were two non-fiction books that portrayed different people with ULDs that were explanatory in nature and featured athletes who had ULDs. The characters with ULDs included nine human males, four human females, a tree, and animals, such as an octopus, bugs, bears, cats, dogs, robots, and chimpanzees. Only one book featured an African American main character with an ULD.

The majority of the books were written by someone who was associated with people with ULDs. Nine books were written by people with ULDs, four were written by parents of children with ULDs, one was written by a grandparent of a child with ULDs, two were collaborations between children with ULDs and their parents, and five were written by medical doctors who specialize in working with people with ULDs. Two authors appeared to have tangential associations. In only one book was there no known ULD association between the authors or illustrators. Within these varied authors, there was not an agreement as to the terminology regarding the different limb. For example, some called it a *special hand*, some referred to it as an *amazing hand*, and others called it a *nub*, among other terms.

What Plot Elements Facilitate Classroom Discussions About ULDs and Differences?

The plot elements facilitated classroom discussion of education and acceptance. Most books were meant to teach children about ULDs, but they taught about ULDs in different ways. Some books discussed medical procedures, medical terminology, prosthetic information, and types of doctors with which children with ULDs might interact. To illustrate, in one book, the main character is a boy without a ULD. He brings his older brother, who has a ULD, for show-and-tell, and the children in the class take turns asking his older brother questions (*Can you ride a bike? Does your arm hurt?*). This book was based on a true story in which the author brought his brother to the classroom and wrote the book to help inform other children who might have similar questions. Other books presented similar content in different ways, such as one autobiographical book in which the main character discusses various emotions, experiences, and adaptations that have worked for her. The book included stereotypes she has encountered throughout her young life, such as her frustrations when people stare at her hand or when they assume it is connected to her intelligence level.

The books were typically designed to promote acceptance of people with ULDs, either through peer understanding of their experiences and similarities or through sharing experiences designed to allow children with ULDs to connect with the authors' stories. One book included names and illustrations of the authors' heroes with ULDs, including Jim Abbott, a Major League Baseball pitcher, and Nicole Kelly, Miss Iowa 2013. Many books were designed to show that people with ULDs are similar in nearly every way with other children, including their feelings and home lives, and showed that some excel in unexpected areas. Some books also contained information for teachers. One book was written by a parent of a child with ULDs about their child's first day of school. During that day, the teacher painted all the children's hands for a classroom banner and the text explained how the teacher approached asking the child if they could paint both of their hands.

Potentially Problematic Elements

There were potentially problematic elements found in some books. Nineteen of the 24 books contained loaded words (e.g., different, stupid, disgrace, and ashamed). In all but one book, loaded words were resolved with the storyline. In addition, the majority of the books utilized loaded words as a learning tool for student acceptance and were provided to explain feelings, emotions, and experiences of people with ULDs. The book that included unresolved loaded words was published in 2008 by a person without a ULD. This particular text presented a character with a ULD as being weak and defenseless as a result of his ULD. The character relied on others to help save him from his mishaps on a river, and could only be *made whole* by a prosthetist. The story concluded with the prosthetist fitting him with prosthetic, which fulfilled the character's feeling of wholeness. This feeling of being incomplete without a prosthetic may be a harmful viewpoint for children who should work on self-acceptance.

Another book, also written by a person without a ULD, was problematic in its presentation of self-acceptance. The book began with a character who was missing both arms thinking to himself about why he is alive, which is a problem itself. The character immediately resolves this existential crisis by praying, and by the flip of the page, he has accepted himself. There is evidence that religion or spirituality can assist some people with self-concept and self-acceptance, but this book presented major problems—the belief that one should wonder if their existence is warranted if they have a ULD—and created more in how quickly it claimed deep emotional distress could be completely resolved.

A further element that might be problematic is the simplicity of acceptance. It is expected in children's books that the storyline stays fairly concise, but a number of the books displayed an unlikely immediate acceptance of children with differences. The nuance of self-reflection and discussion that may be necessary for some students to accept others was not often brought up. Simply, in many of the children's books, acceptance was immediately offered by peers once they realized they shared common similarities. Only a small number of

autobiographical books discussed the feeling that peer acceptance was sometimes difficult.

Discussion

Informative, engaging, and appropriate texts may be a way to bridge the understanding of differences among children. These books are desperately needed, as is information for teachers to make decisions on book quality. Based on the analysis, we provide several recommendations for consideration regarding children's books with ULDs.

Recommendation 1: Avoid Narratives about Exceptionality

In books about disability, Nasatir and Horn (2003) believed "the story should be able to be told in the same way even if the main character did not have a disability" (p. 7). In the present study, in all books but one, the storyline was dependent upon one or more characters having a ULD. We argue that writing a book that is specifically about that disability, and could not be told without, is now acceptable and more appropriate because books about children with disabilities are meant to teach and promote acceptance (Ostrosky, Mouzourou, Dorsey, Favazza & Leboeuf, 2013). Spotlighting differences among students by integrating the difference into the storyline is now common practice. What might be inappropriate, though, is how many of the books in the present study emphasized that the characters with ULDs are exceptional in other areas, using phrases and storylines about being braver than their peers or extraordinarily talented in certain areas like sports or music. Although children should understand that ULDs do not hold individuals back in many areas, and they may, indeed, be extraordinary in any area, the concern is that some stories relied on a character having to be extraordinary to gain acceptance. Stories that promote excelling as being a gatekeeper for peer relationships may be harmful in teaching children about differences.

Recommendation #2: Diversify the Setting and Characters

There was a lack of diversity within the settings and characters. Settings took place in the daily lives of

children, but the settings were generally limited to school, home, and occasionally in a doctor's office. While these are often the main settings of children's lives, it would be relevant for future books to take place in other settings, including community centers, culturally diverse venues, performance and sports arenas, as well as imaginary locations. This may broaden interest in reading the texts. Children with and without ULDs may better relate to books with more diverse locations and storylines.

In addition, there is a significant lack of diversity of characters with ULDs. Only one character was African American. To illustrate, there were fewer racially diverse characters than the number of bugs with ULDs ($n = 2$) featured in these books. More attention needs paid to representing BIPOC characters with ULDs. In addition, males with ULDs were represented more in the texts ($n = 13$) than females ($n = 7$). Specifically, all males were White. An increase in female characters as well as racial and cultural representation across genders would increase the representation of diverse character with ULDs. This would provide characters that are more relatable to a diverse array of children.

With these recommendations, it is important to keep in mind that seven books ($-1/3$) were published in 2017. This trend is likely due to the increased public awareness of ULDs and self-publishing opportunities. There currently exist a number of avenues for authors to self-publish books without a publishing company, including crowd-sourced funding programs. Two books in this study resulted from a popular crowd-sourcing website. In general, we believed the quality of storyline and illustrations were strong in the self-published books. However, there was a wide range in quality in the self-published books, and a few contained grammatical errors in the text itself. There are also limited upper-elementary appropriate books and very few appropriate books for middle-school students representing characters with ULDs.

Recommendations #3: Know Your Students with ULDs

If a teacher has a child with an ULD in the classroom,

it is important they understand the individual child with ULDs when selecting texts. We recommend first choosing books that represent the specific type of ULD the child may have. There are children's books available for above- or below-elbow ULDs, books with characters who only have a hand difference, and books with unilateral (affecting one side) and bilateral (affecting both sides) ULDs. Next, teachers might consider books representing children who either do or do not use a prosthetic. Similarly, there are books featuring characters who live successfully with no prosthetic and books that either feature prosthetics or delve into the science of prosthetics. If the child is comfortable, they could possibly discuss their own prosthetic, if they have one, with the class.

Next, teachers should identify the purpose of the books. If the purpose is to teach children about the condition, a number of ULD books exist that explain what ULDs are and feature a number of different types of ULDs as examples. There are also books explaining the life experiences, both good and bad, of people with ULDs, and books that offer tips for children with ULDs, including tying shoes and making art. There are books that are written to inspire, entertain, or connect with children with ULDs. Regardless of the intended purpose of the book, the authors highly suggest teachers read the book ahead of time. Look for instances of stereotypes and negative portrayals of people with ULDs. If they are present, and they often are, decide if they exist to resolve common misconceptions. If they do not resolve in the book itself, we recommend not reading these books with the student with ULDs or the class.

Similarly, if teachers feel that issues are not presented at an appropriate level of complexity for the age of students, they must decide if they can facilitate a conversation that would lead the class to that level of complex understanding. In this study, we found many instances of peer or self acceptance presented in a simplified fashion; although ideal, acceptance likely takes longer and teachers should be prepared for a longitudinal process of relationship-building with students in their class. We believe it is also important that the book's author has a direct connection with ULDs. If the book's author has

a ULD themselves, or intimately knows a person with a ULD, their experiences may be more accurately represented in the text.

Next, teachers should be cautious when choosing self-published books. There were several identified that represented a high quality in writing, storyline, representation of children with ULDs, and illustrations, but others were poor quality in all areas. If the trend of self-publishing continues, and it most likely will, the majority of these types of books will come from this arena. The final suggestion we have for teachers is to allow the parent(s)/guardian(s) of children with ULDs to first read and review the books. Parents likely have a sense of appropriateness of the storyline and experiences presented in relation to their child. Use them as a resource because they have lived with the child through meetings with doctors, discussions with the child about their ULDs, and through positive and traumatizing social experiences.

Exemplars of ULD Books

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