

5-2012

Down Syndrome: Awareness and Understanding Through Children's Literature

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DOWN SYNDROME: AWARENESS AND UNDERSTANDING THROUGH CHILDREN'S LITERATURE

By

Megan K. Wright

Honors Capstone Project

Submitted to the Faculty of

Olivet Nazarene University

For partial fulfillment of the requirements for

GRADUATION WITH UNIVERSITY HONORS

May, 2012

BACHELOR OF ARTS

In

English

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Megan K. Wright

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To Allison, for your inspiration and continual sunshine in all our lives

ACKNOWLEDGEMENTS

I acknowledge first and foremost, Ryan, who encouraged me, believed in me, and supported me through it all. Most importantly, for giving me the idea to write this book and telling me I could when I did not think the same. To my parents, thank you for reading to me when I was young and instilling the passion in me that has fueled this project. Thank you for supporting me through college; without you, this would not have been possible. To the Gifford family, thank you for loving me, supporting me, and giving this world all your beautiful children.

I owe gratitude to Professor Schurman, for being my mentor throughout this project, giving me ideas and being patient with me. You did not give up on me when I wanted to. Also, thanks go to Dr. Belcher-Rankin and Dr. Forgrave for their insight and hard criticism that kept me searching for answers.

To all my editors, thank you for finding my mistakes, giving me feedback, and helping to shape this book and paper into what they are.

For my illustrator and friend, Laura, I cannot express how grateful I am. I have loved your artwork since it was doodles in your high school planner, and I am honored to have you illustrate my book.

Lastly, I owe gratitude to the Olivet Honors department for the opportunity to do this project and the funding to make it a reality. Through the research grant, I was able to pay an illustrator.

This project would not be the same without any one of the above people or organizations. Thank you all from the bottom of my heart.

TABLE OF CONTENTS

Dedication	ii
Acknowledgements.....	iii
Abstract.....	vii
Introduction	1
Review of Literature.....	2
Down syndrome.....	2
Genetics	2
Physical Characteristics.....	4
Speech.....	5
Stigma	7
Self-Awareness.....	9
Typical Children’s Literature	11
Down syndrome in Children’s Literature.....	15
Getting Published.....	16
Conclusion.....	19
Description of Performance.....	20
Performance Flier	20
Performance Notes.....	21
Professional Evaluations	21
Connie Hitchens, Library Director.....	22
Ken Earls, 3 rd Grade Teacher.....	23

Dr. Roxanne Forgrave, Children’s Literature Professor	23
Other Reviews.....	25
Mother, Sibling, Social Worker	25
Mothers.....	26
English Majors and Teachers	26
Expenditures Provided by Grant.....	28
Methodology.....	29
Topic Identification	29
Research of Typical Children’s Literature	29
Research of Down syndrome Specific Children’s Literature	31
Writing and Editing Process	32
Choosing a Topic	32
Choosing an Illustrator	32
First Draft	33
Choice of Names	33
Revisions	33
Performance and Feedback	34
In Depth Research of Stigma, Speech, and Awareness	34
Final Revisions.....	36
Reflection	37
Self-Evaluation of Performance	37
Knowledge Gained	37

Changes for the Future	38
Original Manuscript	40
Works Cited.....	44
Works Consulted.....	47

ABSTRACT

For decades, there has been a stigma attached to those with Down syndrome and their families. Society has seen individuals with Down syndrome as people who are incapable of contributing to society, imposing a lifelong burden on their families. Though this mentality has changed in the last forty years, it has not been completely eradicated. Thus, this research seeks to bring awareness and understanding through the writing of children's literature about Down syndrome. First, a basic understanding of Down syndrome was necessary, followed by consideration of the components of well-written children's literature. When it came to finer details, it was important to have a fuller knowledge of speech difficulties and stigmatization as they relate to individuals with Down syndrome. The research influenced the writing of a children's book about a girl with Down syndrome, supporting the factual elements of the story. It was concluded that although there have been great strides in the last few decades for people with Down syndrome, there are still negative mindsets that lead to stereotyping. Changing these mindsets in children is especially important in order to influence future generations toward greater acceptance of all types of people; Children's literature is one avenue to use as stimulus for change.

Keywords: Down syndrome, Children's literature, Stigma, Stereotype, Awareness, Self-Advocate

INTRODUCTION

The market for children's literature is complicated and competitive, but in need of special topics literature such as that about Down syndrome. Such literature can be used as an instructional tool in classrooms or as a method of learning and coping for families just receiving the diagnosis of their child. Many negative views of Down syndrome exist in the medical community as well as in the general population. Literature and stories including characters with Down syndrome can assist in changing those views to be more positive through bringing a greater awareness of the reality of the disorder. The following research provides deeper evidence about Down syndrome and connects it to the themes portrayed in the book written for this project.

REVIEW OF LITERATURE

Down syndrome

Genetics

Down syndrome is not contagious, and it does not go away after a couple weeks. Rather, it is a genetic condition, programmed in a human fetus from the time of conception or shortly after, that will affect the person for the rest of his or her life. Down syndrome (DS) results from “the presence of one extra chromosome in some or all of [a person’s] millions of cells. Instead of having two copies of the twenty-first chromosome, [a person with DS] has three” (Skallerup 2). It is classified as a syndrome because it is a “set of signs and symptoms that tend to occur together and which reflect the presence of a particular disorder” (Skallerup 2). While people with DS do look like their family members, they also share many distinct characteristics due to their genetic makeups and the nature of the syndrome.

In 2008, figures from the Centers for Disease Control placed the frequency of Down syndrome in the United States at 1 in 733 births (Skallerup 3). Down syndrome is one of the most common congenital disorders, occurring “in all races, ethnic groups, socio-economic classes, and nationalities” (Skallerup 3). While DS is possible to detect before birth through genetic testing of the amniotic fluid, nothing can be done to prevent it. On the same note, parents cannot purposely cause DS in any way. Older men and women do have a higher risk of having children with Down syndrome, but any parent could receive the diagnosis.

On the genetic side of DS, there is a set of issues that many, but not all, people with Down syndrome may face. The first is mental intelligence. Every person with Down syndrome

will have some degree of intellectual disability, but the “degree of intellectual impairment varies tremendously” (Skallerup 8). Scientists do not yet understand how the extra chromosome affects mental ability, but “most children with Down syndrome score within the mild to moderate range of intellectual disability . . . [with] some possessing intelligence in the near average or even average range” (Skallerup 9). With the correct support, people with Down syndrome will succeed to the best of their ability in school and at work, no matter IQ level. Mental achievement for children with Down syndrome is on the rise with “appropriate treatment for medical conditions, early infant intervention, better education, and higher expectations” (Skallerup 10). Learning does need to be facilitated in different ways, but it is not impossible simply because of a label of disability.

Other genetic issues associated with Down syndrome are heart problems. According to Skallerup, “approximately 40 to 60 percent of all infants with Down syndrome have some type of heart defect” (76). These can be defects of the septa, or walls, of the heart or other artery defects. They can usually be detected in physical exams; some heal on their own while others require surgery. Before, these defects could not be treated, but “advances in surgical techniques over the last two decades have enabled many babies with heart defects to recover and live long, healthy lives” (Skallerup 78). Advances in medicine have not only helped individuals with DS live longer, but have also kept them away from institutions where they used to be placed because of their “fatal” diagnosis.

Every system of a person with Down syndrome is affected because the extra chromosome is present in all or most of the cells in the body. Therefore, people with DS may

experience other genetic problems such as cataracts, hearing loss, acid reflux, joint problems, chronic skin conditions and many others which are irrelevant to this research, but important for families to know and understand if their child has Down syndrome.

Physical Characteristics

People with Down syndrome are usually identifiable by certain physical characteristics, though these characteristics can be found in people without DS or may not be found in those with DS. Skallerup points out that there is “tremendous variety among babies with Down syndrome; not every baby possesses all of the characteristic features” (4). The most positive way to determine a diagnosis of DS is to have genetic testing done. The most common physical characteristics of DS are upslanted eyes, a wide gap between the first and second toe, and a smaller mouth that causes the tongue to appear larger (Skallerup 5). There are many other small distinguishing features that do not affect a child’s development or health.

One distinct feature of DS that does affect development is low muscle tone, or hypotonia. Hypotonia affects all areas of development including “gross motor skills such as rolling over, sitting, standing, and walking . . . the development of feeding and speech skills can also be affected” (Skallerup 4). Many of these concerns are addressed through physical, developmental, speech, occupational, and/or feeding therapy. When problems are corrected early, muscle tone can “improve over time” (Skallerup 5). People with Down syndrome may take longer to learn skills such as walking and talking, but with encouragement from their families and the correct medical support, many are able to achieve these skills to varying degrees of ability.

Speech

People with Down syndrome will face a lifetime of speech struggles due to their smaller mouth and larger tongue, but they can be overcome or managed with treatments such as speech therapy. Similar to every other issue related to DS, when it comes to speech difficulties, there is “considerable variability among children” (Roberts, Chapman, and Warren 77). Some may begin talking early; others may not talk until they are much older. Some children will require intensive speech therapy for many years while others may only require mild therapy. Roberts, Chapman, and Warren state that “intelligibility is a problem frequently reported as an area of concern,” but it typically improves with age (118). Intelligibility does not mean the person with DS cannot be understood by anyone, but it may mean that only those family members, friends, and therapists closest to the person are able to make sense of what the person says. Therapy works to bring clarity to the person’s speech as well as broaden the vocabulary.

Speech in children with Down syndrome can be broken down into expressive and receptive vocabulary to better explain what they can understand and communicate. Expressive vocabulary is language production such as “grammar and morphosyntax,” while receptive vocabulary is what the child comprehends (Ypsilanti et al. 354). Ypsilanti et al. found that, overall, “language production is more affected than comprehension” (354). Children with DS show more of a delay in producing spoken language, but are usually capable of sign language or matching “a spoken word (noun or verb) to a picture among four semantically related

detractors” (Ypsilanti et al. 356). Not all cases can be classified together though. In one study, “Thirty-five percent of the children with DS had expressive vocabularies consistent with expectations based on mental age” (Roberts, Chapman, and Warren 81). Some children with DS will function at a degree closer to average and their speech will not be as affected.

A difference also occurs between conversational speech and narrative speech in people with Down syndrome. In conversational speech, where they are being asked many questions, children with DS may give short replies that do not elicit further response. Contrarily, in samples based on personal narratives, “mean length of utterance has been found to be longer than in conversation and does not show the plateauing in sentence length reported for conversational samples” (Roberts, Chapman, and Warren 122). When children can recount a story, event, or situation, they are more descriptive and speak more than they would in a conversation.

When taken into account in classrooms or therapy sessions, these differences will influence outcomes and assessments. Children with Down syndrome are capable of productive speech if they receive the proper therapy, patience, and assessments. The burden of coordinating such support typically falls on the parent(s) or caregiver(s) and it can be wearisome. Children with DS will face difficulties in speech and other areas of development, but these obstacles do not have to dictate limits on their abilities. Support programs and laws are in place that can assist parents and caregivers in learning about what resources are available for their child. One such law to support children in school settings is The Education of All Handicapped Children Act, now called IDEA, established in 1975. This civil rights law

“established that all individuals with disabilities have the right to an individualized, free, and appropriate public education in the least restrictive environment” (Cohen, Nadel, and Madnick 120). Whether in a regular classroom with an aide, or in a special education classroom with a specialized teacher, all children have a right to the education that will help them achieve the skills mentioned above.

Despite more social acceptance, individuals with Down syndrome are often “forced to alter their dreams, adapt their goals, and be confined by the limitations society continues to place on them” (Cohen, Nadel, and Madnick 442). This may mean staying home instead of going to college or experiencing a hindrance in academic growth due to inadequate education. Many, but not all, individuals with DS now receive the proper support to avoid such limitations society may place on them.

Stigma

Stigma can be noted as “the situation of the individual who is disqualified from full social acceptance” (Goffman i) or “a negative connotation of inferiority/devaluation of the social category Down syndrome and/or disability” (Cunningham and Glenn 351). For many years, this has been the case of individuals with disabilities and specifically Down syndrome. People with DS have been viewed as unable to contribute to society, be productive citizens, or learn in a regular school setting. Programs such as early intervention have helped change previous mindsets about Down syndrome. The National Down Syndrome Society explains how beneficial such programs are: “Early intervention, research and case histories have shown that children with Down syndrome have a far greater potential for learning and for functioning as

contributing members of society than it was believed to be possible even 10 to 15 years ago” (Parks 17).

In the early to mid-twentieth century, babies with Down syndrome were sent to mental institutions such as that in Kim Edwards’s novel *The Memory Keeper’s Daughter*. In the past, parents usually heard, “the child [will] never walk, talk, read, or think; the child [will] not be able to relate to parents or family; and the child [will] remain a drain on the family financially and emotionally” (Parks 12). Although it has improved, this stigma still exists in some settings.

Not only does stigma affect those with DS, but it reaches out to their close friends and family every day as well. Families may receive sympathetic looks or condolences from strangers who believe Down syndrome to be tragic and depressing when usually DS changes families positively. Contrarily, some families still struggle with a diagnosis because it is not the child they had expected. According to Parks, an estimated 90% of prenatal diagnosed cases result in abortion (9). Financial burdens on the parents, mental capabilities of the child, and possible birth defects other than the syndrome are all factors among others that could affect a decision for or against abortion. Speed and level of development as well as the abilities of the child cannot be determined until after birth, leaving the future unknown. Every family will handle the diagnosis differently from the next based on their situation in life.

Stigma is so embedded in society though that it may begin as early as age five. Between five and eight years old, “typical children describe themselves and others in concrete terms based on physical features and actions, and form social categories based on such distinctions” (Cunningham and Glenn 338). These categories lead to stereotypes which could lead to bullying

based on the distinctions. The children will begin to “attach value judgments based on their experience and the attitudes of others” (Cunningham and Glenn 339). Cliques are then formed at an early age and children with Down syndrome are not excluded from these groups. Some schools have support systems such as Best Buddy programs, which encourage friendships between typical students and students with Down syndrome, but not all schools are so lucky. Therefore, educators and parents must work to build positive viewpoints and relationships among their students and children that encourage inclusion rather than stereotyping.

Self-Awareness

Having an extra chromosome and being labeled with different diagnoses does not mean individuals with Down syndrome are unaware of their surroundings and the way they are treated at home, school, or work. In one study by Jahoda, Markova, and Cattermole, all participants with Down syndrome, age twenty-one to forty, “had an insight into their situation as stigmatized individuals . . . [and] experienced restrictions at home which they knew did not apply to their non-handicapped siblings or peers” (107). The individuals were aware of the stigma because it was something “with which they had to cope in their everyday lives” (Jahoda, Markova, and Cattermole 113). Another study, done by Begley, observed self-perceptions of children with Down syndrome, age eight to sixteen, and produced similar results. Begley found that, “With the development of the capacity to make social comparisons around middle childhood, children begin to base their competence evaluations on normative standards generated from comparisons with others” (517). The children with DS were aware of their label

and compared themselves with their classmates, furthering the notion that they were not as capable as their peers.

People with Down syndrome that have mild to moderate capabilities are generally aware of their diagnosis and go through processes to understand what it means. One way that Down syndrome awareness has spread is through self-advocates: people with DS who speak, write, and endorse themselves and others with DS. They become self-advocates because they feel so strongly about promoting positive views of Down syndrome. One advocate, Mia Peterson, says, "Please remember we, the self-advocates, can speak for ourselves and don't let anyone else speak for us" (Cohen, Nadel, and Madnick 111). It is important that people with DS have a voice; there has even been an "I Have a Voice" campaign started that travels the country as an exhibit promoting Down syndrome awareness.

Another self-advocate highlights the importance of balance in life: "Everyone needs a chance to work, to learn, to have relationships, to stay fit, to follow their faith, and to enjoy leisure" (Cohen, Nadel, and Madnick 108). This advocate, Jeffery Mattson, understands that people with DS need stimulation in all areas of life, just as any other person does. Some self-advocates are even famous, such as Chris Burke, who acted in the TV show *Life Goes On*. He says that the show revealed to the world that "people with disabilities have ability, too" (Cohen, Nadel, and Madnick 114). As self-advocates continue to fight for rights and acceptance, people with Down syndrome will have an increased chance of being accepted for who they are.

Along with self-advocacy comes self-awareness of emotions. Roberts, Chapman, and Warren discuss how children with Down syndrome were able to label and identify emotions as

easily as their peers within the same mental age (82). They showed some deficits in labeling fear and anger, but were otherwise capable of recognizing a range of emotions (Roberts, Chapman, and Warren 82). As Andrea Lack puts it, “Individuals with Down syndrome are living, breathing, thinking, feeling people, and they want to be treated as such” (Cohen, Nadel, and Madnick 440). Their feelings can be hurt and they have the capacity to injure others’ feelings as well.

On the negative side of self-awareness is low self-esteem. When individuals know their diagnosis and the stigma attached to it, they are likely to be more hurt by negative treatment and responses from others. This may lead to low self-esteem. Some strategies the individuals may use in response to the stigma include “denial, unrealistic self-appraisal and minimization of the disability, overcompensation such as working harder and being more compliant, and trying to ‘pass as normal’” (Cunningham and Glenn 336). Self-advocates work to fight these attitudes and empower individuals with Down syndrome to be unique and accept who they are.

Typical Children’s Literature

The world of children’s literature is competitive and vast. In order to have a better understanding of children’s literature about Down syndrome, “typical” children’s literature was first researched. Elements such as style, plot, characters, theme, etc. are core essentials in any literature, whether adult, children’s, or special topics. Having a basic understanding of these as they pertain to children’s literature provides a foundation for writing in this genre.

Children’s literature follows the conventions of writing with a few twists in style. Johnson discusses some of these elements in her book *The Joy of Children’s Literature*. Lynch-

Brown, Tomlinson, and Short support many of the statements in Johnson's book in their own, *Essentials of Children's Literature*. Style can be viewed as "the writing itself, as opposed to the content of the book. However, the style must suit the content of the particular book; the two are intertwined" (Lynch-Brown, Tomlinson, and Short 41). The style of children's literature is concise due to the limited number of pages. Authors must set the pace and the mood of the story through their writing style (Johnson 6). Style includes aspects such as word choice, sentences, organization, point of view, and symbolism. Words should be "appropriate to the story being told . . . [and sentences] varied in length and structure, and enjoyable to read and hear" (Lynch-Brown, Tomlinson, and Short 42). Style is especially important in children's literature because it will determine reading levels and audiences based on the complexity of the text. The author holds full control of style and uses it to affect readers in a particular way.

Setting affects the other portions of a children's book such as plot, characters, and theme. Setting is the "time and place in which the story occurs" (Lynch-Brown, Tomlinson, and Short 40). In historical fiction, an integral setting is important because "the authentic re-creation of the period is essential to the comprehension of the story's events" (Lynch-Brown, Tomlinson, and Short 40). If the story takes place in another setting, then it is not the same story and it is not factual.

In contrast, there can be a vague setting, called a backdrop setting, which is "meant to convey a universal, timeless tale, one that could have happened anywhere and almost anytime except the present or very recent past" (Lynch-Brown, Tomlinson, and Short 40). Every book

must have some type of setting and a backdrop setting provides an environment that does not detract from the story or characters, but merely supports them quietly.

When it comes to the characters of a children's book, the reader "must be involved with and care about them" (Johnson 6). Children must be able to relate to the characters in some way, otherwise they will not connect to the message of the story. Lynch-Brown, Tomlinson, and Short echo these sentiments saying, "A well-portrayed character can become a friend, a role model, or a temporary parent to a child reader" (39). One way characters can become so memorable and influential is through character development. These are the changes a character goes through during a major event of a story that should result in the character being different afterwards (Lynch-Brown, Tomlinson, and Short 39). This creates a rounded, well-developed character that is similar to people in reality and therefore understood by children.

The plot of a children's book, like any work of literature, must have a conflict and resolution. The plot is the most important element to the child reader because "by age 4, children want to find more excitement in books" (Lynch-Brown, Tomlinson, and Short 35). A conflict causes suspense that keeps the reader engaged. Conflicts may arise from a number of different sources, including a self-conflict. Plots are also constructed in different ways, but "the most common plot structures found in children's stories are chronological plots, which cover a particular period of time and relate the events in order within the time period" (Lynch-Brown, Tomlinson, and Short 36). Writing in this way is easier for children to understand and follow, while still providing a story that is intriguing and thought-provoking.

The theme of a story is the “central idea of the entire story” (Johnson 7). While this could mean a moral of the story, it is not always so. Theme is usually “better expressed by means of a complete sentence than by a single word” (Lynch-Brown, Tomlinson, and Short 41). The author’s purpose in writing the story, or what the author is saying through the story, is summed up in the theme. When applied in children’s literature, the themes should be “worthy of children’s attention and should convey truth to them . . . [but] must not overpower the plot and characters” (Lynch-Brown, Tomlinson, and Short 41). Children want to read for enjoyment, not for a lesson, so themes must be inconspicuously worked in. When children become involved in the text based on characters or plot first, they will understand the theme secondly.

Picture books, a subcategory of children’s literature, have certain qualities that distinguish them from longer children’s books with or without pictures. Maurice Sendak, author of *Where the Wild Things Are*, says a picture book is a “juxtaposition of picture and word, a counterpoint. Words are left out and the picture says it. Pictures are left out and the word says it” (Johnson 77). Sendak’s explanation gives the reason why authors must choose their words wisely when writing children’s literature. The words must tell a story well enough for pictures to describe it, but the pictures must tell enough of a story to describe the words.

Rhythm, repetition, and rhyme are also important to children’s literature, according to Mary Quattlebaum in her 2009 article “Write A Picture Book That Grabs The Ear.” Children’s books are read aloud, so “it’s not just what you say but how you say it—and how it sounds—that’s key to delighting children” (Quattlebaum 30). Writing techniques such as alliteration will catch the attention of children and make the story more interesting. Although pictures also tell

the story in a picture book, the eye “does not pick up what only the ear can hear” (Johnson 102). These small details will make the book more appealing to children and to editors.

Research from primary sources was also conducted by visiting the children’s section of a bookstore. Approximately thirty random books were read to get ideas of elements such as alliteration, rhyming, plot, etc. firsthand. *Goodnight Moon* demonstrated repetition by repeatedly saying goodnight to the various objects in the room. The book *Today I Feel Silly & Other Moods That Make My Day* by Jamie Lee Curtis connects to young children through silly actions and pictures of funny faces. Rhyme is popular in children’s literature, including *Miss Lina’s Ballerinas*. These books are fun for kids to read and they teach about words that rhyme. Lastly, classics such as *Brown Bear, Brown Bear, What do you see?* are widely read because of rhyme, repetition, and suspense that keeps the reader turning the page. The other books that were read for research demonstrated many of the same qualities as those mentioned.

Down syndrome in Children’s Literature

Children’s literature about Down syndrome is still children’s literature and so it uses the same writing styles and techniques mentioned above. Research in this category was done through primary sources because there were very few secondary sources about the specific topic. Lisa Kupper’s “A Guide to Children’s Literature and Disability: 1989-1994” was used as a starting point for finding literature about Down syndrome, though it is slightly outdated.

Longer books about Down syndrome, such as June Rae Wood’s *The Man Who Loved Clowns*, had essential elements of children’s literature. This chapter book had themes of love, friendship, and family, as well as characters that were believable and could be related to. There

was a plot with a rise and fall of action. The book catered to older children wanting to know about Down syndrome.

There were also many picture books about Down syndrome, even if they were not as abundant as other children's literature. They were generally for younger children, introducing the topic of Down syndrome. Some titles included, *My Friend Isabelle*, *Our Brother Has Down's Syndrome: An Introduction for Children*, *The Best Worst Brother* and *We'll Paint the Octopus Red*. These books and others showed children with DS participating in activities that other children do including eating, going to school, visiting the zoo, and playing.

Literature about Down syndrome had the same literary elements as other children's literature while simply including characters with DS or story lines showcasing what people with DS are capable of. Reading many of these stories and picture books provided a basis for how to approach the book in this project.

Getting Published

As previously stated, children's literature is a vast and competitive market. Many publishing companies do not take unsolicited manuscripts, and if they do, the manuscripts need to be a topic or concept the editors have never seen before. So many different types of children's literature exist about so many different topics that it is hard to produce fresh ideas. Following are some elements and rules a picture book such as this project would need to comply with if it were sent to a professional publisher.

Laura Backes explains many of these requirements in her article "Getting Started Writing Children's Picture Books." Picture book texts are short, usually 32 pages, or no longer

than 1500 words (Backes 4). They are compact books with a large impact. If they cannot be summed up in two to three sentences, they are “too complicated for a picture book” (Backes 7). When picture books are going to carry a message, it should be “the result of the story, and come out through the characters’ actions” (Backes 6). Children want to read books that are fun or adventurous, not burdened with a lesson. Telling the story from the child’s point of view is also very important. Picture books should “be about a child’s concerns and how a child sees the world” (Backes 7). Therefore, main characters are generally children or animals, not adults.

Once the text is written, it must be edited before sending it to the publisher. Backes recommends cutting “at least ten percent of your manuscript off the bat” (9). Any part of the text that does not advance the plot is most likely “superfluous” and can be removed without any consequence to the outcome (Backes 9). Dialogue is also important in this aspect. It should be meaningful and help advance the story through action. Dialogue is also significant in helping “each person have [a] unique voice” (Backes 10). Authors must also remember that child characters need to talk like children. The manuscript will be rewritten many times before it is ready. Another way to check it is to read it to children and “watch them as they listen” (Backes 10). This will provide clues to where the manuscript may need work, based on how the children respond.

After the manuscript is edited, the author can move on to submitting it to a publisher. The manuscript needs to be typed, generally “double-spaced with at least one inch margins” (Backes 11). A title page is required as well as having the pages numbered and titled in some way. Specific requirements should be gathered and verified from the company that the author

is submitting to because it may be different for each publisher. A cover letter should also be included, but illustrations are not always required. If an author does include them, they should be separate from the manuscript and should be “detailed enough to give the editor a good idea of how you envision each page” (Backes 12). Each requirement should be reviewed carefully; one mistake could cause an editor to dismiss a manuscript before even reading it.

CONCLUSION

An extensive review of literature and research has provided a number of conclusions about Down syndrome and how it relates to children's literature. Down syndrome, a genetic disorder, affects every part of an individual's life, physically, mentally, and emotionally. A strong stigma has been attached to the disorder since it was discovered. Although improvements have been made, stigma still persists in the medical and personal worlds of those with Down syndrome and their families. Through this project, stigma was evaluated and confronted through the lens of children's literature. It was discovered that individuals with Down syndrome are usually self-aware and capable of understanding the stigma attached to their diagnosis. In this sense, children's literature can be used to bring awareness to a larger community about the capabilities of those with Down syndrome. This project combined the techniques for writing children's literature with the research about Down syndrome to provide a children's picture book for awareness.

DESCRIPTION OF PERFORMANCE

Performance Flier

Come and listen to a new book at CCLD!

HOPE'S HALLOWEEN HIDEOUT

A book by Megan K. Wright • Illustrated by Laura Elliot

- *What: Reading night*
- *Where: CCLD Library*
- *Date: October 27, 2011*
- *Time: 6:30 PM*



Come early for refreshments and a good seat! There will be punch and dessert available before and after the reading. The author will begin her presentation and reading of the book at 6:30 PM, followed by a time for questions. Books will be available for ordering. Come out for a great time; bring your kids and your friends!

See you there!

Megan Wright is a 2008 graduate of Central High School. Now in her senior year at Olivet Nazarene University, she has written "Hope's Halloween Hideout" for

Wright 20

her Senior Honors project. It is a story of a girl with Down syndrome and her struggle with difference, acceptance, love, and hope.

CCLD Library is located at the Central High School complex: 1134 E. 3100 N. Rd., Clifton, IL 60927

Performance Notes

The first performance of my book took place on October 27, 2011 at the CCLD Library in Clifton, IL. Although the book was not in its final state, I received many positive reviews. Approximately forty people were in attendance including family, friends, teachers, and members of the community. I began by introducing my project and then reading my book. I had a question and answer session, then served refreshments and further discussed my project with various audience members wanting to know more. A Gigi's Playhouse board was on display, promoting the new playhouse opening in the Bradley/Bourbonnais area. I had various books on display that were other examples of children's books about Down syndrome. The evening was a successful first step in completing all of my requirements for the project.

Professional Evaluations

The following reviewers were chosen based on their areas of expertise that pertained to the level and content of the book. They were asked if children would understand and enjoy the story, if the story would be beneficial in a library or classroom setting, what was most positive about the text, what they would change about the text, as well as any other professional opinions they may have.

Connie Hitchens, Library Director

“Young children will be able to relate to Hope’s excitement over the quickly approaching Halloween holiday and her fear of being teased and called names by her fellow classmates. This book would be beneficial in a classroom setting as the basis for discussion on bullying and learning to be more accepting of those with differences or disabilities. Hope’s friend Shannon provides a positive role model of a good friend. Shannon’s Favorite Thing report outlines for readers the positive characteristics of those that may not be considered ‘normal’ by their peers. The story gives readers insight into Hope’s feelings as she struggles to deal with her disability.”

“The web resources and fast facts provide helpful background information on Down syndrome. Readers of all ages may also benefit from a description of the disease and its symptoms. I was disappointed that neither Hope’s teacher nor classmates provided any feedback to Hope after she had worked so hard in preparing her Favorite Thing report. The detail of Shannon’s report and Ms. Amy’s praise sent the message that Hope’s work was not as deserving of a response as Shannon’s had been. I also wonder if Hope was really hiding from her disease at Halloween as the title suggests. Shannon’s report opened up a new awareness for Hope and her classmates and that positive message should be highlighted.”

Ken Earls, 3rd Grade Teacher

“The children will understand and enjoy the story. As you know, more students like Hope are in general education classrooms. The students know and understand more about the diversity of our school populations and I believe are more accepting of all students.”

“I intend to use your story as a building block for a unit in our "Pillars of Character" and "Second Step" programs. It will be a great starting story to introduce the topics of diversity and tolerance.”

“Hope's inner dialogue stands out as an accurate portrayal of what the thought process is for a student with similar disabilities.”

“I hoped to find a brief description of Down syndrome with some statistics at the end. I think a page of facts would be beneficial for the readers and parents. I know the book is not necessarily intended to educate anyone on Down syndrome, but I think it is an opportunity missed. I did enjoy the text as it stands and do not feel any changes need to be made in that regard.”

Dr. Roxanne Forgrave, Children’s Literature Professor

“Here are my thoughts after reading this new version:

“First, I do see that you have made some positive changes to the text. Teachers are not ignoring bullying and the Down syndrome child is participating in more realistic activities for her, but, I still hear some unrealistic ideas. In the current book, I still struggle with the idea that a Halloween costume makes her a ‘regular’ student. A Downs child will never be ‘regular’ and no Halloween costume will ever change that. Her speech won't change, the way she walks won't change, the fact that she loves to hug everyone won't change.”

“I would like to know if you have spent time with 3rd grade Downs children - what can they do - what can't they do. I just don't want the wrong perceptions to be in such a book -

dealing with disabilities is very difficult if you haven't lived with it. Although I have a niece who is Downs, I don't feel comfortable writing a book about her because I haven't "lived" with her to see how she lives."

"At the beginning you have the main character Hope struggling to write the paper/assignment, but then you focus on Shannon and her paper at the end – which was good – but does it flow from a writer's standpoint?"

Will children understand and enjoy the story: "Stories about children with disabilities really need to be introduced to the children by the librarian and/or teacher. Children don't always pick up books like these on their own. I had several in my Dwight library and they were seldom checked out."

Is the story beneficial in a library or classroom setting? Why: "I am still struggling with the content dealing with this disability as stated above."

Most positive aspect of the text: "You've written it at a vocabulary level that most primary students will understand whether it's read to them or they attempt to read it on their own (2nd – 4th grade)."

What would you change about the text and why: "Please see my notes above."

Any other professional opinions you may have: "See above information."

Other Reviews

The following portions from reviews were collected at various stages of the writing process and used to shape the text grammatically, structurally, and thematically. Some

reviewers were asked to look for certain qualities such as accuracy and probability of the situation, but most reviewers were simply asked to read and respond honestly.

Mothers, Sibling, Social Worker

A mother of four children, ranging in age from 17 years to 20 months old, reviewed the book, had her daughter read it, and sent it to the school social worker, as well as another mother. Their comments follow: "I am a mother of four children . . .two boys and two girls. My oldest son is 8 years old and happens to have Down syndrome. I was given the opportunity to read Megan's book . . . [and] I enjoyed the book. [I] thought that it was well written for the age group that the book is meant to target and that it was very possible scenario, even with the main character having Down syndrome."

"This book directly addresses an important issue inside all schools- bullying. This book provides a refreshing take on how students with disabilities are just as affected by bullying as neuro-typical students. My son with Down syndrome is eight years old, and included fully in the general education classroom as a second grader. While he's not a straight A student, he is maintaining grade level academics and definitely knows when his peers are making fun of him."

"My fifth grader read the book also. She felt that it was a good children's book and would recommend her school library to buy the book for others to read and learn the lesson."

"Our school social worker read it as well and wants to be kept informed of when this is available to the public as she feels this would be a great teaching tool for the children at the school."

“Another parent who has five children, three who were adopted and have Down syndrome along with a biological son who has Down syndrome, read the book as well. She felt it would address many concerns that she has in her children’s school setting as well as in other social settings (church, etc.).”

Mothers

Other mothers of children with Down syndrome reviewed the book. One said:

“[The book] was to the perception through a child's eye and what a child really feels like. A person, whether child or adult, with Down syndrome only wants to be accepted by their peers and not be laughed at or looked down at. They are a person and like to do things that the other kids like to do. It is a wonderful way you made Hope's class see this through Shannon's eyes. I also loved the way the pictures in the book looked.”

Another mother made the following comment:

“Most generally DS has been more accepted, but, there is always going to be "that guy" that is going to bully or laugh or whisper or point! But thank God for the "Shannons" in this world!”

English Majors or Teachers

Two recent English graduates and a former English teacher read the book. The teacher said the section about Hope being teased “draws attention to the reasons Hope is teased and

provides for a greater emotional impact” because of how it was written. He also said, “You write a cute story that teaches a good moral lesson. I'd read it to my kids!”

One English graduate stated, “I really like the plot, and story-line for this piece. Especially the way you tie in Halloween as a means of escape for the main character. I also like the resolution in the end, but it seemed a bit short.”

The other English major responded, “The friendship theme is excellent in here and really carries your message so I would try to highlight that relationship above all else.”

EXPENDITURES PROVIDED BY GRANT

The grant from the Olivet Nazarene University Honors Department was in the amount of three hundred dollars. The grant provided compensation for an illustrator to create unique, quality images to accompany my text.

METHODOLOGY

The following sections describe the process in greater detail, from identifying a topic to researching and writing as well as presenting.

Project Topic Identification

This project went through two or three different forms before shaping into what it is now. At the time of writing our initial proposals, my future-sister-in-law was born with Down syndrome. The idea to write about this topic stemmed from her birth and all the questions surrounding it. I knew I wanted to do a performance project and decided the best way to present on the topic of Down syndrome would be through children's literature. Therefore, I proposed to research and write a children's book about a girl with Down syndrome for the second through fourth grade level.

Research of Typical Children's Literature

Some of the initial research for this project involved going to a well-known bookstore and pulling thirty random books from the shelves in the children's section. The main purpose was to identify the key qualities of children's literature. They generally had bright covers and pictures, short sentences, and rhythmic tones. The books were about imagination, learning, and creativity.

The second purpose of the bookstore search was to determine the market for children's books about disabilities. Out of the thirty books randomly selected, only one discussed a disability. While discouraging, it was not an accurate sample of the representation of disabilities

in children's literature. Upon further research, many books about disabilities and specifically Down syndrome were revealed, even if they were not presented in a popular book store.

Getting a feel for children's literature allowed me to see how I should approach my book. I looked mostly at picture books since that was the kind of book I was going to write. I also reviewed classics to see why they were popular and why they appealed to children. After secondary research on the topic, mostly from Johnson and Lynch-Brown, Tomlinson, and Short, I had a better idea about how to write my book. An in depth summary can be found in the review of literature section. Based on my findings, I learned the style I wanted to write my book in as well as what categories it fit into.

Hope's Halloween Hideout has a backdrop setting, as described by Lynch-Brown, Tomlinson, and Short. The setting does not demand center stage in the story, but rather is needed to support the actions of the plot. Hope's story could take place in a different setting and still give the same message, but I chose the school setting because it is familiar to children and because that is where Hope is most likely to experience the challenges she faces in the story.

I also followed a chronological plot because it seemed most appropriate. A chronological plot is easiest to understand for readers in my audience. While some second through fourth grade readers are very advanced, possibly experimenting with plots that include flashbacks, most will still appreciate a plot that progresses forward through time. It seemed most logical for readability and also for relaying Hope's story.

Character development, discussed in the review of literature, is another major component of Hope's story that also contributes to the theme. Hope goes through some life changing events in the story and is therefore expected to change afterwards. After her friend's speech, not only does Hope change, but so do her classmates. The characters develop based on the events and provide realistic depictions of well-rounded individuals. The character development lends itself to the theme of the story, supporting the friendship between Shannon and Hope and how it changed others' minds. Hope's story does have a message, but it is played out through the action of the plot and development of the characters.

Research of Down syndrome Specific Children's Literature

The next step in research was discovering how children's literature about Down syndrome was written and whether or not it was similar to typical children's literature not written about disabilities. Books were ordered from many different libraries and some commonalities emerged between them. Most of the books were for very young readers; only a few were novels. The books were positive, showing children with Down syndrome doing many activities expected of any child at that age. Many of these books used pictures rather than illustrations from an artist. These books and novels gave insight into how authors chose to portray children with Down syndrome, how children with Down syndrome were seen and treated by peers, and what children with Down syndrome were capable of. They gave me a better understanding of ways I could approach Down syndrome in my own book. Technical aspects such as plot, character, setting, and theme were approached in the same way as the typical children's literature that was researched.

Writing and Editing Process

The writing and editing process for the book manuscript included many stages and revisions before finalization.

Choosing a Topic

I already knew I was going to write about a young girl with Down syndrome, but I was not sure what kind of themes or storyline I wanted my book to have. The idea of using Halloween to essentially hide from others and become someone else for a day struck me as a viable topic. I began to develop that idea into a story of having a reason to hide from others and a friendship that could overcome those insecurities and fears. The story developed from that point and then shifted after multiple sets of revision.

Choosing an Illustrator

My book was a children's picture book from the beginning, so it was crucial to have illustrations with the text. I chose my illustrator, Laura Elliot, based on familiarity and trust. Laura has been a friend since middle school. I have been able to watch her artistic abilities flourish throughout the years. She has done art projects for me in the past, so I knew the level of her ability and trusted her to create unique illustrations that would complement the text. I sent her the manuscript with minimal instructions for my ideas about the main characters. Within a few weeks, she delivered illustrations that fit well with my text and helped tell the story through visuals.

First Draft

The first draft of the book was very rough, simply getting my thoughts on paper. When I write a paper or story for the first time, my technique is usually to write without stopping. My thoughts flow better this way and tend to be more cohesive. Later, I spend a few hours revising the text, which is what I did with my manuscript.

Choice of Names

One area of the text that I put a lot of thought into was the names of the main characters. The protagonist Hope is able to trust and find fulfillment in her friend Shannon. Shannon gives her hope that she is not alone. At the conclusion of the book, there is hope for the protagonist and her classmates.

One meaning of the name Shannon is small but wise. Although only a third grader, Shannon shows maturity and wisdom beyond her years. She is able to see the value in Hope as a person and share that with her classmates through the report she gives. When Shannon steps up and takes action, the other characters follow her lead.

Lastly, the teacher's name, Amy, means greatly loved. Ms. Amy is gentle and kind to all of her students. She encourages Shannon after her report and the other class members see that Ms. Amy cares about Hope too.

Revisions

After initially writing the story, I sent it out to a number of reviewers including family, friends, English majors, English teachers, professors, and mothers of children with Down syndrome. Each reviewer provided a different area of expertise, which allowed me to assess the

story from every angle. I took each review into account as I revised the story. Since the initial writing and editing, the text has undergone many more revisions based on research and further reviews. With each piece of information or suggested revision I received, I had to evaluate how it would change the text and whether it was valuable and applicable to the story.

Performance and Feedback

I chose to do a reading night at my local library for my performance outside of the Honors symposium presentation. After contacting the library director, I was able to set up a night that worked for both of us and fit within the timeframe of Halloween, to go along with one of the themes of my book.

After discussing my project and reading my draft, I presented those in attendance with a survey to fill out. I used this feedback to shape my text after seeing how the general public responded to it. More details can be found in the description of the performance.

In Depth Research of Stigma, Speech, and Awareness

While I did some initial research before my first draft of the book, the bulk of my research came after the draft. Doing the research before writing the book would have been beneficial, but much of the research was prompted by questions that arose because of the book. My research included stigma surrounding those with mental handicaps and specifically Down syndrome, how those with Down syndrome see themselves, speech abilities and patterns in children and adolescents with Down syndrome, as well as other related topics. An in-depth analysis is located in the review of literature.

My research in this section supported some topics of my book. Research showed that children with Down syndrome tend to be more responsive when telling narratives (Roberts, Chapman, and Warren 122). Based on this information, it is possible for Hope to give her report to the class, even though the report is not included in the text of the story. In other areas of the book, Hope's speech is short because it is in conversational settings.

The topics of stigma, as discussed in the review of literature, support the issue of bullying. Despite many medical and social advances for people with Down syndrome, there is still a stigma attached to the disorder, causing bullying and misconceived notions. These topics are addressed through Hope's story and how her friend Shannon helps her overcome them and educate her classmates.

Through a number of personal interviews and discussions, as well as some research, I learned the emotional capabilities of children with Down syndrome. I heard and read many accounts from parents that said their child withdrew or became shy after being made fun of either at school or on the bus. Although many parents said their children could not easily detect sarcasm, the children were able to tell when someone else or they were happy, sad, or being verbally or physically abused. In the same way, Hope knows her classmates' words are hurtful and it makes her sad.

All of the research completed shows that Hope is on the higher end of functionality within the spectrum of Down syndrome. In every aspect of life for an individual with Down syndrome, there is a broad range of abilities. Compared to the research, Hope is at the high-achieving end because she participates almost completely in a general classroom, understands

her disability and how others treat her because of it, and experiences a broad range of emotions that not all would be able to understand or enunciate.

Final Revisions

Final revisions to the text were made after all research and reviews. The book was edited for consistency, accuracy, sentence structure, and overall thematic stability while keeping the audience in mind. The text could be endlessly revised, but at some point had to be considered complete. This was only decided after numerous revisions and responses as well as adequate research.

REFLECTION

Self-Evaluation of Performance

Overall, my project had many positives. I took part in a journey that was completely new to me, I faced some personal fears in the process, and I created a product with a message to be shared with the world. I completed the project to the best of my ability, and I am satisfied with the end result. My performance was received with positive reinforcement and attitudes. I realized the need for literature such as mine and I am excited to present my product to the community. I am happy I had the opportunity to complete the book.

Knowledge Gained

This project provided an excellent learning opportunity in a number of ways. I learned more about Down syndrome than I ever knew before. That knowledge helped me understand people with Down syndrome in a more realistic way, as well as gave me insight into the future of my sister-in-law as she grows and develops. Through scientific research, I learned the technical side of Down syndrome. Through novels, stories, and personal interviews, I learned the emotional side of Down syndrome represented by real people who live it every day.

Through the process of writing my book, I also learned about writing and publishing children's literature. I read articles and researched publishers' websites to see what the general requirements were. While I may not publish my book on a large scale, I know what steps I would need to take to do so. I learned about keeping sentences short with a rhythm to them, as well as how many words to a page and how many pages to a book in children's literature. I

never knew how picky an author must be with words when writing a children's book that is limited in page count. I learned to write in a different way because of this aspect.

Lastly, I learned that writing is not a one step process. It takes many revisions and revisits and even then, it can still be improved. It taught me to keep striving for precision and quality in my work. I learned to keep fighting no matter what obstacles came in front of me. This knowledge can carry over to other areas of my life as well.

Changes for the Future

If I had a chance to redo this project, the book, and my performance, I would change a few key aspects. First, I would allow more time for each step which would give room for error and corrections. With each step, new questions arose and there was not always time to address each one. By allowing more time for each step, I would be able to adequately react and respond to any questions that were presented.

Second, I would do more research before writing the book. Much of my research came after writing my first draft. If it had been done before writing, some questions could have been answered before they were even asked. I would have felt better prepared to begin writing my text and would have been more equipped with the essential information I needed.

Lastly, I would advertise more for my performance. Although I do not like speaking in front of crowds, my project carries an important message and it would have been better to present to more people. It was a busy time and many people had other commitments at the schools that evening, but I would have liked to advertise more and see more of the community at my presentation.

Overall, I feel that I ended in the place where I wanted to be, even if I took a different route to get there. I completed the project, wrote my first book, and advocated for people with Down syndrome, teaching myself in the process. I have grown tremendously after going through this process. It was stressful, difficult, and discouraging at times, but I would not trade it for anything.

ORIGINAL MANUSCRIPT

Hope's Halloween Hideout

by Megan K. Wright

Pages 40-43 excised

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