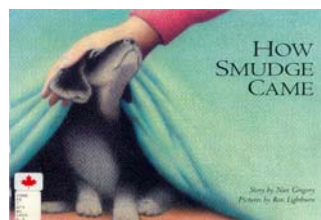
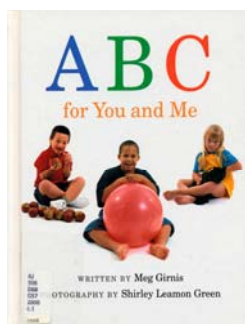


Moving Forward: The Inclusion of Characters with Down Syndrome in Children's Picture Books

by Tracey Kalke-Klita



Used by permission of Albert Whitman & Co. *A B C for You and Me* by Meg Gurnis and Shirley Leamon Green, 2000.

Used by permission of Red Deer Press. *How Smudge Came* by Nan Gregory, 1995.

Introduction

The sunrise on July 12th, 2000 marked a life-changing event for me. On this morning, my daughter Rachel was born, making me a first-time mom. Of course, I expected my new role to turn my world upside down, as there would inevitably be many adjustments to make. However, the diagnosis of Down syndrome that accompanied Rachel's birth was more than I had bargained for, leaving me struggling to cope. As the months passed, the "fog" lifted. Ever so slowly, I worked through my grief and began to accept Rachel for who she was. Eventually, I began my quest for knowledge and information in order to support my daughter's development. A particular area of interest for me was literacy, as I had spent eleven years teaching upper elementary and junior high students, focusing more on the areas of reading and writing as the years went by.

Books have always played a significant role in my life—as a person, as an educator, and, most recently, as a parent. Personally, I believe that these treasures provide the door to the vast world of pleasure, identity, and possibilities. As an educator, I have always believed that

“[c]hildren’s books can be effective tools to present the unique needs of every individual” (Kitterman, 2002, p. 238), and provide insight into the lives of others. As a parent, my endeavour is to nurture Rachel’s literacy development through books in order to give her the key to this fascinating world. Fox (2001) comments, “The ability to harness literacy in any situation gives the literate in society a solid sense of power, at least, if not power itself” (p. 112). Therefore, my investigation of children’s literature began in order to discover books that contained characters with Down syndrome (DS).

When I first began to look for books that included characters with DS, I was unsure of what I might find. However, I was pleasantly surprised to discover fifteen picture books (See Appendix A for an Annotated Bibliography) and seven novels (See Appendix C for Listing)! Therefore, I decided to focus in on the picture books for the time being, believing there was sufficient material to analyze. However, research concerning picture books that include characters with DS was practically non-existent. Therefore, many of my findings are based on my own perspective as an educator and as a parent of a child with this genetic condition. These fifteen picture books have led me to an investigation of how this group of books has changed over time, the common threads that connect these books despite their age, an evaluation of the books, and suggestions for using some of this literature in the educational setting.

Changes in these Picture Books Over Time

The fifteen picture books I found that contain characters with DS range in publication dates from 1977 to 2000 (See Appendix B). After analyzing them, I was astounded to see the drastic changes in book appeal and character depiction over this relatively short period of approximately twenty years.

Our technological world has greatly increased the overall appeal of more current books, leaving titles published only a short while ago looking dated and old-fashioned. A couple of earlier titles, including *Jon O: A Special Boy* (Ominsky, 1977) and *Special Kids Make Special Friends* (Shalom, 1984), used black-and-white photographs in order to accurately portray some of the common physical characteristics of children with DS—upward-slanting eyes, light spots in the colored part of the iris called Brushfield spots, a smaller nose, smaller ears that are set lower on the head, shorter limbs, and often a shorter, heavier stature (Kozma, 1995, pp. 17-21).

Although using photographs is an excellent idea, black-and-white pictures were soon replaced by colored ones. Current books that use wonderful color photographs of children with DS are *ABC for You and Me* (Girnis & Green, 2000), *Russ and the Apple Tree Surprise* (Rickert, 1999), *Dustin's BIG School Day* (Carter, 1999), and *Big Brother Dustin* (Carter, 1997). Titles published in the late eighties and early nineties that used photographs are still useful, but will soon be retired from the shelves. Examples include *Our Brother has Down's Syndrome: An Introduction for Children* (Cairo, 1985) and *Where's Chimp?* (Rabe, 1988). Strangely enough, the book entitled *Charlsie's Chuckle* (Berkus, 1992) uses both color and black-and-white photographs, but the reason is unclear, leaving the reader confused by the layout. The quality of art reproduction has also made some of the older titles such as *Ben* (Shennan, 1980) unappealing for today's audience. The most visually enticing newer books include: *The Hangashore* (1998), beautifully written and illustrated by Canadian author/illustrator Geoff Butler; *How Smudge Came* (Gregory, 1995), illustrated by Ron Lightburn who has won numerous awards for his artwork, including the 1992 Governor General's Award for Children's Illustration; and *Be Good to Eddie Lee* (Fleming, 1993), illustrated by Floyd Cooper, who captures the warmth of summer days mentioned in the text.

The acceptable language concerning people with DS has also recently changed, leaving a number of books simply not suitable anymore. For example, *Our Brother has Down's Syndrome: An Introduction for Children* (Cairo, 1985) uses the terms “retarded” and “handicapped”. *Jon O: A Special Boy* (Ominsky, 1977) and *Special Kids Make Special Friends* (Shalom, 1984) both use the term “retarded”. *Ben* (Shennan, 1980) uses the term “mongol”. In her article that examines “people-first” language in Canadian society, Titchkosky (2001) writes:

The phrase “people with *disabilities*” has been in circulation since at least the 1970s, but until the 1990s such phraseology was one of a number of ways to make reference to disabled people...Since sometime after the 1983 International Year of the Disabled, these various expressions of *disability* have been supplanted almost entirely by “people-first” phraseology. (p. 125)

Interestingly, my investigation of the fifteen picture books that contain characters with DS concurs with Titchkosky’s findings concerning acceptable language use for people with disabilities—the picture books published in the late eighties onward avoid the use of these derogatory and obsolete terms. Terminology for people with DS, and for other special needs groups, has changed radically in the past fifteen years!

Educational settings deemed appropriate for children with DS have also changed dramatically. Alongside this notion is the current belief that children with DS are capable of reading, writing, thinking, and functioning in a regular classroom with just more time and help needed to develop their abilities. The story entitled *Ben* (Shennan, 1980), published earlier on, is told from the perspective of a boy whose older brother, Ben, has DS. The narrating brother mentions the special education class that Ben attends, leaving the reader feeling little hope that he will learn anything significant. The text says, “Because he is a mongol, Ben goes to a special

school where the teachers understand how to teach children who can only learn slowly” (Shennan, 1980, unpaginated). In the book *Special Kids Make Special Friends* (Shalom, 1984), readers discover how children with DS learn in a special preschool setting. Even though early intervention is critical for these special students, most current preschool sites include some typically-developing children in the classes as role models, contrary to what is depicted in this book. In *Jon O: A Special Boy* (Ominsky, 1977), quite a dated book, Jon, the boy with DS, is integrated into a regular classroom, an idea quite revolutionary at the time. However, the expectations that surround Jon’s potential are extremely low. In fact, the text states:

But when all the other children learned their colors, Jon O could not remember which color was red and which color was blue. When all the other children had learned their numbers, Jon O still had a hard time counting from one to ten. (unpaginated)

In contrast to these earlier educational depictions of children with DS, three outstanding books come to the forefront. In *We’ll Paint the Octopus Red* (Stuve-Bodeen, 1998), six-year-old Emma and her dad come to the conclusion that the new baby, Isaac, would be able to do most everything they had planned; he would just need more time and patience. Written from Emma’s perspective, the text says, “By the time we were done talking, we couldn’t find one of those million things that Isaac wouldn’t be able to do with me” (Stuve-Bodeen, 1998, unpaginated). In like fashion, children with DS are photographed displaying objects that correspond to each letter of the alphabet in *ABC for You and Me* (Girnis & Green, 2000). The idea that children with DS can and will learn is implied. *Dustin’s BIG School Day* (Carter, 1999) is an outstanding, realistic example of inclusive education, as it shares both Dustin’s ability to capably function with his typically-developing peers, and his need for special help in some areas such as speech, fine motor skills, and the subjects of language arts and math.

Stereotypical assumptions are also falling by the wayside. People with DS are now seen as capable of conducting more independent, satisfying lives instead of needing constant care. Bainbridge and Pantaleo (1999) write, “Stereotypical . . . images have existed in literature since books were first written, and can be found in many texts” (p. 113). In the story *Ben* (Shennan, 1980), which is narrated by Ben’s younger brother, the text says, “Ben is learning to help himself but he will always need someone to look after him” (unpaginated). After finishing the book, the reader gets the sense that Ben, a boy with DS, will never achieve any sort of independence. In similar fashion, Jon O, the boy with DS who appears in *Jon O: A Special Boy* (Ominsky, 1977), is depicted as one to be pitied. “When he was born the doctor told his Mommy and Daddy that Jon O would never be like other children” (Ominsky, 1977, unpaginated). When Jon O’s classmates ask why he is different, “[t]he teacher tells them, ‘Jon O has a special problem. He will not grow the way most children do. He will not be able to learn the way most children do. He is retarded’” (Ominsky, 1977, unpaginated). Throughout the book, Jon O rarely smiles or exhibits any excitement; rather, he seems to struggle with everything. In fact, the text actually states, “Jon O never forgets he is different. Sometimes he is unhappy because he cannot do all the things that people want him to do” (Ominsky, 1977, unpaginated). On the other hand, some of the more current titles display a much more positive outlook for children with DS. In the book *ABC for You and Me* (Girnis & Green, 2000), all of the children with DS are depicted as capable of playing, engaging, interacting, and learning. In *We’ll Paint the Octopus Red* (Stuve-Bodeen, 1998), the reader is left with the understanding that children with DS are able to do most everything that other children can; they just require more time and help to do so. Dustin, a second-grader with DS in *Dustin’s BIG School Day* (Carter, 1999) is shown as a very capable boy. He rides the yellow bus to school, is integrated into a regular classroom with extra help in

areas of need, has a couple of close friends, anticipates special school events, and displays an overall sense of satisfaction with who he is.

Even though much has changed in a very short window of time, there are also a couple of common threads that weave their way through a number of these picture books, regardless of the publishing date.

Common Threads Connecting these Picture Books

Through the years, many authors, and others associated with the creation of the fifteen picture books, were personally connected to children with DS, either through family, friends, or their profession. Cairo, the author of *Our Brother has Down's Syndrome: An Introduction for Children* (1985), is the mother of the two sisters who narrate the story and the little boy who has DS. Likewise, Rickert, the author of *Russ and the Apple Tree Surprise* (1999), is the mother of Russ, the boy who has DS. The photographer involved in *ABC for You and Me* (2000), Shirley Leamon Green, dedicates her work in memory of her sister-in-law who had DS. Rabe wrote the book *Where's Chimpy?* (1988) based on her neighbor and his daughter Misty, who has DS. In the information given about the author at the end of the book, Rabe told her editor:

I must do a story about Misty and her daddy—a story other children with Down syndrome can identify with. I want her to have the lead role, not the secondary role usually allocated to children with this handicap. I want Misty to be the *star*. Every child has the right to be a star sometimes!

Shennan, who wrote *Ben* (1980), is the Publications Director of The National Society for Mentally Handicapped Children and Adults. Also connected by profession, Shalom, the author of *Special Kids Make Special Friends* (1984), works at the preschool for children with DS shown in the photographs contained in the book.

Another common element in a number of the picture books, whether they are older or more current, is an explanation of Down syndrome. These explanations take a variety of forms, from paragraphs written for adult readers to questions and answers written for children. *Ben* (Shennan, 1980) explains that DS is one cause of mental handicaps, as depicted by the character Ben in the story. A brief explanation of DS, written by the Executive Director of the National Down Syndrome Congress, is included at the beginning of *Where's Chimpy?* (Rabe, 1988). The President of the National Down Syndrome Congress wrote a brief description of DS included at the end of *Charlsie's Chuckle* (Berkus, 1992). *We'll Paint the Octopus Red* (Stuve-Bodeen, 1998) contains a wonderful collection of thoughtful questions and answers about DS at the end of the story, written in simple language for children.

An Evaluation of these Picture Books

Besides discovering both great change and some similarity in the picture books containing characters with DS over twenty years, the fifteen titles seem to fall quite neatly into four categories, each group having a common purpose. Interestingly, the books within each group have publishing dates close in range!

The first grouping is written in order to provide readers with information about DS. In a sense, these four texts are almost expository in nature. *Jon O: A Special Boy* (Ominsky, 1977) shares the childhood story of Jon O, discussing his delay in developmental milestones, school and learning issues, social concerns, and family relationships. The story *Ben* (Shennan, 1980) is written from the perspective of a younger brother. Readers learn about the sibling's feelings of responsibility, Ben's special school setting, and social issues. In *Special Kids Make Special Friends* (Shalom, 1984), readers discover how children with DS learn in a special preschool setting. The final book in this grouping, *Our Brother Has Down's Syndrome: An Introduction*

for Children (Cairo, 1985), is also written from a sibling's perspective. Two sisters explain what it is like to have a younger brother with DS. "Mostly Jai is like every other brother or sister in the world. Sometimes he's fun and sometimes he's not, but no matter what, we love him very much" (Cairo, 1985, unpaginated). The two sisters go on to say, "[T]here are many things we can do to help people with Down's Syndrome. We help Jai mostly by playing with him and talking to him a lot and giving him lots of love" (Cairo, 1985, unpaginated). As the text continues, the two sisters discuss the many similarities that their brother has to other people, yet recognize that it takes him a while longer to meet some of the developmental milestones such as walking, climbing stairs, talking, and using his hands. In summary, the sisters write, "Jai may be a little different (we *all* have different things about us), but mostly he's just like the rest of us" (Cairo, 1985, unpaginated). From the collection of fifteen books I could find, this group of four was published the earliest, from 1977 to 1985. I do not recommend any of these titles for use with students because they are dated, they use derogatory and obsolete language, and there is little sense of story.

The second group of books are stories that contain either major or minor characters with DS. All of the titles use illustrations as opposed to photographs, with the exception of one. This second group includes *Charlsie's Chuckle* (Berkus, 1992), *Harvest Window* (Sallows, 1992), *Be Good to Eddie Lee* (Fleming, 1993), *How Smudge Came* (Gregory, 1995), *The Hangashore* (Butler, 1998), and *We'll Paint the Octopus Red* (Stuve-Bodeen, 1998). Even though these narratives are more complex than books from the other groups, the quality of story within this group varies greatly. The most outstanding selections are *Be Good to Eddie Lee* (Fleming, 1993), *How Smudge Came* (Gregory, 1995), and *The Hangashore* (Butler, 1998), all eliciting emotion from readers. In the selection *Be Good to Eddie Lee* (Fleming, 1993), Eddie Lee, a boy with DS,

follows his neighbours Christy and JimBud into the woods, wanting to be included in their explorations. Even after being rejected a number of times, Eddie Lee persists in sharing his amazing discoveries in the woods with Christy. As a reader, one cannot help but be upset by the way that Eddie Lee is initially regarded and treated by his two peers. Early on in the text, while Fleming (1993) reveals the story's setting, the character Christy shares her thoughts about Eddie Lee—"Her mama said God made him that way. But Christy thought maybe, just once, her mama was wrong, because God didn't make mistakes, and Eddie Lee was a mistake if there ever was one" (unpaginated). As the story unfolds, and Eddie Lee attempts to join in Christy and JimBud's explorations, JimBud tells Christy, "'Come on. Don't stop to talk to that dummy'" (Fleming, 1993, unpaginated). This title conjures up the feelings of rejection and ridicule that most children experience at some point in their lives, whether they have special needs or not.

How Smudge Came (1995), written by Gregory, illustrated by award-winning Lightburn, and edited by Tim Wynne-Jones, is a moving account of how an adult with DS named Cindy must give up the puppy she desperately wants to keep all because of the rules of the group home where she resides. As Cindy attempts to explain to the people who run the group home how she will be able to take care of the puppy, "they drown her with their words. She tries to tune out. 'SPCA,' she hears. 'Good home.' She will not weep, but tears squeeze by. She starts to hum. 'GO TO YOUR ROOM, CINDY'" (Gregory, 1995, unpaginated). This simple story creates a very aesthetic experience for its readers and allows a myriad of connections between reader and text. *The Hangashore* (Butler, 1998) is an outstanding Canadian book set at the end of World War Two on a small Newfoundland island. John Payne, a sixteen-year-old minister's son who has DS, is an accepted part of the fishing village where he resides with his family. However,

when Magistrate Mercer arrives to represent the government of England, John's honest opinions clash with the magistrate's pride, causing the magistrate to make the following threat:

“That boy should be in an institution, perhaps at the Mental Hospital up in St. John's. I intend to see about it on my next trip. It's too bad when a God-fearing person can't go to church without being harassed by some half-wit.” (Butler, 1998, unpaginated)

This book, appropriate for upper elementary and junior high students, allows readers to connect with the story in both an aesthetic and efferent way, as the historical period and the eastern coast dialect revealed by the language used in the text is relevant to the story. Appendix A lists the other titles mentioned in this group. Even though they are not as powerfully written, they certainly could be used with children. The publishing dates of this group range from 1992 to 1998.

The third group includes four books that relay childhood experiences common to both children with DS and their typically-developing peers. Nowhere in these texts are the characters identified as having DS; rather, this fact is shared with readers through the photographs used in each of the books. *Where's Chimpy?* (Rabe, 1988) tells the story of Misty and her father who relive the activities of the day in order to find Misty's lost stuffed monkey, Chimpy. In the book *Big Brother Dustin* (Carter, 1997), the boy with DS, Dustin, helps his parents and grandparents excitedly prepare for the arrival of a baby girl. “Dustin helped set up the crib he'd used when he was a baby,” “helped his mom get out the baby clothes and blankets,” “put a mobile over the crib so the baby would have something to watch,” attended “a class at the hospital to learn how to be a big brother,” and chose the perfect name for her (Carter, 1997, unpaginated). This same boy also stars in *Dustin's BIG School Day* (Carter, 1999), where he is shown in an inclusive educational setting eagerly awaiting the arrival of two special visitors, a ventriloquist named

Dave and his puppet Skippy, to the school. Because of the special event, “[e]veryone wanted to talk about Dave and Skippy” (Carter, 1999, unpaginated), including Dustin. *Russ and the Apple Tree Surprise* (Rickert, 1999) features a day in the life of Russ, a five-year-old boy with DS. In the story, he helps pick apples from the tree in his backyard, bakes a pie with his mom and grandmother, and receives a swing that hangs from the apple tree’s branches from his grandfather. At the end of the simple text, Russ exclaims, “‘Daddy was right. Apple trees really are fun’” (Rickert, 1999, unpaginated)! As much as I understand the need for children with DS to participate in “normal” life experiences, and typically-developing children to recognize what they have in common with special children, I do have one concern. This group of books does not address the challenges that children with DS and their families face throughout the course of each day. Bainbridge and Pantaleo (1999) write, “Many ... books purporting to be multicultural have been criticized as ‘melting-pot books’. Such books treat all people the same, focussing on similarities rather than differences” (p. 113). So long as educators are aware of this concern, using picture books that focus on the “common experience” does have its place. This group of books is more current in publication (1997 to 1999), although one dates back to 1988.

The most recent publication stands in a category of its’ own—a delightful alphabet book entitled *ABC for You and Me* (Girniss & Green, 2000). “[M]ost alphabet books are intended to entertain and introduce new vocabulary and concepts. The alphabet is often used as a categorization scheme or as an organizational structure to present concepts and/or information” (Bainbridge & Pantaleo, 1999, p. 27). Through the use of wonderful photographs, children with DS display familiar objects that correspond to each letter of the alphabet. For example, Girniss and Green (2000) use a ball for the letter *b*, a kite for the letter *k*, a mirror for the letter *m*, sand

for the letter *s*, and a xylophone for the letter *x* (unpaginated). The message is clear—children with DS are capable of playing, interacting, and learning!

Suggestions for Use in the Educational Setting

Picture books containing characters with DS can be used in the educational setting in a number of ways. Rohner and Rosberg (2003) give the following suggestions:

Through contemporary fiction starring characters with special needs, educators can help students develop self-awareness and empathy, and also show special-needs children that they are not alone. Children with disabilities who encounter protagonists with special needs may also for the first time discover characters with whom they can relate. (p. 40)

Kitterman (2002) adds, “Children’s books are a valuable source for teachers to bring topics before their students, begin discussions that promote the acceptance of special needs learners, and teach children about the differences that individuals bring to learning situations” (p. 236). Overall, consideration must be given to the purpose for which these books are being used, the make-up of the student body within a classroom and/or an entire school population, and the age of the target audience.

One purpose for these books is to increase children’s awareness of and knowledge about DS. Unless people have someone with DS in their immediate circle of family or friends, chances are they will know little about this chromosomal anomaly and its implications. Likewise, children’s awareness of and knowledge about these special people will also be limited unless their personal experiences afford them the opportunity. To serve this purpose, picture books containing a character with DS may be available from the classroom or school library for general student use. At their leisure, students could peruse these books, learning about the similarities and differences between children with DS and their typically-developing peers.

Through reading, students would realize that children with DS have many of the same experiences they themselves do. Recommended titles include: *Big Brother Dustin* (Carter, 1997), which tells the story of a boy who helps his parents and grandparents excitedly prepare for the arrival of a new baby in the family; *Dustin's BIG School Day* (Carter, 1999), starring Dustin, a second-grader in an inclusive educational setting, who eagerly awaits the arrival of two special visitors to his school; *Russ and the Apple Tree Surprise* (Rickert, 1999), a story about five-year-old Russ who receives a surprise from his grandfather after picking a basket of apples and helping his mom and grandmother bake a pie; and *Where's Chimpy?* (Rabe, 1988), a story about a little girl and her dad who revisit the day's activities in the search for her missing stuffed monkey, Chimpy.

A number of books use photographs of children with DS, which allow students to actually see the physical differences without forming incorrect pictures in their imaginations. Recommended titles of books with up-to-date color photographs include: *ABC for You and Me* (Girnis & Green, 2000), an alphabet book containing wonderful pictures and a simple word for each letter of the alphabet; *Big Brother Dustin* (Carter, 1997) and *Dustin's BIG School Day* (Carter, 1999), both starring Dustin as the main character; *Russ and the Apple Tree Surprise* (Rickert, 1999), featuring a day in the life of five-year-old Russ; and *Where's Chimpy?* (Rabe, 1988), starring Misty, a little girl with DS.

Some titles help to build understanding of the challenges that children with DS may face. In *The Hangashore* (Butler, 1998), John Payne, a sixteen-year-old teenager with DS, is misunderstood because he voices his honest opinions about the small community's new magistrate, who threatens to put John in an institution. Another title dealing with acceptance and social issues is *Be Good to Eddie Lee* (Fleming, 1993). An upper-elementary-aged boy with DS,

Eddie Lee, struggles to find a way to be included in the activities of two of his peers, who see him as a nuisance. A third title dealing with social concerns is *Harvest Window* (Sallows, 1992). In this story, Carissa, a girl with DS, is a minor character who gets lost in her quest to go see the outstanding window display created by the main characters, Jordan and Warren. She finally arrives crying at the store where the two boys work, but is intent on developing a friendship with them. Carissa openly shares her honest feelings with Jordan, saying, ““Having Down’s is hard, because sometimes it makes you think that nobody wants to be your friend. It’s hard being different”” (Sallows, 1992, p. 43). *How Smudge Came* (Gregory, 1995) is a powerful story depicting the struggle between independence and having to follow the rules. In this book, Cindy, an adult with DS, must face giving up the puppy she desperately wants to keep because of the rules of the group home, where she lives somewhat independently. It is the challenge of living in a group home during adulthood that may be a new concept for many students. A book appropriate for younger readers is *We’ll Paint the Octopus Red* (Stuve-Bodeen, 1998). In it, six-year-old Emma and her father discuss what she will be able to do with her new baby brother Isaac, subsequently adjusting their expectations to accommodate the diagnosis of DS. They come to recognize that Isaac will most likely be able to do all they had planned, but would need more time and patience.

A second purpose for using books containing a character with DS arises when students have a sibling with this genetic condition. Much healing and empowerment can occur when readers identify with a character or situation that mirrors their own lives. It is difficult to predict how a particular story may impact a student, as “[r]eading is a transaction, a two-way process, involving a reader and a text at a particular time under particular circumstances” (Rosenblatt, 1982, p. 268). However, the following titles may be suggested on an individual basis, chosen

because they are either emotionally powerful or from the perspective of a sibling, allowing more possibilities for connections. Upper elementary students with a special sibling who is school-aged or older may be able to identify with the friendship issues and social concerns presented in *The Hangashore* (Butler, 1998), *Be Good to Eddie Lee* (Fleming, 1993), *How Smudge Came* (Gregory, 1995), and *Harvest Window* (Sallows, 1992). Lower elementary students with a special sibling who is younger than they are may be able to connect with the ideas in *We'll Paint the Octopus Red* (Stuve-Bodeen, 1998) and *Our Brother has Down's Syndrome: An Introduction for Children* (Cairo, 1985), as both stories are told from the perspective of siblings. However, the latter title needs to be used with caution as the terms "handicapped" and "retarded" are used in the text. On the other hand, these terms we generally view as derogatory and obsolete may still be used in some contexts today.

A third 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. Bainbridge and Pantaleo (1999) warn that "multicultural literature should not be used in a classroom simply because children from a particular cultural or ethnic group are present in that classroom. This is a form of discrimination because it singles out those individuals and categorizes them as representatives of a larger group" (p. 118). However, with consent of the child and family beforehand, and sensitive discussion accompanying reading, some books may be very useful in creating understanding and acceptance of children with DS. In fact, I, as a parent of a child with DS, would welcome the opportunity to be involved in presentations concerning DS, as it may dispel some of the uncertainty and misinformation concerning my child. Depending on the age and previous experience of the students who are learning about

children with DS, various titles may be used. Younger students may benefit from *We'll Paint the Octopus Red* (Stuve-Bodeen, 1998), which portrays children with DS as able to do most things others do, but needing a bit more time and help. Books that depict children's common experiences include: *Big Brother Dustin* (Carter, 1997), which focuses on preparing for a new baby in the family; *Russ and the Apple Tree Surprise* (Rickert, 1999), a story about picking apples, baking pies, and having a tree swing in the backyard; and *Where's Chimpy?* (Rabe, 1988), which discusses finding lost toys. *Dustin's BIG School Day* (Carter, 1999) would be another excellent choice, allowing discussion of both the similarities and differences between the schooling of a child with DS and a typically-developing child. Upper elementary students would benefit from more complex stories, where they can connect in a variety of ways depending on their individual perspective. Recommended titles include: *The Hangashore* (Butler, 1998), a Canadian book that focuses on social concerns for people with DS; *Be Good to Eddie Lee* (Fleming, 1993), a story also concerned with social issues; *Harvest Window* (Sallows, 1992), a third title with the same theme of friendship and acceptance arising; and *How Smudge Came* (Gregory, 1995), dealing with a group home situation.

A fourth purpose arises when a child with DS is part of a class or school community—the special child may appreciate seeing other children with similar challenges represented in literature. All readers feel understood when they encounter characters representative of themselves or situations similar to their own; children with DS are no different. Being able to identify with a situation and feeling part of a group is necessary for all individuals. Once again, it is difficult to make general book recommendations, as the interaction between reader and text at a particular time in a particular context is so unique. What can be suggested are titles based on the general age and developmental issues of the reader. The titles suggested for particular age

groups in the preceding paragraph would be the same recommendations made for children with DS. Added to this list would be *ABC for You and Me* (Girnis & Green, 2000), an outstanding alphabet book appropriate for preschool and early elementary-aged students.

One final purpose for using children's picture books containing a character with DS occurs during Down Syndrome Awareness Week, usually in early November. Whether or not any children with DS are part of the school population, some individual teachers or entire schools may choose to make their students aware of a variety of groups during the course of the year.

Multicultural literature should be selected on the grounds that all children have a responsibility to learn about a wide range of cultural and social groups; it should be part of the program of studies in every classroom, regardless of the social and cultural composition of each individual room. (Bainbridge & Pantaleo, 1999, pp. 118-119)

Depending on the age and experience of the students learning about DS, Appendix A may provide some guidance for suggested book titles. In addition, the Canadian Down Syndrome Society (CDSS) is a helpful organization that provides information and resources.

Most importantly, the advice given by Bainbridge and Pantaleo (1999) should be heeded when educators are choosing children's literature to use with students:

Any book chosen for inclusion in a program of study should be used because it is a good book and not because it is a book about a certain cultural, social, or ethnic group.

Problems arise when a book is selected because it is about a certain physical disability, for example, and due regard is not paid to other aspects of the book. ... Teachers need to look at all books critically and ensure that they include only good books in their programs. (p. 113)

Conclusion

Carol Johnson, who is an author, international speaker, consultant with Chaos Consultation of Calgary, and member of the Canadian Down Syndrome Society Professional Resource Council, shared the following bit of information at a conference I recently attended (November 7, 2003 in Edmonton, Alberta)—only fifteen years ago, a teenager with Down syndrome was placed in an inclusive educational setting under court order, all because he and his family felt this would be the most beneficial situation for him!

Since the mid 1980s, there have been incredible changes in how children with Down syndrome are educated. Parent advocates have brought about shifts in societal thinking that now give their children more options; an integral one being inclusion in the regular school. (Prep Program, 1999, p. 98)

Nowadays, the acceptance of children with DS in the regular classroom is much more common.

In similar fashion, children's picture books that include a character with DS have developed and changed significantly over the same brief period of time. There are more titles available than ever before, stereotypical ideas and assumptions are slowly vanishing, quality stories are emerging, and the variety of purposes for which these books are written has increased.

My daughter's birth provided the impetus for my investigation into picture books containing a character with DS. As a result of my study, I have discovered a number of excellent picture books to use in order to continue promoting Rachel's literacy development, which, in turn, may allow her to experience greater success within an inclusive educational setting. As Rachel gets older, some of these picture books may also provide the opportunity for her to feel understood because she may personally identify with the characters and their issues. In addition,

a number of the more current titles provide an avenue for increasing awareness of and fostering understanding for children with DS within both the educational setting and our broader society.

The notion that people with DS are a valued part of our society continues to move forward. This population is more visible in our current society (as opposed to institutionalized) and is allowed increasing opportunities to participate in the many facets of life, resulting in changing perceptions of people with DS within the general populace.

When Chris Burke was born with Down syndrome, doctors advised his parents Frank and Marian Burke to put their newborn son in an institution. The Burkes ignored the advice, and treated Chris the same as their other children. That decision which was made more than 33 years ago led to a remarkably talented life. Chris is best known for his role as Corky Thatcher on the ABC-TV series “Life Goes On” which earned him a Golden Globe nomination. Most recently Chris can be seen as Taylor on the CBS-TV series “Touched by an Angel”. (Chris Burke website)

In addition, Chris has published his autobiography, filmed a public service announcement with President Bush, marched in President Clinton’s inaugural parade, received numerous awards, and had a New York City public school named in his honor. Marian Burke (1995), mother of actor Chris Burke, states:

I truly believe we must accept our children as they are presented to us, then work hard on all facets of their education—at home, in the community, and at school—so they can be independent. We do this for our other children, why not for our children who happen to have Down syndrome? (p. 20)

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Appendix A –An Annotated Bibliography of Picture Books Containing a Character with Down Syndrome

Berkus, C. W. (1992). *Charlsie's chuckle*. Rockville, MD: Woodbine House.

Charlsie, a young boy with Down syndrome, stars in this story about a group of town council members who stop arguing, because of Charlsie's contagious chuckle, in order to solve some serious community problems. The book contains both color and black-and-white photographs, the reason not apparent. Readers learn that Charlsie has Down syndrome through both the photographs and the text. In addition, information about Down syndrome is provided at the end of the book. The message is somewhat didactic, suggesting that children with Down syndrome have a positive effect on others. This book may be most useful for middle elementary students, as there is more text and the layout is too busy for younger children. Overall, other books in this list may be a better choice.

Butler, G. (1998). *The hangashore*. Toronto, ON: Tundra Books.

John Payne, a sixteen-year-old minister's son who has Down syndrome, is an accepted part of the community on a small Newfoundland island. At the end of the Second World War, Magistrate Mercer arrives in this small fishing village to represent the government of England. On a number of occasions, John's honest opinions clash with the magistrate's pride, causing Magistrate Mercer to threaten to send John to live in an institution. Through an accident at sea, the magistrate gains an appreciation for John. The Newfoundland term "hangashore" (= a person who is too lazy or unreliable to fish in the sea; a person without the heart and courage to get on with life; an unlucky person

deserving pity) plays an interesting role as its definition is applied to the story in a myriad of ways. Language representative of speech in Newfoundland adds to the authenticity of this work. Geoff Butler is both the author and illustrator of this beautiful Canadian picture book that would be appropriate for upper elementary or junior high students. Highly recommended!

Cairo, S. (1985). *Our brother has Down's syndrome: An introduction for children*. Toronto, ON: Annick Press.

This book is written from the perspective of two girls who explain what it is like to have a younger brother with Down syndrome. Through text and photographs, they share aspects of life that are specific to children with Down syndrome, but focus on the commonalities between these special children and their typically-developing peers. Somewhat outdated photographs and obsolete terms such as “handicapped” and “retarded” do not make this book appealing, but the sibling perspective is interesting.

Carter, A. R. (1997). *Big brother Dustin*. Morton Grove, IL: Albert Whitman & Company.

This book is the first one written by Carter that stars Dustin, a boy with Down syndrome. Dustin helps his parents and grandparents excitedly prepare for the arrival of a baby girl, choosing the perfect name for her. The use of photographs allows readers to identify Dustin as having Down syndrome without stating so in the text. However, readers also understand that children with special needs have many life experiences in common with their peers, such as the expectancy of a new baby in the family. Highly recommended!

Carter, A. R. (1999). *Dustin's BIG school day*. Morton Grove, IL: Albert Whitman & Company.

Dustin, a boy with Down syndrome, reappears in a second book written by Carter. In this story, Dustin is a second-grader in an inclusive educational setting who awaits the arrival of two special visitors to his school. Once again, photographs are used to inform readers of Dustin's genetic condition rather than explaining it in the text. In addition, the story depicts Dustin's school day, portraying the similarities and differences in relation to his classmates. Highly recommended!

Fleming, V. (1993). *Be good to Eddie Lee*. New York, NY: Philomel Books.

Christy and JimBud consider Eddie Lee, a boy with Down syndrome, to be a nuisance. However, Christy's mother always told her to be good to Eddie Lee. One afternoon, Eddie Lee follows Christy and JimBud into the woods, wanting to be included in their explorations. After being rejected a number of times, Eddie Lee persists in sharing his amazing discoveries in the woods with Christy. Virginia Fleming's realistic portrayal of characters, together with Floyd Cooper's enticing illustrations, makes this picture book altogether wonderful. Highly recommended!

Girnis, M. & Green, S. L. (2000). *A B C for you and me*. Morton Grove, IL: Albert Whitman & Company.

This delightful alphabet book contains photographs of children with Down syndrome who display objects familiar to young children's lives that correspond to each letter of the alphabet. Each page is simply and effectively presented, including one letter in both

upper and lower case, the actual photograph, and the corresponding word printed in large font. Highly recommended!

Gregory, N. (1995). *How Smudge came*. Red Deer, AB: Red Deer Press.

This moving story is written by Nan Gregory, actually her first book, and illustrated by Ron Lightburn, who won the 1992 Governor General's Award for Children's Illustration for his artistry in *Waiting for the Whales!* Through simple text and beautiful illustrations, the story of Cindy, an adult with Down syndrome, is told. She finds a puppy that becomes known as Smudge, and desperately wants to keep it. However, the group home where she lives does not allow pets, so Cindy must give it up. The residents at the Hospice where Cindy works realize what Smudge means to Cindy, and attempt to reconnect the two. This Canadian book is emotionally powerful, causing the reader to truly identify with Cindy's feelings. Highly recommended!

Ominsky, E. (1977). *Jon O: A special boy*. Englewood Cliffs, NJ: Prentice-Hall.

Through black-and-white photographs, the story of Jon O's childhood is shared, discussing his delay in developmental milestones, school and learning issues, social concerns, and family relationships. Even though much of the information is accurate, such as Jon's frustration with himself concerning things he has difficulty doing and his unclear speech, the story is disjointed and the derogatory term "retarded" is used directly in the text. Readers may also end up with the stereotypical idea that children with Down syndrome do not have any strengths. In addition, the photographs are dated. Overall, this book is not recommended.

Rabe, B. (1988). *Where's Chimpy?* Niles, IL: Albert Whitman & Company.

Misty, a little girl with Down syndrome, and her dad revisit the day's activities in the search for Chimpy, Misty's missing stuffed monkey. Once again, photographs are used to inform the reader of Misty's genetic condition rather than having it stated outright in the text. Instead, an explanation of Down syndrome is given on a separate page before the story begins. Readers also learn that children with special needs have many of the same experiences as their same-age peers, for example, losing a stuffed friend. Highly recommended!

Rickert, J. E. (1999). *Russ and the apple tree surprise.* Bethesda, MD: Woodbine House.

This is the first book in a series for young readers, featuring a day in the life of Russ, a little boy with Down syndrome. After five-year-old Russ picks a basket of apples and helps his mom and grandmother bake a pie, his grandfather invites him into the backyard for a surprise. Photographs are used to depict the fact that Russ has Down syndrome. However, the story shares life experiences common to many children, whether or not they have a special need. The author, Janet Elizabeth Rickert, is the real-life mother of Russ. Highly recommended!

Sallows, R. (1992). *Harvest window.* Toronto, ON: Gage Educational Publishing Company.

After spending eighteen months in a wheelchair as a result of a car accident, Sallows created the *Jordan and Me* series of books. In this particular story, Jordan, a boy in a wheelchair, comes to terms with his own prejudices when he encounters Carissa, a girl with Down syndrome. Because of the significant amount of text, this illustrated book

would be appropriate for middle to upper elementary school students. This Canadian author writes from an interesting perspective that typically-developing children may identify with. The caution I have is the stereotypical idea that children with Down syndrome are desperate for friendship. This book could be used effectively, however, in the classroom, provided the teacher addressed this issue.

Shalom, D. B. (1984). *Special kids make special friends*. Bellmore, NY: Association for Children with Down's Syndrome.

In the introduction, the author shares the purpose of this book—to educate young children about the genetic condition. Through black-and-white photographs, readers discover how children with Down syndrome learn in a special preschool setting. Differences in learning are alluded to by recognizing special teachers, physical therapists, and speech therapists. On the other hand, common feelings that all children experience are also shared in hopes of building acceptance of all people. Because the photographs are somewhat dated and the derogatory term “retarded” is used, this book is not recommended.

Shennan, V. (1980). *Ben*. London, England: The Bodley Head.

This picture book is written from the perspective of a boy whose older brother, Ben, has Down syndrome. The text deals with the boy's feelings of responsibility for Ben, a special school setting, and social issues. However, the reader gets an overall sense that children with Down syndrome are people to put up with; there is a total lack of expectation that they will lead productive, independent lives. In addition, the obsolete

term “mongol” is used, and the assumption that children with Down syndrome are “happy” is stated outright. Overall, I do not recommend this book.

Stuve-Bodeen, S. (1998). *We'll paint the octopus red*. Bethesda, MD: Woodbine House.

Six-year-old Emma gets used to the idea of becoming an older sister after a discussion with her father about all of the things she will be able to do with the new baby. However, when her brother Isaac is born with Down syndrome, the discussion begins over again, with adjustments made to the expectations. A wonderful collection of questions and answers about Down syndrome is included at the back of the book. This book would be useful for children in the early elementary years, particularly for siblings of a child with Down syndrome.

Appendix B - Chronological Listing of Picture Books Containing a Character with Down Syndrome

Ominsky, E. (1977). *Jon O: A special boy*. Englewood Cliffs, NJ: Prentice-Hall.

Shennan, V. (1980). *Ben*. London, England: The Bodley Head.

Shalom, D. B. (1984). *Special kids make special friends*. Bellmore, NY: Association for Children with Down's Syndrome.

Cairo, S. (1985). *Our brother has Down's Syndrome: An introduction for children*. Toronto, ON: Annick Press.

Rabe, B. (1988). *Where's Chimpy?* Niles, IL: Albert Whitman & Company.

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Fleming, V. (1993). *Be good to Eddie Lee*. New York, NY: Philomel Books.

Gregory, N. (1995). *How Smudge came*. Red Deer, AB: Red Deer Press.

Carter, A. R. (1997). *Big brother Dustin*. Morton Grove, IL: Albert Whitman & Company.

Butler, G. (1998). *The hangashore*. Toronto, ON: Tundra Books.

Stuve-Bodeen, S. (1998). *We'll paint the octopus red*. Bethesda, MD: Woodbine House.

Carter, A. R. (1999). *Dustin's BIG school day*. Morton Grove, IL: Albert Whitman & Company.

Rickert, J. E. (1999). *Russ and the apple tree surprise*. Bethesda, MD: Woodbine House.

Girnis, M. & Green, S. L. (2000). *A B C for you and me*. Morton Grove, IL: Albert Whitman & Company.

Appendix C - Chronological Listing of Novels Containing a Character with Down Syndrome

Perske, R. (1984). *Show me no mercy: A compelling story of remarkable courage*. Nashville, TN: Abingdon Press.

Laird, E. (1988). *Loving Ben*. New York, NY: Delacorte Press.

Wood, J. R. (1992). *The man who loved clowns*. New York, NY: G. P. Putnam's Sons.

Dodds, B. (1993). *My sister Annie*. Honesdale, PA: Caroline House.

Fox, P. (1997). *Radiance descending*. New York, NY: DK Ink.

Mazer, H. (1998). *The wild kid*. New York, NY: Simon & Schuster Books for Young Readers.

Rottman, S. L. (1999). *Head above water*. Atlanta, GA: Peachtree Publishers.

Biographical Statement

Tracey Kalke-Klita recently completed her Master's degree in Elementary Education at the University of Alberta, with a focus on literacy. She is currently enjoying spending time with her two children—her four-year-old daughter who has Down syndrome, and her one-year-old son. Previous to being a mom, she taught upper elementary and junior high students for eleven years. Email: tkalke@telusplanet.net

Abstract

This article analyzes fifteen children's picture books published over the past twenty-five years that include a character with Down syndrome (DS). From the perspective of both an educator and a parent of a child with DS, this article focuses on the changes in these picture books over time, the common threads connecting these books, an evaluation of these titles, and suggestions for use in the educational setting. In addition, an annotated bibliography is provided.