

Mindful Portrayals: Using Fiction to Create Awareness, Understanding, and Support for People with Autism and Developmental Disabilities

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Abstract: Considering the arts model as a tool for promoting awareness, understanding, and support for people with autism and developmental disabilities, this paper discusses stories as a measure of societal thinking as well as a vehicle for societal change. The author's dual perspectives are shared as a researcher of books for children and young adults, as well as an award-winning writer of books for young people. Data from an ongoing qualitative study related to award-winning North American picture books for young people offer understandings of current patterns and trends regarding portrayals of characters who are differently abled, and this article has wide implications for teaching, learning and further research.

My interest in portraying characters with developmental disabilities, as well as my current academic research platform related to an exploration of characters in contemporary children's literature, was inspired by the children with whom I worked in regular and special education classrooms over a span of twenty years. My students' gifts and challenges did not typically appear in our classroom texts, prompting my reflections on the young heroes we encounter every day and the need for all students to see a range of lived lives reflected in society's artefacts.

Galda's (1998) metaphor of books as mirrors and windows, illuminating how reading allows us to see ourselves and others through the revealing yet comfortable distance of text, is a compelling lens through which to examine books portraying characters with disabilities. If the landscape of school and community reading material is to offer children and young adults authentic pictures of self and other, a variety of content and form in quality literature is needed. Our classroom and public library collections must go beyond what

have emerged as 'popular' aspects of difference—most notably, gender, social class, and ethnicity. Disability is the single category of difference that can present at any time during a person's life, eclipsing other differences with its very prevalence, yet it continues to be relatively uncommon in terms of fictional character traits.

Research on classic fiction that portrays characters with disabilities has identified previous patterns including the trend that authors often 'cure' or 'kill' these characters during the course of a story (Keith, 2001), a tendency that suggests authors have not been able to envision a positive future for someone with a disability. My previous research on contemporary children's novels (Brenna, 2011; Brenna, 2010a; Brenna, 2010b; Brenna, 2009; Brenna, 2008) illuminates new trends, including the lack of travel opportunities for characters with disabilities and the absence of minority sexual orientations and particular cultural backgrounds in characters that are 'differently abled.'

A recent study of award-winning North American picture books (Emmerson, Fu, Lendsay, & Brenna, 2013) foregrounds texts available to North American readers at a time when schools and communities are working towards social justice through a healthy respect for human differences in self and other. In addition to supporting school curriculum

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through suggestions for diverse classroom resources, a focus on messages about disability conveyed through children's books provides an intriguing avenue for further research. A key question underpinning the current discussion is: what do contemporary North American picture books tell readers about disability?

North American Children's Picture Books: Patterns and Trends

First of all, numbers of North American picture books published since 1995, portraying characters with disabilities, are comparatively small. This matches a statement by Jaeger and Bowman (2005) who say, "Disability is ordinary. Yet disability is rarely considered as a societal issue in a thoughtful and humane manner" (p. ix). If the landscape of picture books for children is to offer authentic selections as windows and mirrors, it is going to take some creative problem solving on the part of educators and parents, as well as some new work from writers. The following section provides a discussion of preliminary findings from a current study by Emmerson, Fu, Lendsay, and Brenna (2013) related to particular award categories for award-winning books published since 1995.

Canadian Governor General's Award for Children's Illustration

Only two of the sample of 18 Canadian Governor General's Award winners in the category for illustration represented characters with disabilities, and none of the disabilities included involve autism or developmental disabilities. The first, Cybele Young's (2011) *Ten Birds*, recounts an oblique view of physical disability through a story about how seemingly flightless birds manage to use various innovative strategies to cross a river, with perhaps the cleverest bird of all simply walking over the bridge. The second, Kyo Maclear's (2012) *Virginia Wolf*, appears to depict a character with childhood depression; however this diagnosis is relatively ambiguous within the context of the story.

Canadian Governor General's Award for Children's Text

Two picture book award winners portraying characters with disabilities appear in the category for text, out of the 18 winning titles. These include Paul Yee's (1996) *Ghost Train*, where the central character has a physical disability, as well as Rachna Gilmore's (2001) *A Screaming Kind of Day*—about a little girl who is hearing impaired, where her disability is simply one aspect of her characterization.

American Caldecott Medal

A scan of the 17 American picture book winners of the prestigious Caldecott medal for children's illustration has turned up even fewer examples of characters who are differently abled. Only one book published since 1995 has depicted a character with a disability, and it is P.O. Zelinsky's (1997) *Rapunzel*, a rendition of the fairy tale that includes a prince who is temporarily blind.

Schneider Family Book Award

Since 2004, a separate awards category has been utilized by the American Library Association in addition to the Caldecott award, and this new award—the Schneider Family Book Award—uses portrayal of disability as part of the award criteria. When Dr. Katherine Schneider was nine years old, she began borrowing books in Braille and longed to find more books about children who were blind or had other disabilities. Dr. Schneider and her family have since set up this award to encourage authors and illustrators to produce books that will express disability as an authentic part of the human experience. To date, the Schneider Awards have been given to eight titles, and included in this list are three picture books portraying characters who are blind or visually impaired, three picture books depicting characters who are deaf, and two picture books presenting characters with orthopedic disabilities. Again, none of the award winners include characters with autism or developmental disabilities.

Dolly Gray Literature Award

The Dolly Gray Literature Award was established in 2000 by members of the Division on Autism and Developmental Disabilities (DADD) of the Council for Exceptional Children (CEC) working with the Special Needs Project—a distributor of books related to disability issues. This award has served a very real need—to recognize, through a book award, authors, illustrators, and publishers of high-quality fictional and biographical children's, intermediate, and young adult books that authentically portray individuals with developmental disabilities. A list of winners can be found at: <http://daddcec.org/Awards/DollyGrayAwards.aspx>. This list includes the two picture books that tied for the award in 2012: Rebecca Elliot's *Just Because*, and Holly Robinson Peet and Ryan Elizabeth Peete's *My Brother Charlie*, illustrated by Shane W. Evans. Also in 2012, Kathryn Erskine's (2010) novel *Mockingbird* tied with *Waiting for No One*, one of my own published novels (Brenna, 2010c); both these two books deal with female protagonists who have Asperger's Syndrome.

Other Picture Books

Widening the search outside of the specific awards mentioned, one Canadian title appears that presents a character with Down syndrome: Nan Gregory's (1995) *How Smudge Came*. This picture book narrates the story of a young woman living in a group home who is prevented from having a puppy. How the hospice where Cindy works eventually adopts the dog is a satisfying ending to a heartbreaking tale that emphasizes a society where decisions are made for and about people without thorough consultation. Not only is this book unique in its treatment of Cindy and her gifts—it uses the picture book format to present a story geared for older children and adults, with a protagonist who is clearly not a child. Ron Lightburn's evocative illustrations carry messages beyond Gregory's words, and it is through his depiction of Cindy, not in the text itself, that her Down syndrome is evoked.

Another Canadian picture book worth noting is Sheree Fitch's *Pocket Rocks* (2004), illustrated by Helen Flook. While autism isn't mentioned, the character of young Ian sug-

gests traits of people with Asperger's Syndrome, including naivety, fine-motor difficulties, meltdowns, sensitivity to smells, a unique perspective on things, an unusual and perhaps obsessive interest in collecting rocks, supported stress breaks, and the need for assistance at school. The book is an uplifting tale about the power of stories, and emphasizes without didacticism the positive application of strategies for self-management.

A local investigation of books in two major Canadian bookstores has offered the following information. Out of the collection of 252 Canadian picture books sampled in one store, only one portrayed characters with disabilities, and, in the case of Epp's (2007) *Hope and the Dragon*, the storyline hinged on the character of a boy who uses his imagination to help himself deal with a chronic illness. No picture books portraying characters with disabilities were found in the second bookstore.

While there has been considerable research on gender and multicultural diversity with regard to classroom texts (Finazzo, 1997; Galda, 1998; Gilbert, 1997, 2001; Rueda, 1998), little treatment has been given to the characterization of ability (Keith, 2001), although there are select discussions of the treatment of particular disabilities within contemporary fiction (Dyches & Prater, 2000; Dyches, Prater, & Cramer, 2001; Greenwell, 2004; Kalke-Klita, 2005; Mills, 2002; Pajka-West, 2007). Picture book illustrations are illuminated as a particular lens for studying the inclusion of characters with disabilities in children's material (Matthew & Clow, 2007) and another avenue for study involves how books about characters with disabilities may be evaluated and used with children (Dyches & Prater, 2000; Landrum, 2001; Smith-D'Arezzo, 2003).

Picture Books in a Wider Context of Fiction for Children

Dyches and Prater's (2005) content analysis of thirty-four children's fiction books published between 1999 and 2003 identified that the sample depicted characters with developmental disabilities as having either autism spectrum disorder or intellectual disability, within a rich and dynamic profile. Although significant of a positive trend in characterization compared with their 2001 study, because of

the dynamic nature of newer portrayals, these researchers do suggest aspects worth consideration including the fact that the majority of characters presented were male. Another recent study examining graphic novels indicated that within the graphic novel form, people with disabilities are represented, however these portrayals most frequently fit a negative and stereotypical image (Irwin & Moeler, 2010).

A previous study related to novels for children and young adults (Brenna, 2010a) provides some interesting comparisons to the results of the current North American picture book study. Of the fifty Canadian novels in the study sample, there were characters represented with autism, intellectual disability, Down syndrome, and Fetal Alcohol Spectrum Disorder (FASD), within a group of texts that included portrayals of characters with other disabilities. The inclusion of developmental disabilities in this study sample of novels contrasts with the lack of characters with these particular challenges in picture books. It appears as if particular disabilities are considered more ‘appropriate’ for inclusion in children’s picture books than other disabilities, just as polio and blindness were common disabilities included in classic texts (Keith, 2001), and this hierarchical treatment of ability is a finding worth further consideration by contemporary researchers, disability rights activists, and educators.

Comparisons between characters with autism and characters with FASD in another previous study (Barker, Kulyk, Knorr, & Brenna, 2011) demonstrated that North American novels for young people seem to present autism much more avidly than FASD, and, in fact, the single title dealing directly with FASD—*The Moon Children*—was one of my own books (Brenna, 2007). Certainly more investigation of the lack of representation of characters with FASD is warranted, especially when considering that incidences of autism and FASD are similar in number.

Writing Characters Who Are Differentlyabled

As a classroom and special education teacher working with populations of children with FASD, I began to notice how few community

resources were available to elicit discussions of this condition outside the traditional medical model. The children I worked with were complex and different from each other, and yet had challenges similar to those faced by other children—challenges related to acceptance and support of their unique profiles—in addition to the negative stigma associated with their biological mothers. The medical model didn’t seem to be affecting prevention or further support in the context within which I was working, nor did it assist with positive parental engagement, and I wondered whether a model based on the arts could help. What if a travelling gallery containing artistic representations of FASD could visit communities to elicit discussion and deepen understanding of children and their parents? In addition to assisting with additional support for the population of people with FASD and their families, could such a gallery—Faces of FASD, I thought it could be called—affect prevention? Not an artist myself, this idea, provocative as it was to me, slowly faded.

What replaced the idea of a traveling gallery was the notion of a children’s novel—accessible to adult readers as well—featuring FASD and including a non-negative depiction of a biological mother whose son was affected by prenatal alcohol consumption. It took some research, and a lot of time, but when I finished the manuscript that would become my novel *The Moon Children*, I hoped it would be a good story and, in addition, I hoped it might exemplify how people might become more mindful of FASD-related issues through response to literature.

Billy is a ten-year-old boy with gifts as a storyteller and an open loving heart. Because he can’t read, he doesn’t easily access what to others is simple communication, and this makes for challenging experiences that make him angry at the way he is. While the plot of the story involves a developing friendship between Billy and a girl with selective mutism, including for Billy the importance of winning a talent show in hopes his father might return to the family, the book is also about Billy’s special needs and the relationship he has with his mom. A few readers have suggested to me that the story’s close was less than satisfying—that Billy deserved a happier ending, although the ending as it stands is not exactly unhappy.

The reason this isn't a 'happily ever after' book is that for kids like Billy, happy futures are going to take more than what we are currently offering in our communities to people with FASD. I hope that readers of this book will begin to think more deeply about what kind of supports Billy and his parents need in order to stretch into a happy future, as well as what kind of human heartaches prenatal alcohol consumption causes.

In addition to *The Moon Children*, I have written a number of other books spotlighting characters who are differently abled. *Something to Hang On To* is a collection of a dozen short stories for teens, and includes stories about characters who have Down Syndrome, pervasive developmental disorder, and cerebral palsy in addition to a cameo of the character of Taylor Jane, a teenager with Asperger's Syndrome who appears as the protagonist in my trilogy of young adult novels: *Wild Orchid*, *Waiting for No One* (winner of a 2012 Dolly Gray Award), and *The White Bicycle* (winner of a 2013 Printz Honour Award). The series about Taylor Jane took considerable research, as I wanted to make sure I achieved as authentic a voice as I could without actually understanding autism first-hand. I was lucky enough to attend a lecture by Dr. Tony Attwood where an introduction to the positive characteristics of Asperger's Syndrome made coherent the argument that Asperger's is a different, not defective, way of experiencing the world. Trying to see the world through Taylor's eyes taught me a great deal, and I am grateful for the perspective that working with her fictional characterization provided to me as an educator, a researcher, and a writer.

One of the decisions I made in the books about Taylor Jane was to concentrate on filling a gap in literature regarding characters who are differently abled in that these characters don't often travel. In my trilogy, Taylor spends time at Waskesiu—Saskatchewan's national park—then Cody, Wyoming, and then Lourmarin, France. The latter setting was achieved in part due to financial support from a Canada Council grant that allowed me research funding in order to capture the setting with as much real detail as possible. A conceptualization of gaps on the contemporary landscape of books for children is important to authors as we attempt to produce original

work that affects social justice. There is still more work to be done—in research as well as authorship—if we are to create a world in fiction that truly represents the world we have at hand.

Changing the World

In addition to representing the world and its contents, I believe that stories can change the world. By offering mirrors and windows to readers, stories build understandings of self and other critical to positive renderings of identity and community. As an educator, I think that the stories we offer to children in our homes and classrooms matter. As a researcher, I think there is important work yet to be done in cataloguing the messages children receive from contemporary texts portraying characters with different abilities, as well as noticing voices yet unheard on the textual landscape. As a writer, I know that my stories have changed me—have changed how I think about the navigation of disabilities from a personal standpoint as I attempted to create characters from the inside out. I predict that as more people who are differently abled are supported in telling their own stories, and as these authentic autobiographies follow biographies into supporting fictive works, we can improve the possibility of authentic mirrors and informative windows offered in children's reading—helping our leaders of tomorrow see and actualize the world in a more complete way.

References

- Barker, C., Kulyk, J., Knorr, L., & Brenna, B. (2011). Open inclusion or shameful secret: A comparison of characters with Fetal Alcohol Spectrum Disorders (FASD) and characters with Autism Spectrum Disorders (ASD) in a North American sample of books for children and young adults. *International Journal of Special Education, 26*, 171–180.
- Brenna, B. (2007). *The Moon Children*. Calgary, AB: Red Deer Press.
- Brenna, B. (2008). Breaking stereotypes with children's fiction: Seeking protagonists with special needs. *International Journal of Special Education, 23*, 100–103.
- Brenna, B. (2009). Creating characters with diversity in mind: Two Canadian authors discuss social

- constructs of disability in literature for children. *Language & Literacy*, 11, retrieved on July 17, 2013 from <http://ejournals.library.ualberta.ca/index.php/langandlit/article/view/9748>
- Brenna, B. (2010a). *Characters with disabilities in contemporary children's novels: Portraits of three authors in a frame of Canadian texts*. Unpublished doctoral dissertation, University of Alberta, Edmonton. <http://hdl.handle.net/10048/1110>
- Brenna, B. (2010b). Assisting young readers in the interpretation of a character with disabilities in Iain Lawrence's juvenile fiction novel "Gemini Summer". *English Quarterly*, 41, 54–61.
- Brenna, B. (2010c). *Waiting for No One*. Markham, ON: Red Deer/Fitzhenry & Whiteside.
- Brenna, B. (2011). Characters with disabilities in contemporary novels for children: A portrait of three authors in a framework of Canadian texts. *Language and Literacy*, 13, retrieved on July 13, 2013 from <http://ejournals.library.ualberta.ca/index.php/langandlit/article/view/9781/7981>
- Dyches, T. T., & Prater, M. A. (2000). *Developmental disability in children's literature: Issues and annotated bibliography*. Reston, VA: Council for Exceptional Children, Division on Mental Retardation and Developmental Disabilities.
- Dyches, T. T., & Prater, M. A. (2005). Characterization of developmental disability in children's fiction. *Education & Training in Developmental Disabilities*, 40, 202–216.
- Dyches, T. T., Prater, M. A., & Cramer, S. F. (2001). Characterization of mental retardation and autism in children's books. *Education and Training in Mental Retardation and Developmental Disabilities*, 36, 230–243.
- Emmerson, J., Fu, Q., Lendsay, A., & Brenna, B. (2013). *Picture book characters with disabilities: Patterns and trends in a context of radical change*. Unpublished manuscript, College of Education, University of Saskatchewan, Saskatoon, Saskatchewan, Canada.
- Erskine, K. (2010). *Mockingbird*. New York: Puffin.
- Finazzo, D. A. (1997). *All for the children: Multicultural essentials of literature*. New York: Delmar Publishers.
- Galda, L. (1998). Mirrors and windows: Reading as transformation. In T. E. Raphael & K. H. Au (Eds.), *Literature-based instruction: Reshaping the curriculum* (pp. 1–11). Norwood, MA: Christopher-Gordon.
- Gilbert, P. (1997). Discourses on gender and literacy: Changing the stories. In S. Muspratt, A. Luke & P. Freebody (Eds.), *Constructing critical literacies: Teaching and learning textual practice* (pp. 59–76). Cresskill, NJ: Hampton Press.
- Gilbert, P. (2001). (Sub)versions: Using sexist language practices to explore critical literacy. In H. Fehring & P. Green (Eds.), *Critical literacy: A collection of articles from the Australian Literacy Education Association* (pp. 75–83). Newark, DE: International Reading Association.
- Greenwell, B. (2004). The curious incident of novels about Asperger's syndrome. *Children's Literature in Education*, 35, 271–284.
- Irwin, M., & Moeller, R. (2010). Seeing different: Portrayals of disability in young adult graphic novels. *School Library Research*, 13, retrieved on December 31, 2012 from www.ala.org/aasl/slr/volume13/irwin-moeller
- Jaeger, P. T., & Bowman, C. A. (2005). *Understanding disability: Inclusion, access, diversity and civil rights*. Westport, CT: Praeger.
- Kalke-Klita, T. (2005). Moving forward: The inclusion of characters with Down Syndrome in children's picture books. *Language and Literacy*, 7, retrieved on July 17, 2013 from <http://ejournals.library.ualberta.ca/index.php/langandlit/article/view/16315/13093>
- Keith, L. (2001). *Take up thy bed & walk: Death, disability and cure in classic fiction for girls*. New York: Routledge.
- Landrum, J. (2001). Selecting intermediate novels that feature characters with disabilities: characters with disabilities can create opportunities for learning about and accepting differences. *The Reading Teacher*, 55, 252–258.
- Matthew, N., & Clow, S. (2007). Putting disabled children in the picture: Promoting inclusive children's books and media. *International Journal of Early Childhood*, 39, 65–78.
- Mills, C. (2002). The portrayal of mental disability in children's literature: An ethical appraisal. *The Horn Book Magazine*, 78, 531–542.
- Pajka-West, S. (2007). Perceptions of deaf characters in adolescent literature. *ALAN Review*, 34, 39–45.
- Rueda, R. (1998). Addressing the needs of a diverse society. In T. E. Raphael & K. H. Au (Eds.), *Literature-based instruction: Reshaping the curriculum*. Norwood, MA: Christopher-Gordon Publishers.
- Smith-D'Arezzo, W. (2003). Disability in children's literature: Not just a black and white issue. *Children's Literature in Education*, 34, 75–94.

Annotated Bibliography of Award Winners

Governor General Awards: Illustration

Maclear, K. (2012). *Virginia Wolf*. Toronto, ON: Kids Can Press.

Vanessa attempts to cheer up her sister Virginia, who is in a "wolfish" mood, and eventually succeeds by painting a magical scene on the wall. Illustrated by I. Arsenault.

Young, C. (2011). *Ten birds*. Toronto, ON: Kids Can Press.

Ten birds who are differently gifted navigate across a river in unique ways. *Governor General Awards: Children's Text*

Gilmore, R. (2001). *A screaming kind of day*. Markham, ON: Fitzhenry & Whiteside.

Scully, a little girl with hearing aids, experiences the emotions of a difficult rainy day. Illustrated by G. Sauve.

Yee, P. (1996). *Ghost train*. Toronto, ON: Groundwood Books.

Choonyi, a Chinese teenager with a physical disability, encounters her dead father's ghost on a train. Illustrated by H. Chan.

Caldecott Awards

Zelinsky, P. O. (1997). *Rapunzel*. New York: Puffin Books.

The familiar Grimm's tale—enhanced with early Italian and French elements and Renaissance illustration—in which a prince, blinded for several years, regains his sight when Rapunzel's tears fall upon him.

Schneider Family Awards

Bertrand, D. G. (2004). *My pal Victor/Mi amigo, Victor*. McHenry, IL: Raven Tree Press.

A boy's disability emerges when he is pictured in his wheelchair at the end of the book. This is a bilingual story of the theme of friendship. Illustrated by R. L. Sweetland.

Christensen, B. (2009). *Django*. New York: Roaring Brook Press.

A lyrical story of the life of Django Reinhardt, jazz guitarist, who re-taught himself to play guitar after he was injured in a fire.

Lang, G. (2003). *Looking out for Sarah*. Watertown, MA: Charlesbridge.

Based on a true story about a guide dog and his owner who is a teacher, dancer, and musician.

Lyon, G. E. (2010). *The pirate of kindergarten*. New York: Atheneum Books for Young Readers.

A young girl is considered clumsy until she is diagnosed with double vision. Illustrated by L. Avril.

Parker, R. A. (2008). *Piano starts here: The young Art Tatum*. New York: Schwartz & Wade.

An (auto)biography of Art Tatum, presenting the story of the pianist as a youth with low vision.

Seeger, P., & Jacobs, P. D. (2006). *The Deaf Musicians*. New York: G.P. Putnam's Sons.

A jazz pianist loses his hearing but gains a band when he joins other deaf musicians on the subway. Illustrated by R. G. Christie.

Stryer, A. S. (2007). *Kami and the Yaks*. Palo Alto, CA: Bay Otter Press.

A Sherpa boy who is deaf rescues his family's yaks high in Nepal's Himalayan mountains. Illustrated by B. Dodson.

Uhlberg, M. (2005). *Dad, Jackie, and me*. Atlanta: Peachtree.

Baseball player Jackie Robinson plays a special role that affects the lives of a boy and his father, who is deaf. Illustrated by C. Bootman.

Annotated Bibliography of Other Picture Books Featuring Characters with Disabilities

Elliot, R. (2011). *Just because*. United Kingdom: Lion.

Toby's sister Clemmie is his best friend. Without mentioning the word 'disability' this lyrical text promotes sibling friendship with humour and grace.

Epp, M. (2007). *Hope and the dragon*. Mississauga ON: Aspirations Publishing Inc.

A young boy uses his imagination to help him deal with cancer.

Fitch, S. (2002). *Pocket rocks*. Victoria, B.C.: Orca Books.

Ian Goobie collects rocks, and connects with a storyteller who does the same thing. Illustrated by Helen Flook.

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

In the group home where Cindy lives, no dogs are allowed. How she befriends a puppy, and finds an opportunity for him to live at the Hospice where she works, offers opportunities for strong critical discussions about decision making and independence. A picture book for older readers where the

disability—Down syndrome—is portrayed in the illustrations rather than the text. Illustrated by Ron Lightburn.

Peete, H. R., & Peete, R. E. (2010). *My brother Charlie*. New York: Scholastic Press.

A young African-American girl shares affectionate stories of her twin brother who has autism. Illustrated by S. W. Evans.

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