

## Children & Youth:

### First-Person and Other Unique Children's Books on Disability and Difference

By Barbara Kolucki ([bakoluck@aol.com](mailto:bakoluck@aol.com))

The number of books on topics related to disability has steadily grown since the 1980's. Many are excellent, and have often been written by family members with a disabled child or by adults who remember their experiences as disabled children. Just like the first "dolls with a disability," these books serve at least two purposes. They try to present disability in ways that children who are disabled can find or see themselves in more positive and active roles, countering their previous invisibility or negative presentation. Second, they attempt to sensitize young children to their disabled peers who through advocacy movements and legislation, would now be integrated into school, play and community life.

Particularly over the last decade, new first-person books have started to appear more frequently. These are often aimed at children with a particular disability or illness. They have even branched out into related fields such as being a foster or adopted child. All of these books aim at reassuring readers that they are not alone in their feelings about being different. And many of the best also suggest some creative coping strategies to the young readers.

Here is a short list of some of the books in this new category. We are interested in hearing from other countries so that we can include and reference these as well.

***Kathy's Hats*** (1992) by Trudy Kisher and illustrated by Nadine Bernard Westcott is published by Albert Whitman & Company, Illinois, USA. Kathy begins by talking about her first hat - when she was just born and almost bald and her mom tied a little green ribbon to her "puff of fuzz". She goes on to talk about knitted hats from her grandmother, beach bonnets, playing dress-up with grown-ups' old hats, Easter hats, sun-visors, bathing caps and baseball caps. Then Kathy became seriously ill with cancer. She talks about her feelings about being so ill and scared. She describes her chemotherapy and how her mom made her squeeze her hand really tight when the intravenous needle was put into her arm. And about how sometimes watching cartoons or drawing pictures helped her when she felt sick. But then Kathy's hair began to fall out - and she was "bald as when she was a baby". She then was given lots of different hats - and she hated them. She complained about how she felt about wearing hats and one day her mom told her that she needed one more hat - a thinking cap. This cap, she suggested could help her change how "she felt about things". After thinking about what her mom had said, she started to pin a little teddy bear on her hat and slowly, friends started to give her special pins that she could use to decorate her hats. Then slowly "Sometimes I would even forget I was bald."

The book is precious and very honest. It is written by the mother of "Kathy" who did have cancer as a young child. The book is a moving tribute to her daughter's courage, and the courage of all children with cancer or similar illnesses.

***My ABC Book of Cancer*** is written and illustrated by Shannon Chamberlain, a 10 year old with cancer. It is a 1990 publication of Synergistic Press, 3965 Sacramento Street, San Francisco, CA 94118 USA. Shannon takes us through each letter of the alphabet and tells us the story of her life with cancer. She teaches us new words, like "B for Broviac" - the inserted catheter that keeps her from getting poked with needles all the time. She takes us through the feelings and emotions she relies on to keep going, including "C for courage, E for Effort and S for Strong". The book gives us a portrait of her supporters: F for father and friends, D for doctors and N for Nurses, P for

People that pray for me (and please don't stop). And one of the most powerful is "Q for questions like, "Why me?", "Will it hurt?", "Will I die?" and "When is it going to be over?"

There is also detailed information at the back of the book about Shannon and her type of cancer, leukemia, a glossary of terms related to cancer, a resource list and bibliography. The bibliography included other books written by children with cancer as well as those about cancer, death and dying and being in a hospital. A few books are written and illustrated by children as part of their "therapy". Some books are written from the point of view of a sibling and a few are references for adults. This book is highly recommended - perhaps some children could use it as a resource for a class project, even if the illness has not affected them or their family to date.

***Nervo to the Rescue: A Guide to Understanding MS for Kids and their Parents*** is a unique workbook published by the National Multiple Sclerosis Society and Deborah Miller, Ph.D. of the Mellen Center. Their website is: <http://www.beaseron.com>. The address is P.O. Box 52171, Phoenix, AZ 85072-2171 USA. This publication was designed to help children whose parent or family member has multiple sclerosis. It addresses some of the child's fears and suggests several creative activities to help children cope with their parent's illness.

Nervo is a cartoon character who helps address children's questions ranging from simply answering how MS affects the nervous system, why their parent now acts differently (has trouble walking, talking or seeing) and various things that might help parents (physical therapy, injections, medications). A number of games are included in this activity book: unscrambling words related to MS, writing a poem (a cinquain of five lines of words that describe feelings or things), drawing a picture, making a greeting card, etc. It also lists suggested ideas for what children can do to help or better understand their parent such as making a simple meal for them by themselves, choosing a simple chore, trying to remember that it is normal for their parent to feel both sad, confused and perhaps scared too.

The wonderful thing about this publication is that it demonstrates that it is OK to ask questions and to have a variety of feelings. And it stresses that even with a new illness in one's life - this does not change the way a child and parent feel about one another. This is a workbook that can be adapted to any illness or disability.

***Ear's Looking at You Kid: A Fun and Easy Look at Your Hearing Impairment*** is written by Carole Marsh. The book was published in 1998 by Gallopade, 200 Northlake Dr., Peachtree City, Georgia 31269 USA. It is one of a series of Carole Marsh Books that include titles like "*The Mystery Van Takes Off: Handicapped Kids in YOUR State go on a Wild Adventure*", "*Math for Girls!: The Book with the Number to Help Girls Love & Excel in Math*", "*Get Ready, Get Set, Go!: Space Stuff for Kids*", etc.

The book is written in a very distinct and interesting style. The author teaches about the physiology of the ear, continually making analogies to objects and other things that children might already know (e.g. she describes and illustrates the cochlea with an analogy of a snail). She describes an earful of terms simply showing the root of a word and how different endings mean different things (oto, otoscope, otolaryngologist, etc.). She includes information about famous people who had hearing impairments (e.g. Beethoven, Alexander Graham Bell, Linda Bove from the Sesame Street television program, Helen Keller). Simple technological devices are explained - from hearing aids and TTYs, to alarm clocks and doorbells adapted using lights or vibrations.

One chapter, entitled "How to Help Yourself", features suggestions on how to balance asking for help with focusing and asking for a signal when it is time to listen and watch what someone is

saying. Also included are many interactive pages where the child reading the book is encouraged to write out opinions, questions, feelings, etc.

Deaf people and their advocates might object to Ms. Marsh's concentration on hearing impairment when she really is talking about deafness as well as impairment. But the book is worth reading and presents a new genre of very open and engaging books that explain disability in a new and interesting way.

***I'd Rather Be with A Real Mom Who Loves Me: A Story for Foster Children*** is written by Michael Gordon, Ph.D. and illustrated by Janet Junco. It is a 1995 publication of GSI Publications, Inc., P.O. Box 746, DeWitt, New York, N.Y. 13214 USA. The book begins with a page written for adults who are reading this book along with a foster child. The author talks about the dearth of materials designed to help children deal with this difficult issue and their separation from their families. He stresses the importance of the emotional concerns of the child and how if they are addressed early, they might possibly prevent some of the more difficult emotional or behavioral issues later.

The book is written from the point of view of a little boy who talks about being a foster child. He shows in a picture that he changes the title of a drawing from "My House" to "Where I Live". He talks about his memory of his real mom being drunk and a father who was "scary and did things I don't want to talk about". He remembers wondering why someone could not love and protect him from bad things. He talks about his world being taken over by people like case workers and therapists. And he asks: "Can you believe they expect me to do well in school?"

The book is a very honest look at how foster children can feel about the changes in their lives and the difficulties they can have trusting and loving again. One of the best things about this book is that it first acknowledges the many problems but then focuses on several solutions for difficult feelings. The major hurdle is to "get it through my thick skull that it's not my fault how things have worked out". Emphasized are ways to find others in similar situations, learning to use a safe ways to express feelings, talking when they need to talk, etc.

The author has written several other books on a variety of topics including: *Jumpin' Johnny Get Back to Work! A Child's Guide to ADHD/Hyperactivity*, *I Wish I Could: A Teacher's Guide to ADHD/Hyperactivity*, and the "Jumpin' Johnny" book in Spanish.

***I Am Not Dumb*** is a 1981 publication by Ahmed Motiar and published by Z.A.N. Press, 151 Snowshoe Crescent, Thornhill, Ontario, Canada, L3T 4N1. The book begins with a mother and son walking down a street where they see Peter playing ball. The son thinks that the boy must be lazy and that is why he cannot learn. His mother explains how different people have different skills and encourages her son to talk to Peter. As they get to know each other, Peter confides that he is often made fun of and also sometimes gets into fights with people who call him names. He explains too, that he has a learning disability and which things are difficult for him to learn. The boys ask their teacher to explain what a learning disability to their class as one way to get all children to understand differences.

The book is old (1981) but it was one of the first that I found about addressing learning disabilities. It is very matter-of-fact and a very readable book for children 10 years or older. I have contacted the publisher to find out if there are more recent versions or additional books. Do any of our readers know?

***The Jester Has Lost His Jingle*** is written and illustrated by David Saltzman, a young adult who has Hodgkin's disease. He had previously written a poem about humor and when he was diagnosed with his disease in his last year at Yale and was crying about his situation - this line popped into his head. "Here I lie, I have a tumor" "And you ask me where's my sense of humor?" And the Jester was born.

The book is written in verse and is about a world where everyone lost his or her sense of humor - all except a Jester. The King banishes him away and he goes on a journey to find and bring laughter back to the world. He travels all over the world and sadly finds it empty of songs of birds, and full of bitter people, pain and tears. He moves on to a hospital where he stumbles into a room with a little girl and asks her "How come laughter's not with you?" and she responds with his original line "Here I lie, I have a tumor" and you ask me where's my sense of humor?". She tells him that she is sick of trying and does not feel like laughing at all. The jester then in a sensitive, sweet and funny way, helps the girl to smile - and then laugh! The laughter slowly spread throughout the hospital and as one person smiled - another smiled back. He returns to the King and tells him that laughter was not lost - it was hiding deep inside everyone. Including "YOU".

The young author died in 1990. His book was published in 1989 by The Jester Co., Inc., P.O. Box 817, Malaga Cove Plaza, Palos Verdes Estates, CA 90274, USA.

***Nos Todos Somos Diferentes*** is one of a series of books published by UNICEF - Mozambique and the Secretariat of Social Action in 1992. The author and illustrator is Angelina Neves.

This particular booklet, "We are all Different" is about three girls who are friends. They spend a great deal of time together playing, pretending, doing homework, etc. One likes to sew, another likes animals and the third is a "tomboy" always climbing, running and jumping. The girl who narrates the book had polio. As she talks about how they all help and complement one another, she notes how when she is doing her "exercises," the others join her. The "tomboy" helps her with these and always encourages others to exercise - she believes that if people did more exercises and sports that they would expend their energy and the world would have fewer fights and wars.

At the end of the booklet, there is a simple explanation of polio and a list of important things to remember about children's rights and their health.

This is a wonderful series - there are other booklets about different disabilities. They are written in a simple, direct way and are of interest to both children and adults. The health issues are those of more critical importance in developing countries - but the overall message of difference and value is of critical importance to everyone, anywhere.

The booklets can be obtained through UNICEF-Mozambique, 3 U.N. Plaza, N.Y., N.Y. 10017 USA.

### **International Documentation Center**

**International Board on Books for Young People (IBBY): Outstanding Books for Young People with Disabilities.** This documentation centre is part of the Department of Special Education, University of Oslo, Norway. They publish a list on a biennial basis and the 1999 list includes a wonderfully diverse selection of books from various countries. For example:

- ***The Handmade Counting Book*** by Laura Rankin which shows children how to count using American Sign Language (ASL).
- ***Der kleine Lalu (the little Lalu)*** by Helga Hornung is a Swiss picture book with Bliss symbols and regular text.
- ***Hvad er Dat? (What is that?)*** by Virginia Allen Jensen and Dorcas Woodbury Haller is a Danish version of a tactile picture book that can be read by sighted and blind children.
- ***Gol ya Poutch (Full or Empty)*** by Zahra Farmani and Mahin Mahboobi is a handmade washable book about an Iranian guessing game that children play.
- ***Limpan ar sugen (Doggie is hungry)*** by Eva Lindstrom is a Swedish book without text that can be appropriate for all children, including those who are mentally retarded or have a learning disability.
- ***Soren er mongo (Soren has Down Syndrome)*** by Mette Jorgensen and Henrik Bjerregrav is a Danish photo book about a seven year old and his friends and family.
- ***Ian's Walk*** by Laurie Lears is about a boy with autism and his siblings.

The booklet also includes an annotated list of several other books from India, France, Columbia, Japan, Brazil, Finland, Greece, Iceland, the Slovak Republic, South Korea and Switzerland. It is a unique international resource.

The catalog is distributed through the IBBY Secretariat, Nonnenweg 12, Postfach, CH-4003 Basel, Switzerland. Email: [ibby@eye.ch](mailto:ibby@eye.ch) or [n.s.a.reidarson@isp.uio.no](mailto:n.s.a.reidarson@isp.uio.no)

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