

Knowing your neighbors – The special children

For many generations disabled children, whether mentally or physically disabled, were hidden away or placed in segregated institutions, sometimes far away from their families. In most countries today society's view of disability has changed profoundly in the past years. We have now acknowledged that everyone belongs in their own local community. Disabled children have a right to take part in kindergartens, schools and cultural activities alongside children with no disabilities. One important aspect of culture is literature, which provides the framework for our identities and is an instrument of communication and participation as well as enhancing the quality of life. *Mainstreaming* disabled children offers a wonderful opportunity for a fuller life for those who are disabled, as well as for those who are not. But school principals have often created special classes in distant wings of the school building, or organized activity periods and bus transport for disabled students at different times from those of the regular school children. Teachers then report that the disabled children are left out, isolated or excluded from the rest of the school. I wonder why?

One way of changing attitudes is to make sure that children have access to good books when they are young. Because schools do not teach their students about disabilities or because many children have little contact with a disabled person, we need quality books that reflect our society through a variety of characters and settings -books with disabled persons as a natural part of the cast.

Children are born without prejudices, but as they meet persons who look or act differently from themselves, they are often affected by attitudes handed down from ignorant or anxious parents or other role models. For many years bullying or teasing directed at a person with a disability was just looked upon as bad behavior, and stand-up comedians still expect their audiences to laugh at silly jokes about blind persons bumping into things, and so on. Books and education provide an opportunity to help all children perceive persons who look a bit different than themselves, - be it persons with a different colour of their skin, or persons with a disability, - as part of normal, everyday life. Books help children explore what it means to have a disability. The Italian filmmaker Federico Fellini once said, "Accept me as I am. Only then will we discover each other". It is time we – the grownups - start to be more accepting of diversity in several forms. Young people inherit beliefs and morals from their elders; we must now give them books that give insight about various disabilities and social barriers, the same barriers that stop disabled persons from living full lives.

As early as 1990 Dr. Rudine Sims Bishop, a language arts specialist, began writing about the concept of *mirror books*, books in which we see ourselves, books that reflect our culture and experience. She also discussed *window books* as those books that provide children with a glimpse of the world outside of their experience, and noted that these were equally important. Illustrations and book covers give children a fair idea of what the story is about. Artists have an obligation to depict disabled persons in picture books or on the cover of a book, as naturally as they depict the more able-bodied persons. Subtle hints like including a person in a wheelchair in a street scene, or the easily recognizable slanted eyes of a child with Down Syndrome in a kindergarten situation may show our children that these persons belong in the picture as naturally as some people have grey hair or some people wear glasses. Likewise, they will give the disabled child the chance to wonder, "Is this book about someone like me?" If a disabled child never reads about or recognizes itself in a book, this becomes a sort of affirmation of not being good enough, of not belonging. Similarly, if disabled children have

good role models to identify with, it will help them feel that they belong to society, which is another reason for giving them a presence in children's literature. These books must combine a profound knowledge of the various disabilities with literary and artistic quality.

Traditionally, images of people with a disability in children's books have tended to be negative — from Captain Hook in *Peter Pan* to the ugly witches in fairytales such as *Hansel and Gretel*. The disabled people are there either to add a little colour to the plot or they are miraculously cured (like Clara in the books about the Swiss girl Heidi) - as if this is the only possible positive outcome. In the past 20 years there have been more books with children with disabilities as protagonists, but so many books have tended to be too factual, too didactic, or simply one-dimensional. Fiction explaining autism, for instance, but fewer books containing feelings, colour, fun and imagination. It is time we realize that people with disabilities have individual personalities and that many are capable of a full range of emotions. Why not write about those?

The IBBY Documentation Centre of Books for Disabled Young People is a sub-department of the International Board on Books for Young People (IBBY) and was established to promote research, production, mediation and the use of books especially designed for disabled young people. Through the network of IBBY contact persons and publishers the Centre's international book collection relating to young people with special needs is kept up-to-date. *Outstanding Books for Young People with Disabilities* is an annotated catalogue/international travel exhibition launched every two years at the Bologna International Children's Bookfair. The books are then frequently displayed in connection with national and international conferences, book fairs and exhibitions.

I have called this paper "The special children". The term "*special*" is a mollifying interpretation of the old term "retarded". To some people *Special* has come to mean: a gift beyond riches, as I will show you in a few books picked from the last three Outstanding Books selections, books that in my opinion are both *mirrors* and *windows*:

Rules

Cynthia Lord

New York: Scholastic Press, 2006

ISBN 978-0-439-44382-1

David and Catherine are siblings of twelve and eight years. While their parents are working, Catherine has to take care of her autistic brother – something that she does not really like. She is obsessed with the thought of having a normal family situation and is dreaming of a pill that would make David wake up one morning and be just like everybody else. She has invented a set of rules to help him understand the world and appear more normal to others – rules like "Keep your pants on in public", or "Say thank you if someone gives you a present, even if you don't like it". Catherine desperately wants to be accepted by her class mates. She longs for a friend to do "normal" things with and is excited when a new girl her age moves in next door. Catherine wants Kristi to like her and tries to explain away David's peculiar behavior. This summer Catherine also meets Jason, a young man with cerebral palsy. He is confined to a wheelchair, is unable to talk but communicates using a card system. Catherine is uncomfortable around Jason, but after her initial self-consciousness and insecurity about his disability she starts making new cards for him – cards that let him use words and expressions

Heidi Cortner Boiesen

Ibby Documentation Centre of Books for Disabled Young People

like any other young adult. Gradually their friendship grows, but when Jason wants to go to a dance with her, Catherine is forced to look into herself and does not like what she sees there. Is she just as superficial and selfish as Kristy turned out to be? The story is inspired by the author's own family and their family dynamic, and shares several both heartbreaking and happy moments. Catherine is an endearing girl who struggles to fit in with her peers and tries her best to make her brother to appear "normal", until she finally understand that she has to accept him the way he is. David loves Arnold Lobel's *Frog and Toad* books and repeats lines from those stories to communicate, which makes the conversation quite funny at times. (10-12 years)

Out of my mind

Sharon M. Draper

Toronto: Atheneum Books, 2010

ISBN 978-1-41697-170-2

Eleven-year old Melody has cerebral palsy and is considered by her teachers at school to be mentally disabled. Melody is trapped not only in a wheelchair but also in her own body. She has very little control over her physical functions. She can't talk, walk or feed herself and needs help with the most mundane things. The only way she can communicate is with grunts, squeals and unreliable facial expressions. She is part of a class of special education students and has little to do with the rest of the school. The teachers do not realize that Melody can read, that she has a photographic memory and remembers everything she has ever heard or read. Then her parents buy her a medi-talker – an electronic device that allows her to type her thoughts into a computer that speaks – and people finally start to understand how intelligent she is. She is mainstreamed in a few regular classes and becomes a valuable member of the school's quiz team. However, although Melody now can express herself it does not mean that adults, teachers and fellow students are comfortable with her. Nobody wants to sit next to her at lunch and when the quiz team gets the chance to enter a National competition they leave without her. *Out of my mind* goes a long way to change the minds of people who think having physical limitations means that one is also limited in intelligence. This is more than a book about a girl with special needs. It holds up a mirror for all of us to see how we react to people with disabilities that make us uncomfortable. The writer covers everything from the physical challenges to the crushing guilt associated with having and raising a child with the condition such as Melody's.

Pretty like us

Carol Lynch Williams

Atlanta, GA: Peachtree Publishers, 2008

ISBN 978-56145-444-0

To be called Beauty while having virtually white eyelashes and being desperately shy and self-conscious is not easy. Beauty has no real friends at school but is determined to make friends as they start 6th grade. Beauty's mother and grandmother have taught her the family motto, "Pretty is as pretty does" and she has always tried to live up to that motto. But when a new girl with a strange and rare condition, Progeria, suddenly sits next to her at school, she finds that this is easier said than done. Progeria is a rapid aging disorder, and Beauty is both disgusted and intrigued by Alane's wrinkled skin, shriveled hands, thick glasses, and tiny, frail body. Her initial repulsion gives way to understanding and acceptance when Beauty discovers

Heidi Cortner Boiesen

Ibby Documentation Centre of Books for Disabled Young People

that, on the inside, Alane is just like any other twelve-year-old girl. The class has decided that they want nothing to do with Alane, as if her condition is contagious. Beauty initially tries going along with the class, only to discover that when she finally speaks up for herself, she is at last starting to earn respect from her peers. This book gives a sensitive, but realistic view of the trials and challenges of adolescence, while at the same time discussing illness and death in an honest and often humorous way. Alane is perfectly aware of her own condition but chooses to live each day at the fullest, even though it may kill her. (10-12 years)

Another book about shocking appearances is

Wonder

R. J. Palacio,
New York, NY: Random House, 2012
ISBN 978-0-375-86902-0

Ten-year-old August (nicknamed Auggie) was born with a severely deformed face that not even 27 surgeries can correct. "I won't describe what I look like," Auggie says in the first chapter. "Whatever you're thinking, it's probably worse."

Though he is kind, funny, brave and smart, his "tiny, mushed-up face", as Auggie calls it, causes others to turn away in horror and not want to be around him. After a number of years of home-schooling, Auggie's parents enrol him to attend fifth grade at a local private school. Auggie is initially against this, but having no choice, decides to give it a try. His class mates treat him with varying degrees of kindness and disgust. He gradually makes friends and, while there are many ups and downs and social dramas throughout the year, Auggie and his classmates grow into a vibrant middle school community.

While Auggie is the primary teller of the story, the author masterfully weaves in sections with first person tellings by other characters, for instance his sister, who always has had to come second. The varying points of view not only provide rich insight into Auggie, but also into the thinking and learning of those around him. "What he looks like, in a sense, is very incidental to him," says the author. "He really doesn't dwell on that very much. What he dwells on is the reaction that people have to him. Because all he wants is to be an ordinary boy. But he really can't, because he'll always have people staring at him and reacting to him in a certain way." Throughout the story, one of Auggie's teachers writes what he calls "precepts" – or fundamental rules – on the blackboard. His first lesson is: "Given the choice of being right and being kind, always choose to be kind."

This is a compelling story of courage, bullying, acceptance and friendship. In this book readers aged 10+ will grapple with a range of issues related to being different.

The next book is

Bartolomé - The Infanta's pet

Rachel van Kooij
(translated from German by Siobhán Parkinson)
Dublin: Little Island, 2012
ISBN 978-1-908195-26-5

17th century Madrid is not a kind place for a dwarf like Bartolomé; his family keeps him hidden in a small back room to avoid the mocking and jeering he would otherwise experience on the city streets. Bartolomé longs to be able to read and write, and when he hears about a

Heidi Cortner Boiesen
Ibby Documentation Centre of Books for Disabled Young People

dwarf just like him working in the king's court, he and his siblings come up with a plan to sneak him out of the house for secret lessons in a nearby monastery. But one day, the king's young daughter, the Infanta, sees Bartolomé on the street and wants to have him as her "human dog". He is then dressed in a dog costume and has his face painted to look like a dog. Life in the royal palace as one of the Infanta's retinue is scary and humiliating – until Bartolomé discovers the artists' studio, where he is shown some kindness and discovers his talent for painting. Colourful and gripping, this is an optimistic story of courage and hope on the edge of society. We see all the aspects of life from Bartolomé's refreshingly honest perspective and very much feel the cruelties and petty jealousies of court life as he is treated like an animal or plaything by the child princess. Based on the painting *Las Meninas* by Diego Velazquez, this is a special book about being "different" and about overcoming seemingly insurmountable obstacles. This is a very readable novel for readers aged 10+.

Then we have a novel for young people of 12-15 years

Butterflies

Susanne Gervay

Sidney, NSW: Angus & Robertson, 2001

ISBN 0-207-19850-0

As a toddler Katherine stumbled and fell into a bonfire and was severely burnt all along her right side. Her hair was gone in places and her muscles grew contracted. Her father was unable to face the added responsibilities and left the family. Katherine's mother has always been there for her, but now, after fifteen years of operations and painful skin grafts, Katherine is ready to free herself from her mother's loving, but almost suffocating, protection. She wants to be able to be herself, Katherine, a young woman who must start making her own decisions, not those of her mother. She wants people to see her, Katherine, not just a burns victim or hospital case. She is a strong swimmer, but when the Coach tries to persuade her to enter the Paralympics and swim for Australia, she feels this would be like cheating. Her burns are ugly and the contracted skin troublesome, but not disabling. She gets her share of thoughtless and cruel comments, but refuses to hide. In Katherine's own words, "I have to choose to stay burnt or not. But I'm not burnt inside. I'm perfect inside." She comes to realize that basic values like commitment, love and trust are more important than the texture of her skin. Her message is: "Change what you're able to change, but accept what you are". (12-14 years)

The last book I am going to share with you is

Twomates

Prewett, Melanie (text)

Prewett, Maggie (ill.)

Broome, WA: Magabala Books, 2012

ISBN 978-19-2124-845-0

Two Mates is a simple picture book for young children, telling about the day-to-day activities of two boys who are best friends: together they hunt for hermit crabs, go fishing, explore the markets, dress up as superheroes. The illustrations are clear and lively. The story is based on the real-life friendship of Jack, who is Indigenous and Raf, who is non-Indigenous. The fact that Raf has spina bifida and is in a wheelchair is revealed only in the illustration at the end of

Heidi Cortner Boiesen

Ibby Documentation Centre of Books for Disabled Young People

the story. The book is a successful proof that physical disability needs not be a barrier to friendship and adventure.

Sources:

Accept me as I am – Best books of juvenile nonfiction on impairments and disabilities, (Joan Brest Friedberg et al. R.R. Bowker Company, New York, 1985)

Notes from a different drummer; a guide to juvenile fiction portraying the handicapped. (Barbara Baskin and Karen H. Harris, New York, R. R. Bowker Company, New York, 1977)

Rudine Sims Bishop, Ohio State University. "Mirrors, Windows, and Sliding Glass Doors" originally appeared in Perspectives: Choosing and Using Books for the Classroom. Vol. 6, no. 3. Summer 1990.

Barn og Bøker,(Tordis Ørjasæter, Oslo, Cappelen, 1987)