

**Butterflies: Youth Literature as a
Powerful Tool in Understanding Disability**

Disability Studies Quarterly: Winter 2004 Volume 24 No. 1 ISSN 1041-5718
www.dsq-sds.org February 2004.

Susanne Gervay, B.A., M.Ed., M.A.,
Sydney, Australia

Extracts from *Butterflies* are reproduced by kind permission of HarperCollins Publishers.

In the 1940s a change began to emerge in youth literature that reflected a new frankness and a willingness to write literature from a youth perspective. J.D. Salinger's *Catcher in the Rye* (1951) exploded onto the scene, marking a greater push for literature specifically catering for youth wants and needs. This new realism in youth literature impacted on the portrayal of disability and opened the way for disability to move from secondary to primary characterization. The landmark books *I Can Jump Puddles* (1955) by Alan Marshall and *The Cay* (1969) by Theodore Taylor were part of this change. Baskin and Harris (1984) found that characters with disabilities began to slightly increase in representation in youth literature. They noted 311 books published between 1940-1975 in the USA. Between 1976-1981, this increased to 348.

The passage of the Individuals with Disabilities Act in 1975 in the USA, which integrated disabled children into public classrooms, was a facilitator in the increased portrayal of disability in youth literature and prompted closer analysis of disability imagery. Baskin and Harris (1977) had suggested that the separation of those with disabilities from the rest of the community had led to the creation of stories, myths and expressions which developed into literary responses to rationalise disabilities. Biklen and Bogdan (1977) presented 10 typical disability models — pitiable and pathetic; an object of violence, sinister and evil, the person with disability as atmosphere, a super cripp with super qualities, laughable, his/her own worst-and-only-enemy, a burden, non-sexual, incapable of fully participating in everyday life. A greater consciousness emerged regarding disability, which would be reflected in children's literature with more realistic disability models (Pirowski, 2002). These models depict disabled children as independent, equal, and socially active, and disabling conditions in contemporary children's novels are more likely to be described in accurate medical terms.

The legislation in the United States is extensive in its coverage and is also the oldest legislating for disability. In Australia Disability Discrimination Act (DDA) was passed by the Commonwealth Parliament in 1992 and took effect from 1 March 1993. The objectives of the DDA are, as far as possible, to eliminate discrimination against people on the grounds of disability, to ensure that people with disabilities have the same rights before the law as the rest of the community; and to promote the principle that people with disabilities have the same rights as the rest of the community. Although the DDA is a Commonwealth Act, most Australian States and Territories

have similar legislation. Canada, the United Kingdom and New Zealand also have legislation dealing with disability discrimination in education and other areas of life.

Since 1975 books with disabled characters have increasingly begun to emphasize the reality of medical conditions as well as the influence of social attitudes on disabled persons capacity for independence, social integration, equality and pride in their uniqueness. Harrill (1993) found that the frequency of stereotypes in the portrayal of disability in children's literature decreased significantly after the introduction of legislation regarding the rights of disabled people. However, the quality of children's fiction books depicting characters with disabilities has been varied with many attempting to meet the spirit of anti-discrimination legislation at the expense of literary quality. Quicke (1985) noted that a great deal of literature targeting disability, although well meaning has been in effect didactic and often poor, using bland language, weak story lines, predictable plots, with one dimensional characters. Harris and Baskin (1977) found there was a serious problem with poor character development.

As Robertson says in her annotated bibliography (1992), "Not every impairment portrayed has to be critical to the action. Not every disability in a story should be a metaphor for the protagonist's development. Juvenile fictions will feel much closer to the truth when it's what the disabled characters think, say and do that makes them stand out, not what they can't do."

Increasingly, disability has become a small but legitimate thematic area drawing slowly into its net some important literary children's authors. Award winning children's authors including British authors Jacqueline Wilson and Tim Bowler, New Zealand author Margaret Mahy, American author Cynthia Voigt, Australian authors Colin Thiele, Patricia Wrightson, and John Marsden have addressed disability in their books, taking it from stereotypical presentations and didactic teaching into the realm of meaningful human experience focussing on the person and story.

With youth literature becoming more confronting and realistic, conditions ranging from emotional disorders, autism, epilepsy, anorexia, learning difficulties, cancer and AIDS are increasingly being tackled in children's and youth literature either as a primary or more frequently as a secondary theme. The award winning novel *Two Weeks with The Queen* (1989) by Morris Gleitzman deals with AIDS and cancer. Intellectual disabilities and learning difficulties are sensitively addressed in Robin Klein's *Boss of the Pool* (1986). *The Illustrated Mum* by Jacqueline Wilson (1999) powerfully portrays the impact of psychiatric disorders on a family. However, the impact of growing up from infancy with severe burns has not been written about in children's and youth fiction.

Burn survival is not a mainstream disability, although it is complex, medically, emotionally and physically. There is a natural discomfort for many people when confronted by a severe burn victim. As a consequence, when I was asked to write about growing up with burns by a young survivor, my immediate reaction was "NO." I knew very little about burns and instinctively felt inadequate to deal with such a confronting topic. However the young burn survivor kept asking me to write about it. Burns slowly began to plant itself into my consciousness. My brother-in-law had been badly burnt as a child with prolonged hospitalization and long lasting psychological

and social effects. A friend was burnt severely when she was five years old. I reflected on when my daughter was burnt as she pulled boiling soup from the kitchen table and recalled the months of hospital treatment that followed. I started to collect newspaper clippings on burn survivors, bush fires, and medical and rescue teams. I searched the Internet for information especially trying to locate children's literature on burns. There appeared to be little fiction on growing up with burns. I became increasingly drawn into the area until I found that burns were starting to choose me.

I continued a process that would take six months of research. I needed to understand burns from a medical perspective before I could seriously grapple with a novel. I trawled through the huge second-hand bookshop in Sydney's student area and emerged with two heavy medical books on burns. I found the graphic nature of the pictures of burns, grafts, scarring, and loss of body parts was horrific. In some, the faces of people had become unrecognisable and I had to cover these photos with one hand as I read, so that I could cope. I underlined key concepts, wrote notes and read and re-read the text. Burns are complex, and I am not a doctor. Doubts about my ability to correctly understand the medical process undermined my confidence. That is when I started my visits. My first visit was to see Professor Wayne Morrison, Director of the Bernard O'Brien Institute of Microsurgery at St Vincent's Hospital Melbourne. The Institute's mission is "to undertake clinical and experimental research in the field of reconstructive surgery and especially microsurgery for the betterment of the health of those afflicted by injury, disease or abnormality." Professor Morrison explained the process of burns and the surgery, the complexity of reconstruction. He gave me answers to questions I did not have the experience to formulate. Later I visited Dr Hugh Martin, Head of the Burn Unit at the Children's Hospital, Westmead in Sydney. Dr Hugh Martin lectured me on burns, grafts, pain control, scarring, and survival. There were diagrams and explanations and I began to really understand the trauma of a major burn and the huge and lengthy challenges facing burn survivors, their families, community and the medical and support teams. As Professor Morrison and Dr Hugh Martin spoke to me, it was as though my escape routes were closing. How could I avoid writing *Butterflies*? As these men gave so generously of their time, I realized that I was trapped. I had to write this book.

I spent many hours talking to social workers, physiotherapists, nutritionists and nurses committed to assimilating burn survivors into normal life and helping the family cope with the trauma and many years of operations that would follow. I investigated the Burn Unit in The Children's Hospital, Westmead with its routines of bandages, heat lamps, dressing and undressing wounds, the creams, the pressure suits, and the processes of healing. The commitment of the family to their burned child was revealing—the daily dressing, physiotherapy, and care. I saw social workers helping the burn victim, parents and siblings. There are often complex emotions and issues to be dealt with including guilt by parents about how their child became burnt, which can lead to breakdown in family relationships and resentment over the long and arduous support needed to help the child. There can be sibling anger at becoming marginalized, and anger and fear by the burn victim over the disability and the processes involved in becoming independent.

I discovered the Burn Support Foundation, where parents created a community for their children and the families of burn victims. There are newsletters and socials. The highlight is the burn camps sponsored by the New South Wales Fire Brigades, where

children in pressure suits and splints, with their scars and restrictions can play without the fear of being socially ostracized.

I interviewed children who had been burnt. I was seeking to discover how burns impacted on the cognitive, personal-social, psychosexual, moral and needs development of young people. This was a long and exhausting process of interviews. Typical comments were:

Adolescents. "I feel like nothing sometimes." "I don't care about the burns. People have to take me as I am." "I dream about being normal all the time. I just wish that I could be." "I feel scared a lot of the time." "I want a boyfriend but who'd want me?" "I'm sick of the pain. Sick of it." "I hate people staring." "I'm as good as anyone else." "Mum wants to control everything." "My friends don't get it." "I wish I was normal." "I miss a lot of school. Makes me feel dumb." "Mum doesn't get it. I can do things for myself." "Hate being called disabled."

Teenage siblings of burn survivors. "I wish I was the burnt one sometimes." "I've got to help all the time." "People don't get what it's like." "We can never afford anything." "It's not fair." "Sometimes people are cruel to my sister." "I defend my brother." "Dad left us." "We're good mates."

Pre-adolescents. "Mummy goes with me to the hospital." "I don't like the operations." "I hate Mum putting on the cream." "It's fun at camp." (Burn Camp.) "Bad things come in the night." "There's a school in hospital that's fun." "The operations hurt." "I don't have many friends at school." "Kids laugh at me." "No one likes me." "I get lots of presents in hospital." "I like some of the nurses. They're kind, but some are horrible. They have needles." "I just want to play soccer."

I sought to understand the emotional journey of burns from the point of view of the burn survivor, a child at different ages, and the siblings. In addition, I interviewed parents and discovered that many had serious problems with guilt over the burn incident; exhaustion and anger at the dedication needed to help their child; a profound need to protect their child; serious difficulties in maintaining the family unit, and fear of letting go their child.

Younger children with severe burns were very dependent on their main carer, usually the mother. The carer's issues generally centred around safety, acceptance, the immediate experience of surgeries, recovery, school, and family. When there was not any surgery and the children felt better, they played and laughed. Younger children reacted to the immediate impact of their environment. Adolescence presented greater challenges as young people faced issues of identity, peer group pressure, dependence versus independence, sexuality, self-esteem, acceptance of self, individuality, the search for understanding of the world and their place in it. These issues of adolescence were heightened by the impact of burns. Unlike the younger children, adolescents brooded over their situation and worried about the future.

When I finally felt that I understood the experience of burns, the medical facts and the social aspects, the viewpoint of the burn victim and survivor, the family's perspective, the role of health workers and the community, when the emotional experience of burns was internalized and melded into my own personal experience of growing up,

then I put away the research. Only then did I begin the yearlong journey of writing *Butterflies*.

I had a definite agenda. *Butterflies* would be medically accurate, but it would not be a medical book. It would be psychologically accurate in terms of child growth and development, but not a didactic textbook. It would reflect the stories and journeys of the young people and families whom I had interviewed. I wanted to write a story where disability is part of the fabric of life, but not life itself. The main character Katherine would be burnt but never be a one-dimensional stereotype. Katherine would be complex like all human beings with a real family, a background and a personality that reaches from the page into the lives of readers. Katherine's life would show that disability does not separate burn survivors from the community, but unites them in the common bond of humanity. *Butterflies* would be good literature and a powerful tool in understanding disability.

Butterflies — the Young Adult Novel

Katherine is nearly 18, brought up in a close-knit family. There is her mother, older sister Rachel and Katherine herself. Katherine's mother migrated from Italy with a young Australian backpacker. However Katherine's father left after the accident. Katherine was three when she was severely burnt. She dreams that one day her life will be different. No more operations and pain. No more restrictions of movement. One day, she will have hair that covers all of her head and she will feel beautiful. She wants to be like everyone else. Katherine experiences the full range of emotions as she searches for identity. She is angry at being torn between the world of patient and schoolgirl, angry at being burnt and meeting challenges that make life so hard. She loves her girlfriend as they race out on their shopping trips and study together. She loves her sister who has to take second place in a family where Katherine dominates. Katherine's life is full. There are friends, schoolwork, study and boys as she deals with her developing sexuality, need for independence, aspirations, fears and hopes for the future.

Katherine is never an "invalid", although she gets very sick. Katherine is funny but never laughable. She does wicked things but is never wicked. There is violence, but Katherine is not its object. At times Katherine is a "burden" especially on her mother and sister, but then she gives back love and humour so magnificently. She develops strengths that enable her to meet the challenge of disability and becomes a super person, never a "super cripple". Katherine is a vibrant, emotional, sexually developing young adult participating fully in everyday life.

The trauma of burns and the following disabilities are a total life experience involving the whole family. The following segment from *Butterflies* is a retelling of one mother's experience as she sat by her baby's side after the burn. The mother is emotionally traumatized at the shock of the injuries.

Swollen eyelids shut tight. Head shaven bare. The woman strokes the baby's face. A seven-year-old girl holds onto the woman's skirt. A plastic tube feeds into the baby's nose and a drip is taped onto her arm. A catheter empties urine into a bag. Her arms are in splints. Her small body wrapped in gauze. Her hands are in mittens also tied to splints. She tries to open her eyes, searching through the swelling,

The nurse comes to check tubes and vital signs.

The woman brushes back her dark wispy hair and looks up at the nurse. "What is wrong with that baby? Where is her hair? Her face? ... Her body?"

"Remember the doctor spoke to you about it?" The nurse's voice gently persists. "Remember? Remember?"

"No. Spoke to me? No."

"About her body, her face." Pulling a chair close, the nurse sits next to her. "The baby will she will..... look a little different."

The woman stares confused at the nurse in her white uniform. "Where is Katherine? Where is my baby? My little girl?"

The nurse answers softly. "This is Katherine. You can see her."

"But I can't. I can't.... see her. I can't see her." (Butterflies, pages 52-53)

Disability exaggerates the challenges of growing up. While the medical needs of burns survivors are real, these can be dealt with medically. However the real challenges are the social consequences of the medical condition. Katherine is starting school. The issue of where Katherine can go to school; the role of her mother as advocate for her child; the sister's role as carer are part of the complexity of disability. This incident is drawn from stories revealed during interviews.

The school is a brown brick two-story building with steps disappearing into corridors and closed doors. Children fly down the steps like bees on a mission from their hive. They stop to stare at Katherine, who holds onto her mother's skirt. They flap and flutter before they continue their flight onto the green playing fields or the canteen line.

Her mother is wearing her cream jacket, knitted by Nanna. Katherine loves that jacket and when terrible monsters frighten her in the night, her mother gives it to her. In the morning the jacket is crushed and warm. Her mother irons it then.

They have an appointment with the Principal. The secretary tells them to wait. Katherine wanders around the room investigating timetables pinned on a board and a lime green playing block that is stuck under a bookcase.

The secretary tells Katherine's mother that they can go into the office. The Principal stands when they enter. Motioning to two brown vinyl chairs, he stiffly introduces himself before sitting down in his swivel chair. He bends forward, resting his hands on the brown wooden desk. Protected by a computer, a stack of multicoloured files, a phone and the paraphernalia of his job, he starts.

"I have discussed Katherine with the Education Department." He presses his hands together. "She's an unusual case. We haven't the back-up staff to really cater for her special needs."

"What do you mean?" Her mother takes Katherine's hand.

"Well, she's got. How can I explain? You understand."

"No, I do not understand." She strokes Katherine's head and Katherine smiles.

"She's not quite ... Her movement is restricted. She can't play like the other children, can she?"

"That is untrue."

"There needs to be a special education teacher allocated to help her with her work." He fidgets. "With her writing at least."

"Katherine can write her name already and a lot of other things. In two languages, she can write." She turns to her daughter. "Come here, Katherine. Show the man that you can write in English and Italian."

"No, please don't. I'm sorry, but this is really getting us nowhere." He clears his throat. "We have no facilities for disabled children."

Her mother leaves confused, holding Katherine's hand tightly. She walks past the secretary without acknowledging her, through the corridors, down the steps, past the children flying back into their hive, over the grassy playing fields to the yellow-posted bus stop.

"Am I going to Rachel's school, Mamma?"

"We will see."

There are phone calls and meetings and letters. Community Services say, "No, your daughter isn't disabled. No, she doesn't qualify for any assistance. No, there is no disability allowance. Yes, you should enrol her in a local school."

The Education Department says, "No, your daughter is disabled. She can't go to a local school unless a principal agrees."

Katherine says, "You read to me Mamma." "Rachel, you play ball with me." "I don't like them. They're staring at me." "Am I going to school?"

The principals say, "No."

But then there is one principal who hesitates, listens. She says she'd like to meet Katherine.

With both Rachel and Katherine beside her, their mother stands outside the principal's office. "Come in." The principal catches her breath for a moment when she sees Katherine with her head exposed, unprotected by hair.

"How nice to have you girls visit." She hands Rachel and Katherine a picture book. Rachel, who is ten, sits on a mat in the corner and reads to her sister the story of how the kangaroo found his tail. Katherine points to the drawings in the book raising her hand. But she can only reach halfway. She giggles with her sister at the pictures of cheeky possums and wise old owls. The principal watches the girls for a while. Then she turns to ask the mother about Katherine.

"Yes, Katherine does fall over sometimes. Yes, it is hard for Katherine to stretch her arm fully, to run as fast as the others. Yes, Katherine becomes upset sometimes, but Katherine tries everything. She is a happy girl. Katherine is happy even though she has been through so much. Katherine wants to learn, to go to school. You will like Katherine. You will like her. You will."

"I'm sure I will." The principal asks the secretary to bring them coffee. The girls don't notice that their mother is quietly crying and that the principal has her arm around her.

Rachel leaves her old school. She's sad to say goodbye to her friends, but there'll be other friends at the new school and there is Katherine to look after (ibid. pages 80-84).

From observations and personal experiences in the children's hospital ward, discussions with parents and staff, the world within the hospital is filled with conflicting needs and roles of all the players as they seek to make life better for Katherine and all the children.

In the morning the children's ward is always busy. Children who aren't critically ill, but aren't allowed out of bed, play board games with children who are allowed. Some have assignments set by the hospital teacher. Kids with tubes in their noses, kids with drips attached to mobile units, kids with cancer and diabetes and cystic fibrosis and spina bifida play because they feel better today. Eight-year-old Katherine with no hair is drawing a picture of her mother and Rachel. Posters of the children's work are hung throughout the ward.

The nurse's station in the middle of the ward has a view of everything. Parents, nurses, doctors, social workers and teachers centre on the children who are the focus of a private world within the ward. Visitors come in from time to time bringing presents and there are parties with balloons for birthdays. Mothers come in all the time and the children get individual attention that their brothers and sisters don't receive.

Sometimes disturbing things happen there. Parents challenge the system. They argue with the doctors and nurses, guarding their children against decisions they question. The children are afraid then.

Sometimes terrible things happen there. Children get very sick. Some never go home.

Katherine cries after her surgery. The skin of her back has been cropped for her graft. It's red and throbs and she vomits from the anaesthetic drugs. She calls for Mamma who holds her and stays throughout the night and the nurses are kind and all the people in the ward are kind. Even though it hurts, she knows she's special and safe because they all look after her.

The ward is her home (ibid. pages 112-113).

Ultimately Katherine is a young adult with the normal need of developing a relationship, insecurity about herself, sexual growth. Her fears about her disabilities increase the anxiety of her first romantic relationship.

William touches her hair. "It's so soft."

Don't touch my hair. It's been pulled and dragged over scars. There are burns. Don't you remember? I'm too complicated.

He starts stroking her hair and she wants to stop him, but it feels so warm, comforting and Katherine is weak as though her body's soft plasticine. She half whispers a protest. You don't like me, do you? Her stomach butterflies into knots and yearnings and she murmurs "stop" stop William, stop, and please ... don't stop.

He turns her face to him.

You're too close. Don't William. Don't. I'm ugly. You know it. You can see. Instinctively she raises a hand to hide scars. (ibid. page 218)

When *Butterflies* was completed, Dr Hugh Martin read the manuscript to ensure medical veracity. He made valuable technical changes after which he generously offered to endorse *Butterflies* because he regarded it as a breakthrough book in the revelation of the developmental experience of burns on a young person. *Butterflies* is currently used in the Education Burn Unit in The Children's Hospital, Westmead. Belle Alderman, Professor of Children's Literature at the University of Canberra, Australia suggests that traumatic experiences, such as those of a burn survivor, can be difficult for others to understand. "That's where novels such as *Butterflies* are so valuable. Katherine's burn experiences are sufficiently detailed to enable readers to fulfil their curiosity and fears about what it means to be a burn survivor. No longer are we outside this traumatic experience. We can now empathize. Characters that we come to care about very much doubly enrich the whole experience."

Butterflies was Highly Commended for Australian Family Therapists' Award 2002 and Children's Literature for Peace Award 2001, and short-listed for the WAYBRA (Western Australian Older Reader Award 2003). Reading Notes on *Butterflies* can be found on www.harpercollins.com.au — select READING NOTES.

References:

Alderman, Belle. Unpublished correspondence.

Baskin, Barbara. H., and Harris, K.H. 1977. Notes from a different drummer: a guide to juvenile fiction portraying the handicapped. New York: R.R. Bowler Company.

Baskin, Barbara. H., and Harris, K.H. 1984. More notes from a different drummer. New York: R.R. Bowler Company.

Biklen, Douglas, and Bogdan, R. 1977. Media portrayals of disabled people: a study in stereotypes. *Interracial Books for Children Bulletin*. 8 (6&7): pages 4-9.

Gervay, Susanne. 2001. *Butterflies*. Australia: HarperCollins (Angus & Robertson).

Harrill, Juanita, L. et al. 1993. Portrayal of Handicapped/Disabled Individuals in Children's Literature Before and After Public Law 94-142. Eric Data Base ED357557 Retrieved 23rd September 2003 <http://ericae.net/ericdb/ED357557.htm>.

Pirofski, Kira. 2002, revised 5th February 2003. Disability in Children's Literature: Stories About the Wicked, the Weak, the Laughable, and the Inspirational Saints. *Delirium Journal*. www.deliriumjournal.org/writings/pirofski_k/disability.htm. Retrieved 21st May 2003.

Quicke, John. 1985. *Disability in modern children's fiction*. London: Croom Helm.

Robertson, Debra. (Ed) 1992. *Portraying persons with disabilities: an annotated bibliography of fictions for children and teenagers*. 3rd ed. New Providence, NJ: R.R. Bowler.

Biographical note:

Susanne Gervay combines her background as an educator (B.A. Uni of Sydney, M.Ed UNSW) and author (M.A. UTS) to tackle youth issues through her children's and YA literature. Her books include junior fictions: *I Am Jack* (bullying), *Super Jack* (Blending families and aging parents), *The Cave* (youth male culture today), *Shadows of Olive Trees* (multiculturalism and feminism), *Butterflies* (burns and disability). Further details about *Butterflies* and Susanne Gervay's other novels can be found on her website: www.sgervay.com