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### What Disability Studies Can Do For Children's Literature

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This paper explores an apparent lack of engagement between scholars of disability studies and those of children's literature, and shows that the application of contemporary ideas about disability to the analysis of children's literature develops a broader dimension to the criticism of children's texts, offering advantages to both children's literature and disability studies.

It is unusual to find discussions of disability issues in commentaries that examine broad genres of children's literature, although these texts have often included observations on race, gender or other major forms of bias. Critical works looking specifically at the subject of disability and/or disabled characters in children's books have appeared only sporadically, primarily in response to legislation bringing disabled children into inclusive schooling, for example, Baskin and Harris 1977, 1984 and Robertson, 1992 in USA with Quicke, 1985 and Reiser and Mason, 1990 in the UK. Pinsent (1997) examined disabled characters in some modern texts as one influence among several forms of bias. Rudman's (1995) "issues approach" to children's literature commented on selected constructive portrayals.

Recent issues of *Bookbird* (2001), *British IBBY Newsletter* (2001) and *BooktrustEd* (2002), all independently featuring disability in children's books show an increasing interest in the disability genre. However, in comparison to analysis of race and gender bias, an ongoing debate on the impact of disability images in children's material, informed by an analysis of disability in contemporary society, has been slow to develop in the fields of both children's literature and

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disability studies. This appears to dismiss the power of these portrayals to create societal attitudes to disability, and to ignore their resonance among those who have personal or close experience of disability. Most significantly, it neglects the needs of huge numbers of young readers whose ideas are formed by misinterpretations, many of whom will have to renegotiate their misunderstanding of the nature of disability at a later date in order to successfully manage disability, whether their own or others', in private and public life.

The emergent field of disability studies is the study of the sociological, political, historical and cultural perspectives of disability, rather than medical or rehabilitative concerns. Individuals who have self-declared their personal experience of disability have analysed various aspects of children's fiction quantitatively rather than qualitatively (Carlisle, 1997), assembled annotated lists (Mettler, 1996) or offered criticism, principally of classic texts (Keith, 2001, Pirowski, 2002), but the major effort at the intersection of children and disability has been in progressing equity issues for disabled children in mainstream education rather than in the critical study of disability in children's material. Disability scholars, like many adults, may not be fully conversant with the radical changes which have occurred in children's literature over recent decades and the potency of children's texts as an agent in creating, preserving and reflecting cultural attitudes appears to be underestimated. Margaret Meek (1988) urges adults to "Read (picture books) with your most adult awareness of life and literature and text, and you will see that the invitations they offer to young readers are far from infantile" (p. 19).

A lack of scholarly consideration in both disability studies and children's literature obstructs each field being better informed by the other. A recent example of dissociation is the "disability" entry in *The Cambridge Guide to Children's Books in English* (2001) in which Kate Agnew and Juliet Partridge, both scholars of repute in children's literature, present an overview of salient titles which include disabled characters (p. 209). Their descriptions of protagonists being "imprisoned" in their wheelchairs, "wheelchair-bound" and "crippled" indicates that the affirmative language preferred by disabled people has been overlooked and suggests that their analysis may not have been informed by other contemporary ideas about disability. They express concern that "novels which feature disability have had only limited success in the marketplace" and point to melodramatic depictions of disability being more commercially successful than those which feature children coping with a disability. This claim may now have achieved the status of a self-perpetuating myth, since evidence to confirm or refute this often-repeated assertion is hard to obtain. An argument against this supposition is the borrowing rates of children's texts in a local county library (personal communication) which show top texts to be film and video link-ins that include characters with conditions such as speech impediments (*The Little Mermaid*), unusual body image (*Shrek*), and learning difficulties with scoliosis (*The Hunchback of Notre Dame*) among others. Disability also has a high profile in children's books' literary awards. Four of the last six Whitbread Book Awards winning titles include clearly defined disabled characters: *Saffy's Angel* (McKay, 2002) has a wheelchair user, *Coram Boy* (Gavin, 2000) is about a boy with learning difficulties, *Skellig* (Almond, 1998) has multiple disabled and ill characters and in

...abilities, *Opening Windows* (1999) has multiple disabled and ill characters and in *The Tulip Touch* (Fine, 1996), Tulip herself has a personality disorder. Anne Fine's *Up On Cloud Nine* (2002) is a highly commended Carnegie title, telling of Stolly whose unusual relationships and abilities include suicidal tendencies; Phillip Reeve's 2000 Smarties Book award winner, *Mortal Engines* features Hester, identified mainly by her scarred face, and a 2003 Newbery Honour Book, Ann M. Martin's *A Corner of the Universe*, concerns a young girl and her uncle who is "mentally disabled".

These titles suggest both commercial success and relative literary merit, and although some postdate Agnew and Partridge's analysis, it is not hard to find numerous well-established books that touch on disability issues. However, it is probable that disability scholars will more easily identify elements of text and illustration that imply societal attitudes about disability than others whose expertise lies elsewhere. This difference goes beyond whether disability or illness is the main theme of a book, or whether disabled characters can be categorised as principal, subordinate, child or adult characters, or whatever the medical condition happens to be. It extends into a fundamental appreciation of the definition of disability. Linguists such as Gee (1999) explain that we bring understanding to words according to our own experiences and expectations, which are themselves mediated by our own cultural norms. The insight that disability scholars can bring to analysis of children's literature lies in their understanding of "disability" not as a personalised, wholly biological and medically mediated characteristic, but as a social construction evidenced in texts as the described attitudes of both disabled and non-disabled characters, and in the rationale of plots which both create and consolidate the attitudes and circumstances that are commonly found in contemporary society.

### **The Social Model of Disability and Children's Literature**

The essential reasoning of what has become known as the Social Model of Disability was first suggested by Paul Hunt (1966). Its principles developed into

the disadvantage or restriction of activity caused by a contemporary social organisation which takes little or no account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities (Union of the Physically Impaired Against Segregation, 1975).

This definition was extended to all medical conditions, and contextualised by Oliver (1990), among others. Social model philosophy now underpins most disability discrimination legislation. It identifies ways to establish social equity that do not depend on a medical response, but on modifying man-made societal arrangements. Some commentaries, particularly those published prior to mid 1980's, can be confusing in their different local interpretations of terms such as "handicapped", "impairment", "condition" and "disabled", (Baskin and Harris 1984, preface, pg. x) and debates continually challenge the social model to represent the disability experience of individual groups of people. However, there is wide agreement that to differentiate the medical and social models of disability is a useful investigative technique.

I suggest that an examination of texts in terms of whether a story presents a

suggest that an examination of texts in terms of whether a story presents a medical or social portrayal of disability offers a basis for critical interrogation, which reaches closer to the "disability experience". It can help to identify hidden bias or ideological representations that might be otherwise non-critically assumed to describe the inevitable nature of life. A clear parallel of the usefulness of this insider's perspective is seen in a study by Mendoza and Reece (2001), which contrasts the portrayal of Mexican American characters in a highly commended but biased text with one that accurately illuminates Mexican American culture but has a very limited circulation. They also comment on the lack of "extraliterary" or "political" criticism in mainstream journals and publications.

The social model of disability separates the biological "medical condition" from the social consequences of that condition. The medical model finds expression in a person's actual corporeal condition, a recognition that when compared to the majority of the population, a person experiences a difference in their physical, sensory, intellectual, emotional or psychological functioning. The word "medical" carries its own huge weight in cultural expectation drawn from historical influences. It leads us to expect a pathological state, but this is by no means universally applicable to conditions that commonly attract social consequences - many conditions do not involve ongoing illness or medical intervention. Crucially, the medical definition locates the cause of the "problem" in the individual due to their medical condition. In contrast, the social model of disability addresses the barriers to full participation in society caused by the practical, environmental, attitudinal or administrative framework of that society. A very simple example of the difference between the two is to consider a wheelchair user trying to gain access to a stepped entrance of a building. By the medical definition, the person is disabled by a medical condition that makes use of a wheelchair appropriate. By the social definition, the same person is disabled by the absence of ramps or lifts which allow the person to enter and proceed unhindered. Where lifts or ramps are present, the person is not "disabled" although their medical condition remains unchanged. This principle does not in any way negate or minimise any appropriate medical assistance but recognises the cumulative capacity of society to influence the well-being of the individuals of which it is composed.

Rudman (1995) goes some way to recognising the social model of disability. Her analysis of books depicting elderly characters describes the portrayal of the medical conditions of old age such as deteriorating physical and mental conditions, asexuality, helplessness, dependence and feebleness, but suggests the major difficulties are social:

problems ... imposed upon them not through their own failings but as a function of unresponsive social and governmental services. Pressure to withdraw from the workforce, insufficient security benefits, inadequate and expensive care and a society that tends to ostracise the elderly all present situations which are difficult to overcome (p. 118-119).

In contrast, Rudman describes "disability" principally in terms of "special needs" and "medical conditions" (p.304). Priestley (2002) highlights the essential

similarity in the social situations of disabled people of all ages, despite the disguise of the social conventions which are commonly described in children's texts that include elderly characters.

When the social consequences of disability and illness are considered, the number of available titles with disability interest rises significantly, giving a more realistic estimate of the potential for children to absorb unhelpful ideas about disability issues. Hobson and Madden's *Children's Fiction Sourcebook* (1995) gives more than 600 titles, but indexes only six (1%) under "disability" in Social Situations. Additional titles can be found under other relevant headings, for example, Berlie Doherty's *Spellhorn*, in which the main character is a girl with visual impairment, is listed in "Fantasy", *Annerton Pit* by Peter Dickinson, again with a visually impaired character is found under "Mystery", and *Why the Whales Came* by Michael Morpurgo with its hearing impaired character is placed in "Conservation". Close attention to the detailed annotations shows that a conservative estimate of forty-four titles (14%) have disabled or ill characters in them. Examples are Rosemary Sutcliff's *The Witch's Brat* which features a "hunchback", Nick Warburton's *The Thirteenth Owl* which includes a girl with a scarred face, and Lois Lowry's *All About Sam*, about a boy with learning difficulties. Beyond this listing, individual writers may include disabled characters to a higher level: close analysis of Margaret Mahy's titles shows over 20% have some form of disability interest in the plot, characters or illustrations (Saunders, 2004). Anecdotal evidence suggests that the rate of inclusion of disabled characters in fiction is weighted towards books for the older reader, and that for younger readers, when disability is portrayed it is mainly in "explanatory" texts which concentrate on biological/medical details. If proven, this would be significant in establishing an expectation of personal limitations regarding disability at a very early age.

### **Young children's perceptions of disability issues**

Evidence for the effect of children's literature on the formation of attitudes about disability in young children relies heavily on extrapolating from studies of other social bias, for example Brown (1998), or on studies of teaching methods such as those presented by Arizpe and Styles (2003) concerning visual literacy. They quote Perry Nodelman in Hunt (1996 p. 116-118): "picture books are a significant means by which we integrate young children into the ideology of our culture. Like most narratives, picture book stories most forcefully guide readers into culturally acceptable ideas about who they are through privileging the point of view from which they report on the events they describe."

Arizpe and Styles used picture books by Anthony Browne and Satoshi Kitamura in which the words and pictures tell contrasting stories to challenge young readers to make their own interpretations of story. Using carefully composed questions to draw out "real" responses, they showed that children as young as four years old are capable of determining complex, subtle meaning and attitude in texts, and that this skill is well developed prior to the children's ability to articulate their reasoning. Contributing her experience of using art to help young children visualise their reasoning, Kate Rabey concludes (p. 138): "Looking at the drawings in this study has demonstrated to me that even the youngest children

can interpret, comprehend and communicate the visual -- far beyond what they might be assumed to know."

Marriot (1998) supports Nodelman's view that picture books are, like all children's texts, "inherently ideological" (p. 4), referring to the "network of beliefs, values and social practices which are explicitly espoused by or more often implicitly sustained within the text". He describes picture books as providing "perspectives on ethical and moral issues which reflect the author's perception of value and his or her aspirations for the present and future nature of social life." (p. 5). Marriot calls this "the moral imperative", "that is, consciously or unconsciously, overtly or covertly, picture books provide through the combination of images and words, themes and ideas, texts and subtexts, a representation not only of how the world is, but also of how it ought to be." (p. 5-6). Further, noting studies more than two decades ago by Dixon (1977) and Stones (1983) on sexism in children's literature, Marriot observes that only recently has it been widely recognised that the "pervasive sexism of stories in which patronising and patriarchal gender relationships are portrayed as normal and thus simply taken for granted" (p. 5) . is an ideological position taken within fiction for children. From this, it may be judged that it will be some while before disability bias is equally well recognised despite its similar origins and effects.

Further observations on gender stereotypes which might parallel the means by which children absorb attitudes towards disability are provided by Janet Evans (1998) noting Gilbert (1994) who suggests that girls have comparatively modest ambitions because "it is the texts which surround us in our culture that tell us how to 'read' the world. These texts tell us what it is to be a man or a woman in today's society, that is we are 'positioned' by the texts and hence begin to act accordingly" and that the texts "tell other people how to view us." (p. 99). Evans quotes Davies and Banks (1992) who assert that "unless children are given the opportunity to talk about and begin to understand how the gendered discourse works, then no amount of exposure to literature claiming that girls and boys are equal will change their views" (p. 99). Evans further observes from her study with 8 and 9 year olds that if the concepts presented by the texts have not been fully understood, then there will be no transfer of learning to real life, (p. 112) and she suggests that "opportunity to respond to texts and to begin to deconstruct the meaning of texts is therefore a crucial step along the road to allowing children to become aware of how they can be positioned by texts" (p.100).

Baddleley and Eddershaw (1994) comment that "children experience emotions as deeply as adults do. They can become totally involved in the books and can reflect on their own experiences and empathise with the experiences and feelings of others" (p. 75). In two studies, they confirm that talking about the stories in picture books can develop young children's understanding of the human behaviour being portrayed in text and pictures and the role of the author/illustrator and format in its telling. Using the book and video of *John Brown, Rose and the Midnight Cat* (Wagner and Brooks, 1985) they asked children for interpretations on the story of widowed Rose, whose dog John Brown is unwilling to invite the Midnight Cat into their home. Rose takes to her bed until the cat comes in, when all three then live together in peace. Various interpretations were offered, including Rose "pretending to be ill" (p. 66), but in

a disability analysis, Rose could be genuinely ill, and the cat could symbolise a person whom Rose needs to help her in the house. This presents John Brown as symbolising a child or other adult who resents an unfamiliar but beneficial adult in the home, such as a home help or personal assistant.

Baddley and Eddershaw's later study (1998) used several picture books to extend pupil's interpretations, using books with the common theme of characters who had difficulty in seeing another character's point of view. *Cousin Blodwyn's Visit* (Vesey 1983) tells how the cheerfully untidy witch Capillaris, is visited by Blodwyn who cleans the house, against Capillaris' wishes. The children suggest a range of motives for Blodwyn's imposition of her standards on Capillaris, ranging from Blodwyn thinking Capillaris needed to be tidied up and was trying to be kind, to Blodwyn being selfish in wanting the house to be how she liked it and ignoring what Capillaris wanted in her own home. The children passed over the intended theme but proposed their own - that people do not understand each other because they do not talk, so they help in the wrong way. A disability perspective on *Cousin Blodwyn's Visit* would highlight its similarity to a familiar situation for disabled people, that of trying to maintain control of their own lives in the face of others who impose their wishes onto those they are supposed to be helping. *Cousin Blodwyn's Visit* is an example of a text which does not include characters who are visibly portrayed or described as having medical conditions, but whose structure, vocabulary and theme are relevant to discussions about disability. Such texts are especially useful when considering the consequences of non-visible medical conditions.

*Winnie the Witch* (Paul and Thomas, 1987) is another very popular picture book which at first glance has no connection with disability but could be used to introduce an important principle to young children. Winnie lives with her black cat Wilbur in a completely black house. Only his green eyes tell her where he is. She often trips over him and decides to cast a spell that makes all his fur green, but now she can't see him in grass and falls into a thorn bush, which makes her so cross that she makes him multicoloured. Poor Wilbur, Winnie knows he is miserable. She solves the problem by making everything in her house multicoloured, and restoring Wilbur's natural colour. This story about colours also demonstrates that it is more effective to change the human-made environment than to force individuals into ways that do not suit them. This principle is the essence of the social model of disability. I am indebted to Norfolk Disability Awareness Trainers group for bringing my attention to this interpretation of *Winnie the Witch* when they used it in a forum of adults involved with young children, further illustrating the capacity of picture books to present complex ideas to readers of all ages.

Turning now to commentary on texts for older readers, I will use two recent analyses of Anne Fine's novels to show that disability criticism can offer an additional dimension. *Family Fictions* by Nicholas Tucker and Nikki Gamble (2001) charts the changing representation of the family in children's fiction against a backdrop of family history, and social, political and economic influences, from the 16<sup>th</sup> century to the present time. Gamble observes that "it is now widely acknowledged that concepts of family are socially and culturally constructed, influenced by economic, religious and political trends" (p. 1-2). She

suggests that writing for children has become "an increasingly powerful site for challenging politicised discourse" but that "it is important to acknowledge that more than one attitude co-exists at a given time in any culture or subculture" (p. 2). In the second analysis, Jim Jones highlights the wealth of material that can be used to expand pupils' understanding in the chapter *Anne Fine's Stories for Life* (2000, p.151- 161).

Anne Fine was UK Children's Laureate (2001-2003) and her books include *Bill's New Frock* (1989) on a theme of gender stereotypes and *Madame Doubtfire* (1987) on the challenges of separating parents. Her work includes several titles with disabled characters. Tucker characterises Anne Fine's work as "sparkling on the surface but morally serious underneath" (p. 54) and Jones describes her writing as "fixed in the realities of school or family life...as experienced by children...taking the readers' perceptions to places they are not used to visiting... embedded in the wider theme of personal growth - of learning through (often difficult) experience" (p. 150-1).

Both Jones and Tucker comment on *The Granny Project* (Fine, 1983). This tells of two teenagers and their younger siblings who live with their Russian mother Natasha, father Henry and Granny. Granny's Alzheimer's disease is overwhelming Natasha, who describes Granny's many idiosyncrasies as deliberate selfishness. The plot opens with a doctor's evaluation of Granny's physical and mental problems prior to her placement in a home for elderly people but the children object and decide to use an upcoming school project to assemble an argument that will shame their parents into keeping Granny at home. The children waver when Henry breaks down in tears as they attempt to inspect a home for Granny, and Ivan continues the project alone. When his strategy is revealed, Henry condemns Ivan as a blackmailer in tones of what Fine calls "cold and absolute hostility" (p. 58). Granny stays at home, but their parents direct that the children will take up the 30-odd jobs required to look after her, leaving Henry and Natasha free to go dancing. The children manage at first, and Ivan gets Granny to reminisce for his history homework. After a while the children tire, the delegation of tasks is disputed, and Ivan falls ill with bronchitis. At this point, the parents reconnect with the children. Various chores and timetables are reorganised to lessen their impact on the family as a whole and they arrange a nurse so that Natasha can return to work and the family can think about going on holiday (p.105). Granny catches Ivan's cold and dies of pneumonia, leaving the children resolute that they were right in their defence of her, but that their experience would lead them to deal differently with the difficulty if they faced similar challenges again.

Tucker uses the novel to identify conflict within family relationships and describes *The Granny Project* as one in which "genuinely hostile feelings sometimes become dangerously exposed". Jones suggests it portrays the effect on family life of a relative with Alzheimer's and its "almost unimaginable stress."... [which] leads to a state, almost, of guerrilla warfare" (p.151). Both consider the cause of the conflict to be Granny, rather than more precisely identifying it as the consequences of Alzheimer's, and both analyse the characters' emotional reactions as if these were themselves the cause, rather than a symptom of the problem. If, as both Jones and Tucker imply, this were only a



story of "Granny is disabled, causing trouble for everyone", then *The Granny Project* would be a disablist text that creates and consolidates expectations of difficulty without suggesting that the consequences of the illness could be more efficiently managed.

An analysis that identifies the social consequences of Alzheimer's offers an interpretation in which all characters respond according to their perceptions. These are informed by deliberately placed medical jargon, impersonal social data and pre-packaged notions concerning incapacity, all most skilfully laid out for the reader in the guise of the school project. Fine has identified the most common and debilitating factors in caring for sick relatives at home, but she does show, albeit in a rather low profile, that these factors can be addressed not by altering Granny's medical condition, but by reorganising the family timetable and utilising public resources that are designed to relieve exactly those pressures. I suggest that Fine has a purpose for introducing Granny's youthful concepts of social fairness in welfare and her insistence on voting, as well as Natasha's experience of the old Russian system and Henry's cynicism about governments of every shade. She is hinting that the grandparent's passion to free society from poverty, to have basic good health, equity and self determination might also be applied with an equal force today.

Tucker asks "where is the formula by which all parties can agree on what should be the boundaries?" Possibly deliberately, Fine avoids dialogue which asks Granny's opinion of going into a home, and although readers might take from this that Granny is not to be allowed self-determination even in her more lucid moments, this enables Fine to extend the plot to show her young characters wrestling with their own feelings through which they gradually mature in a characteristic coming-of-age novel. The question of boundaries should not be addressed by an analysis of the rights and wrongs of emotion alone, but by considering the social issues which underlie the character's reactions, to judge if those emotions are a necessary personal defence, reasonable reaction or plain callous selfishness. Fine offers a critical perspective: that of a wider social responsibility to enable all family members to function fairly and with dignity, without the destructive obligation to deny their own lives to care for someone else, or to force that person to depend on the reluctant assistance of others. The likelihood that provision outside the family will fall short of all that is required forms a continuing echo of the grandparent's battles, but these questions reframe *The Granny Project* not as "just a story", but as an informed, politically charged text for children. It is a study of how individuals behave towards each other when challenged by socially imposed perceptions, leaving the story of relationships to provide a vehicle for more significant issues.

Disability scholars debate the acceptability of writers using medical conditions to generate conflict and emotion because those conditions form part of the persona of some disabled people. Although imperfect, a level of understanding has been achieved regarding parallel portrayals of gender and race that accurately focuses attention onto the wider social issues, to help young readers negotiate their way through life hurdles. Critical analysis informed by the social model of disability may hasten a similar situation regarding disability, when texts for children will identify social attitudes as the true causes of conflict and will

balance these with resolutions that suggest ways of addressing them. Anne Fine's novels are indeed "cunningly crafted" (Tucker, p. 55), and as Jones observes, they create an "all-important link: the reader is always there, working out the coggy business of life along with the characters" (p. 160). The worry with Anne Fine's novels is not that children will absorb unhelpful disability messages from them, but that without being taught what to look for, readers might not see in them all that there is to see.

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- Kathy Saunders' interest children's literature arose when her own children began to read books that presented a view of disability that differed from her own experience. Her book, *Happy Ever Afters - a storybook guide to teaching children about disability*, was published by Trentham, 2000. Her email address is [k.saunders1@ukonline.co.uk](mailto:k.saunders1@ukonline.co.uk).

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be accepted both in children's literature and in real life, people with disabilities are put in positions of being over-achievers. Thus, people with disabilities are thought to be endowed with super powers, ranging from studying ballet to studying ballet. The book, written by Nancy's brother (who is also deaf), shows how first-hand knowledge contributes to a bias-free story.