

**THE PORTRAYAL OF
DISABILITY IN YOUNG ADULT
FICTION:
A CRITICAL EXAMINATION.**

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DECLARATION:

I hereby certify that this material which I now submit for assessment on the programme of study leading to the award of Ph.D. in Humanities (English) is entirely my own work and has not been taken from the work of others save and to the extent that such work has been cited and acknowledged within the text of my work

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ABSTRACT:**The Portrayal of Disability In Young Adult Fiction: a critical examination.****Audrey Baker**

This inter-disciplinary dissertation explores the depiction of disability in realist young adult fiction from 1980 to 2014, published in Ireland and Britain. It examines narratives to test whether it may be possible to portray the reality of disability, present positive role models and enabling fictions for the disabled while simultaneously increasing the nondisabled's understanding of disability. Thus it examines fiction's relation to ideology. To date research into the subject of disability in children's books has been concentrated on titles for the very young with young adult literature receiving minimal attention internationally. No academic study has been done at all in the Irish context.

The project is informed by sociology, psychology and, most particularly disability studies as well as literature. Young adult books are critically examined to see if, or how far, each adheres to modern perceptions of disability and it considers the images used, what 'message' is conveyed to the new generation of readers as well as how realistic a picture is created. The books analysed in this work were chosen to highlight the current picture of disability found in young adult fiction.

I concluded that some novels have dealt with aspects of the disability experience well, especially those written since 2000. Others show inaccuracies, mediocrity and even prejudice with an overall lack of excellence.

My thesis will make a contribution to the body of research in Children's Literature, especially in young adult fiction. It will also contribute to the relatively new use of disability studies to inform criticism in general literature. As disability features in all eras and all genres of literature, it is logical that it should take its place along with gender, post colonialism and Marxism, for example, as a basis for literary criticism

INTRODUCTION:

This interdisciplinary dissertation explores the depiction of disability in realist young adult fiction from 1980-2014, published in Ireland and Britain. The current assumption is that young adult fiction around disability can usefully be co-opted into the process of improving the quality of life of people with disabilities, that, for example fictional disabled characters can provide positive role models within narratives. This dissertation tests whether it is possible to depict the reality of disability and simultaneously present positive role models and enabling fictions and, in this way, examines fiction's relation to ideology. The premise on which this dissertation is based is the belief that reading does affect the reader.

The work examines the accuracy and realism of the impairments depicted; the complexity of characters, including their natural adolescent development; the role of disability within narratives; the role of society and societal settings and issues that pertain particularly to disability. These aspects will be covered in the eight chapters – institutions, schools, home and family, friends and relationships, appearances, the environment, communications and interpersonal relation. This dissertation is informed by literature, sociology, psychology and disability studies. Disability studies criticism is a relatively new discipline, and is defined in more detail below. The subject of disability in children's literature has received minimal attention internationally and no academic study has been done at all in the Irish context. To date most studies of the portrayal of disability in fiction have concentrated on books for the very young. 'In the Picture', an initiative by Scope¹ (a UK organisation giving support to children with cerebral palsy) is an example; it endeavours to encourage the inclusion of children with disabilities in picture books. Yet young children tend to be more accepting of and open about impairments than older ones. The young adult world is very different and it is here where fiction can play an important part. Usually adolescents all behave in a similar way, follow the same fads and fashions, do the same thing. It is difficult for one to break out of the mould. Consequently teenagers who *are* different are frequently ignored or marginalised, teased and even bullied. It is also excluding for disabled readers to rarely, if ever, have the opportunity to read about 'people like themselves'.

Kapria Daniels (2004) explains that;

it is essential for people with acquired disabilities or even others who are just recognizing their role as part of the disability community to be able to find themselves reflected in the literature. Finding oneself in literature is a fundamental part of self-analysis and a crucial part of the identity formation process because it allows a sense of community to develop as one relates to others who have been down similar paths in life. (no pg).

¹ Scope is a U.K. based charity supporting people with disabilities. 'In the Picture' was an initiative to encourage the inclusion of disabled children in picture books and illustrations.
<http://www.scope.org.uk/support/families/books/kids/10-principles>.

A parallel exploration of this issue is rarely found, yet it has an equal validity; that is the effect of literary images of disability on the able-bodied. Young adults tend to be inexperienced in life, their knowledge and familiarity with disability may be limited if indeed they have any experience of it at all. Therefore, on meeting a disabled person they are inclined to avoid involvement. This, in turn, can add to the disabled person's sense of isolation and 'difference'. However, if familiarity with disability can be achieved through fiction then when meeting it in real life it will not appear so strange. The alleviation of fear can allow interaction and an understanding to grow. Thus both the disabled and the nondisabled will benefit. Essentially, of course, the portrayals of disability, of those who are 'different', must be accurate and realistic and the characters, plot and community must be credible for this to have a positive influence. As a minority, the disabled do not control what is written and for this very reason literary criticism informed by disability studies is crucial.

Disability studies seek to examine how disability is understood in society and the ways in which society excludes those with disabilities through the attitudinal, economic and political stances that it adopts. The founding editor of the *Journal of Literary Disability Studies*² (2006), Dr David Bolt, points out in the introduction that disability is found in every era, in every genre throughout the history of literature and yet criticism informed by disability studies is not yet fully accepted in academia. He contends that 'the vast majority of literary works will be enhanced by critical readings that are informed by disability studies' and that disability will take its place with Marxist, feminist and postcolonial approaches (2007:2).

Literary criticism informed by disability studies can best be understood by examining the current ideologies of the disability movement. In the 1960s to 1970s the disability movement became active and began to politicise itself. It rejected what is known as the medical model of disability. In this model the focus is on the impairment as the disabling factor and disability is portrayed as an individual, personal tragedy. This is the basis for the literary ideas about the disabled as being dependent, pitiable, requiring medical attention to 'cure' the condition and deserving of charity, leading to patronising and paternalistic attitudes where the disabled are not seen as full members of society. This was replaced by the social model. In this model, the impairments are no longer seen as the disabling factors but rather it is society that is the disabler. It is society that erects barriers – physical, attitudinal, cultural, economic or environmental – which prevent or impede people with impairments from equal access to and full participation in society. One can understand how the popularity of the social model grew in the 1970s as it signified a whole new way of thinking about disability. Instead of the disability movement

² In 2009 this journal became *The Journal of Cultural and Literary Disability Studies* and is published by Liverpool University Press.

depending on grace and favour, it became rights-based, demanding equality. People with impairments began to see that their problems arose from social oppression and so they themselves are not to blame. It is not they who need to change but society. Tom Shakespeare and Nick Watson (2002) point out how very liberating this was and is for disabled individuals. The disability movement was able to take its place alongside the other movements demanding equality and a full place in society.

There has been, however, a growing movement of criticism of this theory which was led by some leading feminist disability writers chiefly Morris (1991), French (1993) and Crow (1996). A need has arisen to re-examine the social theory. Although the social model has not suggested that impairment is not part of the model, it has been so played down that it gives that impression. This appears to be deliberate by some theorists like Vic Finkelstein (1996) whose argument is that adding personal experience is to render the social model less effective. Sally French suggests that originally the reason may have been one of 'radical rhetoric' in an effort to convince 'a very sceptical world that disability can be eliminated or lessened by changing society rather than disabled people. Plainly it sounds much better to say: 'people are disabled by society, not by their bodies' than to say 'people are disabled by society as well as by their bodies'. But the result is that impairment is completely bracketed, just as sexual difference was the taboo subject for the women's movement in the early 1970s' (French (1993, p.24: quoted in Shakespeare and Watson (2002, pp.5, 11)),

It is simply untenable to view disability as purely socially created or to believe that 'Once social barriers to the reintegration of people with physical impairments are removed, the disability itself is eliminated' (Finkelstein 1980, p.33). A barrier free environment for one group of disabled people might create difficulties for another group; tactile paving to inform blind pedestrians of a crossing may be hazardous for persons with limited mobility or poor balance. Even if it was possible for every social barrier to be dismantled many people would continue to be disabled by their impairment. Liz Crow (1996) highlights the disabling experiences of pain and of limitation as examples. Simon Williams (1999) contends that seeing 'disability solely as social oppression is really only an option, and an erroneous one at that, for those spared the ravages of chronic illness.' (p. 812). Often it is not possible to differentiate between the effects of impairment and social disability on a person. And for some other impairments there is nothing that society can do. For example no environmental or attitudinal changes can alter the fact that a blind person cannot read body language nor a deaf person hear birdsong. Crow (1996) argues that:

Impairment simply means that aspects of a person's body do not function or they function with difficulty. Frequently this is taken a stage further to imply that the person's body and ultimately the person, is inferior. However, the first is fact; the second is interpretation. If these interpretations are

socially created then they are not fixed or inevitable and it is possible to replace them with alternative interpretations based on our own experience of impairment. (p.6).

Dichotomies tend to be limiting, misleading and often dangerous. So often a situation, any situation, not just one in a disability context, is not a matter of 'either or'. It is surely not a dichotomous situation here and perhaps now, that half a century later, a new model should be forged from the better parts of both the medical and the social models as there is little doubt that the latter has become ideologically narrow and rigid. It should not be forgotten though that politically it has served and indeed continues to serve the disability movement well. There is a third model which incorporates both. This is known as the *biopsychosocial* model which is slowly becoming accepted.

The barriers that the social model erects are usually listed under the headings of physical, economic, political and attitudinal. But most societal barriers can really be reduced to one underlying one, the attitudinal. It is how society views those with impairments that is important. A change of attitude would surely lead to a mitigation of all the other barriers. Jenny Morris (1993) writes:

Nondisabled people's behaviour towards disabled people is a social problem – social because it is an expression of prejudice which take place within personal relationships as well as socio-economic and political institutions (p.67).

It seems clear that the greatest effort should be concentrated on attitudinal change. If societal attitude became more understanding, inclusive and positive about disability the lives of the disabled could be fuller and easier, even 'normalised'. An important part of this could be through examining the representation of disability in literature.

This is not to say that there is no place for the social model in literary disability criticism. On the contrary it provides an excellent foundation if is not too narrowly interpreted. It will become evident from my research that society does further disable those with impairments but impairments can be, and usually are, disabling in themselves.

An understanding of the two models of disability that underlie literary disability criticism allows the critic to seek out any unconscious or hidden prejudice by the author and to assess his or her depth of understanding of what Tom Shakespeare (2014) calls 'actually existing disability', the meaning of disability and the reality of the disability experience including its diversity regarding both impairments and contexts and 'the breadth of everyday life' (p.4).

However, Tom Shakespeare (2014) is critical of literary disability writers. He says they are more concerned with the written word than with the lives of disabled people, preferring to study representation rather than engage in experiential research. He does accept that while Rosemarie Garland Thomson is 'not wrong in stating that cultural representations inform lives – at least to some extent I would hypothesise that even the best book or film review is unlikely to be as powerful as hearing the voices of the disabled' (p.52). This is debatable: he could be right if society listened to the voices of the disabled but there is little evidence of this. It should also be remembered that empirical research is not completely neutral, it 'always produces results implicit in its underlying assumptions' (Cameron, 2014, p.34), and its efficacy can be over emphasised.

Perhaps Shakespeare is underestimating the possible influence and power of the written word and thus the works of cultural disability writers. Dr Chris Saad (2004) in an article entitled 'The portrayal of male and female characters with chronic illnesses in children's realistic fiction, 1970 to 1994' is one amongst many who argues that literature changes children's attitudes. He quotes a meta-analysis of studies of children's books published between 1970 and 1982 in which twenty-one studies demonstrated the ability of literature to affect children's attitudes; only two had inconclusive results. Robert Probst suggests that adolescents may be seen as ideal readers as they are usually characteristically preoccupied with themselves and thus likely to participate fully in the text. (1988:4). Another endorsement of the premise on which this dissertation is based is the belief that reading does affect the reader comes from Ann Pointon (1995)

Society informs literature but it is also informed by literature. Images help to build up and reinforce negative attitudes to disabled people that have accumulated since man began to write), which translate . into discrimination in life. (no pp).

If there is no literary disability studies criticism, overwhelmingly negative, erroneous and inaccurate representations and prejudiced opinions remain unchallenged and reinforced. Stephen Kuusisto and Petra Kuppers (2007) writing in *The Journal of Literary and Cultural Disability Studies* suggest that:

the most radical project of disability studies is not only to show, how deeply disability is woven into our shared cultural fabric, but also to offer ways forward, towards aesthetics that do not merely reproduce any master's voice, but that show the beauty in the irregular, the pied, aesthetics that willfully (*sic*) play with language's location on the limits of personal embodiment and social construction. (p.74).

Writers Rebecca Butler and Kathy Saunders agree that an awareness of the two models of disability is essential for literary disability criticism in order to seek out prejudicial attitudes.

Butler (2005) writing in *A Journal of Children's Literature Studies* claims that the gravest problems of the disabled lie in the eye of society and that it is important for the future that young readers should be encouraged to view disability from a social model view Saunders (2004) in an article, 'What disability studies can do for children's literature' proposes that texts should be examined to ascertain if the author has created a medical or social model of disability. This, she contends, 'offers a basis for critical interrogation, which reaches closer to the 'disability experience' and so can 'help to identify hidden bias or ideological representations that might be otherwise non-critically assumed to describe the inevitable nature of life.'

This dissertation sets out to do what Saunders proposes. One of its essential tenets, though, is that neither model of disability should be interpreted narrowly or rigidly but seen as open ended and fluid structures in order to include the many and diverse aspects and issues of the disability world. .

Several constraints were evident at the onset of the project with regard to choosing parameters and the organisation of material. The reading choices and habits of any young adult are not confined to what are now marketed as young adult novels, novels published expressly for young adults. The line between young adult and adult is by no means clear-cut. This fact is highlighted by the 'crossover' book. A crossover book is one deemed by publishers to be interesting to adults of any age and is produced with two different covers, one apparently appealing more to the younger and the other to the older readership. The young adult novel is a relatively recent phenomenon. The emergence of a serious body of literature, targeting young adults was finally acknowledged in the US in 1971, according to Michael Cart (1996). The emergence was a little later in Ireland and Britain. All the novels examined in this dissertation are novels published since 1980 specifically for young adults. The writers are either Irish or British and the majority of books are published in Ireland or Britain with a few published elsewhere but written by British or Irish authors. I chose the 1980s because by then, the disability movement was firmly rights-based and concurrently there was an upsurge in children's book publishing particularly in its new genre, the young adult novel.

The works chosen for this dissertation all depict disability within realistic rather than fantastic settings. While there is an argument that difficult issues and subjects can be dealt with sensitively through fantasy novels, the aim of this work is to find narratives that reflect as far as possible the reality of disability and the lives of young adults. The plot, the setting, the characters and the impairments which, in the most part are lifelong, should be possible in the non-fiction world. Consequently any 'magical' solutions or resolutions are avoided.

Each novel featuring disability is examined with a view to ascertaining its possible contribution to the improvement of the lives of young adults with disabilities. It is difficult, if not

impossible; to describe what the novel should contain to do this. There cannot be one single answer; it would be like producing a definition of a 'good' book. I will argue, however, that there are four vital elements: the first is an accurate and realistic description of the impairment and its effects: the second is that the book should appeal to the nondisabled as much as the disabled readers; a third element is that the chosen fictional social world, in which the disability is portrayed should also be credible. Finally, it should create a picture of disability which does not perpetuate the negative attitudes or erroneous beliefs of the past. Disability need not be the central theme or even part of the central plot, Lois Keith (2004) points out that;

young readers today need what they have always needed: good books which let the imagination do its own work; provide them with a valuable literary experience; teach them things they don't know. and help them understand things they do; make them laugh or cry. They need books with lively, well rounded, memorable. characters. Some of these characters will be disabled... (no pp)

Ideally, too, food for independent thought and critical reflection might be included. Underlying the narrative is the author's attitude and it is his or her use of the medical or the social model of disability which gives a conscious or unconscious 'message' to the readers.

Disability is not homogeneous; a person with impaired hearing will have different needs and experiences from a person with an amputated leg for example. There are wide differences even between people with the same impairment; its effects depend upon its severity. Cerebral palsy is an example where the effect can vary from being barely discernible to causing almost complete immobility and lack of speech. At the same time all those with any sort of impairment will experience some barriers in common. Michael Oliver (1990) found in his work that if a sociological study is organised according to impairments, a medical model bias is suspected but it should be borne in mind that this dissertation is not a social study of the disabilities of 'real' people in the 'real' world but fictional characters in imaginary worlds. One cannot research their lives any further than the page. The young adult novelists' choice of social barriers is so overwhelmingly attitudinal that to organise it according to social barriers would be unwieldy. This is not to imply that the writers' choices are narrow, but most writers tend to focus on one or two particular aspects of the general experience of disability. In order to make a framework for judging the usefulness of a piece of fiction in improving the quality of lives of young people with disabilities, I have devised eight categories in which to analyse the narratives. Each is based upon what is central in the lives of adolescents and each constitutes a separate chapter which, together with an introduction and a conclusion, form the structure of this work.

The overall question asked in each chapter is simply what picture of disability is given? The first three chapters explore the described experiences in the places that would be most familiar

to young people with impairments – institutions, schools and the home. These are followed by an investigation of the portrayal of the most significant concerns of adolescents: making friends, appearances (looking different) mobility, and communications. The final chapter examines the treatment of those who have problems with interpersonal relationships (leading to behaving differently). Consequently, where appropriate, a novel may appear in more than one chapter, as different aspects are analysed. For example, friendship might be an important factor in the same novel as communication, so each issue is analysed in the appropriate chapter.

A further problem arose in regard to the terminology to be used. Throughout this thesis the noun impaired is used to denote a person who has some physical, sensory, cognitive or psychological problem which impedes or prevents full functionality in some or all aspects of life. When the word disabled is used to describe a person, the impairment is included along with societal barriers. The words nondisabled and able-bodied are used interchangeably.

Chapter 1: Institutions include hospitals, rehabilitation homes as well as asylums. Institutions are still firmly connected with disability in the mind of the public. It is not many years since those who looked or behaved differently from the norm were put away, out of sight and out of trouble. The fictions in this section include three historical novels namely Rachel Anderson's *Black Water* (1996), Julie Hearn's *Rowan the Strange* (2005) and James Riordan's *Sweet Clarinet* (1997) where there is a challenge for the writers to create an authentic historical atmosphere without endorsing the nineteenth and early twentieth century attitudes towards the disabled, not least the demeaning language. There is also a challenge for those writers who chose more contemporary institutions as a setting and I will discuss three further novels: Susan Sallis' *Sweet Frannie*³ (1981), Hannah Cole's *Bring in the Spring* (1993) and Jane Mitchell's *When Stars Stop Spinning* (1993). I conclude with the argument that, for the most part, they endeavour to blend the social with the medical model.

Chapter 2: Schools are undoubtedly an institution by another name. They have been treated separately in my dissertation as, school is an experience shared with almost all young readers and the place where the nondisabled young adult is most likely to meet a disabled young adult. There are several parallels between schools and institutions, the sense of belonging or exclusion, bullying and the quality of education offered and Rachel Anderson's *Black Water* is used here as well as in the previous chapter. School, as a setting, does not feature as frequently as one would expect, although most protagonists are of school-going age. It tends to appear sporadically in various episodes, rather than as a consistent background. Snapshots of school life discussed in this chapter are found in Lois Keith's *A Different Life* (1997), Brian Conaghan's *When Mr Dog*

³ Also published in the U.S.A. as *Only Love* Harper & Row, New York. 1980

Bites (2014), Mark Haddon's *The Curious Incident of the Dog in the Night-Time* (2003) and two stories in Rachel Anderson's *The Bus People*⁴ (1989). A negative picture of special schools is common to all. Jean Ure produces a fuller picture of school life in *Cool Simon* (1992) but she is targeting a younger audience. Finally Jay Ashton's *Killing the Demons* (1994) is discussed. The problems of making friends and bullying in school are topics in this novel, but remain unresolved. It is surprising that the complexities of school life facing young adults do not take a more prominent place in young adult fiction. This contrasts with the emphasis on home and family relations, which are the subjects of the next chapter.

Chapter 3: Home and Family. In this chapter one of the most common settings, the home, is discussed. Several barriers can be identified here like lack of finance or community support, forced dependency and overprotective parents. The effects of disability vary considerably depending upon the member who is disabled. There are examples of a grandmother with Alzheimer's in Ann Fine's *The Granny Project* (2006). There are also examples of disabled parents: a mother who has Alzheimer's in Ishbel Moore's *Daughter* (2001) and two fathers, one with a brain injury and the other with depression in Judi Curtin and Roisin Meaney's *See If I Care* (2007). Sibling relationships are investigated in detail, mainly through Helen Flint's *Not Just Rescuing* (2002), Rachel Anderson's *This Strange New Life* (2006) and Elizabeth Laird's *Red Sky in the Morning* (2001). The value of the inclusion of an impaired character in a secondary role, that is one not vital to the main plot, is demonstrated in this chapter as well as in others. The medical model of disability appears to be used in several narratives and this chapter will show that it does not necessarily suggest prejudice or a lack of understanding of disability

Chapter 4: Friendship. This chapter highlights what is undoubtedly the major concern of adolescents. Research suggests that it is more difficult for disabled children to make friends than it is for their able-bodied contemporaries (see for example Morris (2001) Watson (2002) O'Connell (2005) Gay (2009)). Chapter Four examines whether this is reflected in young adult novels and suggests some possible reasons for this. There are also comparisons with the handling of romantic and sexual relationships between narratives that feature disabled protagonists and those that feature able-bodied protagonists. The titles chosen for examination in this area are Jean Ure's trilogy featuring Marianne and Abe (1981, 1985, 1989) Lois Keith's *A Different Life* (1997), Shelley Ashworth's *Paralysed* (2006), Helen Flint's *Not Just Rescuing* (2002), Linzi Glass' *The Summer the Gypsies Came* (2006), Jean Willis' *Naked without a Hat* (2003) and Brian Conaghan's *When Mr Dog Bites* (2014). There is a brief discussion on the difficulties of being a friend to a

⁴ *The Bus People* is a collection of short stories or vignettes, each centring on a young disabled person who is a passenger on a bus going to a special needs school. There is a variety of stories but most of the characters have been failed by an adult. This is the only book of short stories used in this thesis, all the other books are novels.

disabled person with reference to two novels, Tabitha Suzuma's *A Note of Madness* (2006) and Siobhan Parkinson's *Blue Like Friday* (2007). Several important issues and different perspectives appear in this chapter, the endorsement of old myths and misunderstandings and the almost taboo subject of sex and disability for example.

Chapter 5: Young adults are self-conscious about their appearance. The current emphasis on impossibly perfect bodies in advertising and the media in general, naturally increases oversensitivity but comparison with peers will always have an effect too. Therefore those who have a physical disfigurement like the lack of or a differently-shaped limb or some other deficit or blemish feel at a considerable disadvantage. The question of cosmetic surgery arises. Unexpectedly in almost all the novels where the characters look 'different' they are represented by facial scarring or disfigurement. There are few other disfigurements portrayed. The novels discussed here include James Riordan's *Sweet Clarinet* (1997), Gareth Thompson's *Anarchist's Angel* (2009), Helen Atunase's *Face to Face* (2002), Benjamin Zephaniah's *Face* . (1999) and Melvin Burgess' *Sarah's Face* (2006). These are concerned with facial scarring and its attendant social problems. The problems of those with the characteristic appearance caused by a chromosome disorder or Down's syndrome is highlighted in two very different stories, one by Rachel Anderson in *The Bus People* (1989) and the other by Jean Willis in *Naked Wearing a Hat* (2001). These in particular, raise questions as to how one judges others by appearances. A very positive picture of a character with severe physical deformities is drawn by Siobhan Parkinson in *Sisters No Way!* (2001)

Chapter 6: Mobility. Travelling around is also something that teenagers like to do, not necessarily to faraway places, but merely to the local shopping centre to 'hang out' with their friends. Physical barriers like steps instead of ramps, pavements without dishing are impediments that society can easily rectify. There are remarkably few references to the physical environment in young adult novels. Where it is mentioned, it is almost exclusively the concern of a wheelchair user. Wheelchair users are an important part of this study due to the fact that as the wheelchair is the universal logo for disability, its familiarity might tempt writers to use it as a short cut to denote disability. Consequently, the depiction of the wheelchair user is investigated in order to see if she or he is a fully fledged character or merely an extension to the wheelchair. Books referred to in this context include Lois Keith's *A Different Life* (1997), Jay Ashton's *Killing the Demons* (1995 c.1990), Catherine McPhail's *Wheels* (2003), Catherine Sefton's *The Beat of the Drum* (1989), Susan Sallis' *Sweet Frannie* (1981) and Gillian Cross' *Calling a Dead Man* (2004) with some passing references to Hilary McKay's *Saffy's Angel* (2001) and Róisín Meaney's *Don't Even Think About It*. (2006) In addition to a discussion of environmental barriers and wheelchair users, I include one piece of fiction which has some reference to the socio-economic barriers, *Walking on Cracks* by Julia Donaldson (2009) and I conclude this chapter with an analysis of

environmental barriers experienced by those with impaired sight, using Jean Ure's trilogy of Abe and Marianne (1981-89) and Michael Coleman's *Going Straight* (2003). Another barrier to making friends is the inability to communicate freely and this is examined in the next chapter.

Chapter 7: Communications. The importance of communication especially for the young adult in current society cannot be overestimated. It is the portrayal of the barriers facing those with impairments which affect their ability to speak that is investigated here. How much these difficulties are due to the impairment and how much to society, according to the depictions, is discussed. The portrayals of three groups of young adults with impairments are analysed, those with impaired hearing, those with cerebral palsy and those who have undergone some traumatic event or experience. The novels chosen to illustrate these groups are Melvin Burgess' *Loving April* (1995), *Secret Songs* by Jane Stemp (1997), Jana Novotny Hunter's *Read My Lips* (2002), Jean Ure's *Cool Simon* (1992) and Geraldine McCaughrean's *The White Darkness* (2005), all featuring characters with impaired hearing. Rachel Anderson's story 'Micky' in *The Bus People* (1989), Hannah Cole's *Bring in the Spring* (1993) and James Riordan's *The Gift* (2004), feature characters with severe cerebral palsy which has affected their ability to speak. Malachy Doyle's *Georgie* (2001), Siobhan Parkinson's *The Moon King* (2007) and Rachel Anderson's 'Fleur' in *The Bus People* all centre on the rather unusual disorder of elective or selective mutism. The singular difficulties created by Tourette's syndrome are examined in Brian Conaghan's *When Mr Dog Bites*. The measure of success that the writers have in conveying the thoughts of those with speech difficulties within the narrative is examined. A novel published in the US, *Stuck in Neutral* by Terry Trueman (2000) is introduced in this chapter as an example of a book which contains controversial issues, much greater than any found in books published in the UK or Ireland.

Chapter 8: Interpersonal Skills (Behaving Differently). Although the main issues in the fictions in this chapter could come under the heading of the previous chapter, there is a complete shift away from the physical inability to speak to using a different world view based on a different logic. This is caused by Asperger's syndrome, a popular disability chosen by young adult writers. To single out a particular impairment might seem contrary to the previous arguments against using the medical model of disability as a basis. The reasons for making this exception is the number of young adults novels featuring this syndrome, and the competent handling of it allows comparisons to be drawn. Three novels, Anthony Masters' *Spinner* (1995 c 1993), Siobhan Dowd's *The London Eye Mystery* (2007) and Mark Haddon's *The Curious Incident of the Dog in the Night Time* (2003), each with a different approach, are chosen and compared and contrasted. It is then clear how disability can be incorporated into a novel successfully, how a novel 'about' disability can be an inclusive book (that is appealing to both disabled and nondisabled readers). It will also show that at least one of them, Mark Haddon's *The Curious Incident of the Dog in the Night-Time*, fulfils all the criteria that are set out in the opening of this introduction.

The novels discussed in each chapter of this dissertation were each chosen to illustrate a particular point or to substantiate the arguments. They might show either a firm understanding of disability or hidden, even unconscious, prejudices. This dissertation will not only alert writers to the complexity of depicting what Tom Shakespeare calls the ‘experience of disability’ by showing how the writers have achieved a representation of some aspect of disability successfully and conversely how they have failed. But it will also highlight how a successful portrayal can be achieved within a narrative. Although, for the most part, the examples given are positive, weaknesses, prejudicial attitudes and unsuccessful writing examples are included to point out possible pitfalls for future writers. It is hoped that this dissertation will assist writers in producing high quality literature featuring disabled characters. It is also hoped that this dissertation will be built upon by other researchers. Publishers, editors, librarians and parents will be able to use the research as a guideline for judging future narratives featuring disability. Thereby, by denouncing prejudicial approaches, children’s literature as a whole is enriched.

CHAPTER 1: INSTITUTIONS

Institutional care is now looked upon as a last resort; family and community are seen as the preferred carers of the disabled. It was not always thus which is probably why institutions and the disabled are still closely linked in the public mind. Three young adult authors have set their narratives in times past: Rachel Anderson's *Black Water* (1996) shows a nineteenth-century institution in England for the disabled. It was during that century that there was a great enthusiasm for building institutions to house the sick, the disabled and the unwanted. There was an equal enthusiasm and optimism for finding cures for every sort of illness or disability and much experimentation took place. Julie Hearn's *Rowan the Strange* (2009) and James Riordan's *Sweet Clarinet* (1998) are set during the Second World War when institutions were still widely used. Sometimes however there is no alternative and children and young people need to spend long periods away from home in hospitals or rehabilitation centres. These are represented in young adult fiction by Susan Sallis' *Sweet Frannie* (1983). Hannah Cole's *Bring in the Spring* (1993) and Jane Mitchell's *When Stars Stop Spinning* (1999). There have been many horrific anecdotes told of ill-treatment and cruelty meted out to children in institutions and rarely does one come across a personal account extolling their virtues. Even when the residents are cared for well, there tends to be other drawbacks – the postcolonial attitudes of paternalism or authoritarianism create dependency and these attitudes can be found in the more modern small homes as much as the old large hospitals (Goble 2004). Psychologists and sociologists concur that spending extended time away from a family life tends to be psychologically and behaviourally damaging. Jenny Morris (2001) for example claims that institutionalised care in childhood can increase the likelihood of social isolation in adulthood. Other research concludes that, 'disabled children in residential schools are in grave danger of growing up without the opportunity to develop 'ordinary' relationships with family, school friends, neighbours, or other young people in the wider community. Instead, these relationships are replaced with paid staff who teach or look after them leading almost inevitably to an institutionalised adult life' (Wilson and Jade 1999). Donal Toolin (2003) from his personal experience reminisces that he had a very confused idea of family as he had spent much of his early years hospitalised far from home. He also draws attention to the fact that growing up in that situation there was an emphasis on what was wrong with you which was very negative.

Historical novelists need to convey past society's perceptions and ideologies for their novels to be convincing and successful. It might be argued therefore that is not worthwhile examining historical novels with a view to judging the modern depiction of disability. On the contrary it can be quite revealing especially as the authors may be influenced by the social model of disability, while the medical model would be authentic in their novels. It is likely that the authors would expect their readers to, at the very least question bygone customs. Besides,

although the physical conditions and the treatments may have improved exponentially, prejudices and misconceptions still linger. The idea that mankind has become more enlightened through the ages cannot be sustained, especially in the field of disability: superstitions may be fewer but suspicions, prejudices and stigma remain and the barriers of isolation are as real today in many contexts as they were a hundred years ago.

Rachel Anderson's novel, *Black Water*, shows conditions in Britain in the nineteenth century. Her description of 'The Royal Sea Bathing Hospital for Sick and Crippled Children' is unattractive, of large dormitories with a row of twenty beds down one side facing an equal row the other, a typical Nightingale ward of the period. The children were aged between three and fourteen with all sorts of impairments. The environment, the treatments (based on sea water) and the lack of rehabilitation would not be tolerated today in most Western countries. Anderson is able to convey the nineteenth century perception of disability through Albert's eyes: '[they had] all manner of extraordinary deformities ... victims of rheumatic fever and the wasting disease, children with unseeing eyes, twisted backs, withered limbs or clubbed feet, such unnaturally misshapen creatures they seemed scarcely children, more like the gargoyles spouting from some ancient church guttering' (pp.114-115). He speaks of the crippled, hunchback and midget (p.122).

The words and phrases used by Albert would be unacceptable nowadays. However, intrinsically words have no value; it is the intent behind them that counts. It is possible to trace changes in terminology to show how one term, pejorative to contemporary ears, was once coined to replace another deemed offensive. 'Idiot' was replaced by 'dunce', then 'mentally defective' became 'educationally subnormal' for example, or 'mentally defective' and in turn the same people were defined as having 'learning difficulties'. There are cultural as well as historical variations as well, for example the word 'retard' is still used in the United States. Indeed the stigma attached to learning difficulties and mental health was and still is so strong that there are a myriad of alternatives and euphemisms. There are more examples of what would now be seen as demeaning language in Julie Hearn's novel, *Rowan the Strange* which is set in the 1940s. With words and phrases like 'lunatic asylum ... big house on the hill, full of murderers and raving idiots', 'helpless feeblers', 'loonies' (pp.79, 100), it is plain that little had changed in the twentieth century. Name-calling continues as can be seen in many of the other books highlighted in this dissertation.

Being stared at is something that most disabled people experience. Albert, who has epilepsy, is aware that people gather to watch when he has a seizure and he himself watches another. Two other young adult novels have characters with epilepsy in contemporary settings and they are given similar experiences (Brian Keane (2001), *Falling for Joshua* and Jenny Marlowe (2000), *The Night Garden*). As Tom Shakespeare (2004) states 'it just happens' that

people stare (p.5). But it is not a chance encounter in the seaside town where Anderson has placed the institution. Tourists view the groups of disabled children as 'yet another local spectacle' and stare and point at them (pp; 117), a reminder that a favourite nineteenth century occupation was to visit asylums to watch the 'mad' or to go to the travelling 'freak shows' where people used to pay money to view those whose bodies deviate from the perceived physical norm. Although it would be seen as unacceptable voyeurism today to put on a freak show as such, television documentaries can be said to fulfil a similar function. In spite of the name not all aspects of these freak shows were negative. They gave the disabled an opportunity, usually denied them, of earning their own living and the enabling feeling of belonging to a group. (Marks, 1999). This is another issue of which Anderson shows an awareness in *Black Water* when Albert joins the hospital and for the first time in his life he 'was not the outsider'. He welcomes having his head shaved as he sees this as a physical sign of belonging (p.119). Segregation is rejected by disability activists who continue to emphasise inclusion. There is an exception. Some deaf people do not want mainstream society to restructure so that they can be included. Instead they want to exist as a linguistic minority within society (Corker 2001, p.7). (See chapter on communication). In this novel, Albert has been isolated outside the institution, always seen as the other whereas within the hospital he can identify with the others who accept him as he is. There is plenty of evidence to sustain the frequency of this in real life. For example Morris (2001) refers to one of her earlier papers, *Space for Us* (1999):

One young woman with cystic fibrosis talked of the importance to her of friends who have similar experiences: 'when I'm admitted to hospital we sit around in a cubicle, not very big, talking about things... It's nice to have a peer group – to have a good chat with' (p.13)

Of course one does not have to be disabled to want to be in a peer group. The Outsider is a familiar figure in all literature and there are many examples in the young adult genre. With his or her impairments, the disabled person is 'different' and an obvious outsider and it does appear to be more difficult for the disabled to find or form a peer group. Again Jenny Morris refers to a worker in an institution for children with multiple impairments who said that the biggest thing missing in such an establishment is peer group pressure on one another to do things differently. The worker claims that the residents tend to communicate with the nondisabled adults rather than with each other (p.12). In tracing Albert's lonely and isolated life up to his entry into the hospital, Anderson has taken an unusual angle to the idea of the Outsider.

Both Julie Hearn and James Riordan have placed their characters in English institutions during the Second World War. Riordan does not convey much institutional detail in *Sweet Clarinet* (1988) but it is referred to from time to time. Hearn's *Rowan the Strange* is a well written

and tautly constructed novel with a serious examination of a cognitive disorder. Hearn has succeeded in creating an interesting narrative with plausible characters. It makes a significant contribution to the body of young adult fiction featuring disability especially as it can be judged as an 'inclusive' book. By this I suggest that it would have a wide appeal for both disabled and nondisabled readers. Although it highlights a medical model view, being set in a private hospital and centring on an attempt to cure Rowan and other patients with cognitive disorders, Hearn introduces other serious and related issues resulting in some food for thought. While other children are being evacuated, thirteen year old Rowan is sent to a psychiatric hospital or private asylum where he undergoes electro-convulsive therapy (ECT). ECT was relatively new, experimental and controversial in the 1940s and remains a very controversial treatment to the present day. It would not be used for adolescents now except on very rare occasions because of concerns about its safety. (www.patient.co.uk/doctor/electroconvulsive-therapy.htm [accessed 22.05.14]). Deborah Marks (1999) suggests that the medical world can overreach itself where the disabled community is involved and actually cause more harm to patients (65-69). Hearn describes the horrors of the treatment but continues the debate by suggesting that some of the patients show an improvement, even a cure, while others do not. Even the doctor championing the treatment expresses doubts in its efficacy in the end as he wonders what part other factors might have contributed to Rowan's possible cure (p.307).

The initial description of life in the hospital is focalised through Rowan who does not fully understand what is happening. The building is isolated on top of a hill. Like the hospital in *Black Water* patients live in large dormitories. Here though the tall windows are nearly all barred and the chairs are bolted to the floor (pp.81, 211, 296). There is also no privacy. A nurse guards the ward at all times and the bathroom and toilet are without doors although later in the story the doctor produces screens. He decides they are necessary as the ward is mixed with regard to age and sex (p.83). Surprisingly, in James Riordan's *Sweet Clarinet* the main character, Billy, has a room to himself. His surroundings appear to be more comfortable than Rowan's as the home he, Billy, is in was a country house before the war, complete with a ballroom and extensive grounds. Many country houses had been commandeered for use as hospitals and homes during the war. Admittedly his room was down a 'dingy' corridor (pp.24, 26) and of course there was no need for bars on the windows. The patients' age range is not clear as Riordan depicts Billy as depressed and very antisocial so the reader meets just one other teenager, a girl, who occupies the next-door room. Riordan gives Billy no feelings of belonging to the group of people who are similarly disfigured or indeed anyone else. As Billy leaves to go to college, he claims 'I gave no backward nostalgic glance: the Home had helped tide me over the 'lost' years yet I felt no warm attachment to it.' He argues that like other evacuees, he finds that 'however well-meaning, their new guardians and friends, they can never replace the love and sense of belonging of home' (p.107).

This is a valid argument, but Riordan never gives the impression that his character feels much affection for anybody although the reader may be surprised to discover that when Billy is in music school, that he 'never forgot' his old friends to whom he wrote regularly (p.113).

Hearn's description of institutional life is more detailed than Anderson's and Riordan's but it does not appear that there had been any great improvement in institutional treatment in the first half of the twentieth century and indeed improvements continue to be very slow in the realm of mental health in general. Some of the others in Rowan's ward illustrate this. For example, the tragic tale of the other teenager in the ward, Dorothea, is not dissimilar to the recent revelations about the Magdalene laundries in Ireland. Dorothea was not locked up because she was pregnant but because she saw angels on people's shoulders. Her family found her abnormal, incarcerated her in the hospital and abandoned her, never visiting, never writing or acknowledging her existence.

Hearn creates a tension which runs through the narrative and peaks at dramatic incidents. This is apparent from the beginning, and a feeling of apprehension deepens as soon as Rowan arrives at the hospital. For example, when the nurse returns having given Rowan a medical examination, she proclaims in answer to the doctor's simple question of 'Well?' that he is thin but in excellent health. This makes Mrs Scrivener shiver because it reminds her of the witch in Hansel and Gretel who put children in a cage and fed them sugar buns and gingerbread until they were fat enough to be cooked and eaten. Further 'A ripple of something – excitement, anticipation – caused each man to fidget a little, to smooth his hair or adjust his tie' when Rowan's grandmother asks what form of treatment her grandson would undergo. She is given no details, just vague lies (pp.73-75). All the elements suggest mystery and threat which draw the reader into the story. The doctors discuss the possible dangers of the treatment but, as it is set during the war, Dr Von Metzger's character, a German, evokes in the reader a sense of potential threat and even torture (pp.88-89). The reader is unsure whether the hospital is a safe place dedicated to healing or whether cruel experiments will be carried out to find cures to make it famous and enrich the director. Certainly the latter hopes to be famous and rich and Hearn subtly uses the director's gold fountain pen to symbolise this. Cruel experiments are carried out, by the benign Dr von Metzger, not with cruel intent but in the belief that he will be able to cure patients with this new experimental therapy. Hearn allows the debate to continue with some of the patients apparently improving from the treatment whereas with others it had unexpected results. In the end even von Metzger wonders about its efficacy and looks at other factors which equally may have influenced some of his patients.

Again the idea of belonging is important. Rowan feels that he and the other teenage patient, Dorothea and indeed von Metzger are like a family (p.160). He is at ease with them and,

later with the rest of the ward. There is, however, no peer group and Rowan spends a great deal of time in adult company during his hospitalisation. He also found it strange mixing with the public (p.296) and on more than one occasion he expressed fear at rejoining his family (pp.247-248, 290) which is a common feeling after a prolonged absence in an institution.

Although Rowan's disability and its treatment are central to plot, there is much more to the story. Eugenics is introduced as the German doctor gets a coded Christmas card telling him what is happening in the medical world of Nazi Germany (pp.214-219). The interest in eugenic and controlled euthanasia may have peaked in the early 1900s but was not confined just to Nazi Germany by the 1940s. Nowhere was it carried out as it was in Germany but for example some states in the US practised sterilisation of the 'feeble-minded,' and the criminally insane up to the 1950s (Marks 1999, pp:27-29). The use of amniocentesis can provide a choice in the prevention of the birth of a disabled person but it raises moral and ethical issues as well. The debate continues and it is a debate in which young adults will increasingly be involved as strides are made in genetic engineering and branches of medical science, making further decisions and choices possible. However, nowhere in Irish or British young adult fiction do these ethical questions come to the forefront. Rather than contributing to the debates when controversial issues arise, they tend to be, as in *Rowan the Strange*, just 'mentioned'.

The three remaining novels are set in contemporary times. Susan Sallis in *Sweet Frannie* (1990 c 1981) places her teenage protagonist, Frannie, in what seems to be a rather unrealistic institution. Like Billy's home in *Sweet Clarinet* it is a country house but well cared for and luxurious. Its twenty clientele comprise the elderly as well as the young. Apart from it having well tended gardens and a swimming pool, there are few other details. Frannie does not show any signs of wishing to be outside the institution. In her own way she is very much part of the community although she does not appear to bond with the other residents until another teenager's arrives and she falls in love with him.

The home for disabled children in Hannah Cole's *Bring in the Spring* (1995) is not physically described but the reader learns a little about the lives of the young children there. There is no suggestion that the care workers are deliberately cruel or careless. On the contrary, Cole shows one of them being anxious that Sarah, the child at the centre of the narrative who cannot communicate, should not hurt herself when kicking her legs and speaking of how pathetic she had been when she first came to the home as a 'scrawny little baby'. These carers are, however, insensitive and unimaginative. Cole illustrates this with the older one finding it 'such a strain lugging her [Sarah] around to get her clothes on.' which seems to her to be rather a waste of effort as she believes that it would not make much difference to Sarah whether she got up or stayed in bed (pp.2-3). The manner in which they use the buggy suggests they see her as an object rather

than a person. For example the buggy was pushed to and fro. 'which made Sarah's head jolt', she 'was tipped back in the chair and spun around,' they 'rattled' over the gravel and 'swung round' (p.5). Furthermore as they believe Sarah is incapable of understanding they talk about her in her presence and she is 'used to listening to people talking above her head or behind her.' (pp.2-5) that Sarah is trying to communicate becomes obvious to the readers as they note whenever she has an opinion she begins kicking her legs or making some vocal noises. The care workers do not make this connection.

Another facet touched upon by Cole is the ease with which the vulnerable children can be short-changed. One carer suggests that the other could use the children's shampoo rather than buying her own. This is rejected as the children's shampoo is 'cheap stuff.' (p.3). There is a more serious incident later in the book where one of the night staff steals money from the children's money boxes on a regular basis. Sarah is the only witness and she cannot speak. Even when the other victims know that their money has disappeared they are unable to persuade the other staff to believe it (p.39). It is not clear if this is because the children are children or because they are disabled.

Cole ends the book with Sarah leaving the home and going back to her mother, thus indicating that Cole prefers the family solution. She also makes it plain that once she has left Sarah will find relationships with her fellow residents changed completely 'she would not belong in this world any more' (p.149). With simplicity, Cole encapsulates the new perception: 'The children stood round Sarah watching her. She had turned into someone new, an outsider.' (p.153)

When Stars Stop Spinning by Jane Mitchell (1993) is set in Ireland, in Lismore House, a fictional rehabilitation home for children. Mitchell conveys the atmosphere of an institution with skill throughout the narrative – the excitement of any change in routine (p.11) and the habit of using euphemisms for the various pieces of equipment used. For example, 'harnessed up' was a term they all used when any of them was wired up to machines. 'It was safer, less direct. They all knew what it meant but it didn't sound so painful' (p.13). The complexity of one's feelings on discharge is presented with sensitivity: 'the sealed self-contained world' which made returning to one's 'previous' life almost 'painful' and certainly frightening (pp.140-141) and so is the awkwardness of returning to an institution as an outsider:

It was very different returning as a visitor to Lismore I felt as though I shouldn't have been walking down the corridors without first reporting to the receptionist. I felt I was interrupting the day-to-day routine of treatment and therapy because I had arrived out of official visiting hours. I felt an outsider immediately. (p.143)

All the narratives set in institutions show a basic medical model of disability; the emphasis on the impairment, dependency, death or cure. The protagonist in Riordan's *Sweet Clarinet* recalls that the matron of the home 'had a habit of reminding us inmates of our disfigurement, as if to emphasise our dependence on her.' (p.87), this an example of expectations in the first half of the twentieth century, yet he is determined. 'to get out there and live life to the full.' (p.94), this suggests the social model ideas of the writer. The medical model background is particularly important in the novel set in the nineteenth century, *Black Water*. But Anderson's own view is also probably influenced by the social model. A large part of the plot is devoted to tracing Albert's struggle in society, with prejudicial attitudes and difficulty in gaining independence. It is similar, if not as marked, with the other writers

Several of the themes which have arisen like communication appear in other chapters, but here, with the exception of *Sweet Clarinet*, the human need to belong is important and the necessity to be part of a group is emphasised. Of course, this need is not confined to the disabled (Smith-D'Arezzo and More-Thomas, 2010). Any random list of young adult novels written over the past few decades will have some titles with plots in which being or not being the outsider or the 'other' is a central component. If it can be a problem for those of a dominant social group which in the young adult fiction included in the study usually would be able-bodied, white and middle-class, then obviously it is harder for those in minority grouping.

What is unusual with regard to institutions, none is depicted as a place to shut away the unwanted except for the case of Dorothy, Julie Hearn's character, who represents the traditional perception, but Anderson, Cole, Sallis, Hearn, Mitchell and, to a lesser extent, Riordan all emphasise the feeling of belonging and safety. At the same time, all the writers ensure that his or her impaired character leaves the institution for what the readers are led to believe would be a better life. The feelings of belonging and safety are not necessarily feelings that young adult readers themselves recognise in the one institution of which the majority of them do have experience, school. School is the subject of the next chapter where other issues are highlighted.

CHAPTER 2: SCHOOLS

Schools are examined here separately from other institutions because most young adults are either attending or have recently graduated from school, and thus it is a familiar trope. However, there is an overlap of issues and two titles, *Black Water* by Rachel Anderson and *Sweet Clarinet* by James Riordan are re-examined in this new context... It might be expected that school or college would feature prominently in young adult fiction, but, more often than not, it was confined to brief snapshots of school life. Only one novel, Jana Novotny Hunter's *Read My Lips* (2002) is actually set in a boarding school. Even then, the context has little impact on the narrative. The school in *Read my Lips* is American and it is a school for students with impaired hearing. Hunter does not deal with the more usual issues faced by disabled students in school because all the students have the same impairment. It features the signing/speaking debate which is of great importance in the deaf world. Consequently, as there are no school issues, this book is examined in the chapter on communications.

With the notable exception of the *Harry Potter* series, school stories so popular with teenagers up to the 1960s are no longer fashionable. In fact, they are no longer possible with the diminished popularity of boarding schools. The traditional school story does not work without the confines of an institution. Day schools mean there is respite from school problems when at home each evening. Social media is altering this but it is a subject that so far is absent from any young adult novel featuring disability. The nearest to the traditional boarding school genre is found in James Riordan's *Sweet Clarinet*, where the author places the protagonist in a music college. It appears to be organised on the lines of the English public school, and one might expect bullying to take place. However, although the protagonist remains very conscious of his scarring, on the whole he experiences less bullying than he does 'outside' and less than his Chinese friend in the college (pp.113-120).

However there are glimpses of school life in several of the novels in this study. The primary issue that manifests itself throughout the novels is accessing suitable schooling. Other issues like making friends and bullying arise, but not quite as frequently as one would have imagined. Other books that are examined in this chapter are Rachel Anderson's *The Bus People* (1989), Jay Ashton's *Killing the Demons* (1995), Mark Haddon's *The Curious Incident of the Dog In the Night-Time* (2003) and Brian Conaghan's *When Mr Dog Bites* (2014). The social model of disability is to the forefront in most of these books as the major barrier is attitudinal. It is also clear in some books that lack of funding and governmental support compounds the difficulties faced by the impaired.

Ironically the novel that best highlights, albeit indirectly, most of the difficulties that are faced by the disabled of today is set in the nineteenth century. It features a character that is denied

education because he has epilepsy. This is *Black Water* by Rachel Anderson (1996). It also illustrates accurately the traditional and historical treatment that was meted out to those with epilepsy. Anderson demonstrates how ignorance and a lack of understanding can cause fear; how fear causes prejudice. She shows how an illness such as epilepsy with its apparently inexplicable seizures provoked fear as it was commonly held that the illness was due to the patient being possessed by spirits, usually ones with malign intent. One 'solution' was to put the person into some institution as has been explored in Chapter 1. The novel is informative from an historical point of view. The protagonist, Albert, has seizures which are part of his 'falling sickness' and from the beginning of the book his mother is terrified that others will get to know about his epilepsy and as a consequence has to be hidden away or avoided. Albert's position as 'an incarcerated invalid' kept hidden in the rooms his mother rents for them changes to that of 'an outcast' when they move to live in a school when his mother remarries (p.83). He is identified by his one disability. He is given no opportunity to show that he might be very capable and competent and able to take a full part in life. There is no effort to include him in any ordinary life or to help him become independent. His step-father, who is by no means unkind to him, articulates the general attitude: 'You will never be able to work, to earn your own bread, to make your own way in life' (p.136). Consequently he is denied education because it 'would be an inappropriate and nonsensical use of effort...' because he is not 'normal' (p.135).

Twenty-first century readers may experience a little complacency in the belief that this would never happen now, that people with epilepsy have better treatment nowadays. This is true, there are drugs to help control seizures and most students with epilepsy are able to go to school. They aim to be independent; they are not put away in institutions. But they, like many others with impairments, still face barriers. Attending school is only part of the solution; appropriate education is paramount. At present teachers, students and their parents might find Albert's stepfather's words that it 'would be an inappropriate and nonsensical use of effort' to make special arrangements for Albert, more familiar if the word effort was replaced by money. Frequently individuals, families, schools and groups are in conflict with government bodies over the funding of aid such as transport, support teachers, assistive technology as well as special classes. Donal Toolin (2001) suggests it is 'because disabled people are not perceived as being equally productive and therefore not an asset within a 'consume and produce' society. (p:98); this evidently is based on the medical model of disability.

Anderson's Albert was told that 'the aim of education is to place children for the position they are thereafter to occupy'. This attitude has not entirely disappeared and many disabled students complain of the teachers' low expectations of them. This is the finding in Goretti Horgan's research (2003) for instance, and Paul O'Connell (2005) quotes one young teenager who was interviewed:

Well, I had heard about science and some of my friends [in mainstream school] were doing science and I thought it sounded interesting. She [the headmistress] said 'There are two things; number one, we don't have the staff and number two, I don't think you are capable of doing it, but anyway I have got a great idea.' So I said 'great'. Ok, it was not going to work out the way I wanted it to but she had got a great idea. So she goes 'There is a guy coming next week and he is a stamp collector', and that was her answer to my education! (p.7)

The debate over mainstream, special, integrated or inclusive schools continues. Young adult writers appear to favour mainstream and paint rather negative pictures of non-mainstream education. Perhaps this is not surprising since studies tend to show students from mainstream schools ultimately become more independent. O'Connell (2005, p.10) refers to a study's findings that disabled people who have attended mainstream as opposed to special education are more likely to live independently and be in employment. But O'Connell further points out that some disabled students have very great difficulty in accessing a place in a mainstream school, that not all schools welcome students who need extra supports and that even when they are accepted, they cannot always take the subjects they wish (*Hidden Voices* 2000, 14-15, Horgan 2003, pp.109ff). This is illustrated in Lois Keith's young adult novel, *A Different Life* when the recently impaired protagonist tries to return, as a wheelchair user, to her local school. The headmaster makes many excuses and suggests she should enrol in a special school instead. Her parents see this as a kind of educational apartheid (pp.229-30).

The special needs schools tend to have negative descriptions. Unlike the school for the deaf in *Read My Lips* where all the students have the same impairment and therefore are equal, most special needs schools in young adult fiction include a variety of impairments. For example, Drumhill Special School in Brian Conaghan's *When Mr Dog Bites* appears to be a rather unpleasant place. The students, who have multiple physical and cognitive disabilities and problems, appear to spend most of their time quarrelling, name-calling and fighting one another. The teenage protagonist, Dylan, describes it thus:

Off-the-radar chats happened every hour at Drumhill – that was why there were always people shouting, screaming, crying or trying to hurt either themselves or each other. On one side of our classroom was Amir with his head down hugging the desk, at the other was Charlotte Duffy doing an impression of the bonkers girl from *The Exorcist*. Add another forty or fifty people to the mix and you had a typical day at Drumhill Special School. (p.144).

There is perhaps a negative outlook within the school. Dylan wants to know about Amir's new girlfriend, 'What's wrong with her?' I only asked because there was always something wrong

with Drumhill students – why else would they be at the school? (p.293). This echoes the negativity found in Toolin’s autobiographical account of his early schooling (pp. 91-92)

Conaghan is creating Dylan’s character partly through his, Dylan’s opinions and as Dylan does not like school he is unlikely to praise it. Drumhill may not be as chaotic as it seems to Dylan because interest has been stirred in Dylan himself in all manner of things, not least his fascination with new words which made him ‘quite like the English class.’ He keeps lists of, ‘mega’ words, one which includes (in descending order):

5. Paradox
4. Discombobulate
3. Degenerative
2. Circumspect
1. Proselytise

and although he realises that most people around him would not understand what ‘big cool words’ meant he persists in using them when he can, adding ‘inebriated, Renaissance, culturally, risotto’ in his essay (pp.29-32).

Another special school, described by a student –the protagonist, Christopher – is found in *The Curious Incident of the Dog in the Night-Time* by Mark Haddon. Christopher states ‘all the other children at the school are stupid’ (p.56). Several of his references to school are negative and he quite often mentions how he has been taught to breathe deeply when hit, which suggests a degree of violence and he includes a ‘poo’ incident (p.129)... However Haddon has balanced the picture with his creation of Siobhán, Christopher’s special teacher, and the reader can see how she is trying to teach him some social skills. Moreover, in a school where apparently some pupils have severe learning or developmental difficulties that at least one other is capable of passing his A- level maths suggests a school where students are encouraged to reach their potential.

The need for special schools is highlighted in one of the short stories in Rachel Anderson’s *The Bus People*, ‘Danny’. Anderson’s Danny is cognitively impaired and cared for by his Aunt Beth. It is a somewhat unconventional upbringing but he is happy making ‘music’ with her from saucepans, painting pictures on the kitchen door and going on bus rides (p.101). Aunt Beth is depicted as having a childlike simplicity and is not very learned. She says ‘... I don’t know about all this reading and stuff. To tell you the truth, I was never too good on that side myself.’(p.111) but she tries to teach Danny practical things. She reluctantly allows him to go to school after a visit from the school welfare officer, but she is not fully convinced that it is the right move; she wonders what good it will be for a ‘chappie like him’ and she is afraid the other children will tease him. (p.105) She is correct in this prediction but the area’s policy is integration and Danny soon finds himself overwhelmed and in trouble with everyone. He ‘couldn’t always speak clearly, or read words’ and he worried about the shape of letters. ‘They

seem to go round and round in front of his eyes, but he couldn't put them in the right order' (p.109). He seems unfortunate with his support teacher and Anderson plainly demonstrates some of the difficulties that can arise for children with special educational needs in mainstream school. As B.Reiser (2002) points out this is trying to change 'the child to fit in with the social and academic life of the school' instead of the school serving the student (quoted in French and Swain 2004, p.169).

Failure to access schooling appropriate to one's needs is not always a social problem. Another of Anderson's characters in *The Bus People*, Micky, is an example. Society has provided a special residential college for school leavers. The barrier he faces is his mother's love. Micky is severely disabled with very little mobility and no speech. Anderson uses a kind of internal monologue for him to tell his tale. He lives with his mother who 'stifles' him with her love. His mother treats him as a child – talking baby-talk to him, decorating his bedroom with curtains of blue teddy bears and stars. This is highly inappropriate but she does not realise that Micky has reached puberty. She makes no effort to teach him to anything to make him independent, possibly because she wants her 'poppet' to remain totally as helpless as a baby. This is suggested as in almost every sentence she uses some infantile word of affection like 'silly billy', 'pet', 'lamb' and even 'wetty boy'. She teaches him colours but not numbers, she does not teach him how to feed himself or how to go to the toilet on his own. In short she keeps him dependent upon her. Her possessiveness is well illustrated, first in her attitude when she is reluctantly persuaded to go to see a residential college home for disabled school leavers and then when he is not accepted because of his high dependency,

He'll be stopping at home with me just so long as I can manage.
I've always promised him that, and whatever you experts say to
the contrary, I'm not going back in my word to him. If you have
a boy like my Michael, he's got to have a lot more love than your
ordinary kid... (p.37)
It was a dustbin place that dump. I'd never let them put you in a
place like that. My own baby. I'll look after you always. That's
mummy's promise. (p.48)

Anderson has made it plain that Micky desires to go to college; he no longer wants to be treated as an infant. So in effect although Micky is unlikely ever to have a 'position', in theory he has the opportunity that nineteenth century Albert was denied, yet he still faces an insurmountable barrier. This is an extreme case, perhaps, but there are many examples of parental overprotection. (Gay, 2009, p. 61. South West Regional Authority, p.27). Anderson has shown vividly how harmful the medical model can be; Micky's mother sees him as a tragic case, a dependent being who needs constant sympathy and care.

The transition from a special school to a mainstream one according to most reports is the most difficult time for any disabled student (see for example Lewis et al 2006:9). This is effectively demonstrated in *Cool Simon* by Jean Ure (1992). Although the protagonist's specific impairment is hearing, and this is very well done, much of Simon's school experiences might be shared by students with other impairments. Simon finds it difficult to understand the teacher in the classroom. He finds himself socially excluded as well as bullied. Reference to bullying or being 'picked on' is found consistently in all the research examined here (French and Swain (2004), Gay (2009), Horgan (2003), Lewis et al. (2006), Smith-d'Arezzo and Moore-Thomas (2010)) Toolin (2003), which suggests it is a major, widespread problem but underrepresented in young adult fiction featuring disability. There are innumerable young adult narratives featuring bullying but few victims are disabled. This is an exception and Ure gives an accurate and convincing portrait of Simon, his impaired hearing and his experiences in school which mirror most of the findings highlighted in recent disability studies research.

Jay Ashton's disabled character, Sam, in *Killing the Demons* (1994) also faces the unfriendliness and bullying mentioned in the above reports. The teenage protagonist, Sam, is a wheelchair user who starts a new school. Her fellow students are unpleasant and appear to go out of their way to make her life difficult. The school had arranged a rota of people to wheel her round which might not have been a good plan. One real-life study noted that some students complained that they were not getting their own work done fully when it was their turn on the rota. (Ballard and McDonald, 1999, quoted in French and Swain. 2004, p: 171). In Sam's case, it would seem that she was dependent on the school bullies, but the scene is unconvincing. This is partially because Ashton is inconsistent with regard to the use of a wheelchair. At times, Sam is apparently dependent upon somebody to wheel her around the school (pp.22, 47) whereas at other times she has no problem wheeling herself around. This sort of inconsistency or perhaps carelessness undermines a sense of reality. Ashton renders the two worst bullies harmless by involving them in a serious joyriding accident (85) but she avoids any resolution to her character settling in school by simply ignoring it.

One other novel in which school is an important context is *How to Write Really Badly* by Anne Fine (1996) but like *Cool Simon* it is written for a younger age group. The subject matter might not interest young adults, but both books are examples of a fellow student giving help to a disabled one. This issue can be problematic in that it can create an unequal relationship of carer and cared for and by obscuring the interdependency of all inhibit friendships. Some students interviewed in the South West Regional Authority's *Hidden Voices* study were enthusiastic about their friends' help and support, others found it embarrassing to be continuously asking for help (p.16).

The socialising aspect of school is particularly important to young people and while this is emphasised almost without exception with regard to the disabled in sociological studies (French and Swain, Smith-d'Arezzo, Gay, Lewis et al, O'Connell), it is not particularly confined to them as it is also important to the nondisabled to be in with the 'cool' crowd (Smith-D'Arezzo and Moore-Thomas, 2010, p.3). School is the place where many people make their closest friends. For the disabled it may be their only opportunity to meet nondisabled people of their own age. Making friends is generally more difficult for the disabled largely because their school contemporaries are not equipped or educated to deal with the issue of disability.

All the disability research consistently shows that disabled students do not want to be different from their nondisabled classmates. They want to 'fit in' and generally do not see themselves necessarily as disabled but as disabled 'for part of the time' or 'only in some ways' (Watson: 2003). Because of this, the impairment is minimised or hidden whenever possible. Jenny Marlow illustrates this sympathetically in *The Night Garden*. Her teenage protagonist starts a new school and hopes to hide the fact that she has epilepsy. Marlowe conveys the lack of sympathy due to ignorance and inexperience that her character receives from her schoolmates. She had 'kidded [herself] into believing that this time, this school, it might just work. And then it was all happening again. (p.6) As she regains consciousness after a seizure she sees' that ring of faces gawping down at her. She recalls, 'some of them were scared, some sniggering nervously – all looking at me as if I was something alien they didn't want any part of.' (pp.6-7). One cannot imagine friendships easily arising from an episode like this and it serves to show the difficulties that young disabled students can face. They are aware of being different and are embarrassed by it. They become alienated, becomes the 'Other '. As long as the nondisabled students avoid getting to know the disabled student it will remain so; yet making an effort to get to know a disabled student may result in the discovery that the disabled '... are very, very normal once you get to know them.' (Smith-d'Arezzo and More-Thomas, 2010, p: 12)

It is surprising that a school environment is so rarely the setting or context for young adult narratives featuring disability. Next to family settings, it would be the most familiar background and would give writers ample opportunity for plot and character development. Adolescents undergo a variety of psychological and physical changes; they are at a stage between childhood and adulthood. School is a stage between home and the outer world. Young people naturally share the societal perception of disabled people; they share society's ignorance and misperceptions. They also are at an age when they tend to be at their most idealistic and are undergoing new experiences. They meet new people and may indeed begin to look at aspects of life from a perspective different from that of will their parents. There is a wealth of material here for any young adult author writing about disability. Yet, the socialising concerns of young adults in

schools highlighted in research reports, such as National Disability Authority's *Encouraging Voices* do not gain such importance in novels. As has been shown, the issue which rises most often is that of accessing suitable schooling: making friends and being bullied are secondary concerns. The analysis of the treatment of disability in schools is hampered by the peripheral place of daily life in schools given in these novels. This contrasts with the place of the home and family, which is examined next.

CHAPTER 3: HOME AND FAMILY

The home and family is a popular context for young adult fiction. It has the advantages of being a natural and familiar background while at the same time, given the dynamics within any family with teenage children, there is plenty of scope for drama, conflict and interest to be used by an author. Additional problems arise when one member of the family has an impairment.

This chapter explores the use of the medical model of disability which is evident in some of the novels in which the home is the basic context and assesses whether its use is justified. It also examines the authors' success in depicting realistically the interactions of the family members, especially siblings and caregivers, and how the inclusion of a disabled family member affects them.

Within this small and enclosed unit of a family there is an individual coping with impairment or a few individuals affected by and often intimately involved with that individual disabled person. From a literary disability perspective this can be problematic. It can result in the over-use of the medical model of disability. The medical model views the impairment as the disabling factor and disability is portrayed as a personal tragedy. The emphasis is on prevention, rehabilitation and cure.

The social model works well on a large scale but it is difficult to see how relevant it can be in more intimate or individual contexts such as the family. The inclusion of a disabled member of the family affects all the members but David Mitchell and Sharon Snyder (2000) explain:

as disabled scholarly partners we have also witnessed the profound impact of disability upon our entire family. The continual navigation and intensive strategies that characterise life with a disability stretches far beyond the parameters of any single individual life; it really routes the circuitry of partners . and children, friends and family in ways that can be described as anything but individual. (xiii).

Generally in young adult narratives the plot revolves around the effects, the coping methods and indeed the impairment itself. Therefore the personal and private lives are the prime interest factors in the plot. Society may have little or no relevance. Further, perhaps the form of the novel itself is a problem because, as Lennard Davis (1998) points out:

The novel as a form relies on cure as a narrative technique. Protagonists must "change," we are told, for their characters to be believable. Interestingly, this aspect of believability flies in the face of probability, since most "real" people do not change easily, if at all. When characters change, they undergo a kind of moral or perceptual transformation that cures them. So Emma is cured of her self-centeredness and

D'Arcy is cured of his pride. Likewise, the plot is cured of its abnormal initiating events. The narrative, at its end, is no longer disabled by its lack of conformity to imagined social norms. (15).

At the same time, constructing a realistically disabled character almost always precludes the author from a 'cure' at the end of the novel. Even with medical intervention the cures found in *The Secret Garden* or *Heidi* or *What Katie Did* are, at the very least, unlikely. The disability activist and writer, Lois Keith, advocates that as there is no cure for spinal injuries it is better to accept the situation and forge a new different but full life. She expresses anger about the representation of 'miracle cures', pointing out how the media love such stories of people who can throw away their wheelchairs or crutches and walk again despite apparently insurmountable odds and their doctors' prognosis. Usually they achieve this through sheer willpower and determination not to give in. The implication is that those who do not walk again lack determination and have 'given in'. The failure to walk is interpreted as 'a sign of moral weakness.' Keith (2001) points out that the publicity surrounding Christopher Reeves, the actor who played Superman, was detrimental to the disabled cause with its strong suggestion that life in a wheelchair was not worth living (pp.:240-243). If the subject of the novel is disability, the author can be challenged to find a satisfactory ending without a cure, a further aspect that is examined in this chapter.

Perhaps it is possible to view the concept of home and family as a microcosm of the wider social world and judge whether the authors' attitudes are formed from medical model or social model thinking. In either case, the individual and the impairment are important components of the plots and one can ask if the author is creating a character to be pitied, like Dickens' Tiny Tim or a character showing extraordinary bravery and willpower who overcomes his or her affliction or some other stereotype. This is examined through family relationships: parent and children, grandparents and siblings.

Family relationships are at the core of many of the novels' plots. In others the relationships are of minor importance used mainly to add verisimilitude. An examination of how the authors handle the relationships will help elucidate their perspectives on disability, especially through those of grandparents and of siblings. Of course, some family relationships are found as often in young adult fictions which do not feature disability such as rather confrontational relationships between parents and their daughters or sons which are very common as teenagers approach adulthood. This occurs often in the fictions which have been examined here. Both Brian Keaney (2001) in *Falling for Joshua* and Jean Ure (1981) in *See You Thursday* have depicted this well: the mother in *Falling for Joshua* being, according to her daughter, overprotective because of her daughter's epilepsy and the mother in *See You Thursday*, overprotective because her

daughter was falling in love with a disabled young man. Both characters fulfil their roles by adding verisimilitude.

Siblings are even more frequently included in young adult fiction, sometimes demonstrating loyalty, sometimes rivalry, sometimes both. In narratives that are concerned with disability, brothers and sisters play various parts ranging from a main one like Digby in Bette Paul's *Becca's Race* (1992) who has major problems arising from his asthma but his bone marrow saves his sister's life, to minor but vital parts like Tom in Rosie Rushton's thriller, *Last Seen Wearing Trainers* (2002). Tom has severe learning difficulties and contributes to the protagonist's difficulties during the first part of the book but he holds the clue which ultimately saves her life. The disabled character in Gene Kemp's novel *(Seriously) Weird* (2003) is introduced as a troublesome brother: when asked to take him bowling with her friends, his sister exclaims, 'NO! He'd wreck it!' (p.3). Most children are concerned as to whether their siblings disabled or not, are treated more favourably by their parents. McHale and Pawletko (1992) point out that their perceptions of the proportion of love and attention given to them may affect their behaviour in general as well as to their siblings (69). This is verbalised by Helen Flint's character, teenaged Joanna, in *Not Just Rescuing* (1992) whose brother has several impairments. She bursts out, '...Everyone loves Ralph more than they love me. I suppose every sibling says that, but in my case it happens to be true...' Her aunt replies, 'You don't understand a thing, Joanna. It makes sense, really: your parents have to love him more; he might die soon, before them. That's all wrong. Complex.' (p.92) It is always a complex situation when there is a severely disabled person within a family but whatever care and attention are required for the disabled, the non-disabled should not feel neglected or 'second class'. The argument that the possibility or indeed probability of an early death should result in *having* to love one son or daughter more than another is unreasonable. The aunt's explanation does not appear to satisfy Joanna as the conversation continues and she says, 'Sometimes, just for a moment, a nanosecond really, I wish I was the one in the wheelchair and needed rescuing' and her aunt replies, 'Don't ever say that. Be grateful to be 'normal'. (p.92). Flint's choice of vocabulary for the aunt is poor as the implication is that Ralph, as a wheelchair user, is abnormal. This is mitigated a little by Joanna concluding that she supposes she is grateful to be 'normal', whatever that is. Like everyone else, I guess. Am I though? Fat chance. If only Mark would ask me out.' Perhaps Flint is endeavouring to show that everyone as 'different' in some way or other – Ralph has limited mobility, Joanna may have limited social skills or possibly limited confidence if she believes she is not 'normal' because the boy (Mark) to whom she is attracted has not asked her out. However it is not clear if this was Flint's intention and using the word 'normal' in this context endorses the misperception of disabled people being abnormal. In another section Joanna says:

Well, okay, I do know it's a sort of tragedy. Mum says, tears in

her eyes, 'The way he *watches* other boys play football'. Yes, all very well, but sometimes I think his wheelchair is a sort of badge for people to win. It's a self-challenge: if I can't manage to make friends with a boy in a wheelchair, what kind of a failure am I? People might say to themselves. And Ralph knows it. (p.67)

There are several important issues raised in this speech. First, the mother's attitude, which is clearly based on the medical model of disability, creates negativity. While of course mothers are negative from time to time about their sons' or daughters' achievements or lack of them and to include some negativity from fictional mothers might contribute to a novel's authenticity, it is misplaced here. Would there be tears in her eyes if her disabled son were watching a chess game or a trapeze artist with envy? It can be argued that she would feel that he simply lacked the gift or the opportunity and could concentrate on something else. Would this not be her attitude if he had full mobility but was simply inept at football though was interested enough to watch other boys playing it? Secondly, the self-challenge to make friends with a wheelchair user is very uncommon, especially among teenagers. People are either friendly naturally or more commonly try to avoid the wheelchair user because they are embarrassed and do not know what to do especially if the user has further disabilities like speech difficulties. To envisage befriending someone with a disability as a self-measure of success is at least improbable. Describing it as 'a badge to win' is another form of condescension as the implication is that is somehow difficult to be friendly with a wheelchair user. It is quite implausible that this type of patronising would occur and this is borne out in a report on disabled adolescents' experiences in secondary schools where isolation rather than condescension was frequently mentioned (McNeela *et al* (2000) pp: 46, 55). Flint's character Joanna shows common and natural reaction in her situation. It is the aunt's replies in the dialogue that undermine any value this book might have from a disability perspective. The author raises highly debatable issues regarding disability without comment or further discussion to challenge traditional views or provoke critical thought (See also chapter on Friends and Relationships). This is a clear example of a writer utilising the medical model of disability.

Most other siblings of a disabled character are background figures and show signs of anxiety, jealousy or fear, bed wetting for instance in *See if I Care* (Curtis and Meaney: 2007) or misbehaviour as in *A Different Life* (Keith:1997) and *Paralysed* (Ashworth: 2006). They help build up a realistic picture.

Grandparents are often used for the same purpose. They seldom play a large part in the novels containing disability which is perhaps a sign of the scarcity of the extended family as a unit. Occasionally a grandmother will help out in a household experiencing problems (for example, Keith, *A Different Life*; Paul, *Beccy's Race* and Curtin and Meaney's, *See if I Care*) but they tend

to be background figures. *The Granny Project* (1993) by Anne Fine is an exception. It is aimed at the younger end of the young adult market and, although it is light-hearted and somewhat improbable, the difficulties arising from the grandmother's worsening dementia are by no means belittled. Nicholas Tucker (2001) says of Fine's work, it is 'sparkling on the surface but morally serious underneath' (p. 54) and this is no exception. Fine believes that 'books are the best instrument we have for ethical enquiry'. *The Granny Project* is one of her revised and reissued books. Generally she has made her books more politically correct by removing the mild racist and sexist references which would have been acceptable when the books were first written some thirty years ago. She has done this with regard to disability as well, both here and in *The Stone Menagerie* (c 1980 /2009) where the setting is a nursing home. Her argument for doing this is that her books are not set in a recognisable historical past – her characters are not Roman or Victorian – they are contemporaries in occupations, speech patterns and fashions to the readers but concepts and phrases belonging to previous generation may now have different connotations (www.annefine.co.uk/changing.php).

The apparent increase in Alzheimer's disease will mean the greater likelihood of young adults experiencing it through their grandparents. Fine identifies the problems faced by home carers of the elderly disabled. As the grandmother of *The Granny Project* becomes more confused she becomes more difficult to care for and her son and his wife are coming to the conclusion that it is time for her to go to a residential institution. While this contributes to a strained relationship between husband and wife, the son's attitude to his mother swings from irritation to exasperation to love. The emotional complexities are skilfully portrayed, culminating in the journey to inspect the nursing home (pp.72-75). The younger characters of the family have a different perception and in an effort to keep her at home, one of them, Ivan, uses her as the subject of a school project. The reader gets only glimpses of the project's contents but sufficient to query impersonal social data, some misconceptions and the problems of dependency. While Ivan is using his project to blackmail his father, the tables are turned and the children find themselves in charge of their grandmother and of themselves every day when they return from school. In this way Fine demonstrates the personal cost of home care-giving as it begins to encroach seriously on their extracurricular activities. Fine is using the medical model in so far as she is depicting a personal tragedy. Yet indirectly, it can be seen that the situation she describes could have been made easier for all with more outside community help. This point does not fully arise in the novel and Fine also avoids the actual institutionalisation of the grandmother as she, somewhat conveniently, dies. Fine does succeed in providing food for thought in a light-hearted humorous style which is rare in young adult novels featuring disability. This is because she does not trivialise the disability itself and its effects.

There are few examples of novels featuring a parent with an impairment. One is in *On the Summer House Steps* (this is another revised and reissued edition of Anne Fine's. Formerly titled *The Summer House Loon* (1978) and its sequel, and republished in 2006) where the protagonist's father is blind. Blindness as an impairment is not explored at all. Fine uses it as a device to allow the daughter considerable freedom to do her own thing especially as her mother is dead.

In contrast a disabled parent restricting her daughter's life is found in Ishbel Moore's *Daughter* (2001). Sylvie, the teenage protagonist, is trying to cope with her mother who is showing increasing symptoms of Alzheimer's disease. On the whole Moore handles Sylvie's difficulties quite well but the reasons she posits for the father's departure are not credible. It is implied that the disease changed his wife and they could no longer live together. She wanted him to go and he apparently had no idea that his wife might be having difficulties. Furthermore neither took Sylvie into their confidence and her mother either forgot or deliberately kept the father from Sylvie and encouraged the alienation. Of course for this story it is absolutely necessary to separate the parents. Obviously if her father had been around Sylvie would not have had such responsibility. She 'wouldn't have, as she herself says, to be 'A teenage mother with a grownup baby.' (p.80). Moore describes the symptoms of Alzheimer's disease well but the background she has chosen is not credible. Sylvie and her mother are not living in some wild, isolated area but in a block of apartments in a city and Sylvie attends school. It is difficult to believe she would not have sought or been offered help. By ignoring the social aspect Moore shows how deeply she is embedded in the medical model of disability.

One novel compares and contrasts mental illness and cognitive disability in the family. This is *See If I Care* by Judi Curtin and Roisin Meaney (2007) in which the protagonists, Luke and Elma who are pen friends, are trying to cope with their fathers' involvement in accidents which have taken place before the opening of the stories. Luke's father stays in bed until midday or sometimes later; he sits, sometimes rocking himself, gazing at the television when he is up; he needs to be fed and helped to wash and shave; he cannot make or participate in a conversation. (Pp.38-39, 74, 91). Elma's father also spends much of his time in bed or watching television; gazing out of the window and apparently does not wish to join in any conversations or activity (pp.32, 45-7, 49, 64-5). His attitude is summed up in a physical description, '... with his stubbly chin, and nothing on besides raggy old tracksuit bottoms and a dirty vest...' (p.79). A big difference between them is that Luke's father was brain-damaged in a traffic accident and will never recover whereas Elma's father has largely recovered from his building site injury but because he can no longer work as a plumber he is suffering from clinical depression. While the comparison is striking, the effect of an incapacitated father on the family is similar. It is difficult for the authors to find a satisfying and satisfactory ending in these circumstances and they are

only partially successful in finding one. Their conclusions appear rather forced and unlikely. Again, the societal aspects have minimal representation and confined to insufficient finances.

Research shows a disproportionate number of disabled children tend to be brought up in single parent families, usually headed by a woman (Cohen and Petrescu-Prahova: 2006). This is reflected in the novels in this study with over forty per cent of the disabled characters living with a single parent, usually the mother. I could find just two fathers managing on their own: Mr Boone in *The Curious Incident of the Dog in the Night Time* by Mark Haddon (2003) and Mr Green in *Zelah Green* by Vanessa Curtis (2009). Haddon paints a sympathetic picture of Mr Boone who, although perhaps not very imaginative, does his utmost to look after his son. He makes mistakes. One of the most moving sections of the novel is perhaps when Christopher resolutely ignores all his father's efforts to explain why he had lied about his wife's death. His parents try to do their best for him and while Christopher is completely unconscious of this, the reader can see what a strain his behaviour has been on his parents' marriage. Ultimately there is no solution or escape for them at least in the short term and they will never have a loving, responsive son. Mr Boone is well drawn and convincing, whereas Mr Green is not at all convincing and plays only a small part in the novel. He warrants little examination.

Traditionally the woman is the carer and anecdotally it is believed that men cannot 'cope' with illness and disability. In *Paralysed*, Ashworth illustrates this; in spite of previous marital difficulties, it appears that the realisation that his son will never walk again is the cause of Simon's father's withdrawal from family life. Some of the disabled characters feel they have been the cause of the father's departure; PJ in *The Night Garden* (Marlowe: 2000) and Kate in *When Last Seen Wearing Trainers* (Rushton: 2002) for instance. Several authors suggest that while the male does not see a role for himself in the sick room, he is anxious to contribute in some way. Libby's father organises a campaign to clean up the sea and becomes obsessed with trying to discover the source of the virus which attacked Libby (Keith, *A Different Life*). There is a much less sympathetic portrayal of a father in *This Strange New Life* (Rachel Anderson: 2005) which is examined in detail below.

This Strange New Life and Elizabeth Laird's *Red Sky in the Morning* (1988) describe extremely well the upheaval that the addition of a disabled member can cause to family life. Each takes a different angle and each is worth analysing in some detail to highlight each writer's technique.

The former is a valuable addition to the canon of young adult fiction featuring disability, although ironically Anderson's presentation of disability is the weakest part of her novel. The tale is focalised mainly but not exclusively through the teenage protagonist, Johanna, nicknamed Johnnie, the youngest of a family of four. She has three disabled brothers. The middle one shows

many classic symptoms of autism and also has periodic convulsions. The two other boys, who have been Johnnie's heroes, are potentially successful university students, until they both fall victims to Chronic Fatigue Syndrome or ME (Myalgic encephalomyelitis). Anderson's handling of the effects of disability on family life is quite outstanding. The novel's opening is somewhat unoriginal, even hackneyed – two parents, four children and a black Labrador living in a rural rambling house surrounded by fields and trees. The idyll and even the chapter heading 'When Trees were Green' with its nostalgic ring are rather too obviously set up to be spoiled by subsequent events.

The family already has experience of disability, the middle son, Peter, is on the autistic scale, has learning difficulties and is prone to seizures. He is fully accepted by his siblings who look after and include him in the activities when possible. His mother, Rose, is his main carer and carries 'the responsibility of having made him [Peter]' and worries as to what will happen to him when he is middle-aged and she and her husband 'are too dodderly to care for him any longer' (p.4). The father, a successful businessman, is uncomfortable with Peter of whom he has little understanding, wondering why, for instance, his wife insists on bringing him to church each Sunday. Johnnie has to explain it is because he likes the singing. (p.45). Anderson shows clearly that what is happening to his other sons is quite beyond his understanding and acceptance; he sees them as malingerers 'deliberately crippling themselves with all their self-pitying complaints.' He is not an evil person but selfish and unimaginative, and his conventionality makes it impossible for him to cope. He decides that his coming home each evening 'late and so tired' is not helping anybody. The intention to do what he could at weekends does not quite work out (p.78). Yet he is 'not the total louse he seemed to those who used to love him' (p.95) and he goes through a phase of researching alternative medical cures and sending home 'glamorous gestures' in the shape of parcels of whatever 'cure' he has been persuaded will work. This may be an example of a male seeking some way to contribute to a disabled family member's care like father in Keith's *A Different Life*. He runs a campaign to discover the origin of the virus that affected Libby but Anderson, strongly suggests that Johnny's father is failing in what he should and could be doing which is to supply the physical and emotional support that is needed by the family. While he waits for the situation to 'normalise' he loses touch with the reality of the home situation and alienates himself from the others. This is shown by his plans for a family holiday in Greece. As Johnnie points out, 'Sporadic interference doesn't help. The family's changed while you've not even been there. So you've not been part of our changing.' (p. 243).

Thus the burden of caring is left to the women in the family. This is unsurprising as it reflects real-life where 'dominant social attitudes exert strong moral pressure on families to provide care, the assumption being that the family or rather the women of the family have primary responsibility' according to Dr Clement (2003, p. 8). Anderson constructs a traditional mother in

her character of Rose who is the main carer. She is the mainstay of the family. She takes on the burden of nursing quite naturally and unquestioningly but Anderson traces her increasing stress as she tries to cope with her job, her 'ordinary' household and the invalids' increasing demands. Suddenly she is in tears over the death of a racing-driver whom she never knew or even met. She and Johnnie snap at each other, each succeeding in hurting the other. (pp.132-3). It reaches crisis point one night when she begins to throw cups and plates onto the floor moaning, 'I can't do it. Can't do. Can'tThere's just so much. Too much. I can't do it all. Can't do any of it.' (pp.145-6). The result of this is Rose going off for a few days. She sleeps non-stop for three days in a hotel, and returns home. She comes to the realisation that 'looking after her family was not a tragic interlude but a long-term project' (p.189). Once she can see the situation in this light she feels calmer and she is better able to cope but as Professor Luke Clement (2013) points out in his paper, 'Does your carer take sugar? Carers and Human Rights evidence in the UK', carers are a third more likely to be in poor health than non-carers and that over half of all carers have a caring related health condition for which almost 50% have sought medical treatment. Here Anderson has dramatised the reality of a home caregiver's life. It illustrates one of the demands within the social model of disability that the disabled should be able to source assistance.

Although Anderson sees the sons with M.E. as the protagonists in her novel, Johnnie is a more interesting creation. A large proportion of the narrative is focalised through Johnny who is a fully-rounded character. Anderson subtly traces her maturing from an exuberant, tomboyish child to a level-headed mature young adult about to go to college. At the beginning of the book Anderson depicts her as hero worshipping her two elder brothers and she is childishly disappointed when they come home so changed, showing no interest in her, no presents, no plans. One of Anderson's strengths is her imagery and here she chooses her language carefully to emphasise Johnnie's youth, 'Johnnie was so excited she jumped like a yo-yo while yelping like a puppy.' (p.44). As the non-disabled sibling Johnnie's freedoms are encroached upon. Naturally she resents this. She 'reckoned Christopher was being allowed to make a fuss about too many things.' She has to remember not to flush the lavatory after 8 pm., not to whistle for the dog, nor slam doors, rattle cutlery when washing up and, the worst of all, she could not practice her viola, even 'extra pianissimo' and so on (pp.60-61). Even the food has changed; no longer does her mother make treats of chocolate cakes. Instead they have organic vegetable hot-pot every night. Anderson captures the tone of an adolescent/adult argument faithfully in this exchange:

"Why don't we eat like a normal family?"
 'We *are* eating like a normal family,' said Rose.
 'A normal family would be eating nice hot oven chips
 and yummy margarita pizzas in front of the telly'
 'Johnnie. Please.'
 'What d'you mean, "please"?'
 'I mean, please try and set a good example.'

‘*Moi?* I’m supposed to be the youngest. Not that you’d know it.’ She pushed her gloopy stew away, grabbed a banana, and stomped up to bed without saying goodnight. She wasn’t going to hang around to help Rose clear up yet again. Why was it always her?’ (p.94)

Her feelings are further emphasised when again she snaps at her mother, ‘But *you* don’t care, do you? Always them, never me.’ (p.95). This is a common reaction of a sibling who has extra responsibilities and relatively stricter standards of behaviour because of a disabled sibling as noted by McHale and Pawletko. (1992, p. 69). Anderson shows an understanding of the reasons a sibling behaves out of character as demonstrated here as she has Johnnie deciding to go to a party with one aim in view – ‘To search for someone to take her seriously to admire her for who she was, as herself.’ Unfortunately the result of this was she has unprotected sex with a guy she meets there and this only increases her worries. But she is growing up although it is barely perceptible at first. She herself is surprised when she can stand up to her interfering aunt (p.87) and she rises to the occasion the night when Rose begins to smash up the kitchen and she manages to take firm action by ringing up the Social Services. This is not easy; the tension she experiences is well described (pp.145-47). She does not suddenly reach maturity but she copes with each crisis and learns to accept reality as she finds her father is not ‘the family safety net, taking control, soothing and smoothing.’ (p.242) or when her hopes crash of the glamorous Miranda filling the place of elder sister and confidant, for example. She begins to see the situation clearly, advising Rose to accept and put up with the situation by incorporating it into her life as part of who she is. Then, Johnnie supposes they all can start to accept it (p.98). This attitude would not be alien to a social model theorist but Anderson is more concerned with the creation of realistic characters. The reader realises how much Johnny has grown up when she, rather than her father, rushes down from London when Andy goes missing. (p.251) and when she tries once again to get her father to understand her brothers and the family’s needs. She shows a mature insight when she explains about the effect of her father’s ostentatious gifts:

... it uses up their resources ...gives them false hope, and then you expect them to be grateful when the thing we have to concentrate on is the best way that they can go on living, now, as we are, and we have to make them feel good about themselves, whether they’re grumpy or happy, ill or well, all of us are focusing on the positive, making the most of everyday things, however titchy they may be. (pp.239-240).

This contrasts vividly with Johnnie’s earlier ‘cure-all’ of tea and a chocolate biscuit some four years earlier. (p.15)

Both Rose and Johnnie experience the reactions of other people who do not understand the household problems. Gossip about anything spreads rapidly. It is whispered that the boys

have AIDS or that it is Rose's fault, being 'over-protective' or 'Always fussing'. Rose's colleagues are embarrassed with her outbursts about the increasing number of problems (pp.98, 99). Johnnie's schoolmates avoid her. She becomes more excluded. The point of other members of a family containing a disabled person becoming isolated is one that can be easily overlooked and does not receive the attention that it should. Although there are numerous studies on disabled people being marginalised, there is little on those intimately connected with them who face associative discrimination.

Anderson includes the environmental changes often needed to accommodate a disabled family member, the invalids' beds brought down to the ground floor to save Rose's endless going up and down the stairs with trays and treatments. Then 'paperwork was shuffled across administrators' desks. [and] In a dozen strokes of a pen, Andrew ceased to be a music student And became a disabled person, just as the same few strokes had demoted Christopher from research geologist to disabled person.' This gives them entitlements to all sorts of equipment and some services (pp.92-3). Anderson describes these as 'the windfalls' of 'the disability subworld' (p.182), the choice of words being a fine example of Anderson's talented and economical use of vocabulary which allows her suggest a great deal. A windfall can be an unexpected perk as the benefits are but a windfall also can suggest imperfection. Indeed early in the book, Johnnie prevents Peter putting a windfall into his mouth. Inside it is a wasp. And the image of a sub world is not one of comfort. One also might query the use of 'demoted' in the sentence. Just as the same few strokes had demoted Christopher 'from research geologist to disabled person.' Is she implying that the disabled Christopher is a lesser person than the research geologist? Or is she suggesting that to be given necessary equipment and services a person loses his or her identity and becomes a being dependent on others? Further her meticulous choice of vocabulary also paints a rather unattractive picture of the invalids, 'The sick cold men shuffled towards the table in their blankets like asylum seekers' (p.93). This is describing two sick young men going to their dinner. They are cold because of their circulatory problems but reading the sentence quickly the c can be missed and they are like old men which is re-enforced by the word shuffled and the addition of towards rather than to increases the idea of effort required. Blankets and asylum seekers immediately conjure up the plight of third world peoples so often seen on TV screens. (p.93). Anderson even uses the dog, an addition to the family to illustrate the changed circumstances:. She [Honey] follows the shuffling men to the table, 'twitching her ears with expectancy. Her presence lent the only note of stability into an otherwise increasingly unpredictable household' (93) or 'Honey, the one conventionally useful member of the household, wandered around picking up fallen bits of food. She loved her people here and, consequently was agreeable about being a vegetarian dog.' (p.94)

Anderson's writing skills have ensured she has created a riveting and convincing picture of disability within the family and home.

Elizabeth Laird has produced a very different novel, *Red Sky in the Morning* (2001) in which the disabled member is a newly born baby. The effect of disability in a family obviously differs depending on which member is disabled and as a baby is dependent in the first place so the pressures are unlike those in *This Strange New Life*. It is different in another way as well; a proportion of the book focuses on the effect on the family of the disabled child's death. It is particularly in this that Laird shows her imaginative strengths.

The baby boy is severely disabled, he has encephalitis and his heart and lungs are so severely compromised that he is not expected to live long. He is loved and accepted from birth by his parents and the teenage protagonist, Anna, although she wonders if she 'would have loved Ben quite so much if Mum hadn't shown me his feet first ... His tiny, perfect miniature toes, pink as shells, soft as petals... I hadn't ever seen anything so beautiful in my whole life.' (pp.18-19). Anna chooses to devote most of her spare time to Ben to the extent that her younger sister, Katie, feels left out. Katie's life is disrupted;

It's always Ben! Mum won't take me swimming because she can't leave Ben. I couldn't have a proper birthday like Tracey's because mum's so tired looking after Ben. Now we can't even go on holiday like a proper, ordinary family ... (p.50)

This natural jealousy is well conveyed by the author who like Anderson she shows the maturing of her main character. Anna learns a lot about people's reaction to a disabled child, some would 'see him, take one long, horrified stare, then the faces would kind of freeze up, and they gaze into the distance trying to pretend they hadn't noticed anything. But the minute your back was turned ... you could practically feel their eyes boring into poor, innocent Ben.' (p.27) or 'this great big head, like a monster in a weird cartoon.' (p.36). At first Anna is ashamed to let her school friends see her brother but a kindly elderly shopkeeper friend helps her adjust her attitude. But it is not until she has a visit from a school friend that she begins to understand this stress that her mother is undergoing. She sees her through a visitor eyes 'slopping about in dirty old slippers, no make-up, her hair unkempt, holes in her tights.' She realises that her mother has been so housebound doing so much to cope with everything she has stopped bothering about herself. (pp.41-43). Again, the woman is expected to be the prime carer. Indeed Janet Finch (1984) when comparing community versus residential care decides that 'on balance it seems to me that the residential route is the only one which ultimately will offer us [women] a way out of the impasse of caring' (quoted in Morris: 1993, p. 63). The father begins to work longer hours, he is not always home at weekends, he has become moody and tensions between him and his wife are increasing.

(pp.80-81). Laird handles this realistically as having a severely disabled child needing care puts a strain on marital relations (see for example Muldoon, 1992)

Laird handles the grieving process from a sibling viewpoint well. It is not sentimentalised and she does not use the baby's death as a 'solution' to his disability. The reader has all along been given the impression that the child's life expectancy was low and the event itself did not happen in any way as a dramatic crisis. Through Anna, the normal stages of mourning are presented in a straightforward manner. Anyone who has experienced a great loss will recognise the stages. For example, there is first the shock, 'one word hammered away in my mind, blocking out everything else: 'No! No! No!' (p.119) and anger bordering on bewilderment: 'Why? I kept saying, Why did he have to be born like that? It's so unfair. Why did he have to die? What was God thinking about, making a child suffer like that? Where was God when he died?' (pp.125-26). These may seem to be clichéd questions but they arise in some shape or form every time one is faced with death. There are also other expressions of grief, the sharp awareness of the gaps in a house or in routines and the days of limbo between the death and the funeral (pp.121, 124). Then guilt and regret follow, the day before her brother's death Anna is keener on reading her book than playing with him. 'If only I'd known, if only I'd realised, I'd have played with him all day, as long as he wanted, as long as he could.' (p.117). Other people's efforts to sympathise with the family include a tactless neighbour who claimed they would 'soon get over it ...a blessed release' (p.127) and this is almost inevitable when disability is involved. Then what teenagers often experience, the embarrassment of peers who, not knowing what to say, treat Anna either like an invalid or avoid her altogether (p.124). Another aspect felt by bereaved siblings is also highlighted: People seem to think a sister's sorrow is not of great depth or importance, 'When anyone came to the house, they always seemed to think it was worst for Mum. And I suppose it was, in a way, but nobody seemed to think it was particularly sad for me. Maybe sisters don't usually love brothers the way I loved Ben. Maybe. (p.135)

Laird includes the things that are not often mentioned but which are instantly so recognisable to any grieving person. An example of this was Anne's inability to recall the funeral service, just vivid pictures in isolation like 'the little coffin, shining, bathed in sunlight, speckled in the jewel-like colours from the stained-glass window ...' (p.131). Another example is Anna's feelings a couple of weeks later when everything seemed to have gone back to normal. 'But all the time, while I was pretending to be just the same as everyone else, I carried this churned up, desperate misery inside.' This feeling which was also described as 'a ton of concrete pressing down on [her] chest' or a 'dull heavy pain' This emotion really does appear to be physical and tends to persist for some considerable time. The lessening of it also can include a feeling of guilt which Anna also experiences (pp.133, 134).

It is the whole family who is bereaved and their reactions differ. Just as Laird traces the changing interactions between the family members as they try to cope with the addition of this severely mentally and physically disabled child, she depicts the family's stages of bereavement equally skilfully and convincingly. There is less detail but Anna's younger sister has different reactions from Anna which are nonetheless perfectly valid. Likewise, Anna's parents use another set of coping mechanisms which are obviously coloured by the need to care for their daughters. They make mistakes. For example by trying to put on a show of cheerfulness in front of Anna, her mother inadvertently makes Anna feel un-needed. (p.135). The acute pain of sorrow slowly and unevenly begins to diminish, as it does in reality. There is no moment, no milestone to mark the end of grieving, of letting go or 'getting over it'. This is close to non-fictional life. There is a great deal in this book which will be recognised by siblings of a disabled child and siblings of a child who has died. Thus both Anderson and Laird have produced novels which have enabling qualities. The contents may comfort, widen experience or understanding or convey a feeling of inclusion. There are not many narratives which are as successful as these but they do show how it is possible to present at least an aspect of disability accurately and convincingly in a book worthy to be included in literary disability studies.

None of the authors in this chapter has adhered to a strictly medical or a strictly social model of disability. Within the environs of the family unit, the medical model of an individual personal tragedy is inevitable, especially if disability is a major part of the plot. By and large, the social model might seem irrelevant, although there are some incidences of attitudinal barriers such as the reactions of the wider community to the appearance of the disabled baby in *Red Sky in the Morning* and to Johnnie and her mother in *This Strange New Life*. But the writers of the novels in this chapter do not appear to be writing from a medical model approach; the simplest example being Elizabeth Laird, who is the only author who includes the death of a disabled child character. The nineteenth century novel's interpretation of the medical model usually had a 'kill or cure' conclusion. But Laird does not sentimentalise or use the death as a solution, nor a conclusion. There are no examples of an impairment being cured. The 'cure' found in each novel takes the form of some sort of resolution of the situation. It is not necessarily a happy-ever-after ending but it is usually one with hope for the future.

CHAPTER 4: FRIENDSHIPS AND RELATIONSHIPS

That it is more difficult for disabled young people to make friends and build relationships than their non-impaired counterpart is shown in many research papers (see for example Morris (2001) Watson (2002) O'Connell (2005) Gay (2009)). The reasons for this are myriad and range from the perception that classroom assistants act as barriers to getting to know classmates to lack of independence compounded by neighbourhood isolation. The barriers preventing a disabled young person making friends and participating in a full social life are both attitudinal and environmental. Efforts on the part of a protagonist to become 'one of the gang' or be 'in with the cool crowd' is a common theme in young adult literature in general as already mentioned in the chapter on schools, yet it is comparatively rare in a plot where disability is concerned. It is difficult to know why this is so but most writers give their disabled protagonists a core of friends who, after initial embarrassment and hesitations if the impairment is newly acquired, remain loyal and supportive. There is one example of a wheelchair user who wants to make friends with the family living nearby. It is in *Saffy's Angel* (2001) by Hilary McKay where the main character, Saffy, and her family are only vaguely aware of a girl in a wheelchair who lives on their road. They do not see her as a person which is not at all uncommon in the non-fictional world either. The wheelchair is invisible. Sarah runs her wheelchair into Saffy and the following conversation ensues:

'how do you know our names?'
'... and you've all been walking past me for years and years and years ...'
'Is that why you bashed me over?'
'... without saying a word ...'
'Is that why?'
'... without even looking at me ...'
'I didn't think it was an accident!'
'Just as if I wasn't there!' (pp.54-5)

Romantic relationships and sex are different matters and are issues of major importance in the adolescent mind. However they appear to cause writers great difficulty probably because there is so much ambiguity about sexual relationships and disability in the non-fiction world and it is an area where possibly the deepest prejudices can be found. For example the latest report on public attitudes to disability in Ireland issued by the National Disability Authority in 2011 found that a small minority of people disagreed that those with physical disabilities should have the same right to sexual relations as everyone else. Although a small majority of respondents would support people with mental health difficulties in having sexual relations, the numbers diminished for people with learning difficulties or autism (*A National Survey of Public Attitudes to Disability in Ireland* 2011). The majority of young adult writers tend to produce a rather sanitised version of romance or ignore it altogether. In this respect they differ from mainstream young adult authors

who seldom ignore it and whose writing has become quite explicit at times. There is no doubt that adolescents spend a great deal of time thinking about sex as a character in *Paralysed* (Ashworth: 2009) says, '[Sex] might not be everything, but it's the centre, isn't it? It's what a relationship is all about' (p.167). Many titles include romantic relationships or sex and the titles examined here are: Julie Hearn's *Rowan The Strange*, Melvin Burgess' *Loving April* and Rachel Anderson's 'Micky' in *The Bus People* all of which feature chiefly pubertal changes. These are followed by Helen Flint's *Not Just Rescuing* and Lizi Glass' *The Summer the Gypsies Came* which illustrate how myths continue. Jean Ure's *Abe and Marianne* trilogy, Lois Keith's *A Different Life* and Sherry Ashworth's *Paralysed* are next discussed followed by Jean Willis' *Naked without a Hat* and Brian Conaghan's *When Mr Dog Bites*.

Several young adult writers include the pubertal changes experienced by an adolescent to indicate their maturing. Hearn's young protagonist, Rowan, in *Rowan the Strange* (2009), is very embarrassed at a young and attractive nurse seeing him completely naked. He falls in love with her and one night is aware of her having sex in the nearby bathroom. He fantasises about her until he eventually realises that she is not this sweet angel of his fantasies and the reader realises he is growing up. (pp.115, 138-40, 205, 327). Tony in Melvin Burgess' *Loving April* is another adolescent becoming conscious of his sexual drives although in this book, Burgess's characters are more concerned with class distinctions rather than disability as can be seen when Tony's mother notices the growing relationship between Tony and April who is deaf, she decides '... Boys will be boys. If he wanted to fool around it was better to fool around with April than with someone who really mattered . . . ' (p.119). Even Tony himself was '... ashamed of April. She wasn't in his class. She was deaf, not right. He would be teased and expected to treat her differently. . . She wasn't the sort of person who ought to be able to make him feel like this. But she did, and for that reason he was ashamed of himself, too.' (pp.118-119)

Rachel Anderson is one of the first young adult writers to break the taboo on sex in one of her stories in *The Bus People*, which was published as early as 1989. Her motive, however, is not to add verisimilitude to a romantic story; she uses it in an exploration of age-appropriate care and support for a person with a disability. Her character, Micky, has multiple disabilities and lives alone with his mother on whom he is entirely dependent, lacking both speech and mobility. Anderson uses Micky as narrator by giving him a kind of internal monologue. Micky is trying to come to terms with the onset of puberty. He does not quite understand what is happening. He imagines a slave caring for him, 'I want something different which I haven't found. It is to do with the touch of the flesh. The slave is a woman and she touches flesh. But it is more than that.' (p.31). This is part of Micky's imagining and similarly he feels that, 'A man desires a woman to call his own whom he may hold close to him. A hand to hold. I seek my own body-woman I can do what I want with behind closed curtains' (p.32). This contrasts vividly with his bedroom

curtains decorated with teddy bears and his mother's attitude towards him. As stated she treats him as a child – talking baby-talk to him, making no effort to teach him anything to lessen his dependency upon her. This is highly inappropriate but she does not realise that Micky has reached adolescence. David Hingsburger, an internationally renowned expert on sexuality and the intellectually disabled, suggests that one major difficulty is that people, especially parents, to understand that the intellectually disabled will never become fully functional adults. They ignore the fact that although intellectually a person may be no older than, say, a five-year-old, his or her body is maturing and there is no reason that he or she would not have the same sexual needs and wants as any other person. (RTE 1 *Outside the Box* 27th April 2007).

Anderson's writing can be quite explicit, '... the curious new power I have between my legs. Two of my legs are short and feeble, requiring splints to hold them straight and firm. The third, lower limb, once as small and helpless as the other pair, is growing in strength, taking on its own life of energy.' This is immediately followed by, 'Who's my wetty boy then?' Never mind. Mum'll clean you up, make you nice and sweet again.' And then disposable napkins, plastic pants and baby oil are mentioned (p.33). It is quite clear that Micky's mother is incapable of seeing him other than as a baby. Anderson reverts to the 'strange sensation between [his] legs' again when, on his visit to the residential home, he sees some suggestive posters in a resident's room. (p.40). The images in this story may not be attractive but they succeed in showing that in this respect Micky is like any other hormone-driven teenager, thus making the point that people with disabilities have the same instincts and drives as any other person. In less dramatic and graphic ways, the other authors do likewise.

Unfortunately myths and misperceptions about disability are still being perpetuated probably unintentionally. *Not Just Rescuing* by Helen Flint (2002) is one example. In the same way as she mishandles the matter of sibling rivalry (see Home and Family chapter), Flint raises a debatable issue without suggesting it is possibly controversial. Here it is just one sentence but damaging nonetheless. The narrator notices her disabled brother is showing signs of facial hair. 'Puberty even gnaws away at the disabled.....I guess Ralph won't ever have a girlfriend' (pp.8-9). She continues then thinking about the fact she has not got a boyfriend and the remark about Ralph is left and is not referred to again. The inclusion of the word 'even' suggests surprise that the disabled become sexually mature and by peremptorily dismissing the idea that Ralph might ever have a girlfriend, the idea that the disabled cannot have a relationship and be sexually active is planted. Without discussion or questioning of any sort, it becomes an accepted fact about which there is no argument or examination. There is no vital reason for her remark and it is not only inaccurate it is also particularly damaging to a more inclusive portrayal of disability. Perhaps Flint envisioned her reader as a thoughtful adolescent who would question the characters' ideas and attitudes and without authorial comment be able to come to his or her own conclusions. This

would be a somewhat idealised reader and one who would have learnt to read critically. While this may be the ideal, the style of writing and the plot suggest the target reader to be a younger teenager who would need more prompts to see that another view is even possible.

From a literary disability perspective, *The Summer the Gypsies Came* by Linzi Glass (2006) is a narrative that perpetuates old myths even more seriously. Steinbeck's Lenny was based on the image of 'the moron as a menace' popular during the early part of this century. Margolis and Shapiro (1987) allude to Kanner (1964) as capturing the essence of this image when he noted that;

mental defectives were viewed as a menace to civilization, incorrigible at home, burdens the school, sexually promiscuous, breeders of feeble-minded offspring, victims and spreaders of poverty, degeneracy, crime and disease. Consequently, there was a cry. For the segregation of all mental defectives, with the aim of purifying Society, of erecting a solid wall between it and its contaminations. (p.18)

Like Steinbeck's Lenny, Glass's character, Otis, has severe learning difficulties although there is a suggestion that he sustained his through injury rather than genetically. Sixteen-year-old Otis falls in love with an attractive girl, Sarah, about his own age. Glass establishes her as a kind person by showing how she acts as a surrogate mother to her younger sister. She takes pity on Otis. She tries to teach him how to write his name. Glass shows how he quite obviously worships Sarah and follows her around like a dog (p.76, 84), perhaps intimating that he is less than human. The girl cannot but be aware of his devotion and is kind to him even after he becomes over-excited while dancing with her. However the dancing has ignited his sexual desires which he does not understand and will not stop until he is physically attacked by his brother. Sarah is forgiving: 'He doesn't know his own strength. That's all. He doesn't understand.' she says (pp.76, 115-6) but she underestimates the power of the young man's sexual drive and his inability to control it. The dance episode prefigures the next one in which he rapes her. It is a well-crafted but horrific piece of writing. The raw, animalistic and violent action of Otis is created by Glass's use of imagery which is based on nature. The imagery also serves as the younger sister's impression of the scene. She is alerted by 'the sound of an injured animal from across Zebra Lake, only the sound is much too close!' Then Otis' 'red baboon bottom arches above her [Sarah] ...' his hands hold her head down 'like she's a small animal needing to be tamed'; she is making 'sounds that come out high and low, her arms and legs twitching, like a meercat that's been caught in a trap.' The younger girl leaps onto his back and bites his neck. He 'howls' and Sarah freed, curls into herself 'like a snail into its shell'. Later she cries 'soft like a dove'. (pp.174-6). It might be argued that the use of predator/prey imagery is clichéd in the context of this scene but Glass uses metaphors and similes to make the younger girl's view of life distinctive throughout the novel

and many, though by no means all, are nature based. Thus the depiction of Sarah, bleeding “red drops” as Otis’ prey, increases the reader’s antipathy towards him, although he or she knows that Otis does not really understand what he is doing; he is sixteen years old and cannot control his sexual drive. Glass really undercuts any sympathy that might arise by showing that he is aware that he has done wrong, ‘Me done bad! Me done bad!’ he wails, and runs yelping from the room.’ (p.176).

The Year the Gypsies Came is a tautly written book with many worthwhile and positive attributes but with regard to the portrayal of disability it is extremely negative. The only mitigating angle is that Glass has created another character, Otis’ father, who is at least equally unattractive and arguably more blameworthy. He is rarely mentioned without a reference to aggression; either one of his sons is speaking of him beating them or he himself is threatening violence. There are numerous examples from when the family first arrives by caravan and he wants to introduce his sons, ‘Do I have to come in there and wallop you both to get your hides moving?’ (p.33) to his use of the native weapon to beat Otis when he finds him masturbating (p.143) to their final departure when Otis having been beaten so badly, is locked into the caravan ‘... moanin’ and spittin’ blood. His face don’t even look like a face no more... (p.184). The reader is in the position of wondering if, with better parenting, Otis would have grown into a more responsible person. Glass’ writing is powerful and this is a memorable narrative but it endorses the popular myth of a person with an intellectual disability being a dangerous monster.

Another writer, Jane Ure, who like Anderson was writing in the eighties, includes the subject of sex. In her romantic trilogy of Abe and Marianne (*See You Thursday* (1981), *After Thursday* (1985) and *Tomorrow is Another Day* (1989)), she is not as explicit as Anderson but her story does not call for it. Abe is a young, blind music teacher who comes to lodge with Marianne and her mother. Within the basic story, Ure depicts a variety of attitudes to blindness. She includes the expected initial embarrassment: Marianne, who has been told to show Abe where to sit at breakfast and where to get the bus, does not know exactly how to do it, how she should hold him. Similarly Marianne is embarrassed using the word ‘see’ and also when he claims he can go somewhere ‘blindfold’ (p.49). What is most revealing though is how Ure handles the changing attitude of Marianne’s mother. She certainly is not prejudiced against Abe. She appreciates Abe’s efforts to be independent and sticks to their agreement without any sentimentality. Yet she sees him firstly as blind and secondly as a man. This is shown by her slowness in realising that romantic relationship was growing between Abe and Marianne. The first sign is her objection to her daughter going to the bathroom in her underwear without a bathrobe. In common with many people, she does not recognise a disabled person as having any sexual drives. Abe explains: ‘...she thought that being blind I would be safe to have around . . . like some kind of pet eunuch.’ (p.190). Dr David Bolt has written several articles on the perception

of blindness or visual impairment and sexuality using the same sort of vocabulary. In *The Journal of Visual Impairment and Blindness* (2005, pp.141-156) he has written an article entitled 'Castrating depictions of visual impairment: the literary backdrop to eugenics' and he claims in another article, 'Beneficial Blindness: Literary Representation and the So-called Positive Stereotyping of People with Impaired Vision' in *The New Zealand Journal of Disability Studies* (2006) that 'it is likely that [the blind character] will be rendered asexual in order that the illusion of Otherness is retained' (p. 25).

Nonetheless as historically blindness has occupied such a significant part in English literature and culture, perhaps more than any other disability, Ure's contribution is welcome. One need only to note the myriad examples of its figurative use in the English language: blind as a bat, blind corner, blind date, blind rage, blind trust, blind leading the blind are just a few. These inevitably affect our perception of blindness and on the construction of blind characters in literature and there are innumerable examples of these as well: the saintly, the evil, the pitiful, the frightening. Ure's contribution endorses normalcy.

As a disability activist, Lois Keith can be depended upon to follow the social model of disability and to further orthodox views, also emphasising normalcy. While doing this in regard to relationships in *A Different Life*, she shows a tendency to refer to them, rather than exploring them. Her idealised wheelchair using character, the young black social worker, says: 'Do I have boyfriends? Yes I do, and shall I tell you something? Sometimes we even go to bed together ... I'm just saying that I have a pretty normal life for a single woman in her twenties. Not perfect, not always easy, but surprisingly normal.' (p.140)

Keith's sixteen year old protagonist falls in love for the first time and her relationship is just beginning. It does not get beyond kissing and although her boyfriend manages this well in spite of the wheelchair, she 'looked over at the bed and thought, I'll put some cushions on it, make it look more like a sofa. Then we won't have to think about metal wheels and spiky brakes' (p.348).

Sherry Ashworth is more outspoken than Lois Keith. When, in *Paralysed* (2005), sixteen year old Emma is faced with the reality of changes that Simon's spinal injury will bring, the hospital nurse underlines them. He is paralysed from the waist down.

... It might be better if you finish with Simon now. Six months isn't that long and both of you are very young. You're not going to be able to have a proper relationship, not now – and even when he's finished rehab, he won't be... You won't have any real control in all of the lower parts of his body. Even some wives find they can't cope. If you feel you need to finish with him, no one will blame you. If I was to sit here and tell you it's going

to be easy, or even possible, to have a normal relationship, I'd be lying. (p.82)

The dilemma facing Emma is traced through novel. She has doubts, but as she herself asks, 'How can I finish with Simon now, when he needs me most?' (p.87) She still loves him but 'it's a different kind of love now'. (p.108). Ashworth highlights the problems by including a conversation between Simon and a young married man, with a similar spinal cord injury, about the possibilities of having sex (pp.163-164) The teenage readers' hopes are likely to be romantic and their expectation would be that Emma's remains loyal. Ashworth is more realistic although she does give her narrative a positive ending.

Within the past few years however two young adult novels have been published, each having a protagonist with a disability and, in both, sex is a major concern and treated quite explicitly. Jeanne Willis '*Naked without a Hat*' was published in 2003 and Brian Conaghan's '*When Mr Dog Bites*' in 2014. Superficially, '*Naked without a Hat*' is a light-hearted, humorous teen romance, narrated colloquially by the protagonist, Will. The readers become aware that Will has a somewhat zany yet innocent outlook on life and as he leaves home for the first time he shares a house with two other teenage boys and the owner, an older woman. It is not stated but it is apparently a sort of supported accommodation for the three teenagers, with mild problems, supervised by the owner. There is plenty of banter and teasing about sex between them as one would expect with any group of boys of this age in real life and it is quite usual in this sort of informally narrated young adult novel. Will has a relationship with Zara, a young girl from a traveller family. The innocent beginnings lead to intercourse and Willis introduces this obliquely with a scene where the two teenagers witness a stallion covering a mare. In the sex-charged atmosphere. Zara satisfies Will's awakening urges and then they 'did it properly after that...' (p.119). It is customary in any romance that the lovers face obstacles to the fulfilment of their dreams. In this case the obstacles are unusual. As previously discussed, parents of children with learning difficulties rarely expect their children to become sexually mature. Will's mother is no exception. She asks if they slept together,

'Not much,' I said, 'We were too busy screwing. Say what you mean, Mother.'

'Oh God, you had full-blown sex? Penetration?'

I told her it was okay, I used a condom. I always used them.

I thought she'd be pretty impressed I was so responsible, but she wasn't. She just yelled, What do you mean *always*? You've done it more than once? (p.161)

But it is the idea of Will getting married that horrifies her. It is not, she claims, that those with learning difficulties should not have sex, it is the fact that Will has Down syndrome⁵. This revelation comes as a surprise to all the other characters in the book and to the readers. His mother explains how this alters the situation. First, if they wanted babies, there is evidence of only one male with Down syndrome fathering a child. This child had not got the extra chromosome causing the syndrome but females with Down syndrome are fertile but have sometimes passed on Down syndrome to their children. This is not fiction. Reference to this research can be found in *Issues of sexuality in Down syndrome* (Van Dyke DC, *et al*, 1995) Will dismisses these arguments. What concerns him is that Zara will have to be told of his syndrome and this he believes will mean she will reject him. There is plenty of food for thought for the reader in this unusual love story which is refreshingly humorous, frank and open regarding sexuality and disability.

When Mr Dog Bites by Brian Conaghan (2014) is another narrative in which the disabled protagonist, Dylan, who has Tourette's syndrome and some mild learning difficulties, spends much of his time thinking about sex. Dylan erroneously believes that he has not long to live and sets himself three goals to achieve before he dies. One of these is to have sex with Michelle Malloy; a fellow student at his special needs school. The most notable characteristic of this book is Conaghan's use of language which is explored in more detail in the chapter, *Behaving Differently*. Conaghan captures the linguistics of contemporary youth culture, includes a great deal of word play and adds many profane and, what would be too many people, offensive words. Consequently, as he is the narrator, Dylan's hopes, strategies and ultimately his success in getting Michelle Malloy into his bed are described quite explicitly, yet naively, usually using slang rather than biological vocabulary. The romantic lead up – dimmed lights, candles and music – could be found in any young adult romance, and then the less usual descriptions emerge:

We do little kisses at first, like longer Goodnight, Mum pecks but on the lips... Then our lips kind of stick to each other's and then round in a wee circle for a while, fast, slow, fast, slow. I enjoyed it... [Then] we play tongue sword fighting together. When the tongue sword fighting stops we do some mouth-to-tongue sucking.

And boy, oh boy, oh boy, oh boy, does my willy like this game! (p.364)

Dylan decides he is:

.... not going to talk about the nitty gritty or any Dirty Biz, but know this:

⁵ Although 'Down's syndrome' is used colloquially in Ireland, the above formulation is that favoured by the Irish Association for Down Syndrome and, with the exception of Britain, by most other national associations. Consequently this is the form used in this thesis

it was capital letters,
 RUDETUBE
 A-MAYONNAISE-ING.
 BONKERINOS
 SHIZENHOWZEN
 JEEZE LOUISE
 and
 NO WAY, JOSE
 all rolled into one. (pp.365-366)

When Mr Dog Bites and *Naked Wearing a Hat* both show clearly that those with disabilities can enjoy sexual relationships as much as any other couple.

Little attention is given directly to the difficulties a nondisabled person may have with a disabled friend. As part of the background and perhaps the rehabilitation of newly disabled protagonists there is often a readjustment of relationships, as in Lois Keith's *A Different Life* or Simon's best mate in Sherry Ashworth's *Paralysed*. Slightly more emphasis is placed on the nondisabled friends of characters with cognitive difficulties as in *A Note of Madness* by Tabitha Suzuma and *Blue like Friday* by Siobhan Parkinson. The difficulties facing friends of disabled people, especially those suffering from an anxiety or depressive condition, should not be ignored. It is likely that most young people either experienced themselves or have friends who suffer. This is suggested by figures from the Royal School of Psychiatry: one in four people suffer from some kind of mental illness, twenty per cent of all deaths by young people are by suicide and it is estimated that there are 24,000 cases of attempted suicide by adolescents each year in Britain, which is one attempt every 20 minutes. (http://www.youngminds.org.uk/for_children_young_people. [Accessed 24.05.2014]) Obviously suicide is not a disability but its root cause can be depression and it is often linked with such conditions as bipolar or disorders that are anxiety based like eating disorders and 'cutting'.

Kimberly Reynolds (2005) in her chapter on 'Self-harm, Silence, and Survival: Despair and Trauma in Children's Literature' in *Radical Children's Literature* claims the lack of children's books about depression, despair, and self-loathing is unsurprising and highlights the fact that 'one of the oldest and most active debates among those involved in bringing children and books together concerns what kind of material is appropriate for children to read.' She notes that attitudes are changing and quotes an observation made by Kenneth Kidd in a forum on 'Trauma and Children's Literature'; 'there seems to be a consensus now that children's literature is the most rather than the least appropriate forum for trauma work' (p.120).

I believe, largely, that attitudes have changed. *A Note of Madness* (2006) and its sequel, *A Voice in the Distance* (2007) by Tabitha Suzuma are examples of novels that show this new attitude and demonstrate how difficult sometimes relationships can be with a person who has this

sort of disability. Most young people experience mood swings, especially during adolescence. It is often a challenge to identify whether the moods are simply a part of life or symptoms of an illness. Bipolar disorder is one of these and affects between one and four people in a hundred, usually in late teens or early twenties. It used to be called manic depression, which implies the alternating moods which can be experienced; (Bailey and Shooter, 2009): Suzuma uses all the classic symptoms in her creation of Flynn, the main character who is a student at The Royal School of Music in London. Anecdotally, it is believed that many people excelling in the arts suffer from bi-polar disorder. Accordingly it is understandable that Suzuma chooses a pianist as her protagonist although, in fact, she has based the story on her own experience of depression. (www.tabithasuzuma.com/#/depression-and-me/). Flynn has two close long-standing friends, his flatmate and his girlfriend. He frequently disrupts their work, lets them down and fails them in all manner of ways. The reader gets a good idea of how difficult he was to live with as Suzuma charts his mood swings with skill. For instance, when he is elated she uses multiple metaphors and similes to convey his tremendous energy: 'His mind was on fire and his body needed no rest. Energy filled him like a sharp white light' (p.51) and she further conveys his inspiration as erupting from within: 'Flynn wrote down the music as fast as his hand would allow He couldn't get the notes down fast enough – only the limitations of his hand slowed him. His brain was on fire.'(p.38); 'The music rose and rose inside his head, reaching a crescendo so powerful, so pure, it was uncontainable. He could barely make out the separate notes, could hardly break the music down into bars, could no longer get his hand to keep up with his head. ' (pp.49-50). There is a good sense of urgency here. Conversely when Flynn's mood changes and he prefers sleep to being awake, Suzuma traces the plummeting of his confidence and his increasing aggression towards anyone trying to help him (pp.60ff). Her description of his room where he has shut himself for three days conveys the lack of purpose in this phase of depression (p.75).

His friends appear extremely patient and forgiving. They are also rather naïve or ignorant about mental health issues. This allows the author to impart, seamlessly within the narrative, a good deal of information about bi-polar disorder, even naming some of the medication which helps to stabilise moods. Suzuma could perhaps be criticised for concentrating on medical aspect of the disorder and having given Flynn, such loyal friends that he does not have to face discriminatory attitudes. At the same time, Suzuma emphasises the apparent arbitrariness of bi polar disorder as she gives plenty of evidence that Flynn had experienced no traumatic event nor suffered any abusive or unhappy family background. It seems to be causeless. Flynn faces few social barriers. His difficulties arise from his condition, a medical model perspective which, in this case, appears acceptable. Bipolar is treated seriously here and the portrayal is sufficiently accurate for readers with or without bipolar disorder to recognise the symptoms and the feelings and perhaps identify with Flynn.

Another representation of a loyal friend can be found in Siobhan Parkinson's *Blue like Friday* in the shape of the narrator, Olivia. Her friend is Hal, whom she frequently describes as 'weird', a word in current use amongst adolescents denoting simply difference. She accepts him as he is even though '... he's not exactly your normal chap' (p.150). Parkinson gives Hal some mild autistic symptoms. His behaviour tends towards eccentricity and he shows an obsession with a kite he is making: 'The kite, the kite, the wretched kite! He couldn't seem to concentrate on anything else. That and his weird, mixed-up senses of colour and taste:' Olivia further explains about his painting of the border around the kite: 'That shade of red. Green curry paste. Funny that, the way the reds and greens get mixed up.' (p.110). Hal might be suffering from another form of intellectual disability. Again, Parkinson hints at this indirectly. The adults tend to say 'Poor Hal' whenever they speak of him and this may be linked to the death of his father which occurred when Hal was five. It is not described but Hal remembers two things, flying a kite with his father and that he died on a Friday, but then when he is thinking about it, he continues,

I don't remember that part' ...
 'My mother told me, that's how.
 I know' ...'except his shoes.
 I remember his shoes. Very shiny
 .like polished chestnuts.'
 His voice got quieter. 'I'd forgotten that.'

The last sentence was as if he was talking to himself.' according to Olivia (pp.90-91). The implication of this is, of course, is that Hal's father had committed suicide and Hal had found him hanging. This could not but have a severe negative psychological effect on a young child, resulting in his 'weirdness' whether or not he has already and intellectual disability or condition. What does become clear, though, is that Parkinson has created an interesting character with a possible mild intellectual disability who is totally accepted by his friend. The narrator acknowledges his 'weirdness' or differences but he remains her friend.

In conclusion friendships and relationships do not appear in young adult fiction featuring disability as often as they do in young adult fiction in general. As they are subjects of prime importance to young adults this is a serious deficiency. As Mitchell and Snyder suggest 'Underlying this problem is perhaps the inherited historical misconceptions and myths which abound, nearly always negative and showing the disabled as either sexually promiscuous or dangerous or else completely sexless. Unthinking attitudes continue.' (2000) There is plenty of scope in this area for writers to explore these attitudes and create fictions to provoke thought and debate as well as exploring young people's relationships. There are of course more barriers to forming friendships than those discussed in this chapter, and one, real or perceived, is that of one's appearance. This can be a major problem for the disabled and therefore it is explored separately in the following chapter.

CHAPTER 5: APPEARANCE – LOOKING DIFFERENT

Appearance is of great importance in young adult culture. There are many reasons for this. It is partly due to their wish to be like everyone else yet, conversely, there is the wish to be really good looking or beautiful, more attractive than the others. Lacking maturity adolescents tend to judge others solely or at least primarily by their looks. Each is seeking his or her own identity, which is formed not only by self, but contributed to by how one is perceived by others. Simultaneously, present day Western culture places much value on the body beautiful which has created and is endorsed by a strong and vibrant consumerism. (Garland-Thompson: 2002). Consequently a young adult whose image is perceived or self-perceived to be marred by a condition, a scarring, a marking, some disfigurement or malformation can undergo many difficulties. Not least of these difficulties is the attitude of others. This is another situation where the disabled tend to be excluded. In this chapter the portrayal of people in young adult fiction who look different from most others is critically examined.

Several points arise with the title of this and a following chapter, *Behaving Differently*. Implicit in the titles is difference from the norm or normal. Normal is defined by the Oxford English dictionary as ‘the usual, typical, or expected state or condition’. Of course ‘usual, typical and expected states or conditions’ are not universal but variable and can be viewed as neutral. The word is an enlightenment introduction to the English language, introduced when categorising the natural world, including humans, was the fashion. The normal state or condition would comprise the largest number and it is this grouping who decides what is included in the category of ‘normal’. It is this group’s reaction to that which is not included and deemed unusual, atypical or unacceptable that causes problems to arise. The antonyms of normal, abnormal and sub normal, are almost always pejorative terms when applied to people thus demonstrating the likelihood of the major grouping’s attitude as negative towards deviation from the norm. Hence the disabled, as one of the minority groups, must struggle for acceptance and inclusion as normal: different perhaps but not abnormal.

In the context of literature Chinua Achebe asserts, ‘there is such a thing as absolute power over narrative. Those who secure this privilege for themselves can arrange stories about others pretty much where, and as, they like’ (2000, p.24). A glance at the depiction of disability in culture and literature throughout history shows the use of physically deformed bodies to signify evil, imperfection and shame as commonplace. Mitchell and Snyder (2001) give examples of some of these: First Man and First Woman according to a Shinto myth sent their newly-born deformed child off in a makeshift boat into the ocean to hide their shame, for example. There were efforts to explain the origins of disabilities by the use of the supernatural, for example the introduction of the changeling and then in the 19th century a tendency to view disability as part of ‘God’s mysterious ways’. Tom Shakespeare (1994), quoting Kriegel, (1987, p.33) who ‘hypothesises that

the world of the crippled and disabled is strange and dark, and it is held up to judgement by those who live in fear of it. The cripple is the creature who has been deprived of his ability to create a self. ... He is the other, if for no other reason than that only by being the other will he be allowed to presume upon the society of the "normals." He must accept definition from outside the boundaries of his own existence.' (p.3).

In classical and popular literature for both children and adults the same notions continue and undoubtedly reinforce people's views and as Jennie Morris (1993) observes, nondisabled people's behaviour towards disabled people is a social problem, social because it is an expression of prejudice which take place within personal relationships as well as socio-economic and political institutions (p.67). It is of course the social relationships that feature most prominently in young adult fiction. This is especially evident in the novels featuring facial scarring as a result of an accident, five of which are now examined: *Sweet Clarinet* (James Riordan: 1997), *Anarchist's Angel* (Gareth Thompson: 2009), *Face to Face* (Helen Atunase: 2002), *Face* (Benjamin Zephaniah: 1999), *Sara's Face* (Melvin Burgess: 2006); I have found fewer examples of other 'differences', just two with the genetic disorder Down Syndrome, a story in *The Bus People* (Rachel Anderson: 1989) and *Naked Wearing a Hat* (Jeanne Willis: 2003), one novel that contains a character with deformed limbs due to thalidomide in *Sisters... No Way!* (Siobhan Parkinson: 1996) and one with an amputee *The Cinnamon Tree* (Aubrey Flegg: 2000).

My research to date has not yielded any outstanding book that deals with facial scarring resulting from an accident. The earliest published one, *Sweet Clarinet* (James Riordan: 1997) is set in the 1940s. The bomb that kills his mother causes the protagonist, Billy, serious disfiguring burns and weakened lungs. After hospitalisation Billy is sent to an institution until he reaches the age of seventeen (this aspect of the narrative is discussed in the chapter on Institutions). Billy's attitude to his appearance is very similar to that of Samson in *Anarchist's Angel*, as they are accustomed to 'stares and cat calls' from others (p.96), they both believe it is natural for people, particularly girls, to be disgusted at their appearance. 'What decent girl in her right mind would fancy an eyesore like me?' asks Billy (pp.48, 115). Samson confesses he 'can't face a new load of strangers. It's the girls mostly, how they stare when they see all this [his scars] ... Why do you think I like burning charcoal? It takes me out there on my own and my face gets good and filthy' (p.76). Samson also grows his hair long to hide some of his scars and whenever he can, he wears a baseball cap, a hooded top and sunglasses, a semi-disguise. Both boys show signs of depression and a lack of sociability as symptoms of the effects of their damaged faces. They could of course also be symptoms of teenage *angst* as well and sometimes this can pose a problem for writers; the necessity to create realistic adolescents who are prone to moods and unsociable behaviour as part of the maturing process which can be similar to the reactions to sudden disability. In fact Samson feels like an outsider even before the accident which leaves his face scarred. His background is

different from that of his schoolmates and this plus the fact he is overweight leads to verbal bullying. Thompson has created a troubled teenager. At home Samson's relationship with his mother is extremely tempestuous. Thompson includes a strong environmental theme and raises questions like the dichotomy of reconciling traditional ways of life and the need to make a living in rural communities with the march of commercialism. Samson's disfigurement contributes to his lack of self-confidence, his anger and his withdrawal from social life but as the narrative gathers momentum, his scars cease to feature and ultimately, in a somewhat banal manner, Thompson lets Samson discover that his scars are, in fact, hardly noticeable and that he can be attractive to the opposite sex. *Anarchist's Angel* is a disappointing novel from a disability studies point of view. The most original angle is perhaps that Thompson uses a girl suffering from some type of personality disorder to sow the seeds of Samson's recovery but her subsequent movements are not explored which contributes to an unsatisfactory ending.

Riordan's concept of disability is plain. He uses the character of a plastic surgeon to stop Billy feeling sorry for himself because as he points out, disfigurement does not prevent one 'from being accepted, from getting a job, from falling in love one day, getting married, having a family . . . doing all the other things that make life worthwhile.' (p.48). This 'pull-yourself-together' attitude is quite commonly found in films, especially in war movies, as Ann Pointon notes (1995). Riordan also acknowledges the difficulties facing a person who looks different. The landlord of the local pub wants to ban Billy because he sees him as 'mental', and explains 'Personally I've nothing against anyone who's mental; but it's bad for business.' (p.119). The perception that anyone with any sort of physical disability is also intellectually disabled is extraordinarily widespread and this is reflected in almost every young adult novel and recorded in countless studies (see for example Morris, 2001, Davis, 1995).

Billy reflects on 'how hard it is for some people to accept anyone who's different – whether with one leg, one arm, one eye, three eyes, black skin, red, white and blue skin. They're different – and unsettling.' (p. 119). In this narrative Billy finally accepts his scarred face and becomes a celebrated musician. It is in this regard that Riordan loses authenticity. The plot is far too dependent on coincidences and luck. By sheer coincidence, Billy finds he is a gifted musician. There are fairy-tale elements here which remove the story from the everyday life of a disfigured teenager. There is a popular belief that if a person has a disability, he or she is compensated with a special talent in another direction. For example it is sometimes held that people who are blind have an extra strong sense of hearing or touch. This is not true except insofar as a person might concentrate more on an unimpaired sense. The myth seems to be endorsed by some of those on the autistic scale who have extraordinary talent in areas like calendar calculating and detailed drawing from memory but this can rarely be harnessed into anything further because as Allan Snyder (2009), quoting Hermelin (2001:177), claims:

there are no savant geniuses about... Their mental limitations disallow and preclude an awareness of innovative developments'. Or to oversimplify it, they have a preconceptual mind that thinks in detail, rather than through concepts. (p.140).

Unfortunately this belief in a compensatory gift can lead to disappointment or even a sense of failure or guilt when no innate special talent is evident in a person with an impairment. Of course a triumph with a special talent can give a novel and optimistic ending, symbolising the coming to terms with the impairment and perhaps a different life. But not every disabled person will find something in which they excel above others. Shakespeare points out that by emphasising the extra-ordinary achievements of disabled individuals the experiences of 'ordinary' people – disabled or otherwise – are deemed unimportant and irrelevant. Hence nondisabled people view super cripples as unrepresentative of the disabled community as a whole and the gulf between the two groups remains as wide as ever (Shakespeare 2014). Although both books conclude with the disabled protagonist accepting his or her disability, there is not really a stage where one can stop adjusting to a disability any more than an able bodied person can expect their bodies to stop changing. It can be argued that an author wants some definite achievement to be reached by the disabled character in order to create a satisfactory ending. There are potential pitfalls in doing this as is shown clearly in *Wonder* by R.J. Palacio (2012) an American novel about a boy born with a severely disfigured face coping with his first term at school having been home taught previously. All he wants is to be treated like everybody else. This is reiterated throughout the book which contains some worthwhile explorations of prejudice but it is all undermined by the boy being singled out as a hero and awarded a medal for coping with all the problems and prejudices. This is not treating him like everybody else.

Face to Face (2002) has a female protagonist. The author, Helen Atunrase (2004), makes her intention explicit in an article in *Disability Studies Quarterly* 2004, which is to portray a person with facial disfigurement in a positive manner. She explains that she was inspired by a badly-burned survivor of the train crash in London in 1999. Atunrase claims to have researched the various issues around facial disfigurement with a view to writing this book which is laudable but not at all evident in her text. She also read fictional accounts and 'noticed that books written with disabled lead characters varied in quality a great deal'. This indeed is true and unfortunately her own book is of poor quality. Neither the plot nor the characterisation is convincing, the former has no shape the latter mere stereotypes and there are frequent contradictions and a lack of consistency in the text. For example on leaving the headmistresses study. The protagonist, Kaley, suddenly catches sight of her reflection in a mirror which makes her shudder. She explains to the headmistress that she has no mirrors at home (8-9) and the grandmother, with whom Kaley lives, 'had tactfully removed all the mirrors in the house' but in the same paragraph the reader learns

that Kaley had secretly kept a mirror on her bedside table (p.30). Later the reader discovers that apparently the mirrors are not removed but have been placed just above Kaley's sight (p.37). These details may not appear important but for a person with facial disfigurement mirrors take on a deep significance. There are other flaws as well, for instance, the reader is told that Kaley had been helped greatly by the charity *Changing Faces* to the extent that 'Without them ... she might never have come to terms with the ordeal' but there is no evidence of her having come to terms with it. All these points undermine the authenticity of the portrayal but the novel has been endorsed by *Changing Faces*, a UK support body for those who have conditions, marks or scars affecting their appearance. James Partridge, founder and chief executive of Changing Faces says, 'It's good to see a book for children and young people open up the subject of facial disfigurement in such a strong and interesting way.' (Back cover of *Face to Face*) The praise is not warranted. The novel is included in this study as an example of a piece of fiction with almost no merit. There are two reasons for this; firstly, it shows what little appeal a badly-written book would have and secondly, it highlights the fact that often children's and young adult narratives that feature disability are included in shortlists for various prizes, deservedly or not. It is probably mainly due to most judges' lack of experience and understanding of disability. This can result in the idea that any literary exposition of disability is desirable or the idea that a book is somehow better just because it tackles a sensitive subject or perhaps because it lessens social guilt. In this case it is unlikely that any reader would identify with the main character or find the plot compelling.

Zephaniah has dedicated his novel, *Face*, (1999) to the Changing Faces organisation. His teenage protagonist, Martin, is left with burn scars on his face after an accident. This is a disappointing portrayal due, at least in part, to Zephaniah's narrative style. He has chosen to be an omnipotent author but the reader is very conscious his authorial presence, because he is very obviously 'telling a tale'. He has sentences which are almost like stage directions, being short and almost directive, before and after pieces of dialogue. They fail to merge into one another. For example: 'Dr Owens entered the room with his mother and father following her'. After an update on Martin's condition and that of the others in the car accident which takes a little more than two pages of conversation, it is followed by 'Soon Martin's parents and Dr Owens left... (pp.74-77). Episodes seem to be rather frequently closed by Martin falling asleep even when sleep might be unlikely. In other places there are quite lengthy 'blocks' of narrative to explain what has happened in between the conversations. The author also shows a tendency to include other unnecessary details. For instance, the reader is told of the background of one of the nurses although she is a minor character, not fleshed out at all, who plays only a tiny part in the plot. This has no bearing at all on Martin's story; therefore, it is totally extraneous (p.82). Although the hospital routines are not completely convincing (pp.74, 82 for example), Zephaniah is using the medical model of disability to a large extent. This is most clearly seen in an episode sometime after Martin has

returned to school and is learning to cope with people's various reactions to his new appearance. Martin is assured by the young priest that all are welcome at the youth club' regardless of age, race – or disability.' (p.149). Martin is enraged and barely controlling his temper he hotly denies that he is disabled. Yet from a social model point of view that is exactly what he is. He is disabled by other people's reaction to his scarred face. Zephaniah does not quite make this clear although he makes his character realise later that night that '*it isn't just about me and how I cope with it, it's me learning to deal with other people's prejudices.*' (p.151). There are some other features in this novel which would be recognised by disabled readers like the embarrassment of his friends, the changing relationship between him and them and especially with his girlfriend. Less expected is the incident when Martin is surrounded by a group of small children calling him names like 'Dog face' or 'Bogey man' or saying to one another, 'Don't let him touch you, he'll kill you'.(p.177). There does not seem to be a solution to this sort of events according to Martin's councillor. However Paul Abberley (1987) claims, quoting a report in *The New Society* 1985, that children do not start reacting badly to abnormal looks until they are at least eleven and suggests that discrimination against different looking people is not an innate result of evolutionary forces it is socially learnt (p.6). Lennard Davis (1998) points out that folk and fairy tales for children containing villains who are often one-eyed, one-legged or ugly, must surely contribute to this (p.330).

Melvin Burgess raises several questions in *Sara's Face* (2006) but gives no definitive answers. The novel is written as a piece of investigative journalism using the devices and clichés usually connected with media reporting. This gives Burgess Freedom to introduce ideas without necessarily exploring them. Celebrity, fame, appearance, cosmetic surgery are all in this extreme, dramatic story. They are real and indeed commonplace aspects of some forms of youth culture and questions arise about all of these issues. However this study is concerned with disability and primarily with the extent to which the emphasis within Western society on the standard of the perfect body image can result in a very low self-image for the many who fall, or believe they fall below that standard. Eating and other disorders can ensue leading to a demand for cosmetic and reconstructive surgery. Disability activists, led by feminist disability writers have problems with this. Garland-Thomson (2002) for example claims: Cosmetic surgery driven by gender ideology and market demand enforces feminine body ideals (p.11). This is certainly the case with Burgess' teenage character, Sara. According to the other characters in the novel, Sara is already beautiful and her wish for cosmetic and reconstructive surgery is totally unnecessary or baseless, but this is not Sara's self-image. Sara suffers from dysmorphia and some sort of personality disorder. The issues that arise in this fiction are dramatic and extreme, exaggerated versions of real-life young adult concerns. There is no explicit comment or criticism, but as one of the main characters has

had so much surgery that he has no real face left and needs a transplant, the readers' thoughts are perhaps nudged in a particular direction.

On the other hand it can be argued that there is certainly a place for reconstructive surgery. As illustrated in the other novels here it is especially important for adolescents to fit in with the crowd even if the focus is on changing bodies rather than on changing exclusionary attitudinal environmental and economic barriers. However this may have the effect of reducing cultural tolerance for human variation. (Garland-Thompson (2002). In Liz Crow's (1996) view, '...the treatment available is dominated by the medical model's individualistic interpretation of impairments as tragic and problematic and the sole cause of disadvantage and difficulty' (p.7). She explains that 'the isolation of impairment from its social context means that social and economic causes of impairment often go unrecognised... [and consequently]... many individuals are prescribed cosmetic surgery and prostheses which have no practical function and may actually inhibit an individual's use of their body' (pp.7, 8, 9). It is blatantly clear in *Sara's Face* that Sara's own view of her body as 'the sole cause of disadvantage and difficulty' is not valid. The functional practicality of cosmetic surgery is a question within this novel and here it adds an element of horror.

Rachel Anderson has two examples in *The Bus People* (1989) of the disabling effects of looking different. One is disappointing: 'Marilyn' suffers from the rare condition of microcephaly which means she has an unusually small head. Anderson chooses to give her other problems as well – her eyes are not aligned, her feet are of differing sizes and she is incontinent. It is a very negative description which opens:

No one likes Marilyn. Gangling Marilyn's a fidget and a drip.
People don't like Marilyn because of her drips. She drips from
her nose And from her panties. She dribbles drips from the
corner of her mouth down on to her patterned pastel sweater.
Chiefly she drips from her eyes. Marilyn is a teenaged cry-baby
Marilyn is always feeling sorry for herself. (p.6)

It is clear that she has been greatly influenced by her parents in feeling sorry for herself; '... it is not fair. She has heard her mother say so, time and again. (p.62) Her parents think it is unfair that they have a child with a disability, that she has to travel with 'those awful paraplegics ... just louts, a threat to any decent society ... should be castrated.' (p.62)

Anderson may have included an unlikeable character for authenticity because of course, with any group of people, there will be some who are less appealing than others and those with disabilities are no exception. Indeed a picture of a bus load of good living, attractive, sweet disabled children would be equally unacceptable. The reader can understand why Marilyn is so

miserable but it is a pity that Anderson made Marilyn physically unattractive as well, thereby endorsing the myth of connecting ugliness and evil so often found in literature and culture. Although some of the other bus passengers almost certainly were not physically appealing this aspect is mentioned only in Marilyn's case.

Anderson's portrait of the protagonist in 'Rebecca' is both sympathetic and successful. Rebecca is a young girl with Down syndrome, a condition which is typically associated with characteristic facial features and mild to moderate intellectual disability. Most teenagers are likely to recognise it as many people with the syndrome participate in schools and the work place. Down syndrome support societies have been remarkably active and successful in many areas, claiming their place in society and the Special Olympics, for example. There is even an Irish TV animation series for children with every day stories about a six-year-old little girl with Down syndrome. When first shown in 2011 it was the world's first animated series to feature a lead character with Down syndrome (www.punky.ie). Therefore it is somewhat surprising that there are few characters with this syndrome featured in young adult fiction. However Anderson's portrait of Rebecca is of a high standard, sympathetic, accurate and poignant. The story is narrated in the third person, chiefly focalised through Rebecca whose thoughts are conveyed convincingly. For example, here she is excited about her sister's wedding:

Tomorrow was the happy day. The most beautiful day since Rebecca's life began fifteen years ago in the labour ward. As chief bridesmaid, she had the third most important job of the day. The most important went to Jane, as bride. The second most important went to Graham who was to marry Jane. and she is to wear a "pink, pinky, pink" dress. (pp.13)

Concurrently, the third person narrative allows Anderson to fill in details about which Rebecca would be unaware or would not understand. Some of the short passages of the girl's physical appearance with the typical characteristics of Down syndrome or her habit of examining of her hands when she is upset or uncomfortable are examples of this. (pp.16, 24). With considerable skill Anderson creates the family dynamics. Through Rebecca's thoughts the reader learns that Rebecca's mother tries to explain why Rebecca must try to stop hugging people she meets, particularly men, because 'it isn't the done thing ... Specially with a girl like you.' This means to Rebecca that she is a girl who has forty-seven rather than forty-six chromosomes; she accepts this fact even if she does not understand it. Her father 'more gently' had explained it did not matter so long as a person is loved and that she is loved. So she feels safe at home and is able to cope with being laughed at and called 'a dummy dumbo' knowing that at home are the family members who love her (pp.13-15, 19). The inclusion of the adverbial phrase "more gently"

suggests that the father is more relaxed about and accepting of his daughter's disability and probably has a better relationship with her.

The crux of the story is the decision not to have Rebecca as a bridesmaid because of her disability. Anderson presents this indirectly by using Rebecca's limited understanding of what is happening. Although Rebecca is looking forward to the wedding the following day, her routine is upset when she comes back from school. There are many people in the house and her mother is not in the kitchen preparing her tea, 'Everything was disturbingly topsy-turvy. But Rebecca would not let herself be upset. Her sister had told her it might be like this.'(p.16) She overhears her aunts and mother talking. It is perfectly obvious to the reader that the subject of the conversation is about telling Rebecca that she is not to be a bridesmaid. Anderson suggests that Rebecca herself is aware of it too but hopes she is wrong:

Although Rebecca heard the words, she knew she must not allow herself to try to understand their meaning because, as her mother so often told her, girls like her were not always very good at understanding things and Rebecca often managed to misunderstand things which were actually quite simple. (p.20)

This is further endorsed when Rebecca's mother leaves the room and the aunts continue the conversation with references to 'the mongol' '... and she could not, would not, understand difficult and important things like what the aunts' brittle words meant' (p.21). During the evening Rebecca is woken by these 'brittle voices' and she can hear the argument continuing fiercely outside her bedroom. By the next morning Rebecca 'could no longer pretend to herself she did not understand the meaning of yesterday's brittle stream of words' (pp.22-24). The re-iteration of the word 'brittle' emphasises the cruelty inflicted on the girl. The only objection to Rebecca being a bridesmaid seems to be her physical appearance. The characteristics of her appearance are linked to learning disabilities, an area where the greatest prejudice is found. There does not seem to be any objection on the grounds of her behaviour being unpredictable or inappropriate and she herself decides to accept whatever the day has to offer. Indeed her efforts not to cry, to be on her best behaviour because she loved her sister 'more than anybody in the world' (p.25) are poignant. Overall this is a convincing picture. The story is a simple, straightforward incident which results in the reader gaining a sympathetic understanding of the effects of prejudice on the girl.

Another protagonist with Down syndrome is found in *Naked without a Hat* (2003) where Jeanne Willis has a different approach. Superficially the story appears similar to many other teenage love stories. It is narrated by the main character, eighteen-year-old Will. The reader becomes increasingly aware that all is not what it seems in this light-hearted, humorous book until

it is revealed to the other characters and to the reader (as discussed in Chapter 4) that Will has Down syndrome. The revelation occurs because Will's intention to marry causes a crisis. The only person against his marrying is the only one who knows he has Down syndrome. The other characters did not 'see' the Down syndrome characteristics because Will as a young child had undergone cosmetic surgery to remove them. Hiding the giveaway characteristic of Down syndrome is a very different use of cosmetic surgery. Chapter xiii of the novel explains how Will's mother, obviously suffering from postnatal depression, could not cope. She claims she was not ashamed of him but of herself (p.157). The family argument echoes a familiar disability debate: there is 'no escaping that people judge us by how we look' on the one hand and the acceptance of one as he or she is on the other. (p.158). Later further arguments ensue, if it was 'for the best' that he had his cosmetic surgery – 'The best for who [*sic*]?' Will asks, meaning him or his mother. An important aspect of this book is that the author highlights how different perceptions result in different expectations and discrimination. When Zara confesses that she is of the Traveller community ('a stupid didicoi' not even 'a proper Gypsy'), she expects Will to laugh at her and stop loving her (p.91). Will claims, 'If you'd let me keep my real face, Zara would never have loved me. I wouldn't be hurting like I am now.' (p.164). This is an unusual and unexpected stance. Will realises how one is judged by appearance; had he retained the characteristic Down syndrome facial features he would be seen primarily as a person with this syndrome and only secondarily a person in his own right, with his own personality traits. Will does not seem to worry about possible discrimination because of his learning difficulties but then these are comparative. To Zara he is clever, he can read and write. The readers might pause for thought here too –they may question how the revelation of this syndrome affects their thinking.

In Siobhan Parkinson's *Sisters... No Way!* (1996) there is a small but important portrayal of an adult with severe malformations from the effects of the drug thalidomide which was taken in the late 1950s and early 1960s by pregnant women suffering from morning sickness. It caused their babies to be born with missing or foreshortened limbs and sometimes other defects. (www.thalidomideireland.com). Cindy, the protagonist in Parkinson's novel, has an aunt 'who is 'a bit unusual ...[with] sad little hands coming out of her shoulders ...' and she uses her feet instead of her hands, even for smoking. The reader learns from Cindy that her Aunt Imelda is not only 'a pet' but 'dead cool' (p.6). So it is understandable that it is to her aunt that Cindy goes when she is unhappy at home. She finds when she spends a week-end with her that, they have fun together and Imelda is a good listener too. Cindy feels that the answer to her problems would be to move in with Imelda and she could be a help to her aunt. However Imelda unequivocally rejects this idea and explains she has her own life which would not 'mingle' with Cindy's (p.47). The reader may speculate that Imelda may be including a sex life here. This, along with her apartment near the canal in Dublin with a variety of gadgets and a mezzanine bedroom suggest

that Imelda needs no help. Rather she has taken her place in society, living a full and independent life while being an excellent adult role model. The inclusion of an adult character with a disability is quite rare in young adult fiction and is important because young people generally do not come in much contact with disabled adults. (See Watson 2002 for example). The portrayal is also one where the disability is not necessary to the plot. This is what I have termed 'incidental' (see also for example *Saffy's Angel* by Hilary McKay) and, when the portrayal is accurate, is a valuable asset to the disability canon reflecting the real world where people with impairments are living their lives as fully as possible.

A.J. Piesse (2007) writing in *Irish Children's Writers and Illustrators* describes the aunt as 'redemptive' (p.101) She reminds the readers that the aunt is part of Cindy's redemption. Although Parkinson's character is undoubtedly a modern woman and the portrayal is unsentimental, she is continuing a tradition of a disabled character redeeming one who had gone astray.

Another, very small, example of an adult with a disfiguration can be found in *Melody for Nora* (1998) by Mark O'Sullivan. It is a First World War veteran whose hands are always in tight black gloves: 'The hand was scarcely recognisable as that of a human being. It was pitted and scarred. The hand of a beast. Red and raw, it webbed with bulging purple veins. His left hand was missing the middle finger. ... [Nora's] revulsion quickly turned to wonder that such hands could produce the most flawless music. '(pp.171-172). It is because of the revulsion people show when they see such imperfection that the person with the impairment deems it necessary to hide it. This is such a tiny example that it would be of little importance except for the unusual idea that O'Sullivan posits: the hand may not look beautiful but its functionality is unimpaired and it can create beauty.

Aubrey Flegg's *The Cinnamon Tree* (2000) features an amputee and this book is an interesting example of disability used as a metaphor for the message that the author wants to convey. Disability is central to the plot but it is not the central theme. Yola, the teenage protagonist, has lost a leg due to a landmine accident. She is training to be a Junior Instructor teaching mine awareness to other children because Hans of *Norwegian Aid* believes that the children would pay more attention to her message since she is an example of what can happen. It seems to me that Flegg is similarly using her to exemplify the possible tragic result of landmines. Because of this, disability is not treated in depth, nor completely realistically. Although the narrative is written in the third person, it is almost all focalised through Yola and there is plenty of opportunity to show her coming to terms with her situation. This does not really happen. For example, after Yola's leg has been amputated she looks down at her bandaged stump and 'Like an overpowering weight the full calamity of what had happened to her hit Yola' (p.18). This the

reader is *told* but given little evidence of it. There is a break in the chapter immediately after this sentence and the story resumes with her return home. We are not given any time frame but as she was thirteen when the story opens and well established at home for her fourteenth birthday (p.43), it seems to be just a few months. Yet at this stage Yola has apparently pretty well come to terms with her accident and loss, both physically and psychologically. While losing a leg is a calamity for anyone, for a young girl in Yola's position it would be completely devastating. Angola, the country on which Flegg's Kasemba is modelled, has few facilities for rehabilitation but more importantly in regard to the local customs Yola would be unable to work in the fields or to fetch water so no man would want to marry her. All her life's expectations would be shattered. Flegg is certainly aware of this. It is conveyed in his description of the formal reception held by her father on her return from hospital when Yola overhears 'the gossips' asking who would give 'a bride-price for that!' (p.21) when she appears. Yola's future in the real world would be extremely bleak. Disability is deemed a shameful thing in some cultures. There are two references to the idea of shame, once as she arrives from hospital and again when she notes that Hans talks about limbs 'as though there was nothing shameful for her to have only one leg.' (p.34) Flegg does not ignore Yola's feelings. She is able to bury her thoughts about the future because she is so happy to be home again but 'the clouds of misery' were gathering and eventually burst one morning as she watches the women going out to work in the fields (p.24). Her frustration is more subtly conveyed by her temper fits with her father's youngest wife. While this is successful to a point, the fact that there was a previous rivalry between them mitigates the impact. In real life a person in Yola's situation would almost certainly experience periods of depression and her recovery from her occasional 'flashbacks' of the accident while certainly a part of post-traumatic stress seems to be surprisingly quick. Equally quick is her mastery of her crutches. There is more emphasis on her learning to walk with her artificial leg where the author conveys the hours of sheer struggle. (pp.99-101) but once she has mastered walking with her prosthesis, she appears to be so skilful that it is not noticeable and hardly affects her mobility at all. Yola is made to feel different or isolated because of her disability and she is left in the compound with the tedious task of grinding maize while the other women go out to the fields (p.24). The same cannot be said regarding her colour or culture. Without any difficulty she apparently fits in easily with her schoolmates and her fellow rehab patients in Ireland and with the Europeans working to clear the mines as well as with her own race. Occasionally there are mentions of her discomfort, in the Dublin traffic for example (p.73) or her claim that she is often only guessing or pretending to understand what people are saying, yet in a very western gesture she shakes hands with Catherine. For the most part Yola accepts the different circumstances, customs and culture with an ease and immediacy which is not credible. It should be remembered that she was of a rural background, living in an isolated compound where maize was ground by hand and where her father had three wives! She would be undergoing such contrasting experiences that in real life surely she would have been

thoroughly confused and intimidated. Oddly too, Yola displays no bitterness towards those who planted the landmine. In fact she does not seem to give them any thought at all. She does enthusiastically join the anti-landmine teams but this would appear to be part of her ambition to leave the village and travel rather than any ideology or political thoughts. Not all these criticisms pertain to the portrayal of disability but they detract from the veracity of the created situation.

Flegg includes minor characters with disabilities in this novel and these are all positive depictions. The two men working in the casting room are deaf, a disability which is seen as an asset due to the noise of the vacuum pumps. (pp.82-85). This is another example of an 'incidental' portrayal of disability in the background of a narrative. Although these characters are merely sketched in, they serve the purpose of reflecting real-life and showing disabled people taking part in the workforce. Yola's two ward companions have disabilities of course. The younger one is very vivacious and cheery. Her symptoms, 'vestiges of fingers remained on the shortened forearms', are reminiscent of those of a thalidomide victim although of course the date precludes this. She appears to accept her disability and delights in playing tricks on unsuspecting people by getting them to shake hands and watching them, 'longing to drop it – *Yuck!* – but then they realise it's rude, so they begin to shake it, not a normal shake but like they were shaking a dog's paw.' The older girl is initially in a deep depression and lies in a 'defensive knot of anxiety and fear'. Eventually she is helped by Yola (pp.74-76). Flegg also raises the issue of child soldiers. In a note at the end of the book, he states that the book was written for its readers' enjoyment but if any readers felt they wished to do something about the issues in it, he gives several website addresses of organisations dealing with landmines, child soldiers and disarmament. (p.208) but none concerning disability. This suggests that disability is not a principal concern of the author. Flegg's treatment of disability and rehabilitation is somewhat superficial. He does succeed in creating a fairly credible world with realistic characters but he suggests rather than depicts someone coping with a disability. In the same way as Martin Waddell uses his character in *The Beat of the Drum* as an example of the effect a bomb can have on the innocent (see Chapter 6), Flegg has used Yola as an example of the possible effect of landmines. This, I suggest, is how their authors see them. It is important for the message of the stories that the readers should like these characters, sympathise and perhaps identify with them and trust them as narrators. There is inevitably a tension between a realistic presentation of a disabled character and at the same time using that character as a symbol.

A glance at the array of anti-acne products on the pharmacy shelf, the number of fashion features in journals for adolescents of both sexes, the representation of the body beautiful on television all suggest the importance of appearance for young adults. This is not really reflected in the number of novels regarding different looks or the depth of fictional exploration of the subject. As already mentioned none of the novels featuring facial scarring is especially memorable

but all, except *Face to Face*, have some merit.. This applies very largely to the other narratives which have been explored. Occasionally small details like Billy in *Sweet Clarinet* noticing that in all his comics every hero was unblemished whereas the evil ones had cruel faces and twisted smiles (p.25), may cause the reader to think about the portrayal of disability. Or, on a larger scale Burgess' *Sara's Face* might make the teenager question the superficiality and dangers of a life centred on celebrity. It would be difficult for a disabled person to identify with any of the disabled characters. Although they are not mere stereotypes they lack depth and tend not to be fully credible. Siobhan Parkinson's creation of the aunt in *Sisters... No Way!* is valuable both as an adult role model and as a background figure who just 'happens' to have an impairment and is seen living a full, independent life.

There is no doubt that there is a dearth of the number of young adult narratives concerned with different looks which is surprising. However, there is another group of people who are immediately identified from their looks as being disabled. This group comprises those whose impairments involve the use of a wheelchair. Wheelchair users are of course very obviously disabled and seem to have a greater appeal for writers. This is examined in the following chapter which although concerned with the physical environment, features wheelchair users quite prominently.

CHAPTER 6: GETTING AROUND – ENVIRONMENTAL BARRIERS.

Environmental barriers are the first to come to mind when discussing the social model of disability; it is easy to see how steps into buildings and inaccessible transport exclude people with limited mobility. Equal physical access to places and wheelchair friendly paths are theoretical ideals that are embraced by almost everyone, whether disabled or not. However, equal access is not simply putting in ramps and ‘dishing’ footpaths. Building access has improved with regard to greater accessibility and, in Ireland legislation (Education for People with Special Education Needs 2004 and the Disability Act 2005, for example) now ensures that the disabled or at least those in wheelchairs are not forgotten. Nonetheless full access should mean more than entrances at the side or the back of buildings with doors frequently locked or impeded with junk. Toilets and lifts are also frequently locked and keys have to be requested and found before these can be used. Toilets tend to comply with the absolute minimum measurements and so preclude entry by the larger power chairs. As any person with mobility difficulties will testify, this is not equal access. People with other impairments fare even worse. Seldom are audio, video or tactile aids found in public places. Tom Shakespeare (2014) points out that ‘disabled people have less flexibility and fewer choices than non-disabled. An accessible environment minimises the inconvenience of impairment, but does not equalise disabled people with nondisabled people’. (p.44).

To most people the word disabled is closely identified with a wheelchair. It is the universal logo for disabled access, driver, parking and almost anything to do with disability. Unsurprisingly, it is always connected to environmental barriers. Although people with hearing or sight impairments are also disabled in the environment; few people can use sign language and not all lifts are ‘talking’ lifts for example. Different sorts of environmental barriers are quite frequently mentioned in research reports (see, for example, Watson (1997), Shevlin and Rose (2003) O’Connell (2005)). It is not only private dwellings and workplaces that are inaccessible. It is difficult at times to find suitable bars and clubs with adequate space for more than one wheelchair (Horgan 2003:104). A common finding in several reports is that young people in particular can find environmental issues a serious barrier to socialising. In spite of that, environmental barriers are very rarely mentioned in young adult novels and almost always in the context of a wheelchair.

In this chapter I examine environmental barriers and the uses of wheelchairs in young adult fiction... I have chosen the following books for discussion - Lois Keith’s *A Different Life*, Jay Ashton’s *Killing the Demons*, Catherine McPhail’s *Wheels*, Catherine Sefton’s *The Beat of the Drum*, Susan Sallis’ *Sweet Frannie* and Gillian Cross’ *Calling a Dead Man* with some references to Hilary McKay’s *Saffy’s Angel* and Róisín Meaney’s *Don’t Even Think About It*. In addition to a discussion of environmental barriers and wheelchair users, I include a novel, Julia

Donaldson's *Walking on Cracks* which shows a socio-economic angle. To conclude this chapter there is an analysis of the depiction of environmental barriers affecting those with impaired sight, using Jean Ure's trilogy of *Abe and Marianne* and Michael Coleman's *Going Straight*.

In only two novels, *A Different Life* by Lois Keith (1997) and *Killing the Demons* by Jay Ashton (1994) are these environmental barriers an issue. Lois Keith, a wheelchair user from the age of thirty five and a disability rights activist, is also the author of *Take Up thy Bed and Walk: Death, Disability and Cure in Classic Fiction for Girls* (2001). This is the only recent study of any length on the theme of disability in fiction for older readers. Her chosen classics were all published between 1847 and 1915 and although she ignores the enormous social changes taking place during this period, she makes many insightful and interesting points regarding the general perception of disability. Keith claims that writers are often limited by 'their own narrow view and lack of any real understanding of what it's like to be disabled.' And the result is 'some joyless books with confusing messages' (p.196).

There are no ambiguous messages in *A Different Life*. A firm believer in the social model of disability, Keith illustrates this clearly and unequivocally in her novel. It can almost be taken as template for a novel based on the social model of disability. She sets out to show that there is a solution other than death or cure, simply 'a different life'. Keith dwells in some detail on the sort of problems and difficulties a person in her protagonist's position would have to face. She encounters the whole gamut of nondisabled reactions, or as Oliver (1990) puts it 'All disabled people experience disability as social restriction ... inaccessible built environment, questionable notions of intelligence and social competence ...' (introduction xiv). . Consequently, this fiction is examined in Chapters 2, 3 and 4 as well as here. Keith's plot is simple, her protagonist, Libby, catches a virus which results in her losing her ability to walk. She faces a major environmental barrier when she is at first excluded from returning as a wheelchair user to her school. The headmaster epitomises a prejudiced narrow-minded attitude. He sees Libby's problems initially as a nuisance. He blames the 'authority' which is unwilling to give extra funds for a lift to be installed. He puts forward excuses as to why the bulk of Libby's classes could not be located on the ground floor and emphasises the obligatory study of science in the school with the laboratories all located upstairs. Finally he uses health and safety as an issue which makes Libby's mother burst out with 'This is the kind of attitude that kept ordinary disabled people locked up in asylums for their whole life ...' and indeed his solution was that Libby should go to a special school. Libby's mother contacts other parents of disabled children and was told by one of them that they see the special schools as a kind of apartheid. (pp.230-242). Keith shows a parallel between racism and what Thomas (2007) has termed 'disablism' (pp.73) throughout this narrative. Libby needs reassurance that she is not a fire risk not causing much trouble. It is easy to persuade the

disabled that they can be a risk or are a nuisance. For example, quite recently a disabled man who had been going to the Peacock, part of the Irish national theatre, for some thirty years was suddenly refused entry as he was considered to be a fire risk (O'Keeffe, Declan. Letter. *The Irish Times* 9 June 2003). The social worker reassures her ; 'Don't let them make you feel you are to blame ... the problem is not your inability to walk ... the problem is the way the buildings have been designed to shut you out ...(244-5). Keith is explicitly rejecting the medical model of disability, replacing it with the social one through the character of the social worker. Keith has created an idealised disabled person in the young wheelchair-using social worker and uses her as a spokesperson and an example.

Libby encounters other environmental barriers. She is told of difficulties getting into leisure venues. She is forced to go 'the long way round' to visit her friend who lives just two streets away because of

those things I'd never given a second's thought to before, like the millions of unramped or too steep kerbs that suddenly presented themselves as enormous obstacles. Not to mention the dog shite, the uneven pavements and the up-and-down people's driveways. I'd always thought that where I lived, was flat. I was wrong....What I'd forgotten was that there was going to be a step between me and Cleo's front door so that the doorbell was unreachable.... (p.247)

She also had to experience 'That hard, dull feeling of knowing you've been left out, excluded.' when she was not invited to a party which was on the second floor of a block of apartments – 'As if that made it alright (*sic*).' (p.218). All these experiences, indeed most of Libby's experiences in this novel, would be recognised immediately by many wheelchair users.

One criticism arose in an online debate (Harbour, Vanessa). "Representations of Physically Disabled Children" Online posting. 24 November 2008. 25 November 2008 LISTSERVE@JISCMAIL.AC.UK) was that the section based in the hospital was far too long and detailed and, as Vanessa Harbour suggests, a 'turn off' for some readers. This is a valid point which might well be applied to other parts of the novel as well. For instance Keith goes to some length to establish Libby as an ordinary person living an ordinary life before her illness. This is probably in reaction to the more usual story where a dramatic accident results in a talented protagonist becoming disabled and losing his or her opportunity to become a champion in some active sports. Unfortunately, Keith's plot is not deep enough to sustain the length of the book. The fact is that she is anxious to spread her message and her ideas about disability take precedence over the narrative.

Ashton's plot is also weak in *Killing the Demons*, but the novel does depict the wheelchair user facing various environmental problems like narrow pathways, inaccessible transport, doorsteps, an elevator's control buttons being out of reach, high kerbs and lack of disabled toilets. Another disabled character loses his job because he is deemed to be a fire hazard. Ashton also includes some home problems like balancing a kettle on one's lap while using one's arms to activate a wheelchair and trying to reach tables or kitchen worktops from the chair. There are also difficulties which are not solvable by society like the hilly countryside where they live and the impossibility of using an ordinary wheelchair on a sandy beach. (pp.6, 11, 13, 14, 56, 63, 83). None of these is a central issue; Ashton uses them to create a realistic setting for her teenage protagonist, Samantha or Sam, who has been using a wheelchair for several years. But Sam has other issues. Ann Pointon points out that a typical able-bodied view of disability is as a tragic event and that 'salvation and success for disabled people come from moving into some kind of compensatory 'supercrip' mode and that a key problem is bitterness about their condition.' (p.17). The term 'supercrip' is not a dictionary word, but it is used frequently within the disability movement to describe a person, most often a wheelchair user, whose achievements are greater than expectations. It is not clear if Ashton has this view, but she has certainly made her character, if not quite a 'supercrip', a strong and fiercely independent teenage girl who is extremely bitter about the unfairness of life. Sam, together with several other characters in this study, creates her own attitudinal barriers. It is her coming to terms with this as well, as her feelings of guilt over the accident, in which she lost the use of her legs and which caused the death of her baby brother that are at the core of the book. Ashton has included several side issues which are never explored as, for example Sam's friend's mother may be a holistic healer.

Sam is subjected to some traditional patronising approaches. Another teenage girl, Angharad, befriends her as part of a 'Good Citizens' project, demeaning in itself, and Angharad typifies a person who does not understand disability. She comes to take Sam out and asks Sam's parents where she would like to go. She is embarrassed when she uses the word 'walk'. She is well-meaning but she is viewing disability through the medical model and expects Sam to be dependent, passive and grateful. Morris (2001) suggests that 'negative attitudes held by non-disabled children and young people may be an important factor. She implies that a key context to the interaction between disabled and non-disabled young people is the extent to which the latter grow up with the idea that the former are to be pitied and made the objects of charity' (p.11). This would appear to be the situation here. Sam does not want pity; she is fighting to be a person, not just one of 'The Disabled', but an individual. It is obvious that she is rejecting the medical model of disability. She rejects activities in which she, in a wheelchair, cannot excel like riding a horse (p.40) or abseiling (p.60). Her anger and resentment prevent her making friends, although her schoolmates also appear to be unrealistically nasty. Throughout the narrative Sam plays computer

games as a form of escapism where she can walk, run, and fight her demons. The games appear to slide into her dreams and the reader is often unclear as to which the character is experiencing. Further, there is a hint of fantasy. Little progression is seen in either the game/dream sequence, or in the realistic part of the narrative but it is clear that Lucy, a fellow member of the Disabled Club, is a catalyst. At first Sam sees Lucy in much the same way as her schoolmates view Sam herself – subnormal. Sam explains, ‘But I’m *normal*... I just had an accident.’ Lucy replies, ‘So am I normal, only I had an accident, before I was born.’ (p.36). Later, Sam is amazed to find that apparently Lucy sees no point being angry about the fact that her lifespan will be short. Ashton highlights the depth of Sam’s feelings in the following outburst by slipping between second person and first person – you to we to us to you:

But it’s not fair. None of it’s *fair*. You’ve never been out without your mum before, you read all those books and never seen the things in them, look at all the fuss and arrangements we have to make and the way people despise us and pity us and patronise us, you have to have someone to help you go to the loo or to use a telephone or go into a shop or pick up a cup of tea and you’re not even going to live long! *Why* aren’t you angry?’

Lucy had stopped smiling. ‘I don’t like feeling angry. It upsets me and it upsets other people and I want them to be nice to me.’ (pp.70-71).

Morris (2001) in a conference paper on social exclusion quotes one young disabled adult which shows the authenticity of Lucy’s attitude:

‘I think that when you don’t have friends you can’t experience real life because real life is how you get on with other people. I can’t do anything on my own so I am completely dependent on people helping me, so if I am not going to be surrounded by only personal assistants, I have got to find a way of making friends’ (p.10).

Equally, using one’s friends can be problematic too, causing an imbalance in friendship. (South West Regional Authority 2000, p.46).

Ashton describes Sam as enjoying herself wheelchair ‘dancing’ on the final page, a pursuit she had previously derided as foolish. Her change of attitude might be due to Lucy’s influence and outlook, which would put Lucy as a disabled person in the redemptive role so often found in the medical model. Or perhaps it is because Sam has saved a boy from going on a disastrous joyride in a stolen car, thereby assuaging her long-standing feelings of guilt. Conversely, she has managed to overcome the demons in her computer game-dream which also might account for her change of attitude. Perhaps all three contributed but Ashton has

endeavoured to fit too many ideas into a very short book, just eighty-eight pages long, which results in a rather unsatisfying novel. There are some interesting aspects from a disability point of view with regard to the social versus the medical model, shown by what Sam wants versus how she is treated, but they are rather superficially examined by Ashton.

Catherine MacPhail in her introduction to *Wheels* (2003) explains that:

she was leading a workshop on writing for children and wrote a first chapter to show how 'I would grab the reader right away. I wanted it to be exciting, intriguing and end with a cliff hanger. I wanted to show that it can be just as exciting when the hero is in a wheelchair... Then I saw a programme about disabled children. They were discussing the lack of disabled heroes in books and I thought about James. He was the driving force behind *Wheels*. He makes things happen. It is James who solves the mystery. (Introduction)

There has always been a lack of disabled heroes in books; Lennard Davis (1998) points out that there is virtually no major protagonist with a disability in a novel written in the eighteenth or nineteenth centuries (p.328). What is particularly noticeable in this study of young adult novels is that almost all of the 'disabled heroes' are either able-bodied at the beginning and become disabled after an accident or have recently become disabled and are having difficulty in coming to terms with it. Few just happen to be disabled; in other words, their disability is always the issue. A noteworthy exception to this is Ted in *The London Eye Mystery* by Siobhan Dowd (2007). Ted is on the higher functioning end of the autistic spectrum and is depicted as taking a full part in his family life and he himself accepts his syndrome. It is not the issue in the novel.

MacPhail depicts her teenage hero, James, as being extremely bitter and angry about the car accident that claimed his father's life and left him unable to walk. In the same way as Ashton's Sam, James is rude to almost everybody showing his bitterness and resentment and his frustration when he needs help or feels he has not been treated equally. He too faces environmental barriers, he has to be carried up the public library steps in his wheelchair for example (19) and at the youth club's disco he goes unnoticed and is either bumped into or used as an empty chair. MacPhail manages to a considerable extent to keep James in control of the actions of the book, but they are so inextricably mixed with his own attitudinal problems that he fails to become a 'hero'. Her stated motive suggests that she could create a perfect social model of disability and there is no reason why James could not be the driving force in a plot. But with such emphasis on his bitterness and impairment, the portrayal becomes more based on the medical model. There is a lost opportunity here to depict a wheelchair user, comfortable in himself, initiating and controlling the action of the narrative.

Few of the other wheelchair users in young adult fiction are shown to struggle with environmental barriers. They are depicted as either facing other difficulties or the authors wish to use them as a metaphor rather than a character. For instance, Martin Waddell, writing as Catherine Sefton, seems to have two purposes for using a wheelchair in *The Beat of the Drum* (1989). Firstly, he uses it to divide his character from the society in which he lives and as secondly as an anti-violence symbol. Waddell's prime intent is the depiction of bigotry and sectarianism in a Loyalist area of Northern Ireland in the 1970s. He presents its negative effect on individuals and communities by showing the consequential results of intolerance and violence in as objective a way as possible. He chooses a narrator who is part of the community, who knows and understands the situation and yet simultaneously is an outsider who can tell the story reliably and objectively. He does this by putting the narrator, Brian, in a wheelchair and using this as an isolating device. Brian describes his own separateness. 'I'm a kind of King's Fool in my chair, given licence by being so obviously different that they don't have to listen to what they say.' (p.22) and as his friend tells him, 'It's a good thing you are a special case ... some of the things you say would get you into trouble round here, if you weren't in your wheelchair' (p.67). This is also a clear example of society viewing a disabled person as the other. Unrealistically or at least unusually, Brian shows no wish to be included in life around him, although he does see the chair as a trap. He has to go where he is wheeled. This depends on who is wheeling him, and from time to time he tends to be abandoned (pp.13, 21, 41). However, this is one of several inconsistencies which make Waddell's portrayal of a wheelchair user less than convincing. It would be highly unlikely that a person who had been a wheelchair user almost since birth would not be able to wheel himself around unless he had a further problem with his arms or upper spine as well. There is no evidence of this. On the contrary, there are examples of Brian wheeling himself around or offering to do so. (pp.16, 82, 88, 99) which rather contradict the claim that he is obliged to go where he is wheeled. Another small incident suggesting that Waddell does not have Brian's disabilities in the forefront of his mind is when UDA men enter the house and want Brian to wake his uncle who is asleep upstairs. Given the working class district in which the story is set, and the delay in getting a replacement chair for Brian, privately funding a stair lift would not be an option so it is presumably a slip on the part of the author (pp.24, 57). On the other hand, Waddell successfully depicts other aspects of disability; the patronising attitude of the able-bodied, so often experienced by the disabled, for example. One woman refers to the protagonist as 'poor Brian' in his presence (p.41). The local councillor treats him as if he were deaf or had difficulties in understanding, even patting him on the head and using 'his special voice for calming cripples' (pp.56-60). The use of the term 'cripples', which is now deemed a pejorative term, in an alliterative combination and followed shortly afterwards by 'The Head Patters are definitely the worst ones.' convey Brian's resentment and bitterness. However, this is rare in the text. Brian usually appears to accept his position. Waddell makes no mention of his feelings with regard to being excluded from the

activities of his community such as the marching band or going around with his school mates or, having established his 'difference', his wishing to be like the others. This is unusual for a teenager. Brian does show a little unhappiness at having to share Val, a contemporary who wheels him around, when she begins a relationship with another teenager and uses Brian as an excuse to be away from her parents. It is not clear, though, whether he sees this as being related to his disability and whether it is jealousy of a sexual nature or simply jealousy for attention (p.73). It also stretches credibility that the boy, who has grown up in a fanatically Loyalist community, been orphaned and disabled by an IRA bomb is without at least a little bitterness. Waddell wanted a reliable narrator so had to isolate Brian. He is not interested in presenting his character's disability except insofar as Brian can be seen as an example or symbol of the effect of violence on the innocent. It is important for the message of the story that Brian should be separated from the prevailing bigotry of his community and this Waddell achieves by using a wheelchair. The isolation means that the reader is more likely to trust the narrator, but a wheelchair user is unlikely to identify with him. There is inevitably a tension between presenting any character as a symbol and as a realistic person simultaneously. An author must show both the strengths and weaknesses of his or her character to make it credible. This tends to detract from its use as a symbol.

Susan Sallis's *Sweet Frannie* made quite a breakthrough when it was first published in 1980. It was one of the earliest portrayals of a feisty wheelchair user treated in a realist manner in contrast to the more usual pitiable needy being. It received critical acclaim and was runner-up in the first Young Observer/Rank Organisation fiction prize. John Quicke (1985) and Pat Pinsent (1997) found it praiseworthy because of its lack of sentimentality but Lois Keith (2001) pointed out the many contradictions within the narrative and how Sallis has used several devices characteristic of the nineteenth century novels treated in Chapter 2. Frannie is an orphan for instance, her medical condition is unspecified and, in a sense there is the 'miracle cure' where Luke, an amputee and a fellow inmate in the residential home, manages to walk on his artificial legs. Further Keith suggests that 'it is impossible not to see her death as the price to be paid for the redemption of another' as in the Victorian tradition. What Keith does not point out is that in a similar way to Katy in *What Katy Did* by Susan Coolidge, Frannie learns to be a better person or more accurately a better female. This can be seen as redemption and Frannie is rewarded, not with a cure, but with the opportunity to live with Luke for the final months of her life. Her death frees him from looking after her and allows him a future relationship with a presumably non-disabled person (pp.215-219). While this novel does have some merit, overall it lacks credibility. Sallis tries to give her disabled character a determination to get the most out of life with a sense of humour and fun. However, Frannie appears to be a very selfish teenage girl, often rude, scheming and lacking in an appreciation of other people. She may be an assertive person, but, while it is unlikely to be Sallis' intention, not a pleasant one. She is bossy, scheming and selfish

– she sees one of the nurses as ‘a soft touch’ (p.21), claims that she ‘like[s] things to happenthings I make happen’ (p.12). Here, it would appear that perhaps Sallis is showing her character compensating for what she feels as a lack of power as a wheelchair user. It is her way of gaining a measure of control. There are many examples of her manipulating others, including Aunt Nell who is a kind of hospital visitor. It is not until the final chapter that Sallis shows Frannie in a better light. She is capable of love and appreciation of others and she who ‘never cried’ (p.14), weeps over Aunt Nell’s death which she, indirectly, has caused.

Frannie appears to have three unrelated and medically unnamed impairments, she has lost the power of her legs, is incontinent, and the reader is told she has some sort of heart condition which together with some respiratory problems kills her in the end. There is no link suggested between her heart condition and her paraplegia. Apart from a bout of pneumonia, she does not appear to be unhealthy and is capable of ignoring any environmental barriers by propelling her manual wheelchair up ramps, over lawns and along garden paths without becoming breathless, experiencing pain or undergoing any sort of stress. This is not believable.

There is often a tension in ‘realistic’ fiction between retaining a reader’s sympathy and showing the less attractive sides to a character. Although this is applicable to all writers, it poses deeper difficulties perhaps for those who are depicting disability because traditionally disabled people are perceived as being dependent on others or on charity and are expected to be grateful and submissive. To counteract this expectation, people with disabilities often have to be assertive and forceful. Finding the balance between the two in fiction calls for considerable writing skill.

The same problem arises for Gillian Cross. It is unclear why she made her character, Annie, in *Calling a Dead Man* (2001) a wheelchair user. In this thriller, Annie, convinced that her fiancé has not been killed in an accident, travels to Russia to find him. She brings her fiancé’s sister, Hayley, to act as a kind of personal assistant. The whole project is beset with problems and dangers and certainly the wheelchair makes their journey in remote areas of deepest Siberia much more difficult and less realistic. It does however underline how alienating a landscape can be. Great determination is required and Cross has given Annie plenty of it. In doing so, however, she has created a rather unlikeable person. Hayley finds it ‘hard work being with Annie’ (p.17) as she is so demanding and forever ‘rapping out instructions’ (p.32). It is excessively important to Annie always to be in charge and frequently she flies into rages. Cross shows no other side to this character and there is no suggestion that the assertive front hides a tender heart, anxiety or great love. Indeed she seems devoid of any emotion other than rage. Her bitterness is exacerbated by her physical appearance. ‘Her face was sharp as a hatchet’ (p.61). She has ‘thin shoulders poking, her small, sharp face, keen and attentive’ (p.4). This is suggestive of an animal and Cross emphasises the image later in the novel, ‘Her face was like a weasel’s, sharp and fine-boned, and

her eyes were fierce' (p.10) and it is repeated towards the end (p.230). The animal imagery contributes to de-humanising of Annie and even her voice, being 'insistent', is unattractive (p.4). Cross may be endeavouring to show that wheelchair users often have to be assertive and fight for independence and respect. She may be trying to create Annie as a determined and courageous person but she has not produced a fully drawn character. Annie is rather one dimensional, reduced to a non-human. It is only in the concluding pages that Cross gives the reader an idea of Annie's inner feelings. Against all odds she has found her fiancé in the wilderness but he decides to stay in Russia for a while. The isolated community's hostile environment serves as a reminder that the natural world is a disabling factor. Annie's fiancé explains his reasons for staying and,

She watched his mouth making the words – and thought of all the effort that had brought her there. Of the energy she'd used up, and the money she'd spent and the pain she'd suffered. Her mind and her body were both bruised and aching and exhausted. And now he was asking her to go through something else. For one split second, she thought, *I can't. I can't bear any more.* Then she took a long, determined breath and braced herself. Ready for whatever he needed her to do. (pp.249-250)

A few lines down from this she seems to be herself again but 'her other hand had tightened on the edge of the window. The end of the fingers showed through the glass, white-tipped.' (pp.250-251). The use of the definite article before fingers rather than 'her' interesting. It is only a tiny point but endorses the perception of Annie as an extension of her wheelchair rather than a fully fleshed-out character. The dangers of depersonalisation for all people, those without as well as those with disabilities can hardly be overestimated. Once any group of people is perceived as less than fully human, a rationale can be created for different treatment. Allan Sunderland (1981) points out that this 'cannot but have a brutalising effect upon the society in which it takes place; the most obvious current example of such brutalisation is probably the infamy of apartheid.' (p.5).

Two successful portrayals of a wheelchair user can be found in Hilary MacKay's *Saffy's Angel* (2001) and Roisin Meaney's *Don't Even Think about It* (2006). In each of these novels the wheelchair user is a secondary character and the fact that this character is in a wheelchair is of only marginal importance. The characters play a significant role, but their disability simply adds to the plot rather than being essential to it. These portrayals show a wheelchair user as part of a community just as a writer might include a student from an ethnic minority in a school setting. When executed well these 'incidental' portrayals are extremely useful in 'normalising' a disabled person by simple inclusion. The general idea is similar to 'In the Picture', the initiative of Scope, already referred to in the introduction to this thesis. It also fulfils the wish of one disabled pupil

participating in Book Trust's project who wanted to see disability included without 'any fuss' (www.bookmark.co.uk).

A large environmental problem is the lack of resources or in the acquisition of sufficient funding for disabled people, the need for community supports and access to medical and social outlets. Colin Goble (2004) claims 'the broader socio-cultural review of disability is the role of professional support and services are to mitigate the effects of the functional deficits faced by disabled people in order to help them to achieve greater normality and personal functional independence.' (p.42) naturally, this is peripheral in young adult fiction because this is rarely a direct issue for the adolescents. It is mentioned in Lois Keith's *A Different Life* when the local council will not fund a downstairs bedroom and bathroom and there are several references to the official welfare in *This Strange New Life* by Rachel Anderson. A vignette of a disabled person dependent on community care is found in *Walking on Cracks* Julia Donaldson (2009).

She gives the disabled character, Mary, a secondary role. The story line necessitates a character with an unconventional outlook on life and a much greater acceptance of a situation that would be expected from an adult so Donaldson has chosen to create a character with some sort of psychiatric problem, perhaps dementia. At first this is not obvious to the narrator, a teenage girl called Leo and hence not to the reader. Mary is an old lady with several shopping bags who is feeding the swans in a public park. Then through Mary's disjointed conversation with Leo that sometimes is without context, it becomes clear that there is something different about her (pp.33-39). Donaldson creates a benign, generous old lady who has recently been discharged from a psychiatric home and whose mental control begins to diminish as she stops taking her medication. Donaldson conveys this by making Mary's behaviour more eccentric, interspersing it with shortening rational (and often remarkably insightful) periods and she uses, with increasing frequency, words like 'cackled', 'cried' or 'screeched' instead of 'said'. Mary gains 'a wild look' (133) and eventually becomes a danger to herself and others. The two teenage characters are shown at this stage to be worried and frightened by what she might do but they are not frightened of Mary herself. Donaldson is writing from the social model by showing how an elderly woman with mild to moderate cognitive difficulties can live happily and successfully in the community, provided she receives adequate support. It was perhaps an unusual but deserving choice as the 2009 winner of the Nasen Inclusive Children's Book Award. The award is for a book that provides positive images of people with special educational needs and disability, including mental health issues.

One would be justified in expecting those with impaired sight to find many environmental barriers but they are rarely mentioned in the books featuring blind characters. In her trilogy, beginning with *See You Thursday*, Jean Ure uses small things to convey any difficulties that her character with impaired sight, Abe, might encounter. For example, at his first breakfast as a new

lodger, his landlady places a plate in front of him and announces... 'sausages at twelve o'clock, tomatoes at six.' (p.46). He does not avoid pity and some people treat him as incapable of understanding and address their conversations to Marianne rather than to him. (p.198), an experience which is familiar to the majority of disabled people, not solely the blind but most people are too helpful, 'the number of times I've found myself whisked across to the other side of the road without even wanting to go there!' (p.51).

On the whole he is portrayed as being extremely independent, but somewhat idealised. He is always good humoured, patient and wise. It is not until the third book of this series that he objects to the traditional perception of the blind being helpless:

... I am sick and *tired* of everyone assuming I am some kind of lower-grade moron! *Will he be all right? Can he manage? Can he cope?* ... I am sick of people being extremely nice, I don't *want* people being extremely nice, I just want to be allowed to get on with things in my own way, the same as everybody else ... I am sick to death of people *doing* things for me . I want to be left alone; I want to be able to manage without everyone constantly fussing at me and flapping at me and *spoonfeeding* me. I don't *want* you [Marianne] moving in as some kind of glorified nursemaid! I want you moving in on equal terms ... I want you to move in because you want to be with me, not because I'm so flaming useless that I can't manage on my own . . . I am sick, I am just *sick* up to *here*, of being regarded as incompetent. (1989, p.160)

Although he does manage to live on his own for a short period, ultimately Marianne's mother actually encourages her daughter to move in with him; one of her reasons is that the flat has a complicated boiler which is safer when worked by a sighted person. This perhaps weakens both her character's ambition and Ure's portrayal of full independent life for a disabled person.

Going Straight by Michael Coleman (2003) is a different type of book, in a sense it is an updated version of the favourite nineteenth century theme mentioned above of a disabled person redeeming another person who has gone astray. The protagonist, Luke, is a persistent young offender from a conventionally deprived background. Luke shows some compassion and a great deal of courage as he saves the life of a girl by pushing her out of the way of a getaway car. She is blind and could not see the car approaching. In the time-honoured way this good deed is rewarded when Luke appears in front of the magistrates who instead of a custodial sentence give him a chance to make good by working with the blind community and particularly with Jodi, the girl he saves. Instead of the stereotypical, piteous, patient creature which her fictional forebears would have been, Jodi is a feisty teenager, fiercely determined to have her own way. She uses Luke to gain further independence from her parents. Like Abe, she is somewhat idealised. Luke

becomes Jodi's guide runner as she first practises for and then participates in the London Marathon. Through his subsequent experiences with Jodi, Luke changes his attitude and gives up his life of crime. Apart from the unlikely redemption, there is a good deal of information about how a person with impaired sight can cope with environmental barriers – having a 'guide runner' in order to enter a running race is the main example and Jodi explains how she knows where a particular shop is:

We turned left at the traffic lights. That's how I knew we were heading for the footbridge. And I'd have known we'd reached it even if I couldn't hear the traffic on the expressway. It's made of metal, so it sounds and feels different when you walk on it. Then there is the chip shop at the corner, I could smell that before we got anywhere near it! Same goes for the cafe, we've just passed, especially when they've got bacon butties on the go. (pp.126-127).

Coleman gives Jodi an awareness that her disability itself is limiting in some ways, but she clearly does not accept that she should be limited by anything else (p.71). This is the social model in practice. Unfortunately Coleman has created an idealised, rather than a realistic, character in Jodi. She is always good humoured, intelligent, tactful and perceptive. In the dialogue 'Jodi said' is not often used without an adverb like 'happily' or 'excitedly' and words such as 'laughed' or 'hooted' are used in place of 'said'. She is also able to 'see right through' Luke (p.196), knowing when he is lying or dissembling from the tone of his voice. She has the ability to motivate him, to encourage him and support him. Ultimately Jodi's father admits to Luke: 'You've taught us that we haven't got a blind girl for a daughter, we've got a daughter who just happens to be blind. Big difference.' (p.204). This is a point which disability activists repeatedly maintain, that the emphasis must be on the individual, not the impairment.

In conclusion, the fact that the main way disability is immediately recognisable is through the use of a wheelchair might make it appear to be an easy way for a writer to create a disabled character. Unfortunately it is not necessarily straightforward and, as this examination has shown, not many authors have been successful in creating a convincing portrayal and environmental barriers are largely ignored. The novels do not seem to be informed by the social model of disability studies which might seem unusual as it was the Union Of the Physically Impaired Against Segregation (UPIAS) formed the basis of the social model. UPIAS is concerned primarily with impaired mobility, so its interest is in dismantling environmental barriers. While the social model has developed hugely physical barriers still remain as part of the environment (see introduction).

The concerns expressed by the characters in this group of novels tend to be personal and emotional and focused on friendship and inclusion. In other words, the characters face attitudinal barriers rather than physical ones either explicitly as in *Killing the Demons* or Sarah seeking

inclusion with Saffy and her family or implicitly with the de-humanising of Annie in *Calling a Dead Man*. All but two of the wheelchair using characters are shown to be creating their own attitudinal barriers. Bitterness, rudeness and resentment are the characteristics used to convey the overwhelming emotion in *Wheels*, understandable perhaps in the circumstances of a newly disabled boy, but although Frannie and Annie have been wheelchair users, presumably since birth or an early age, they appear to have created attitudinal barriers themselves. This may be a misleading impression; the authors may be endeavouring to create a feisty, independent and strong character in contrast to a compliant dependent one.

Other novels featuring wheelchairs are treated in other chapters since their presence is of minor importance. The ones under discussion here In Chapter 6 are chosen to illustrate specific points pertaining to wheelchair users or the environment. However environmental barriers for both wheelchair users and the visually impaired tend to be minimised in the fictions analysed in contrast to many sociological research findings they are not shown as major barriers to socialising, whereas lack of communication skills can be of further possible barrier to integration in society. The latter is the subject under discussion in the following chapter.

CHAPTER 7: COMMUNICATION

Communicating with other people is an essential part of being in a social situation since society in general is structured around the ability of humans to exchange information. Thus people with an impairment that renders them incapable of speech or only imperfect speech face a barrier preventing full participation in a social setting. Further, as Lennard Davis (1995) points out, it is assumed that the dominant language will be oral and the deaf appear to be bereft of language, hence of humanity. The term “animal” or “animalistic” is frequently used to indicate a life without spoken language. But if sign production is seen as written or printed, and if sign reception is seen as reading or signing, then the deaf are fully capable of fitting into that world (p.894).

There are several medical conditions and disorders that affect a person’s ability to communicate fully. That this is an enormous barrier is beyond debate and it is extraordinarily isolating. Most people are embarrassed when trying to understand a person who cannot articulate clearly and who speaks ‘differently’. They do not like to keep asking the person to repeat what she or he has said; they are embarrassed when they misinterpret sounds. With some conditions the speaker is unable to control voice volume and this too can be a source of embarrassment. Interpreting impaired speech can appear to be a painfully slow process. In the busy fast-acting lives of teenagers is not surprising that those with communication difficulties tend to be ignored and isolated as they are clearly not the ‘norm’. A good deal of effort exerted in the improvement of a person’s hearing with hearing aids but it should be remembered that that is only part of the problem. Alexandra Strick, a specialist in the field of children’s books and disability, who facilitated a seminar on ‘deafness and children’s books’ at the London Book Fair (2012) said that the most important quote of the day was ‘the deaf can’t hear – they can’t be heard either’ (<http://www.booktrust.org.uk/books/children/bookmark/blog/author/463>). However, in the deaf community there are two very different concepts of the relation between deafness and disability. There are those, Mairian Corker (2001) for example, who claim that the Deaf are a linguistic minority with its own culture. She uses a capital letter for Deaf to indicate this, or as she expresses it, ‘whose lives are centred on the visio-spatial experience of the world and express themselves through the medium of sign language. Corker further suggests that to ‘speak’ the same language as English-speaking hearing people on a surface level means for her ‘a loss of self’ because at the deeper level of significance, her language is very different (pp.38, 48). There is no exploration of the Deaf as a linguistic minority in any young adult fiction found in this study despite the fact that in Jana Novotny Hunter’s *Read My Lips*, the students comprise both ‘signers’ and ‘speakers’.

Another group of people with communication difficulties comprises those on the autistic scale who may not speak at all but when speech is present it is often clear and articulate although the delivery lacks inflection and expression of emotion. Their problems differ from those of the other groups.

Teenage books have a variety of characters with verbal and other communication difficulties: including those with impaired hearing: those on the autistic scale: some with cerebral palsy and others with elective mutism. The novels are analysed to view the extent to which, and how realistically the authors depict their characters and their disabling barriers. At the same time the methods employed by the writers to convey the characters' lack of speech or verbal difficulties are examined. It can be a challenge for any writer to use words that suggest the lack of words or the inaccurate use of them.

I begin with the four novels which contain a character with impaired hearing: Melvin Burgess' *Loving April* (1995), *Secret Songs* by Jane Stemp (1997), Jana Novotny Hunter's *Read My Lips* (2002), and Geraldine McCaughrean's *White Darkness* (2006). Within this group of books all the important aspects of hearing impairment arise: communication with and isolation from the hearing world, the oral versus signing debate and the attitude of those without a hearing impairment towards the deaf.

Isolation is well depicted in Melvin Burgess' *Loving April* (1995). The impaired hearing of the eponymous April is shown as a serious disability compounded by her poverty and social class. Her father is dead and the need to earn a living forces April's mother to leave her daughter on her own for long periods. Burgess has set the story in 1925, before the creation of a welfare state. Lack of money and membership of the working class make it difficult, even impossible, to access support, respect or a suitable education for April. She grows into her teens and spends more time with animals than with people. She finds it hard to communicate and the villagers, with a few exceptions, view April as 'a 'poor halfwit' or a 'dumb idiot'. Although this terminology might be less heard now, the misperception, which dates back to at least Ancient Greece, of the hearing impaired having learning difficulties remains (see Corker, 2001, Davis 1995). It is mentioned in all four novels.

The plot focuses mainly on Tony, a young teenager, coming to terms with his changed social circumstances and his awakening sexuality. Burgess looks critically at the British class system that pertained at the time. He appears to suggest that April's social class is a greater disability than her deafness: When Tony's mother notices a growing relationship between Tony and April, she decides will '... Boys will be boys. If he wanted to fool around it was better to fool around with April than with someone who really mattered . . . 'Even Tony was ' . . . ashamed of April. She wasn't in his class. She was deaf, not right. He would be teased and expected to treat her differently. . . She wasn't the sort of person who ought to be able to make him feel like this. But she did, and for that reason he was ashamed of himself, too.' (pp.118-119). At the same time Burgess does not gloss over how impaired hearing can have serious repercussions especially if it is not diagnosed early. He shows April's peers do not understand what she is saying they believe

her to lack intelligence and see her as different from them - not the Norm but the 'Other'. These negative angles are explored by Burgess and linked closely to the negative aspects of the class structures plus the lack of health and social services in Britain in the 1920s. Happily there have been improvements in services since then. In modern times April would have a hearing aid which could make a huge difference. Nonetheless anecdotally it is the better educated and those more socially aware who manage to access services more easily and more fully.

Loving April is not 'about' impaired hearing although this plays a vital part in the plot. Burgess shows the barriers which prevent April from becoming part of the social fabric. She is a victim but not altogether helpless. Burgess also shows how April makes the situation worse and he presents her as a fully drawn teenager with adolescent problems as well as her deafness. She matures as the narrative progresses. The result is a book which has a wide appeal to both the able-bodied and the disabled especially with April and Tony's relationship. As Aidan Chambers argues, books should contain every day concerns of modern teenagers and of course one of their central concerns is relationships. And this novel has disability firmly placed in a social setting.

Although Jane Stemp's *Secret Songs* (1997) is set in recent times, there is an element of fantasy in it which makes it almost timeless. The description of hearing impairment is fairly accurate but Stemp links the protagonist's impairment to her imaginary fantasies aspects – which makes it less realistic. The 'secret songs' of the title are the songs that Ceri, the protagonist, can hear inwardly which are part of her imagined undersea world. This fantasy world in Ceri's head connects with the real one when, on holiday in Scotland, Ceri meets and falls in love with her half-sister's boyfriend who swims with the seals and appears to be a silkie⁶ When she is wearing her hearing aids the sounds of the real world overwhelm her music and consequently Ceri hates using aids. Most of the story is concerned with Ceri's conflicting loyalties to her mother, her father and her half-sister but not with her impairment. Like Burgess, Jane Stemp does not place the disability at the centre of the plot and much of the narrative has little or nothing to do with deafness. However she does not create as strong a narrative as Burgess; nor does she show any barriers faced by Ceri. Ceri is able to lip read effortlessly and appears to be slightly ashamed of the hearing aid. She certainly finds it an irritant. As Stemp chose to make her protagonist deaf although this is not strictly necessary to her plot, one would expect her to depict the impairment with more realistic detail so from a disability viewpoint this novel is less successful than *Loving April*.

Adolescents might find *Read My Lips* by Jana Novotny Hunter more interesting as it has a stronger romantic interest although it is not well written and has a rather contrived crisis towards

⁶ It can also be spelt selkie. A mythical creature in Scottish and Irish folklore which can assume the body of a seal at sea or man on land

the end. This crisis seems to me to be an effort to add suspense and action but it does not fit in and is not convincing. The setting is a residential school for the deaf in the USA and it has a first person narrator, seventeen-year-old Debbie Katz, known as Cats. The narrative is concerned with the 'civil war' raging in the school between the 'signers' and the 'speakers'. In spite of the school's policy of 'total communication' which endorses a combination of signing, lip reading and speaking, the student body is divided. To a hearing person the debate might seem spurious since total communication is the obvious goal. But many who are profoundly deaf feel more comfortable with signing alone and there is a strong argument that sign language is a language in its own right with its own vocabulary, structures and nuances and not a poor translation or substitution for a spoken language (Sachs 1989). It is often, as already suggested, difficult for hearing people to understand the speech of a profoundly deaf person although there is only one reference to this in *Read My Lips* (p.134). However, as is illustrated in the novel, without any ability to lip-read or speak with some clarity, a deaf person is at a huge disadvantage when mixing with the hearing population or 'hearies' as Cats' best friend calls them. (pp.75-6). In an ideal world everyone should be able to use sign language which apparently was the case in the community of Martha's Vineyard in the nineteenth century. A recessive gene in the population frequently caused deafness, affecting something like 1:155 of the population (1: 4 in one town) compared with 1: 6000 on the mainland. There was no stigma attached to deafness, it was not a disability, the population was bi-lingual in English and signing (Oliver 1990, p.17).

Hunter has introduced a debate that is of great seriousness to the deaf community, that of speaking or signing. By treating it in a superficial manner, she has missed an opportunity to present the underlying issues of this debate. For the Deaf (written with a capital D) sign language is their native language and they see themselves as a linguistic minority in a phonocentric world. They emphasise coexistence with society, not integration and thus Deaf studies has developed separately from disability studies. Mairian Corker (2002) shows the depth of feeling by her choice of vocabulary: '80% of deaf kids are integrated, with no little thanks to disabled people; we are the ones sent to the valley of Undeaf, not they' (pp.2, 8). Paul Abberley (1987) refers to the chairman of the National Deaf Children's Society speaking in 1985 in reaction to the annual conference devoting its time to cochlear implant information. He said 'They [the children] shouldn't get the idea that the thing is to be more like a hearing person at any cost' (p.9). Sutherland (1981) goes as far as saying that the prohibitions on deaf children signing are "something evil, like wanking – things you do with your hands that you are not supposed to do.' (p.56). Hunter succeeded in conveying a depth of feeling in the row between the signers and the speakers but it appears to be founded less on ideology and more on rivalry between two cliques or gangs.

Lennard Davis (1998) points out the lack of protagonists with an impairment in English literature during the eighteenth and nineteenth centuries and the disabled were either recognisable villains, pitiful innocent children or childlike figures (pp.:328, 330). This situation has improved somewhat but there remains an almost complete lack of protagonists with an impairment where the impairment is not essential to the plot. In other words, a 'normal' person who just happens to have an impairment. A 'normal' person with impairment would in effect mirror real life. The few examples in young adult literature help to show that disability can be found anywhere and they create an idea of a more inclusive society. These characters I have termed 'incidental portrayals' and although most of them are not main characters, Geraldine McCaughrean's Sym, in *White Darkness* (2006) is one of the exceptions. Sym is a character who has not been deaf from birth. How her hearing became impaired forms a small part of the plot but the reader does not know this until near the conclusion. Her deafness is first mentioned casually when Sym, who is also the narrator, has to switch off her hearing aids because the television in a restaurant is too loud (p.16). McCaughrean shows that although Sym found it difficult initially to wear an aid - she listed the first day as one of the days she would like to lose, along with the day her dog died (p.148). She now accepts it and shows a sense of humour mentioning that, 'it is no mean feat to eavesdrop when you are wearing a hearing aid.' (p.39). In a less dramatic way than April Sym in *White Darkness* also finds her speech defects cause her to be viewed as cognitively impaired. Sym, in *White Darkness*, wryly notes the reactions of some fellow travellers, 'whatever they said they said it very loud and slowly seeing my hearing aid and assuming I was a halfwit' (p.37). It is a straightforward portrayal of a person with a disability, realistic and convincing while the disability is not necessary to the plot, it is empowering because it is completely inclusive and here the portrayal shows Sym as an independent person taking a full part in life.

Finally in *Cool Simon* (1992) Jean Ure has produced a very simple book with regard to its plot: Simon has transferred from a 'special' school to a mainstream one where he has great difficulties 'fitting in'. He only partially understands what is happening around him as cannot hear and no one seems to facilitate lip reading. Nobody understands him either because they are unused to his type of speech. He seems to be a perfect target for bullies. He is of primary school age and Ure's target readers are probably not young adults. Nonetheless anyone with an interest in or knowing someone with impaired hearing would find the writing in this novel worthy of examination mainly because of Ure's narrative method. Neither Jane Stemp nor Hunter show their characters having a huge amount of difficulty. Cerie in Stemp's *Secret Songs* can lip read and is depicted as doing this too easily. Even when coping with differing accents, she rarely makes a mistake which is not the experience of people in real life. Stemp does show her character making mistakes occasionally in speech (p.25) but not in hearing. It is surprising that the author glosses over both the difficulties of lip reading and the difficulties of those who are deaf to speak clearly

enough for others to understand as Stemp, a disability activist, has herself both mild cerebral palsy and a hearing impairment which, like Ceri's, resulted from a childhood illness. There is little in Hunter's novel to convey the struggle communicating might be or even the problems of lip reading. The unenlightened 'hearing world's' perception of the deaf as intellectually challenged arises occasionally, for example the man in the photocopy shop speaks to them in pidgin English (p.76) but the dialogue is straightforward. Hunter's characters communicate without difficulties. The author tends to use words like 'blurted out' 'retort', 'cry', 'sneer' and 'snap' without explaining to a 'hearing' reader how these emotions are conveyed using only manual signs (pp.63, 89, 90, 103). Hunter gives little sense of what it is like to be deaf with a few small exceptions. For example when Cat's boyfriend is helping her learn to speak, he discusses the positions of lips and tongues and demonstrates how the words 'to lip' and 'tulip' are identical (p.135). Communicating is not such a problem in *White Darkness* because McCaugheran's character is neither profoundly deaf nor deaf from birth and so does not have too much difficulty in speaking and she uses her hearing aid. In direct contrast Ure demonstrates the difficulties of communication for a deaf person in *Cool Simon*. She writes all Simon's dialogue phonetically so readers are forced to decipher what he is saying. It works best when read aloud and gives a good idea of how a profoundly deaf person's intonations sound. While focalising through Simon, Ure shows how difficult it is for a hearing impaired person to follow conversations, how easy it is to misinterpret the words or shapes he or she hears or reads. She also highlights how misunderstandings can arise when listening to a deaf person speaking. This of course is the other side of the argument that deaf children can lead a full life using other forms of communication such as sign language. (See Abberley, 1987, for example)

Another group of characters in young adult fiction with communication problems are those depicted with cerebral palsy. In 'real' life, the symptoms of cerebral palsy vary greatly, as with most disorders, but the young adult writers have chosen severe cases – two cannot speak at all, Sarah in Hannah Cole's *Bring in the Spring* (1993), Micky in Rachel Anderson's book of short stories, *The Bus People* (1989) and the third, Fee in James Riordan's *The Gift* (2004) has very little speech. People with cerebral palsy usually cannot control their voluntary muscles so a sign language is not an option.

From a general literary point of view the condition has been highlighted by several well-known books for adults, most notably Christy Brown's *My Left Foot* (1964), later made into an award winning film, and Christopher Nolan's *Dam-burst of Dreams* (1981) and *Under the Eye of the Clock* (1987) which can be seen as breakthroughs in disability literature. The overwhelming image in all these works is that of a mind imprisoned in a body. Both writers, and indeed others, had vigorous and active minds whose ideas, opinions and talents were trapped because they were unable to speak. Since the publications of Nolan's and Brown's books and the strides in

technology, the situation has, in many cases, improved both in diagnoses and in electronic aids. Brown and Nolan may have influenced the three young adult authors whose work is examined here. They all hold the image of an active mind trapped in a damaged body.

The plot line in the earliest book, *Being in the Spring* by Hannah Cole is simple and indeed slight but Cole is a skilful writer. The characterisation is good and several interesting aspects of disability are presented. Basically, as part of a school project, Bel and her friend, Claire, are volunteers helping children with special needs. Amongst the children is Sarah who is considered virtually brain-dead and receives little attention. Bel is convinced that Sarah is not only aware of her surroundings but has a lively mind. She sets out to ensure Sarah receives appropriate attention. The first chapter is worth looking at in some detail as it illustrates how Cole conveys Sarah's loneliness and the fact she has a lively mind which is overlooked. The novel is set in a school, Willowbrook, and a children's home. The opening sentence immediately suggests Sarah's isolation, 'The other children were down on the lawn.' while Sarah watches 'the pattern of light wood and dark wood and the moving patterns of children being busy'. One of the care workers suggests wheeling her out to look at the new play house which the other children were exploring but the older one, Mrs Eaton, decides it would not be worthwhile as it is difficult to push the buggy over the rough grass and anyway Sarah 'wouldn't know what it is all about.' (p.2), suggesting early on the story that Sarah has learning difficulties. There is no implication that the care workers are deliberately cruel or careless. On the contrary, Cole shows Mrs Eaton being anxious that Sarah should not hurt herself when kicking her legs. These carers are, however, insensitive and unimaginative. As they believe Sarah is incapable of understanding they talk about her in her presence but she is 'used to listening to people talking above her head or behind her' (pp.2-5). That Sarah is trying to communicate becomes obvious to the readers gradually.

At the same time Cole alerts her readers to Sarah's active mind as she begins her portrayal by describing Sarah's interest in her surroundings, looking at the sun 'emerging from the cloud like an upside down sunrise, and the garden became golden' (p.1). Because of a lack of control of her limbs she is limited in what she can choose to watch. This is emphasised by small incident in the park where Sarah sees a mother pushing a young boy on a swing. One of his shoes falls off. Sarah is wheeled on and she cannot see what happens next. Instead she creates stories about the possible outcomes until she 'ran out of ideas and relaxed in the buggy.' The author fails, however, to make the lack of understanding or awareness on the part of Sarah's teachers and carers fully believable. They have worked with disabled children for years and surely must have familiar with other symptomatically similar children with cerebral palsy.

The frustration and potential risks associated with the inability to communicate is illustrated in an incident later in the book where one member of the night staff steals money from the children's money boxes on a regular basis. Sarah is the only witness and she cannot speak. Even when the victims know that their money has disappeared they are unable to persuade the other staff to believe it (p.39) although it is not clear if this is because they are children or because they are children with disabilities.

On the whole Cole's main characters are convincing. Sarah is shown as a victim but not a tragic one nor a suffering martyr. She cries a lot, gets angry and sulks. The storyline is perhaps a little constricted for a wide appeal lacking the issues which interest most young adults the most – relationships, gender and so forth. Informed by literary disability studies however the novel illustrates some of the problems which can arise from a lack of communication. Both *Bring in the Spring* and the short story, 'Micky' in the *Bus People* show plainly how communication is a two-way exercise, that part of communicating is listening and listening involves much more than hearing words. Cole narrates the story in the third person focalising through Bel and Sarah alternately in *Bring in the Spring* (1993). Cole conveys Sarah's lack of verbal expression very well without putting any strain on the reader trying to decipher a phonetic rendition or on the readers' belief that she wants to speak. It is probably helpful that Sarah is very young and perhaps her speech pattern would not be fully formed. Much of Sarah's point of view is written as an indirect interior monologue this works well as the background is being sketched in and Sarah's situation becomes clear to the reader (p.40). Only once in the first chapter does Cole use 'Sarah said' (p.3). She uses this direct speech occasionally throughout the book to convey Sarah's more emotional moments and also towards the end of the novel when people are beginning to understand the words Sarah is trying to form. Sarah is not mute; she has the physical means to speak. The difficulty lies in the formation of words because the motor area of her brain which facilitates this is damaged. She tries very hard to talk but succeeds in only making a noise. This and kicking her legs are her methods of communication but her minders do not recognise this and interpret them as her being over-excited (see, for example, pp.20, 23). Cole also uses direct narration focalised through Bel.

Rachel Anderson (1989) in *The Bus People* makes it clear that Micky's inability to speak has contributed hugely to the way he is treated. He is unable to make known his wants and needs. Of course for his mother and indeed any carers of non-communicating persons this is a problem too and requires much more sensitivity, imagination and observation than Micky's mother shows. His mother treats him as a child. This has been examined in Chapter 4. Every morning the mother conducts the same conversation, speculating about the weather, the time the bus will arrive, the neighbours and answering her own questions. This is not what interests her son. It is interrupting his thoughts. Anderson tends to give Micky a wider imagination than perhaps he would have had

with his constrained life. However she succeeds in conveying his frustration at his inability to vocalise.

James Riordan has written *The Gift* (2004) in a very informal, light hearted style, the voice being that of a teenager, Fee who is the narrator. Fee's twin sister, Bee, has cerebral palsy. Their mother is depicted as totally amoral and her mothering and home-making skills are minimal. She largely ignores her disabled daughter who has a very limited ability to talk and is a wheelchair user. She expects Fee to look after her sister even to the extent of going to a parents' meeting at her special school (pp.5, 8). There are some very affirmative traits in this novel, the complete lack of sentimentality for example and the fact that unusually for young adult fiction it does not have a middle-class background. The question of communication is not as important as one might expect since Bee makes 'just grunts and whinnies' (p.5) and little more because most of the 'translation' is done by Fee within the story and so she often facilitates her sister but Riordan largely glosses over this issue. He gives Bee some direct speech, usually one or two words written more or less phonetically, 'p'ease' for please, 'no'goin' for not going or 'com'shun' for competition for example. This might have been more effective if the mother's speech not been written phonetically as well. Indeed the mother also pronounces competition as 'com'shun' in one page and 'com'tishun' in another (pp.80, 73). The dialogue of the other characters, including Fee, is reported conventionally. Bee's emotions are conveyed by 'dribbling more than usual' or by 'banging her fists on her knees' (p.53) and sometimes she has to make several efforts before she can pronounce just a 'grunt' (p.38) John Quicke (1986) points out that in Victorian literature the theme of 'unlocking' the talent of the disabled child was very common and still exists (p.156). This is an issue that David Bolt the literary disability exponents, shows how negative this so-called Positive Stereotyping can be in an article he wrote for the *New Zealand Journal of Disability Studies* (2006) by endorsing a sense of 'otherness' Riordan appears, however, to be more directly influenced by people with cerebral palsy like Christopher Nolan and Davoren Hanna, whose method of communication was composing poetry. This is seen when at the climactic ending of the narrative, Bee produces a prize-winning poem. Although the poem Riordan uses was actually written by a girl with cerebral palsy, June Craven, it might appear that the idea is somewhat derivative. However it is quite a few years since Nolan and Hanna were published making them old fashioned in young people's view and therefore unlikely to be read. The going out of date factor in children's and young adult's popular fiction cannot be overlooked. A book published say twenty years ago is relatively modern to an adult but to a young person it was published long ago, indeed often before or shortly after their birth. Hence the short 'shelf life' of so many books in these categories. However, some worthwhile statements are made by the author through some of the characters. For instance, Fee sees Charlie giving his all in a race as making the point that 'being disabled did not mean being denied *normal* pleasures' and she goes

on to explain that 'He may have been born with a disadvantage, but he wanted to be treated like anyone else'(pp.93-4). Riordan has produced an upbeat book but the situations are not believable and characters lack conviction, so lightly sketched that they are almost cartoon characters. . It would be difficult to identify with any of them.

Elective or selective mutism is a symptom of psychological problems, once believed to be caused by a traumatic event but since 2002 there has been some debate about this and although trauma is not ruled out, it seems more likely to be the result of severe anxiety (www.minddisorders.com).

It is a relatively rare condition affecting an estimated one in one thousand school going children.

(www.downsyndromecentre.ie/advisorypanel/.../selectivemutism), yet surprisingly there are at least four examples in young adult fiction: Malachy Doyle 's *Georgie* (1996) , Siobhan Parkinson (1998) *The Moon King* and two in Rachel Anderson's (1989) collection of short stories, *The Bus People*. In each of these books the mute character has experienced some abuse or a traumatic event which he or she is very fearful of remembering. The challenge faced by these writers is not only to find a method to depict an interesting, believable character who does not speak. But at least equally important is the necessity to convey the characters' deep anxiety. Otherwise the condition is not accurately portrayed and is unbelievable. These three writers achieve this mainly through their varying modes of narration and by including just fragments of a back story throughout the main plot or stories although the latter are very slight in themselves. For example Parkinson's Rickey is in a foster home because of his home life and the story centres on his settling in, scared at first he then finds a special chair in attic. Malachy Doyle's eponymous character, Georgie, is angry and confused and has had several unhappy placements in institutions before the story opens. He is violent and uncooperative. Gradually his carer begins to assuage Georgie's suspicions and fears and eventually gains his trust. Some tension underlies the narrative as the reader does not learn Georgie's whole story until almost the end. While the storylines are unremarkable, the style of the narrative is revealing.

All three of these writers use the third person but there the similarities end. In roughly alternate chapters Doyle gives two viewpoints, one from that of Georgie and the other from a fellow teenage patient. Doyle gives an 'internal voice' to Georgie and he uses a great deal of repetition of words to convey his state of mind and immaturity. Gradually Georgie begins to lose his suspicions and this is shown by the gradually lessening of the repetitions.

Both Anderson and Parkinson describe situations mainly through their disabled characters' eyes, showing the characters' limited understanding which helps to convey their

nervousness while at the same time there is enough information for the reader to understand what is happening or has happened. For example when Fleur meets possible foster parents,

The woman did not look like the other woman who used to push her into the darkness where the bird had flapped, where the fleas had hopped.
“You’ve always wanted a kind mummy and daddy, haven’t you, dear?” said the Missreamdutystaff.
And Fleur wondered if Fleur had. It was hard to know. (pp.70)

Economically Anderson tells how Fleur had suffered and simultaneously shows the damaged state further delineated by omitting all pronouns for her. The repetition of ‘Fleur’ is very stark and serves to suggest the child’s withdrawal within herself. The sparing use of it in the second part suggests a relaxation of tension.

Parkinson’s approach is different. She uses disjointed and incomplete sentences for Ricky’s internal monologue or, as Amanda Piesse (2006) puts it, Ricky’s silence is ‘rendered brilliantly by a fragmented interior monologue, usually preceded by a slightly fuller account from a third person narrative that is already shifting towards Ricky’s own idiolect. This treatment of speech imitates a general motif in the novel, that of degrees of anxiety (p.102). Different typeface is also used for the monologue although this is hardly necessary. As with Anderson the back story comes in disjointed fragments as can be seen for example when Ricky sees a rocking chair in his foster home:

High up in the dark, among the books, Ricky could make out the outline of a rocking-chair. Your mother had rocking-chair. Warm and swaying, in your mother’s arms, like big, warm, branchy tree. Rock, rock, rock. Like fast train, so fast you can’t feel ground speeding by, but carriages rock, rock, nice, like sleeping. Must have been very small then. Before all that anyway, before Ed and everything. Wish, wish (p.27)

In contrast to those who can or will not speak the character of Dylan Mint created by Brian Conaghan in *When Mr Dog Bites* by (2014) cannot control his speech. This sixteen-year-old protagonist has Tourette’s syndrome and some learning difficulties. When a person with Tourette’s, syndrome is speaking he or she has great difficulty in controlling his or her vocabulary. It also causes tics which range from eye blinking, limb jerking, grimacing, sniffing, grunting, jumping and barking. The uncontrolled movements can be very noticeable to others, but in regard to communication the lack of control over vocabulary causes frustration and many difficulties as Conaghan shows. He makes Dylan Mint his narrator and creates a distinctive voice for him. He uses the linguistics of contemporary youth culture together with a great deal of vocabulary which too many would be offensive. The language used has probably caused more interest than the novel’s content and certainly caused considerable controversy. It is mentioned by every reviewer and critic. It prompted the cultural editor of the *Daily Telegraph*, Martin Chilton, for instance, to

question the use of profane and offensive language in children's literature without at least some sort of guide lines printed on the book. .

(<http://www.telegraph.co.uk/culture/books/10616640/Should-potty-mouthed-childrens-books-come-with-a-PG-certificate.html>). Certainly there is a great deal of crude language in this novel, added to which is also much 'teen-speak'. Chilton actually counts and lists all the offensive words in chapter 21. This happens to be the chapter describing the bullying incident of Dylan in the park and in part of her reply to Chilton's article Rebecca McNally, Publishing Director of Bloomsbury Children's Books claims:

The book isn't about Tourette's, but it is very much about language – Dylan's own curiosity and playfulness with words (not swear words) is part of the joy of the book, what makes it a-mayonnaise-ing, not shizenhowzen; you'll all be using Dylan-isms by the time you've finished reading. The most offensive words in the book are those directed at Dylan and his friend Amir by the 'normal' kids in the park (Dylan goes to a special school, which again makes us think about language and the labels those in authority put on people, especially children). They're offensive because they reduce, humiliate and dehumanise characters we care about. Those words: "Paki", "spaz", "mong", are like verbal IEDs, and they don't lose their power. (<http://www.telegraph.co.uk/culture/books/booknews/10618985/Why-the-swearing-had-to-stay-in-When-Mr-Dog>).

McNally's makes two inaccurate claims. Her statement that Dylan's playfulness with words does include swear words and secondly her claim that the most offensive words are used by the 'normal' boys is hardly sustainable as those words, or similar ones, are found on almost every page and used by a variety of characters including Dylan and Amir. Indeed, the object of Dylan's desires, Michelle Molloy, rarely speaks without some profanity. One could take almost any page at random to illustrate this: Amir describes his school as a '...Fucking shitey arse place... full of dicks and arseholes.' (p.142) and the text is peppered with Dylan's words which include cunt, shagger, bugger, bitch. It is difficult to think of a word which does not appear in the basic narration in addition to the words used as part of Dylan's syndrome. If the book is not 'about Tourette's' – and this is discussed below – but 'about language' then Conaghan's aims are unclear. He may be endeavouring to show that words have no intrinsic value, it is how they are used which can make them offensive and tools to 'reduce, humiliate and de-humanise'. Yet all the non-adult characters use them both as part of ordinary speech and also as insults to one another. Therefore it is unclear if this was his intention.

He succeeds extremely well in creating a young teenage voice using contemporary slang and wordplay. This may well be appealing to the young adult although it does become repetitive, possibly to denote the obsessive aspect of Dylan's condition but also irritating. Of course teenagers swear and it is often incumbent on an author to include some bad language to create a

realistic dialogue. Conaghan could be criticised here for over doing it, perhaps relying on it to help identify his character or using it to emphasise the working class background. He and Bloomsbury are also open to the accusation that the swearing could be used for commercial purposes by attracting the young. Whatever the motives, the shock element does eventually begin to lose its impact. The importance, of course, is how this affects the creation of Dylan's disability. From the beginning of the book, it is plain that Dylan has learning difficulties but Tourette's syndrome is not introduced until chapter 4 and then obliquely:

Doughnut's comments about Amir started the rumblings.
SMALL VOLCANO SMALL VOLCANO ALERT!
It starts with Mr Right Eye and quickly moves to Mr
Jaw, then the red-hot lava flows and Mr Head shakes
at super-rapid speed.
Whoosh!
Whoosh!
Whoosh!
Mr Head is dizzy Miss Lizzy. That's the worst bit.
Mr Sweaty arrives with Mr Pong and Mr Panic.
Mr and Mrs Eyes start to pee themselves.
Mr Throat doesn't miss the boat.
Here comes: Mr Bloody Twitch.
This is how life's a bitch for Dylan Mint.
Not far behind is Mr Tic. Can't stand that prick.
It's the docs like to call them tics.
I prefer volcanoes myself, because they are like
mega eruptions in my head. (15)

Dylan continues,

I want to shout out.
I want to scream.
I want to bellow, holler and yell.
Sooooooo badly it Hurts like Hell.
Dylan, *don't* shout out scream bellow, holler
or yell!
Don't bawl,' DOUGHNUT, YOU UGLY FAT
WANK. BUCKET FUCK-HEAD SOCK-FACE
BELLEND' (p.16)

The author, who has a mild form of Tourette's, has given his protagonist the most severe form which impels him to swear obscenities uncontrollably. Although this is how it is usually portrayed by the media, ninety per cent of people with Tourette's do not do so. It is not immediately obvious that the character has given an account of what happens when he is in a stressful situation. The tics start in his eye and move to his jaw and then his whole head begins shaking. As the stress continues his tics increase culminating in shouting out some obscenity. This would be more effective as 'an unavoidable subconscious cognitive behavioural action.' (p.239) if most of the other characters did not make equal use of bad language often shouting it at one another (indicated in the text by block capitals). The narrative form probably owes much to Mark

Haddon but it is by no means as convincing and the overriding nature of the syndrome is not always as apparent. This is partly because Christopher in *The Curious Incident* has a syndrome, Asperger's, which by its nature ensures plain, unelaborated language. Christopher's logic may be unusual but he narrates the story simply and clearly whereas Dylan's endless wordplay, tends to obscure his symptoms and the storyline. The lack of differentiation between Dylan's speech with his lack of control over his vocabulary and that of the other young people contributes to the confusion. The result is the overshadowing of the difficulties in communication that a person with Tourette's with its attendant stress and embarrassment undergoes.

The authors of the books examined in this chapter all show an awareness of some of the problems associated with the inability to verbalise and most of them have conveyed these problems in their created characters. Each writer has shown the attitudinal barrier faced by those with communication problems, thus using social model of disability rather than the medical one, although this is not always clear as is explained in the Chapter Three on Home and Families of this thesis. In nearly every example the problems facing the person with an impairment are very personal and there is little with which a reader could identify, although a person with a disability would recognise several events and attitudes. With regard to deafness only one author, Jane Ure has really given an idea of what it is like to be deaf but her narrative is not compelling. *White Darkness* by Geraldine McCaughan is an excellent story but her heroine's impaired hearing plays only a small part in it. However, its value should not be overlooked as an example of disability being part of everyday life and in showing how the person with an impairment can play a full part in it. Although *Bring in the Spring, the Gift* and *Micky* have characters with cerebral palsy this is not an issue for them. Rather the writers have chosen to highlight their lack of speech and the difficulty for others in interpreting their wants and needs. This leads to great problems for two of them, Sarah and Micky, but less so for the third character, Bee whose problems are more familial than societal and little to do with cerebral palsy. As stated, before *The Gift* lacks credibility and as with his other book, *Sweet Clarinet*, Riordan, relies much on compensatory talents. The authors of the three narratives featuring elective mutism have the added difficulty of conveying really deep anxiety as well as mutism. All three authors achieve this through their modes of narration. Each story shows how adults can fail a child and how the child puts up a barrier against the outside world.

What is missing in this category of Communications, and indeed in all the categories examined in this thesis, is a book which might challenge the reader. Although issues of great moral or ethical importance may arise, they are not presented in a way to create debate. To illustrate this I have had to turn to the United States for an example of a controversial, thought provoking novel centred on disability. I have chosen *Stuck in Neutral* by Terry Trueman, which was published in 2000. Not only is its theme, mercy killing, highly controversial in itself but Lois

Keith (2004) has written as strong indictment of the normal in an article entitled 'A Non-Neutral Review' in an edition of *Disability Studies Quarterly*. In it she criticises Trueman for justifying the killing of disabled children, but I believe an equally valid case can be made to show an anti-euthanasia argument. Consequently, both the content and the interpretation of this narrative provide grounds for thought and discussion.

Stuck in Neutral is written from the viewpoint of Shawn whose disability is extremely severe cerebral palsy. He is totally dependent on others – he cannot control any of his muscles or communicate in any way. No one, not even his family, can tell if he is sentient or not. Trueman chooses to have Shawn narrate in a stream of consciousness, thereby enabling the reader to see Shawn's perspective on his life. Within Shawn's useless, twitching and drooling body there is an intelligent fourteen-year-old who is a keen observer of family life around him. He is very aware of the effect he has on the family, whom he introduces,

My parents got divorced ten years ago because of me. My dad didn't divorce my mother, or my sister, Cindy, or my brother, Paul – he divorced *me*. He couldn't handle my condition, so he had to leave. (p.7)

Anecdotally, this is a classic situation; the father is unable to cope at home, leaving the mother as the chief carer, while he seeks some other way of contributing to their daughter's or son's well-being. Somewhat in this vein, Shawn's father, Sydney McDaniel, is made a sort of 'career victim'. A journalist by profession, he has written a poem whose central theme is his son's condition and this has won him the Pulitzer Prize. He spends much of its time appearing on TV chat shows. The father is at the core of the book which, while it is full of humour and pace it is ultimately quite harrowing as Shawn is fully aware that his father is planning to kill him – out of love. His father's motives are not evil. He believes his son is 'a human vegetable' (p.15) and he knows there will never be an improvement in his condition. He believes that Shawn also suffers great pain during the rather violent seizures he undergoes. Shawn explains to the reader that when he was a baby these attacks were painful but medication has obliterated the pain. Now Shawn is able to enjoy the feelings of freedom that these episodes give him. There is no way the father can know this. McDaniel is applying a typical medical model here. He sees his son as a pitiful victim, an individual tragedy with a life not worth living. He tries to generalise the situation and Trueman weaves McDaniel's arguments into the narrative by including some stanzas from his poem and parts of a couple of his television programmes.

Trueman does give the father a convincing argument. It builds up from part of a television documentary, a visit to the school that Shawn attends. Shaun goes to a mainstream school, but his classroom is not part of it – it is where 'normalcy and sanity end' and Shawn's picture is negative although he does seem quite happy to go there. McDaniel asks if taxpayers should be

expected to pay for these children's education – children being taught how to spell CAT who will never be able to speak or understand it. While he sees the State Department of Education and Seattle Public District's intention that 'every child deserves an education designed to help the child achieve his or her greatest level of potential as 'noble', he points out the enormous expense of trying to 'educate the uneducable' (pp.40-45). There is no dissenting adult voice here to point out that education is a great deal more than teaching spelling and if this is the chief aim in this school, criticism might more usefully be directed towards the curriculum. The underlying question here is how much of public resources should be spent on those who will never become functional members of society.

Shawn's father's second project is much more controversial. He takes on the case of Earl Detraux, a father who is serving a twenty year prison sentence for smothering his two-year-old disabled son, in an Oprah Winfrey type of TV show. McDaniel defends Earl strongly. McDaniel believes that if he himself was ever brain-damaged and in a coma he would wish to be 'put out of [his] misery' (p.76). He persuades the audience that Earl is not a murderer, but that he 'loved his son enough to sacrifice his own life to end his child's pain.' (p.77). Earl's son, like Shawn, was severely brain damaged and suffered also from seizures. McDaniel sympathises with Earl's action and it is evident that this is what he himself is contemplating. There are small indications throughout the narrative, suggesting that he is trying to decide if it is the right thing to do. His wife gets to the heart of it, perhaps, when she explains to her friend that:

the thing that kills him is not knowing whether Shawn is aware or not. The doctors have assured us, a thousand times that it's almost impossible that Shawn could have any awareness, but it's that 'almost' that makes is intolerable for Syd. (p.51)

Trueman builds up Shawn's life in the opening pages and in small episodes throughout the novel: his frustration with his inability to communicate in any way at all because of his complete lack of any muscle control; his curiosity about the various sensations and above all his vicarious enjoyments through his family. Trueman gives his character, the gift of total recall, not as a compensation for his disability, but as an obvious device to allow the narrator to repeat conversations and other events in full. He also has Shawn suffering from seizures which realistically would not be unusual. Trueman uses these as a metaphor for freedom for Shawn. Shawn tries to describe what happens to him inwardly during a seizure which look so painful to the observer, 'my spirit leaves my body... I love the feeling of movement, the pure joy of being able to fly, I love the feeling of escaping from my screwed up, worthless body... I have complete control of my motions. I do all the things I see and imagine other people do: I soar, sail, walk, run, skip, sit, lie down, rollover, wiggle like a snake, swim like a fish...' (p.35).

These episodes are somewhat problematic. There is a choice of interpretation. It is not clear whether Trueman expects his readers see them as figments of Shawn's imagination, or whether they suggest some spiritual state. He also rather obviously uses them as a device to increase tension and suspense by making them happen at crucial points in the plot.

McDaniel loves his son so much that he cannot bear to see him in a seizure, he sees him suffering intolerable pain and if his son has no awareness of the surrounding then the pain is the sum total of his life. Shawn of course, has no way of letting him know that these episodes are not painful, but wonderful experiences and that, in any case, he can enjoy life, albeit vicariously. McDaniel's views are perhaps extreme versions of quite common general feelings that nondisabled people have of the disabled: because Shawn will never be able to do the things that father has done, there is no point in him being there (p.29). The arguments are set out: quite explicitly on the pro-euthanasia side and rather more subtly on the anti-euthanasia side. At the end of almost every chapter, Shawn mentions he loves life; he does not want to die. As early as the end of the second chapter he says, 'I'm pretty sure that my dad is planning to kill me. The good news is that he'd be doing this out of his love for me. The bad news is that whatever the wonderfulness of his motives, I'll be dead' (p.12). Shawn witnesses the death of a dog after a road accident and did not like it, '[death] looked to me like when you die, you just, I don't know, your life just disappears. That day death stared at me through bloody eyes and it terrified me' (p.17). Only once is there a slightly ambiguous chapter ending; in the last paragraph of chapter he says, 'I almost trust Dad to do what's best. I almost trust him to know whether 'ending' my 'pain' would be the right thing to do. Almost.' (p.52). Shawn can also show anger. 'End my pain? It made me mad. What right does he have to decide what's best for me? What right does he have to think about ending my pain?' (p.48).

Of course, McDaniel's justification for mercy killing is based on the premise that the child has no consciousness, no awareness of life at all. The reader, from a privileged position, knows that with Shawn at least this is not the case. Thus, McDaniel, on his own terms, is not justified in taking his son's life. But the moral or ethical question remains: if a living being's single feeling is that of pain, should mercy killing be practised?

It is this perhaps that makes Lois Keith claim in review in *Books for Keeps* that she 'would be very reluctant to put this book into the hands of young readers, just as I would not give them a racist book or one which told them how terrible it is to grow up gay or lesbian'. She continues by naming *Under the Eye of the Clock* by Christopher Nolan and *Bring in the Spring* by Hannah Cole as 'better examples of how we can understand the lives, needs and desires of young disabled people, even those with severe communication problems.' (2001). While this may be true the reader is not faced with any moral or ethical challenges in either of these books

Trueman gives no answers. The ambiguous ending leaves the father sitting beside Shawn's bed; he tells him he loves him. He has a pillow on his knee. Whether or not smothers his son the reader does not know as at this juncture Shawn has another seizure and the final words:

‘My seizure begins to spin slowly through me. What will my dad do?
Whatever it is, in another moment I'll be flying free. Either way, whatever he
does, I'll be soaring. (pp.144)

This passage can be read in several ways, some, at least partially, depend on one's interpretation of Shawn's seizures: the final 'I'll be soaring' could either be short-term, as it has been in all his seizures or it may indicate freedom from his body forever. If, however, the final words indicate Shawn's liberation and that he would be happier dead, freed from his body, then this can be interpreted as a justification for euthanasia. If this is the case, then Shawn's emphasis, throughout the novel, on living and wanting to live seems misplaced.

This is one example of a novel to start or stimulate thoughts or discussions on mercy killing and other related issues, as well as the importance of communication. There are many other unresolved and uncomfortable questions pertaining to disability, which are often just 'mentioned' or treated in a bland, conservative manner in British and Irish young adult novels.

The presence or extent of cognitive impairment can be difficult to ascertain with as a means of communication. Undoubtedly many people have been treated as 'vegetables' because they had no means of communicating their thoughts and ideas. (See for example Davis 1995, Corker, 2002) Other, very specific difficulties in communication arise with Tourette's as has been shown and another very different set of disabilities are found with Asperger's syndrome. Because the problems with the latter are so unlike any others connected with communication, they are treated in the following chapter.

CHAPTER 8: INTERPERSONAL RELATIONS – BEHAVING DIFFERENTLY

Lucy Burke (2008), in a special issue of the *Journal of Literary Disability*, claims that there has been a little critical attention given to the representation of cognitive impairment with ‘the notable exception of a rapidly expanding body of work on cultural representations of autistic spectrum disorders’ (introduction p.1). Whatever the reasons for this popularity it is reflected in the high quality of the depictions found in young adult fiction as well. There are more titles in young adult fiction featuring Asperger’s than any other disability. On the whole the authors show a positive and sympathetic understanding of the syndrome; the symptoms are usually described with accuracy and the characters’ behaviours are fairly consistent. In addition, the characters with the syndrome are not only incorporated into the narratives but disability is often integral to the plot.

This chapter differs from the previous ones as it takes three novels, in which the protagonists have the same disability, Asperger’s syndrome. It might appear to be a reversion to the medical model, but the aim of this chapter is different. The three novels are examined to show how the same disability can be used successfully in different ways. The novels chosen for this are Anthony Masters’ *Spinner*, Siobhan Dowd’s *The London Eye Mystery* and Mark Haddon’s *The Curious Incident of the Dog in the Night-Time*.

Asperger’s syndrome is a complex developmental disorder where a person can have an average, even a high, IQ but lacks empathy with others and has poor communication and social skills. There is a communications barrier but it differs from the ones in the previous chapter inasmuch as it is caused by the person with Asperger’s syndrome being unaware of the need for interpersonal relations. This in turn causes a different behaviour and gives rise to the chapter heading. The question of whether realistic fiction constructs characters with Asperger’s syndrome in order to offer readers an opportunity to understand and to relate better to individuals with Asperger’s is of significance. People can often have difficulties when first meeting someone with an Autistic Spectrum Disorder. One of the symptoms in the autistic spectrum is a lack of understanding the necessity for social conventions. Without this framework of accepted customs, it is not clear to the person without the disorder as to how to proceed. The difficulty is compounded by the autistic person often asking inappropriate questions or making inappropriate comments. This can be quite frightening especially for the young who are increasingly likely to meet autistic people in main-stream schools. Thus the depiction of autism in novels, if it is accurate and convincing, could give the readers some idea of what to expect, help them to gain some understanding and lead towards acceptance.

Two young boys, Kenneth Hall (2001) and Luke Jackson (2002), have written autobiographies, *Asperger Syndrome, the Universe and Everything* and *Freaks, Geeks and*

Asperger's Syndrome respectively, in order to help others. Both give a good insight into the way their minds work and into how they view the world. Another example of young adult who has come to terms with his Asperger's syndrome is Adam Harris, who recently (2014) launched a website to help children who have Asperger's and their parents especially as they begin school. His organisational powers and clear thinking are evident on this site (www.asiam.ie) but it must be remembered that the autistic spectrum is very wide indeed. The width is not altogether reflected in the books under discussion here. Asperger's Syndrome is a condition at the more able end of the spectrum and this is favoured as opposed to the 'less able' end of the spectrum, sometimes referred to as 'classic autism' (Department of Education, Ireland: 2002). Almost all the young adult fictional characters are at the high functioning end except for a few who play minor roles as younger siblings to a protagonist as, for example, Tom in Rosie Rushton's *Last Seen Wearing Trainers*.

Analysing each novel and comparing and contrasting the three pieces of fiction will show how it is possible with different approaches and different handling of the same subject can result in a successful novel featuring disability. *Spinner* is chosen because through Masters' protagonist, the reader sees the syndrome from the outside. The other two are written in the first person by the character that has Asperger's syndrome, allowing the authors concentrate on the mind of the character and show how his (there are no female examples) cognitive thinking affects his behaviour. There is no discernible difference between the earlier and later writers regarding their attitudes, it is the modes of narration that are significant. Since the success of *The Curious Incident of the Dog in the Night-Time*, there have been several young adult novels in which the author has used a first person narrator that has cognitive difficulties, but until then a character with any sort of learning difficulty would almost always be observed.

The person with the disability in *Spinner* is Gary who comes to live next door to the narrator, Jane. The plot of this thriller is a little too dependent on chance and not all the characters are fully drawn. For example there is no ambiguity about the main villain, Angel. '... there was something in his gaze that really chilled Jane', his eyes 'were cold, mocking steel but there was something else in them that made her start to shiver.' (pp.41-42). A stereotypical villain is produced. Masters even adds a 'livid scar' (p.41) continuing the myth of equating physical impairment with evil as discussed in the previous chapter of this thesis. The two main characters are more fully drawn. Masters tells the story mainly focalising through Jane, an only child of dysfunctional parents living on a run-down council estate. An atmosphere of neglect and decay is immediately created by details in Master's descriptions of Jane's environment with its pervading sense of desolation and boredom. Her boredom is broken as Jane becomes fascinated with Gary's unusual behaviour. It is through Jane's eyes that the reader gets to know Gary and is introduced to the symptoms of Asperger's syndrome. Masters does this gradually, building up the

character from his actions and it is in this that the value of this book lies. For example, Jane's initial interest and curiosity are aroused when she notices him spinning round and round. He then ignores her efforts to talk to him (p.5). Spinning is a common feature of Asperger's Syndrome and one of the activities that Luke Jackson (2002) admits to doing when very young (p.72). It is Gary's difference that attracts Jane and makes her wonder if he is crazy or 'a nutter'. Due to a lack of understanding of or familiarity with autism people often label those with autism thus. This is illustrated also in the supermarket episode where Gary insists on building a tower with the (full) boxes of eggs (pp.15-19), and the reactions of Angel and his friend (p.54). Masters emphasises Gary's speech characteristics by making Gary speak in a formal manner, using few abbreviations, slang words or colloquialisms and 'His voice was curiously flat and, like his face, without expression. It also had a slightly mechanical quality to it ...' Masters highlights the lack of expression by adding words like 'intoned', 'monotonously' or 'tonelessly'. Occasionally he includes some *echolalia* (meaningless repetition of another person's speech) and he makes Jane notice that Gary's face was expressionless and that he was 'looking through her rather than at her ... as if she didn't exist.' These are all marked and common symptoms of autism (Frith, 1992, pp.8-9). Symptoms vary from case to case but in fiction if an autistic character is being created it is necessary to include sufficient symptoms to describe the syndrome and make the character credible. Masters illustrates the difficulty those with autistic tendencies have with interacting or playing with others as Jane endeavours to make friends with Gary by helping him build the tower of bricks, but he is angry when she picks up a brick and he loses his temper entirely when the stack topples (pp.28-29), an incident that exemplifies the obsessiveness associated with Asperger's syndrome. Gary is obsessed with building tower-like structures whenever he can find material, regardless of its suitability, as shown above in the supermarket episode (pp.15-19). He is also fixated on a kind of Wendy house that his father had built for him. Jackson finds the word 'obsession' opprobrious and prefers 'special interest' He also explains how all-embracing it can be for a person with his condition, '... if one subject is on my mind or I am fascinated by something, then literally everything else is insignificant ... I just *have* to talk about it and the irritation at being stopped can easily develop into a raging fury.' (pp.43-44). A dislike of physical touch often accompanies autism. Masters conveys Gary's abhorrence of it when he describes Gary's 'rigid hand' when he and Jane are holding hands and his anger when she touches his arm (pp.47, 52). Of course while Gary's disability is displayed through Jane's growing awareness and understanding, Masters has to make Jane very much more perceptive than a twelve-year old is likely to be. An example of this is where Jane notices the look of love in Gary's mother's face and realises that she must be lonely with only Gary as a companion (pp.24, 26) The necessity to give a child perception beyond his or her years, is, of course, a common problem for writers using a child's viewpoint whether writing in the first or the third person. It needs considerable skill to overcome it sufficiently for the reader not to notice and Masters does not always succeed.

Masters in weaving these very particular symptoms into his plot them able to create a tense and gripping thriller. Gary is unable to consider the circumstances he and Jane are in and he is quite unaware of the danger of Angel carrying out his threat to harm them. His highly unpredictable actions add to their predicaments, especially when he does not see the necessity to run away or to avoid irritating the enemy. He is certainly the basis of the tension and suspense which makes this a successful thriller. Creating tension is almost certainly Master's chief reason for including an autistic character, but Gary is more than a plot device; Masters has created a realistic portrait in so far as one could recognise him as a person with Asperger's syndrome. It could increase a reader's sympathetic understanding of the disability. Gary may not be a very attractive person but by making him Jane's saviour Masters ensures that the readers see him in a positive light. Although Jane realises 'that he didn't care for people, could never love anybody in the proper sense of the word' she still hugs him (p.111). She is his friend in spite of his unconscious ability to be irritating and his lack of response. In other words, she shows an unprejudiced attitude and an acceptance of difference.

The reader observes the disabled character in *Spinner* from the outside. The following two novels are written in the first person by the disabled protagonist; therefore, the reader is experiencing the inner thoughts. This works in *The Curious Incident of the Dog in the Night-time* by Mark Haddon, so convincingly that it been cited as autobiographical rather than fictional on a list of personal and fictional narratives for students (Rose:p.43). The first person narrative is less successful in Siobhan Dowd's *The London Eye Mystery*. It is inevitable that the books will be compared and Dowd's skill is perhaps not as great as Haddon's. The narrator's voice is not so unrelenting. For example when Dowd is creating conversations she opens into a conventional writing form and intersperses words like 'wailed' or 'squeaked' and often with actions described too – 'looked confused' or 'lips pursed' 'eyes rolled' whereas dialogue is reported by Haddon's Christopher with the repetition of 'I said', 'he said' 'then I said' without any descriptions, embellishments or comment. The voice of Dowd's protagonist lacks the singular Asperger's monotone in both his direct speech and in his narration. Where there are traces of a particular voice within the narrative it works well. Ted's frequent meteorological observations are effective. Interspersed in the text are paragraphs of facts on some subject or other and he has a habit of mentioning 'the best thing' or 'my favourite thing'. Both Hall and Jackson frequently use these phrases when describing their preferences in their autobiographies. But in Dowd's book they are rather too intermittent to make much impact. Basically Dowd fails to make Ted's actions and reactions unavoidable as part of the syndrome. Haddon convinces the reader that Christopher has little or no choice in what he does. He achieves this by not showing any alternatives or by showing the stages of Christopher's unique reasoning together with his restricted imagination for example, when he makes his decision to go to his mother in London (Haddon, pp.161-163). Dowd's

character is more social and sometimes speculates on what people are thinking. He also seems to have the ability to control or modify his behaviour (apart, perhaps, from his waving hand). For example, he tolerates sharing his bedroom with his cousin and manages not only to tell a lie spontaneously but write a lie as well (pp.175, 204). Further, the motive behind the written lie was presumably to stop his mother worrying while he and his sister were out acting as detectives.. This imports to him the capacity to put himself in his mother's shoes; an ability usually lacking in a person with Asperger's Syndrome. Even more unlikely is Ted's imagination on page 133:

Where are you, Salim? I wondered. Then, suddenly, it was as if I became Salim. I felt his laughing presence inside me, almost like a ghost, while I stood looking out. I tried to imagine what he'd have done, alone among strangers in his pod. Would he have chatted to somebody? Would he have stayed quietly in a corner? I divided into two, with the Ted half asking the Salim half what had happened. But the ghost of Salim, like the dodos, lords and crew of the *Mary Celeste*, vanished before we reached nine o'clock.

It would be unlikely that Ted would even endeavour to imagine somebody else's mind. On the other hand, Ted can be seen to be on a different place on the autistic spectrum and Dowd's portrayal of Ted is very positive. The most successful part of this novel is, from a disability point of view, the fact that she has made the disability absolutely integral to the plot. It is because he has 'a funny brain than runs on a different operating system' or in other words, he thinks differently from most other is and this enables him to solve the mystery (p.4). In fact his difference is frequently alluded to by other characters in the novel.

As suggested above the narrative voice used by Haddon in *The Curious Incident of the Dog in the Night-Time* is one of the author's great achievements. His character's sentences tend to be short and staccato, usually with the simple subject-verb-object structure. There are few abbreviations, few similes and no metaphors. Any figurative idioms used are commented upon by Christopher himself as those with Asperger's syndrome have difficulty with non-literal language. He feels the need to explain them as they appear to him unnecessary and unhelpful. Throughout the narrative once an episode or an idea is introduced most of the sentences begin with 'And' with some starting with 'Then' or 'And then' which could be repeated for a whole page or more. Consequently the impression is that of a monotone or measured tone. It is 'different' from usual narration. There is also considerable repetition. Yet it never becomes boring for the reader as Haddon breaks the narrative line in two ways. First, the dense narration becomes a little less detailed when his teacher in school explains that not all details need to be included in a book. Secondly, the text is interspersed with diagrams and mathematical puzzles and thirdly the letters written by his mother are a complete contrast to his precise, non-figurative, unemotional narrative. The reader is suddenly confronted with passionate, emotive language written ungrammatically in letters revealing startling information. Besides, as Christopher's

sleuthing involves him coping with unfamiliar people, places and pursuits considerable tension is built up. The element of surprise also plays a part in capturing the reader's attention. Indeed, it is immediately intriguing to find the first chapter labelled 'Two'. This is because Christopher, one of whose obsessions is with mathematics, decides to use only prime numbers (p.14).

In terms of plot, Haddon shows great originality. Ostensibly the story is a murder-mystery that Christopher is writing for his teacher. As Christopher finds it difficult to imagine things that have not happened, he writes about a neighbour's poodle which he found impaled on a garden fork on her lawn. Christopher sets out to find the murderer. In this way Haddon has created both a framework for the narrative and a reason for Christopher to tell it. Consequently the main character is both narrator and participant in the story. The question arises as to whether Christopher is a reliable narrator. Factually he is dependable. Haddon establishes this by devoting a whole chapter to Christopher explaining that he cannot tell lies because lies make him 'feel shaky and scared' (24-5) and he describes his memory as a film or DVD, '... I can simply press Rewind and Fast Forward and Pause like on a video recorder...' (p.96). Therefore he is portrayed as being very accurate. In fact people with this disability have a very limited imagination and most find it almost impossible to make things up. Hall explains, 'AS kids are very truthful. Honesty is one of the best parts about AS ... maybe the very best...' (p.65) But no matter how truthful and accurate Christopher's reports are, he is incapable of telling the full story. He certainly does not understand the story he is telling. Part of Asperger's Syndrome is the inability of the sufferer to decipher other people's thoughts, motivations or feelings. In extreme cases, like Christopher's, there seems to be a total lack of awareness that others may not share their point of view or 'logic'. For example as James Berger (2005) argues Christopher views people's minds as he sees his own – minds are like computers and consciousness is a picture on it. (p.1). Thus the reader, approaching with his or her own experiences and knowledge, can see much more than Christopher tells and, because he is also a participant in as well as narrator of plot, the reader is enabled to see a larger world. At the same time, Christopher's lack of awareness is enhancing the realistic elements of his character. There are many examples of this. One of the most moving is perhaps when he resolutely ignores all his father's efforts to explain why he had lied about his wife's death. His parents try to do their best for him and while Christopher is completely unconscious of this, the reader can see what a strain his behaviour has been on his parents' marriage, evidenced most clearly and graphically from his mother's letters. Because of the consistency of the narrative voice the reader retains sympathy for and empathy with Christopher in spite of his extreme selfishness. The reader cannot but experience vicariously what Christopher experiences and thus understand the many, vast difficulties which arise as he tries to make sense of this world. The important consequence of this is that Haddon has shown the inevitability of Christopher's thoughts and actions. Christopher has no real choice. He has no conception of how

any of his actions might impact on others and he cannot differentiate between the trivial and the important. It is with great difficulty Christopher learns to modify his behaviour a little and even to 'read' some body language with the help of 'smiley' faces drawn by his teacher. The psychologist, Patricia Howlin in her book, *Children with Autism and Asperger's Syndrome* (1998) gives two examples of the difficulties a person with Asperger's syndrome has to try to overcome by citing one fourteen-year-old boy who showed utter disbelief when his mother asked him if he ever liked to chat 'just for the sake of it'. He replied that he talked only to gain or to give information and 'Anything else would just be a complete waste of time.' Another client asked his therapist to teach him when to laugh. (pp.8, 149).

One of the main reasons for the success of books about autism is that the syndrome by its very nature creates an outsider or the 'other'. As already stated the outsider has a long literary history and including characters who are on the spectrum creates a 'ready-made' literary device. A further reason for their success is that most books featuring autism are either thrillers or in the detective murder-mystery genre. Whodunits are extremely popular in general fiction and the vast majority of the most successful series have a detective who is socially dysfunctional, a 'loner' with a problematic relationship with his family, colleagues or authority. This detective is, however, highly successful at solving the mystery because he is looking at it differently from everyone else. There are many examples of this type of sleuth from Sherlock Holmes to more modern ones like P.D.James's Dalgeish or the television versions of Inspector Morse. One of the attractions of these fictional detectives is that they are different from most people, show a reluctance to be sociable, unafraid to go their own way, work in an unorthodox manner and are obsessed with finding the answer to whatever mystery they are involved in solving. They can be viewed as showing traits of autism and thus Haddon's Christopher and O'Dowd's Ted fit into this genre extremely well. Christopher says he is following his favourite author, Conan Doyle, and Haddon further emphasises the importance of this genre by using a quotation from one of Conan Doyle's lesser known stories, *The Silver Blaze*, for his title.

In both these books as well as in *Spinner Asperger's Syndrome* is recognisable and presented in a way that would increase the reader's understanding of it. This applies particularly to *The Curious Incident of the Dog in the Night-Time* which persuades the reader that Christopher has to be accepted as he is. He behaves as he does because of who he is and the syndrome is simply part of him.

Asperger's syndrome is an example of an impairment which is disabling in itself. Whatever social barriers are dismantled, ultimately there are the problems of human relations. Not only will the Boons never have an affectionate, responsive son and great though his A-level achievements may be, it is questionable how far he can go because, according to Allan Snyder

(2009) those on the autistic scale tend to have ‘a preconceptual mind that thinks in detail, rather than through concepts.’ (p.1403).

All three novels have portrayed characters with Asperger’s syndrome and its attendant problems well, none of the protagonists is portrayed as a victim nor is there any suggestion of medical intervention. Advocates of the social model of disability would claim that Christopher is disabled because he is different and not fully accepted in society although the social model of disability minimises the notion of impairment as problematic, focusing instead on discrimination as the key obstacle to a disabled person’s quality of living. (Crow (1966): 10). Haddon has created a fully functioning character who has been born with a different logic who experiences the world differently from most people. The reader sees the difficulties and his bewilderment as he tries to cope with and make sense of the world around him. His impairment is problematic. Certainly, society could be more understanding and more accommodating but with his impairment could Christopher ever become a fully functioning independent member of society? Even the widest and most liberal of societies demand a large measure of consensus and agreement to function. Christopher’s compulsive aberrant nature suggests he will always need a mediator as will his real-life counterparts. Haddon has produced a truly ‘inclusive’ book of interest to the disabled and the nondisabled. In terms of the depiction of disability the details which Haddon includes all contribute to making both the story and simultaneously a disabled character completely convincing. Christopher appears selfish and rude. Yet the readers remain sympathetic to him because they have gained understanding. Haddon has forced the readers into Christopher’s mind; the readers can view the world as Christopher does. Thus of all the fictions in this dissertation, *The Curious Incident of the Dog in the Night-Time* is the most complete portrayal of disability.

CONCLUSION:

The dissertation begins by examining institutions and institutional life in Chapter 1 as historically, it was customary for the disabled to be institutionalised; some of the books were in the historical novel genre. It was found when comparing them with novels depicting more contemporary institutions that many of the issues remain, although sometimes in a different form. The medical model is used as expected in those set in the past and still often in those in a contemporary setting. Some possibly controversial issues like experimental medical procedures and eugenics are mentioned, but not dwelt upon. Contrary to the general perception that people in institutions are isolated, most characters find the need of belonging fulfilled in their institutions even though at the end of each book they are usually leaving them for what it is expected to be a better life. Most of the writers have done this convincingly. Schools are treated separately from the other institutions in this thesis because young adult readers would almost all experience it. It was found that as a setting school did not feature greatly except in background snapshots. Issues overlapped in these two chapters and some novels are used in both. Surprisingly, the difficulty in accessing suitable education is a primary concern and for the most part, the descriptions of special schools are rather negative. In spite of almost all the sociological and psychological research results which show socialising as probably the most important part of schooling for any young person, socialising does not appear linked to schools any more than any other context. .

Many issues arise in the chapter on Home and Family. In the enclosed intimate unit of a family the medical model has almost certainly to be used, social barriers having little direct effect. It is shown that even if the writer has used the medical model, it is possible that he or she is informed by the social model. In any case, it does not necessarily mean that a writer is prejudiced or does not understand the disability experience. There is a variety of angles on various members of the family, with two outstanding books, Rachel Anderson's *This Strange New Life* and Elizabeth Laird's *Red Sky in the Morning*. The former depicts the effects of disability on a whole family, and includes various issues such as the fact that, reflecting real-life, the chief carer is usually a woman. There is much thought provoking content in the novel. Laird's book deals with the effects of the birth and death of a disabled child has on the whole family. A young adult in a similar situation to either of these protagonists would be able to identify with them and find these fictions helpful. The social model of disability can be seen in a small way in the depictions of Alzheimer's and again in these novels there are many points worthy of inclusion but they are not highlighted.

The same can be said for the issues arising in Chapter 4 on Friends and Relationships. Research suggests that it is more difficult for disabled people to make friends than their nondisabled counterparts, but this is not explored very often in young adult novels featuring disability. Often the impaired person has already got a group of friends. It is shown in this

chapter how myths and misconceptions can be endorsed and perpetuated. Romantic and sexual relations have until recently been avoided or sanitised in young adult fictional characters that are disabled. A significant finding in this chapter is that the more recent novels (those written since 2000) are more similar to the 'mainstream' young adult's canon, both in regard to the interest in romantic or sexual relationships and also how they are handled.

Chapter 5 is concerned with appearances, an important subject for disabled people in this age when there is so much emphasis on the perfect body. There is a disappointing number of titles concerned with this but two important unrelated points arise: the misconception that each disabled person has a compensatory gift and the fact that books featuring disability tend to be at least shortlisted for prizes whether deserving or not. There is almost a complete lack of characters with malformed limbs or other deformities. I could find only one example of an amputee and one example of an adult with severe deformities. Underlying the narratives are serious ethical questions, but they remain unanswered and indeed unasked.

Chapter 6 focuses on Getting Around. Environmental barriers immediately bring to mind wheelchairs, which are examined in this chapter. It was found that sometimes writers use wheelchairs as a short cut to creating a disabled character or use them as a symbol. Those with impaired sight also face environmental barriers but one of the issues that arose in this chapter was that attitudinal barriers are greater than environmental ones. It is significant that attitudinal barriers can be created by the disabled person as well as the nondisabled. Question arose also about the dehumanising of the disabled and the difficulty for the writer has, in creating a strong independent disabled person without making them appear unlikeable.

Chapter 7 is concerned with communications and again while exploring the problems facing those who are hearing-impaired and those who cannot speak properly several other matters arose. For example, it was noted that there was a lack of any disabled protagonists and the few disabled characters whose disability is not the prime concern. One writer missed the opportunity to explore the 'signers versus speakers' debate of the deaf and one might query why all the authors creating a character with cerebral palsy chose a very severe case.

Finally, Chapter 8 is in a different form. Three novels, all concerned with Asperger's syndrome are contrasted and compared and show how it is possible to incorporate a disabled person in a narrative and even make the impairment integral to the plot.

As awareness of the whole disability movement has increased greatly since 1980, predominantly through the dissemination of the social model of disability and its emphasis on equality, one might expect a similar changing of attitude in young adult fiction. Unfortunately the changes are barely discernible. There certainly does not seem to be any sort of steady progression.

Rachel Anderson, writing in the 1989 shows unusual insight and understanding and she was the first young adult writer to include any sexual references in a fiction featuring disability. This is not to say that there have been no changes, because there have been, but they appear to be sporadic. Author Anne Fine is a remarkable for her ongoing awareness of some of the changes required. She has revised and reissued several of the books she wrote thirty years ago, altering some of the concepts and vocabulary to make her books more relevant and acceptable to a new generation. This underlines the short shelf life of children's and young adults fiction. Nonetheless, it is disappointing to find so few truly well written and outstanding books, although that is not to say that other books are valueless; many included valuable insights into a particular aspect of disability. It is clear that the portrayals vary considerably in verisimilitude and conviction. The majority of books where a main character is disabled the chief concern is the rehabilitation of the character. In those involving a wheelchair user, most authors use a formulaic approach, describing the event and then the emotions through which the character and his or her family go as they come to terms with a changed life. There are two problems here, the first is a tendency on the part of the author to create a character that is or has the potential to be a champion in some physical activity. This may add drama but contains the implicit suggestion that it is less serious for 'ordinary' people. The only possible valid reason for this viewpoint might be the fact that the physical champions may have fewer non-physically based interests than the more naturally sedentary but there is absolutely no doubt that considerable adjustment is required for anyone becoming a wheelchair user. Secondly the concentration on the victim coming to terms with his or her life change may give the erroneous impression that that is the only point of interest. Furthermore it excludes those who have never walked and ignores the fact that there can be a full life span ahead. Of course the accident and rehabilitation theme has its place but it needs to be handled carefully.

The idea of inclusivity is conveyed often with secondary characters. Disability is part of real-life and it should be part of realistic young adult fiction. A disabled character need not necessarily be the protagonist, it can be a friend or relative or even a background figure. Another of the findings of this research was that the success portrayal of a disabled character did not depend upon either the character's or the impairment's importance in the plot. The protagonist's aunt in *Sisters No Way!* exemplifies the former and the protagonist's deafness in *The White Darkness* illustrates the latter.

The small number of outstanding books can be explained at least partially by querying the motives of the writers who have included a disabled character in their plot. There are of course myriad valid reasons, but the use of a disabled character as a symbol sits uneasily in a realistic story. Both Martin Waddell and Aubrey Flegg do this.

A question arises as to whether only writers, who are disabled or have had intimate experience of disability, should attempt to write about it. Without going into the debate too deeply, I would just point out that for example both Lois Keith and Rachel Anderson use their personal experiences well in their narratives but others with impairments, like Helen Flint and Jana Novotny Hunter, fail to do so. The best writers can use their imaginations and put themselves in Other people's shoes.

As many of the problems and interests of the young adult able-bodied and the young adult disabled are so similar, why are so many books featuring disability second rate? The answer lies within this research. The major barrier facing the disabled is an attitudinal one. As literature, both reflects and informs society, the situation will remain unchanged unless there are more fictions challenging instead of endorsing unthinkingly received beliefs. Many authors are too influenced by the medical model and see disability as a personal tragedy with which one has to come to terms. This is why the social model of disability is so important in widening the perspective of disability. Disability is much greater than coming to terms with an impairment.

I have discussed at length the 'messages' or impressions that the books have conveyed. Superficially, nearly all of them end on what would appear to be a politically correct note. It seems to me that there is little in any of the narratives that is really provocative, little to make the reader's stop and wonder about the accepted beliefs and ideologies. There are a few exceptions like the doctor at the conclusion of Julie Hearn's *Rowan the Strange*, who queries how much one should try to change those who are 'different'. It is presented, however, in an under emphasised manner and, because Rowan appears to be cured, the question loses its critical impact. There was only one book which caused controversy when it was published; *When Mr Dog Bites* by Brian Conaghan, but the controversy was about the language used and not about the portrayal of disability.

For an example of a thought provoking, challenging novel centred on disability, I chose one from the United States *Stuck in Neutral* by Terry Trueman (2000). Not only is its theme of mercy killing controversial, but it is not clear whether or not the author advocates it. Consequently, both the content and the interpretation of this narrative provide grounds for thought and discussion.

This is one example of a novel to start or stimulate thoughts or discussions on mercy killing and other related issues, as well as the importance of communicating. There are many other important, unresolved and uncomfortable questions pertaining to disability to be asked but as I have indicated none of the Irish or British young adult novels contains a real incentive to critically examine accepted beliefs. There is plenty of room and scope for the introduction of some more challenging young adult novels, featuring disability.

The most encouraging finding of my research is that there seems to be, since 2000 the beginnings of a breakthrough in young adult fictional writing featuring disability. The majority of these more recent books tend to explore cognitive problems, both disability and health issues, in a more realist, outspoken style and cover a variety of aspects with realistic images. The most outstanding of these are (alphabetically): Brian Conaghan's *When Mr Dog Bites* (2014), Siobhan Dowd's *The London Eye Mystery* (2007), Mark Haddon's *The Curious Incident of the Dog in the Night-Time* (2003), Julie Hearn's *Rowan the Strange* (2003), Tabitha Suzuma's *A Note of Madness* (2006) and Jean Willis' *Naked without a Hat* (2001). It is fair to say that these narratives, for the most part, reflect the current thinking on disability, showing how the impairment and society can both be disabling. Although they are not all of a high literary standard, there is material in all of them that is at least thought provoking. Some would be influential and helpful in forming young adults' ideas in a positive way about intellectual disability. Autism is the disability portrayed most often and it is generally depicted well. Of these Mark Haddon's *The Curious Incident* is an outstanding example. Haddon's skill in creating Christopher's voice forces the reader to see the world through an alternative logic. This results in a better understanding of the condition and with understanding comes a much greater tolerance. While the description of Tourette's syndrome cannot be deemed clear, it is encouraging to see some narrative experimentation continuing after Haddon in the realm of intellectual disability. *Naked without a Hat* has caused very little interest but as an addition to the young adult narratives featuring disability it is to be welcomed for several reasons. It is written in an informal 'zany' style reminiscent of many mainstream young adult romances. It is a romantic story, it includes sex and at the same time there is a great deal of food for thought. While researching disability in young adult fiction, I felt very constrained by the relatively low number of narratives featuring a disability and the narrow choice of both impairments and how they were perceived. While many novels conveyed some part of the disability experience well, too many were mediocre, and few were brilliant. There still remains a restraint in young adult writing about the disabled, a dearth of fictions which might ask uncomfortable questions, criticise conservative thinking and challenge their young adult readers. Reflecting on all the books I have explored for this dissertation I have found that there are many examples of various issues pertaining to the experience of disability extremely well executed. For example, Rachel Anderson's portrayal of Johnny growing up with disabled brothers is excellent: the effects of the birth of a severely disabled baby have on a family is well conveyed by Elizabeth Laird and Siobhan Parkinson's role model vignette of a woman with deformities from thalidomide is most effective. Making a disability integral to the narrative plot can hardly be done better than in Mark Haddon's *The Curious Incident Of the Dog in the Night-Time* or Siobhan Dowd's *The London Eye Mystery*.

I have discussed at length the 'messages' these and the other books have conveyed. Superficially all of them end on what would appear to be a politically correct note. It seems to me that there is little in any of the narratives that is really provocative, little to make the reader's stop and wonder about the accepted beliefs and ideologies. There are a few exceptions like the doctor at the conclusion of Julie Hearn's *Rowan the Strange*, where the doctor queries how much one should try to change those who are 'different'. It is presented, however, in an under emphasised manner and, because Rowan appears to be curate, the question loses its critical impact. There was only one book which caused controversy when it was published, *When Mr Dog Bites* by Brian Conaghan, but the controversy was about the language used and not about the portrayal of disability.

Not only is its theme, mercy killing, highly controversial in itself, but, Lois Keith (2004) has written as strong indictment of it in an article entitled 'A Non-Neutral Review' in an edition of *Disability Studies Quarterly*. In it she criticises Trueman for justifying the killing of disabled children, but I believe an equally valid case can be made to show an anti-euthanasia argument. Consequently, both the content and the interpretation of this narrative provide grounds for thought and discussion.

This is one example of a novel to start or stimulate thoughts or discussions on mercy killing and other related issues, as well as the importance of communicating. There are many other important, unresolved and uncomfortable questions pertaining to disability to be asked but as I indicated at the beginning of this section, none of the Irish or British young adult novels contains a real incentive to deliver critically examine accepted beliefs. There is plenty of room and scope for the introduction of some more challenging young adult novels, featuring disability. Reflecting on all the books I have explored for this dissertation I have found that there are many examples of various issues pertaining to the experience of disability extremely well executed. For example, Rachel Anderson's portrayal of Johnny growing up with disabled brothers is excellent: the effects of the birth and death of a severely disabled baby have on a family is well conveyed by Elizabeth Laird and Siobhan Parkinson's role model vignette of a woman with deformities from thalidomide is most effective. Making a disability integral to the narrative plot can hardly be done better than in Mark Haddon's *The Curious Incident Of the Dog in the Night-Time* or Siobhan Dowd's *The London Eye Mystery*.

As there has been minimal academic work in the area of my research I hope this dissertation will form a basis for future academics to build upon. It will make an important contribution to the body of research in children's and young adult literature and especially Irish Children's Literature by closely examining the area of disability in young adult fiction. With its multi-disciplinary aspects it can also be seen within the broader area of the Humanities,

contributing to sociology, education and, most notably, disability studies. It will also contribute to the emerging use of disability studies to inform criticism in general literature. While literary approaches to gender, post-colonial, post-modern and equality studies provide invaluable perspectives on the distribution of power that offer models that may be adapted, disability studies can be more useful. To date, disability theory does not appear yet to be applied to children's literature. Thus my project will be an original and important contribution to the body of academic research. In many ways this is just a beginning and my hope is other researchers, with different experiences and approaches, will build upon it.

I will share the expertise and knowledge developed during the research with scholars from other disciplines in the humanities and social sciences including education and disability studies. Apart from producing this dissertation I will disseminate the results of the project by submitting papers to literary reviews, academic journals and conferences. It will also create a greater awareness of disability and the surrounding discourse and lay down criteria about it for publishers, writers, parents, students of disability studies, teachers and librarians.

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