



**A Postcolonial and Disability Studies Analysis of a Selection of Popular
Contemporary Novels about Disability**

Name: Lauren McNamara
Student Number: 11107898
Award: Doctor of Philosophy
Institution: Mary Immaculate College, University of Limerick
Supervisor: Dr John McDonagh

Submitted to the University of Limerick: 10th August 2020

**A Postcolonial and Disability Studies Analysis of a Selection of Popular
Contemporary Novels about Disability**

Declaration

I hereby declare that this thesis represents my own work and has not been submitted, in whole or part, by me or another person, for the purpose of obtaining any other qualification.

Signed: Lauren McNamara

Date: 10/08/2020

Dedication

I would like to thank everyone who has been a part of helping me through this process.

To my parents Kevin and Bernie and my sisters Christine and Aisling for your inspiration and support.

To the English Department in MIC Limerick, Dr Eugene O'Brien, Dr Kathryn Laing, Dr Eoin Flannery, Dr Marita Ryan, Dr Deirdre Flynn and most specifically my supervisor Dr John McDonagh for your expertise and your kindness.

To the postgraduate community of students and staff, thank you for all your help and for the coffee breaks.

To the International office in MIC and to Columbia University and Dr Emily Bloom for the great experience Erasmus + provided which helped further shape this thesis.

To every other person who has added so much since beginning this project.

Finally, to Aisling White, for all of your support to which words cannot do justice.

Contents

Declaration.....	3
Dedication.....	4
Abstract.....	8
Acronyms Used.....	9
Introduction.....	10
Chapter 1-Disability Studies and Postcolonialism.....	17
1.1 Introduction.....	17
1.2 Literature Review.....	17
1.3 Disability History.....	32
1.4 Disability Narratives.....	38
1.5 Disability as Subalternity.....	45
1.6 Subaltern and Voice.....	50
1.7 Racism; Identifying and Interacting with Difference.....	55
1.8 Viewing Difference.....	60
1.9 Conclusion.....	64
Chapter 2-The Language of Disability.....	65
2.1 Introduction.....	65
2.2 Word Meanings and Associations.....	66
2.3 Limitations of Definitions.....	72
2.4 Language as Communication.....	79
2.5 The Body as Communication.....	87
2.6 The Written Word as Equaliser.....	95
2.7 The Internet and Texting.....	102
2.8 Conclusion.....	110

Chapter 3-Identity Politics; Imagined Communities Real Problems.....	111
3.1 Introduction	111
3.2 Imagined Communities of Disability	112
3.3 Building and Maintaining a Community.....	118
3.4: Identity: What is it and how does it Evolve?	124
3.5 Identity, Intellectual Disability and Childhood.....	131
3.6 Identity, Home-schooling and Mainstream Education	136
3.7 Identity and Special Education.....	143
3.8 Conclusion.....	151
 Chapter 4-Othering Disability	 153
4.1 Introduction	153
4.2 Orientalism and Disability	153
4.3 Divisions; The Writer, The Character and The Reader	162
4.4 Disability and the Other	169
4.5 Othering being Reinforced.....	175
4.6 Performing Disability.....	183
4.7 Judging a Book by its Cover; Masks and Book Covers	191
4.8 Conclusion.....	197
 Chapter 5-Disability, Family and Carers.....	 198
5.1 Introduction	198
5.2 Disability and Infantilization	199
5.3 Disability and Giving Space	205
5.4 Single Parent with a Child with a Disability.....	211
5.5 Leaving a Child with a Disability.....	218
5.6 Siblings and Identity.....	224

5.7 Carer as Narrative Voice	233
5.8 Conclusion	241
Conclusion.....	243
Bibliography	249
Primary Texts	249
Secondary Texts	250
Book Chapters, Secondary Articles, Newspapers, Etc	256

Abstract

This thesis will combine postcolonial theory and disability theory to analyse the representation of characters with a disability and their family members in a selection of contemporary popular novels. The texts examined will include *The Curious Incident of The Dog in the Night-Time* (2003) by Mark Haddon, *Wonder* (2012) by R.J Palacio, *The Revised Fundamentals of Caregiving* (2012) by Jonathan Evison and *Me Before You* (2012) by Jojo Moyes. Language use, identity, othering, community and the role of the author will be explored. The power dynamics of these texts will be deconstructed to examine what aspects of disability are being represented in these novels which are highly influential in popular media and in some cases educational settings.

Acronyms Used

TCI = *The Curious Incident of The Dog in The Night-Time*

TRFOC = *The Revised Fundamentals of Caregiving*

Introduction

When one speaks of disability, one always associates it with a story, places it in a narrative. A person became deaf, became blind, was born blind, became quadriplegic. The disability immediately becomes part of a chronotope, a time sequenced narrative, embedded in a story. But by narrativizing an impairment, one tends to sentimentalize it and link it to the bourgeois sensibility of individualism and the drama of an individual story, as we have seen in so many films treating the subject of disability (Davis 1995, pp.3-4).

Lennard Davis's above quote introduces disability as something that can be lost in a story, that can become a narrative technique, a method to heighten drama and evoke emotion in the reader or viewer. This quote is from Davis's book *Enforcing Normalcy*, and he follows this sentiment by stating that 'I want to defamiliarize disability, denarrativize it' (p.4). This research sets out to accomplish the same thing, to break down and problematise representations of disability in a number of contemporary novels.

The aim of this thesis is to analyse disability representation as depicted in four primary texts; *The Curious Incident of The Dog in the Night-Time* (2003) by Mark Haddon, *Wonder* (2012) by R.J Palacio, *The Revised Fundamentals of Caregiving* (2012) by Jonathan Evison and *Me Before You* (2012) by Jojo Moyes. These four texts were chosen due to their similar representations of the power dynamics of disability, their interconnected receptions by readers and critics and their influential nature. All four texts are very popular, as they have sold very well and also had a mainstream popular adaption to either film or stage. Additionally, all of the novels were published in 2012 except for *TCI*, although the play adaption of *TCI* was also first staged in 2012. These novels capture a popular trend of disability representation in the media in the early 2010's. There is also a level of intertextuality between the novels. For example, there is a scene from the movie adaptation of *TRFOC* featuring a scene copied from *Me Before You* (Christy Brown Impression) as well as the novel *Wonder* featuring a quote comparing it to *TCI* on the cover of a number of its editions. While these novels have had some critical engagement, (*TCI* most prominently) the level of academic study has not matched the level of cultural interest. Additionally, on both an academic and public level these novels have often

been received as more positive and educational than they may deserve as writers have mislabelled inspirational stories as authentic (Dave 2006, Letcher 2010). None of these four texts are written by writers who identify as having a disability. This thesis aims to incorporate the work of both disability and postcolonial academics to investigate the texts both as pieces of fiction and as significant cultural commentaries. The inclusion of a chapter on family members and caregivers is an attempt to highlight the social model of disability and investigate how these novels represent the effect of disability on a character's support network.

It is important to outline both what this thesis aims to do and what it does not aim to do. The aim of this research is to investigate and problematise popular depictions of characters with disabilities. As a researcher I am aware that I do not identify with having a disability. I therefore would not feel comfortable trying to formulate any kind of description of what should be considered good disability representation. While this thesis will also be examining the depiction of family members of someone with a disability, a label to which I would fit, my personal experiences will not be discussed in this thesis so as to ground the work in a more literary based research. It is also important to note that part of the rationale for the choice of primary texts were factors such as level of mainstream success and publication timeframe which allow an analysis of some of the most influential contemporary depictions of disability. Unfortunately, these criteria meant there were some problems. Although there is a 50/50 divide of male and female authors, all of the characters with a disability that will be discussed are male. This is a common issue with popular disability representation however it will not be addressed in this thesis as it is not the focus of this research and would need a more direct platform to be explored. Additionally, as mentioned above, none of these texts are written by writers with a disability. Writers with disabilities have produced successful literary work but very few, if any, have received the level of mainstream attention that the primary texts studied here have been given. Finally, there is a large range of disabilities presented in these texts. As opposed to focusing on one kind of disability I believed it was better to focus on the most popular depictions to investigate what ideas were being explored in popular media. Additionally, while the characters have very different disabilities that are often treated in similar ways due to overarching beliefs about what it means to have a disability.

The first chapter of this thesis sets a foundation on which to base this research. It will begin with a literature review detailing the texts being used, why they were chosen and how they can interact. It will detail the benefits of combining postcolonial and disability theory by highlighting the ways in which the work of chosen theorists leads to a deeper understanding of the texts. It will define the terms that will be used throughout the thesis. It will then continue to offer some examples of societal understanding of disability in western culture and how it evolved over time using the writings of Lennard Davis and Douglas Baynton among others. It will also examine some of the history of disability representation in literature and identify some common and influential depictions. By investigating the evolution of literary representation, it will better prepare the proceeding chapters to discuss contemporary depictions of disability by giving the research a historical context. Finally, chapter one will begin the analytical approach of examining disability in the novels using postcolonial and disability theory. It will use the writings of Spivak and Todorov to examine both voice and perception. Spivak's writings on the subaltern and the importance of voice will be essential in positioning the texts in a manner so as to be applicable to postcolonial analysis. It will also provide a strong lead in to the second chapter exploring language use. Todorov's writings on racism and racialism will provide an initial discussion on how difference can be perceived and understood. This analysis should prove to be an important gateway into many of the ideas of postcolonial theory that will be explored further and in additional depth in later chapters.

Chapter two will examine language use in the texts as it relates to disability representation and identity. It will examine work on language and culture by postcolonial writers Chinua Achebe and Ngũgĩ wa Thiong'o. These writers have debated the importance of one's native language to their culture. The way in which language is used in relation to labels and word associations to position characters within their cultures and communities will be explored. The language used by the authors and their characters, will be examined as will the effect these have on characters with disabilities in relation to their self-identity. Additionally, there will be a specific focus on how communication between characters is depicted while using the writings of linguist Roman Jakobson. Communication can be an essential part of self-expression for the characters. It may also be an opportunity for others to enforce certain

beliefs on characters with disabilities on how they should view themselves. For the character of Christopher in *TCI* it will be interesting to explore communication and the connection between language and culture for someone who often struggles with verbal language and the cultural associations often present in speech. The use of both speech and the written word within the world of the texts will be explored. Additionally, it will be examined as to how technology and the internet may be offering new and evolving ways of expressing oneself through different modes of language as seen in the novels.

Chapter three will focus on the idea of community in the texts. It will examine the notion of a 'disability community' using the work of Benedict Anderson in his book *Imagined Communities* (1983). It will investigate how grouping people together can affect identity creation and expression. Additionally, it will explore how all communities can be considered imaginary yet also powerful and explore what this means for a 'community' of people with disabilities. It will include the writings of Stuart Hall and Charles Taylor to further the discussion on identity. Examples from the texts will be used where characters have been mistreated or misrepresented as they are simply associated with the label of disability and have characteristics applied to them which do not match their situations or personalities. These ideas will be shown in relation to face-to-face interactions as well as online communication. The education system will also be explored, mostly in relation to novels *Wonder* and *TCI*, as examples of community by studying how Christopher and August are treated in school and how they adapt as members of their class groups. The depiction of a special school in *TCI* and a mainstream school in *Wonder* offer good examples for comparing and contrasting the two systems. The threads of self-expression and identity will be expanded upon from the previous chapter and will lead in to chapter four's discussion on othering.

Chapter four will examine othering and difference in the texts using Edward Said's book *Orientalism* (1978). It will discuss how knowledge about a community or group of people can be created and disseminated and what that can mean for individual characters. It will also investigate the idea of performing a role in society by combining Said's research with that of disability and theatre theorist Petra Koppers. It will examine the ramifications of othering in

the novels and how this can create tension between characters. Said's discussions on how cultural myths are created and maintained will be applied to the disability context both within the novels and in relation to the authors as will his work on the power of knowledge in the process of cultural othering. As the authors themselves do not have a disability their role in creating an understanding of disability for their readers will be examined. This chapter will explore how the books depict disability and the relationship their normative writers have to disability and indeed the relationship they create between the reader and the character with disabilities. The work done in chapter two and three about language, communication and identity will lead into an overall analysis in this chapter on the role literature can play in exploring culture in relation to disability by investigating the influential nature of these texts in popular media. This chapter will conclude the analysis of characters with disabilities in the primary texts.

The final chapter of this thesis will analyse the family members and carers of characters with disabilities in the novel. Moving away from a direct link to disability the thesis will investigate through the social model of disability (using the work of writers such as Petra Kuppens and Rosemarie Garland-Thompson), the effects it can have on caregivers and family. The depiction of the family unit in the texts will be examined through detailed exploration of the parent and sibling characters. It will explore what it means in the novels for characters to have a sibling or child with an intellectual or physical disability and how this is represented as effecting the family unit. The thesis will explore whether disability is showcased as positive or negative to the family unit in the texts and how these characters are shown to deal with difference within their own family. It will also discuss the role of qualified carers as seen in *Me Before You* and *TRFOC*; examining the relationships shown between caregivers and care-receivers and how the personal/professional relationship is balanced. The primary texts have taken great time and space to representing how family members and caregivers interact with disability. Examining disability representation in these texts without a detailed study of these characters would leave the research feeling unfinished. The novels do not limit the social effects of disability to the individual so neither will this thesis in its analysis.

Postcolonial theory will be used throughout each chapter as a tool to introduce a theoretical framework to challenge representation. However, within each chapter there will also be an exploration of the work of disability theorists and a broader range of cultural theory to help nuance this research. Rosemarie Garland-Thompson will help focus the work of Spivak and Todorov to a disability context. Jakobson will give a larger cultural linguistics point of view to the writings of Achebe and Ngũgĩ. Stuart Hall and Charles Taylor will expand on ideas of identity that will be introduced using Benedict Anderson's work. Petra Kuppers will help investigate disability in relation to Said's writing. The work of these writers and others will give the thesis a broader scope. This project aims not to simply be a postcolonial analysis into these texts but to create a disability and indeed cultural studies investigation into the representation of disability in these examples of popular literature.

The popularity of disabled stories by normate writers has arguably created a lack of appreciation or even awareness of the disabled voice. For example, in her YouTube video Amanda Brags (2007), a woman who was considered non-verbal for most of her life discusses the idea that normate people often dismiss the disabled voice as not being a voice at all. The disabled playwright Chuck Mee (2006) also argues that popular narrative structures are built for ableist experiences which is not how he writes nor experiences the world. The coverage of the Ashley project (Pilkington 2012), an incident where a young girl with a disability was medically altered to prevent her growing up and becoming susceptible to predators, highlights, in a severe manner, the danger of how disability is understood and positioned in society. Disability is often seen as something needed to be protected and given an infantilised image. From teachers writing in academic journals that these fictional novels are great ways to get into the mind of someone with a disability (Letcher 2010, p113) to the writers of the novels themselves asking for their work to not be used as educational textbooks as they only meant to be fiction (Singh 2015), these novels have had a significant effect on their readers and on popular understanding of what it means to have a disability. The hope for this thesis is that it will create a strong argument for the necessity of further large-scale and continuous research into contemporary popular culture depictions of disability. By examining the role of the writers, as well as the language and power dynamics of the texts, it will argue that these

texts are not as authentic, realistic nor positive as they are often described as by reviewers (Letcher 2010, Russo 2012, Gilmore 2012, Steffens 2012). This thesis is an attempt to challenge the misconception that a text structured to be inspirational is always positive. It also wants to highlight that maintaining a level of criticism is necessary when texts are promoted for representing overlooked and vulnerable groups. Not all representation is positive representation.

Chapter 1-Disability Studies and Postcolonialism

1.1 Introduction

The opening chapter of this thesis will explore the history of disability representation and create the theoretical foundation for applying both postcolonial theory and disability theory to the depictions of disability in the primary texts. The opening section will consist of a literature review that will present the argument for why the primary and secondary texts were chosen and explain how different texts will be integrated throughout the thesis. The following two sections will explore the historical context of disability and disability studies to create a basis for the analysis of contemporary work. The second half of the chapter will use the work of Spivak and Todorov to begin analysing disability representation from a postcolonial perspective. It will explore discussions based on identifying difference, voice and the 'normate' writer that will lay the foundation for the work that will be done in the proceeding chapters.

1.2 Literature Review

The opening section of this chapter will review the literature associated with the fields of postcolonialism and disability studies that will be used throughout this thesis. It will examine the history of disability studies. Additionally, it will present the argument for why the primary texts were chosen and the connections between the four novels. Overall, this section will aim to position this research within contemporary disability studies.

Disability studies explores the social, cultural, and political dimensions of the concept of disability and what it means to be disabled (Adams, Reiss, Serlin 2015, p.21).

The aim of disability studies, as laid out above, in a quote taken from the text *Keywords for Disability Studies*, is to explore the concept of disability and what it means to have a disability.

Literary disability studies take these ideas and applies them to the representation of disability in literature. Disability studies as an academic field is considered a relatively recent phenomenon. Mossman (2009), claims it began in the mid 1990's while Alice Hall (2012) argues it began in the 1970's in association with the disability rights and civil rights movements. There seems to be an element of truth in both of these ideas as can be seen in the opening essay of Wappett and Arndt's collection *Foundations of Disability Studies* (2013). The first essay they choose to include was an updated version of the 1977 essay 'Handicapism' by Bogdan and Biklen which the editors believe was a seminal text in laying the groundwork for disability studies. However, in their updated version of the essay, Bogdan and Biklen (2013) acknowledge the importance of their piece but also note a number of serious flaws in it. They cite lack of focus on the disabled voice, not acknowledging political power over access and services nor the possibility of disability existing with another identity that could create a situation of double discrimination (p.2). Disability studies may have first appeared in the 1970's but it arguably took a few decades for it to focus and begin gaining momentum. Yet disability studies, and particularly literary disability studies can be traced much further back as Alice Hall (pp.7-8) cites work by Helen MacMurphy (1926) and Virginia Woolf (1948) who were discussing disability representation in literature and how it could have real world implications long before the idea of disability studies seemed to be an accepted discipline. As disability itself is difficult to define, the history of disability studies is as well. However, the opening sections of chapter one will attempt to discuss this history.

It is important to define the word disability and how it will be used within this thesis. Disability theorist Petra Koppers writes that 'you will likely not come up with a single firm definition of disability... not something one can name and nail down' (2014, p.10) and continued to say 'language shifts and change in tune with new social arrangements and cultural values, and the journey of the term "disability" shows this malleability of our concepts' (p.10-11). The term is vague, hard to define and often changes significantly with context. The way in which the word will be used in this thesis is as a given label. The thesis will investigate characters who have been labelled as having a disability and examine what this means to their story. The word normate will also be used to refer to non-disabled characters in the texts. Garland-Thompson (1997) and Koppers (2003) argue that normate is an appropriate phrase to make

the division between disabled and non-disabled in an even manner as phrases such as non-disabled or normal carry 'specific values' (Kuppers, p.7). The social model of disability will be used predominately throughout this thesis. The social model came to prominence as a rejection of medicalisation in the era of civil rights in the 1960's (DasGupta, p.343). Conrad describes medicalisation as 'a process by which nonmedical problems become defined and treated as medical problems, usually in terms of illness and disorders' (2007, p.4). Kuppers writes that 'medical views of disability work on finding the abnormal and works toward normalizing the disabled person' (2014, p.24) and that in the medical model 'the disability is here owned by the disabled person, and does not affect others' (p.24). Disability becomes a problem to be carried by the person with the disability and medical staff. She then defines its antithesis as 'in the social model, disability appears in the interaction between the impaired person and the social environment' (Kuppers 2014, p.27). The social model focuses on the social and environmental issues of disability. A popular example is; 'for a woman using a wheelchair, it is not her body or the wheelchair that disables her, but the architectural choice of stairs' (Kuppers 2014, P.27). In this example, the woman's disability is not the issue, it is the inaccessibility of the world around her. 'The social model asks how certain kinds of bodies are disabled by physical barriers, social stigma, lack of legal recognition, adaptive technologies, and economic resources' (Adams, Reiss, Serlin 2015, p.22). Rodas (2015, p.295), notes that social model was a successful challenge to the idea that disability was exclusively a problem of an individual's body. The social model is used here as it allows an analysis of the representation of the treatment of characters with disabilities by both other characters and indeed the authors. It can be used to investigate biases and negative perceptions of disability throughout the text. However, writers such as DasGupta (2015) and Wendell (2001) argue that the social model may have gone too far as the medical aspects of disability become ignored in some forms of analysis. Throughout this thesis, the analysis of disability will not be limited to the social model alone. However, it will be the dominant focus as the primary texts studied here seem to focus much of their narratives on the social model and how their characters struggle with issues such as misrecognition and lack of access to opportunities.

The decision of which primary texts to study for this research is based on a number of factors. When it was released in 2003, less than a decade after the rise of disability studies as seen

above, *TCI* became a massive critical and cultural success winning numerous awards (Ezard 2003) and selling over ten million copies (Higgins 2019). The novel became an unexpected success and became a staple of many school booklists (McRae 2007, p.106). When it was announced that the novel would be adapted to a play in 2012 it seemed like a popular representation of disability would be again brought to a mainstream audience. Interestingly, in the same year this adaptation was staged, three novels which were focused on the experience of disability were also released; *Wonder*, *Me Before You* and *TRFOC*. Whether the publication dates of these texts were purposefully linked or not, it is still worth noting that a large surge of successful texts about disability were released in such close succession. While *TCI* is the only one of these texts to focus on neurodiversity as opposed to physical disability, the success of the novel seems to have allowed for more space in the mainstream media for disabled stories. All the texts also seem to share a number of themes such as challenging low expectations for characters with disabilities and struggling with misrecognition. The second factor is that all four texts were influential in the popular media as they had major adaptations. *TCI* was adapted to stage as mentioned above, and the other three texts were made into major motion films. While this is noteworthy as a way to measure their influence, these adaptations will not be a focus of this thesis as it will attempt to focus on the written versions of these stories to avoid including too many primary texts. However, this is certainly an area worthy of further research in the future. This is also the reasoning behind choosing not to include the sequels to *Wonder* and *Me Before You*, in addition to the fact that the sequels no longer focus on the original text's character with a disability, or indeed any character with a disability.

Thirdly, the novels all focus on characters with disabilities in western society (England and USA) whose disability has a negative effect on their families. Having someone in the family with a disability is consistently represented as very damaging to the family unit. The writers often include first person narration from family members speaking about their interactions with disability. The relationship between a carer and someone with a disability is also often explored in the primary texts. Therefore, the role of family members and carers will be discussed in detail in chapter five. Fourthly, the texts are all written by normate writers. While it is not ideal to study disability representation without including primary texts by writers with

a disability, the criteria of choosing these texts was to examine the most popular depictions of disability. All of the most commercially successful texts seemed to be by normative writers, something that will be discussed in depth throughout this thesis. The final factor in choosing these four texts is they seem to be connected through how their publishers choose to market them. On the front cover of *Wonder* is a quote from The Times newspaper stating 'destined to go the way of *The Curious Incident of the Dog in the Night-Time*'. This is an interesting marketing tool considering August has a physical disability and Christopher has an intellectual disability and in many ways the stories are very different. *TRFOC* has a similar cover quote from The Boston Globe comparing the text to the movie *Rain Man* (1988). Connecting its story about a physical disability to a movie about a character with an intellectual disability. This is particularly interesting as Burks-Abbott (2008) a critic with autism notes that '*The Curious Incident of the Dog in the Night-Time* is the new *Rain Man*, the new definitive, popular account of the autistic condition' (p.294). *Me Before You* does not have as direct a connection, rather it fills its covers with quotes about the sadness of the book, calling it a tearjerker and setting up the inevitable tragedy of disability. These books use disability as their selling point, as a marketing tool. Disability is marketed as an exotic Other for the reader which will be explored throughout. Framing disability as something exotic as opposed to try to tell stories of characters with a disability will be explored in this thesis. While there has been a significant academic interest in *TCI* (Kuppers 2008, Ciocia 2009, Letcher 2010) which will be discussed in this research there has not been as much critical interest in the other texts. Disability and postcolonial theorists will be used to fill this theoretical gap in the upcoming chapters.

It is interesting to note also how these novels can fall into a number of popular culture genres. *TCI* has many elements of a detective novel. *Wonder* would fall into the young adult category. *TRFOC* has elements of a road trip story similar perhaps to that of *Rainman* (which it is compared to on the cover of a number of editions). Finally, *Me Before You* firmly falls into a romance category. Sean Connors (2013) notes that many texts that fall under categories such as young adult literature are often considered as 'genre fiction' (p.xi) and something that does not have enough substance to be considered part of the literary canon. It is interesting to note that Jojo Moyes, for example, is a highly celebrated romance novelist having 'twice won the Romantic Novel of the Year Award by the Romantic Novelists' Association' (Gilchrist 2012)

is uneasy about her own genre. Moyes states in an interview she is unsure about the title romance novelist noting that it sometimes is interpreted as 'something lightweight, and not always of great quality' (Gilchrist 2012). It seems being labelled as being part of a popular genre means the work may be considered 'lightweight' and less likely to be engaged with at a deep level by their readers. Ciocia (2009) also notes that *TCI* was a shock to critics in its crossover appeal among different age groups noting that previously only fantasy texts could appeal to both adults and children seemingly noting that most non-fantasy texts that appeal to younger people are not engaged with by adults. This may mean young adult fiction such as *Wonder* which is set in a realistic and contemporary time and setting may be largely ignored by adults and critics. These popular genres may protect these texts from criticism and may be why many of them have not received a lot of critical attention.

However, while these texts may not always be responded to critically, Garcia (2013) argues that they are often used for presenting complex information to young people. For example, he notes that 'YA [young adult] dystopian novels offer an opportunity for exploring post-colonial theory with young people' p.71. He makes specific note that the genre often interprets the ideas of writers such as Spivak for a younger audience (p.61). He notes that 'though the books may be flawed in terms of representation and plot delineated definitions of success, they often still cast young people as outsiders in a world gone mad, sick, or in some terrible way disabled' (p.71). Garcia argues that young adult fiction often positions young people in the role of other to explore power dynamics between young people and a dominant (usually adult) authority. It is interesting that *Wonder* takes the idea of the damaged 'disabled' world as Garcia puts in and inverts to trope to internalize the struggle to present the dominance of normality as the oppressor. However, the text still functions as putting the reader in position of other and highlighting the struggles of an othered character. Garcia argues that the reason these tropes are so popular in young adult and adult fiction is that othering and the subaltern are easy to replicate tropes that are very marketable. These texts act as potentially educational tools to teach about colonialism but do so in a market focused manner. This thesis will use postcolonial theory to examine what the texts say about postcolonial ideas of identity and power.

Young (2003) notes that 'since the early 1980's postcolonialism has developed a body of writing that attempts to shift the dominant ways in which the relations between western and non-western people and their worlds are viewed' (p.2). This is interesting as it mirrors the rise of disability studies, which as mentioned above, is believed to have started in the mid-seventies and rose to prominence in the nineties, again likely connecting to the rise of individualism and civil rights movements. The idea of shifting dominant ways of viewing between two groups is also the foundation of disability studies itself. Young notes (p.6) that postcolonial theory is not a unified whole, rather 'a coherently elaborated set of principles' which can be used to analyse power structures and sets of knowledge. This implies it is something that can be expanded for use in literary analysis of disability.

We use the term 'post-colonial', however, to cover all the culture affected by the imperial process from the moment of colonization to the present day. This is because there is a continuity of preoccupations throughout the historical process initiated by European imperial aggression. We also suggest that it is the most appropriate as a term for the new cross-cultural criticism which has emerged in recent years and for the discourse through which this is constituted. (2003, p.2)

The above quote from Ashcroft, Griffiths and Tiffin gives a definition of postcolonialism that will be used for this thesis. Postcolonialism refers to the relationship between coloniser and colonised after the moment of colonisation, rather than after colonisation has ended. In fact, much of the power dynamics that will be explored throughout this thesis will be more in line with a colonised people than a recently liberated people. The above authors noted in their introduction to *The Postcolonial Studies Reader* (2006), that some of the major focuses of postcolonial theory are representation, language and difference (p.2). These themes and their effect on self-identity will be the main themes of this research. Chakrabarty (2000) noted, that post-colonialism has become intrinsically linked to literary studies. It's suitability in this thesis is connected by the fact that many of the theorists focus on the power of literature on framing and changing identity in the texts. Anderson noted that the novel offered the means for re-presenting imagined communities such as the nation (1983, p.25). Said noted (1978, p.94) that people often attribute expertise to books and that they use them to frame their understanding of subjects they are not knowledgeable about. Achebe noted that literature can 'offer the kinetic energy necessary for social transition and change' (1989, p.167). The

writers chosen put a great emphasis on focus on literature in their work and the importance of being critical toward literary work due to its ability to frame cultural understanding.

Disability studies and postcolonialism have a lot in common in relation to power dynamics, representation and identity. The combination of disability studies and postcolonialism is not a new connection. However, Mark Sherry (2007) argues that the combination is rarely done well. He states:

Neither disability nor postcolonialism should be understood as simply a metaphor for the other experience; nor should they be rhetorically employed as a symbol of the oppression involved in a completely different experience (p.10).

Sherry is unhappy with the way these two fields are often conflated in literature and academia. He argues that they are separate disciplines and that the comparisons go against the different histories and intricacies of the areas of study. Indeed, Barker (2011) spends much of her book trying to dismantle the many ways postcolonial and colonial societies used disability as a metaphor for their lives. However, Barker also identified numerous connections between the fields historically, which reveals Sherry's criticism as problematic. Barker showcases how intertwined disability and postcolonialism were in colonial representation. While some metaphors between the two may not be useful, many of them may be revealing an unnamed connection that exists. The history of colonialism and disability are not that different as will be discussed in the following sections on historical context. Sherry argues against the use of postcolonial writers when analysing disability, yet, their intertwined history makes their philosophical foundations both applicable and almost necessary or else a writer may be ignoring entire sections of the history of disability. This thesis will use the work of postcolonial writers, as well as disability studies writers, to examine contemporary representations of disability as the history and power dynamics of postcolonialism and disability are closely connected. Postcolonialism is not being used here as a metaphor for disability or vice-versa. This thesis will explore the connections between the two areas to be able to give a more in-depth analysis of the primary texts.

Sherry's argument as presented in the last paragraph does highlight an important issue that could be raised about using metaphors. The characters examined in this texts are all white males living in a western country. This may at first seem to discredit their inclusion in a postcolonial analysis. However, this thesis is examining identity defining narratives created by a dominant western society about a minority group. Postcolonial theory is a necessary tool to use in challenging controlling representations created by white western writers. This thesis sets out to not use disability and postcolonialism as a metaphor for each other but as a way to understand how the creation and spread of knowledge throughout literature is used to create popular cultural beliefs that integrate into cultural understanding. While the power dynamic here is insular in the writers' own countries, Anita Ghai (2012) has noted, reinforcing her work using the writing of Bell Hooks (1995) on race that 'achievement of colonialism does not require the assumption of power in someone else's country. Rather colonialism can be accomplished by dominant and normative hegemonies through social apartheid' (p.284). When postcolonial theory is not nuanced enough to interpret the representation of disability the thesis will lean more heavily into its use of disability theory as well as a wider use of cultural theory. Ghai also notes her worry about using one theoretical field to examine another field, noting for example, how different the life of a person with a disability is in India to that of a person with a disability in western society. It may be the postcolonial studies is less suitable in analysing the lives of people in western society, however this thesis is not looking at the lives of people directly rather the representation of what these lives are believed to be.

Stuart Hall writes that "texts restore an imaginary fullness or plenitude, to set against the broken rubric of our past' (p.225). These novels reinforce the notions of difference between disability and non-disabled. They use white western male protagonists to restore an imaginary fullness of binary identity as the other aspects of their identity are presented as unproblematic. Gabbard has noted in his article on the word 'human' in *Keywords for Disability Studies* that model of a liberal subject in western society was 'presumptively male, white, Anglo-European, and heterosexual' (p.286). These novels seem to remain loyal to this image and perhaps this has aided to their popularity. Petra Koppers, for instance, notes that perhaps the main draw of *TCl* is its 'possible simplicity' (p.193) that readers can feel

comfortable in their protective of Christopher. These texts imagine a purified version of disability, where disability itself is the only problematic identity marker that needs to be challenged. While contemporary disability studies have slowly come around to how layered identity can be and issues of multiple levels of discrimination (Bogdan and Biklen 2013, p.2), some of the most popular representations of disability in western countries have yet to engage with this. To focus on what these texts do present, postcolonial theory was chosen to directly problematize these representations. To attempt an overview of what identity representation is as presented in the texts, it chose a number of postcolonial theorists to try and discuss specific ideals of language, community, expression, othering and performance. Spivak, Todorov, Achebe, Ngugi, Anderson, Hall and Said were chosen both for their extensive work in these areas as well as their interconnectivity with each other. Additionally, it chose to include additional cultural theorists from outside the field the more broadly cover some of these areas such as Roman Jakobson on communication, Charles Taylor on Misrecognition and Michel Foucault on enforcement of power.

Introducing characters with more varied cultural backgrounds may have led to a higher level of difficulty in focusing solely on disability. For example, Subini Ancy Annamma (2018) has written about the high number of young black women with a disability in America who end up in the prison system. The socio-economic realities for many women, black men and specifically black women in America and Britain present a more complex reality than is seen in the somewhat sanitised narratives of these books where one issue is capable of being the sole focus. Annamma has further noticed that many of the young women she worked with in the prison system spent much of their time themselves as carers for family members. Annamma further notes, while citing Crenshaw, Ocen, & Nanda, 2015, that 'girls of colour are often punished for caretaking in their families' (p.33). She details a number of situations where young women with disabilities are punished for missing school when they are expected to take care of younger family members on a full time basis. This idea of a person with disability as a carer does not fit into the grand narrative of disability that is presented in these popular texts which present people with disabilities as to be cared for but never as carer. These texts focus on the exploration of othering toward western white males due to having a

disability, this does not allow room for the stories of double or triple discrimination that could occur for other kinds of characters.

Tsitsi Chataika (2012) has noted that 'postcolonial theory looks at literature and society in two ways' (p.254). Firstly, by examining 'how the writer, artist, cultural worker, and his or her context reflects a colonial past, and how they survive and discover a new way of creating and understanding the world' and secondly 'colonial nations who take their colonies as the subject matter. The theory is based upon the concepts of otherness and resistance' (p.254). This thesis will use postcolonial study in this second form by challenging representations based on otherness. Ghai (2012) notes that a main focus of postcolonial study is 'is the understanding of the Other, historically and symbolically' (p.273). Both Ghai and Chataika highlight Said as the main contributor to developing a method of investigating the representation of the Other. Said's writing is a main pillar that this thesis will build around. Furthermore, to understand othering the thesis will also analyse different factors of it using the work of other postcolonial theorists. Chapter one will include Spivak and Todorov's writing which examines how difference is identified and the effects of othering on a subject. Chapter two analyses Ngugi and Achebe's work which investigates how stories and language can be used to create a representation of an other. Chapter three will discuss Anderson, Hall and Taylor's work on the effects of misrepresentation of an individual and a community. All of these writers' work is interconnected in attempting to achieve Ghai's goal of understanding how the other is represented 'historically and symbolically'.

In the introduction to the book *Manifestos for the Future of Critical Disability Studies* (2019), the authors, a collective of highly respected academics in the area, discuss the phases of disability studies. They refer to Paul Longmore's book *Why I Burned My Book and Other Essays on Disability* (2003) which argues that the first phase of disability studies refers to its creation and the identification of a need for analysis. The second phase was the evolution of this study which incorporated much of the work being done today such as intersectionality, language, the body. The text then refers to Rachels Adams 2013 essay 'Disability studies now' which argues that we are currently in the third phase of disability studies where the field is trying to

define itself and tensions and conflicts are arising between areas of research. Sherry's writing in the previous paragraph is perhaps an example of this conflict. Sherry is challenging one form of disability analysis. The state of disability studies is ever changing. In the same book of manifestos mentioned above prominent scholars David Mitchell and Sharon Snyder argue that the future of disability studies should be highlighting 'what disabled lives bring into the world' as opposed to existing as 'a perpetual site of exposé' (p.189). While this may be a positive direction to bring some of the research in the field there remains much work to be done in the exposé of negative representation as will be shown throughout this thesis. As disabled voices slowly become more prominent in society numerous problematic representations in the media remain conspicuous. To put forward a quote that will be discussed in more detail later in this thesis Edward Said noted that: 'one ought never to assume that the structure of Orientalism is nothing more than a structure of lies or of myths which, were the truth about them to be told, would simply blow away' (1978, p.6). As will be discussed throughout this thesis, Said and other postcolonial writers have noted that the memory of negative representations often stand strong even in the face of new realities. While highlighting the importance of disabled voices should be an essential part of the future of disability studies this thesis will highlight that this should be done in conjunction with, not instead of, a continuing challenge of problematic literary and media representation.

Choosing which postcolonial writers to use for this research involved envisioning which research areas would be adept in examining the major themes presented in the chosen novels. Before focusing on the main areas of language, community and othering, it seemed appropriate to introduce the combination of disability and postcolonialism with a couple of shorter introductory sections. The first writer chosen was Gayatri Spivak and her work on voice and the subaltern. Spivak's essay, *Can the Subaltern Speak?* (1988), redefined subaltern studies (Ludden 2002) as she changed the focus from a working class written about by Antonio Gramsci to a more specific kind of marginalised person who has had their voice completely repressed. It discusses the ideas of Foucault and Deleuze, and asked the titular question 'can the subaltern speak?' and asks why anyone would not want this to happen. It focused on the importance of voice and ensuring neglected voices speak for themselves. This is an issue that is also prevalent in disability studies in relation to the popularity of normate writers and

performers telling the disabled story (Ellis 2016). This introduction to voice in postcolonial theory was an important introduction to build on in the following chapter on language use and indeed in discussions on representation in chapters three and four. While not always considered a postcolonial writer, Todorov's work on Racialism proved to be an important introduction to some of the ways in which difference is identified and interacted with. The comparisons between Todorov's writing, in his book *On Human Diversity Nationalism Racism and Exoticism in French Thought* (1993), and that of the disability theorist Garland-Thompson highlights the similarities in how the colonised Other and the disabled Other are viewed. Additionally, both writers explore how difference is identified and how this leads to different kinds of mistreatment. Todorov's exploration of the influence of community on different ways of interacting with difference is a helpful basis for an exploration of Benedict Anderson's writing in chapter three.

In chapter two, the writers Achebe and Ngũgĩ were chosen for their discussion on the importance of language to one's identity. Longmore noted that 'the language of disability indicates that persons with disabilities are usually perceived exclusively in terms of their disabilities' (1985 p.419). Ashcroft, Griffiths and Tiffin write in their introduction to their language section of *The Post-colonial Studies Reader* that 'language is a fundamental site of struggle for post-colonial discourse because the colonial process itself begins in language' (2006, p.261). They then choose Achebe and Ngũgĩ as their two opening writers on this section. Both of these quotes indicate the power of language in relation to control and identity. While Achebe and Ngũgĩ write largely about native language vs the language of the coloniser, their discussions on language's importance in one's culture and ability to express oneself is very applicable in relation to the primary texts. While ideological rivals in this area, Ngũgĩ and Achebe highly respected each other with Ngũgĩ writing after Achebe's death that 'he was the single most important figure in the development of modern African literature as writer, editor' (2013) which highlights his influence on postcolonial identity in many African countries. The literary discussion between the two was very influential on ideas of language and identity in postcolonial theory. The role of their work in shaping chapter two of this thesis was an essential bridge from Spivak's work on voice to the more identity focused work of Anderson and Said.

Anderson and Said were chosen as the focus of chapters three and four respectively due to the relevance of their work on identity, community and othering, work that mirrors much of the focus of contemporary disability studies especially in the writings of Garland-Thompson, Koppers, Snyder and Mitchell. Anderson's discussion on community and its power dynamics in his book *Imagined Communities* (1983) connects to Linton's argument that people with disabilities are 'bound together... by the social and political circumstances that have forged us as a group' (1998, pp.4-5). Anderson explores this kind of forced together imaginary communities that are created by circumstance as opposed to compatibility and examines the effect that they can have on identity expression. This discussion also allows for a strong tie in to Said's writing about how othering is created and maintained in *Orientalism* (1978). The imagined community is created as the result of this othering. Koppers has noted that to her 'disability culture is not a thing, but a process' (p.4). However, she understands that this is not often the way culture is seen and notes that 'community emerges as many things in the following; as a national label, a marketing tool, as experience, a hope, and a problem' (p.72). Anderson and Said's work examines these ideas by exploring how community is enforced through marketing, cultural representations and labels. Said's discussion's on performance also overlaps with Koppers in her work as a disability performance critic, especially in the book *Disability and Contemporary Performance: Bodies on Edge* (2003). The characters in the primary text are often compelled into performing roles expected of them. Said and Koppers both explore this phenomenon in their work and examine the power dynamics of performing identity.

The first disability theorist chosen for this thesis was Petra Koppers. One of the primary reasons for this decision was that it proved necessary to include the writing of someone with a disability. Postcolonial writers such as Said and Spivak have noted the dangers of examining a community without including the voices of people from that community. Furthermore, disability writers such as Eric Chen (2005) and Koppers herself have reinforced this idea specifically in relation to disability which will be explored in depth in chapter four. Koppers' writing on disability as performance had many comparisons to Said's writing on the Other as performance in *Orientalism* (1978). Her work was foundational in her introduction to both

the writing of other academics and more specifically disabled artists and academics while highlighting the importance of the disabled voice and the issues that can arise from one group speaking on behalf of another. Her text *Studying Disability Arts and Culture: An Introduction* (2014) as well as Adams, Reiss and Serlin's *Keywords for Disability* (2015) and Wappett and Arndt's *Foundations of Disability Studies* (2013) proved a solid basis upon which to build a collection of writing on disability and to understand what writers were influential in the area. *Keywords for Disability* provided a helpful introduction and overview into almost every aspect of contemporary disability studies, as well as to which writers were most associated and influential in each part of the field. *Foundations of Disability Studies* offered a good insight to the growth of disability studies as an area of research over the last few decades and introduced some of the writers who were integral in steering it toward its current focuses. The following sections will focus on the history of disability perception in both the media and general society. It was informed by a number of writers such as Simon Whitaker (2013), Douglas Baynton (2001), Walter Penrose (2015) and Lennard Davis (2006). This collection of work gave context to this study in understanding both how disability has been perceived historically and how the perception of disability and disability representation has evolved over time.

The work of disability theorist Rosemarie Garland-Thompson was a necessary inclusion to discuss how disabled characters are viewed and how this affects relationships between disabled and normate characters. Her discussions on the power dynamics of how a character is seen and perceived is explored in depth in her article 'Seeing the Disabled: Visual Rhetorics of Popular Disability Photography' (2000) and updated in 'The Politics of Staring: Visual Rhetorics of Disability in Popular Photography' (2002). These discussions were instrumental in developing the argument in this thesis about the importance of how characters are framed in literature. Additionally, the writing of Alice Hall in her book *Disability and Modern Fiction: Faulkner, Morrison, Coetzee and the Nobel Prize for Literature* (2012) proved to be a strong example on what an effective exploration of contemporary writing featuring disability should look like. A number of other writers were included to help the application of postcolonial theories into the field of disability studies. The work of Roman Jakobson on linguistics and communication (1960) offered a great way to discuss the importance of language and

communication for representation in chapter two. Additionally, the work of Stuart Hall and Charles Taylor on identity and the effects of misrecognition provided a strong basis in chapter three to discuss Anderson's work on imagined community and indeed help lay the foundation for the use of Said's writing in chapter four.

This section has given an overview of some of the reasons why certain writers were chosen as well as the connections between different texts. The following two sections will expand on the introductory aspects of this thesis by exploring the historical context of disability and disability representation.

1.3 Disability History

Historians grapple with and learn from disability via two distinct but overlapping methods of analyzing change over time. First, they examine the daily and structural lives of those considered disabled and others who interact with them; second, they analyze changing historical conceptualizations of disability, able-bodiedness, and able-mindedness (Burch and Nielson, p.272).

Before beginning textual analysis in this thesis, it is important to give some historical context of both disability studies and disability representation in literature. The following sections will explore some examples of how disability has been perceived and represented in the past so as to better understand the analysis of contemporary texts that will follow. It will interact with both of the methods mentioned above by Burch and Nielson, discussing some examples of the lives of people with disability in historical contexts as well as examining how ideas around disability have evolved over time. This section will examine a number of writers who have attempted to contextualise disability historically and who have been highly influential in contemporary disability studies.

Connor and Ferri (2013) write that people with disabilities have always existed in all cultures. In connection to the upcoming section in this chapter on the subaltern it is interesting to make a comparison to Chakrabarty's writing that 'the declared aim of Subaltern Studies was to

produce historical analyses in which the subaltern groups were viewed as the subjects of history' (2000, p.15). Arguing that if a group does not have a history it is much easier to exclude them from society. Chakrabarty further notes that 'Subaltern Studies historiography... [attempted] to make the subaltern the maker of his own destiny' (2000, p.24). Gramsci, the founding father of subaltern studies discusses that once someone had a history they could no longer be ignored. They became a 'protagonist' (Gramsci 1971, p.647) of history. This is something that disability studies has attempted to correct; the idea that disability or disabled people's stories did not exist or were not important in the past. Writers such as Baynton are proudly revisionist as he attempts to uncover disability in historical contexts where it was not previously considered to have played a part. Benedict Anderson writes, in relation to postcolonial ideas of nationalism and national identity, that 'it became available for pirating by widely different, and sometimes unexpected, hands' (1983, p.67). He is arguing that the nation could not be patented and the concept of it would often be manipulated for others uses and to serve other causes. This can be considered true for disability as its history was often hidden or twisted into a tool for damaging other identities.

The disability historian Penrose offers an interesting example of an older society interacting with disability as he writes about the notion of disability in ancient Greece:

While an ancient model of disability may have been somewhat different from a modern one, the divide between normal and abnormal bodies is not a uniquely modern construct (Penrose 2015, p.507-508).

In ancient Greece disability was treated differently in the societies of Athens and Sparta. In the military focused society of Sparta people who acquired a disability through work or war would be praised if they managed to overcome and continue fighting but were seen as outcasts and weak if they were unable to. In Athens, people with impairments would be given a stipend by the state so as to avoid them begging (p.508). Penrose states that 'deformities or other congenital physical differences were often viewed as markings of disfavour of the gods in the ancient world' (p.510). Although support was given from the state, people with disabilities would still receive much social stigma as it was ingrained into religion and tradition that disability was a punishment from the Gods. Additionally:

Ableism through infanticide, the killing of unwanted, potentially disabled or deformed infants occurred at both Athens and Sparta (Penrose, p.509-510).

Infanticide was common in the country; enforcing the belief that a life that didn't, in society's view, have the potential to be useful to society was not worth living. Penrose states it was believed that 'it is better neither for him nor for the city to remain alive as from the beginning he does not have a good start towards becoming healthy and strong' (p.510). Disability being a burden on the state is a clearly agreed upon belief here. Baynton writes of 'the abnormal signifying the subnormal' and it seems apt here (p.36). Society should not have to support people with disabilities as each birth must benefit both the individual and the state. Interestingly, many contemporary issues in disability studies can be seen in this account. Athens and Sparta struggled between the narratives of overcoming and the tragic narratives. Yet, in Athens where state support helped people, social stigma still made their lives difficult. This example of infanticide highlights a link to the eugenics movement in the 1900's which will be discussed in more detail momentarily. While Penrose may be applying modern ideals to this reflection, he seems to have unearthed many tales of disability that may have been otherwise ignored in amongst larger discussions on religious beliefs or war.

Baynton discusses the history of disability more recently in an American context. He makes numerous connections between discrimination and disability. He discusses how disability has been used as a justification for various forms of inequality:

Disability has functioned historically to justify inequality for disabled people themselves, but it has also done so for women and minority groups. That is, not only has it been considered justifiable to treat disabled people unequally, but the concept of disability has been used to justify discrimination against other groups by attributing disability to them (Baynton 2001, p.33).

Baynton argues, that for communities such as African American people, disability was used as a justification of a lower place in society as it was considered equal to inferiority. He discusses how the most common argument for slavery in America is that African-Americans were perceived as not intelligent enough to compete with white Americans. The concept of disability was also manipulated into an oppressive tool against women. Baynton notes women

had restricted rights due to the perceived 'psychological flaws of women, their frailty, irrationality and emotional excesses' (p.39). He even quotes one politician discussing the 'great temperamental disabilities' women faced (p.40) and citing a doctor in 1891 who noted that over educating women would cause their reproductive organs to be 'dwarfed, deformed, weakened, and diseased' (p.41). Baynton also notes that being gay was considered a mental illness in the 1970's (p.44) a trend of oppression which arguably continues today to many members of the LGBTQI+ community for example those against the Trans community discussed by Jasbir Paur in her chapter 'Bodies with New Organs: Becoming Trans, Becoming Disabled' in the book *Right to Maim* (Paur 2017). The numerous examples here showcase the prominence of disability in this timeframe even though Baynton argues that it is not often seen for what it is. That historians have focused on disability as a form of racism, sexism or homophobia but 'they have largely ignored what the attribution of disability might also tell us about attitudes toward disabled people' (p.48). Having the focus of disability as a tool of oppression as opposed to an oppressed group removes people with disabilities as the 'protagonist' (Gramsci 1971, p.647) of their own history. Though it is also interesting to note how large a catchment of people the term disability has applied to:

When historians do take note of disability, they usually treat it merely as personal tragedy or an insult to be deplored and a label to be denied, rather than as a cultural construct to be questioned and explored (Baynton p.50).

While noting that disability 'has rarely been the subject of historical inquiry' (p.33) Baynton concludes his work by emphasising that 'disabled people have a history, and a history worth studying' (p.50).

To expand further on the notion of, in Baynton's words, 'the abnormal signifying the subnormal' (p.36) it is helpful to explore prominent disability critic Lennard Davis' writings on the notion of normalcy. Davis has written in detail about the history and creation of what modern society deems to be normal. Davis discusses that the concept of normalcy has changed over time and that the notions of 'normality' and 'disability' cannot be believed to be the same in previous eras as it is today. Davis writes that the word 'normal' only entered the English language around 1840 and only came to have its current meaning circa 1855 (Davis

2006, P.3). Titchkosky (2015) writes that a norm is a way of smoothing out difference and quoted Canguilhem as saying:

When we know that *norma* is the Latin word for T-square and that *normalis* means perpendicular, we know almost all that must be known about the area in which the meaning of the terms “norm” and “normal” originated.... A norm, or rule, is what can be used to right, to square, to straighten... to impose a requirement on an existence (1978, p.239).

Davis discusses, in his essay ‘Constructing normalcy: The bell curve, the novel, and the invention of the disabled body in the nineteenth century’, that the modern notion of normalcy and disability may have begun with the mathematical concept of statistics in 1749 which was used to create averages and norms (p.4). He argues that when statistics began being used to analyse people in the 1830’s and 1840’s it led to the creation of normalcy, an idea of what most people are or should be like. He states that Marx may have been a driving force of this, unintentionally, as he made connections to statistics and people in his manifesto with the idea of abstract labour. When statistics were introduced to study people it created a perception of what most people should be and consequently separately grouped people who did not fit these criteria.

Before this, the notion of difference and class did of course exist. But Davis believes that previously there wasn’t a norm or average but an ideal. He argues that the images of Gods and Goddesses in older societies created an ideal for people to strive for. But as these images were unrealistic nobody could obtain them so therefore, to a certain extent, it created a level of equality as everyone was less than the ideal. But Davis continues ‘the concept of the norm, unlike that of an ideal, implies that the majority of the population must or should somehow be part of the norm’ (p.6). Everybody must be placed somewhere on the scale with the majority considered normal or average. Those who were not in the average group, those who were different would be considered ‘deviants’ (Davis 2006, p.6) to the norm. The double meaning here of the word deviant is interesting. Deviant means different but also means negative or bad. Deviant is a word often given to criminals. It is implying that different is bad. People with disabilities would be considered within this deviant group. Whereas the ideal, through its unattainable goals, may have created a level of equality among all people,

alternatively then statistics through its creation of the average or norm created a clear sense of difference, of inequality. It highlighted and created language that could be used to discriminate. It allowed a way to clearly set different classifications for people and created an easy way to separate oneself from the other, to create a more hierarchal society.

This notion of difference that was enforced by statistics was not merely dangerous on a social level. One of the main users of the data were eugenicists (Davis 2006, p.9) who argued for the elimination of disability. Davis cites Karl Pearson who was a leading figure in the eugenics movement and also happened to be head of applied statistics at the University College London. Pearson sought to eliminate those who he deemed unfit which included 'the mentally defective' and 'the diseased from birth or from excess' (Kevles 1985, p.33). Davis additionally highlights another quote from Kevles research which is taken from an officer from a eugenics record office noting:

The calculus of correlations is the sole rational and effective method for attacking . . . what makes for, and what mars national fitness.... The only way to keep a nation strong mentally and physically is to see that each new generation is derived chiefly from the fitter members of the generation before (pp.39–40).

Whitaker (2013) further investigates this developing perception of intellectual disability in western society. He discusses the beginnings of the popularity of the eugenics movement and the factors that affected it. He writes that in 1840's America, fiction often portrayed people with disability as loving and caring but by the 1870's there was an emphasis on the danger of disability and the need to 'protect society' (p.4) from it.

Richards (2006) noted that periodicals in 1840's America such as the Ladies' Repository and the Southern Literary Messenger often published fiction where having a child with a disability was shown to be a positive force for the enrichment of the family. Richards notes these same periodicals in the 1870's were including short stories about the sins of a parent causing disability and how disability created shame for a family. One of the reasons Whitaker suggests for this change was the publication of Darwin's *The Origin of Species* (1859) which put forward

the idea of survival of the fittest. This led to what Whitaker calls 'the fear of the moron' (p.6), that disability was weakening the human race. The application of statistics that Davis mentions seems to combine with Darwin's work to showcase eugenics as a positive movement. That eliminating weaker, deviant or indeed 'unfit' as Pearson was quoted in the last paragraph, was essential for the continuance and advancement of the population. It was not until the atrocities of Hitler's Germany in World War II that this began to change. In the aftermath of the war, the popularity of eugenics declined dramatically. With the rise of individualised rights movements in the 1960's and 70's disability perception changed again (A. Hall, p.7) becoming more popular. However, as will be discussed in the next section, there remains much negativity and prejudice toward disability in western society. The notion of what disability is has changed over time also. Whitaker has noted (pp.53-56) that intelligence is culturally constructed and what disability represents varies through time and culture. However, the difficulty in defining disability has not prevented the negativity toward people with disabilities over the many time periods seen throughout this section.

This section has briefly outlined some examples of how disability perception has evolved. Disability, similar to Anderson's imagined community, is very difficult to define and yet has remained powerful. It has been used as both a label of oppression and a tool to oppress others. Another comparison to Anderson's *Imagined Community* (p.25) is the impact literature has had on the growth of public perception. The following section will explore the evolution of the literary portrayal of disability.

1.4 Disability Narratives

Nobel Prize winner Toni Morrison has written that 'cultural identities are formed and informed by a national literature' (1993, p.15). Morrison states here that identity is not simply reflected in literature but informed by it. Literary representations of disability have been powerful cultural signifiers. This section will examine tropes prominent in a number of older texts such as fairy tales are still seen in many of the contemporary novels that will be studied in this thesis. These connections and influences will be discussed throughout the thesis. This

section will give an overview of some ideas about disability depiction in literature and the popular types of representations that have been created.

Disability has been used throughout history as a crutch upon which literary narratives lean for their representational power, disruptive potentiality, and analytical insight. (Mitchell and Snyder 2000, p.49).

Mitchell and Snyder term this phenomenon 'narrative prosthesis' (2000) and argue that the use of disability to act as a metaphor for social or moral issues has been commonly used and will be explored below. This metaphor has been applied to disability both by making it represent something to be protected or indeed something to be feared. Different bodies have often been used in fantasy literature and fairy tales to denote evil. Margolis and Shapiro discuss this and note that 'authors often used the device of the "deformed" outer body to reflect the "deformed" inner qualities of their characters' (1987, p.19). While this is a common trope in fairy tales and fantasy it is also seen echoed in some of the contemporary texts such as *Wonder* as the characters are often insulted by being connected to popular versions of these stories. Other representations focus on the tragedy and vulnerability of disability. The most commonly cited example is likely that of Tiny Tim in Dickens' *A Christmas Carol* who suffers due to the moral shortcomings of Scrooge and his obsession with money. Dickens story revolved around the conflict of whether Scrooge would see the error of his ways and become kinder. To raise the tension of this story the disabled character of Tiny Tim was included and whether the character lived or died rested on Scrooge deciding to be a better person. Tiny Tim enhanced Scrooges' narrative by being a vulnerable pawn in his story. Additionally, characters with disabilities were never really allowed to be the main character in their texts. More likely as seen in the example of Tiny Tim they were positioned to aid the protagonist. Either by being an obstacle to overcome, as will be shortly discussed in fairy tales. Or alternatively as a character to save or endure a tragedy that will make others reflect and better themselves, as seen in *A Christmas Carol*. As seen in the previous section, disability is primed for pirating by a number of different sources historically. This was mimicked in literature as it was used for many different metaphorical and narrative purposes, few of which ever tried to actually focus on or benefit characters with disabilities or the understanding of disability itself.

Disability was a popular tool used in fairy tales and folk tales. These representations were often inherently negative and sometimes associated with real world disabilities (Schmiesing 2014). 'One of the most popular literary devices for conveying evil or disparagement is 'the twisted mind in the twisted body'' (Margolis and Shapiro 1987, p.19). Villains such as witches and monsters were often instantly recognisable as antagonists because of their hideous looks and often had damaged bodies to reflect their evil ways. The exoticness of disability (Garland-Thompson 2002) makes it an easy symbol to use in a narrative. Unfortunately, this often has real life ramifications. For example, the effects of folk tales such as that of the changeling in Irish mythology. Changelings were considered monstrous creatures who would be put in the place of babies after they were taken by fairies. 'Changelings are most commonly depicted as deformed, disfigured, or physically and intellectually disabled' (Schmiesing 2014, p.15). These characters were partially based on babies with intellectual disabilities. While uncommon there were cases as recent as 1895, with the killing of Bridget Cleary, of people being murdered in fear of these creatures (Bourke 2001). Bridget Cleary's family believed she had been replaced by a changeling and proceeded to torture and kill her in fear of the creature. Garland-Thompson notes that media representations of disability 'often transformed disabled people into "wild men" or other exotic "savages", whose impairments were translated into marks of alien ethnicity' (2002, p.66). Disability became the quintessential other. The easiest way to symbolise a character that was different, that was an outsider. More recently, these kinds of representations have become somewhat less common, or at least less overt. The primary texts studied here do not show characters with disabilities as monsters, although all four novels do show echoes of these previous kinds of representations as they haunt the protagonists. However, much contemporary mainstream representations of disability now highlight either the tragic character or the inspirational story.

As well as using disability to clearly define characters disability representation has other common literary tropes, 'recent narrative work in disability studies examines formulas for their drive toward the solution or curing or killing off disabled characters' (Snyder and Mitchell 2007, pp.6-7). Disability is often seen in literature as an obstacle to be solved or a plot point to be resolved. As noted above, common ways of doing this are either by curing the disability

or be killing of the character. This leads to common tropes such as the Tiny Tim character or the supercrip. Tiny Tim, in Dickens classic *A Christmas Carol*, is often considered a poster child for disability in literature. 'Tiny Tim reinforce[s] the stereotype that people with disabilities are totally helpless and need to be cared for and even cured by the able-bodied' (Margolis and Shapiro 1987, P.21). A character whose main role was to create sympathy and to try and change the heinous ways of protagonist Ebenezer Scrooge. The character is used to prop up the story. Tiny Tim is presented as a mirror for Scrooge to look into and learn about himself. When the final spirit tells Scrooge that Tiny Tim will die he quotes Scrooge's own words back to him 'If he be like to die, he had better do it, and decrease the surplus population' (Dickens p.91). Scrooge is confronted with his own sternness is the face of vulnerability in an attempt to make him a better person. His actions can change Tiny Tim's faith. When Tiny Tim is believed to have died the image which defines him is that of his crutch. His narrative role is to represent a cautionary tale for the effects of society's greed. The Tiny Tim character became so popular as he fulfils both of the conceived popular outcomes mentioned above. His disability is resolved through both death in one reality and by having his difficulties overcome through the kindness of Scrooge in the other. This image of a tragic character who needs the help of others to survive became a popular media image. Barker notes (p.12) that these images were adopted by many charities such as UNICEF to raise money for disadvantaged areas due its symbolic power. Additionally, the popularity of Tiny Tim was in his lack of agency. He 'is observed from the outside, narrated by an omniscient narrator' (A. Hall p.9). Tiny Tim presented a world where disability, or indeed tragedy, could be prevented by the kindness of others. It allowed an easy to spread message about the power of the agency of normate people and the effects it can have. Interestingly, this has been reintroduced in the marketing for the novel *Wonder* and its #choosekind movement (Guglielmi, 2017), where it focuses the themes of the novel on showing kindness to people with disabilities and others.

Thomas Hehir discusses the common tropes of disability representation and argues that 'the belief that disability could be overcome led to the rise of the other dominant image of disability: the inspirational disabled person, or the "supercrip"' (2002, p.4). The supercrip acts as a character who is able to overcome all adversity, overcome disability itself and to inspire

the reader. *Wonder* and *TCI* showcase characters that overcome adversity. José Alaniz (2014) writes that the supercrip is the direct opposition of the pitied Tiny Tim character (p.31). Interestingly, Alaniz in his book *Death Disability and the Superhero* (2014) makes the connection to the superhero world of comic books. He quotes numerous examples of literal supercrips who shed all aspects of their disability (p.36) such as Thor (Lee and Kirby 1962) where a character loses his difficulties walking after transforming into the Norse god of thunder or Iron Man (Lee 1963) where a severely wounded character accesses superhuman abilities through a technologically advanced suit. The list goes on; Doctor Strange (Lee and Ditko 1963), Daredevil (Lee and Everett 1964), and X-men (Lee and Kirby 1963) among others all overcame their disabilities. Jacobs and Jones (1985) noted that this became a trend in comic books as characters could be both flawed and perfect, characters who could overcome their impairment, often in a very short time period. The supercrip could defeat disability. This image became damaging as it often focused on disabilities that often could not be solved in reality and reduced characters to only becoming fully actualised after managing to rid themselves of their impairments. Interestingly, this image was also seen in fairy tales such as Brothers Grimm story *A Girl Without Hands* (1972) where happily ever after could only be achieved after disability was removed from the life of the protagonist, in this case, and regularly, through magic. Once again disability became a narrative obstacle in need of solving. Hehir notes that 'both of these dominant stereotypes of disability, "Tiny Tims" and "supercrips," have at their core ableist perspectives, the failure to accept and value disabled people as they are' (p.4). These images are arguably still very prominent as *Me Before You*, *TCI* and *TRFOC* at times fall into the Tiny Tim trope while *Wonder* and some aspects of *TCI* and *TRFOC* also fall into the supercrip definition.

Barker (2011) discusses that postcolonialism and disability also have a long history of literary association. However, it has often been examining how disability has been used in colonial and postcolonial literature. Barker argues that the child, and in particular the disabled child, was a popular image in colonial literature to represent colonised countries and their inability to care for themselves (p.7). For example, the image of the evil child in Rudyard Kipling's poem 'The White Man's Burden' (Kipling 1994, p.344). Barker quotes Wallace (1994) who argues that this representation of childhood supported 'the parent-child logic of imperialist

expansion' (p.13). This relationship allowed a justification of a dominant power relationship similar to the ones spoken about above in Baynton's writing. In fact, not only does it allow for a justification of such a relationship, it establishes it as both a necessary relationship while also showcasing the coloniser as a kind and caring entity. The coloniser becomes Scrooge showing kindness to save Tiny Tim. Alternatively, Barker notes (p.7) that the child, and indeed the disabled child, are often used in postcolonial literature as a symbol of the new nation; a nation that must struggle and overcome their past. Barker writes that 'disabled children conveniently evoke the themes of development, inclusivity and healing that are so relevant to postcolonial cultures establishing identities and norms' (pp.6-7). The mention of healing in this quote evokes the image of the supercrip. Disability becomes a symbol of colonialism. Prentice (1997) notes that some postcolonial literature uses images of the disabled child as a link 'to the violence of colonialism itself' (p.67). Both colonial and postcolonial literature seem to have colonised disability for its own purposes; seemingly by using the Tiny Tim and Supercrip tropes respectively. Throughout this thesis will explore how these tropes and the way disability have been used historically as seen in the writings of Barker, Baynton and Davis have proved quite damaging to disability narratives in contemporary texts.

Playwright Charles Mee, who himself has a disability, writes:

I find, when I write, I don't want to write well-made scenes, narratives that flow, structures that give a sense of wholeness and balance, plays that feel intact. Intact people should write intact plays with sound narratives built of sound scenes that unfold with a sense of dependable cause and effect; solid structures you can rely on. That is not my experience of the world (2006, p.233).

Mee here challenges the common notion discussed above that disability, or indeed any story, needs to be resolved in a narrative. He argues that the idea of the well-structured narrative is something created by normate writers that may not make sense for a writer or reader with a disability. Disability has been so long used as a tool for other writers that disabled writers and their stories and way of storytelling is often ignored. As Alice Hall (2012 pp.2-5) notes, work by or about people with disabilities can often be considered too disruptive to become mainstream. The popularity of disability in the previously mentioned forms is that it allows normate writers and readers to bring disability closer to the norm. The primary texts studied

here are all written by normate writers and fulfil some of the above tropes. This thesis is focusing on these texts as they are some of the most popular depictions of disability in contemporary literature, even though they are not always positive or authentic depictions of disability. Siebers (2013) has noted that 'the array of disability life writings is now vast, as are the types of disabilities represented by them.' However, these kinds of stories are not as popular as they often do not have the removal of disability at the end.

Writers such as Sinead Gleeson (2019), Christina Crosby (2016) and a wide array of disabled storytellers such as those examined in Couser's *Signifying Bodies: Disability in Contemporary Life Writing* (2009) have produced high quality work based on their own experiences of having a disability. However, public interest in people with disabilities being part of disabled or abled stories seems to be much lower than the interest in narratives about disability. Ellis (2016) has noted the extreme lack of representation in the media of people with disabilities. She notes while citing Breeden (2012) and Woodburn and Kopic (2016) that the percentage of actors with disabilities playing characters with disabilities on television is between one and five percent depending on the definition of disability. Shinn (2014) argues that it is reassuring for audiences to see normate actors return to their non-disabled life after finishing their role. Therefore, disability can remain an Other, remain a role that is played or something that does not have to be a more imminent and permanent part of life. Raynor and Hayward conducted a study of actors with disabilities (2005) which seemed to put forward a census among its participants that it was better not to disclose that they had a disability if possible. This negativity toward the perceived bias against disability in the media seems understandable given what has come before. BBC writer Rodgers noted (2012) that playing a character with a disability is one of the best ways to win an Oscar. Normate actors such as Eddie Redmayne in *The Theory of Everything* (2014), Jamie Foxx in *Ray* (2004), Leonardo Di Caprio in *What's Eating Gilbert Grape* (1993) have all been given praise and awards for the roles as disabled characters in major motion films. They were then able to move on and leave that character trait behind. Film, literature and television showcases disability but not as anything permanent only as a storytelling device.

This section has explored some of the history and tropes of disability in literature and the media to help create a basis to explore the main primary texts throughout the rest of this thesis. It can be seen that disabled characters played a very limited number of roles and that these stories were rarely told by people with disabilities. The previous sections have strived to set a foundation for this research. The upcoming sections will begin an analysis of the primary texts using a combination of disability and postcolonial theory.

1.5 Disability as Subalternity

Subaltern is a term defined by Antonio Gramsci (1971) to represent workers and outcast groups. Chakrabarty (2000) writes that Subaltern Studies owe 'a certain intellectual debt to the Italian communist Antonio Gramsci in trying to move away from deterministic, Stalinist readings of Marx' (p14). Gramsci reinterpreted Marx to try and highlight the issues facing the working class at the time. While initially the subaltern was linked to Gramsci, Ludden argues that 'Subaltern Studies deployed some of Gramsci's ideas', (2002, p.5) but ultimately 'Subaltern Studies reinvented subalternity' (p 15). One of the major influences of this development was the writings of Gayatri Spivak who defined the subaltern as 'a person without lines of social mobility' (Spivak 1988, p.98). It is predominantly through Spivak's interpretation of the subaltern that this section will analyse the depiction of disability in the novels. Gramsci's writings focused on subaltern as either a word for working class or, as Green (2011) argues, as a term for marginalised political groups in Italian history. Spivak's version of the subaltern is a more specific type of oppression. Her understanding of the subaltern seems to have many similarities with the social model of disability in relation to voice as well as societal positioning. The social model of disability discusses the limitations put on people with disabilities due to inadequate social opportunities. Both subaltern studies and the social model of disability also explore lack of voice and the inability to represent oneself. The characters in the primary texts represent many of the aspects of the subaltern such as having their voices ignored, the lack of opportunity to change this and being desperate to be heard. In this section the overlap between subalternity and disability will be examined through low expectations, lack of opportunity and how this affects the identity of the characters. Spivak,

in her work, puts great emphasis on the voice as an essential component of the subaltern. This will be examined through analysis of narrative structure and character speech.

The social model of disability dictates that disability is not simply medical (Kuppers 2014, p.27). It examines the difficulty of being a person with a disability and interacting with the world around you both physically and socially. Disability also often positions someone in a poor societal position as Kuppers states 'the social status of the disabled' takes some from the 'centre to the periphery' (2003, p.24). Subaltern and disabled are both societal positions similar in their linguistic definitions of a lower or negative position; subaltern meaning of lower status, disability meaning negative ability. This position is not easily changed. Spivak has written that 'everybody thinks the subaltern is just a classy word for oppressed, for Other' (Spivak 1992, p.45). But the subaltern runs deeper than that, for someone who is subaltern it is believed that they are inferior and permanently so. A subaltern is not merely oppressed, but oppressed without the possibility of escaping oppression. Gramsci, writes 'even when they appear triumphant, the subaltern groups are merely anxious to defend themselves' (Gramsci, P.207). Being subaltern alters the identity of the subaltern person and puts them in a perpetually defensive position.

Spivak writes 'what must the elite do to watch out for the continuing construction of the subaltern?' (p.295), positioning subalternity as a continuous power dynamic. This links to influential philosopher Michel Foucault's writings on power. While not a postcolonial theorist, Foucault's writing on power dynamics and control can add a lot to the study of colonised groups. Foucault has stated that 'the assertion that power is neither given, nor exchanged, nor recovered, but rather exercised, and that It only exists in action' (1980, p.89-90). Subalternity is being shown as something that must be active and continuous. There are numerous examples in the texts of characters who have limitations put upon them and are separated from the rest of society. *Wonder* features a symbolic realisation of this; in class one day August sees the person beside him struggling with maths. The student had placed his backpack between them as a very real barrier. August states 'the funny thing is, if he hadn't put the backpack between us, I most definitely would have offered to help him' (Palacio 2012, p.55). This example showcases a character actively creating separation. Interestingly it is

mostly harming the aggressor. The bully August is dealing with creates this separation because of preconceived ideas and not wanting to be near August. The social model of disability and subalternity create separations that are not always based in reality but in social understanding or expectation.

Foucault also argues that 'we are forced to produce the truth of power that our society demands' (p.93-94). This leads to society creating its understanding of power in whatever way it needs. In a relational society people look to those worse off to reinforce their own self-worth. Many of the characters with disability in the texts suffer because of this. Interestingly, Christopher in *TCI* follows this trend also. He creates his own self-worth by comparing himself to the other members of his class. He discusses them with a fierce sense of superiority stating 'all the other children at my school are stupid. Except I'm not meant to call them stupid, even though this is what they are' (p.56). The book is rampant with Christopher writing in an insulting and demeaning manner about his other classmates. It seems Christopher builds his self-worth by looking to those around him who he believes to be less intelligent. Christopher's writings on the subject are meant to be ironic. He does not realise that he is in a school with his peers because the world views him just as he views the other students. Spivak argues against groups that fight for equality for themselves while excluding others or that fight on behalf of someone while excluding that person from the discussion (Spivak 1988, p.296). However, this example of Christopher seems to showcase a need for superiority for identity creation. An idea that will be explored in detail in relation to Said's work in chapter four of this thesis.

The novels are rife with low expectations and limited opportunities for characters with disabilities. In *Me Before You*, Louisa, early in her career as Will's carer, is afraid to be left alone with Will as she wouldn't know what to do. She never thinks to ask him. Will becomes aware of this and sarcastically states 'I can't possibly be expected to know anything about my own care?' (p.87). Will is someone to be cared for, not someone to take part in the activity of caring. In *Wonder*, the mother of one of August's classmates, attempts to get him removed from school due to the baseless assumption that he has profound learning difficulties (p.206).

In *TCI*, Christopher is constantly set limitations, for example, he is not allowed to take mainstream school exams even with proof that he is capable (p.56-57). These are a small selection of the many examples of limitations or low expectations put on characters with disabilities in the novels. Spivak has stated in an interview that 'many people want to claim subalternity' (Spivak 1992, p.47). The characters in the novels do not claim to be subaltern but seem to have a kind of subalternity thrust upon them. The assumptions made above about Will above challenge his ability for self-representation and those made about August and Christopher have the potential to severely limit their opportunities in life.

One of the ways the social mobility of the some of the characters is challenged is in educational settings, specifically in their school lives. Christopher and August's educational progression is challenged in both of their respective novels. In each case the boys are not hindered by their abilities but by the perceived effect they will have on their classmates. In *Wonder* a classmate's mother tries to get August removed from school because she feels her son's education is being damaged by his presence. August has no difficulty with his classwork and is in fact considered one of the brighter students in his class. His classmate's mother is trying to use his disability as an excuse for her son's own shortcomings in emotional maturity (his bullying of August led to him receiving backlash from friends). As Christopher previously looked down on others to help solidify his identity, this mother is trying to do the same. She wants to punish August for her son's behaviour. The subaltern is used as an excuse for the shortcomings of one's own. It is not the fault of the mother's child in dealing with difference it is August's fault for being different. However, it could have been August who missed out on educational opportunities because of these views. The principal of Christopher's school does not want to allow him take his A grade exams as she argues it is special treatment that others students would then want also (p.56). The limitation of mobility here is two-fold. Not only does the principal not want to give Christopher the option to progress, her reasoning is out of fear the other students will do the same thing. The image of a school principal not wanting her students to excel academically if they are capable seems bizarre. However, these are the kind of stories that novels tell, characters who are constantly challenged in their attempts to advance. The examples may not always be so blatant but they are consistent.

Christopher, in *TCI*, outlines his hopes and dreams for the future:

Then, when I've got a degree in maths, or physics, or maths and physics, I will be able to get a job and earn lots of money and I will be able to pay someone who can look after me and cook my meals and wash my clothes, or I will get a lady to marry me and be my wife and she can look after me so I can have company and not be on my own (Haddon 2003, p.58).

This seems like a relatively realistic set of goals to aim for. However, for a character with an intellectual disability, a character who could be considered subaltern, these goals will not be easy to reach. Christopher's social skills, his emotional responses and his general behaviour are not often easily accepted by those around him. Even though Christopher does manage to overcome adversity and take his A-levels exams in the novel it will likely only get increasingly difficult after that. Christopher has stated he does not like being away from home (p.163) or having too many people around him (p.245). This will make college life difficult. The world is not designed for Christopher, some parts may adapt but he is always positioned as behind others. Most tragic and problematic though is his dream of getting married. People with disabilities are often seen as needing to be protected. Disability and romantic relationships are not something that is easily accepted. Garland-Thompson who has worked in examining how bodies are framed in media photos noted that 'women with disabilities are often stereotypically considered undesirable' and 'asexual' (2005, p.1567). There is also a belief that someone in a relationship with a person with a disability must only be there to take advantage of them. The 2016 Irish film *Sanctuary* dealt with this issue highlighting the difficulties two people with learning difficulties had in having a sexual relationship. This comedy film received praise at film festivals, yet its comedy lay in showcasing the severity of society's discomfort with disability and romantic relationships. Sex is often not considered something that should be part of a life with disability. Christopher is seen as someone strange and unpredictable. He invokes predominately only two emotions in passers-by; sympathy or fear. Whether it is sympathy for his condition or fear of not being able to predict what he will do, neither of these emotions leaves room for romance. Protecting someone from romance is actually protecting the notion of the subaltern. As Spivak herself writes 'who the hell wants to... protect subalternity?' (Spivak 1992, p.46). Christopher is seen as someone to be protected, not an actual person. What is being protected is an artificial state of being.

1.6 Subaltern and Voice

One of the dominant discussion points in subaltern studies is voice. Spivak's seminal essay was titled *Can the subaltern speak?* The argument of protection vs freedom mentioned above intertwines heavily with this discussion. If someone is not heard they cannot enter into a conversation, a debate, an argument for their rights. If a person is not heard, Spivak argues that takes away their 'humanity' (p.45). In *Wonder*, when August begins school, he is nervous and won't speak. Jack, one of his classmates tells him 'you're gonna have to talk' (Palacio 2012, p.41). Here Jack is trying to explain to August, that to fit in, to be part of the student body, he needs a voice. This sequence occurred after Jack and a few other children were giving August a tour of the school. Julian another boy began asking questions about August's face. Instead of answering him August just remained quiet. The other children spoke for him but August did not enter into the conversation. He did not speak for himself and thus missed the opportunity for self-representation. However, August's behaviour has been learned as he has been taught not to fight back. In a 1992 interview Spivak responded angrily toward the idea of people claiming she is not allowing the subaltern to speak as she is speaking for them. She argues that 'in fact, every accusation that G. C. Spivak is not letting the bloody subaltern speak is a proof that the subaltern cannot speak,' (Spivak 1992, P.44). Here Spivak is trying to defend herself. In her writing she tries to get the subaltern to speak for themselves. She uses their stories and writing to try and have their voices heard even if they are framed within her own voice. Perhaps similarly to how some of the novelists being studied here do. Mark Haddon has stated that he has experience working with people with disabilities (Powells.com 2006) but also stated it was a long time before writing *TCI*. This seems to be the closest connection any of the four novelists have to disability in real life. Palacio in an interview with NPR.Org noted that her novel was inspired by a chance meeting at an ice cream store with a girl with facial differences (NPR Staff 2013). Haddon and Palacio were seemingly inspired by the stories of others. These novels are a form of advocacy, channelling their voice and stories through someone who is more likely to be heard. Palacio even proudly accepts the title of advocate in the above interview. Spivak does arguably go against her own teachings in her writing. But

perhaps it is necessary in the short term, that the work of Spivak and the novelists exist to create an awareness and better understanding of the issues. But still it is the subaltern who must claim their own voice. It is not something they can be given. Spivak notes in an interview that the thing 'which is the worst, that is, you don't give the subaltern voice. You work for the bloody subaltern, you work against subalternity' (Spivak 1992, p.47). Here Spivak states directly and passionately that if a subaltern is given a voice they do not leave subalternity. They must take it for themselves, only then can it truly be their own voice. Spivak argues that you work for the subaltern to help them make that change. She is trying to situate her work as for the subaltern thus trying to protect her own work and in theory that of the novelists studied here.

Moyes, in her novel *Me Before You* makes an unusual choice for representing her character Will. The novel features numerous narrators whose lives are all focused at this time on Will. The narrator that is conspicuous by his absence is of course Will himself. This may be Moyes' attempt to try to highlight the fact that disability representation rarely includes people with disabilities. The only glimpse Will has of self-representation in his letter to Louisa after his death is perhaps an extreme and morbid example that the subaltern only gets a voice after death. This is similar to Spivak's essay where she writes about a young woman, Bhuvaneshwari Bhaduri, whose voice could only be heard through the action of suicide. Bhaduri planned her suicide to occur at the time of menstruation as Spivak notes that otherwise it would have been dismissed as a young woman ashamed of getting pregnant. Spivak notes that Bhaduri wanted to displace 'the physiological inscription of her body' (p.313). Bhaduri fought to not have her body be politically twisted to define her narrative. This fear of not only having life but even death controlled by other people is very relevant to Will's story. Will has been rejected from his own life, his own narrative and he is unable to accept this. Camilla recalls Will first asking to die, telling her:

I don't want to live like this, Mother. This is not the life I chose. There is no prospect of my recovery, hence it is a perfectly reasonable request to ask to end it in a manner I see fit (Moyes 2012, p.140-141).

When Will understands that he cannot return to his previous life he gives up. He believes his old life is the only one worth living. It is in this moment that Will completely rejects his position as subaltern while also fully becoming it. As his most adamant request is rejected. Gramsci writes that 'subaltern groups are always subject to the activity of ruling groups' (P.207). Will's life has become subject to the will of his parents, of his carers. It is only through a, very difficultly achieved, failed suicide attempt he convinces them to agree. However, it is still his parents who must agree to it for his wishes to be completed.

However, the two instances above of Will and Bhaduri's situation pose a large number of differences. While Spivak's discussion of representation provided an insight into suicide and voicelessness Will's situation in text is of a very different social position than that of Bhaduri. Will's identity was challenged by his disability however Bhaduri's live was affected by a more complex layering of identity. As a wealthy white male in western society Will should have more options than Bhaduri. In essence, as will be discussed further in chapter three, binary identities can be limiting and problematic. Will and Bhaduri may both have their lives controlled by others but their struggle is not the same. One colonised subject will have a different experience to another. Ghai has more specifically commented that 'the disabled/non-disabled divide is also extremely knotty and theoretically limited' (p.275) Will is shown to struggle to have his voice heard and has his identity challenged however his wealth and cultural privileges in relation to other identity markers cannot be ignored. Homi K. Bhabha (1990) has discussed "'in-between' spaces' (p.2) of identity and how these can be created by 'moments or processes that are produced in the articulation of cultural differences' (p.2). For Bhabha identity is fluid. It is in these moments that we can find a link between Will and Bhaduri, while Will has much more options than Bhaduri, there are moments where he exists in the same place of helplessness, where suicide is seen as the only option. Additionally, the interesting point to note here, is that Will's understanding of disability makes him believe he faces the same position as Bhaduri and that for him, his wealth and relationships are not actually worth living for due to the limitations of his disability.

Ghai has noted that Spivak has received criticism for at times focusing too much on voicelessness as opposed to how voice might be achieved (p.276). However, Spivak (1990) argues that it is better to deconstruct stories of voicelessness and that it can lead 'to better practice' (p.122). The conflict is notable as it mimics the issue seen in *Me Before You*. Just as Spivak may be criticised for focusing too much on situations where people were not heard Moyes constructs her novel around the Tragedy of Will not having his voice heard as he is the only major character who doesn't get to tell part of the narrative. While Ghai's worries are well founded in relation to analysis of real people, Spivak does offer much to literary criticism understanding the representation of voicelessness and how agency and voice can interact as depicted by novelists. Ghai notes that 'Spivak's argument is that elite or hegemonic discourses are 'deaf' to the subaltern, even when s/he does speak or resist' (p.276) Bhaduri's death is a final act of resistance while Will's suicide is actually an acceptance of his wishes. Yet Bhaduri fears her suicide may be used for covering her voice believing it would be attributed to an unwanted pregnancy. Will's suicide does also end up being a launching point in the ongoing trilogy of novels about Louisa. While Will and Bhaduri have very different backgrounds and lives there link is that their final act of agency, of having their voice heard will be attempted to be manipulated by others into a different story.

Spivak also discusses the oppression that she herself experienced in the form of sexism, trying to make connections with certain power dynamics that can lead to subalternity. 'The worst thing about sexism, that it makes you believe what is being told' (Spivak 1992, p.34). The most powerful tool of subalternity and arguably most forms of oppression is not its ability to forcefully oppress people but rather its ability to convince the oppressed to give in to oppression wilfully. What frequently occurs throughout the novels is examples of characters who have given up trying after being taught to fail, becoming discouraged and beginning to believe that they actually are less able. The example of August not defending himself against Julian is arguably because he does not believe he should or even can. Additionally, Ben, in *TRFOC*, after working with Trevor for a number of weeks states 'I'm downright annoyed that Trev doesn't take more risks, that he wilfully imprisons himself inside of his routines' (Evison, p.7). Spivak continued her writing on sexism writing that 'you see, so that to an extent this had led to great intellectual insecurity. Yes, I was quite prepared to believe that I was not

good enough for the best institutions. And, to an extent, I still feel that way' (1992, p.34). In a similar manner, she discusses her fear of taking power or being intrusive, feeling at times it would be better to do nothing in fear of upsetting others. Trevor has placed himself in a very limited routine, hating having to leave his house, due to negative past experiences. When Ben finally convinces him to break the routine things are only made worse as Trevor's chair scares a small child in a diner (P.30-31) and Trevor falls deeper into the belief that the world cannot accept him. Ironically Ben is 'annoyed' at Trevor while he does the exact same thing. Ben cut out everyone from his own life after the accident the cost him his family, he writes about his best friend that 'for a year he tried to coax me to dinner at his house' (p.16) but Ben would turn him down. Both Ben and Trevor limit themselves before the world is able to. They fear how or if they will be accepted. Trevor' fear of society comes from experience, from being constantly rejected by the world, from his experiences of children fearing him and from so many areas being inaccessible to him. Eventually he does the work of the oppressor for them, keeping himself down.

Christopher and August prove an interesting contrast when discussing subaltern status. The aspects of social rejection and lack of opportunities associated with subalternity come from different places for each character. Christopher takes on elements of subalternity because of his behavioural issues and is often considered normate until his actions give him away, for example when he began to threaten passengers on a train out of fear (Haddon 2003, p.226). August is subaltern because of his look but on occasion where he manages to hide his looks his behaviour allow him to present as normate. Both characters enter in and out of the subaltern sphere. August writes about his favourite time of year being Halloween, stating 'for me, Halloween is the best holiday in the world' (p.91). At Halloween time, August is allowed to dress up and interact with the world on an equal level. It is the one time of the year where people do not judge him on his appearance. Christopher is unable (or unwilling) to hide his behaviour, but many people assume he is normate at first. August and Christopher receive brief escapes from subalternity. Though these brief moments are not true escapes according to Gramsci who wrote that 'only "permanent" victory breaks their subordination' (Gramsci 1971, p.207). To cease being seen as subaltern for a period of time does not lose a subject subaltern status. There has to be permanent change. When August returns to not wearing a

mask he again becomes subaltern. When Christopher's different behaviour is identified he returns to being subaltern. Christopher and August are taking on the role of a non-subaltern, they are not losing their subalternity. The critic El Habib Louai writes that it is difficult if not impossible to define a subaltern group in any given moment and believes this is why Spivak argues that the subaltern is truly 'situational' (2012, p.7). This makes it difficult to really pin down subalternity or who can be considered subaltern. Also, the experiences of these characters are not equal. Will and Trevor's disabilities may be similar; however, their lives are very different as Will comes from a very affluent family. This challenges whether Will can be considered subaltern as money can remove some of his obstacles (through purchasing expensive technological aids and affording better care for example) and allows him opportunities that Trevor cannot have. As it will be discussed in chapter three's discussion on Anderson's *Imagined Communities*, there are many difficulties with largescale grouping and trying to connect the experiences of people based on a single connection such as nationhood or disability. These characters might not fully fit with the notion of subalternity but there is much overlap.

The social model of disability and notion of the subaltern are very similar in many ways, in relation to low expectations, oppression, and loss of voice as well as the effects these have on identity. This is the first example in the thesis of how postcolonial study can help inform disability representation. The characters may not fit fully into the notion of the subaltern but there is much overlap that can advance the understanding of the area and the power dynamics of oppression. Understanding the subaltern is an essential beginning in using postcolonial studies to help investigate texts about disability. Next Todorov's writings will be explored to further help understand the idea of difference.

1.7 Racialism; Identifying and Interacting with Difference

'Human diversity is infinite' (Todorov 1993, p.1) is the opening line of Tzvetan Todorov's book, *On Human Diversity Nationalism Racism and Exoticism in French Thought*. It seemed apt to also make this the opening line of this section on interacting with difference. The previous

section on the subaltern explored the treatment of people with disabilities by the normate population in the novels. This section will examine more closely the relationship between normate people and people with disabilities and how society interacts with difference. Todorov's discussion on the understanding and treatment of difference has much to add to this thesis. While Todorov focused on different nationalities and races of people much of his ideas are applicable to a normate/disabled divide. His book is broken into five sections: The Universal and the Relative; Races; Nations; Exoticism; and Moderation. The notions of universality and relativism will be explored in this section. Todorov's ideas of racism (a behaviour) vs racialism (the study of difference) (1993, p.91), will also be discussed in relation to race and nationalism. His writings on the exotic will offer an interesting comparative study to disability theorist Rosemarie Garland-Thompson's writings in her article the 'Politics of Staring' (2002). Finally, Todorov's chapter labelled moderation details the practicality of some of these ideas and how one can situate themselves within their own identity.

Todorov discusses the notion of ethnocentrism and how it consists of 'establishing of the specific values of one's own society as universal values' (1993, p.1). The problem here is that values of a society are rarely united even within the 'smallest group' (Anderson 1983, p.6). Attempting to apply one's own values onto others creates expectations for others. If these values are not mirrored this can create tension or, as Todorov discusses, hierarchies. Todorov writes that identifying difference often leads to both superiority and inferiority (p.5-6) and the latter is seen to be common in relation to characters with disabilities in the novels. For example, in *Me Before You* Louisa has a conversation with her boyfriend Patrick about Will (p.68). Patrick discusses how he believes Will's life isn't worth living. Here difference is seen as lesser. August (p.41) and Christopher (p.33) often come across people who assume they are stupid. An interesting example of recognising difference is in the relationship between Trevor and his father, Bob, in *TRFOC*. Bob left Trevor and his mother when Trevor was young as Bob was not able to handle having a child with a disability. Trevor refuses to have a relationship with his father throughout his life due to this until an accident causes his father to use a wheelchair also. When Bob is forced to live with disability Trevor sees him in a different light. The two characters are at no point in the text able to connect as normate and disabled. Only when they both have a disability are they able to interact. While Todorov noted

the difficulty in recognising difference, he remained positive, stating that ‘what is common to human beings is not any particular trait... but their freedom, their capacity to transform themselves’ (1993, p.21) Garland-Thompson’s also noted that disability showcases humanity’s ability to adapt and change (2012). While Todorov and Garland-Thompson seem to see a positive approach of people coming to accept difference this is represented as very difficult to achieve in the texts as the protagonists struggle to be accepted by their peers. In relation to Todorov’s second section it may seem that racism is more common than racialism in the texts.

Todorov notes the difference between racism and racialism stating “racism” [is] a term designating behaviour and “racialism” a term reserved for doctrines’ (1993, p.91). He argues that racism is an active behaviour identifying difference and reacting to it in a certain, usually negative, manner. Racialism is the scientific method of identifying difference and investigating how best to interact with it. Todorov states that for racialism to be possible, to be able to study difference, it must incorporate five doctrines. The first of which is the belief in ‘the existence of races’ (Todorov 1993, p.91). As noted in the previous paragraph, disability is seen as an identity marker. Characters with disabilities are treated and identified differently. This fact the Christopher in *TCI* attends a special school separate from most students his age highlights that disability is considered a prominent and influential identity marker in the texts. The second doctrine is the belief in ‘continuity between physical type and character’ (p.92). In *Me Before You* there are initially many expectations of Will by Louisa and Louisa’s family with their only knowledge of him being that he uses a wheelchair. Lou’s mother asks how Louisa will manage because Will ‘can’t communicate’ (Moyes 2012, p.33) believing he will not be able to speak. The other family members make jokes believing he will have a communication device associating him to Stephen Hawking and mocking his imagined computerised voice. This leads Louisa ask ‘why would being in a wheelchair mean he had to speak like a Dalek?’ (p.34). The assumptions here are based on the idea that if someone has difficulties physically, they are likely to have intellectual difficulties also.

Literature is possibly partially to blame for this as Margolis and Shapiro have noted there has long been a history in disability representation of showcasing the 'the twisted mind in the twisted body' (p.19) for example images of witches and monsters in fairy tales such as those in Grimm's Fairy Tales (1972). Will is aware of this. When he first meets Louisa, he takes on the role of Christy Brown, an iconic movie portrayal of disability from the 1989 film *My Left Foot*; 'he let out a bloodcurdling groan. Then his mouth twisted, and he let out another unearthly cry' (p.40). Will carries on this impersonation for a couple of minutes until he ends the act once Louisa introduces herself. Then Will's mother explains 'I'm afraid you just got Will's best Christy Brown Impression. You'll get used to him. His bark is worse than his bite' (p.41). Will becomes upset at this stating that 'you don't have to talk across me. My brain isn't paralysed. Yet' (p.41). Will takes on the role of Christy Brown in his first meeting with Louisa because he believes this is how everyone sees him initially. They see his physical body and assume a certain kind of character. He believes this to be a popular portrayal of disability such as Christy Brown. He may not have been wrong considering Louisa and her family were expecting Stephen Hawking. Interestingly, a near identical scene occurred in the movie adaption of *TRFOC* when Trevor first meets Ben although it was not in the book once again highlighting Todorov's point.

The third doctrine mentioned by Todorov is 'the action of the group on the individual' (Todorov 1993, p.93). Here Todorov believes there must be a certain manner in which the individual is treated by the majority due to their race/difference. Arguably the most consistent action seen on characters with disabilities in the texts is that of control. In the texts, people with disabilities are constantly having their agency challenged by the actions of those around them. Christopher's goals in life are constantly challenged as people in his life don't want him to become an astronaut (p.33), or do his final exams (p.57), or even to know the truth about his own mother (p.143). Trevor's mother will only allow him eat particular kinds of food (p.29) and challenges his idea to go on a road trip (pp.129-130). August has most of his decisions made for him by his parents though this is more understandable due to his age. The most severe example is of course Will not being allowed make the decision about ending his life (p.141). These characters are treated in a certain manner because of their disabilities. Additionally, August (p.27, p.52), Will (p.193) and Trevor (p.30) have all had instances where

they are looked at strangely when first meeting someone and how people often either stare or avoid eye contact. They are all treated similarly by the people they meet despite differences in disability, age and societal position.

Todorov's fourth doctrine is a 'unique hierarchy of values' (Todorov 1993 p.93). Here Todorov states that a racist does not simply believe that 'races differ; he also believes that some are superior to others' (p.93). A belief in hierarchy is evident throughout the novels. As has been mentioned above normative characters often believe they know what is best for characters with disabilities and try to dictate their lives for them. People with disabilities are seen as different and lesser. Even architecturally, there is not room given in the world of the texts for those with disabilities. For example, in both *TRFOC* (p.30) and *Me Before You* (p.182) there are areas not accessible by wheelchair. The world is built for the needs of the normative and the needs of those with disabilities are not taken into consideration as they are not deemed as important. The fifth and final of Todorov's doctrines is 'knowledge-based politics' (1993, p.94). As Koppers has stated understanding oneself is done through discourses of knowing, and disability is one such discourse (2003, p.21). The politics of disability are devised by seeing disability as different. This idea can be seen as classroom politics in *Wonder*. The kids in August's school create an understanding of him through games. They frame his position in the school society by playing a game where if someone touches him, they will acquire his disability (p.89). This microcosm of disability representation shows how it can be understood on a larger scale. Assumptions create political and social realities. Disability can be seen to have all of Todorov's required doctrines to be considered racism which may indeed lead to the mistreatment toward the characters with disabilities in the books.

Todorov argues the racism can be used as a justification of the mistreatment of people or even for identifying certain races as superior and scientifically validating that lesser races should be eliminated (1993, p.94). The representation of disability in the novels does not showcase characters who want to eliminate people with disabilities but it does showcase a world where characters with disabilities are made to struggle. Characters live in a world not

designed for them as has been noted in terms of accessibility. There are examples in the texts of characters attempting to hide those with a disability or erasing them from the public eye such as when Julian's mother edited August out of the school picture (p.193, p.196). August is being defined by his disability as he will not look good in a photo. Disability is seen as a fixed identity just as race is in Todorov's work. However, Omi and Winant argue this should not be the case for race:

The effort must be made to understand race as an unstable and 'decentered' complex of social meanings constantly being transformed by political struggle (1994, p.11).

This effort is not made though for disability in the texts. Characters are trapped in a fixed identity as their way of life is looked down on, ignored or even has attempts at being erased. When Will takes on the role of Christy Brown, as mentioned above, it is because he may feel this is all the world will allow him to be. Another result of the superiority that can come with racialism is Christopher's father not telling him the truth about his mother in *TCI*. Christopher's father Ed told Christopher that his mother had died after she left the family due to feeling incapable of taking care of her son. Ed did this because he felt he knew what was best for Christopher, stating 'I did it for your good, Christopher' (p.143). Ed who becomes Christopher's sole carer after his mother leaves, overextends his power over his son. He believes because he is Christopher's carer he is allowed to decide what Christopher should and shouldn't know about his own life. Christopher has lost agency over his own life as those around them feel they have the right to make major life decisions for him. Ed believed he had the right to make decisions for Christopher, to take away his agency.

1.8 Viewing Difference

There are a number of different ways that disability as difference is viewed. One of those methods, which Todorov identified in his book in section four, is as the exotic. This overlaps strongly with Garland-Thompson's paper on 'The Politics of Staring' (2002). Todorov states that exoticism defines someone 'exclusively by their relation to the observer' (p.264) and that it positions identity as 'purely relative' (p.264). Garland-Thompson writes that 'the history of disabled people in the Western world is in part the history of being on display, of being visually

conspicuous while politically and socially erased' (2002, p.56). People with disabilities are positioned as being constantly seen, but not as people, only as images or as a mirror, a two-dimensional image for normative people to compare themselves to. In relation to exoticism, disability holds a somewhat paradoxical place. Todorov states that 'the best candidates for the role of exotic ideal are the people's and cultures that are most remote from us and least known to us' (p.265). People with disabilities are often considered different but they also come from within every community. There are both known and unknown. Perhaps it is this combination of making the familiar strange that has made disability such an alluring visual subject. This idea will be explored further in chapter four in relation to Said's writing on othering. Currently, Garland-Thompson's writing about the many ways which people view disability will be expanded upon. She lists four 'visual rhetorics' (2002, p.58) that are useful for understanding how disability is often framed.

The first visual rhetoric is the 'wondrous' (2002, p.59) and 'capitalises on physical differences in order to elicit amazement and admiration' (p.59). For example, the child examining Trevor's chair with awe in *TRFOC* (p.31). Disability is here seen as something to marvel at. The second visual rhetoric is 'the sentimental' this situates the subject as a 'victim' who invokes either 'pity' or 'inspiration' (p.63). This is a long running trope in disability representation. Tiny Tim in *A Christmas Carol* may be the most commonly used example of this. In *Me Before You* Louisa, Will and Nathan go to dinner together while at an event at a race ground. Louisa describes the reaction of people at the restaurant when they struggle to get a table 'the gaze of the diners swept over us and travelled past me to Will, where they clouded with faint pity or distaste' (2012, p.192). Although Louisa, Nathan and Will are all in an awkward situation being unable to get service, the eyes of the diners all float towards Will. They see him as the prime victim in this situation. The word gaze here seems to offer some power to the diners as well. That they have to power to structure his place in the situation. Garland-Thompson and Todorov argue the power of observation allows the observer to create their own reality. Whether it is a sentimental one, a wondrous one or the third visual rhetoric 'the exotic' which according to Garland-Thompson situated the person with disability as 'distant' 'sensationalized' and 'entertaining in their difference' (p.65). Garland-Thompson believes this type of staring elicits a certain fascination, that people are entertained by disability. In

Wonder, when August gets confronted and attacked by kids in the forest while on a school trip, the gaze of his attackers seems to be very fitting with the visual rhetoric of the exotic. The children are shocked but then entertained by August. They laugh at him and mock him and compare him to sensationalist media representations of ugliness such as 'Gollum' (p.312), the creature from 'The Lord of The Rings' franchise or the monstrous 'orcs' (p.312) from the same series. The children see August as something designed to be looked at for their entertainment.

The fourth and final visual rhetoric is that of 'the realistic' (p.69). This view, Garland-Thompson argues, works at 'normalising' and 'minimizing' disability (p.69). This view can be seen to be ignoring the disability or trying to control it or as Garland-Thompson states 'realism domesticates disability' (p.69). It can be argued at times that Louisa attempts to do this in her relationship with Will. That when she attempts to give him the same opportunities he had before acquiring his disability such as being active and going on holidays she hoped 'that would change Will's mind' (P.367) on his negative perception of his disability. However, removing certain limitations was not fulling understanding the difficulties Will had with his new identity, something that will be explored more throughout the thesis. Whichever rhetoric is used, these methods of framing disability can all prove damaging to the opportunity for self-representation for the characters. Staring can be dangerous as people frame their understanding of a person by viewing them as a two-dimensional image and forcing their assumptions on said person. While this is a common trait; using assumptions to fill in gaps in knowledge, it is not necessarily a positive one for the people who are being looked at (Morris 2002). While the fourth visual rhetoric avoids this exoticism it still frames characters through their disability and often tries to ignore disability rather than engage with it.

Todorov's concluding section tries to offer solutions to the problems identified when dealing with difference. Todorov identifies the many ways people have studied difference and examined some of the possible solutions offered such as those of the universalist and the relativist. His conclusion seems to be that the only solution is complete unity. Perhaps a similar permanent solution to Gramsci's 'permanent victory' (1971, p.207) as the only way to break subalternity. Todorov notes that when identifying and interacting with difference unity

must take priority and that 'the absence of unity allows exclusion, which can lead to extermination' (p.389). If people do not focus on their similarities as opposed to their difference's equality is impossible. This notion links with Donnelly's writing on human rights:

Human rights, following the manifest literal sense of the term, are ordinarily understood to be the rights that one has simply because one is human. As such, they are equal rights, because we either are or are not human beings, equally (2007, P.282).

However, focusing on the similarities and seeing everyone as equal may lead to differences being ignored which need to be recognised as seen in Garland-Thompson's fourth visual rhetoric. If Will and Trevor's disabilities are not recognised, for example, this would prevent the change needed to better accessibility to the diners mentioned throughout this section. Their differences need to be incorporated as opposed to ignored. The notion of a permanent victory or true equality in society may be both idealistic and dangerous if not carried out properly. Todorov himself realises this as he continues to argue that a perfect society is not an end goal but a continuing process. He states that:

The best regime in the world is never anything but the least bad, and even if it is one under which we live, everything still remains to be done (Todorov 1993, p.399).

This seems true in the case of the novels as at their end there is still much to be done. For example, in *Wonder* August receives recognition from his school but notes that this may be more for the value of others than for himself. August's journey feels like it has taken a positive step in a much longer journey.

Todorov's writings have helped showcase the issues with identifying difference and how it is easy for this to lead to discrimination. This connected with Garland-Thompsons writings on the ways difference can be identified through how disability is visually framed. These ideas around understanding difference will be important as the thesis goes more in depth in the writings of Achebe, Ngũgĩ, Anderson and Said. Difference as a method of identifying and creating identity seems to be a pivotal aspect of disability representation.

1.9 Conclusion

This chapter has introduced the primary and secondary texts as well as many of the arguments that will be made throughout this thesis. It has discussed through a number of examples the historical context of disability and disability representation, showcasing how popular representation has evolved and changed over time. The section on subalternity highlight a number of issues such as voice and authenticity. Areas that will be explored in more detail in following chapter on language. Todorov's writings opened up a discussion on living with difference that will a foundational argument throughout this thesis in particular in relation to the work of Anderson and Said in chapters three and four respectively.

Chapter 2-The Language of Disability

2.1 Introduction

The choice of language and the use to which language is put is central to a people's definition of themselves in relation to their natural and social environment, indeed in relation to the entire universe (Ngũgĩ 1986, p.4).

Ngũgĩ wa Thiong'o's declaration of the power of language to create reality and change perception has numerous ramifications on the reading of literature about disability. The medical model of disability, discussed in chapter one, constantly links disability with labels and descriptions. The choice of words used in these novels to describe characters with disabilities effects their self-identification and social standing throughout the narratives. The ways in which the novelist, through description and character dialogue, uses language to create an understanding of disability will be explored here. The literary discussion between Achebe and Ngũgĩ about the power of language is one that is very relevant to disability studies and mirrors in many ways the issues around disability representation. Their argument about the purpose and power of literature will also be examined. Additionally, their ideas on the question as to 'what African literature is' will be transposed to this research by applying it to the question as to what is the nature of disability literature. This chapter will examine the language used around disability within the novels and how this leads to the development and understanding of the protagonists. It will analyse how the protagonists use language for self-expression. Foucault's discussions on power will be used to examine the power dynamics of language usage in the texts and how language is often used to oppress. This section aims to explore the language used to identify and describe disability, the relationship between the character being described and the describer and how language can affect the perception of characters in the story. It will make use of Roman Jakobson's communication model to examine the relationship between characters. Finally, it will examine the role the written word, technological advances and the internet play in changing communication for the characters in the texts.

2.2 Word Meanings and Associations

In the opening quote of this chapter Ngũgĩ states that 'the choice of language' is central to 'a people's definition of themselves' (p.4). This highlights that both words themselves and how they are used have power. Words associated with disability are used in the texts to identify characters, usually negatively, and to create a certain expectation. This section will explore the way in which words are used within the primary texts, along with the meanings and associations behind them.

The word 'disability' can be broken down into two parts; the prefix 'dis' and the word ability. 'Dis' is used here as negative, not only cancelling out the positive associations of the word ability but suggesting the opposite. If someone has a disability it is something negative, something that impedes them. Someone with a disability is someone, as indicated by the word, with negative ability. This word will immediately position them as less able than anybody not labelled as such. Ngũgĩ states that 'language, any language, has a dual character: it is both a means of communication and a carrier of culture' (1986, p.13). The label disability is not simply a means of description, it is a societal position in a given culture. Labelling by an outside force can offer great power to the labeller and take agency from those being labelled. When disability is discussed in the primary texts it is rarely, if ever, seen as positive. Language around disability is used in the texts only in relation to limitations, negative associations and insults. Furthermore, the term disability is seen as an identity for the protagonists. The use of words such as 'spaz' (Haddon, p.56), 'special needs' (p.56) and 'retard' (Evison, p.83) mean the reader is constantly reminded that the main focuses of the novels are not the characters of Christopher, Will, August and Trevor. The main focus of the texts are actually their disabilities; autism spectrum disorder, quadriplegia, facial differences and Duchenne muscular dystrophy. While the authors attempt to steer the narrative toward challenging these perceptions, the language their characters use constantly undermines this work. As will be discussed, their attempts to portray a well-rounded view of the characters personalities are limited due to being seen through a consistently negative view of disability.

While Ngũgĩ and Achebe argue over many points in their work, they do agree on the creative power of language. Achebe has stated that 'unquestionably, language was crucial to the creation of society' (1989, p.128) which mimics some of the sentiment of Ngũgĩ's above quote. The main argument which fuels the disagreement between the two writers is the position of the English language. For both men, English was a colonising language forced upon them in their youth. Ngũgĩ believed (1986, p.7) in Achebe's original claim about the 'fatalistic logic of the unassailable position of English in our literature' (Achebe 1964). Achebe however changed his views and later wrote on his belief that English would be able 'to carry the weight of my [his] African experience' (1993, p.103). Part of Ngũgĩ's argument is that English is seen as the one true language, making it more difficult to challenge words or cultural associations. In North America and Britain where the primary texts of this thesis are located, English is the only language shown. Due to only presenting one language word structure and meanings are rarely debated. When words such as disability are used it is incredibly difficult to challenge it, as it is not simply challenging the origins and structure of a word, rather challenging language itself. This chapter will also explore how language often fails characters with disabilities in representing their interactions with the world. Whether language is currently able to carry the weight of a disability experience is disputable. Arguably, it is debatable whether any language is capable of carrying the weight of any culture. However, the use of language associated with disability in the texts to both create community and to exclude makes this a necessary discussion.

Throughout the texts, the term disability is used as an umbrella term to describe something that affects a large number of characters in an almost infinite number of ways. Christopher knows he is somewhat connected to this term and his way of understanding it is an interesting view on the meaning of words. For Christopher, terms or concepts such as disability or having a disability are much too vague. He needs the idea to be made concrete. The trouble he had with this shows a flaw in language and labelling as it can be difficult for language to accurately reflect the reality of a situation, of any situation, not just of the disability experience. As a child Christopher learned he would be treated differently because he had behavioural problems. Christopher decided to formulate his own more definitive definition by creating a list to understand the meaning of his relationship to words such as 'disability' or 'behavioural

problems'. How or when he devised this list is unclear but as a young man it created a foundation for his own understanding of disability. It seems he may have created the list by noting behaviours that made his parents act in a certain manner, such as when they got angry or shouted or when his mother said something like 'you are going to drive me into an early grave' (p.61). These criteria are of course problematic yet it is the conclusion Christopher came to. Later in life it may have also aided the problem he had connecting with other people labelled with having a disability as they did not fit his list of criteria:

- A. Not talking to people for a long time
- B. Not eating or drinking anything for a long time
- C. Not liking being touched
- D. Screaming when I am angry or confused
- E. Not liking being in really small places with other people
- F. Smashing things when I am angry or confused
- G. Groaning
- H. Not liking yellow things or brown things and refusing to touch yellow things or brown things
- I. Refusing to use my toothbrush if anyone else has touched it
- J. Not eating food if different sorts of food are touching each other
- K. Not noticing that people are angry with me
- L. Not smiling
- M. Saying things that other people think are rude
- N. Doing stupid things
- O. Hitting other people
- P. Hating France
- Q. Driving Mother's car
- R. Getting cross when someone has moved the furniture (p.59).

Christopher's list seems to be made up of a combination of more serious offences such as 'hitting other people' and driving a car as a child to much more minor offences such as 'not smiling' or the vaguely described 'doing stupid things'. A number of these issues would of course not label someone as having a disability but combining enough of them seems to make it true. Christopher's understanding of disability highlights a larger failure of language's ability

to define, that language is incapable of capturing an individual's experiences. For Christopher, language has failed to properly articulate his experiences so he has had to fill in the gaps of logic himself. Considering his definition only incorporates disability in relation to himself and as other people create their own meaning of the word, misunderstanding and confusion is bound to occur and does occur within the novel. Ngũgĩ and Achebe discuss whether a foreign language can carry the experiences of a non-native speaker but for Christopher it seems verbal language itself, even his own native language, fails to carry the weight of his experiences. This seems to connect with the writings of psychoanalyst Jacques Lacan and his idea of language as symbolic. Lacan argues that language could attempt to mirror a person's experience yet it would never truly capture it. He noted that language is symbolic and that 'symbols in fact envelop the life of man in a network so total that they join together, before he comes into the world' (1968, p.42). He argues that language can overtake reality as opposed to capturing it as can arguably be seen in relation to Christopher. Jacques Miller, an editor of Lacan's work discusses the connection between symbolic language and the real subject that with language the real 'may be approached, but never grasped' (1964, p.280). Christopher struggles with this gap, expecting that language should be able to articulate his experiences so tries to force these gaps closed with his own logical ideas.

In *Wonder*, words are constantly used to define August and also often used to try and hurt him. There are a number of words used to describe August throughout the book in relation to his appearance and these can be broken up into two categories; definition words and words of association. To first look at definition words we can see similarities to Christopher's problem with the words 'disability' or 'special needs'. For example, the word 'deformed' is used by Via (p.112), in recounting the ways other people have described August to her. It is also used by Jack, August's classmate, who also uses the word (p.171) to describe August to his mother after their first day together in school. 'Deformed' like 'disability' is a word created by adding a negative prefix, 'de' to a more positive word. To be formed, in this instance, alludes to one's body looking aesthetically average. Adding the prefix 'de' means that it is describing someone that is different and strongly hinting that it is negative or even dangerous. This word positions August as both different and less than other children. Much of the language used to describe August works as a separator, excluding him from his peers and

highlighting his differences. In one section of the book August refers to himself as a 'freak' (p.137). This word is again used to signify abnormality, someone that is different from the majority. August uses this word in frustration after receiving unfair treatment from his classmates. He adapts the beliefs of his tormenters and accepts the position they have given him. August's language is indicative of submission. His classmates see him as a freak (p.95) and he is accepting of their judgement. Ngũgĩ writes that 'to control a people's culture is to control their tools of self-definition in relationship to others' (1986, p.16). Using language August's classmates have managed to control his self-definition, making him see himself as they do. The power of language not only gives August's classmates the power to define him from their perspective, but additionally gives them control of August's self-perception.

The second category of words used in *Wonder* to describe August is words of association. Throughout the novel August is constantly compared to characters from popular fiction. 'Freddy Krueger. E.T. ... Mutant' (p.97), 'orc' (p.247), 'Gollum' (p.312) and 'Darth Sidious' (p.59) are all characters used to describe August predominantly as a method to insult and demean him. Achebe writes that 'language is a handy whipping boy to summon and belabor when we have failed in some serious way' (2009, p.102). For August's bullies the fact that he is different is considered a failure and insulting him verbally is seen as a suitable punishment. The characters he is associated with are characters considered to be very ugly. A number of these characters, such as orcs from *The Lord of the Rings* trilogy or the popular horror movie villain Freddy Krueger, follow the classic trope of ugliness equating to evil. August is not only being associated with ugliness but also being positioned as a villain, as someone who deserves to be punished. The bullies that use these words have been given numerous cultural icons to associate difference with disability. The majority of them are negative. *Wonder* uses real life examples of popular media which have been filled with violent and negative representations of disability. In the novel, these representations have had a strong influence on the understanding of disability by young children and in how they interact with those who are different. Palacio is attempting to showcase the power of artistic and media representation by highlighting the negative effects these portrayals have had on the life of her protagonist.

Early in the book August and his mother have a, notably upsetting, conversation about how he looks which showcases an interesting example on August's view of language:

"Why do I have to be so ugly, Mommy?" I whispered.

"No, baby, you're not . . ."

"I know I am" (p.76).

August's mother then proceeds to try and comfort her son but August writes 'she said soft words that I know were meant to help me, but words can't change my face' (p.76). August's views of the limitations of language clash with the reality of his situation. While words won't physically change his face, the narrative of *Wonder* is an attempt to showcase the power language has to change perception. August calls himself 'ugly' and is so upset at that moment because of the words of a classmate. After a boy in his class calls him ugly by associating him with the *Star Wars* character 'Darth Sidious' (p.59) August's self-perception is severely damaged. Language has caused August to feel this way. In the novel, negative perception is much easier to create than positive perception, as in that moment August feels that a few bad words can never be countered by any amount of 'soft words' his mother can offer.

Ngũgĩ states that 'The choice of language and the use to which language is put is central to a people's definition of themselves' (1986, p.4), it can also be argued that it is central to people's understanding of others. In *Me Before You* the word 'disability' carries with it a lot of meaning and expectation. Upon hearing that Louisa will be caring for someone with a disability, who uses a wheelchair, her family immediately jump to a number of conclusions. Louisa's mother wonders if Louisa 'will have to learn sign language?' that 'if he can't communicate, how will you [Louisa] know what he wants?' (p.33). Here the danger of assumption can be seen and how vague people's understanding of disability can be. Josie, Louisa's mother, assumes that a person with a disability is incapable of communicating in a way she understands. This belief would likely prevent her from attempting communication and therefore cause someone with a disability to have no contact with her. Louisa's father wonders whether Will 'talks through one of those devices' (p.34) connecting him to famed scientist Stephen Hawking who uses a computer system to speak. The looseness of the term disability and the family's experience of wheelchairs mean their expectations of Will are very different to the reality of the character. The controlling nature language has on culture that

Ngũgĩ (1986, p.16) discusses is relevant here as the idea of what it means to have a disability is here dictated by associations with popular culture and popular images. Later in the novel, Nathan explains using a more specific medical term Will's disability stating he is a 'C5/C6 quadriplegic. That means nothing works below about here...' He placed a hand on the upper part of his chest' (p.91). The word quadriplegic is much more specific than the term disability. It means 'paralysis of both the arms and legs especially as a result of spinal cord injury or disease in the region of the neck' (Merriam-Webster Dictionary, 27/09/2018). While this word is better at explaining Will's situation it still seems to be used to override all other identity markers. While the label is more specific it is still problematic as it denotes that Will 'is' quadriplegic, positioning his disability as a dominant identity as opposed to something he has.

In conclusion, it can be seen that the novels do try and highlight and challenge the negative associations and meanings of words connected with disability even do they also use them frequently. *TCl* and *Wonder* take particular interest in having their protagonists discuss the negative associations these words have. The following section will further explore the effect this has on the characters.

2.3 Limitations of Definitions

The words used to describe disability are not only problematic due to their negative meanings they are also used to assert power over characters with a disability. Language can be used to control people's identity and their self-perception. Definitions are very common in the area of disability. Johnstone (2004, p.2) noted that use of labels and descriptions are very limiting for people with disabilities. This section will explore how these limitations are created in the novels and how it affects the characters.

Foucault in his work on power and knowledge states that power is claimed through 'assertion' (1980, p.89) and then asks the question that 'if power is exercised what sort of exercise does it involve?' (p.90). Use of language in the novel is often an exercise in power dynamics. Words

and labels used by characters toward those with disabilities are used to weaken their position and often to demean them. Verbal language is an integral part of life and society in the novels and its use as an assertion of power, and its ability to control has become almost subliminal. The word 'disability' is not seen as harmful or damaging, rather as a natural indicator of a person believed to be less. The associations and meaning of the word become not simply a label but an identity. An identity which the characters are now expected to follow whether it matches with how they view themselves or not. Similarly, to previously discussed writings of Garland-Thompson on the notion of the gaze, language also has the ability to give one character control of another. Foucault states that 'power represses nature, the instincts, a class, individuals' (p.90). Using language to label and define limits self-expression. This has had a damaging effect on numerous characters in the primary texts and is often discussed directly by Christopher in *TCI*.

While Christopher is never given the label of having autism or being on the ASD in *TCI*, author Mark Haddon makes it perfectly clear that Christopher is different. It is interesting though that Haddon never includes the word autism in the novel. It may be that he is attempting to allow Christopher to express himself without the weight of the label upon him. However, for Christopher labels and word associations are still a problem and a constant challenge. This discussion of labels is confronted in an unusual manner when Christopher writes that he is upset about the meaning of his name. Christopher is discussing language and how he dislikes metaphors because he finds them illogical. He then discusses how names can be metaphors; 'my name is a metaphor. It means carrying Christ... and it was the name given to St. Christopher because he carried Jesus Christ across a river' (p.20). He then continues:

Mother used to say that it meant Christopher was a nice name because it was a story about being kind and helpful, but I do not want my name to mean a story about being kind and helpful. I want my name to mean me' (p.20).

Christopher's analysis of language is interesting as he is not simply rebelling against a label but a positive label. He doesn't want to be associated with 'being kind and helpful'. Christopher is not challenging a label, he is challenging the notion of labels and arguing that they are inherently confining. He does not want associations to define who he is. He wants to

world to see him for him. He wants his 'name to mean me'. Christopher wants to be identified through his own personality and actions. Haddon intelligently uses discussion of names, as opposed to one of labels indicating disability, as it highlights how ingrained language is in culture and how difficult it is to avoid associations.

Later in the book, Christopher more directly challenges words commonly associated with disability. He quotes his teacher in school saying:

But Siobhan said we have to use those words [Special Needs] because people used to call children like the children at school spaz and cripp and mong, which were nasty words. But that is stupid too because sometimes the children from the school down the road see us in the street when we're getting off the bus and they shout, "Special Needs! Special Needs! (p.56).

Here Christopher is confused why certain words are considered positive and negative. He is told the words 'spaz and cripp and mong' are bad words and instead he should use words such as 'special needs' even though other children use it to insult him. Haddon is critiquing the notion that words are inherently good or bad. Instead, he is arguing that the danger of language lies in how it is used and the context it is used within. Achebe writes that 'language, like any other human invention, can be abused, can be turned from its original purpose into something useless or even deadly' (1989, p.133). This is very reflective of the development of the disability vernacular. The disability critic Galvin writes that:

This is why it is so difficult to resist oppressive identifications through using "politically correct" language, for, if the concepts behind the words remain unchanged, then the new words end up being just as negative in their connotations (2003, p.153-154).

In the past a word such as handicapped was considered a scientific medical description but due to negative usage and association is now considered very offensive. Baynton notes that the word began being identified with people with disabilities in the late 19th century and it was 'tied to the kind of competitive, social-evolutionist worldview' (Baynton 1998) of the time. It positioned disability as something to be overcome in reference to a handicap in sport and likely coincided with the growth in connecting disability representation with overcoming obstacles. However, as views of disability evolve and language carries ever changing associations words can become damaging. It is quite possible from what is presented here,

the term 'special needs' could follow a similar path. Both Achebe and Haddon are echoing Galvin's point highlighting the language is not simply dangerous in itself, but also and perhaps more importantly, in how it is used. However, as previously mentioned in the discussion of the origins of the word disability, language in itself can indeed be dangerous in its meaning.

In Evison's *TRFOC* a word that appears a number of times is retarded. The word 'retard', which comes from the French *retardé*, refers to slowness or a delay and has become considered to be a highly offensive word. The word is used in the novel to describe Trevor but is also used by Trevor to describe someone else. While Ben is at a pub, his friend Max enquires about 'the retarded kid' (p.83). Ben replies stating 'he's not retarded. He's got MD' (p.83). The word 'retarded' is generally used only to refer to someone with an intellectual disability and this seems to be consistent here in Ben's retort. Ben seems insulted that Max would think that Trevor had an intellectual disability, implying that intellectual disability is considered less socially acceptable than physical disability. As the conversation quickly moves on, it is unclear whether Max believed Trevor had an intellectual disability associating the word 'retarded' more with intellectual disability or whether he simply thought the word 'retard' served as an umbrella term for any disability. Interestingly, the second time the word is used in the novel is by Trevor himself. He describes his new caregiver, whom he loathes, firstly as a 'scalp-eater' (p.127) as he believes she picks dandruff from her head and eats it. Then he uses this example, along with her general demeanour, as his rationale to state 'yeah, I'm pretty sure she is retarded' (p.127). It seems odd that Trevor, someone with a disability, would use the word, but he does not see himself as associated with it. This again highlights the failing of grouping terms in understanding what or who their definition actually refers to. For Trevor, the word is solely used to describe someone with an intellectual disability. Trevor has no problem insulting others in this way and positions himself firmly above someone with an intellectual disability, deeming himself as more competent than his new carer.

Use of offensive language (words considered insulting or having explicit connotations) is actually something Trevor finds quite liberating in the novel. He uses language as a tool for self-representation throughout the book as a way to take control over his self-definition.

Achebe notes that 'we play politics with language, and in doing so conceal the reality and the complexity of our situations from ourselves and from those foolish enough to put their trust in us' (2009, p.102). This playing politics with language is seen in *TCI* also. In the example of Christopher in the previous section explaining his disability by making a list he is trying to convince both himself and the reader about his identity. August's debate about not being ordinary but feeling ordinary on the opening page of *Wonder* is his attempt at taking narrative control of his identity for the reader. Returning to *TRFOC*, Trevor uses languages to try and place himself in a position of power and respect, to help him create a persona different from how many people perceive him. He discusses in detail, particularly towards the beginning of his relationship with Ben, explicit sexual acts he would like to carry out on both by-passers and celebrities. He has conversations with Ben where he uses language such as 'look at the turd-cutter on her', 'would you tap that?', 'I'd give her a gorilla mask' and 'I'd give her a German Knuckle Cake' (p.9). Engaging in this kind of conversation helps Trevor feel relaxed and confident around Ben. When Ben meets Trevor, his mother Elsa states about Trevor's hobbies 'he likes girls' (p.5) so this is not just something he talks about with Ben. Talking about sexuality is a common occurrence for many teenage boys and while Trevor has few people to talk to, he revels in these discussions. Talking about such an explicit matter seems to help Trevor feel mature and on an equal level with Ben. The more he discusses it the more open he is. Trevor's expression through language is not limited by his disability and he uses words to help create a mature and confident persona for himself which societal views of his appearance often do not allow. Trevor used explicit language to conceal his reality, his fear of not finding a relationship.

Additionally, verbal language aids Trevor in the novel by giving him hope and something to aspire to. In the beginning of the novel Trevor is largely housebound, trapped in a repetitive life cycle by a combination of his disability and his routine. When Ben begins working with Trevor he comes up with the idea of mapping out trips to tourist spots around America. Ben believes this will give Trevor something to be excited for; 'it's an opportunity to note the conditions he will never experience himself' (p.18). Ben does all of the actual researching and plotting while 'Trev delegates like a field general from his wheelchair' (p.19). Ben believes that through language, through description and planning, the idea of travel can help Trevor

experience some of the world. Planning and talking about it makes it feel real even though Ben states 'it'll never happen and we both know it' and that it is 'just another exercise in hope' (p.19). This exercise does indeed bring Trevor hope as he continues planning until language itself fails to be enough and he wants to turn his plan into a reality. It is this hope, that Ben's exercise created, that leads to the road trip they eventually take in the book. Trevor and Ben used language as a powerful positive force. Not only did it lead to him eventually getting to travel, much more importantly it allowed him to open up his world to the possibility of this happening. For Trevor, language changed his perception of his own limitations and gave him the opportunity to live a more fulfilled life. Evison is highlighting the power of stories to inspire and to motivate. While an author cannot control how a reader reacts to a piece of work Evison (as well as Haddon and Palacio) seems to want to inspire the reader with a narrative of overcoming.

Before Louisa first meets Will in *Me Before You* she offers an interesting anecdote. 'I had never had a disabled friend before – only Treen's friend David, who was deaf, but would put you in a headlock if you suggested that meant disabled' (p.39). The first thing to note from this is the odd tone of excitement that Louisa has at the prospect of having a 'disabled friend'. The notion of disability here relates back to Garland Thompson's writing as viewing disability as exotic. Thompson argues that 'the visual rhetoric of the exotic presents disabled figures as alien, distant, often sensationalized, eroticized, or entertaining in their difference (2002, p.65). Louisa seems to enjoy the thought of having a friend with a disability while knowing nothing about him other than he has a disability. It seems here that disability is the sole identity trait given to Will in this moment. The other thing to note from Louisa's story is her friend David's response to being called disabled. David strongly feels that deafness is not a disability. The Deaf¹ community in general seem agree with this statement believing deafness to be a positive identity and culture. Oscar nominated documentary *Sound and Fury* features a number of Deaf people discussing their culture with one stating "I would never say I would prefer to be hearing. I really am happy being deaf' (Aronson 2000, 2.10). Distancing themselves from the word disability can be seen as a positive action by the Deaf community

¹ The Deaf community have asked that the word deaf be given a capital D when referencing Deaf people as a group (Kuppers 2014, p.13).

to repute any negative connotations to their way of life but it is also very damning of others who have a disability. Here disability is seen as a dirty word something that is to be ashamed of. Deaf people don't want to be associated with the notion of disability or to be included in that category. Perhaps though this is understandable, as it has been discussed in detail throughout this section that the label disability brings with it numerous difficulties for anyone who is given it. The Deaf community reclaiming the language of their disability links to Ngũgĩ's writing on the link between control of language and control of self-identification (1986, p.16). They took control of the words and in turn took control of their identity. The inclusion of this short antidote in the novel is likely as a contrast to the difficulty other characters with disabilities have in achieving this.

The final point to examine in this section is language's ability to allow agency in *Me Before You*. In contrast to the hope that language brings Trevor in *TRFOC*, language only highlights the hopelessness of Will's situation. Will asks his mother to help him die:

I don't want to live like this, Mother. This is not the life I chose. There is no prospect of my recovery, hence it is a perfectly reasonable request to ask to end it in a manner I see fit (pp.140-141).

Will is trapped physically and only has language to try and plead for his own agency. He has to beg his mother to allow him to carry out his own decision. For Trevor, verbal language is a method to develop his self-esteem and open up new opportunities. However, for Will language is the final plea of a desperate man. When Will states that his request of assisted suicide is 'perfectly reasonable' it challenges both his mother and the reader. It also positions Will's mother, as opposed to Will, as the decision maker for his future. Will cannot carry out his own wishes only ask others to do so for him. Will and Trevor both had to convince others using words to allow them to have their wants and needs fulfilled. For characters whose physical agency has been diminished, language is the most powerful tool they have left. The power of language, as seen above in the Deaf communities reclaiming the word Deaf, and Ngũgĩ's discussion on control, highlights the power of a character's own voice for both expressing their identity and changing their reality. However, language is only powerful in the

way in which it is received, something that will be further explored in the next section of this chapter (2.4).

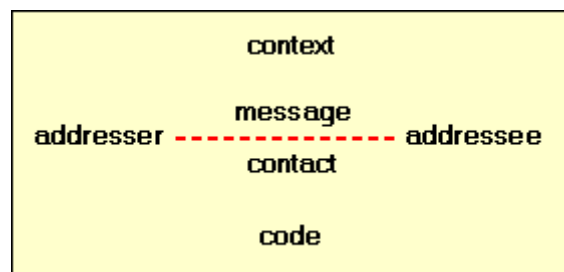
It can be seen throughout this section that the structure and use of language is considered to be very powerful within the novels, not only for self-expression and self-representation but also for oppression and control. Language expression is represented as incredibly important to characters with disabilities in all four texts. The description of disability both through the authors descriptions and furthermore through the dialogue of the characters they write, often prove harmful to those whom the labels are used to describe. The controlling and influential nature of language discussed by Achebe and Ngũgĩ is seen throughout the primary texts through association and its effect on the creation of identity. These past two sections have explored the author's use of language through identifying meanings of words, word associations and imaginative use of language. The next section will examine more directly, methods of communications and how these are seen to be difficult for the protagonists in the novels.

2.4 Language as Communication

The previous sections have discussed that language is powerful as a method of control. To continue this discussion there will be examination of language as communication. Communication does not simply comprise of definitions of words. The understanding of language is heavily dependent on context, on the method of communication used and on how it is understood by both sides. This is seen to pose a number of problems for the characters of the novels and their interactions with their peers. To analyse communication within the texts, this thesis will use Roman Jakobson's Communication Model (1960, p.353). Jakobson breaks down communication into six different factors, all of which have the potential to completely alter the intended meaning of a message. Jakobson's writing on language also offers an avenue to study the novels themselves as methods of communication and how they pass on information to a reader. In the novels, any variance from the norm seems to hinder conversation as characters with disabilities struggle to have their voices heard by normate people. For

Christopher, for example, the intricacies of communication often prove to be very difficult for him to comprehend as he does not understand a lot of the context around language. This section will analyse a number of situations and conversations had by the novels' characters and examine, using Jakobson's model, how their disability or the perception of their disability affects these interactions.

Linguist Roman Jakobson has written extensively on methods of communication and how they affect meaning. He builds upon the work of Ferdinand de Saussure on signs and the connection between language, culture and the physical world (Eds. Bally and Sechehaye, 1966). Jakobson is working in the field of semiology which Saussure explains 'semiology would show what constitutes signs, what laws govern them' (1966, p.16). It is an examination of how meaning is interpreted and created often focusing on language. In his work, Jakobson breaks communication down into six parts, 'the six basic aspects of language; addresser, context, message, contact, code, addressee' (1960, P.353). He has plotted these onto a graph which he has called Jakobson's Communication Model and can be seen below:



(Jakobson 1960, P.353)

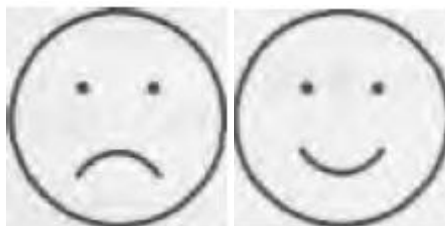
Wood and Lodge noted that 'Saussure's crucial point was that the connection between the two [Signified and Signifier] is arbitrary - that is to say, a convention accepted by all users of a given language' (1966, p.1). The argument is that language is an agreed upon series of meanings as opposed to something that is intrinsically linked to a certain meaning. Jakobson used this idea and wrote about how these meanings can change. While a message is given by an addresser to addressee, the manner in which this is actually carried out can completely

alter meaning during this transaction. He breaks these variables down into four categories; context, message, contact and code. Meaning is created from a combination of the message itself, the context around the message, the contact as in the method with which it is given (e.g. face to face, phone, email) and the code (e.g. the English language), an agreed upon system of language that can be at least partially understood by both sides. This method of understanding communication offers a helpful way to explore language in the novels. Now, the meaning and association of words are no longer the sole focus. The variables around how a message is transferred become a vital part of communication. For example, the background of the person must be considered, as must the place where they receive the message as well as the relationship between the addresser and the addressee. In Jakobson's model everything is interconnected, it is all part of communication. Each of these factors has a possible influence on how the message is received. Jakobson writes that 'each of these six factors determines a different function of language... we could, however, hardly find verbal messages that would fulfil only one function' (1960, p.353). Character's disabilities and the perception of their disabilities consistently affects most, if not all, of these variables throughout the novels.

To delve more into how Jakobson's model affects the interactions between the characters of the books it is perhaps best to start with Christopher. Christopher writes in detail about his difficulty in communicating with others. He notes that 'people do a lot of talking without using any words' (p.19). Christopher focuses very much on the words people say but finds it difficult to understand the context in which they are used. Jakobson in his work discusses the story of the Russian actor who was given the phrase 'this evening' in Russian and asked to perform it fifty different ways only changing intonation. It is revealed that once he performed this, an audience were able to understand the context of each of the fifty different messages (1960, p.354). This verbal contextual awareness is something Christopher struggles with. Christopher says he doesn't understand jokes (p.10) and takes words very literally. When Christopher says people talk a lot without words, he is referring to several things such as body language and also the different meanings that are brought about during speech using methods such as tone and rhythm. For Christopher, words have agreed upon meanings and language comprises solely of these meanings. Social cues, movement or tone should not affect this. This is of

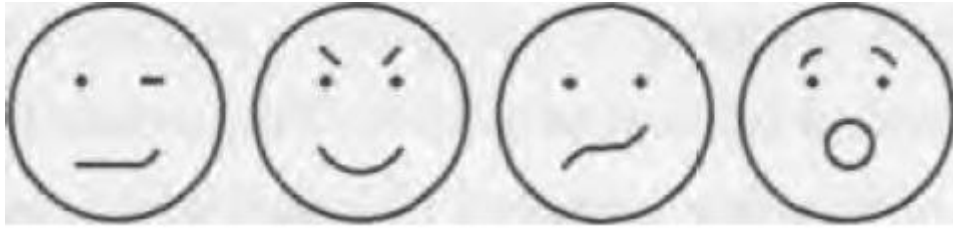
course not how language actually works and this causes a lot of frustration for Christopher. He states that if he cannot understand someone he will often just 'walk away' (p.3). In these instances, communication has completely broken down. The message the addresser is trying to give to Christopher is lost in the process of communication. Christopher does not understand the code the message is being given in. He also makes the point that he likes dogs because 'you always know what dog is thinking' (p.4). Christopher values a simpler form of communication that he sees in dogs. This is interesting as Christopher's main way of communication seems to be through the meaning of words and yet a dog cannot speak. It is possible that similarly to how people make assumptions about Christopher's communication skills, he himself does the same thing with dogs assuming he knows what they are saying and how they say it.

Facial reactions and their effect on language is something Christopher struggles with. Foucault writes in his book *Discipline and Punish* (1995) that observation and the knowledge gained from observation granted the observer power. As Christopher is unable to acquire the same knowledge as others from observation, he is struggling to maintain social interactions in the same way as those around him. Christopher discusses his first meeting with his teacher Siobhan and how they talked about faces (p.2). When shown pictures of happy or sad faces, such as those shown below, he was able to understand what they meant and can relate them to times in his life when he was either happy or sad.



(p.2)

Though when shown more complex facial images Christopher finds great difficulty in knowing what they mean.



(p.2)

For Christopher, this is seen as difficult as these pictures aren't exactly replicas of what shape a face makes and he finds them confusing. Christopher is given these pictures to help him understand people. He compares the pictures to people's faces when in conversation but it doesn't work as he gives the valid point that 'people's faces move very quickly' (p.3). Siobhan responds to Christopher saying doing that in the middle of a conversation probably made people feel very confused giving him this picture:



(p.3)

If Christopher has to stop to look at a page in the middle of a conversation that of course changes the contact and context of the message. This face-to-face method of conversation that Christopher is training for is expected to be understood immediately in the moment without question. To fully take part in a conversation in the way other characters in the book do, Christopher needs to be able to do this flawlessly. Even if the other person is patient, doing this changes the context of the situation. As Christopher finds it difficult to judge people's facial reactions he often does not know how to react to other characters. Desmond Morris in his book *Peopewatching* (2002) discusses in great detail the many different types of meanings that can be derived from gestures and facial cues. He divides them into numerous categories such as protective behaviour (p.201), guiding signals (p.88) and threatening behaviour (p.290). If these gestures cannot be distinguished from one another, threat can

often be inferred in the confusion. In his introduction, Morris writes that 'the more we know about the body language of other people, the more human they seem. They are no longer frightening figures' (p.xvii). Christopher finds anxiety and difficulty in not understanding body language and facial cues. He cannot understand body language so usually relies on spoken language to infer meaning. However, Christopher does enjoy obvious visual symbols that he can understand. He states in the book that 'I like the police. They have uniforms and numbers and you know what they are meant to be doing' (p.7). Christopher finds comfort in being able to understand a person's appearance but finds it difficult to do so.

Early in the novel, an example of the danger of the breakdown of communication is seen in Christopher's confrontation with a policeman. The book opens with Christopher finding his neighbour's dog dead, killed by a pitchfork. He hugs the dead dog whom he had cared for. His neighbour Mrs. Shears finds Christopher with the dog and assumes he killed it. When the police arrive, Christopher is at first happy to see them as he believes they are a sign of order, not realising they are there for him. The police ask Christopher a series of questions to which he gives very specific answers such as 'I am 15 years and 3 months and 2 days' (p.7) when asked his age. Christopher begins to struggle though when asked more difficult questions such as why he was holding the dog. Christopher is unable to answer the question as he himself is unsure why he is so upset. The police officer repeats the question which causes Christopher to become more frustrated. Christopher becomes unable to maintain the conversation. The policeman preservers and when he does not get an answer he grabs Christopher's arm. Christopher panics and hits the officer. This situation climaxed in such a violent manner due to a breakdown in communication. Christopher did not understand the context of the situation and was not able to respond to the policeman's questions. Christopher, whose mind is portrayed as very logical, was unable to answer questions about emotional matters. The onslaught of questions was something he was unable to handle as he states 'the policeman did not give me enough time to work out the correct answer' (p.7). Christopher's inability to understand the context of the situation and eventually his refusal of physical touch forced him to lash out as the situation made him feel confused and uncomfortable. It is interesting that all of this is told as a first-person narrative account from Christopher. He tells the story after the event, allowing him a measure of control of the situation. However, Christopher's

position as the narrator of the book who struggles with understanding social cues means most readers will know more than Christopher, again changing the communication dynamic.

The novels themselves are methods of communication that communicate a story from the author to the reader. The format and stylistic choices the authors decide to use affects the story and the reader's relationship with individual characters, for example, use of a narrator or multiple narrators, first, second or third-person narration etc. In *Me Before You* there is a cycle of first-person narrative voices in which almost every central character is allowed to tell their story. The only character not truly allowed to do this is Will. He is never properly given a narrative voice in a story centred on him not having agency. Will becomes a 'narrative prosthesis' (Mitchell and Snyder 2000). His story carries the narrative forward and supports the developments of the other characters. Only at the end of the novel (pp.478-480) is Will able to tell his story. This is done in the form of a letter read only after his death. Only in death does the man, whose final days were spent trying to have his voice heard, receive a voice. Moyes attempts to have form imitate story as her character with a disability struggles to have a voice within the narrative and the story is also rarely told from their perspective. Highlighting both the power and futility of the written word to change things. The context of Will's death allows his words to gain a level of significance they were not afforded while he was alive. Will leaves an envelope for Louisa after his death with the following written on it:

ONLY TO BE READ IN THE CAFE MARQUIS, RUE
DES FRANCS BOURGEOIS, ACCOMPANIED BY
CROISSANTS AND A LARGE CAFÉ CRÈME (p.478).

Due to the context of the situation Louisa follows Will's instructions and travels to France before opening the letter. Here, Will is finally allowed to have his say, to offer his direct thoughts and feelings of the situation to the reader. Moyes offers up the character of Will as a sacrifice to showcase the difficulty people with disabilities have of having their voice heard. However, by doing this she also gives into the stereotype, as another writer writing about disability denying a character with a disability a. The fact that *Me Before You* is not a standalone novel but rather a launching point for Louisa's story in a number of sequels means that Will's sacrifice benefitted not himself or his story but indeed the character development

of Louisa. Subsequently, referring back to Jakobson's model, knowing the context of the story arc means Will's story becomes less important. While a major character in this novel he becomes a more minor character in the series as a whole, someone who's story is not worth as large an investment by a reader.

These stories are delivered to the reader through the written word. In *Wonder*, the author tries to portray that August, the young man with facial differences, is just like any other kid. The book describes his emotions, his thought processes and his actions and how they are common with that of other children around him. Palacio wants to show how normal August is. Yet, in the novel there is constant, albeit portrayed as negative, allusions by other characters to how different August is. This is done through name-calling, shocked reactions of other characters, and even attacks. The story told is affected by its medium. The novel form is utilised well, as the readers are unable to see a visual image of August and are forced to focus solely on his character. Although there are descriptions of his visual look, the written word means August's appearance matters much less than in other mediums. For example, in the movie adaptation of the book (2017) or even the picture book adaptation the experience of the viewer/reader may be very different as they are constantly visually reminded of how August looks. The contact and code of the message were chosen deliberately to be able to convey the message of the story in a way that is different to its film and picture book adaptations.

The context in which the novels are written is important. Apart from *Me Before You* the primary texts seem to aim to give a positive and relatively uplifting view of living with disability. *TCI* tries to show the independence of someone with an intellectual disability and different kinds of intelligence. It is attempting to represent the exploration of the mind of someone with an intellectual disability. But in context it is written by someone without an intellectual disability. This changes the meaning from, an exploration of the mind of someone with an intellectual disability to the exploration of what a writer believes the mind of someone with an intellectual disability may be like. The effects of this will be explored in depth in chapter four in connection with the writer Eric Chen. Reading fiction means there will always

be an element of imagination. These novels are often presented as educational as much as entertainment especially with some of these books (*TCI and Wonder*) being aimed at children and are often taught in schools (Letcher 2010, Powells.com 2006). Achebe wrote that he believed literature can 'offer the kinetic energy necessary for social transition and change' (1989, p.167). He believed writers were important to society for change and as an influence for young people (p.42-43). Interestingly, the debate between Achebe and Ngũgĩ is also the debate seen here, examples of writers attempting to make a positive change but perhaps not using the correct method. Just as Ngũgĩ argued that the African experience must be captured in an African language many disabled writers such as Eric Chen (2005) argue that the disability experience can only be captured by the voices of people with a disability. An idea that will be explored further in the upcoming chapters.

Jakobson's model of communication provides a method of analysis of how communication works in the novels both for the writer and the character. The ability of the characters to communicate in the texts is adversely and consistently affected by disability and the perception of disability. For Christopher, his way of perceiving the world is different from most of his peers and he uses a different code when communicating. This creates much frustration for him as he is unable to understand people's tone or their body language. In the following section the role of the body in communication will be explored in more depth.

2.5 The Body as Communication

For Will, Trevor and August, the role the body plays in language has a significant effect on their communication with others. The ways in which they are viewed by other characters as well as their ability to control their own body language is a constant challenge in how they communicate and indeed how relationships blossom from this communication. Jakobson's model of communication will be used in relation to body language, just as it was in the previous section with verbal and written communication.

Disability affects communication in a number of ways. For Christopher, he could not understand the nuances of communication and suffered because of it. For the other characters with disabilities in the texts though, it is often the person addressing them that is causing the problem. The notion of infantilisation of disability is common in disability portrayal (Hall, A. p.7). For example, this can be seen in *Wonder* when August's dad doesn't want to let him go to school (p.19) and in *TRFOC* when Trevor's mother refuses to let him go on the road trip (p.114). This often leads to conversations where the person with a disability is talked down to or even talked about or spoken for while they are in the room. An example of this is seen in the first meeting of Louisa and Will. After Will presents his best 'Christy Brown impression' (p.41) to try and make a mockery out of people's assumptions of him, the situation that follows only proves his point. Once he begins speaking to Louisa his mother cuts across him and tells Louisa about his care and how Nathan will explain the daily routine and equipment. Will frustratingly replies 'I'm here mother, you don't have to talk across me (p.41). Will's joke about being seen as someone who cannot speak for themselves is immediately grounded in a stark reality. His mother responds stating that 'if you're going to be foul, Will, I think it's best if Miss Clark does talk directly to Nathan' (p.41). Camilla tries to change the context from being about Will's disability to his rudeness, but the fact that she asks Nathan to explain Will's life while he is in the room is degrading and is likely much more than the response to a rude introduction. Nathan, who seems to be the only person Will is comfortable around for much of the novel, asks Will's permission before speaking on his behalf to Louisa. Will and Nathan's relationship is strong and partially founded on the fact that sometimes Nathan seems to be the only one to treat Will as an equal.

This exchange between Will and his mother mirrors a discussion mentioned by Achebe. He discusses European white men talking to Africans as if they are talking to a 'dumb beast', not waiting for a reply, not actually entering into dialogue (1989, pp.23-24). Will's mother seems to do this for Will, not waiting for him to explain himself and speaking for him in this situation. Achebe's image of the dumb beast links to Jasbir Puar's discussion on the 'anthropocentric' (2017, p.29) nature of language. Puar cites Mel Chen who argues 'linguistic criteria are established prominently and immutably in humans' terms, establishing human pre-eminence before the debates about the linguistic placement of humans' (2012, p.112). Puar argues that

is hierarchical distinction is used not only in relation to an animal human divide but also to limit the voices of disadvantaged groups similar in a way to what Achebe is referencing. Puar argues that this anthropocentric form of privilege is additionally an ableist form of privilege denoting that only certain kinds of voices are valid. She notes while alluding to Spivak's writing that the subaltern must have a voice so as to 'destabilize privileged modes of communication, representation, and language altogether' p.27). The ways in which communication occurs and how someone is engaged in conversation can be very demeaning if one-side is not considered equal. Will often tries to subvert this, especially with Louisa, as he tries to become the dominant voice. However, it is more often a struggle he loses.

Much of Will's interactions with others revolves around his disability. Will struggles greatly with his new identity since acquiring a disability and often uses language to try and hide his insecurities. In his discussions with Louisa, and with Rupert and Alicia, Will continues the trend that Achebe discusses of playing politics with language (2009, p.102). Conversations become filled with careful wording and pauses to try and influence perception. Most of Will's time is spent with Nathan and Louisa, his carers. His relationship and conversations with Louisa throughout the novel are interesting from a contextual view as Louisa is being employed to be Will's friend. As Nathan explains to Louisa what her role will be, she doesn't think she will have a lot to do and asks 'what am I here for?' to which Nathan responds 'try to cheer him up a little? He's ... he's a little cranky. Understandable, given ... the circumstances' (p.44). This means that much of the interactions and the relationship between Louisa and Will has the context of being forced for much of the book even though it eventually leads to a romantic connection. This seems to further reduce Will from a character to just a disability as his main relationship is with a carer who is being paid to spend time with him. However, Will does take advantage of this relationship also, often ordering Louisa around as an employee and forcing her into odd situations such as watching movies and reading books she does not want to. Will understands the context of his position, insulted that his mother hires someone to help cheer him up, he uses language to belittle Louisa and try to recapture some sense of control. He is aware that the relationship being set up is essentially that of a carer and minder, where he is positioned as having less power. He changes the message to try and change the context and place himself in a better position. Louisa eventually stands up for herself, reprimanding Will

and stating 'I'm just here day after day trying to do the best job I can' (p.74). Only when this happens can their relationship evolve. The context has changed from both the original carer/caree and the employer-employee situations. Louisa moved herself from the servant role, to someone who will challenge Will. In that moment, she is neither his carer nor his servant, she becomes his equal. As Will and Louisa proceed to challenge each other through the novel it allows their relationship to evolve romantically as they push each other to be better.

A difficult conversation for Will takes place as he is visited by Rupert, his best friend and Alicia, his ex-girlfriend as they come to inform him they are to be married. They are first introduced to the reader as 'Will's friends' (p.58) by Camilla. However, the reader quickly realises that something is not right as Camilla describes Alicia's relationship with Will by saying 'they were... very close... for a bit' (p.59). It is revealed that Alicia and Will were dating at the time of his accident and as he pushed her away she took refuge in his best friend Rupert. As the conversation begins Will refuses to speak as his wheelchair becomes a central talking point. When Will does talk it is to Louisa, asking her to leave. Will is forced to confront his past both literally and metaphorically. He does not want Louisa to see him in that moment in a weakened position. Having people from his past, who knew him before his accident, arrive and speak solely about his chair makes it seem they only see the chair, that Will himself is not part of the conversation. As the discussion continues to revolve around disability and medical treatment Will cuts to the point asking 'to what do I owe this pleasure? It's been ... eight months?' (p.61). After making a number of feeble excuses they reveal their marriage plans. Alicia mentions that 'this is so awful. I have absolutely dreaded telling you' (p.64) firmly establishing herself as the victim. Will replies with a simple congratulations as Alicia responds angrily, desperately trying to explain the situation. Will repeats the word congratulations again and follows with "I'm sure you'll both be very happy' (p.64). Rupert responds stating that 'Will, it's not like we came here expecting your blessing. It was a courtesy' (p.64). They leave soon after. Will is being told his former best friend and girlfriend are getting married and he is made out to be the one at fault. The author emphasises Will's powerlessness after the conversation as Louisa describes hearing Rupert and Alicia's footsteps as they walk away from Will, as he is left sitting in his wheelchair. Will is trapped in the conversation, he cannot

leave. He is positioned as an obstacle for their happiness as opposed to a friend and is dehumanised in this conversation. Foucault writes that power is created through assertion (1980, p.89). Each sentence, reaction and pause in this scene is an attempt to maintain the upper hand, an attempt to control the conversation and the situation. No action is wasted. Rupert and Alicia fear being seen poorly as Will is positioned as a character to be pitied. Therefore, he must be made by them to seem either less human by focusing on the chair or less sympathetic by making him the antagonist. The couple get frustrated when Will does not respond angrily as it reflects badly on them. The conversation plays out as a verbal war with each side attempting to maintain a position of power.

In *Wonder*, much of August's communication with others is impeded by his appearance. August is fully aware of this and it makes him nervous to meet new people or go to new places. He has become finely attuned to people's body language and initial reactions when they meet him. When he is first introduced to Mrs. Garcia, the school secretary, he notes that:

Then that thing happened that I've seen happen a million times before. When I looked up at her, Mrs. Garcia's eyes dropped for a second. It was so fast no one else would have noticed, since the rest of her face stayed exactly the same (P.27).

For August this is a constant occurrence that for him frames much of his communication. While Mrs. Garcia acts very friendly towards August, for him the relationship was already partially failed. She sees him as different, as something she must take a moment to prepare herself for. The contact has immediately changed the context and August is made to feel uneasy and different. Garland Thompson noted that:

In a first encounter with another person... when one person has a visible disability it almost always dominates and skews the normal person's process of sorting out perceptions and forming a reaction (1997, p.12).

Interestingly, it is in this split second of involuntary body language, that August believes people use to create a perception of who he is, that he creates a perception of them. Catching someone doing this means that August becomes weary and distrusting toward said person. This small moment damages August and Mrs. Garcia's ability to converse. "You can call me Mrs. G," Mrs. Garcia said. I think she was talking to me, but I was looking at all the stuff on

her desk now' (p.28). August's inability to maintain eye-contact means that he is missing out on the conversation and the opportunity to create a meaningful relationship with Mrs. Garcia. He eventually warms to her, constantly taking note of her smile, which ironically means he is judging her on her facial features. When the conversation finishes August states 'I guess I liked Mrs. Garcia' (p.29). Thus, while the initial issue impeded the conversation it was not detrimental to their relationship. Achebe writes that 'language is not inherent in man- the capacity for language, yes; but not language' (1989, p.128). Arguably this is not true with body language as seen above. Achebe also notes about language that there is an 'incompetence and carelessness of its ordinary users' (p.133). This may be especially true for understanding body language. This relates to many of August's encounters such as the one mentioned above. The reaction of Mrs. Garcia is not malice but surprise and perhaps to an extent carelessness, how August is looked at is often a result of people not considering what they are doing.

The relationship between August and his classmate Jack begins in similar fashion to that of Louisa and Will. Jack is asked by the principal to befriend August to help him acclimatise to the school. Jack does not want to do this and it creates a very insincere relationship. This again completely changes the context to the conversations Jack has with August in the beginning of the book. Jack begins as civil and kind to August, standing up to Julian for him (p.40), sitting next to him in class (p.52) and trying to help him fit in 'dude, you're gonna have to talk' (p.41). This leads August to put his trust in him; 'I like Jack, though. He was nice' (p.46). August's conversations with Jack contrast strongly with how Jack speaks about August elsewhere. When he first learns of the principal's request, he tells his mother he does not want to do it because August is 'deformed' (p.167). Jack has made up his mind about August after a chance meeting with him a few years earlier (p.168). In a situation where Jack saw August and was given out to by his babysitter for acting surprised. Garland-Thompson noted that:

The interaction [between someone with a visually evident disability and a normate person] is usually strained because the non-disabled person may feel fear, pity, fascination, repulsion or merely surprise, none of which is expressible according to social protocol (1997, p.12).

Arguably Jack's inability to express this shock when first meeting August meant he lost a chance to properly engage with him and perhaps even create a more meaningful relationship. This means Jack could only judge August on his look as he no other option.

This negative memory meant that Jack was only pretending to be August's friend because he was asked by the principal. However, Jack does begin to legitimately care about August as they spend time together. Though this falsehood creates a volatile situation as August was not aware of the context of what was happening and feels fiercely betrayed upon learning Jack's true intentions. Only after Jack defends August and pleads that he did enjoy being his friend does their relationship begin to mend. It is also aided by Jack becoming an outcast in school. Stating "'it just feels so weird," I said, "to not have people talking to you, pretending you don't even exist"' (P.211). August responds 'welcome to my world!' (p.211). This shared experience of feeling outside of the group brings them together. Jack's betrayal initially causes August to question the validity of a number of his relationships. The change of context in one set of conversations manages to change the context in many. This means that in relation to Jakobson's model of communication even past communications can be completely altered by one aspect changing. Every kind conversation August had with a classmate is now tainted. For example, August now assumes his friend Summer had also only been hanging out with him due to the principal arranging it. Summer eventually convinces August this is not true. Even when the narrative moves to her perspective she defends their friendship "'did Mr. Tushman ask you to be friends with him?" Charlotte Cody asked. "No. I'm friends with him because I want to be friends with him," I answered' (p.145). While Jack's answers on his relationship with August change with context when speaking to different people Summer is firm in her beliefs and friendship. Mr. Tushman's seemingly nice deed of asking a few kids to look out for August backfires. August now feared all of his communication and relationships with his peers were false and the situation puts his friendship with Summer at risk.

In *TRFOC*, Trevor initially speaks like a crass, angry teenager. He chats to Ben at the beginning of the book and when asked if he likes girls he states 'I'm crippled, not gay' and 'of course I like girls' (p.5). Trevor feels the need to defend himself against the perception of himself by

others as anything other than a normal teenager. For a normal teenager a question about relationships may be seen as mild or embarrassing but for Trevor it is seen as an attack on his image. When asked what kind of girls he likes he has the following exchange with Ben:

“The kind who wants to get with a guy like me”

“You mean because of your... because of your wheelchair?”

“I mean because I’m horny. But yeah, that too” (pp.5-6).

Jakobson writes that the “expressive’ function [of language] ... aims a direct expression of the speaker’s attitude toward what he is speaking about’ (p.354). The language and approach Trevor uses in response to these questions is an attempt to make himself seem mature or knowledgeable. It is used to shock and as an attempt to shatter the image of him as childlike or innocent. It is interesting that later in the book when Trevor engages in a relationship with Dot he becomes much less confident in his discussions on romance. When first interacting with Dot he is unable to speak to her. As their relationship grows he speaks in a much more mature voice. As Trevor experiences the world his language becomes less forceful, it loses its tone of desperation. He no longer feels the need to prove himself. He becomes happier and more reserved. When the opportunity arises to go on a dinner date with Dot, he does not brag to Ben or make sexual remarks. Instead he smoothly asks Ben, who was originally going to the dinner too if it was ok if he ‘flew solo on this one’ (p.223). Trevor’s experience of being in a relationship completely changes his ideas of romance, he no longer has to prove he is someone who could be in a relationship. Highlighted by his initial conversation with Ben, his disability was a large factor in his understanding of his own romantic life.

For Will, Trevor and August much of their communication is impeded as it is consistently focused on their disability as it is visible. This challenging form of communication has changed the characters own self-perception. For example, the expectations the characters have for themselves such as August’s ability to fit in or Trevor’s ability to have a relationship changes how they themselves speak about certain topics. The context of disability has changed both how the characters speak and how they are spoken too. After focusing on words and context the next section will now discuss the contact strand of Jakobson’s model and examine how meaning changes in communication that is not face-to-face.

2.6 The Written Word as Equaliser

Jakobson in his communication model defines code as ‘a physical channel and psychological connection between the addresser and the addressee, enabling both of them to enter and stay in communication’ (p.353). A code can come in many forms. In previous sections, verbal face-to-face meetings have been the predominantly discussed form of code but the following two sections shall investigate the written word through letters, postcards, internet forums, emails and text messages. The difference between verbal and written communication is often highlighted in the novels. *TCI* illustrates that there is a different skill set to be mastered for verbal and written language. Christopher who struggles with verbal language is tasked with writing a murder mystery story and finds both comfort and confidence in the written word. The written word is often depicted as an equaliser for people with disabilities in the novels, as their disability, in these examples, does not affect their ability to write and therefore their disability is not part of the context of the conversation. The process of writing, in all four novels, offers a set of opportunities and possibilities for characters with disabilities that they do not often receive through verbal communication. The role the written word has in the texts in relation to identity and self-perception will be explored throughout.

When Achebe and Ngũgĩ argued over the use of language and how different languages affect identity their arguments largely revolved around literature. Ngũgĩ in the introduction to his book *Decolonising the Mind* (1986) states that this will be his last book in English (p.xiv) as he believes he must write in his native tongue for his work to be authentic and to keep his language and culture alive. For both Achebe and Ngũgĩ literature is seen as vital in creating and protecting culture. Considering the popularity and reach of the primary texts being studied it is likely that they too will be influential. Whatever meaning is retained by the reader will have an effect on their perspective on disability, especially with younger readers. The importance of the written word is highlighted in all four novels, both as a carrier of culture and as a method of communication and is often used as a literary device for characters with disabilities to have their voices heard.

In the fictional reality in which *TCI* is set, it is the character of Christopher Boone who is writing the story. Christopher begins writing the book as an exercise from his teacher; 'Siobhan said that I should write something I would want to read myself' (p.5). He chooses a murder mystery novel as it is the only kind of fiction he likes. Christopher includes himself as the protagonist of the novel and includes his process of writing as part of the narrative. The form of the story he is writing and his own life meld together in a murder mystery story with numerous twists and turns. He states that 'I wanted to write about something real' (p.6) and that he chose his subject matter because 'it happened to me and I find it hard to imagine things which did not happen to me' (p.5). The form allows him time to reflect, and then present his experiences to the reader in a way he is comfortable with. The novel is about self-representation, about telling one's own story. For the character of Christopher, in his fictional world, it is a triumph of expression. His novel allows him the freedom of discussing his views on his life in a manner he is comfortable with. He is able to articulate his thoughts to his teacher Siobhan much more successfully than he can through verbal language. It also offers him a way of working through a number of issues he is facing. It gives him a sense of control and stability that is missing in his own life. The written word allows Christopher to create his own rules. When he wants to only number chapters using prime numbers he is able to do so. He is able to add pictures and diagrams when he feels they can better represent what he wants to say. If he wants to add an appendix (pp.269-272) at the end to explain the mathematical equations he mentions in the books he can. Although Siobhan offers some advice along the way such as leaving the equations until the end (p.260) as opposed to insert them within the main story. Emily Bloom (2016) has noted that disability has been used as a novel method for telling a story stating that in radio 'the role of blind characters is a broadcasting cliché, one that suggests a connection to the listener who listens to a 'blind medium' (p.84). For listeners, they can use these characters to mirror their sensory experiences and allow them to feel more immersed in the work. Disability becomes a storytelling aid. The structure of *TCI* seems reminiscent of this idea, that disability bonds with the medium as a way of conveying the character and their way of seeing the world. Christopher is presented through this combination of form and content. Portraying in a visual manner a character who craves control but rarely gets it in his day-to-day life, showcasing a side of the character that would be difficult to present through dialogue.

Christopher's love for order and control is shown when he meets Mr. Jeavons, the school psychologist. Christopher explains to him his process of deciding if a day would be good or bad. He discusses that he decides this by counting the number of red and yellow cars he passes on the bus to school:

4 red cars in a row made it a Good Day, and 3 red cars in a row made it a Quite Good Day, and 5 red cars in a row made it a Super Good Day, and why 4 yellow cars in a row made it a Black Day, which is a day when I don't speak to anyone and sit on my own reading books and don't eat my lunch and Take No Risks (p.31).

Mr Jeavons is taken aback by this stating that it is strange that Christopher, such a logical person would abide by such rules. Christopher responds stating that:

I said that I liked things to be in a nice order. And one way of things being in a nice order was to be logical. Especially if those things were numbers or an argument. But there were other ways of putting things in a nice order. And that was why I had Good Days and Black Days (p.31).

He then compares this to the example of people deciding whether to be happy depending on the weather even if they worked inside. Mr Jeavons and Christopher discuss this 'Mr. Jeavons asked me whether this made me feel safe, having things always in a nice order, and I said it did' (p.32). For Christopher life needs order, it needs a structure to understand and perceive every event. Christopher enforces strict and unusual rules to his life to create this order so as to feel safe. Siobhan may have introduced this writing project to Christopher due to this sentiment. In the world of his novel Christopher can enforce any and every rule he likes. While verbal language may not act as a form of identity expression for Christopher written language does. The dual character of language as communication and carrier of culture that Ngũgĩ speaks of (1986, p.13) is something that can only be fully actualised by Christopher through the written word.

Throughout the narrative of the novel Christopher encounters a number of challenging situations. Writing about them seems to be a form of relief for him and allows him to situate them in a manner he feels more comfortable with. Traumatic events such as being jailed or

finding out he was lied to about his mother's death are discussed. By recalling the events through writing Christopher seems better able to process what has happened. When finding the dog dead and meeting the policemen Christopher describes himself as being overwhelmed and upset (p.4, p.8). But his descriptions of these events are not written with a very emotive tone. Christopher is calm when writing. Being able to describe the situation and his reasoning behind his actions makes him feel more comfortable. Here he is in control of how he is perceived. This is his story. Where the policeman may have simply seen a violent young man, Christopher can give his side of the story and the reader understands he was overwhelmed by the situation and felt violated when the policeman grabbed him. Although, Christopher does not write this as a defence, he writes what he sees as fact. He wants the reader to understand his perspective. When Christopher reads the letter, he finds from his mother, his remembers to explain to the reader what happened as well as explaining his emotional response. 'Then I stopped reading the letter because I felt sick' (p.141). Christopher seems acutely aware of the reader and must make his narrative make sense, not allowing it to break down into a description of emotions. While this may seem restrictive it helps Christopher as the structure lets him feel more comfortable in the act of writing. Continuing the narrative also forces Christopher to confront his issues and work through them.

During the story, the book that Christopher writes becomes a plot device in itself and changes the direction of the story. Achebe writes that language can be used for not only 'expressing thought' but also for 'preventing thought' (p.133). The novel features a struggle over expression and repression of voice, a struggle between which character has control of the narrative. The book, which Christopher is writing as the story progresses, is found by his father who reacts violently. The existence of the book and Christopher's writing process causes the book's own story to be altered. This creates an interesting discussion on literature's power to change and affect reality. In *TCI*, literature has a literal and immediate effect on the reality it discusses. When his father finds the book, he becomes furious with Christopher over its contents. After reading about Christopher's investigation, which he had told him not to do, he becomes enraged; 'holy fucking Jesus, Christopher. How stupid are you?' (p.102). He questions Christopher about the contents of the book 'what the fuck did I tell you, Christopher?' (p.102) and when Christopher becomes unable to respond he becomes even

angrier 'come on. You're the fucking memory man' (p.102). Christopher's chooses to include this event in the book recalling 'I found it hard to work out what to say because I was starting to get scared and confused' (p.102). The book is a central plot point in its own story, as it effects the narrative and directly changes Christopher's relationship with his father. The book is a symbol of expression for Christopher but his father's harsh and demeaning words towards him challenge this expression and attempt to stop it completely.

While the written word had a damaging effect on Christopher's relationship with his father it arguably saved Trevor's relationship with his. In *TRFOC*, Trevor's relationship with his father is portrayed as very difficult. After leaving the family due to Trevor's disability when Trevor was only three years old, his father, Bob has tried and failed numerous times to reconnect with his son. Bob's attempts to connect with Trevor in person are both sparse and usually rejected. Bob then begins using different methods to communicate with Trevor; first with phone calls and then with postcards. Ben describes how Bob is the only person who will consistently call Trevor on his mobile as he doesn't realise how difficult it is for Trevor to answer his phone (p.37). Trevor answers every time, Ben believes this is because he 'seems to savour these opportunities to make his father work' (p.37). To return to Foucault's point about power being an active process (1980, p.89), Trevor knows he is in control of these phone calls. It seems to be the only time he has control of his father's attention. He uses the conversation to punish his father and make him work as hard as possible on their relationship when calling. When Bob calls Trevor, Trevor answers, upon hearing his voice he replies 'oh, it's you' (p.37) in a deadpan voice. Trevor relishes the opportunity to exude dominance. Every part of the conversation is carefully worded to show his father who is in control; 'well, that figures', 'hmp, that's a first' and 'what did you expect?' (p.38). Trevor is bored throughout the conversation, he is difficult, his responses never aid to the flow of the conversation. Foucault discusses that while power can be seen as repression, it could also be seen that 'power is war' (p.90). That it is a constant battle between two sides. The relationship between Trevor and Bob exemplify this. All of the work of keeping this phone call going rests solely on Bob's shoulders. Although ringing Trevor forces him into the difficult situation of trying to answer and hold his phone, the phone call itself allows Trevor control and it is a trade-off

Trevor is more than willing to accept. Both sides want control, Bob wants to be accepted and Trevor does not want this.

As Bob realises neither his attempts to make infrequent face to face connection nor his phone calls are having any success, he shifts to the written word to try and mend his relationship with Trevor. He begins sending him daily postcards. One would think that a postcard, especially in the manner Bob is writing them, would not encourage communication. The postcards he is sending seem more a compilation of a trip he is taking than an attempt to start a conversation. However, Trevor seems to enjoy this fact as there is nothing Bob wants from him in this situation, he doesn't expect anything in return. Bob keeps his messages short which Ben believes is 'a smart move, since Trev isn't a big reader' (p.105). He also signs them as Bob instead of Dad which Ben considers 'another wise move' (p.105) highlighting Trevor's maturity and a more relaxed relationship. The postcards seem to be designed for Trevor's enjoyment as opposed to Bobs. He treats him almost like a friend, not using the word Dad and writing jokes on them that would appeal to Trevor's sense of humour. Ben offers examples of jokes that Bob sends such as on the Mormon Tabernacle postcard he writes; 'Q: Why do you take two Mormons fishing with you? A: If you bring one, he'll drink all your beer' (p.105). On the Two Storey Outhouse postcard he says 'Unfortunately, no wheelchair access for the top one. But at least there's no line for the bottom one' (p.105). Appealing to Trevor's sense of offensive humour is a smart way to connect with him. It is an avoidance of the clash of culture and language that Achebe and Ngũgĩ have been discussing. Here Bob is speaking Trevor's language. Humour is the language Trevor likes to use. Bob is using the kind of language Trevor speaks instead of forcing him to converse in the way he wants to.

Ben points out that it is nice to downplay and ridicule the notion of travelling to these places as Trevor can't visit them. Trevor does not acknowledge these postcards nor tells anyone that he reads them but Ben notices the references he makes about them and how well he keeps them in order. The written word, and Bob's ability to communicate with a focus on his son's needs and wants is the first moment in the book that gives hope to their relationship. While Bob is travelling and sending these postcards he ends up in an accident, breaking his leg and

a number of his ribs and Trevor decides he wants to go see him. The postcards allowed Bob to reconnect with his son. Bob connects to Trevor in a way he had never been able to in person. He treated him not as his son but as a grown man, perhaps a friend. The postcards demanded no response and were written with Trevor's likes in mind. Achebe writes that speech 'seems so natural that [people] rarely give much thought to it' (1989, p.128). Achebe here discusses that speech often is given with little forethought even though he goes on to argue lot of meaning is still conveyed some of which may be unintentional. The written word however offers a more focused and deliberate method of communication where the addresser can at least attempt to have more control into what message is being conveyed. Bob's phone calls and face to face interactions were misguided and never fully thought out beforehand. However, with the written word he planned what he would say carefully choosing his form, words and tone. This level of care given to his writing meant a lot to Trevor. Trevor no longer had to make him work in conversation, Bob is offering to do the work willingly. Verbal language was not the right channel to use for Bob, the written word proved much more beneficial for him. The highlights the importance changing one aspect of Jakobson's model can have on communication.

Additionally, in *Wonder*, the notion of precepts is introduced by Mr. Browne the English teacher (p.61) and are used throughout the book as a kind of moral compass. Mr. Browne describes precepts as 'rules about really important things!' (p.61). He gives out a monthly precept while asking the children to write their own. His first precept, for the month of September is 'WHEN GIVEN THE CHOICE BETWEEN BEING RIGHT OR BEING KIND, CHOOSE KIND' (p.63). These messages written in large letters on the chalkboard and are given a certain level of gravitas by the written word. They remain on the board and are a constant reminder to the students of how they might live their lives. As August doesn't get around to mentioning all of the precepts in the story, he adds an appendix for them similarly to Christopher adding one for his maths equations. He also adds all of the student's precepts in his class which were written over the summer and often mimic the journey of the students. These words are often quite reflective. These are different from the text messages as they are more professional but also from Jack's emails as they are not defensive (will be discussed in the next section). They are perhaps more similar to Bob's postcards (and indeed the student's precepts are written

on postcards) and are hopeful and life assuring. August's own precept which closes both the appendix and the book 'everyone in the world should get a standing ovation at least once in their life because we all overcometh the world. — Auggie' (p.365) represents his journey and the moral of the book itself; that everyone deserves to be celebrated. Here the novel attempts to highlight the power of words to capture a journey and how literature can inspire readers through these journeys. If Mr. Browne's words can inspire his students perhaps the novel itself can inspire also. As previously discussed, *Wonder* pointed out the danger of bad representation and now wants to highlight the power of positive messages aimed toward young people. Palacio is attempting to accomplish Achebe's idea (1989, pp.42-43, p.167) that writers have both an obligation and power to affect social change. The novel reads as not only a fictional text but an attempt at being educational by highlighting its own positive messages.

The written word in the texts is seen as powerful tool for both agency and change. Christopher uses writing as self-expression and additionally as a method to work through life challenges. The written word was seen as a method of healing in the relationship between Bob and Trevor as the method of communication caused Bob to put more thought into Trevor's wants. The idea of the word as inspiration is also seen in *Wonder* in the precepts. The novels attempt to highlight the written word as positive, healing and inspirational in relation to disability arguably as a self-defence of the existence of the novels themselves.

2.7 The Internet and Texting

Communicating through the use of technology is featured in *Me Before You* and to a lesser extent *Wonder*. The speed of online messaging, the freedom of anonymity and the power of assistive technology are seen to strongly effect how characters with disabilities can communicate. The benefits of internet usage are introduced in *Me Before You* as Louisa joins an online forum for people with disabilities allowing a variety of disabled voices to be heard, that would not otherwise have been given the chance. Technology in the novels creates opportunities for different kinds of communication for characters with disabilities.

Online communication is seen as less stunted in the novel by visual prejudices that can occur in face-to-face conversation similar to those highlighted by Achebe (1989, pp.23-24). In *Wonder*, a full chapter is written in the form of various text messages, letters, emails and Facebook messages. The conversations that occur in this chapter between characters act as a way to combine and consolidate numerous storylines in the book. The relative frugality and pragmatism of the written word compared to spoken word is used to help move the narrative towards a conclusion. As is seen with Christopher, writing allowed him a way to feel confident when representing his story and it seems to be a similar experience for many of the characters in *Wonder*. The exchanges that occur happen in response to an incident between two of August's classmates, Jack and Julian. We learn from the previous section, which is from Jack's perspective, that he punched Julian in the face (p.188) and even knocked out a tooth (p.189) due to Julian insulting August. The chapter works as a method to showcase clearly and minimally the emotions and personalities of the characters. Initially the chapter is reminiscent of the narrative structure of *Me Before You* focusing on August without him actually having a voice or being part of the conversation. The reader is shown letters sent to both the principal and to Julian by Jack as he tries to convey his remorse for hitting Julian, 'I am very, very sorry for punching Julian' (p.194). Jack, who had confronted Julian over his bullying of August, refuses to get Julian into trouble stating he will not give his reasons for the punch as he 'would rather not make Julian get in trouble for having said something he should not have said' (p.194). It is interesting that in the first few examples of correspondence, August seems to loom over them as an unnamed character.

The email from Julian's mother sent to principal firmly brings his character into the discussion, though not by name, as she refers to him as the 'new child with special needs' (p.196). She firmly puts the blame of Jack punching Julian on August as she believes his presence has caused Jack to become overburdened with responsibility. The principal responds to her by stating August, whom he does mention by name, 'does not have special needs. He is neither disabled, handicapped, nor developmentally delayed' (p.197). This is said defensively trying to disconnect August from these socially harmful identification terms referring to disability. Achebe writes that there is an 'incompetence and carelessness of its ordinary users' and also

language that is 'engineered deliberately by those who will manipulate words for their own end' (1989, p.133). The words of Julian's mother could fall into either of these categories. Her words could be from lack of knowledge due to the context of the situation. However, they seem more likely to be malicious as she manipulates words for her own wants. Using the term 'special needs' as something demeaning and as a separator, a reason someone should be removed. The principal's words are also somewhat ambiguous. As the personification of the education system in the novel it could be argued that he is challenging the 'incompetence and carelessness' of language usage and the importance of challenging these words. His message though can be seen as either positive or negative as a whole. He is either protecting August by stating he is not any of these negative words or challenging the words himself. It could be read as challenging the words as the context it supposed to be uplifting but it seems that he is being somewhat dismissive, if not demeaning, of people associated with these labels. The principal, as a representation of the school, challenges careless use of language while also himself being careless in his own language usage. The book could be showcasing good intentions with poor follow-through. However, considering the principal is never challenged afterward this seems like good intentions with a bad follow through by the writer as much as by the character.

After a short email from Jack Will's parents to Julian's parents, we see numerous messages and friend requests from Jack to August beginning with a Facebook friend request. This is interesting as the modern perception of friendship on the site turns the relationship into a binary state. The request is either accepted or rejected and as August does not respond, his lack of response is damning. Jack emails him in a panic, with poor punctuation (which differs from his email to Julian and the principal) that 'I noticed im not on ur friends list anymore. Hope u friend me agen cuz im really sorry' (p.199). Jack does not quit, he uses multiple forms of 'contact' from Facebook, to email, to text message. His hope is either one of them may be the right form to address this or perhaps that the abundance of correspondence may get his message through. Attempting to change the 'contact' saw success in *TRFOC* as Bob's move to postcards as a form of communication finally gained him a new relationship with his son. Eventually, Jack is also successful as August finally responds via text message. Then in a short thirteen text messages, filled with poor grammar and spelling, sent over the course of twenty-

three minutes August and Jack's friendship is mended; 'yes dude we'r frenz agen' (p.202). Social media allowed for a different type of communication. It seemed to lessen the emotion of the situation as it wasn't as immediate as face-to-face. The same can be said about the written word in the case of *TRFOC*. This is a strength of these forms of contact. However, whether these altered relationships can be maintained when returning to a more intimate form of communication is not certain. While Jack and August's relationship seems to mend quickly, that of Trevor and Bob in *TRFOC* is a much slower process and communication that is successful in one form of contact may be limited to that form of contact. Arguably meaning that while social media and other forms of written language can be beneficial to communication for characters with a disability these benefits may be contained to only that method of communication.

The language of the text messages is more similar to oral language than written language. The speed in which they are sent does not allow for the careful formatting that Jack's emails to Julian and the principal had. Their messages are too urgent, both parties want the issue to be resolved immediately. The longest message takes only four minutes to send and ends with Jack's plea for them to be friends again. After months of avoiding each other and countless issues, everything managed to be solved in thirteen text messages of which the total word count is only 160 words (pp.199-202). The concise and direct nature of the text messages allowed a quick and clean way to mend the relationship. This section highlights how variations of the 'contact' in Jakobson's model can alter communication and how characters approach different forms of communication, such as emails, changes the message. Each method has different rules and norms that are expected to be adhered to. What is normal in one method may be non-existent in another. Emails are written differently to texts and the written word acted as more concise than the spoken word. It also highlights how different methods can have different outcomes as Jack searched for the correct medium to reconnect with August. The method chosen is important as seen in Jakobson's model, it means something. Jack changed his medium to try and have more success reaching August and it worked. The 'contact' is an intrinsic part of the message and can greatly affect the meaning of the message and whether it will be positively received.

The written word takes on a powerful role in *Me Before You* through the use of the internet. The novel has a number of examples of the ability of the written word to empower characters with physical disabilities through the use of the World Wide Web. The re-introduction of technology into Will's world began when after Louisa asked him to send a thank you card to a friend he responded saying 'you have no idea, Clark, how frustrating it is to rely on someone else to put your words down for you. The phrase "written on behalf of" is ... humiliating' (p.220). Technology allows Will an opportunity to regain some of his independence as Louisa finds equipment which allows him to type himself. This has a positive effect on Will's psyche. The equipment Will uses allows him a level of freedom and the opportunity to once again have his voice when corresponding online. Returning to Koppers' quote that 'disability appears in the interaction between the impaired person and the social environment' (Koppers 2014, p.270), this technology removes the barriers of interacting with his surroundings for Will and puts him on an equal level with his peers. He no longer has to sacrifice his voice due to his physical relationship with the social world. Koppers' quote is important here as by changing his interactions he is also changing his identity. By being better able to control how his message is received Will loses the limitation the perception of his disability has on his ability to communicate. His message becomes less tainted by negative perception within Jakobson's model. The social environment becomes less of a difficulty as Will can blend in more with those he communicates with.

Will is not the only character with a disability who benefits from using the internet. While researching ideas for Will, Louisa comes across a forum for people with disabilities. Comments on the forum from characters with disabilities are written into the narrative. While these comments vary as to whether they are positive or negative they offer arguably the most freedom given to any character with a disability in the novel. Bowker and Tuffin in their writings on disability and the internet state 'disabled people can operate within an intersubjective space where impairment is inaccessible to others' perceptual fields. Impairment no longer necessarily affects social exchange' (p.329). The forum offers communication untouched by the difficulty of visual cues or their effects on verbal communication. 'We live in a world where reality is mediated by visual ontology' (Bowker and Tuffin, p.327). This ties into Jakobson's model highlighting the effect the visual has on

communications and relationships as well as Garland-Thompson's writing on the *Politics of Staring* (2002). By eliminating the role that the visual body plays in communication, people with physical disabilities do not have their online identities affected or even associated with their disability unless they chose to reveal it. Jakobson's model highlights that any change in any part of the model can completely alter the meaning of a message. As has been discussed, the visual look of many of the characters (Will, August and Trevor) alters and often limits their communication. Online their impairment is inaccessible, it is up to themselves to choose whether to reveal their identity and even if they do their physical body does not act as a constant reminder in conversation. When August texts people he does not have to worry about what direction people are looking at as he often does (p.27). Will and Trevor can gain a freedom in which the restrictions of their body do not affect their communication. While Christopher is only seen to benefit from handwritten communication as opposed to online, it could offer him a new way to communicate as it would allow him time to respond giving him a chance to fully comprehend his situation and not be confused by facial expressions or body language as discussed in section 2.4 of this chapter. The characters are allowed a level of control over their identity not possible in face-to-face conversation.

Much has been much written about coming out discourse in relation to disability. Disclosure of disability become a prominent discussion point as Bowker and Tuffin note 'a guiding question for this work was whether disabled people would elect to disclose or continue to mask their impairment in a context where normal perceptual cues are absent' (p.329). Online use can offer an opportunity for people with a disability such as Will to not be tied down to his disability or for any character to escape a fixed identity:

The development of virtual environments and their reliance on textual communication has opened up the potential for constructing new identities. Online communities are deconstructing traditional notions surrounding the concept of identity as a stable and permanent entity (Bowker and Tuffin, p.329).

Surprisingly however, while the novels do explore the freedom written language and use of the web can offer the books rarely delve into identity expression in relation to online representation. The only character who really talks to people they have not met online in any

of the primary texts is Louisa. While this at first may seem like a missed opportunity it is perhaps a wise choice about representation by the writers. Showcasing people with disabilities pretending to be something they are not may result in the novels perpetrating an image of people with disabilities as false or manipulative. Furthermore, it could discredit the disability experience as Bowker and Tuffin write:

Withholding information about impairment leads to assimilation with able-bodied conventions and thereby invokes a non-disabled image. Consequently, this serves to reject the way disabled people operate in the world, and leads disabled people to reconstitute their sense of personhood within an able-bodied framework (p.330).

Hiding one's disability could be interpreted as being ashamed of it.

However, *Me Before You's* focus on a disability forum where users freely discuss their disability may be a more positive message to portray. It also subverts the idea that while people with disabilities have to be honest about their identities, normative people's identities are taken for granted. Louisa immediately labels herself as being a carer and not someone with a disability when joining the forum as her first sentence reads 'hi – I am the friend/carer of a 35 yo C5/6 quadriplegic' (p.268) positioning herself somewhat as an outsider. Here the novel seems to portray the necessity of honesty about identity but does not really explore the politics about how it would work from a disabled perspective. Should a person with a disability be allowed as Bowker and Tuffin have said challenge 'the concept of identity as a stable and permanent entity' (p.329) or is honesty a necessity. The novel asks this question but does not offer an answer instead leaving a number of competing ideas linger. The online forum element of the novel was removed from the movie adaptation of the book. This loss took from the story one of its most intricate debates on identity and agency. The forum provides a much-needed injection of disabled voices challenging perceptions. These voices offer a wide range of thoughts of Louisa and Will's situation, some reassuring, some angry. While these characters do provide views from characters with a disability they are limited. Very little is known about these characters other than their username. While this can be a positive for someone having their identity oppressed it also removes them somewhat from reality. Additionally, the question as to whether these characters are reliable becomes debateable. The people Louisa talks to online and asks for advice about disability could be lying. They

might not have any connection to disability. The use of usernames and lack of real world connection makes these characters seem less real and arguably while their voices may be listened to more online, the anonymity might mean this rebalance of power may result in little to no effect on the real world. Bowker and Tuffin noted the online world created the opportunity for 'new identities' (p.329) however whether this benefits characters away from this technological space is debatable. Especially whether this freedom is used to create new non-disabled identities. 'By eliminating disability from the social sphere in order to pass as non-disabled, differences are denied and already marginalised voices are silenced even further.' (p.330). If voices gain power through becoming non-disabled, this is problematic when trying to merge one's online identity with their physical identity and limits the positive work that can be achieved for disability perception. This also arguably goes against both Achebe and Ngũgĩ's discussions about challenging language as a colonial power as it is not confronted but rather ignored and bypassed. It also goes against Gramsci's discussion of voice in chapter one and his assertion that the only true break from oppression must be a permanent one (1971, p.207).

Me Before You and *Wonder* have touched on the opportunities that exist online for characters with disabilities to communicate and indeed to play with and change their identity. Even more so than the written word, internet usage allows for a rebalance of power for people with disabilities. An equaliser for methods of communications. Characters can decide whether or not to reveal their disability and how to do so. Language becomes purer in its written form as it is not in these instances affected by associations or presumptions about disability. While the inclusion of technology is seen to help improve real world interactions and ability to do tasks (Moyes, p.221) the benefits of internet usage are not explicitly seen to improve expression or quality of life in the texts outside of having a better online identity.

2.8 Conclusion

As Achebe and Ngũgĩ have discussed, language is a very powerful indicator of identity. The words used to discuss disability have created a harmful perception of it in the novels which is used to limit the protagonist's self-expression. While communication around disability in the novels is seen positively at times the characters often find it difficult to overcome oppressive language in relation their own identities. Throughout this chapter, Jakobson's model of communication provided an effective method of language analysis in relation to disability in the texts. Whether it is the visual issues that arise for Will, August and Trevor or the contextual issues of Christopher, characters with disabilities are portrayed as having difficulty communicating with others face-to-face. The novels at times discuss disability discourse specific issues in relation to language use such as coming out theory, use of technology and the evolution of harmful labels. However, they often skim over them as opposed to actually challenging them. The novels highlight the effect literature has to influence readers and try to use this power in their own works to challenge misconception. Prejudice is rampant throughout the texts as characters frame their communication with preconceived ideas about disability. It can be seen that technology offers a short-term potential way to avoid some of these issues but it has its own limitations.

Chapter 3-Identity Politics; Imagined Communities Real Problems

3.1 Introduction

And so the discourse of recognition has become familiar to us, on two levels: first, in the intimate sphere, where we understand the formation of identity and the self as taking place in a continuing dialogue and struggle with significant others. And then in the public sphere, where a politics of equal recognition has come to play a bigger and bigger role (Taylor 1994, p.37).

In the above quote, philosopher Charles Taylor defines identity as both relational and fluid within the private and the public spheres. In the previous chapter, the effect of language could be seen on the creation of identity. The language used to describe a character or to address them could alter their self-perception and their perception to other characters. This chapter will investigate this notion of identity further by examining what identity is and what does it mean to the characters portrayed in the primary texts. It will use the writings of Benedict Anderson in his book *Imagined Communities* to examine how communities of people with disabilities are created and portrayed in the novels. It will also include the work of Stuart Hall and Charles Taylor using their work on identity. How identity can be formed and the ramifications of being unable to express one's own identity will be examined in relation to the portrayal of the protagonists in the four books. This chapter will examine grouping identities and explore the meaning behind phrases such as 'people with disabilities'. It will examine the relationship characters have with this group and how it affects their self-perception and their treatment by others. The education system as seen in the school lives of both August and Christopher in *Wonder* and the *TCI* will be explored as they can be seen as microcosms of the difficulties created by grouping together people with disabilities. Additionally, how literature featuring disability helps to both reflect and create the disabled identity will be explored.

3.2 Imagined Communities of Disability

Benedict Anderson in his book *Imagined Communities* has written that 'nation, nationality, nationalism — all have proved notoriously difficult to define, let alone to analyse' (1983, p.3). Anderson's writings on nationhood and community overlap significantly with aspects of disability studies such as identity representation. The group titled 'people with disabilities' is problematic in much the same view that Anderson views the nation. This group is very difficult to define and often creates false connections however it remains very powerful. Anderson (p.3) further quotes Hugh Seton-Watson's *Nations and States: An Enquiry into the Origins of Nations and the Politics of Nationalism* 'that no "scientific definition" of the nation can be devised; yet the phenomenon has existed and exists' (1977, p.5). The power of nation or indeed of any large imagined community is that it is influential in creating a widespread and influential identity on a largely ideological foundation. Those grouped together by nationality will have certain characteristics assigned to them, both positive and negative. The label 'people with disabilities' is often used to group together people who have a disability, not just as a descriptive word but to apply a certain number of expectations and assumptions, many of which are often negative. In *Wonder*, when Julian's mother states 'Beecher Prep is not an inclusion school' (p.196) she is trying to remove August due to a classification. Additionally, when Christopher is mocked for his dream of going to space by a classmate's brother who told him 'they didn't let spazzers drive rockets that cost billions of pounds' (p.33) he is being mocked through association with a group. The characters of August and Christopher have nothing in common apart from both being viewed as part of the community of 'people with disabilities'. Their futures are threatened and aspirations demeaned due to their classification as part of this imagined community being given priority over their individual needs and abilities. Inclusion in this grouping of 'people with disabilities' creates a number of challenges toward the identities and opportunities of the characters with disabilities throughout the novels.

While Seton-Watson mentions, as quoted above, that the nation cannot be defined his own closest attempt is as follows:

All that I can find to say is that a nation exists when a significant number of people in a community consider themselves to form a nation, or behave as if they formed one (1977, p.5).

This may not seem at first to correlate with the representation of disability in the text as a number of the characters (in particular Christopher in TCI), do not consider themselves in this group nor want to be. However, Anderson's proposed definition allows a more applicable method. Anderson notes:

I propose the following definition of the nation: it is an imagined political community – and imagined as both inherently limited and sovereign (1983, pp5-6).

In this approach it is not necessarily the group themselves who must imagine this unity. The imaginer is not specified. As will be discussed in the next chapter in relation to Said's writings on Orientalism a group can also be defined by others. In the following sections this designation will be seen to be defined by peers, educators and friends, many of whom are normative.

Anderson discusses the 'three paradoxes' (p.5) of nationalism which will be shown here to also prove relevant to disability studies. The first paradox mentioned by Anderson is 'the objective modernity of nations to the historian's eye vs. their subjective antiquity in the eyes of nationalists' (p.5). Historical significance is given to the nation and this historical importance is rarely questioned even though it may not be accurate. This is particularly interesting in relation to the writings of Lennard Davis which were discussed at the beginning of chapter one of this thesis. He argues that disability as a social concept is relatively new. Yet disability as both a physical and social model is seen as something that has always been. This historical precedence gives credence to Anderson second paradox helping to position disability as a prevailing identity marker within the novels. The second paradox Anderson discusses is:

The formal universality of nationality as a sociocultural concept - in the modern world everyone can, should, will 'have' a nationality, as he or she 'has' a gender - vs. the irremediable particularity of its concrete manifestations (p.5).

As everybody has a nationality, everyone is considered to either have or not have a disability. Whether someone is believed to have a disability will influence how they are treated in

society. Christopher challenges this in *TCI* when he states that 'everyone has learning difficulties' (p.56). This highlights the point Anderson makes about the 'the irremediable particularity of its concrete manifestations'. Disability cannot be a blanket term as it cannot have a definitive definition. As Christopher points out everyone will have difficulties in learning something or doing something so how can certain individuals be classified as having a disability while others do not. However, disability or lack thereof is still seen as an essential part of identity throughout the texts.

Many of the characters with a disability in the novels struggle with consolidating their self-identity and public identity. However, in *Me Before You*, Will's journey revolves around balancing his identity before and after acquiring a disability. This transition is something Will is never able to truly reconcile. The second paradox states everyone has a nationality and it can be similarly argued that, as part of one's identity, everyone either does or does not have a disability. Acquiring a disability then later in life, as the character of Will does, is represented as being incredibly difficult for his self-perception. Ellen Samuels has written 'that disability has more in common with sexual orientation than with race, ethnicity, or gender (p.234)' and that a person with a disability must go through a process of 'coming out' similar to the commonly seen idea of someone coming out as gay. She writes that the identity of disability is something that is thrust upon someone and it must be actively accepted. She writes that while 'to "come out"... usually refers to the time that one first realized and came to terms with one's own identity' (p.237) it is not 'a static and singular event' (p.237). Coming out can be seen as a process of self-acceptance and of portraying oneself to others. This process of coming out is portrayed as very difficult for Will. Whereas the narratives of the other three novels promote self-acceptance Moyes novel does not allow such an outcome. She highlights the difficulty of disability and portrays it as something that cannot be lived with. This depiction can also be linked to a post-colonial or indeed colonial representation of a new identity being forced upon an individual. Will is told he is now one thing and perceived as such when he himself feels he is still something else and the difficulty in balancing this causes him a great deal of grief.

Will's identity before acquiring his disability is shown in the opening pages. He was active, work focused and very independent. The story opens with Will in bed with his girlfriend discussing work and exotic trips. The initial impression of Will is he lives an idyllic life, he has the job, the girl, the money everything that a character in a traditional romance novel longs to have. Moyes seems to have placed the happily ever after story at the beginning of her book. This setup is written to emphasize the loss that acquiring a disability cause Will. Will is the stereotypical prince charming character; rich, handsome, intelligent and exciting. Moyes positions disability as the opposite to happily ever after, as the loss of all things good. While Will's story improves throughout the novel, he never again reaches the same levels of happiness. Johnstone notes that 'disability as an identity is often a personal construction, a purposive attempt to make meaning of self in the world' (p.2). This personal identification with disability is something Will cannot accept as anything except negative. Will created his identity through his actions, he existed in his work and in his hobbies and once they were taken from him, once independence as he knew it was lost, he gave up hope.

It seems for Will that his identity and his self-perception is with his past self and no matter what happens now it will never be enough for him. Even his relationship with Louisa does not enable him to let go of his past. He tells her 'the thing is, I get that this could be a good life. I get that with you around, perhaps it could even be a very good life. But it's not my life' (pp. 425-426). Will is incapable of accepting his new identity. Louisa in a heated argument tries to convince him that he does not need to let his disability be his identity 'you don't have to let that...that chair define you' (p.426). Will refuses to listen 'but it does define me, Clark. You don't know me, not really. You never saw me before this thing' (p.426). In this sentence Will shatters the strongest relationship he has managed to build since his accident. He believes Louisa will never truly know him because who he is, his identity, is already gone. 'I am not designed to exist in this thing – and yet for all intents and purposes it is now the thing that defines me. It is the only thing that defines me' (p.426). Will's understanding of disability is as an identity that is all-encompassing. Johnstone's notes that "people with disabilities often have a limited range of identities to choose from because of societal labels and ascriptions' (p.2). Will feels trapped in his new identity. He feels he is unable to express his true self. It is

worth referring here to Bhabha's discussion on hybrid identity. Bhabha has written about hybridity and how identities can interact. He notes:

The social articulation of difference, from the minority perspective, is a complex, on-going negotiation that seeks to authorize cultural hybridities that emerge in moments of historical transformation (1994, p.2).

This sentiment seems to relate strongly to Will's experience. The complex on-going negotiation occurring with his new identity, not just as disabled but as a combination of two worlds. The fact that he no longer is accepted as normate but struggles to accept his role as disabled means he arguably fits in this category disrupting area of hybridity. The change that occurred in his moment of transformation also changed his position from a member of the majority to the minority, a place where identity seems to be much more complex and challenging. Will's identity has been changed and he struggles to accept this however, he is also aware he cannot go back. Throughout the novel a lot of who Will was seems to be recaptured through his new relationship with Louisa such as his confidence and access to activities he enjoys. However, the lack of agency he is allowed, or even allows himself, means he either cannot see this or refuses to see it. Will is trapped physically but also trapped psychologically in the memory of his past self, something he cannot let go. He is stuck in a new identity that he cannot accept, he is unable to imagine his position in this new community or indeed any community.

Will's understanding of what disability is has a damaging psychological effect on him. He ignores opportunities to recapture his past. The separation of identity for Will is comparable to Anderson's second paradox. To expand on the above, Will understands his identity through his work and his hobbies but more universally he understands his identity as someone who does not have a disability. Will views disability as a binary identity. Someone either has a disability or does not have one. He cannot accept that it is possible to cross this divide. Louisa manages to recreate opportunities from his past life, of trips to concerts, holidays away and even the opportunity of skydiving (p.366) but Will cannot not accept this as his understanding of his reality has been fundamentally broken. He is a person without a disability forced to live

the life of someone with a disability. It does not matter how many opportunities Louisa creates or how much love she gives him, for Will his life is already over.

The third paradox Anderson discusses is 'the 'political' power of nationalisms vs. their philosophical poverty and even incoherence' (p.5). Disability as an identity in the novels has a powerful effect on those given it. The rationale behind being given this identity is highlighted as inconsistent and prejudiced throughout the novels as has been seen in previous chapters. Throughout the texts this identity is used as a political force in societal interaction. As discussed in chapter 2, disability as a social construct is almost impossible to define, cannot be consistent and yet remains very powerful. As the title of Anderson's book describes, the disability community, like the notion of nationhood, is an imagined community. Throughout the four books characters with disabilities face many of the same problems and the same prejudices even though they have a wide variety of disabilities, backgrounds and cultural statuses. This is due to an assumed belief about people created by this notion of an imagined community of 'people with disabilities' which has been integrated into the societies seen in the novels.

An interesting example of a community of people with disabilities is the online forums in *Me Before You*. As mentioned in chapter two, the internet is seen as a positive force in the book for people with disabilities. It is a way to share information, to create connections and to have more power over one's own self-identity. The extracts from the forums included in the novel also offer a more well-rounded discussion on disability as the voices of other characters with disabilities are heard. Bowker and Tuffin wrote that 'for disabled people the online medium reportedly offers easy and accessible communication, as well as greater command over aspects of one's life' (p.330). While much of the use of online forums in the novel is by Louisa, rather than Will, it still offers an interesting perspective. Even within a small group of people with very similar disabilities the perspectives are very different. For example, the first response Louisa receives to her post about Will is from a religious person who seems very judgemental about Will's position and mentions that Will's condition is the Lord's decision. 'He [God] decided to change your friend's life, in His own wisdom and there may be a lesson

in it' (p.269). Louisa quickly moves on from this piece and the reader is shown a number of other responses. The following responses are from people who have similar conditions to Will, one of whom, Richie, offers a very positive response stating from his experience things will get better (p.269). Another response from a responder with the username Gforce, agrees with Will and wishes they themselves had the courage to end their life.

So I think you are asking the wrong question. Who are the AB [Able-Bodied] to decide what our lives should be? If this is the wrong life for your friend, shouldn't the question be: How do I help him to end it? (Moyes p.271).

Although the forum is mostly presented as a positive support system in the novel it also highlights how different people can be. It is difficult to find common ground for people with very similar disabilities yet across these novels characters whose disabilities are vastly different are treated as one group. The following section will further discuss how literature can help both create and reflect the disabled identity and its role in popular media.

3.3 Building and Maintaining a Community

Anderson writes of 'the novel and the newspaper' that 'these forms provided the technical means for re-presenting the kind of imagined community that is the nation' (p.25). This highlights the power of literature to help create the identity of the nation. He also notes (p.12) that the nation is built by aligning itself, or against, previous structures and ideas such as religion and monarchy. This section will explore how these texts connect with older representations of disabled characters to both modernise and maintain traditional understandings of disability.

Anderson noted how symbols are very important to the creation of the nation (p.9). It can be argued these texts, due to their popularity, could be considered symbols of disability. An image or idea that helps solidify the disabled identity. Anderson writes that 'no more arresting emblems of the modern culture of nationalism exist than cenotaphs and tombs of Unknown Soldiers' that they are revered 'precisely because they are either deliberately empty or no

one knows who lies inside them' (p.9). The tomb of the unknown soldier is so powerful as it is a representation of the nation through a faceless individual. It allows people to connect to an emotion instead of a particular person. This symbol is safe and controlled as the nation cannot suffer from the flaws of any particular individual. In contrast, traditional images of disability are often considered disruptive. Alice Hall, in her book *Disability and Modern Fiction* (Hall, A., 2012), offers an example of a contemporary monument of a person with a disability. A statue called Alison Lapper Pregnant was unveiled in London in 2005 to a very negative response. The statue was made in the image of Alison Lapper, a woman with no arms and shortened legs, while she was pregnant. Hall gives a record of the negative response the statue received in the press (Mouland 2005) noting it was deemed 'repellent' (Simon 2005) and not considered as 'art' (Jones 2006). The monument of the unknown soldier provides pride and a feeling of belonging while a statue of someone with a disability brings about resentment and estrangement. Alison Lapper Pregnant received such backlash as it was disruptive. It challenged popular understandings of disability both by combining pregnancy and disability, and by including the disabled female body in a popular public space (Trafalgar Square) where it had not been seen as such before. However, the primary texts studied here have avoided this issue. They are not disruptive in the same way the statue is. The texts carefully built upon literary representations of disability that came before it. They are usually safer, more controlled and while they occasionally have challenged some aspects of disability representations they never push too far.

The novel is capable of achieving the same aim as the tomb of the unknown soldier. First person narration can offer this feeling of connection in literary texts as readers can place themselves in the shoes of a protagonist. This is not truly allowed happen in disability literature however. Even when August or Christopher are allowed to tell their own stories the appeal of their tales is in their otherness as opposed to their relatability. The disabled body is always on show for its difference (Garland-Thompson, 2002). However, these texts exist somewhere in between the tomb of the unknown soldier and the statue of Alison Lapper Pregnant. They build on previous tropes of disabled characters; the inspirational story, the fairy tale stories, the eccentric other. Even when they challenge or subvert these images, they only do so to a certain point so as not to alienate the reader. A. Hall argues that 'disability,

while prevalent in literary and artistic representations throughout the centuries, has remained, until recently, a critical blind spot' (p.3). It can be argued, this is because the most popular and accepted images of disability never sought to challenge too strongly the status quo. Those works that did, such as the above-mentioned statue, were rejected. The success of the novels studied here can be attributed to their relative inoffensiveness. The novel that received the most backlash, *Me Before You*, did so not simply for putting forward a potentially negative view of disability but more importantly putting forward a more challenging, disruptive view of disability. These texts introduce disability but do not put forward a portrayal that is too challenging. This seems reminiscent the educational theory of Vigotsky's Zone of Proximal development (Matsumoto 2009, p. 586). Vigotsky argues that a child learns best in the safe area between what is too advanced and what they already know. The success of the imagined community is building upon what is already there while slowly pushing forward but never too abruptly so as to lose the attention of the audience. Ideas such as religious belief and monarchy were not challenged too strongly too quickly in the rise of the nation and historical representations of disability could not be swept away too swiftly.

Anderson discusses the foundations of nationalism and how it built itself through association with what came before:

Nationalism has to be understood by aligning it, not with self-consciously held political ideologies, but with the large cultural systems that preceded it, out of which — as well as against which - it came into being (Anderson, p.12).

The idea of a disabled identity, similar to that of a national identity, does not exist in a vacuum. It is created in relation to the systems that came before it. Contemporary disability representation has evolved by basing itself on its literary predecessors. Chapter one discussed the history of disability representation in literature and many of the trends that were discussed continue in these novels. The primary texts lean heavily on storytelling devices from older texts. For example, the quirkiness or strangeness of the main characters is a commonly used trope. The use of the disabled body or mind as exotic, a continuation of the fairy tale or comic book character where difference is highlighted to inspire awe in the reader. *TCI* even gives Christopher a certain kind of superpower to connect him to the comic book history that

came before him. Christopher showcases his abnormal mathematical skills (p.84) to unintentionally elicit amazement from his father's friend. Christopher's role as a character with perceived superhuman intelligence or talent that struggles to fit into his own home world is similar to comic stories such as Marvel comics' X-Men (Lee and Kirby 1963). The X-men features a comic book world where characters known as mutants are rejected in their home towns due to genetic mutations that make them different. Anderson argues (p.22-32) that the nation didn't usurp the previous systems (such as religion and other political systems) however, it did use their structures to evolve and managed to create a space for itself to exist alongside what came before. The success of these novels certainly did not come at the cost of the superhero industry for example, although, as mentioned the texts used what was familiar to draw in an audience and to then create its own niche. Taking this into consideration the recent success of mainstream novels focusing on a character with a disability is not actually surprising as a rise in popularity in texts such as Marvel and DC comics created a space for these stories to be told. Additionally, as A. Hall (p.7) notes the sudden rise in critical discussion around disability can be somewhat attributed to the rise in identity politics in the civil rights, feminist and LGBT+ movements. The intersectionality of these movements challenged foundational ideas of the permanency of identity. Stiker (1997, p.223) noted it became part of a 'grand movement' focused on dismantling the ideas of identity, and in the process disability, as a social construct.

Anderson in his work discusses that the idea of the nation was not solely used for the purpose of nationalism:

The 'nation' thus became something capable of being consciously aspired to from early on, rather than a slowly sharpening frame of vision. Indeed, as we shall see, the 'nation' proved an invention on which it was impossible to secure a patent. It became available for pirating by widely different, and sometimes unexpected, hands (p.67).

This idea is interesting both in the ways that these contemporary novels continue much older trends and in how disability and difference as an idea has been represented in literature in many forms. The understanding of disability has been 'pirated' in a wide array of uses. In chapter one, Baynton's historical discussions were highlighted regarding how disability was

used as a way of justifying discrimination towards groups such as women and black people (2001). Additionally, comic book characters such as the mutants of the X-Men series highlighted mutation of genes, or natural born differences in people to showcase the struggle of marginalised groups. Even the primary texts studied have also arguably pirated that idea of disability. As these texts are written by normate writers and feature inspirational stories of overcoming they could be considered to be more benefit to normate readers than the plight of a person with a disability. Trevor in *TRFOC* is seen to overcome his disability by challenging his fears and insecurities and learning to take risks. Along the way his journey helps inspire others such as his father Bob and his carer Ben do the same. Much of Trevor's characters role seems to be to inspire those around him. This is also seen in *Wonder* as August finishes the book by being quite literally celebrated for inspiring others by overcoming his hardships as he is given an award that is for 'recognizing greatness' (p355). However, even though it is an award for 'recognising greatness' August believes he receives this award for being himself (pp.357-8). The novel often tries to challenge negative representation. The opening of the book attempts to show August as an ordinary kid even though he does not look like one. However, it does follow the inspirational storytelling trope, arguably reducing the scope of August's character as he becomes a symbol of inspiration to those around him. Yet, in terms of gaining mainstream success and attention and becoming part of contemporary understanding of disability, this method of storytelling has seemingly worked.

Me Before You received some backlash for its story as it arguably too strongly challenged the conventions of traditional disability representation. Much of the controversy garnered was due to a disabled character choosing assisted suicide over living with disability. However, this reaction may be more multi-faceted than just that. The book portrayed a disability that could not be overcome; a story that was set after the fairy tale ending instead of in the lead up to one. It also highlighted a disabled character with a controversial voice, which was neither silenced nor changed and a tragedy that did not prove obviously beneficial to the development of other characters. It can be seen as too challenging to the other systems for it to be an easy and accessible depiction. It disrupts disability's societal place in relation to a number of factors. For example, religious belief is questioned as Georgina challenges her mother in relation to agreeing to Will's decision 'what about your religion?' (p.133). The other

texts prod and poke at certain ideas, but they do so in a less obtrusive manner as when Christopher, August and Trevor challenge their perceptions it is inspirational. Will's decision is not considered inspirational. It challenges religious belief as mentioned above, the legal system as Louisa notes 'I watched the news reports and listened to the legal arguments' (p.241), and parental instinct when Camilla states 'I never set out to help kill my son' (p.135). It is not even simply that it challenges these systems but it challenges them in a way in which they cannot co-exist, in the way Anderson writes that the nation was able to do and needed to do with its opposition.

It is interesting to note that while *Me Before You* is disruptive arguably in a comparable manner to how statue Alison Lapper Pregnant was it did not receive a rejection by the mainstream in the way the statue did. There are a number of reasons for this. Firstly, the novel itself tries to negate some of the disruption to the systems mentioned above. In response to religious belief Camilla states; 'I chose to believe that God, a benign God, would understand our sufferings and forgive us our trespasses' (p.141). Louisa's sister bluntly states about Will's decision about assisted suicide 'it's legal as well. It's not as if they can stop him' (p.161). Camilla's final decision is framed as a mother sacrificing her own happiness for the sake of her child, something that would be considered much more acceptable (p.143). Secondly, while the book did receive backlash the reason it managed to become so popular is that this is not Will's story. This is a story about Louisa. The novel has two sequels that focus on her character after Will has died (Moyes 2015 & 2018). By not having the story actually focus on Will it allows for a small degree of separation. Will remains the character being observed and the tale of tragedy can remain an exhibition, an oddity, something to consider and reflect upon instead of being empathetic toward. This is the story of how Louisa overcomes a meeting with disability and carries on. Louisa is the inspirational story. It is the fairy tale ending of a character interacting with disability and moving on without it being part of their story any longer. In a number of fairy tales, such as the Brothers Grimm story *A Girl Without Hands* (1972), a disabled character's story ends by having her disability taken away. In *A Girl Without Hands* the main character loses her hands toward the beginning of the story. However, she grows back through magic at the end so the girl can live happily ever after now that disability has left her life. For Louisa, disability is also taken away. She endures a tragedy

but she survives. As with the tomb of the unknown soldier, a soldier has died but the nation lives on in their sacrifice. The status quo remains. Mainstream disability representation has grown and been maintained by staying close to the work that came before it and by being inoffensive to any opposing structures.

This section has explored how largescale ideologies such as nationalism or disability can evolve by building on previous ideologies and representations. It has discussed how the primary texts have built on previous depictions of disability and used this familiarity with an audience to become popular. Even when the novels seem to challenge a reader, they usually do so within in a safe way by sticking to an overall story trope such as overcoming disability. This section explored how disability identity is created and interpreted in the texts. The following sections will continue to investigate more closely how the disabled identity is seen to affect the characters with disabilities in the novels.

3.4: Identity: What is it and how does it Evolve?

To further explore the effects of forcing an identity onto a character it will be useful to engage with how identity is formed. Stuart Hall has written that 'identity is not as transparent or unproblematic as we think' (p.222). The characters in all four primary texts struggle as they each go through a process of having their identity challenged and changed. The ways in which identity is formed and reformed is something that Hall examines and will be explored here in relation to his writing. This section will focus on identify creation and development by predominantly focusing on these issues in *Wonder* and will be continued in the next section with a similar discussion focused on *TCI*.

Perhaps instead of thinking of identity as an already accomplished fact, which the new cultural practices then represent, we should think, instead, of identity as a 'production', which is never complete, always in process, and always constituted within, not outside, representation. This view problematizes the very authority and authenticity to which the term, 'cultural identity', lays claim (Hall, p.222).

In this quote, Hall challenges two aspects about identity. Firstly, that identity is something that is static and unchanging, that is an 'accomplished fact'. Deconstructing identity in these ways seems compatible with the narratives offered in the novels. *Wonder*, *TCl* and *TRFOC* all offer characters whose identities transform. Additionally, *Me Before You* presents a character who cannot accept their identity changing and suffers greatly as a result. Secondly, that identity is not created separately from representation as Hall argues that identity is something that is created 'within, not outside, representation'. As cultural representations these novels have the power to challenge and affect the understanding of disability for the reader as was discussed in the previous section. Furthermore, the characters in these novels are shown to change in relation to how they are perceived and treated by others. While the protagonists do a great deal of self-discovery in the texts much of their evolution comes in reaction to hostile environments. For example, August in *Wonder* feels like he is always seen as different from those around him even though he doesn't believe himself to be different. August is a character identifying with those who do not identify with him and a strong tension arising from this.

Hall offers two positions from which to view cultural identity. The first position, one which he attempts to challenge, defines 'cultural identity' in terms of one, shared culture, a sort of collective 'one true self' (p.223). He states that this belief allows people to connect to each other on a deeper level:

Within the terms of this definition, our cultural identities reflect the common historical experiences and shared cultural codes which provide us, as 'one people', with stable, unchanging and continuous frames of reference and meaning, beneath the shifting divisions and vicissitudes of our actual history. This 'oneness', underlying all the other, more superficial differences. (p.223)

Hall's description of identity focusing on 'common historical experiences' through a faux stable frame of reference echoes Anderson's first paradox of 'the objective modernity of nations to the historian's eye vs. their subjective antiquity in the eyes of nationalists' (p.5). Communities are formed by expectations based on historical context and a frame of reference that is considered true and definite. The understanding that there is a core unity at the heart of a community no matter the 'superficial differences' seems to match the description of an

imagined community. The phrase 'actual history' is problematic. Hall himself challenges this idea stating that 'cultural identities... like everything which is historical, they undergo constant transformation' (p.225). Hall argues that history is subject to change based on interpretation and perspective.

Hall's long quote above arguably positions the novels studied in this thesis as colonial literature as opposed to post-colonial literature. Hall continues to note that this view of cultural identity situates the arts as:

A very powerful and creative force in emergent forms of representation amongst hitherto marginalised peoples. In post-colonial societies, the rediscovery of this identity is often the object of what Frantz Fanon once called a passionate research (p.223).

He is proposing in this theory that post-colonial societies use arts and representation to try and rediscover their true identity. These texts seem to attempt to portray this. However, these books are not written by members of a community or society exploring their own identity. They are novels written by normative writers to further strengthen their view of what a disabled person should be. The characters with disabilities in these novels are seen to be exploring and challenging their identities and what it means to have a disability. These are novels masquerading as post-colonial literature about disability as it is only the characters not the authors who are processing a personal disabled identity. Hall writes that 'practices of representation always implicate the positions from which we speak or write' (p.222) and that 'we all write and speak from a particular place and time, from a history and a culture which is specific. What we say is always 'in context' (p.222). The position of the writer needs to be considered in understanding their work. The role of writer will be further explored using Said's writings in the next chapter.

To return to Hall's first view of identity, the idea of focusing on similarities instead of differences may at first seem positive. However, as it has been discussed throughout this thesis not engaging with differences within communities can be challenging for identity expression. Additionally, Anderson writes that 'the nation is imagined as limited because even the largest of them, encompassing perhaps a billion living human beings, has finite, if elastic,

boundaries, beyond which lie other nations (p.7).’ By focusing on similarities, differences become more divisive. Characters within and outside of the community who do not conform with the social norms quickly become ostracised and this can prove damaging to their self-perception. This also links into Said’s writings on the land of the barbarians which will be discussed further in the next chapter. How is identity understood by an individual if their place in their community, their culture, is constantly challenged? This sentiment seems to be highlighted in the opening line of *Wonder*. ‘I know I’m not an ordinary ten-year-old kid (Palacio, p.11). This is the introduction to August that the character themselves offers the reader. August knows he does ‘ordinary things’ (p.11) but he knows he is not ordinary. He knows this because ‘ordinary kids don’t make other ordinary kids run away screaming’ and ‘ordinary kids don’t get stared at wherever they go’ (p.11). August’s identity is divided. He struggles between how he views himself and how other people view him. This is the first aspect of August that Palacio show the reader highlighting how prominent a part of his character it is. Hall’s first view of cultural identity fails here. August has numerous similarities to his peers:

I do ordinary things. I eat ice cream. I ride my bike. I play ball. I have an Xbox. Stuff like that makes me ordinary. I guess. And I feel ordinary. Inside (p.11).

Yet he is constantly rejected by those around him.

The ‘shared cultural codes’ have been superseded by the fact that August looks different. However, August is still expected to adhere to these ‘shared cultural codes’ he is expected to live in his own community as an outsider. The ‘boundaries’ created by community that Andersons notes, even if they are as he says ‘elastic’, will always be intrinsically exclusionary to someone, either to those outside of it or those on the fringe of the community itself. Therefore, a focus on similarities is not only damaging to the expression of difference but also, in this instance, not realistic. Hall notes that identity is created within representation. August’s identity is challenged by others views of him. His self-perception does not exist separately to how he is seen or treated by others. This treatment, often informed by literature and movies as discussed in chapter two and in the previous section, undermines how August sees himself. His self-identity is being moulded by representation and by the cultural norms of the world

around him. When he gets compared to 'Gollum' (p.312) or 'Darth Sidious' (p.59) these representations have taught his peers to treat him poorly. This treatment over a long period of time effects August. A character who is considered caring and fun loving is also seen as fearful and mistrusting of others because this is how he is treated.

Hall offers a second way to view cultural identity:

This second position recognises that, as well as the many points of similarity, there are also critical points of deep and significant difference which constitute 'what we really are'; or rather - since history has intervened - 'what we have become' (p.225).

Hall argues that this view is somewhat more realistic, that a community is made of collective differences. If identity is founded in difference and individuality, Hall claims that "It is only from this second position that we can properly understand the traumatic character of 'the colonial experience' (p.225). Colonialism forges an identity of a colonised group. The coloniser seizes control of the colonised and will attempt to identify them using the lowest common denominators to achieve the 'oneness' Hall mentions in definition one. Self-definition by members of these groups can be empowering, but having an outside power create this definition can be very damaging. Hall then references Foucault's power/Knowledge paper:

Every regime of representation is a regime of power formed, as Foucault reminds us, by the fatal couplet, 'power/knowledge'. But this kind of knowledge is internal, not external. It is one thing to position a subject or set of peoples as the Other of a dominant discourse. It is quite another thing to subject them to that 'knowledge', not only as a matter of imposed will and domination, by the power of inner compulsion and subjective con-formation to the norm (Hall, pp.224-226).

This use of knowledge to alter identity is powerful. Hall is stating that the trauma of colonial identity is that an Other defines a community and forces that definition upon them until it becomes an accepted discourse. Ngũgĩ's writing (1986) is echoed here, as he discusses colonised countries fighting back using the language of the coloniser. When an outside force is able to get someone to internalise their view of what their identity should be, Hall and Ngũgĩ argue this is the true trauma of colonialism. This trauma can be seen in terms of the disabled

identity in *Wonder*. August believes he is not ordinary because of how he is treated by others. He is ordinary, he is only different when others reject him.

August learns to accept himself as different, as an outsider. He states he is not ordinary (p.11), and that he is ugly (p.76) and only really learns to change these views as his peers slowly accept him. His identity throughout the novel is intrinsically linked to his treatment by others. External forces altered his internal knowledge meaning he accepts himself as someone who is different. August himself admits this stating 'here's what I think: the only reason I'm not normal is that no one else sees me that way' (p.11). August does not state that other people do not see him as normal, he states that he is not normal because of how other people see him. Here he freely admits that his identity is defined by how others view him not by what he says or does. An interesting example of public perception vs self-perception can change identity is the story of August's hair. August, in an act of taking control of his appearance grows his hair out. He seems to have a number of reasons for this. Firstly, August himself states 'one of the reasons I grew my hair long last year was that I like how my bangs cover my eyes: it helps me block out the things I don't want to see' (p.32). This has both positive and negative connotations, it is a show of agency that August chooses his look even if it is to hide away from those who won't accept him.

Choosing to cover his face doesn't explain why he grows a small braid at the back of his hair though. It is shown, through questioning from Julian, that this is due to his love of *Star Wars*.

"Wait, I have a question for August," said Julian, raising his hand. "Why do you have that tiny braid in the back of your hair? Is that like a Padawan thing?"

"Yeah." I shrug-nodded.

"What's a Padawan thing?" said Ms. Petosa, smiling at me. "

It's from Star Wars," answered Julian. "A Padawan is a Jedi apprentice."

"Oh, interesting," answered Ms. Petosa, looking at me. "So, are you into Star Wars, August?"

"I guess." I nodded" (pp.58-59).

Later in the text, Via explains that the ponytail actually carries much greater meaning for August:

I had always found his obsession with everything *Star Wars* kind of geeky, and that braid in the back of his hair, with its little beads, was just awful. But he had always been so proud of it, of how long it took him to grow it, of how he had chosen the beads himself in a crafts store in Soho. He and Christopher, his best friend, used to play with lightsabers and *Star Wars* stuff whenever they got together, and they had both started growing their braids at the same time (p.120).

For August this hairstyle was part of who he was, a part of his appearance he could be proud of that connected him to both a close friend and a community of fans. But this was shattered by Julian as the moment *Star Wars* is mentioned he begins associating August to Darth Sidious, "What about Darth Sidious?" he said. "Do you like him?" (p.59), a *Star Wars* character who in the films 'gets burned by lightning and becomes totally disformed' (p.59). The outsider perspective of Julian completely altered August's identity in a mere moment. Gone was the August who loved *Star Wars* and showed off his braid with pride, as he immediately runs home and cuts it off. Julian contorts a part of August's identity changing it from something positive to something to be ashamed of. The exterior judgement and association altered how August both sees himself and presents himself.

August constructed an identity for himself in connection with, a 'padwan', a young hero in training. Here it is used to associate him with the antagonist of the story instead. This took away the one part of his appearance he felt he had control over. August has part of his identity taken from him. Hall writes of the coloniser that 'they had the power to make us see and experience ourselves as 'Other'' (p.225). August cut off his braid because it no longer served as a symbol of his love for *Star Wars* or a connection to the young protagonist from the series, it now served only as a symbol of difference and deformity. August cut away part of his own identity because it had been twisted into something unrecognisable and unwanted. August's braid represents something that is outside Julian's 'stable, unchanging and continuous frames of reference' (Hall, p.223) of a person with a disability. He forces August to accept his position as the twisted antagonist as opposed to the heroic young protagonist that the braid previously represented.

Hall's writing helps to challenge the idea of a formed identity and indeed the notion of the imagined community. Highlighting identity as fluid and ever evolving further undercuts the power of the large permanent community. It can be seen throughout this section the difficulties August encountered due to having a specific identity forced upon him and trying to understand his own identity in this environment. Hall's writing also offered a broader discussion into the power of identity manipulation in colonialism. This will be explored further with the character of Christopher in the next section.

3.5 Identity, Intellectual Disability and Childhood

Hall and Anderson's writings on how identity is formed and used as a tool for colonialism will be explored further here predominantly in relation to the character of Christopher in *TCI*. It will examine how Christopher explores his own identity and deals with misrecognition in the novel. It will also be discussed how colonial and postcolonial literature have used childhood and disability to enforce certain ideas. Colonial literature has previously used images of childhood, or child-like adults as a way to justify the controlling nature of colonialism. Disability can be seen to have been used in relation to this to further this power dynamic.

Clare Barker in her book *Postcolonial Fiction and Disability Exceptional Children, Metaphor and Materiality* (2011) notes how disability, and additionally childhood, have been used as a tool by the coloniser. She argues, in a somewhat similar discussion to historian Baynton (2011) that disability was used to justify colonisation. Barker notes that "the child' is employed in historical, cultural and fictional texts of imperialism and its aftermath as both national symbol and manipulated subject' (p.7). She references Rudyard Kipling's 'The White Man's Burden' (1899) as an example of this. She argues that child characters or indeed childlike traits were used to symbolise a person or group of people that needed to be protected. There are numerous examples in *TCI* of Christopher exhibiting traditional childish or innocent traits and being treated like someone much younger than he is (Christopher is at least fifteen for the duration of the book (p.7). Ciocia states that 'Christopher can reclaim this idea of pure innocence, not because of his age, but because of his disorder' (p.331). After the opening

page of the novel sets up the mystery of a dog's death, the following page has Christopher introduce himself with his full name and then stating 'I know all the countries of the world and their capital cities and every prime number up to 7,507' (p.2). This phrasing is something more likely heard from a small child than a teenager. This sentence is a twist on power dynamics. Christopher states this to show off his intelligence, yet it seems set up to be read as a sign of immaturity by the reader. The writer is using Christopher's own way of viewing the world against him. The introduction then continues by showing how Christopher struggles understanding emotions and facial expressions. Therefore, by the third page of the book Christopher is seen as someone with hints of childlike expression as well as emotional and empathetic immaturity, a character who would likely find day to day life difficult. Indeed, it is not for another five pages until we find out Christopher's age, it would be easy to first mistake the narrator as much younger. None of what Christopher has said or done is particularly damaging or negative. However, the writer has structured Christopher's way of life so as to make him seem vulnerable and in need of care. Barker writes, while building on the work of (McEwan 2009), that by 'naturalizing colonial subjects as 'permanently childlike' European imperial powers were able to assume the role of 'permanent guardians' (Barker, p.7). Christopher's representation attempts to ensure he is perceived in a long lasting or even permanent state of childhood due to his disability. Harking back to Todorov's writings (1993 p.94) discussed in chapter one, identifying difference can often be used to justify hierarchy and give one side a sense of control. Disability was used a tool to accentuate difference and position Christopher as less socially intelligent than the reader.

Barker's work focused on how disability was used in colonialism and postcolonialism. However, here disability is not used a tool to aid another ideology or indeed damage another group, instead it is more insular. In *TCl*, disability becomes the imagined community being undermined. Christopher is the symbol of the disabled person 'permanently childlike' and in need of 'permanent guardians'. Stuart Hall writes that "texts restore an imaginary fullness or plenitude, to set against the broken rubric of our past' (p.225). In the wake of the disability rights movement (A. Hall, p.6) in the 1970's and the pursuit of more independence for people with disabilities this text restores the traditional story of those with disabilities requiring help. Christopher is seen at times in the text to be quite independent. However, this independence

is usually only positive when it is in a controlled environment. When Christopher presents independent thoughts and challenges social norms and expectations when in school it is seen as positive and heroic (p.32). However, when Christopher leaves home to travel to see his mother (p.154) it becomes more worrying for the reader as Christopher is no longer safe. Christopher choosing to make the journey and successfully completing it could be seen as a symbol of agency. However, Ciocia argues that throughout the text the reader will feel a 'desire to protect and prolong the state of "innocence"' (p.332) of Christopher. He can be independent to a point before it becomes uncomfortable. The novel puts Christopher in a position that highlights his vulnerabilities and weaknesses such as his fear of people and lack of social awareness instead of his strengths.

It is interesting to investigate Christopher's representation by revisiting Stuart Halls methods of viewing identity. The first way he positions viewing cultural identity is 'in terms of one, shared culture, a sort of collective 'one true self' (p.223). Christopher really struggles to connect his identity to other people. He is often treated poorly or at least not accepted by others (p.33, p.206). Christopher also finds it difficult to understand those around him and questions a lot of their ways of life. For example, he challenges religion (p.203), common language use (p.13) and the idea that his way of life is any less logical than others (pp.31-32). Other characters find it as difficult to connect to Christopher and he finds it difficult to connect to other characters. He especially dislikes his classmates, the only peers with disabilities he seems to know (p.56). This collectiveness or unity does not seem to work for Christopher. The second method of viewing disability that is presented is: 'that, as well as the many points of similarity, there are also critical points of deep and significant difference' (p.225). While there are many differences between Christopher and the close community of people around him they do seem to be able to co-exist. However, most interactions Christopher has in the book (excluding meetings with characters such as Siobhan, for instance, where she is paid to be there) are uncomfortable either for him, the other character, or both. At school Christopher does not like his classmates, at home the stress he caused his parents led to a separation and possible emotional breakdowns by both parents. Christopher recognises his differences to those around him yet this recognition does not seem to make anyone's life easier. Christopher does not seem to be able to fit comfortably with either of these views of cultural identity and

consequently spends most of his time as an outsider. The other primary texts show disability, physical disability, as an obstacle to cultural identity and community that can be difficult to overcome. However, in *TCI* this obstacle seems to become insurmountable. Christopher has to find different, more unusual ways to cope with this.

Christopher was not able to relate to people around him. Instead, to help create a sense of connection and community he mostly connected to animals and to fictional characters. For instance, Christopher is a fan of Arthur Conan Doyle's Sherlock Holmes character and some of the story of the book mirrors Christopher's desire to be like the character. Christopher states that:

I like Sherlock Holmes and I think that if I were a proper detective he is the kind of detective I would be. He is very intelligent and he solves the mystery and he says

The world is full of obvious things which nobody by any chance ever observes.

But he notices them, like I do (p.92).

This is one of the most powerful connections Christopher's admits to in the book (outside of his relationship with his teacher). On pages 109-110 Christopher states the only reason he knows there is love between himself and his father is because of a list of things they do for each other as he struggles to comprehend the idea of love. However, he has no issue proclaiming his affection and admiration for Sherlock Holmes due to the character's intelligence and logical thinking. Sherlock Holmes is also known as a character who dislikes other people and struggles to make social connections. The Sherlock Holmes series even features a club for people who dislike the company of others called the Diogenes Club of which Holmes himself was a member as seen in the collection *The Memoirs of Sherlock Holmes* (Doyle 1894). Christopher also feels a great connection to animals. He writes at the beginning of the book; 'I like dogs. You always know what a dog is thinking. It has four moods. Happy, sad, cross and concentrating. Also, dogs are faithful and they do not tell lies because they cannot talk' (p.4). Christopher feels connected to dogs because he sees similarities in them and finds them easier to understand. He says dogs do not tell lies and later exclaims 'I do not tell lies' (p.24). He is also very caring toward his pet rat Toby and feels that rats are misunderstood creatures (p.52) because that world makes assumptions about them that are

not true. Christopher also equates the lives of animals to his own and once finding out his dad killed the neighbour's dog becomes fearful for his life 'Father had murdered Wellington. That meant he could murder me' (p.152). There are also a number of instances in the text where Christopher mimics animals stating that when he sees strangers that he does not want to interact with, he 'made a noise like a dog barking to scare them off' (p.190, p.213). When Christopher gets scared on his journey, he writes that; 'and there was sweat running down my face from under my hair and I was moaning, not groaning, but different, like a dog when it has hurt its paw' (pp.216-217). Christopher is forced to find a sense of community wherever he can as he has been shunned by his own.

Barker has noted that:

The trope of child development lends itself persuasively to narratives of nation-building and cultural transformation in postcolonial communities. The disability of these children is, in turn, frequently used by fiction writers to embody both the postcolonial nation-states potential for radical difference and its supposed fragility (Barker, p.2).

As previously mentioned, the disability rights movement in the 1970's sought to create a new identity for people with disabilities allowing for more independence. This created an opportunity for literature to present new interpretations of disability to be included in this framework. TCI has become one of the most popular literary representations of disability since the disability rights movement. His journey into adulthood and agency could be considered a representation of a new identity. A disabled character, who pushes boundaries and tells his own story. A character who, as Barker notes above, has both the potential for radical difference but is also very fragile. Christopher in his own way is very confident about his own identity (p.2, p.32, p.59) and the reasons he does the things he does, yet, much of his identity is rejected by others. He is the image of a new identity, or indeed symbol of a community, that has come to terms with its own self but struggles to be accepted by the world around it as it is haunted by previous representations.

This postcolonial image can be argued further by connecting it to Stuart Halls quote:

The past continues to speak to us. But it no longer addresses us as a simple, factual 'past', since our relation to it, like the child's relation to the mother, is always-already 'after the break'. It is always constructed through memory, fantasy, narrative and myth. (Hall, p.226)

Hall's image of the mother figure representing the past is made concrete in *TCI*. In a more extreme version of the birthing symbol, the book begins with Christopher's mother being lost and assumed dead. In the book, Christopher has to flee from his controlling father to discover his mother and by doing so uncover the secrets of his own past and be able to fully come to terms with his present. When Christopher meets his mother, it isn't exactly what he expected. He does not end up living with her fulltime. As Hall states of the past that is constructed through memory and myth, so was much of Christopher life at the beginning of the book. His mother was not actually dead. When he realised she was alive and went to live with her she was not able to accept that level of responsibility, nor was her new partner. Christopher, the new image of disability is not able to rely on his past, or his present, but has to struggle and fight to create a new life for himself. However, much of the rest of the analysis in this chapter undermines a lot of these ideas.

This section has allowed a further exploration in identity representation in relation to both childhood and intellectual disability. It has discussed the ramifications of misrecognition on the character of Christopher in *TCI*. Additionally, it examined the role disability can play in both colonial and postcolonial literature. The following sections will move to examine further the notions of identity and the imagined communities by examining the education system as seen in *Wonder* and *TCI*.

3.6 Identity, Home-schooling and Mainstream Education

This is why so often in the 'nation-building' policies of the new states one sees both a genuine, popular nationalist enthusiasm and a systematic, even Machiavellian, instilling of nationalist ideology through the mass media, the educational system, administrative regulations, and so forth (Anderson pp.113-114).

In the above quote, Anderson lists a number of systems that both reflect and help to create the idea of nation. The following two sections will bring chapter three to a close with a discussion of one of these; the educational system. Characters struggling with their education system are pivotal plot points of the novels *Wonder* and *TCI*. The next section will explore Christopher's time in a special education school. Firstly though, this section will examine August's journey from being home-schooled to entering into mainstream education and the issues that arose for him. These investigations will be examined in relation to the effect education had on the identities of these characters as well as how the school systems created and enforced a number of norms.

It has been argued in this chapter so far that there are a lot of problematic associations created through this imaginary connection of people with disability. Anderson's comment on the authenticity of imagined community is worth nothing when he writes: 'Communities are to be distinguished, not by their falsity/genuineness, but by the style in which they are imagined' (p.6). While a number of falsehoods can be gleaned from the texts, this may not be the only value in this analysis. A number of examples such as the instance of Christopher being separated from mainstream education highlight the power structure of creating this community of having a binary opposition for the normate to compare themselves. A power structure that cannot be comprised by allowing different groups to resume being together or for differences to be forgotten. The editors of the collection *Schools as Imagined Communities The Creation of Identity, Meaning, and Conflict in U.S. History* (2006) note that 'we think of schools as communities, but with the knowledge that communities can push out as well as pull in people, divide as well as unite' (p.2). They also note that schools are places where 'where adults can consciously build community' (p.16). The word 'consciously' here is denoting the idea that there is a purpose in building a community the reflects the value and social rules of those who create it. Therefore, it is not surprising the number of the wider issues of the imagined community seen so far in this chapter will be exemplified in similar ways in the educational system as seen here in the final two sections.

The opening of this chapter began with a quote from philosopher Charles Taylor who wrote about identity existing in both the public and private spheres (1994, p.37). Taylor noted the importance of recognition in connection with the public sphere. He argues that:

The thesis is that our identity is partly shaped by recognition or its absence, often by the misrecognition of others, and so a person or group of people can suffer real damage, real distortion, if the people or society around them mirror back to them a confining or demeaning or contemptible picture of themselves (p.25).

The idea of misrecognition of identity is something that has featured throughout this chapter and indeed in chapter two in the many ways these characters have suffered as they are unable to express their identity or have it recognised. Taylor deems that the inability to have your identity recognised by your peers creates 'real damage'. It is interesting to consider the school systems seen in the texts when thinking of identity recognition. August in *Wonder* experiences both home-schooling and mainstream schooling. The character is seen to struggle with both in different ways. Anderson writes that the nation is often imagined as 'the idea of a sociological organism moving calendrically through homogeneous, empty time... which also is conceived as a solid community moving steadily down (or up) history' (p.26). He continues to challenge this idea of an imagined community, or indeed the identity of nationalism, as something that is solid or fully formed. For August, his community and his identity as disabled changes and evolves in different ways in relation to his time spent being home schooled and his time in mainstream education. Koppers (2011) writes that 'to me, disability culture is not a thing, but a process' (p.4). She highlights that culture and identity, as seen in the previous sections, is an active process, that the world a character finds themselves in can shape and change their identity through recognition or misrecognition. For the character of August this effect is highlighted in his journey through the education system.

At the beginning of the novel, August is being home-schooled by his mother. This is shown to have a number of interesting effects on him. August's interactions with others are somewhat limited. He is protected as there are less opportunities for him to have his identity rejected by others. However, he also has less opportunities to express himself or to grow as a person. The representation of home-schooling here seems linked to historical precedent of removing

disability from mainstream life. Whitaker notes that in the early 1900's there were campaigns in the US and Europe to 'identify those with mild disabilities and institutionalise them'. (2013, p.7) promoted by groups such as the organisers of the first International Congress of Eugenics held in London in 1912. August was protected but also sheltered. By having a large amount of his interactions limited to his homelife, being the youngest child remained a very large part of his identity. August admits (p.19) to acting babyish to play up to his parent's expectations of him. August's identity has been partially shaped by the recognition he has received from fearful and overprotective parents. He also speaks about losing contact with friends who have moved away or who 'have all these new friends now' (p.14). August is being left behind as he does not have the opportunity to maintain or create new friendships in a school setting. August believes the reason he isn't in mainstream school is because of health reasons; 'people think I haven't gone to school because of the way I look, but it's not that. It's because of all the surgeries I've had. Twenty-seven since I was born' (p.13). Perhaps this was true for a time, however, we later see the social fear August's parents have for him with his father stating 'sending him off to middle school' is like sending 'a lamb to the slaughter' (p.20). The medical difficulties August experienced may have been the original reason for his isolation but it seems the social issues are what maintained it.

Home-schooling is not seen in the text as a completely negative experience. In terms of actual educational value August is considered to have benefited from being home-schooled. August is seen to do very well on the admissions test for a prestigious middle school which he is accepted into (p.22). He seems to have little to no difficulty transitioning to middle school in terms of intelligence or educational ability. Although it is seen that his home-schooling may have peaked and been unable to be continued as August's mother tells him 'I just think you need to learn more than I can teach you' (p.18). August needs to learn more and learn from other people. He himself has mixed feelings about going to school as he notes:

I can't say I always wanted to go to school because that wouldn't be exactly true. What I wanted was to go to school, but only if I could be like every other kid going to school. Have lots of friends and hang out after school and stuff like that (p.13).

As seen in section 3.4 with Alice Hall's discussion of the statue of Allison Lapper Pregnant (2012, p.1) disability is again seen as disruptive. It is not disruptive for August's learning per se but for social interactions that would occur in educational settings. It is seen as disruptive to others also in relation to August's relationship with bully Julian throughout the novel. The disruptiveness of disability occurs here in interaction, in that active process of recognition and misrecognition that has helped create perceived and imaginary identities. August fears these interactions and this fear has stopped him from being happy or experiencing the things he wants to experience. He said the above quote before actually being confronted with the opportunity of going to mainstream school. When he is offered the chance to attend a school, he is terrified and tries to get out of it. However, interest eventually overcomes fear and he agrees to try it (p.23).

What follows is the book's argument that while disability can be disruptive, this disruption must be endured for inclusion to take place. Mainstream education does eventually become an overall positive experience. However, it begins quite difficultly:

The rest of September was hard. I wasn't used to getting up so early in the morning. I wasn't used to this whole notion of homework. And I got my first "quiz" at the end of the month. I never got "quizzes" when Mom homeschooled me. I also didn't like how I had no free time anymore. Before, I was able to play whenever I wanted to, but now it felt like I always had stuff to do for school (Palacio, p.77).

Here August's transition into mainstream education and indeed society is seen as difficult due to a number of stark differences with his home-school education. While August was academically prepared for his new school, he was not prepared for the structure or intensity of the new system. August's above quote highlights some of the unforeseen losses that can be occurred by being separated from one's peers. Whitaker (2013) has noted that historically the move from the institutionalisation of people with disabilities to a process of community and social integration was due to was due to a rise in belief in individualised rights (as well as being cheaper for the state) (p.10). Whitaker doesn't seem to explain though how this transition went though. The transition process does not seem to garner as much historical interest. While the school sets up a number of safety nets for August, such as recruiting children to befriend him, it seems to just predominantly put the emphasis on him to adapt to

much of their rules. The systems that were set up are poorly thought through as one of the children August is paired with is Julian who seems to be known as a bully. August's transition here seems illustrative of a wider issue of social integration where the perceived outsider is considered to have to do the majority of the adapting. Whitaker noted that people with disabilities inability to 'adapt to the demands' (p.7) of a changing way of life in the industrial revolution was used as a reason to segregate them into institutions. If they could not adapt to the world, the world was not going to adapt to them.

August's struggles to make these adaptations, along with the bullying he received from Julian due both to his lack of social knowledge and his look, lead to him nearly quitting school completely. The bullying he receives leads to August often internalising the misrecognition and hatred he receives. For instance, saying 'I'm weird looking' (p.78) and calling himself 'ugly' (p.76). Taylor gave the following example when discussing internalising negative identities:

Thus, some feminists have argued that women in patriarchal societies have been induced to adopt a depreciatory image of themselves. They have internalized a picture of their own inferiority, so that even when some of the objective obstacles to their advancement fall away, they may be incapable of taking advantage of the new opportunities (p.25).

This nearly happens to August a number of times in the book. As he is judged by most of the other students, he finds it difficult to accept someone who actually wants to be friends with him. August's relationship with Summer (p.67) is the first and arguably most pure relationship he has with another student in the novel. Yet due to his rejection by others August almost loses this relationship (pp.153-154). August finds it difficult to believe someone in the school wants to be friends with him just because they enjoy his company. August attempts to quit school during the novel but Via forces him to continue telling him:

You have to go back to school. Everyone hates school sometimes. I hate school sometimes. I hate my friends sometimes. That's just life, Auggie. You want to be treated normally, right? This is normal! (p.139).

Hating school might be normal but August's reasons behind it are not. Most of the students in his school believe his disability is an infectious disease that can be spread through touch

(p.89) as malicious rumours spread around school. There is a large focus in the text on August overcoming all these obstacles in his stereotypically inspirational story of disability.

Apart from the severity of bullying he received there were also some more subtle struggles August endured when entering mainstream education. Not all students were bullies, but August still struggled in the beginning as students became accustomed with his look:

And being at school was awful in the beginning. Every new class I had was like a new chance for kids to "not stare" at me. They would sneak peeks at me from behind their notebooks or when they thought I wasn't looking. They would take the longest way around me to avoid bumping into me in any way, like I had some germ they could catch, like my face was contagious (p.77).

August is on show in his new school. He is constantly walking onto a new stage every time he changes classroom. He becomes the exotic disabled character that Garland-Thompson speaks about in her writing (2002), the Other being put on show instead of being integrated. Initially this feeling almost makes the bullying an unnecessary obstacle in the book as August already feels rejected. As Taylor writes 'nonrecognition or misrecognition can inflict harm, can be a form of oppression, imprisoning someone in a false, distorted, and reduced mode of being' (p.25). August fear of being in school and not 'being like every other kid' (p.13) has come true. His attempt to leave school from bullying is reducing his own opportunities, his own expression and mode of being. Similar to Trevor and Will being afraid to leave their homes or attend events in *TRFOC* and *Me Before You* respectively, August was willing to take himself out of school to eliminate the disruption of disability.

Following on from his quote in the above paragraph August notes that:

It took about one week for the kids in my class to get used to my face. These were the kids I'd see every day in all my classes. It took about two weeks for the rest of the kids in my grade to get used to my face. These were the kids I'd see in the cafeteria, yard time, PE, music, library, computer class. It took about a month for the rest of the kids in the entire school to get used to it (p.78).

Familiarity breeds acceptance in Palacio's novel. August's daily interactions with his fellow students removes his exoticism. Eventually August overcomes all the bullies in his class as he slowly wins over friends through his personality and determination. The book shows inclusion as overall positive even though it might be a difficult transition. The transition from home-school to mainstream education in the text exemplifies the transition from institutions to community inclusivity. However, the novel highlights a number of flaws in this transition. August's story of overcoming his difficulties showcase what seems to be a necessary suffering for him. The other children took months to accept him and there was relatively little assistance from adults or administration in this process. For the most part it was August who had to learn to adapt to the social rules of his school. There was little genuine effort made by others to engage with him until this happened. It can be seen that August grew as a person and matured through the opportunity to interact with more people, yet, it really felt like he had to do most of the changing. This was possible as his disability was mostly contained to the physical and didn't really affect educational ability or social skills. It may not have been as successful otherwise as will be seen with Christopher in the next section.

August's relationship with the education system promotes inclusion and integration. However, the method of inclusion may not be ideal here as August is reluctantly being included in the school as opposed to both sides really making compromises to learn about each other's differences. The novel seems to be showcasing the struggle of cohesiveness without really logically explaining its resolution. The compromise of the school seems to be simply allowing August in and slowly allowing him to show his personality. Whereas August is expected to adapt, change and go through months of necessary rejection to be allowed exist in the same world as his peers. The novel seems to mute August's disability through constant presence as opposed to integrating it into the mainstream setting.

3.7 Identity and Special Education

First, there needs to be a recognition that education plays a central role in the integration of disabled people in all aspects of society both by giving children the education they need to

compete and by demonstrating to nondisabled children that disability is a natural aspect of life (Hehir, p.27).

In the above quote Hehir, long time professor in the Harvard school of education, argues for the necessity of inclusion in education for both the benefit of normate and disabled children. His argument seems to coincide with August's journey through mainstream schooling in the previous section. However, in *TCI*, Christopher's placement in a special school seems to remove the potential benefits Hehir states. This final section of chapter three will explore Christopher's experience in special education in relation to his identity. It will discuss his relationship with staff and peers. It will also examine the advantages and disadvantages presented in the text of attending a special school instead of a mainstream school.

Dorn discusses that during the 1970's in America advocates disability advocates challenged school system in court over treatment of children with disabilities. While this brought about tremendous positive change in access it also unintentionally 'defined two communities—the community of the school and the community of the disabled' (2006, pp.143-144). In practicality this was likely just defining something that already existed. Dorn further discusses that this community of the disabled was short-lived in practice as once it achieved some of its aims it quickly fractured due to more individualised goals. The role and integration of special educations is seen here as still relatively new and perhaps indeed still defining itself today. Yet the image of cohesion may still exist in relation to the correct way of including those with disabilities in education. Therefore, people who challenge the current system may be seen as disruptive to a common goal. This may in fact be seen in the case of Christopher in *TCI* in relation to his education.

Kuppers (2011) writes that 'many disabled people do not see themselves as part of a movement or a group of movements, as part of a minority formation, or even a civil rights group' (p.91) and that even those that do often struggle to balance group identity with their individual identity. However, this sense of unity is deemed essential to the imagined community. If this sense of togetherness is not coming from inside the community it may be coming from outside it as people are assumed to be of similar ideals. The representation of

special education in *TCI* seems to highlight this forced sense of togetherness. Christopher attends a special school as he has an intellectual disability, even if he does not feel a connection to his classmates. Whitaker in his book, *Intellectual Disability an Inability to Cope with an Intellectually Demanding World* (2013), argues that the idea of intellectual disability is flawed. He argues (pp.53-56) that intelligence is both culturally constructed and also measuring it is a much more difficult process than it is often deemed to be. He argues problems such as 'chance errors', (2013, p.54) 'human errors', (p.55) different kinds of intelligence (p.53) and not predicting a person's ability to expand their intelligence (p.130) as reasons intelligence tests should not be considered accurate measures of intelligence. This may explain why Christopher is in a school for children with intellectual disabilities where he feels like he is not like anyone else. Noll and Trent (2004) noted that in the late nineteenth century it was believed in the U.S. and the U.K. that people with disabilities should be segregated from the rest of society and were not worth educating. While Christopher's education is shown in the text to help him develop and is quite individualised, his separation from mainstream education and inability to take mainstream exams upsets him greatly. Whitaker writes that 'it is quite clear that the concept of intellectual disability is a function of the culture in which it is currently operating' (p.18). While Christopher's education is not inherently negative, it is built on a system promoting segregation where barriers to opportunity still stand.

The history of special education is interesting when considering nationalism in Britain and America, the countries where *Wonder* and *TCI* are set. Gellner noted that the 'cultural shreds and patches used by nationalism are often arbitrary historical inventions' (1983, p.56). The presentation of special education seems to be a combination of previously held beliefs. Furthermore, Chatterjee has argued that "Nationalism ... seeks to represent itself in the image of the Enlightenment and fails to do so. For Enlightenment itself, to assert its sovereignty as the universal ideal, needs its Other' (1986. p.17). Chatterjee notes that nationalist countries aim to seem progressive but must maintain an other to do so. Dorn has noted in America that:

Nationally, the expansion of educational rights for children with disabilities piggybacked on the broader expansion of the "school community" in the postwar civil-rights era, after

advocates developed a broad network and lobbying skills. But the broad definition of special education rights also conflicted with many educators' and parents' desires to limit the community of schools to well-behaved students (p.146).

Shown here is a conflict between supporting children with disabilities but also a desire to segregate them from mainstream education. As has been noted in Whitaker's writing the history of western societies views on disability swayed dramatically between positive and negative views throughout the 18th and 19th century. However, both Dorn and Whitaker noted that the rise of individualised care and education for those with disabilities did become an important focus in the late 20th and early 21st century in America and Britain.

While segregation through asylums and 'mental handicap hospitals' (Whitaker p.10) largely ended by the 1990's, Whitaker notes that there was still an element of control within the new ideas of care. Firstly, he argues, as mentioned in previous paragraphs that intellectual disability is culturally constructed. He further notes that to receive services such as access to a special school a child usually must have a diagnosis (Whitaker p.11). Therefore, normative society are deciding what it means to have a disability and indeed choosing, on a case by case basis, who they believe fits into this category. Britain and America's views of educating people with disabilities are made of, as Gellner puts, 'cultural shreds and patches' of their past. Special schools are much more positive than the previous asylums, however they are maintaining elements of segregation. Just as Chatterjee noted that nationalism aims to be like the Enlightenment but must retain its other, these nationalist societies must build on the progressive civil rights movements while maintaining control of the other of disability. Whitaker notes that 'today the philosophy and practice of care, as least as it is articulated, has changed dramatically to one of providing people with help and support to function as normally as possible' (p.11). This statement reinforces that the end goal here is not an acceptance of difference but to try and educate students to function as 'normally' as possible. Some exclusion is seen as necessary to 'normalize' students to better fit into mainstream society. If students are not able to function normally, even within the support system, issues may arise.

Christopher's relationship with his peers is predominantly negative. Much of Christopher's issues seem to stem from the misrecognition of his identity that has been discussed in relation to Taylor's writings. Often in the book Christopher will redirect negative treatment by others onto his classmates. When Christopher is called a 'spazzer' (p.33) he immediately claims 'I'm not a spazzer' unlike another person in his class 'who is a spazzer'. Christopher also seems to be very worried about being considered stupid due to being associated with his classmates. Christopher notes that 'all the other children in my school are stupid' (p.56) and shortly after notes 'I am going to prove that I'm not stupid'. Christopher's fears for his identity being misconstrued by others. In his list of reasons as to why he believes he has behavioural problems (p.59) one of the factors is 'doing stupid things'. Christopher seems to have conflated stupidity with intellectual disability. By proving he is 'not stupid' by being accepted into college it seems he hopes to also remove the identity of intellectual disability and the stigma that comes with it. Unfortunately, being in his school setting seems to make Christopher fear that he is stupid. In his mind it is only by leaving the school that he will be allowed to be seen as smart by others. Additionally, and more importantly, it will allow him to be judged on his own intellectual merit as opposed to be judged by being part of a community he does not feel connected to. Christopher did not always consider himself that different to his peers. Christopher states he used to do stupid things. However, he then spends much of the book proving to the reader how intelligent he is and giving examples of how much he has learned since he was younger (p.145). Christopher is desperate to show that he has changed, that he is no longer part of this community.

Charles Taylor writes that identity creation and representation is an active process, that:

We define our identity always in dialogue with, sometimes in struggle against, the things our significant others want to see in us. Even after we outgrow some of these others—our parents, for instance—and they disappear from our lives, the conversation with them continues within us as long as we live (pp.32-33).

Taylor argues that how an individual sees themselves is very dependent on how they are seen by others and indeed how they see themselves in relation to others. Although Christopher feels like he has matured and grown away from his peers he still sees himself, and is fearful

of others seeing him, in relation to his classmates. Christopher's want to leave his school can be seen to reflect his aim of taking himself out of an oppressive identity. The school Christopher is in is not inherently negative and while he sometimes does not give it the credit it deserves, it has helped by offering services such as counselling, one-to-one contact time with teachers etc. However, Christopher's focus is on the cost of attending this school instead of the benefits. Anderson's idea of members of the imagined community that 'in the minds of each lives the image of their communion' (Anderson, p.6) is certainly not true here. Interestingly, as Hehir notes, literary figures such as Christopher often become 'poster children' (p.4) for disability. Christopher as a poster child for disability is troubling as he is an arguably a character who represent the idea of disability while he belittles every character he meets with a disability. Much of Christopher's struggles seem to come from being forced into close proximity with people he does not identify with and the fear of misrecognition that accompanies this. It also highlights the problematic understanding of what intellectual disability is and that by giving a character this label it forces together a community that may not want to exist as a group.

The positive social aspect of Christopher's time in special education is not time spent with peers but with staff members. It is here, arguably, that Christopher is most allowed to express himself. Christopher doesn't particularly enjoy spending time with classmates and his conversations with his father are quite limited. Taylor writes that 'on the social plane, the understanding that identities are formed in open dialogue' (p.36) exists, that identity is a constant negation with others. The only time Christopher gets to explore his identity in a positive manner is when speaking to staff members in school. His closest relationship in the book seems to be with his teacher Siobhan. Siobhan is first mentioned in the novel on page two. This is before any mention of Christopher's own family. Her first appearance is teaching Christopher how to recognise facial emotions indicating that she is a large part of who he is today. Christopher trusts Siobhan, she is the one who helped him start writing the book. Interestingly she is the one who convinced Christopher to write the first page about the dog dying (p.5) which meant otherwise the opening of the book may have been about his interactions with her. She works as Christopher's editor (p.34) and is the only person he trusts to read the book. Christopher feels Siobhan understands him in ways others do not. When he

argues that most people do not say what they actually mean he notes that 'Siobhan understands' (p.38) and when he seeks advice from her after feeling misunderstood, he agrees with her and says 'Siobhan was right' (p.106). A lot of Christopher's ideas and ways of being are things Siobhan taught him or things that he figured out when with her. It is in the open dialogue with Siobhan that Christopher grows and evolves as a person. He may not receive positive opportunities to grow in interactions with his peers, however his school setting does provide a positive connection; his affiliation with Siobhan is his closest and most productive relationship in the novel.

Christopher notes the only reason he does not go live with Siobhan when running away from home is that he knows that he cannot do something like that with a teacher (p.161). It must be difficult for Christopher to be aware of this professional divide when staff members seem to be the only people he feels connected with. There are other staff members that Christopher writes about in the book, though not as regularly nor as positively as Siobhan. Mr Jeavons, the school psychologist is a character whom Christopher can talk to openly in a conversation and is allowed express his ideas. However, Christopher does not put as much faith in his ideas as he does Siobhan's (p.31). He also briefly mentions Julie who was his teacher when he started school. Julie is conspicuous by her absence for much of the book considering how good Christopher's memory is. This may be due to the fact that in the one instance he does mention her he disagrees with her about his ability to learn:

That was because when I was little I didn't understand about other people having minds. And Julie said to Mother and Father that I would always find this very difficult. But I don't find this difficult now (p.145).

Christopher may think of Julie as working with an older version of himself. Someone who didn't understand the things he does now and, in his mind, might still have fallen into the category of having special needs. Julie is a reminder of what he once was and how much he had to work to change himself, to prove his intelligence. The lack of confidence Christopher believes Julie had in his ability to grow is something Christopher would likely be very hurt by. He is being limited in his expectations, limited in his individuality, once again not believed to not be judged on his own merits.

Christopher's identity suffers from being part of the grouping of disability in his school. However, he does benefit from the resources he receives in the school through his interactions with staff members. There is another major obstacle Christopher faces in the novel linked to the education system, which is the opportunity to take his A level exams. Hehir has written that:

Ableist assumptions become dysfunctional when the educational and developmental services provided to disabled children focus inordinately on the characteristics of their disability to the exclusion of all else, when changing disability becomes the overriding focus of service providers and, at times, parents (Hehir, p.4).

When the main focus is the disability, the child can often be left behind. This can arguably be seen as true in *TCI* as disability focused needs are seen as more important than other educational endeavours. Christopher's additional needs are taken care of in his school but when he tries to push his educational opportunities in a more mainstream direction, he encounters a problem. Christopher states; 'I'm going to take my A level in maths and I'm going to get an A grade. No one has ever taken an A level at our school before' (p.56). However, he receives resistance from the principal in relation to this. Christopher wants to move in a direction away from his school's educational focus on managing disability. He wants to take these exams to be able to progress onto third level education. However, his school has never done this before. The apparent goal of the school, admittedly often out of necessity, is to tend to needs of individual disabilities and help the children to learn life skills. They are not equipped to bring their students further in their education which is a flaw in the system. The school helps bring a level of equality to students with disabilities but cannot support those who want to advance their education. Hehir writes that 'the education of students with disabilities has been plagued by low expectations' (p.18). This can be seen here for Christopher who struggles to be allowed to advance as his school does not expect any of their students to do so.

The headmistress, Mrs. Gascoyne, didn't want me to take it at first. She said they didn't have the facilities to let us sit A levels. But Father had an argument with Mrs. Gascoyne and he got

really cross. Mrs. Gascoyne said they didn't want to treat me differently from everyone else in the school because then everyone would want to be treated differently and it would set a precedent (pp.56-57).

The argument the headmistress seems to present here is a strange one. Facilities and funding aside, her comment on fear of other students wanting to be treated differently is very odd, especially in the context of a special school. The reason Christopher seems to attend a special school is that he has individual needs that cannot be cared for in a mainstream classroom. Yet, now the principal wants him to be treated the same as every other student. This brings forward an important point made by Taylor which also showcases a potential danger of the imagined community. In fear of not accepting difference Taylor noted 'the collective goals may require restrictions on the behaviour of individuals that may violate their rights' (1994, p.55). Christopher is here suffering from having his educational opportunities restricted so as to keep in line with his fellow students. While at times, having the label of disability has helped Christopher learn and grow through the resources he has gained, his community is now holding him back. His headmistress challenges the idea of him taking these exams in case he sets a precedent. The precedent in this instance seems to be either having her students' individual needs met or more specifically pushing forward to try and achieve more in life. This challenges Hehir's opening quote from this section that education's role in relation to disability should be to give children the tools they need to be able to compete.

The school system as a representation of the imagined community here showcase that it can be supportive to a point. However, there is a cap on what the individual can achieve. The school also highlights the fact that while a number of characters may all need additional supports it does not make them into a community. Furthermore, forcing an association, as seen in the example of Christopher, can be quite damaging to an individual's identity.

3.8 Conclusion

The notion of an imagined community in relation to disability can be seen in the assumptions and associations made about characters with disabilities by their peers, strangers and even

friends and family. Through both the difficulty in identity creation and the harm of misrecognition the notion of a community of people with disabilities is portrayed as damaging to the protagonists. The imagined community damages both the individual and the community as associations and misrecognition manifest to create an increasingly negative view of disability. It creates a scenario where the characters with disabilities are forced into a certain role and are not allowed to express their own individuality. The issues with misrecognition and how it affects expression and identity will be further explored in the next chapter looking at Edward Said's writing on the Other as well as Petra Kuppers' writing on disability and performance.

Chapter 4-Othering Disability

4.1 Introduction

Chapter three discussed identity, perception and the damaging effects of misrecognition for characters in the primary texts. In this chapter, the role of identity will be further explored by examining how stereotypes are created and maintained using the writing of Edward Said in his book *Orientalism* (1978). Said's writings will be used to examine the creation of knowledge around a specific group, while also readdressing the question 'what is disability literature?' through Said's exploration of middle eastern representation in the western world. Said writes about the effect literature has on real world understanding and how fictional representation can affect real life situations. The process of othering within the world of the four primary texts will then be discussed, using Said's writing about the Other and how it affects both sides; those being othered and those carrying out the othering. It will be followed by a discussion on performance and the Other using the work of Said and Petra Kuppers. It will discuss the role people with disabilities are expected to play and the pressure to fulfil these roles. It will examine the idea of performing disability and additionally how previous representations of disability influence these contemporary texts. Finally, it will examine the use of masks in *Wonder* and how they can affect and alter performance. This chapter will conclude the examination of the portrayal of characters with disabilities as the final chapter will focus instead on the family members and carers of these characters within the primary texts.

4.2 Orientalism and Disability

Chapter two asked the question 'what is disability literature?' inspired by Achebe and Ngũgĩ's discussion on 'what is African literature?'. Said's writing can add much to this discussion. Said questions how much of Orientalism, and arguably any similar cultural collection of knowledge of a group such as the 'disability community', is 'a kind of *willed human work*' (1978, p.15). Said writes that:

Anyone who teaches, writes about, or researches the Orient—and this applies whether the person is an anthropologist, sociologist, historian, or philologist—either in its specific or its general aspects, is an Orientalist, and what he or she does is Orientalism (1978, p.2).

He also notes:

Orientalism, a way of coming to terms with the Orient that is based on the Orient's special place in European Western experience (1978, p.1).

Said argues that Orientalism is western society's (more specifically Europe) way of understanding eastern culture. It is not necessarily the study of the Orient (the east) but the effect of this study on western identity. This idea will be adapted to analyse how the normate identity is affected by its interaction with the disabled identity, or more specifically, the representations of the disabled identity that it has created. Said argues that cultural understanding is something that is not simply reflected in but created by 'philology, lexicography, history, biology, political and economic theory, novel-writing, and lyric poetry' (p.15). To view literature about disability within this understanding means the primary texts being studied are not simply fiction nor entertainment but part of a cultural framework that will inform disability relations in the real world in the future. This places an importance not just on the work but also on the writer:

Everyone who writes about the Orient must locate himself vis-à-vis the Orient; translated into his text, this location includes the kind of narrative voice he adopts, the type of structure he builds, the kinds of images, themes, motifs that circulate in his text—all of which add up to deliberate ways of addressing the reader, containing the Orient, and finally, representing it or speaking in its behalf (p.21).

The writers of these texts may at times take on the voices of characters with disabilities but none of the authors of the texts identify with having a disability. Therefore, normate voices are framing the understanding of disability in the texts. Said continues:

Every writer on the Orient (and this is true even of Homer) assumes some Oriental precedent, some previous knowledge of the Orient, to which he refers and on which he relies (p.21).

The authors of these texts are working within the cultural framework of disability, building on the texts that came before it. The works these writers produce are having expertise attributed to them. For example, Mark Haddon has discussed how his novel has become an educational

tool for teaching special needs assistants and police officers how to interact with disability (Singh 2015).

Said further notes that 'the Orient has helped to define Europe (or the West) as its contrasting image, idea, personality, experience' (pp 1-2). Said argues, as was also seen in Anderson's discussions in chapter three, that one community can have its identity strengthened through comparisons with an othered community. Again, similar to Anderson Said argues that 'none of this Orient is merely imaginative' (p.2) and that it holds a level of power. Petra Kuppers notes that characters with disabilities are often compared to the 'heroic cripple, twisted madmen, whiny losers, idiots savant, fed by popular cultural depictions as other to the 'norm' (2006, p.3) highlighting that these ideas are used as comparison to help understand the norm by understanding what it is not. Just as Kuppers lists these images that have been created to help supported the image of disability Said notes that Orientalism had 'supporting institutions, vocabulary, scholarship, imagery, doctrines, even colonial bureaucracies and colonial styles' (p.2). This method of othering is philosophically similar to Anderson's Imagined communities and this chapter will build on the previous chapter to examine how Othering can affect disabled characters and how images of disability can be used to reinforce certain tropes.

The novelists are adding to each other and as mentioned above the understanding of disability on a wider scale. This interconnectivity can be seen even among the four texts studied. *TCI* was published in 2003. It was a commercial and critical success and inspired numerous other writers to write about disability. It is interesting that the launch of stage adaptation of *TCI* coincided, in the same year, with the publication of the three other primary texts created what seemed to be a literary trend in 2012. Another connection can be seen when the film adaptation of *TRFOC* (2016) copied a scene directly from *Me Before You* when Trevor pretends to be unable to speak copying the description of Will's 'Christy Brown impression' (p.41). Said writes that:

Most humanistic scholars are, I think, perfectly happy with the notion that texts exist in contexts, that there is such a thing as intertextuality (p.13).

Said argues that literature is not a series of individual separate publications but connected series of works, where the interpretations of a text will often be depended on its connections and relationships with other work. Will's mother's description of his Christy Brown impression also adds to this connective framework. Moyes includes Christy Brown as a specific connection to the cultural understanding of disability as she does when naming Stephen Hawking earlier in the novel. This can be further seen with the numerous comparisons to literary and film characters in *Wonder*; 'Freddy Krueger. E.T. ... Mutant' (p.97), 'orc' (p.247), 'Gollum' (p.312) and 'Darth Sidious' (p.59). The intertextuality that Said mentions is evident here. The texts are speaking to each other, referencing others texts like an academic essay trying to reinforce its argument. When Christy Brown or Stephen Hawking, or even Gollum or Darth Sidious are mentioned, they are used as figures of cultural importance that individually signify different images of what disability means. They are mentioned because the author believes the reader will know these characters and be able to understand the significance of their inclusion in the texts.

Palacio believes that mentioning literary figures associated with disability will mean something to the reader. Due to rise of popularity of *Wonder* her characters have been added to this disability canon in a similar way and it is likely that a reference to *Wonder* or August could appear in other novels. Said writes that:

A text purporting to contain knowledge about something actual... is not easily dismissed. Expertise is attributed to it (p.94).

Palacio's writing is more believable than *The Lord of the Rings* or *Star Wars* as her text is written in a realistic setting. *Wonder* reads not only as a story about August but as a guidebook to how disability should and should not be treated within the school system. It has become a staple of the many school reading lists for example it is a recommended text in the Irish school system (Professional Development Service for Teachers 2015) and has even inspired the #ChooseKind movement (Guglielmi, 2017); a movement designed to promote kindness in children both in relation to disability and in general. The choose kind movement was inspired by the line in the book by August's teacher 'when given the choice between being right or being kind, choose kind' (p.63). The campaign was launched with Random House Children's

Books and was designed to be ‘an online anti-bullying campaign designed to encourage students, educators, families, and readers of all ages to combat bullying’ (Maughan 2012). The campaign was aimed to all children but had a focus on children with disabilities due to its source material. *Wonder* is being seen not simply as fiction but as a story to educate readers, especially children, on how to interact with people with disabilities.

A number of educational critics have noted their belief that reading young adult fiction about othering or a character who is an other to the reader can be helpful in creating empathy. While this is a positive and potentially beneficial outlook sometimes this idea is misinterpreted as reading fiction about an other allows someone to understand the other. In the journal the ALAN review a peer reviewed journal about literature for adolescents by the National Council of Teachers of English Freeman and Guarisco (2015) note that:

While the explicit message of *Wonder* may be to show kindness to people with physical differences, it appears that, with the right exercises, the result is improvement in nonspecific empathy skills needed for generalization of compassion to a wider social circle (p.67).

However, the writers continue their discussion by quoting *To Kill A Mockingbird* ‘you never really understand a person until you consider things from his point of view . . . until you climb into his skin and walk around in it’ (Lee, 1960, p. 39). Here the writers seem to push the point the by reading fiction a person can understand what it means to actually live someone else’s life. The authors also highlight the fact the creating empathy is much better when reading fiction than non-fiction which makes their argument of understanding the other even more dangerous.

This issue is taken to a more extreme view in another article in the same journal by Coombs and Mayans where they are note the power of fiction to understand other points of view. In their article ‘Insider or Outsider? Using Young Adult Literature and Experiential Learning to Understand the Other’ (2015) they discuss not only the ability of young adult literature to help children’s understanding of the other but further recommend simulations based on the texts. They give an example of a student dressing as a homeless character to understand what it is like to be homeless. These writers also recommend *Wonder* as a book to understand

disability. Therefore, the writers seem to be recommending the possibility of simulating disability for children so they can understand what it means to have a disability. Not only are these articles arguing that reading a story about an other allows an understanding of what it means to live that life, they are further basing these examples a fictional text from a writer who has not experienced what they are writing. The prominence of othering in young adult fiction (Garcia 2013) and the popularity of using these texts in schools means young people are being taught that fiction captures reality completely.

In opposition to these attempts at teaching positivity *Me Before You* faced much backlash upon release as it was believed to be glorifying suicide as an answer to the lack of opportunities for people with a disability (Pritchard, 2016). Screening of the film especially brought protests from the disabled community. The Sydney Herald reported that 'Australian screenings of *Me Before You*, starring *Game of Thrones*' Emilia Clarke, are being picketed by activists who have labelled it a "disability snuff movie" because they believe it suggests the disabled are better off dead' (Quinn 2016). Further protests were held in other countries with protesters holding signs that read '#MeBeforeEuthenasia' (Goldberg 2016). This backlash was so strong because it was believed the novel would affect how people understood the lives of those living with disabilities. Whether *Wonder* does promote a positive approach to understanding disability or whether *Me Before You* is an intrinsically negative representation is open to interpretation. However, as seen in the above citations many readers accept them as such. They are being considered as influential literature on disability and are being accepted as having an effect on the cultural framework and understanding of disability in western society.

Moyes in a 2012 interview noted that she was worried about the inclusion of assisted suicide stating 'I knew it was potentially very alienating' (Gilchrist 2012). She also states she intentionally used Louisa as a narrative voice to present the story as less disruptive to the reader. This is an interesting point as only a couple of questions before in the same interview she states she finds it unfair that the genre of romance novels is often considered 'lightweight' and yet proceeds to discuss how she didn't want the writing to be too challenging for a reader.

Later in the same interview she answers a question on including the challenging material such as assisted suicide and Moyes responds stating 'my agent and I used to joke that it was going to be the book that killed my career. Thankfully it didn't turn out that way'. Avoiding the question somewhat, she focuses more on the harm the text could have done to her as opposed to people with disabilities. While this interview came before some of the more extreme backlash that occurred when the movie was released Moyes does answer the question about how it has been received at the time and that she was happy at the response she has gotten. She discusses emails she received first from normate people who felt inspired them to live their lives to the fullest, then from carers who are thankful of their representation. She does mention some emails from people with disabilities who enjoyed the book but quickly moves on to her favourite email from a person whose brother had been to Dignitas. This person thanked Moyes for giving her 'an insight' into the mind of someone going to Dignitas. Moyes takes pride in representing the experience of something she has never endured. The person sending the email picked up the book stating that she didn't expect this content. The genre of romance novel seemed to have worked as a way of presenting itself as light reading and then managing to position itself as realistic and unproblematic due to its reputation of being light reading.

In *Orientalism*, Said outlines three of what he calls 'qualifications' (p.5) that must be considered when discussing Orientalism. These qualifications can also be applied to disability representation. The first qualification that Said purposes is that 'it would be wrong to conclude that the Orient was essentially an idea, or a creation with no corresponding reality (p.5). All four primary texts are based on real disabilities. However, these are stories written through writer's perceptions of how this affects people's lives. The representations of disability in the novels do have a basis on real disabilities. Yet, these characters and their relationship with disability is still fiction. Additionally, they often seem overly focused on the tragedy of having a disability. As Garland-Thompson notes 'a common prejudicial belief that people with disabilities suffer more than the nondisabled' (2012, p.350). Literature such as *Me Before You*, and to a lesser extent the other novels, perpetrates this belief. These novels, written by normate writers are written based on their perception of what disability is as opposed to first-hand experience of living with a disability. While this perception may have

some basis in the lives and experiences of real people it is not authentic, it is fiction. This fiction is both reflecting and further creating the framework of how disability is understood. These novels are situating disability as inherently negative by highlighting the suffering of their characters.

Said writes that:

A second qualification is that ideas, cultures, and histories cannot seriously be understood or studied without their force, or more precisely their configurations of power, also being studied (p.5).

Understanding the trends of disability representation and their power dynamics is essential in the study of these texts. The protagonists in the novels have struggled greatly with being unable to express themselves. Other characters' perceptions of them limit their opportunities. All four texts seem, in some way, to be advocating for self-expression for people with disabilities but as the writers are normate this means they are exploring identity on behalf of another group. To remember Spivak's quote that 'you don't give the subaltern a voice. You work for the bloody subaltern, you work against subalternity' (1992, p.47). The texts themselves are power structures, they are part of Said's 'ideas, cultures and histories' that create a cultural understanding. They are disseminating knowledge. As the writers themselves do not have a disability, they act as an outside force defining a community. Whether it is positive as the case of *Wonder* promoting anti-bullying or the more challenging issues presented in *Me Before You* the power structure remains that of the normate creating their own image of disability.

Said's third and final qualification is:

One ought never to assume that the structure of Orientalism is nothing more than a structure of lies or of myths which, were the truth about them to be told, would simply blow away (p.6).

Similar to Anderson's writings on the imagined community, Said argues that just because something is not tangible does not mean it is not powerful. The cultural framework of disability is ingrained in society. When Louisa's parents believe Will Traynor will be similar to

Stephen Hawking it is because there is a set of preconceived expectations that are difficult to challenge. Will's father also makes a joke about Louisa having Will as a boss stating 'still, you won't have to worry about the old sexual harassment, eh?' (p.33). This seems to be mocking Will's lack of mobility while also promoting the often-seen belief that people with disabilities are not interested or capable of being in sexual relationships (Garland-Thompson 2005, p.1527). When Will comes to visit Louisa's home for her birthday, Louisa's mother panics. 'Mum went into a complete tailspin at the thought of hosting a quadriplegic (p.224)' even though Louisa had informed her all about Will and her work with him for months. She panicked about everything that could go wrong as her understanding of disability was being challenged by actually meeting someone with a disability.

However, when Will finally does meet Louisa's family and boyfriend much of their ideas about him do change. While Louisa had told everyone about Will her words were seemingly ignored. Patrick reacted poorly to Will, seeing him for the first time as a threat as opposed to the asexual person Louisa's father's joke had implied. When Louisa noted 'it took a minute to register Patrick's expression' (p.230) and when noticing the look on his face 'stop staring, I told Patrick silently. Finally, he caught my eye and looked away. He looked furious.' (p.230). The notion of Will as a helpless dependent has been broken. Patrick immediately begins to reassert his dominance returning to Said's discussion on force as he believes he must correct the balance and push Will downward. He starts discussing how he can cure Will using an exercise regime. He begins talking about a paraplegic client who is 'almost fully recovered now' (p.231). Patrick is trying to prove his dominance, that he has something he can give to Will while also highlighting Will's inferiority and incapability of doing certain things himself. Patrick finishes this display by telling Will he is 'just trying to help my girlfriend get the best out of her job' (p.237); further lowering Will's position to not simply a person with a disability but a chore at his girlfriend's work. Patrick is reinforcing his position as both boyfriend and as normate, correcting his framework of understanding that had been challenged when faced with the reality of Will. This scene acts as way of challenging disability representation by showing that beliefs about disability will falter when normate people actually interact with people with disabilities. But this instance is not common. Louisa's parents understanding of Will does change when meeting him. However, their initial belief about his communication

skills meant that outside of these extraordinary circumstances they never would have interacted with him. Furthermore, Louisa conveying to them all of her learned knowledge about Will did not change their expectations. Their view of Will seemed to remain the same until they met him. In this we see the power of Said's statement, even when the truth is told, it can be difficult to change perception. Additionally, in this instance even when perception was changed characters attempted to reinstate the power dynamics and maintain their beliefs even when a different reality was presented to them.

4.3 Divisions; The Writer, The Character and The Reader

Said's first qualification highlights the difference between perception and reality. The manner in which Louisa's mother prepared for Will was based on perception as opposed to asking Louisa or contacting Will to find out what was needed. Said writes that 'Orientalism overrode the Orient' (p.96). Characters perception of disability can be more powerful than the reality of disability that they are told about or even see themselves. An interesting discussion on this in relation to Haddon's *TCI* can be found in Eric Chen's book *Mirror Mind: Penetrating Autism's Enigma* (2005). Chen, who himself has ASD (Autism Spectrum Disorder), outlines a number of issues he has with Haddon's representation of Christopher and how it often does not correspond to his own experiences. Now before examining it is important to remember there is no one correct representation of disability. A phrase sometimes used in relation ASD and identity is, 'if you've met one autistic person, you've met one autistic person' (Drevner 2010, 4.40) highlighting that there is not one way of experiencing autism or indeed disability. This can make it difficult to identify authenticity in relation to the representation of disability. However, Chen does challenge Haddon, believing that he does not fully understand the thought processes of someone with a disability. Chen writes that:

An autistic has to struggle to understand human speech, especially the context behind every word. The smooth flow of thoughts and the apparent ease of understanding human speech are highly unrealistic experiences for an autistic (2005).

While Christopher does at times struggle with language in the novel Chen believes his language abilities are much more advanced than they should be. Of course, people's

experiences of autism are varied which makes this difficult to prove or disprove. However, the argument Chen is trying to make is that Haddon is attempting to recreate the thought process of someone with Autism and he can never authentically do that if he himself does not have autism.

Chen gives an example to back up this argument. He believes for a normate person, they can see what happens to a person with autism and how they react to it but they cannot comprehend what happens in the middle, what process their mind goes through. To highlight this, Chen rewrote a section of *TCI* that he found problematic and recreated it in a way that he believed was more accurate to his own experiences. The section details an incident when Christopher is asked by a family friend to do a maths question and Haddon describes how he works out the answer. The original section in the book reads:

“What’s 251 times 864?” And I thought about this and I said: “216,864”. Because it was a really easy sum because you just multiply 864×1000 which is 864,000. Then you divide it by 4 which is 216,000 and that’s 250 864. Then you add another 864 on to it and get 251×864 . And that’s 216,864 (Haddon 2003, p. 84).

Chen took issue with this section, arguing that Haddon’s method is too logical and does not describe the process in the way it works for Chen, who also has an ability for solving large mathematical equations. Chen rewrote the section as:

“What’s 251 times 864?” As Christopher heard this, in his mind appeared two green shapes that looked a lot like uneven cubes. The shapes clashed into each other and rippled with lots of tiny cubes, squares and triangles. Eventually a new shape was formed. Christopher replied: “216,864” He was shocked. “Wow, that’s even faster than a calculator. How did you do it?” Christopher was puzzled and thought carefully about what he meant. Perhaps he was asking who solved the sum. “I did.” “I mean, what trick did you use?” It took a while for Christopher to understand what he said. Maybe he means, tricks as in cheating. So he means did Christopher cheat. “No.” “I don’t get it,” he declared. And to this very day, he still could not figure out Christopher’s secrets (Chen 2005).

Chen’s description seems illogical for a normate person. Haddon’s novel reflects what normate people believe autism to be like, an outsiders logical understanding of the text.

Chen's argument coincides with an essential part of Said's writings (and many of the other postcolonial writers mentioned in this thesis); that one cannot truly understand a culture from the outside. While it can be argued that a culture cannot really be fully understood or represented at all, there are nuances and ways of being that are understood and only understood by being part of a culture or way of life. Chen also comments on whether authenticity is necessary in Haddon's work. Koppers writes about Chen's article that 'as he acknowledges himself, the aim of this exercise is to educate people about autism, not to write a best-selling novel (2008, p.193).' This highlights the fact that *TCI* and arguably the other three primary texts, all of which have been commercial successes, are not focused on authentic representation. Haddon himself notes 'I'm a little worried if people are saying, if you want to work out how to treat people on the spectrum, read this novel' (Singh 2015). Koppers continued saying that Chen's writing aims to present the experience of autism, as he perceives it, but it clearly also makes for a less compelling, more pedantic, slower moving, and more frustrating read' (p.195) questioning whether authenticity can be as compelling as fiction. Chen and Koppers argue these novels are written with the purpose of being best sellers as opposed to educating readers. Haddon himself worries about the perception of his novel as he told a festival audience 'it is used as a textbook for social workers, and for policemen, which is something I heard recently. I never meant it to be a textbook' (Singh, 2015). Haddon himself admits to the undeserved educational recognition his novel has received and seems weary of it. The novel, despite its own authors reservations, is highly influential as an educational tool and will be accepted and read by more people that are ever likely to engage in Chen's work.

Chen's writing may seem too alien for a mainstream audience, whereas the work of Haddon allows normative western audiences to view disability through a lens that feels logical and comfortable. Koppers has written that Christopher 'is a child, learning adult rules, and also a disabled character' (p.193) and that this firmly situates the reader in a position of power where they are likely to be more knowledgeable than the protagonist in a form of dramatic irony. Christopher experiences the reader's world through an 'alienated lens' (Koppers, p.193) making it both new but also known and safe. Koppers also adds that 'I would also venture

that another main draw that makes [The Curious] Incident [of the Dog in the Night-Time] such a success is its narrational glimpse of a possible simplicity' (p.193). Christopher is portrayed as simple, allowing for a relationship with the reader in which they can position him as both Other and as less. Their position as more knowledgeable means the reader worries for Christopher as the novel progresses in a manner that lets the reader believe they understand Christopher's struggles and decisions better than he does. When Christopher decides to run from home and travel to by train to see his mother it is a new world of discovery for Christopher but readers immediately know the dangers. They are not discovering with him, they already know more than him. The relationship is clearly one-sided and has been designed as such by Haddon. Christopher's 'possible simplicity' positions the book as a world where the reader can predict what will happen before the protagonist.

Christopher is consistently defined as both Other and lesser. Kupperts writes that 'this is indeed what makes Christopher so compelling: his distanced view of the rules that make up love, relationships, need, and care rings so true, and seems so perceptive' (p.193). Christopher's relationship with his family and peers is seen as attractive in its strangeness reinforcing Garland-Thompson's writing on disability being exotic. When Christopher explains his disdain for classmates or his father's decisions, he becomes a character not trapped by social convention. He becomes a character who offers a reader a chance vent about the issues of contemporary society while also being able to chastise Christopher for not understanding the world he lives in. Christopher is a release of the stress of societally enforced behaviour. His story is attractive to readers because he is an outsider in a familiar land even if it is his own home. The problems he faces are positioned as ones that many normative people themselves could often easily remedy. However, it has a dual purpose of also allowing to reader to think about their own lives. It is an example of one side using an Other to more clearly understand their own experiences. Readers are better able to understand their own culture as they see an outsider struggle and make mistakes within it. Christopher's voice is 'compelling in its otherness, and yet in its deep familiarity' (Kupperts, p.193). He is the perfect other; he fulfils the role of being different while also being controlled in a society where he does not fit in.

Christopher represents and explores a number of roles and relationships in the text while always remaining othered. Said writes that:

In a quite constant way, Orientalism depends for its strategy on this flexible positional superiority, which puts the Westerner in a whole series of possible relationships with the Orient without ever losing him the relative upper hand (p.7).

Christopher represents childhood, innocence and disability. In all of his roles the normative reader maintains their upper hand. When Christopher does something that challenges the reader such as his mathematical skills mentioned above, Haddon breaks down his process making it both less alien and less impressive for the reader. Throughout the novel Christopher constantly feels the need to explain his actions and thought processes. It seems he feels a need to validate himself and his way of life to those around him. For instance, Christopher explains his hatred of yellow and brown by listing things associated with the colours that he dislikes. Christopher is told by a teacher his reasoning is silly, while Siobhan, his main teacher, chastises the other teacher for saying so, Christopher admits:

It is sort of being silly. But in life you have to take lots of decisions and if you don't take decisions you would never do anything because you would spend all your time choosing between things you could do (pp.105-106).

Christopher has strong reasoning behind his actions. He thinks about the logic of everything he does, partially because his teachers such as Mrs Forbes constantly question it. Christopher believes not all of his decisions are rational, but chooses options that make him feel comfortable in his world. However, others will not accept this. They want answers and when he gives them they are deemed to be invalid. Christopher is constantly othered and made to feel like his way of doing things are wrong. He is always made to explain his actions and ways of viewing the world.

Said writes that 'Orientalism is—and does not simply represent—a considerable dimension of modern political-intellectual culture, and as such has less to do with the Orient than it does with "our" world' (p.12). He is arguing that othering is used to benefit the understanding of the self as opposed to the Other. The English Journal produced by National Council of Teachers of English in America promoted how realistic *TCI* was. The article written by Mark

Letcher in 2010 is promoting the novel to teachers by stating it is 'a fascinating look inside the mind of a young person living with a developmental disability' (p.113). They are promoting an authentic experience of disability in the novel, and advocating for its use in educating school children about disability. He also deems it 'fascinating' seemingly highlighting again the exotic gaze of disability. Letcher continues to write that in relation to *TCI* 'whenever books can open eyes to different situations and challenges facing students, those books should find their way into the hands of readers' (p.116). While the emotion behind Letcher's statement is admirable it is also very problematic. Letcher wants the challenges being faced by students to be discussed in schools, this is a positive sentiment, however, how these issues are discussed and the resources used need to be carefully chosen. Having a class of children read and discuss *TCI* is not a discussion of a disability experience but of a fictional novel. Letcher's article is a prime example of the danger of these primary texts. They are pieces of fiction that due to being considered positive and inspirational are often deemed to be viable educational resources for how to teach about disability. They are seen as instructional books as opposed to fictional novels.

While Letcher's article was aimed toward American teachers in 2010 in response to the growing influence of the novel it may have been unnecessary as McRae wrote three years earlier that it 'is one of the most widely read novels in the context of overseas secondary education, being widely adopted as a class reader, a main title and a reading group mainstay in several countries' (2007, p.106). The novel was already being read widely for many of the reasons Letcher discussed. Ciocia (2009) argues that this appeal is also not limited to children, that it has crossover appeal for all ages (p.322) and that:

To the sophisticated reader, he is the innocent crying out that the emperor is naked, offering a refreshingly new perspective on the obvious and the familiar. The less experienced reader, instead, will probably find it easy to relate to Christopher, even from a reassuring and confidence-boosting position of superiority (Ciocia p.330).

Christopher acts as both a 'refreshing' (p.330) Other for older readers and a character of inferior cultural understanding to allow younger readers engage 'from a reassuring and confidence-boosting position of superiority'. Ciocia argues that before the release of this

novel the ability to have mainstream appeal to both children and adults was only believed possible in fantasy literature. However, considering the exoticness of disability it could almost be read at times as similar to fantasy. Ciocia further states that the success of the novel is 'due in great part to the appeal of Christopher's idiosyncratic narrative voice' and 'from seeing the world through the eyes of a boy with Asperger's' (p.322). The novel offers a form of easy escapism, allowing the reader to see their world in a new light, with a voice that is othered enough to be fascinating to a reader. Ciocia states about Christopher that he is an unreliable narrator 'not because he sets out to deceive the reader' but because he 'is likely to miss—all the possible nuances of meaning' (p.328) highlighting his inferior position to more socially intelligent reader and even to children. Here, Christopher's voice, his disability becomes an interesting way to frame the world. Disability becomes a method of storytelling. Ciocia in her critical approach to the novel doesn't seem to see this representation as inherently negative though. She states that for a reader Christopher is 'this idea of pure innocence, not because of his age, but because of his disorder' (p.331). She relates this to the normate experience writing that:

Christopher embodies our current worries and mixed feelings about adolescence; like Asperger's syndrome, young adulthood these days is a "condition" that warrants a dual response: a desire to protect and prolong the state of "innocence" that comes with it, but also an anxiety towards what we know to be different from us, and what we fear to be potentially violent and uncontrollable (p.332).

This argument highlights the nature of othering in Said's writing. This is not a story to aimed at creating a better understanding of disability, instead it attempts to better understand the normate world as Christopher's disability is used as an exercise to examine societal views on adolescence and innocence. Christopher's story is a tool to bounce ideas for the development of the normate identity. To finish her review Ciocia writes in a positive conclusion on the novel that:

Haddon manages to create a spellbinding balance for readers of every age and literary competence: we follow the protagonist on his journey with a mixture of fascination for his qualities as a savant, and compassion for the more disabling aspects of his disorder (p.330).

She is writing that the novel allows readers to be both fascinated by Christopher's disability, 'for his qualities as a savant' and to revel in their own compassion for Christopher. Even in a

critical analysis of the text, the novel is being praised for the damaging effect it has on disability representation.

In this section, the relationship between the writer and novel has been explored using Said's *Orientalism*. The voice of the writer is often unfairly deemed to be both innocent and expert which has been challenged using the writing of Eric Chen. The 'positional superiority' (p.7) that Said wrote about has been discussed in relation to how the texts are written. The section has challenged the perceived positive force that many of the primary texts represent and questioned their educational value.

4.4 Disability and the Other

The four primary texts in this thesis are built around the notion of the Other. August, Christopher, Trevor and Will are presented as different, as oddities. The dynamic of being seen as different infiltrates the relationships these four characters have with their peers and family throughout the novels. While the previous section examined their relationships with their writers and readers, this section will examine in more detail how power dynamics and othering affect their interactions with other characters. This section will examine how and why othering occurs in the novels as well as how it is ingrained not just in interactions but in the material world of the books. It will examine briefly, from an orientalist perspective, how the characters internalise this otherness and often come to accept it as fact. It will analyse how disability is seen in the novel and use Said's writing about heroism and the Other to examine how characters interact with disability in an attempt to make themselves seem more compassionate. In contrast to this it will also examine how some characters treat those with disabilities poorly, such as the bullies in *Wonder*, and create a unique identity for themselves in the texts through their interactions with the protagonists. Finally, it will touch on otherness in relation to Pierre Bourdieu's writing on cultural capital and how an Other is needed for a social hierarchy and how normative knowledge and procedure is used to challenge characters with disabilities.

Said discusses his notion of Other using the following example:

A group of people living on a few acres of land will set up boundaries between their land and its immediate surroundings and the territory beyond, which they call "the land of the barbarians." In other words, this universal practice of designating in one's mind a familiar space which is "ours" and an unfamiliar space beyond "ours" which is "theirs" is a way of making geographical distinctions that *can be* entirely arbitrary (p.54).

Disability acts an unusual representation of this idea. Disability is both 'theirs' but also 'ours'. It exists in both worlds. It blends these two ideas to create the comfortable fascination that was discussed in the previous section. Said further states that 'it is enough for "us" to set up these boundaries in our own minds; "they" become "they" accordingly, and both their territory and their mentality are designated as different from "ours"' (p.54). The relationship to physical space is also interesting to note in Said's example. As disability can exist in any group it can be easy to think that space does not play as important a role. However, the novels feature numerous examples to the contrary, where space and physical access can cause Othering and segregation. For example, the incident mentioned in the last chapter of August and his classmate Henry where after being seated beside August Henry places his backpack between them (p.55). The use of space can be a powerful way to separate people, even if it is a smaller symbolic gesture. The physical design of the buildings in the novels must also be taken into account.

In both *TRFOC* and *Me Before You* issues arise when the characters interact with the physical world around them. For both Will and Trevor being in a wheelchair means they encounter accessibility issues as they live in a world that is not designed for their needs. For example, when Trevor finally breaks his routine toward the beginning of the book by going to a restaurant, it begins very awkwardly. Ben writes 'no sooner do we reach the entrance than I note the three cement steps and the absence of a disabled ramp' (p.30). What follows is a very awkward encounter where the owner calls attention to the situation in front of the other customers. He then brings Trevor around the back, has his chair lifted by staff members onto a step and is brought in through the kitchen. All the other customers watch everything

unfold as Trevor is placed at the end of a table due to his chair not fitting into the booth, where he now blocks much of the aisle. This incident highlights the normative world these characters are placed in. Trevor is embarrassed, pushed and pulled and put on show in front of the other customers all in an effort to have lunch at a diner. When Ben and Trevor saw the steps, they tried to leave but the owner forced them to stay, not wanting to allow his establishment to look inaccessible to wheelchair users. It is not simply interactions that create otherness. Buildings themselves are built for the average person and do not allow room for people with different needs. Trevor encounters this throughout the book as many of the places they want to go to are inaccessible to him or at least very difficult to get to. The barbarians have been kept out, not by a fence but by cement steps.

Anita Ghai (2012) has noted that within the idea of othering there is often a focus on the grand narrative in relation to the other. This can be seen in the previous paragraph. While the scene as an isolated incident may not seem overtly negative it exemplifies that the only position Trevor is allowed fill in his daily life is that of the victim. The limitations of Trevor's ability to express himself here creates an inability for growth for both sides. Homi. K Bhabha's writes that when two different cultures or identities clash or interact "new signs of identity', that is, culture or societal meaning, are created' (1994, p.277). However, by not allowing Trevor any expression and forcing to perform his expected role there is no opportunity for difference to be actually interacted with. Bhabha notes that this in between space, which he calls the 'seminal space' (p.50) is like a stairwell and the movement and passage between the two stops them from becoming 'primordial polarities'. The interaction between the two is necessary for both to grow and for ideas about identity to develop. However, Ghai points out, challenging Bhabha's metaphor, that the stairwell is not an accessible place for many people with disabilities (p.277). By not allowing Trevor to actually interact in this relationship the binary opposition of normative and disabled, of normative self and other are maintained.

Many of the same difficulties face Will in *Me Before You*, as Louisa attempts to raise his spirits by taking him on trips away. The difficulty of accessibility becomes immediately abundant. Louisa writes, when on her first trip with Will out of the house, 'there are things you don't

notice until you accompany someone with a wheelchair. One is how rubbish most pavements are, pockmarked with badly patched holes, or just plain uneven' (p.89). She also notes about Will 'every uneven slab caused him to jolt painfully, or how often he had to steer carefully round some potential obstacle' (p.90). Even travelling on a footpath is a difficult and painful journey for Will. It is worth noting that this journey is outside of a hospital also, a place where accessibility should be a focus. Louisa further writes:

The other thing is how inconsiderate most drivers are. They park up against the cutouts on the pavement, or so close together that there is no way for a wheelchair to actually cross the road. I was shocked, a couple of times even tempted to leave some rude note tucked into a windscreen wiper, but Nathan and Will seemed used to it (p.90).

Moyes is noting that the accessibility of someone with Will's mobility issues is not something that most drivers would consider. The world is not only built for a normate population but normate people within this world react to it only in relation to the needs of other normate people. Louisa states that 'Nathan and Will seemed used to it' noting that this is a regular occurrence and something they have merely learned to live with. Inaccessibility is part of daily life for Will as the world is no longer designed for his needs. Said's designation of familiar space and unfamiliar space is seen through areas that are either accessible or inaccessible to wheelchairs.

Following on from his above quote, Said writes that 'to a certain extent modern and primitive societies seem thus to derive a sense of their identities negatively' (p.54). The othering in the novels seem to exist as a method to construct identity by identifying what one is not. A character is normate because they do not have a disability and vice-versa. Characters such as August's classmates treat him differently and initially understand their role through this difference. The game they play where no one can touch August exemplifies this. They are not like August, they are normal, if they touch him they will lose this part of their identity. This treatment affects the person with a disability also as they are situated as Other and start to understand their own identity as negative, as a collection of the things they cannot do. This is arguably the foundation of Will's identity in the novel. He does not judge himself by what he

is but by all of the things he is not. He is the antithesis of who he was before the accident. Will says in the book:

I loved my job, my travels, the things I was. I loved being a physical person. I liked riding my motorbike, hurling myself off buildings. I liked crushing people in business deals. I liked having sex. Lots of sex. I led a big life (p.426).

All Will can see in himself is all the things he is not. He is no longer an employee, nor a regular traveller. He is no longer a physical person, a motorcyclist, a domineering businessman nor sexually active. Will continues to comment on his wheelchair 'I am not designed to exist in this thing – and yet for all intents and purposes it is now the thing that defines me. It is the only thing that defines me (p.426).' However, is not always the wheelchair that defines Will but the limitations he believes it represents. The language used to describe disability often includes words that are creating identity through a negative lens. 'Disability' and 'deformed' indicate that someone has negative ability or is formed in an incorrect way. The identity this create stipulates that the individual is not normal. Will has accepted his position as the opposite of everything he once was. He says to Louisa 'I get that with you around, perhaps it could even be a very good life. But it's not my life' (pp.425-426). For Will his disability is the opposite of everything he once was.

Said argues that Orientalism is a closed-system:

And so, indeed, is the Orientalist attitude in general. It shares with magic and with mythology the self-containing, self-reinforcing character of a closed system, in which objects are what they are because they are what they are, for once, for all time, for ontological reasons that no empirical material can either dislodge or alter (p.70).

In Will's last comment above, he admits his life could be positive and enjoyable but he has accepted the fate that his new identity is wrong, that disability means his life is not worth living. Louisa is hired by Will's mother to try and change his mind and throughout the novel she does indeed do everything possible to succeed in this. She forms a very real romance with him as they fall in love, she shows him all of the opportunities to avail of, the events and activities he feels he can longer take part in. She dedicates months of her life to alter Will's view but nothing works. Will's attitude toward disability, is as Said writes about Orientalism,

it is a closed system. No amount of positivity or effort from Louisa or Will's family could 'dislodge or alter' (p.70) his decision. It does not matter how much of his life and opportunities are returned to him, Will's mind is set. His binary view of his identity is set. Of course, Will's physical struggle and daily issues with pain cannot be underestimated. However, his declaration that 'it's not my life' (p.426), in the face of ever-changing circumstances, is indicative of Said's argument.

This closed system seemed to be in place for Trevor also at the beginning of *TRFOC*. Ben is quite harsh on Trevor's acceptance of his life with his disability; 'he wilfully imprisons himself inside of his routines' (p.7). Ben believes Trevor is allowing himself to be trapped in his own routine, that his relationship with the world is 'self-containing, self-reinforcing'. If Trevor doesn't push himself, he cannot fail. Ben continues saying that 'once you're forced to endure his routines time and again, you'll want to strangle him' (p.8). He feels as a carer that Trevor's routine is almost smothering. 'All his pants are khaki cargoes and all his shirts are identical black tees with a left-breast pocket (which is annoying in itself). Even his boxers are an identical royal blue' (p.8) Ben writes. However, he does say Trevor changes his trainers often but that seems to be part of his routine also. 'He buys a new pair at the mall on the second Thursday of every month' (p.8). Ben believes it is Trevor's small attempt at controlled independence or variety. Ironically, Ben also struggles with the same issues Trevor does. However, Ben is represented in this situation as somewhat of a hero figure, which Said believes is a common role created through othering. Said writes that 'the modern Orientalist was, in his view, a hero rescuing the Orient from the obscurity, alienation, and strangeness which he himself had properly distinguished' (p.121). Ben saved Trevor from himself and his disability.

The role of hero is a prominent representation not only in Orientalism, but in disability representation. From the 'Tiny Tim' representation of disability where the readers are shown a tragic character that must be saved, to the more contemporary texts being studied here where so many characters feel it is their duty to help and protect a character with a disability. In *A Christmas Carol* Ebenezer Scrooge's 'saving' of Tiny Tim allowed for a redemption of his

character, similarly to that of Ben in *TFROC*. This trait is of course very prevalent in the role of the carer, particularly with Louisa in *Me Before You* and Ben in *TRFOC*, whose roles in the book are as both carer and saviour. Their roles allow them to take care of the day to day needs of Will and Trevor but they go beyond in an attempt to save them from their disability. Both characters go above and beyond their job criteria. Louisa makes it her personal mission to prevent Will's suicide and Ben takes Trevor on a trip cross country against Trevor's mother, Ben's employer's, wishes so Trevor can visit his father. This discussion in relation to the position of carer will be expanded upon in the next chapter which will have a section dedicated to the position. However, it is not simply carers that take on this role, many minor characters try to position themselves as the hero throughout the novels. Even in small instances such as the diner incident, mentioned above, where the owner believed that he was being a heroic character by going out of his way to make sure Trevor could get into his restaurant, and of course doing so in front of all of his customers. The role is seen perhaps most prominently and most varied in the reactions of August's classmates.

4.5 Othering being Reinforced

This section will complete the focus on comparison between normate and disability, in light of Said's comparison of Occident and Orient. It will then lead into the final sections of this chapter on performance and how social roles are performative using sections from Said's writing.

The heroic and identity defining interactions with disability that were seen in the previous section are also evident in August's beginnings in mainstream education. When August arrives in his new school, he is given a welcoming committee of three children to show him around; Julian, Charlotte and Jack. Charlotte is shown to be doing this mainly for the praise, as Jack writes 'she is such a Goody Two-Shoes' (p.171). Julian also seems to be doing this for the

perception of being helpful as even during the tour he becomes insulting to August. 'What's the deal with your face? I mean, were you in a fire or something?' (p.40). After this meeting Julian also becomes August's resident bully. As August recalls the tour his mother is surprised by Julian's behaviour asking 'okay, so is he the kind of kid who's one way in front of grown-ups and another way in front of kids?' (p.47). This is arguably quite an apt summary of Julian, who exudes the perception of being a heroic figure, of being kind and genuine to August but he only does this to help himself. Charlotte's role is also self-fulfilling, she wants to be seen as good as opposed to the focus being on helping August. Later in the book the reader is shown this situation from Jack's perspective. When the principal asks his mother about volunteering to help August she responds saying 'well, it's actually very flattering' (p.165) believing it to be an honour that her son was chosen for such a role. Jack initially is resistant to the idea but when he agrees to do it when his mother reacts favourably; 'Mom smiled. "I knew you'd rise to the occasion, kiddo. Good for you. I'm proud of you, Jackie"' (p.173). Jack's agreement is seen as something to be proud of, a sacrifice he is making to help the other. Jack accepts the role because he feels sorry for August saying he 'doesn't stand a chance in middle school' (p.173). He accepts the role of hero, accepting the call to a challenge despite his personal feelings about August. Jack and August relationship does eventually blossom but initially Jack accepted the role to impress his mother.

Jack writes about his relationship with August:

Now that I know him, I would say I actually do want to be friends with August. At first, I admit it, I was only friendly to him because Mr. Tushman asked me to be especially nice and all that (p.175).

It is unfortunate that a number of August's relationships seem to start like this. Summer's writes in the novel about her friendship with August that 'some kids have actually come out and asked me why I hang out with "the freak" so much. These are kids that don't even know him well. If they knew him, they wouldn't call him that' (p.145). She continues writing "'you're a saint, Summer," Ximena Chin said to me the other day. "I couldn't do what you're doing"' (p.145). Summer is seen as saintly or heroic simply for being friends with August. While

Summer is upset at the heroic status she is receiving her original interaction with August was similar to that of Jack's:

'I sat with him that first day because I felt sorry for him. That's all. Here he was, this strange-looking kid in a brand new school. No one was talking to him. Everyone was staring at him' (p.145).

August's two closest relationships at school were created by pity. Towards the end of the book the heroic nature shown to August becomes more literal when August is saved from a group of bullies from another school by Henry and Miles who had formerly bullied August themselves. They befriend August after this. The novel seems to present friendship between normate and disabled as only possible once the heroic action has taken place as seen in the examples above of August's relationship with Jack, Summer, Henry and Miles. A power dynamic is set in place at the beginning of the relationship to ensure the normate's positional superiority.

An interesting example of the power dynamics of cultural capital can be seen while August is being given a tour of the school. During the tour August asks what homeroom is, having never come across it during his time being home schooled.

"I have a question ...," I said, trying to keep my voice steady. "Um. What exactly is homeroom? Is that like a subject?"

"No, that's just your group," explained Charlotte, ignoring Julian's smirk. "It's like where you go when you get to school in the morning and your homeroom teacher takes attendance (p.34).

August's lack of awareness of an essential part of the student's life makes him seem stupid to Julian who smirks at the question. Julian mistakes August's lack of cultural capital to poor intelligence and it changes his view of August.

Nothing much to see," Julian said, walking in after me. He started pointing to a bunch of stuff around the room. "That's the incubator. That big black thing is the chalkboard. These are the desks. These are chairs. Those are the Bunsen burners. This is a gross science poster. This is chalk. This is the eraser" (P.36).

Sociologist Bourdieu writes that 'there is an economy of cultural goods' (1979, p.1) that knowledge about specific cultural ways of life is important toward one's place in society. Cultural capital is a way of measuring the amount of value individuals hold in this economy (Bourdieu 1979). Shircliffe, Dorn, and Cobb-Roberts define it as 'the knowledge of common cultural resources that allow people to share cultural values, referents for discussion, or even a common group affinity' (2006, p.16). August's time being home schooled has meant he has not experienced some of this shared knowledge. Due to his misunderstanding of homeroom Julian feels the need to explain everything from a blackboard to an eraser. While August is very intelligent and later shows up Julian by pointing out his inability at pronouncing a certain word, he was seen as lesser because of a gap in cultural knowledge. The value of shared cultural knowledge is used here as a tool to Other August. Julian assumes lack of shared experience means August is stupid and highlights this gap in experience to try and embarrass him.

This gap in cultural capital is also seen in relation to Christopher's experiences in *TCI* as he often struggles to understand something in the same way as those around him. Bourdieu writes about the power of culture and cultural hierarchy as well as stating that:

There is no way out of the game of culture; and one's only chance of objectifying the true nature of the game is to objectify as fully as possible the very operations which one is obliged to use in order to achieve that objectification (p.12).

Christopher attempts to do this in the novel challenging all of the perceived norms of the world around him. This is perhaps part of the appeal of the book, especially for younger readers as Christopher may not understand words or social conventions in a similar way to some children. Christopher often does not understand things that others take for granted. For example, his following exchange with a policeman who is helping him buy a train ticket:

And I asked the policeman, "How much does it cost to get a ticket for a train to London?"
And he said, "About 30 quid."
And I said, "Is that pounds?"
And he said, "Christ alive," and he laughed. But I didn't laugh because I don't like people laughing at me, even if they are policemen (p.187).

Here, similar to August's lack of knowledge of homeroom, Christopher's lack of knowledge of a common word leads him to ridicule. Said notes that 'the Orient was viewed as if framed by the classroom, the criminal court, the prison, the illustrated manual' (p.41). Judgement can come with every small misstep. August's lack of knowledge of mainstream education or Christopher not understanding slang are small examples of the difficulty for characters with disabilities in the novels to keep up with the experiences of those around them. They are represented as having a difficult cultural capital. All of the intelligence both boys have does not save them from their lack of cultural knowledge. Christopher may be a mathematical genius but his struggle to do day-to-day tasks means he is looked down upon by people intellectually even though in his own areas of interest his intelligence is far superior to the average.

Me Before You has an interesting discussion on cultural capital. Will is in a different position than the other characters as he obtained a disability later in life. Before his accident he lived quite a luxurious life as he managed to obtain a large amount of cultural capital through his wealthy background, work and travel. The novel then proceeds to tell a story where Will challenges the power dynamics of the carer-patient relationship by positioning himself as superior to Louisa through cultural knowledge. Bourdieu writes that 'the socially recognized hierarchy of the arts, and within each of them, of genres, schools or periods, corresponds a social hierarchy of the consumers' (p.1). It is this knowledge of the arts and culture that Will uses here. Louisa is considered to be uncultured. When her sister mentions looking up something in the culture section of a newspaper, Louisa seems uninterested and Treena responds saying "You're just frightened because I said "culture"" (p.170). Will notices this and for example, when he finds out Louisa has never watched a film with subtitles, he orders her to watch one with him 'You have to watch this film, Louisa. In fact, I order you to watch this film... You sit there. Don't move until it's over' (p.83). When Louisa mistakenly mentions she doesn't like foreign films (meaning subtitled films) Will responds with a similar phrase the policeman used toward Christopher 'Never watched a foreign film. For Christ's sake' (p.83). The frustration of Will toward Louisa for her perceived lack of culture continues throughout the book, be it by forcing her to read certain novels, watch certain films or even travel to France as part of his will. Will uses cultural knowledge to constantly position himself as

superior in a relationship where he is more likely to feel inferior. He also positions himself as Louisa's saviour as she similarly does for him. He makes it his mission to save her from her small-town life. The discussion presented by Moyes here may argue that disability is not limiting in terms of the disability itself but in terms of the perceptions which it can create in terms of self-image and cultural expertise.

Will's position as a character with a disability and the power struggle he has with it has an interesting effect on those around him; in particular for his carers and family. Many of the characters in *Me Before You* and in the other novels alter their identities in relation Will and the other characters with disabilities. This is particularly true for carers and family whose identities are affected directly by disability which will be discussed in greater detail in chapter five. However, many other characters use another's disability to help define their own identity. Said notes that Orientalism is a style of thought based upon an ontological and epistemological distinction made between "the Orient" and (most of the time) "the Occident" (p.2). He argues that this distinction is not based on reality but on the needs of the Occident. Said writes that 'the Orient existed for the West, or so it seemed to countless Orientalists' (p.204). Said describes the Orient as a creation by the west to help define what they are and are not. This kind of identity formation can also be seen in relation to disability in the texts as for the perception of some of the characters, disability seem to exist to help them define themselves. Whether it is a perceived positive definition such as the hero role discussed above or perhaps a more power obsessed position such as those taken on by August's bullies. Koppers, who herself has a disability, argues that many people believe that they 'already know a lot about disability: it is one of the organising principles of what we think it means to be human, and how a society organises itself' (2014, p.9) she further states that her aim is 'to make these knowledges more complex' (p.9). She wants to highlight that the knowledges about disability that have been used as building blocks for a normate society may not be as accurate as they are believed to be. This identity building through association may be built on false foundations. However, it is something that remains very common even among characters with disabilities themselves in the texts. Christopher himself uses the disabilities of his classmates to help define his own identity 'I'm not a spazzer, which means spastic, not like Francis, who is a spazzer' (p.33). Just as identity is created through cultural capital by what

one does or does not know, it is also created by what one is or is not, by comparing themselves to another person. Ben also uses different disabilities to help define Trevor when he argues with his friend that Trevor is 'not retarded. He's got MD' (p.83). Koppers argues that people with disabilities 'have to negotiate cultural representations which threaten to fix them' (p.54). Ben is seen here sampling some of the problems that come with the weight of these representations and lack of nuance that Trevor faces regularly.

August's bullies in *Wonder* get a sense of comfort from their superiority to August. At Halloween August overhears his classmates talking about him when they do not realise that he is there. He hears Julian saying "'Oh yeah!" "If I looked like that," said the Julian voice, kind of laughing, "I swear to God, I'd put a hood over my face every day"' (p.95). This is followed by the even more severe statement by Jack, who later regrets immensely and tries to excuse it as peer pressure:

"I've thought about this a lot," said the second mummy, sounding serious, "and I really think... if I looked like him, seriously, I think that I'd kill myself."

"You would not," answered Darth Sidious.

"Yeah, for real," insisted the same mummy. "I can't imagine looking in the mirror every day and seeing myself like that. It would be too awful. And getting stared at all the time" (p.95).

The effect of peer pressure here on othering is apparent as Jack who by now has become quite friendly with August utters such a harsh statement just to try and fit in. He wants to join the other students in reaffirming their 'positional superiority'. For Julian especially, his identity is very much linked throughout the year to August and his treatment of him. He is August's superior, his bully and much of his focus throughout the school year is to enforce this understanding. Summer recalled how 'Julian had nicknamed him [August] the Zombie Kid' (p.145). He mocks August often, comparing him to Darth Sidious, a *Star Wars* character who has much facial scarring, even dressing up as the character for Halloween to mock August (p.94). Jack even writes that 'Julian's the biggest phony there is. And he's trying so hard to be popular all the time' (p.171). It seems that Julian has decided that bullying and othering August is his pathway to popularity, to show off his power and make himself important within the social framework of the school.

Another character whose identity is dependent on August's disability is Miranda, Via's childhood friend, who had built a very close relationship with August. Via writes:

Miranda had almost always been the sweetest to August, hugging him and playing with him long after Ella and I had moved on to playing something else. Even as we got older, Miranda always made sure to try to include August in our conversations (p.115).

Miranda felt a very strong connection to August. When Miranda and Via's friendship became strained and limited to occasional short conversations it would be often focused on August. 'Miranda would ask me how August was doing, and then say "tell him I say hello"' (p.132). Miranda comes from a broken home; her parents have divorced and her relationship with both of them has suffered greatly from it. During her time at camp she decided she cannot handle her life and creates a new identity, or that is to say takes Via's identity. 'Then one day I blurted out that I had a little brother who was deformed' (p.278). She then continues to say 'and the strangest thing is that these lies I told, these fictions, did wonders for my popularity' (p.278). Miranda uses August's disability as a way to become popular, as Julian did also. The sympathy that came from the other people at camp due to her revelation was immediate and widespread. Miranda felt terrible about the lie but she also felt she had a justification to this sympathy due to the care and friendship she had given to August over the years:

I have to admit, there was a part of me that felt a little entitled to this lie. I've known Auggie since I was six years old. I've watched him grow up. I've played with him. I've watched all six episodes of Star Wars for his sake, so I could talk to him about the aliens and bounty hunters and all that. I'm the one that gave him the astronaut helmet he wouldn't take off for two years. I mean, I've kind of earned the right to think of him as my brother (p.278).

Miranda has focused a lot of both her real and fake identity on her relationship with August. Her friendship with him allowed her to see herself as a caregiver, and August who was very appreciative of her friendship, made her feel loved after coming from a home where relationships were difficult.

The multiple perspectives *Wonder* highlights the different effects that August has had on each character's individual identity. Palacio showcases the widespread effect of disability on

others. Additionally, and perhaps unintentionally, she also presents normative characters using the disabled character to help form their own identity. As seen in the examples throughout this section Jack, Miranda, Summer and others have much of their identities shaped in connection to their relationship with August. This is seen throughout all four texts as the readers encounter bullies, heroic characters and saviours whose identities all hinge on their relationship to someone with a disability. Othering can be seen to exist through separation by cultural capital as well as physical space such as the design of buildings and streets. It is not always understood as an active process, as it can become ingrained enough in social interaction to be mistaken for passive. As Louisa only noticed for the first time when travelling with Will, these power structures are constantly present but are not always seen by the dominant class.

4.6 Performing Disability

Said notes that during the 19th and 20th centuries the West made 'an assumption' that the 'Orient and everything in it' was inferior to them (p.40). This relationship created a number of assumptions based on ideas of the Orient. A character which is othered will be expected to act in a certain way in relation to the role assigned to them. Whether this role is fulfilled or not can create problems socially. Performance is an essential part of the Other. This section will examine Said's writing about the Other being put on display. This is also a prominent idea in disability studies as both Koppers and Garland-Thompson have written about disability and performance in detail. This section will examine the characters with a disability in the primary text and how they are often positioned as a performer or a spectacle.

Said writes that 'the idea of representation is a theatrical one; the Orient is the stage on which the whole East is confined' (p.63). This coincides with Garland-Thompson's writing where she states "the earliest record of disabled people is of their exhibition as prodigies, monsters, omens from the gods, and indexes of the natural or divine world' (p.56). Garland-Thompson's comment positions disability as something that has always been on display, always been

something to look at, just as Said writes that the Orient is the stage. In *Me Before You* when Will and Louisa attend a concert Louisa notes about people watching Will:

Here's the thing about middle-class people. They pretend not to look, but they do. They were too polite to actually stare. Instead, they did this weird thing of catching sight of Will in their field of vision and then determinedly not looking at him (p.211).

Everywhere they go Will is on display. Louisa further writes; 'I don't know if Will noticed it. Sometimes I thought the only way he could deal with it was to pretend he could see none of it' (p.211). Before deciding to go to the concert Will lets slip his fear of this very situation 'Clark, every single place I go to now people look at me like I don't belong' (p.206). Will feels othered, he feels as if he is being watched and judged everywhere he goes. This feeling of being on display, of constantly being on stage, is debilitating for Will. He had stopped attending events and was very reluctant to go anywhere with Louisa. This sounds very similar to Trevor's situation in *TRFOC* where he refused to leave his routine, doing the same thing in the same places every day. The pressure of constantly having to perform and the fear that can induce is seen throughout the novels. It is not simply the judgement that these characters struggle with but the constant act of being judged.

To return to Trevor, the incident in the diner mentioned in the last section provides an interesting example of the relationship between performer and audience in this idea of Orientalism and performance. Garland-Thompson writes that 'staring at disability choreographs a visual relation between a spectator and a spectacle' (p.56). It is not simply the person with a disability who is transformed in their role as performer. The normate character can change as well. In this example, the chef made a spectacle of Trevor and his disability, dragging him through the restaurant in front of the customers. Here Trevor is trapped in the 'Tiny Tim' role, a tragic character who must be saved by a normate character in front of the diner filled with a fascinated audience. Ben writes 'we are nothing less than a spectacle. People are craning their necks' (p.31). The positioning of the disabled character as performer allows another character to feed into whichever caricature of disability they so please and manipulate it so they come across in a positive light. 'The waitress and busboy are cleaning a booth furiously to accommodate us. Obviously, Trev is not going to fit in a booth'

(p.31). The relationship here between performer and audience is a power-dynamic that often favours the audience. The waitress and busboy seem to be putting on a show to play up to the spectacle even though it is not actually for the benefit of Trevor as he won't fit in the booth with his chair. The disabled character is there to entertain or enhance the lives of the normate. When Trevor ends up accidentally frightening a child with his chair he fails in his performance as the tragic character the owner portrayed him as and is instead transformed into the monstrous. Ben writes:

Poor Trev is mortified, his oily face has gone as red as a stop sign. I'm glad that he has diverted his gaze, so he doesn't have to see the scowl on the mother's face (p.32).

Ben tries to chastise the mother stating "'Watch your kid," I snarl' (p.32). However, for the mother it is Trevor who has failed as she let down her defences for the 'Tiny Tim' version of him and was tricked into a sense of security. Trevor has failed in performing to expectations.

Both the monstrous and the tragic versions of disability were seen in Trevor's incident. At the end of *Wonder* we get another version of disability in the representation of the 'Super Crip'. August and his disability are figuratively and literally put on a stage at the awards ceremony at the novel's conclusion. During the end of year awards ceremony, after all the academic achievement awards had been given out, the principal announced that there was one award left:

"The final award this morning,"... "is the Henry Ward Beecher medal to honor students who have been notable or exemplary in certain areas throughout the school year. Typically, this medal has been our way of acknowledging volunteerism or service to the school" (p.355).

While presenting this award, the principal on a number of occasions gets choked up, 'Mr. Tushman's voice cracked a bit, like he got all choked up. He actually cleared his throat and took a big sip of water' (p.335). 'And again, out of the blue, he got all choked up. He put his two index fingers over his mouth for a second before continuing' (p.355). He discusses strength and kindness using the line 'He is the greatest whose strength carries up the most hearts' (p.355) before finally announcing the winner:

Without further ado, this year I am very proud to award the Henry Ward Beecher medal to the student whose quiet strength has carried up the most hearts.

"So will August Pullman please come up here to receive this award?" (p.355).

This moment serves as the feel-good culmination to the novel, as August's classmates cheer wildly for the announcement.

It is noted the award is usually given for volunteer work, however the principal in near tears, awards it to August for his bravery for being himself. Now while it cannot be argued the August struggled throughout the school year with other children's perception of him, and his own self-perception, this moment seems artificial. August is given the award for being different. It turns the story from being about August's life to being about his struggles. He is put on stage as the inspirational character who overcame his disability. The glamorised ending arguably takes away from the heart of the novel where August simply wants to be treated as a normal kid, idolising him on a pedestal as the inspirational character. August himself does dispute the award too as the novel tries to regain some credibility.

I wasn't even sure why I was getting this medal, really. No, that's not true. I knew why. It's like people you see sometimes, and you can't imagine what it would be like to be that person, whether it's somebody in a wheelchair or somebody who can't talk. Only, I know that I'm that person to other people, maybe to every single person in that whole auditorium (p.357).

August's insight here is very wise for someone of his age, as he realises that the award is not really for him. The award is to inspire everyone else. It is presented to him because he is different and the others in the auditorium see August's difference as struggle something that deserves to be commended. August himself re-emphasises that 'I'm just me. An ordinary kid' (p.358). The award is part of August playing the role of inspirational character, something he doesn't need but his classmates and the school staff are portrayed as needing.

Said writes that 'on this stage will appear figures whose role it is to represent the larger whole from which they emanate' (p.63). In the above examples the characters have had to do this, not simply play a role but to play a role which reinforces the idea of what having a disability is. Koppers writes that "'performativity" refers to performance, as echoed in the word itself: identity is performed, is not a set given, but is rehearsed, shaped, and enacted again and again' (2012, p.45). If identity is performed and these characters are being forced to perform

in a certain way, their performance becomes, for a time, their identity. When characters do not fulfil these roles, it causes tension. Koppers writes that:

Work on discourses of disability has reverberations beyond the issue of disability: it focuses on identity as a negotiated issue in the social realm, and the body and mind as carriers of social meaning (2012, p.22).

The idea that identity is 'a negotiated issue' refers again to Foucault's writings on power and how it exists in each moment through action. Both sides are trying to gain power. If a character with a disability reinforces a certain role, the normative character gains power. If a character with a disability does not play the expected role it shatters some of the normative characters' understanding and weakens their position of power. There are a number of examples throughout the book of this happening and problems arising from it. During the tour given by his classmates August corrects Julian on his pronunciation of a word:

"The word's 'supposedly,' by the way," I said.

"What are you talking about?"

"You said 'supposably' before," I said. "I did not!" (p.41).

August had failed in his role. Julian expected August to be stupid. He believed he had never been to school before and seemed to initially pity him. When August showed off his intelligence and that he may in fact be more intelligent than Julian, it shattered Julian's perception of him. This failing led to months of Julian bullying August. Immediately after the incident August writes that:

I started to follow her, but Julian cut right in front of me, which actually made me stumble backward.

"Oops, sorry about that!" said Julian.

But I could tell from the way he looked at me that he wasn't really sorry at all (pp40-41).

This began a journey by Julian to attempt to regain his position of power which caused August to become the focus of his rage until the next summer.

Another incident of failed expectations is when Patrick, Louisa's boyfriend, finally meets Will. Patrick's idea of Will was similar to Julian's initial perception of August, he was someone harmless, to be pitied. Upon meeting Will and seeing he was in fact a charming, capable man Patrick becomes very upset, believing that Will is now competition for his affections toward

Louisa. Patrick never considered someone with a disability could be a romantic threat. When Patrick starts arguing with Louisa about her work with Will after meeting him Louisa asks:

“Is it because he’s good looking?” I demanded. “Is that it? Would it all be so much easier for you if he looked like – you know – a proper vegetable?” (p.239).

Louisa’s blatant questioning perhaps does give the answer. ‘A proper vegetable’, whatever that actually looks like is likely more similar to what Patrick expected, than the charm and good looks of this early-thirties millionaire. Patrick tries to convince Louisa to sue, upon learning that she occasionally helps bathe him as it wasn’t part of her initial job description. ‘You could sue. Constructive dismissal, I think it is, when they change the terms of your job?’ (p.238). Patrick is struggling to correct the power dynamic as quickly as possible. Will failed to perform the expected role and Patrick wants to correct the status quo.

Christopher suffers often in *TCI* for not playing a certain role. Christopher arguably does not understand his role to the same extent as the other characters with disabilities do. The other characters seem to show more awareness of their role as performer. Will and Trevor seemed to be constantly embarrassed by how people look at them, and as mentioned above at the end of *Wonder*, August writes about his position as different and how it affects his classmates. Christopher does not play into this idea; he is simply trying to be himself. Christopher’s plight is for authenticity and he will portray this authenticity whether it is accepted or not. This causes problems for him. Christopher’s disability affects his performance. For the other characters their visual look gives people a false view of their abilities. For Christopher, his performance, how he carries himself and his actions damage his ability to interact or progress socially. When he speaks about wanting to get married and become an astronaut he is mocked:

Terry, who is the older brother of Francis, who is at the school, said I would only ever get a job collecting supermarket trollies or cleaning out donkey shit at an animal sanctuary (p.33).

Christopher’s disability is that he cannot perform a role that the people in his life can accept for him. Christopher performs without a script of social understanding and because of this his options in life are limited.

Judith Butler (1990) on her writing on performance and identity, in this case gender, notes that there is a belief that ‘discrete genders [a cultural binary] are part of what “humanizes” individuals within contemporary culture; indeed, we regularly punish those who fail to do

their gender right' (p.178). The past few paragraphs have detailed examples of characters being punished for not performing their disability correctly. Butler argues that this belief in a natural binary is created through a form of 'sedimentation' (p.178) of enforced performances building up to create the notion of a truth. As Trevor, for example, is chastised for failing to live up to the idea of a person with a disability he retreats back into his more rigid and solitary lifestyle. He again fulfils the expected role and by doing so may reinforce others views that this is correct. The 'truth' of disability, like the 'truth' of gender can be seen as a carefully constructed historical effort. Each role Trevor, Will, August or Christopher are cast to play by the normate people they meet reinforce this truth. Butler writes that:

As in other ritual social dramas, the action of gender requires a performance that is repeated. This repetition is at once a reenactment and reexperiencing of a set of meanings already socially established; and it is the mundane and ritualized form of their legitimation (p.178).

The repetition of these performances legitimise the false beliefs that inspire them.

Kuppers writes that 'performativity is not performance in the common art practice sense' (p.45). That what has been written about above is performativity, it is performing a social role. It is a more continual performance that is intertwined with power struggle and an attempt to present an identity. However, there is also an interesting example in the text of a more traditional artistic performance. Although it has been mentioned already in this thesis, it is important in this context to revisit Will's 'Christy Brown impression' (p.41). Upon first meeting Louisa Will performs a routine mimicking the portrayal of Christy Brown in the film *My Left Foot*. A very similar scene was also included in the film adaption of *TRFOC*. In this scene, Will performs in a literal sense the role that is expected of him. This scene showcases characters that are worn down and forced to play the role that is expected, the role that has been perpetrated by numerous literary and media representations of disability. Will and the other characters are haunted by images such as that of Christy Brown as people assume Brown's story is the story of every character with a disability. Kuppers writes that:

The history of the representation of disability and illness can be seen to be structured by attempts to contain the Other, to isolate it, present it as outside 'normal' society and bodies, and thus to exorcise its threatening, disruptive potential (2003, p.4).

A character such as Christy Brown becomes a figurehead of disability for the normate as it is a caricature that is easy to contain, easy to recognise in its otherness. Will feels trapped by the connection with Christy Brown that others create. He feels trapped by the connection to images of disability that have nothing to do with him. Koppers argument seem to position the normate's othering of disability as a way of control. Similarly, it seems to Garland-Thompson's description that some forms of disability representation 'domesticates disability' (2002, p.69). Continuing to highlight classic tropes of disability Other's a character with a disability in a way that is sanitised and easy to accept by the normate population.

Will of course is not the only one who suffers from these kinds of associations to classic tropes and figures. As has been mentioned performances and depictions of certain characters throughout popular literature and media plague August in *Wonder*. Comparisons to characters from franchises such as 'Star Wars' and 'The Lord of The Rings' follow August everywhere in the novel, constantly used to demean him and limit his self-expression. Said writes that:

In the depths of this Oriental stage stands a prodigious cultural repertoire whose individual items evoke a fabulously rich world: the Sphinx, Cleopatra, Eden, Troy, Sodom and Gomorrah, Astarte, Isis and Osiris, Sheba, Babylon, the Genii, the Magi, Nineveh, Prester John, Mahomet, and dozens more; settings, in some cases names only, half-imagined, half-known; monsters, devils, heroes; terrors, pleasures, desires (p.63).

The Orient, and arguably disability itself is best known through its myths and legends, through famous images and characters to which people can give and receive meaning. Just as the Orient has the above list, disability has Christy Brown, it has orcs and Gollum and Darth Sidious. It contains characters such as Frankenstein and Dr Jekyll and Mr. Hyde that have become popular representations of the divide between normate and Other and provide visual images to contain disability within. Disability representation has a plethora of popular images to choose from, to be defined by. But disability is not a separated history, it acts as an Other in almost every other history, infiltrating every mythology and society. Koppers writes:

Legends are stories that are told again and again, and that contain something that needs handling, something that sticks out, that somehow needs smoothing into the flow. Disability is something that sticks out (2012, p.9).

Disability is the quintessential other. It allows normative people to help define their own identity while maintaining control of an Other. However, it has often proved disastrous for those othered by it. They are trapped within the perceptions and images that came before. Will and August cannot escape a cultural framework of images, characters and stories that allow the normative to understand their lives better than they themselves do.

4.7 Judging a Book by its Cover; Masks and Book Covers

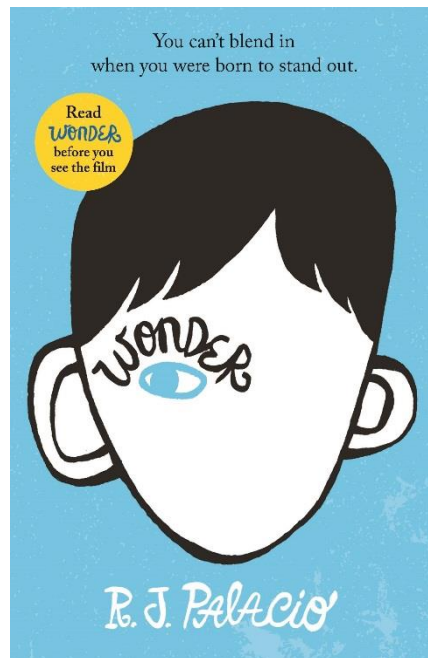
This haunting of classical images of disability is not limited to within the text. On the cover of *TRFOC* is a quote from the Boston Globe used to advertise the book that reads ‘Little Miss Sunshine meets Rain Man. Big-hearted, very funny, and full of hope’ (Evison 2012). The mention of hope once again harks back to the notion of disability as inspirational. Though, the more interesting allusion here is to Rain Man. Rain Man is the title of a 1988 film where Dustin Hoffman portrays Raymond Babbitt a.k.a Rain Man. Hoffman’s portrayal was of a character believed to be a savant with ASD. ‘Rain Man’ became a popular representation of disability for many years and remains so today as emphasised by *TRFOC* using it as part of their advertising. The problem with it this is that it is using a character with an intellectual disability to help advertise a story with a character with a physical disability. The characters of Trevor and Raymond have little to no similarities. The quote could be almost considered false advertising. It is stating that if you liked that movie about a person with a disability, you may like this book about a person with a disability even though their story and character are completely different. But this has been accepted, it is not just a review of the book, it is the review the publishers themselves choose to advertise the novel. Characters such as Rain Man are dangerous in their ability to offer certainty about disability, to allow for an easy explanation. Whether the characters are positive or negative portrayals they become highly influential. The interesting thing is that while the characters in the primary texts studied here

often suffer from these associations, they are becoming the very things they are fighting against, dominant cultural representations of disability.

It has already been noted that the books are very influential as they are taught in many schools and have had mainstream adaptations. For example, the Professional development Service for Teachers in Ireland 2015, has *Wonder* on its recommended reading list for schools. It can be argued the *TCI* may be remembered in a similar fashion to *Rain Man* mentioned above. It may not be Christopher's story that is remembered instead it might just be his disability. For Trevor and Will their lasting images may simply be seen as their wheelchairs, similarly to how *Tiny Tim* is often remembered for his crutch. On the cover of *TRFOC* all we see of him are his feet in his wheelchair giving the reader the first and possibly most long-lasting image of the character. Garland-Thompson writes that:

These visual rhetorics seldom occur discretely; rather, the photographs blend together in individual photographs. They wax and wane, shift and combine over time as they respond to the purposes for which the photographs are produced' (p.58).

Here Garland-Thompson argues that the images may respond to the purpose for which they were produced, for these characters their unique selling point in the media is their disability. The purpose is to tell a story about disability so this is likely what it will be remembered for. *Wonder* is perhaps a more interesting discussion in terms of a lasting image. Due to the difficulty of describing August, his visual image was originally largely left up to the imagination of the reader. However, Palacio then decided to manufacture an image of *Wonder* to sell on the cover of books. While August was for a while seen in his astronaut helmet, the following image began becoming more popular:



The image of a young boy with only one eye became the representation of August. This image doesn't really seem to equate with August. While the character has had difficulties with his eyes there is never a mention of having more trouble with one eye than the other. Via describes August by writing:

His eyes are about an inch below where they should be on his face, almost to halfway down his cheeks. They slant downward at an extreme angle, almost like diagonal slits that someone cut into his face, and the left one is noticeably lower than the right one. They bulge outward because his eye cavities are too shallow to accommodate them. The top eyelids are always halfway closed, like he's on the verge of sleeping. The lower eyelids sag so much they almost look like a piece of invisible string is pulling them downward: you can see the red part on the inside, like they're almost inside out. He doesn't have eyebrows or eyelashes (p.109).

The picture doesn't connect to this description. Perhaps the image is more a link to the book's discussion about how people see things and the idea of vision. This is one of *Wonder's* lasting images, it was manufactured to become so. However, the image seems to say less about the character and seems to be more about linking to the exotic rhetoric of disability that Garland-Thompson wrote about. The image is different enough to grab the reader's attention, but safe enough not to be off-putting, taking away much of the more striking parts of August's image that Via describes. Garland-Thompson writes 'disabled people have variously been objects of awe, scorn, terror, delight, inspiration, pity, laughter, or fascination but they have always been stared at' (p.56). This image is vague enough that it can really allow for a large number

of these. While the image doesn't necessarily inspire terror, the notion of having one eye for a small child could be frightening. The image of August allows for the reader to incorporate their own perception of disability and put it onto the book.

Wonder itself has also been adapted by Palacio into a children's picture book entitled *We're All Wonders* (2017). The same image of August, a face with one eye, is used throughout the children's book. The existence of the children's book again highlights the influence of these texts as the book will be used to teach very young children about disability, and could quite possibly be a child's first interaction with the subject. The book highlights August differences without going into too much detail. The book has a very clear message of kindness. It also includes the line 'I know I can't change the way I look. BUT maybe, just maybe, people can change the way they see'. This line of course encapsulates not just the story of *Wonder* but a lot of the arguments about disability. This clear image, which is spread across three pages of the short book is attempting to be the lasting image of it for young children. It is interesting that in the children's book the only difference August seems to have is that he has one eye and different sized ears. The adaption takes the representation of August that was created and makes that his character. The representation went from being the cover of a book for a character it doesn't really connect with, to becoming the character in an adaptation. The danger of surface level representations is clear here as the novelist herself removed all depth from August. Her character was diluted to becoming simply an image that did not even correspond with him. By making the character easier to envision or understand she took away his substance and left a vague image to represent disability.

Another visual representation of August that is frequent in the children's book is that of an astronaut. This was originally very strong on the covers of the novel also, as it showed August in his astronaut helmet. The helmet along with masks play an interesting role in relation to performance throughout the novel. It is interesting that both August and Christopher have such a deep interest in space and being an astronaut, likely due to wanting to get away from prejudice or a world that won't accept them. August's use of masks and a helmet is very theatrical. Koppers writes that 'one's body isn't 'natural' or 'fixed' means that the act of taking on disability as a social phenomenon can be an act(ivity), a role, a story, that needs rehearsing' (2012, p.9). It has been discussed above how characters both tried and rejected to play the

role of disability but as well as this through mask August is able to take on the role of normate. As discussed in chapter one in studies seen in Katie Ellis's *Disability Media Work Opportunities and Obstacles* (2016) disabled actors often find it very difficult to get roles that are not of disabled characters and often times characters with disabilities are also given to normate actors. A point to note in relation to this is that Said writes that 'the Orientalist can imitate the Orient without the opposite being true (p.60). However, the novels do seem to offer examples of characters with disabilities imitating being normate. By hiding his face August allows the rest of him to be seen, his body, his personality, an identity not hindered by disability perception. August writes:

For me, Halloween is the best holiday in the world. It even beats Christmas. I get to dress up in a costume. I get to wear a mask. I get to go around like every other kid with a mask and nobody thinks I look weird. Nobody takes a second look. Nobody notices me. Nobody knows me (p.91).

Halloween is the only day of the year August is able to be like everyone else. When August goes to school on Halloween it is a completely different experience than normal.

Walking through the halls that morning on my way to the lockers was, I have to say, absolutely awesome. Everything was different now. I was different. Where I usually walked with my head down, trying to avoid being seen, today I walked with my head up, looking around. I wanted to be seen. One kid wearing the same exact costume as mine, long white skull face oozing fake red blood, high-fived me as we passed each other on the stairs. I have no idea who he was, and he had no idea who I was, and I wondered for a second if he would have ever done that if he'd known it was me under the mask (p.94).

August gets to dress up not only as, in this instance a character from *Scream*, but as a normate character. He is treated like any other child, he performs the role of normate and his visual differences are not seen and so not able to contradict this. He is, for once, accepted by his audience as normate. Koppers writes that 'no one has to change what he, she or ze does in response to the fact that someone who is different is among them' (2014, p.24). However, it can be seen in this instance that people do. A kid high fived August when in costume when no one would touch him any other time, people react differently when difference is not recognised. Halloween allows for one day a year when August can play a different role, one day a year when he can choose the role he plays. However, when he was younger it wasn't limited to one day a year.

When August was younger, he had an astronaut helmet given to him by Via's friend Miranda.

August writes:

When I was little, I used to wear an astronaut helmet everywhere I went. To the playground. To the supermarket. To pick Via up from school. Even in the middle of summer, though it was so hot my face would sweat. I think I wore it for a couple of years (p.91).

The helmet allowed August to have Halloween every day, having the opportunity to choose a different identity. August used the helmet to hide his identity, to blend in with the other children but of course an astronaut helmet is not exactly subtle. Jack Will later writes; 'he used to wear an astronaut helmet sometimes. But I always knew it was him underneath the helmet. All the kids in the neighbourhood knew it was him' (p.170). As August grew older the helmet went missing and August mourns its loss and the opportunities it provided him. He knew the helmet attracted attention however, he states 'believe it or not, people would think seeing a kid in an astronaut helmet was a lot less weird than seeing my face' (p.267). August chooses this way of representing himself because he believed it would be more socially accepted than his own face. The character he chooses to perform allowed more freedom than being himself.

4.8 Conclusion

Throughout this section, otherness and performativity were explored in the novels. It was seen that the texts highlight the struggle of their characters to fulfil certain roles inspired by expectations created through literary and media representations. It also examined the struggles these characters had when they failed in these roles. Said's writing on Orientalism proved helpful in discussing disability and identity and how characters with disability often have their identities controlled by normative characters. Said's writing allowed for a critical approach to show the danger of readers attributing expertise to these novels. As seen in the writing of Eric Chen, these books are fiction, they are not meant to be authentic teaching tools but they often are used as such. Throughout the novels disability can be seen as a performance forced upon characters that damages them socially.

Chapter 5-Disability, Family and Carers

5.1 Introduction

I'm always going to be the sister of a kid with a birth defect: that's not the issue. I just don't always want to be defined that way (Palacio, p.113).

The above quote from August's sister Via highlights that disability and the negative perception of disability, is not limited to the person with a disability. The social model of disability, how disability is interacted with socially in society, which can have negative influences on self-identity, is represented in the novels as effecting family members of people with disabilities also. The previous chapters of this thesis have largely focused on examining the representation of characters with disabilities in the chosen primary texts. This chapter will focus instead on the representation of family members and carers. It will examine how these characters are affected by living or working with someone with a disability using the postcolonial and disability studies theories seen in the previous chapters. Firstly, it will explore the depiction of parent characters in the texts. It will analyse how the novels represent the life of a parent of a child with a disability and how the parent-child relationship is affected. The relationships the parents have with their children in the novels are varied but almost always portrayed as very challenging. The novels feature stories of parents leaving because of their children's disability and the consequent struggle of a lone parent left to raise a child without support (*TRFOC* & *TCI*). All four novels highlight an intensified version of the parental struggle with balancing the need to protect their children with allowing them the freedom to grow. These issues will be examined by revisiting the writings of Said and Spivak.

Following this, there will be an exploration of the representation of siblings in the texts. This area will focus on Via from *Wonder* and Georgina from *Me Before You*, as neither Christopher (*TCI*) nor Trevor (*TRFOC*) have any brothers or sisters. This section will explore identity issues in relation to the siblings using the work of Hall, Taylor and Anderson. Finally, the portrayal of carers in the novels will be examined. The characters of Ben (*TRFOC*) and Louisa (*Me Before You*) served as the main narrative voices in both novels. The role of language will be explored

using the writing of Achebe and Ngũgĩ in relation to these portrayals. The way in which these characters represent the people they care for through their narrative voice as well as how the unique relationship between caregivers and care-receivers develop will be examined. Overall, this chapter will examine the representation of the impact of disability on those close to characters with a disability.

5.2 Disability and Infantilization

Being a parent of a child of a disability is highlighted as being very challenging in the novels. Parents struggle with how to treat their child as they grow older, often finding it difficult to allow them a necessary level of freedom out of fear of how they will be treated by the world. Shapiro writes that one of the prevailing images of disability is that 'disabled people are childlike, dependent, and in need of charity and pity' (1994, p.14). The heightened fear characters, such as Nate (August's father) in *Wonder* and Camilla (Will's mother) in *Me Before you*, have for their children mean that they often treat them as more dependent and childlike than they actually are. This section will explore this idea and how overprotection leads to parents denying their children the opportunity to have a voice.

Wonder features the strongest family unit of the four primary texts. However, a number of issues still arise in the book. An early example of this is the decision on whether or not August should attend a mainstream school after years of being home-schooled. Chapter one noted that the characters with disabilities represented could be at times considered subaltern as, for example, they struggle to have their voices heard. Spivak noted in an interview that no one should want to protect subalternity (1992, p.46) yet the following sections will examine a number of characters who are overprotective of people with disabilities in their family to the extent that they have opportunities taken away. Clare Barker (2011, p.7) notes that the image of disabled child to represent a colonised county was often used to provoke feelings of protectiveness in colonialism, arguing that the image of disability can often evoke protective action even at the cost of the agency of those being protected. In *Wonder*, neither August nor his father Nate want him to go to school:

"Don't you think you're ready for school, Auggie?" Mom said.

"No," I said.

"I don't, either," said Dad (p.19).

August proceeds to play up a childish image after realising his choice is supported by his father. 'Then that's it, case closed, I said, shrugging, and I sat in her lap like I was a baby' (p.19). Nate cares greatly for August and is quite worried about his wellbeing. While this may be seen as Nate respecting his child's wishes, as is seen in the below quote, it is more likely him being fearful for his child and fearful of him growing up. August seems to try and manipulate his father's feelings to ensure he gets his way here. He feeds into the childlike image his father wants to see:

"I don't want to," I said. I admit: I made my voice sound a little babyish.

"You don't have to do anything you don't want to do," Dad said, coming over and lifting me out of Mom's lap. He carried me over to sit on his lap on the other side of the sofa. "We won't make you do anything you don't want to do."

"But it would be good for him, Nate," Mom said.

"Not if he doesn't want to," answered Dad, looking at me. "Not if he's not ready" (p.19).

Nate and August both want the same thing, for August to remain as this image of a small child. Nate angrily tells his wife that it would be 'sending him off to middle school like a lamb to slaughter' (p.20), truly highlighting his belief in the helplessness of his son. Both August and Nate are blinded by fear of August growing up, but Nate, as the parent, should be leading by example for his son. Overprotecting his son proves damaging to both their relationships to August's mother Isabel as she is then presented as forceful or unfair. August, as a ten-year-old child, stating 'I don't want to' in a forced babyish voice leads to his father literally picking up in his arms and taking him away from the danger.

Going to school is not the only instance of Nate placing his wants over August's needs. Interestingly, a later example in the text is of Nate forcing August to grow up faster. In *Wonder*, August often refers to an astronaut helmet he loved to wear (p.91, p.278, p.341). The helmet itself became one of the main marketing images of the book. However, in the novel the helmet is actually missing and is referenced to only when discussing past events. It is revealed later in the book that it was Nate who got rid of the helmet. "Oh, it didn't get

lost," he answered casually. "I threw it out" (p.340). It should be noted that August is the youngest of the characters being studied in this thesis and at age ten his parents should be making some decisions about his life. However, Nate seems to make decisions based on how he wants August to be viewed by others rather than what is in August's best interests. His resistance to August going to school seems to be more about keeping August childlike than respecting his opinion. When discussing the helmet, he stated "'good God, I hated that thing," he laughed, almost more to himself' (p.340). Then after admitting to August that he had thrown out the helmet, and realising how upset this made August, Nate attempted to explain his actions stating "'Auggie, I couldn't stand seeing that thing cover your face anymore," he said clumsily' (p.341). He continues his defence arguing:

Come on, Auggie, please try to understand," he continued, putting his hand under my chin and tilting my face toward him. "You were wearing that helmet all the time. And the real, real, real truth is: I missed seeing your face, Auggie. I know you don't always love it, but you have to understand . . . I love it. I love this face of yours, Auggie, completely and passionately. And it kind of broke my heart that you were always covering it up" (p.341).

Nate's actions are partially based on love for his son but also for what he wants his son to be. Sinclair, on his experience as a person with autism and from working with families that have children with disabilities writes that parents 'try to relate as parent to child, using [their] own understanding of normal children, [their] own feelings about parenthood, [their] own experiences and intuitions about relationships' (1993, p.17). Nate took August's helmet away believing he would adjust, that he would be brave enough to live without it. However, he did not base this on August's abilities but his own perceptions. Even though it arguably had a positive effect on August it was a still an example, in the words of Spivak, of giving the subaltern a voice instead of helping them speak (1992, P.47). Nate once again punishes his wife in this instance also as he let her spend days searching for the helmet believing she had lost it and convinces August to not tell her the truth. The tension of this situation in the novel is quickly defused (p.341-342) using humour, something Nate and August often use to connect. The character of Nate in the novel is seen as a kind loving father but one who sometimes chooses what he wants for August over what August wants or needs for himself. While this is a common trope of parenthood, the novels seem to represent it as amplified due to the heightened feeling of protectiveness due to the presence of disability. Even though it

is from a positive place Nate is taking away August's 'social mobility' (Spivak 1988, p.98). He is limiting his opportunities to grow and advance.

It is interesting to note in Spivak's writing what the idea of protection represents. Spivak argues that 'the protection of woman (today the "third-world woman") becomes a signifier for the establishment of a good society' (p.298). The distinction she makes between what was the signifier and what became the signifier at the time of her writing seems to make this idea less about women in particular and more a focus on the protection of those most disadvantaged becomes the establishment of a good society. This sentiment is not negative, however Spivak debates that this can be twisted to objectify and perhaps commodify women and the act of protecting them noting; 'Imperialism's image as the establisher of the good society is marked by the espousal of the woman as *object* of protection from her own kind' (p.299). Nate protectiveness of his son is understandable but it may be a way of proving he is a good father also. His claim mentioned early of sending his son to school like 'a lamb to the slaughter' (p.58) evokes dramatic imagery of a fragile innocent character facing death. Nate is arguing his actions are noble and that he is right to want to protect his son, somewhat demonising his wife for thinking otherwise. August himself researches the phrase coming up with the definition 'something that you say about someone who goes somewhere calmly, not knowing that something unpleasant is going to happen to them' (p.58). This definition denotes the need for protection, but in August's case this protection would have come at a great cost to him.

The struggle with overprotection and infantilization is highlighted with the ten-year-old August but also with the much older Will in *Me Before You*. Camilla Traynor, the mother of Will is initially introduced in the novel as someone hiring a carer for her family (originally believed by Louisa to be her husband). In the interview setting she is firm and business like (p.26). She is initially portrayed as cold and unfriendly. Louisa mentions her poker face a number of times at her sternness in response to jokes (p.28). From the first meeting Camilla is portrayed as someone cold and uncaring, someone who sees the caring of her son as a business. However, this is revealed as being untrue throughout the chapter where Camilla

takes over the first-person narration (pp. 135-144), the perception of her to the other characters is more difficult to change. Garland-Thompson writes that 'in contrast to normatively feminine women, women with disabilities are often stereotypically considered undesirable, asexual, and unsuitable as parents.' (2005 p.1567). While Camilla is not considered someone with a disability, as a mother of someone with a disability she seems to take on these attributes. Her husband is trying to leave her, and her love for her son is constantly challenged, especially in relation to her helping him travel for an assisted suicide. Upon finding out about this, Louisa's first response is not to be angry at Will or indeed the situation but instead the first person she blames is Camilla. 'I couldn't believe Camilla Traynor could contemplate doing that to her son' (p.144). Louisa then challenges Camilla's character and more specifically her maternal abilities:

Yes, I had thought her cold, and yes, awkward around him. It was hard to imagine her cuddling him, as my mother had cuddled us – fiercely, joyously – until we wriggled away, begging to be let go (p.144).

Louisa's mother also attacks Camilla's character after finding out about the assisted suicide, initially chastising both parents she quickly focuses in on Camilla and angrily states 'that woman must be heartless. Heartless' (p.449). Due to her helping Will, Camilla's public perception is changed to someone who is uncaring and cold.

Camilla's desire to protect her child is contrasted to her want to give him agency. Will asking her to help him die goes against everything she believes in. Camilla tells the reader 'I never set out to help kill my son (p.135)' and that 'it took his [suicide] attempt to make me agree' (p.141). Spivak, in her essay, *Can the Subaltern Speak* gave an example of a woman killing herself to have her voice heard. Spivak herself later commented on the story in an interview:

Now the incident is a situation where a subaltern person had tried extremely hard to speak, to the extent of making her damned suicide into a message. I cannot think of a situation where somebody really tries to communicate that is more urgent than this (1992, p.44).

Will carries out the same act in the novel. Will requested a number of times that he wanted to travel for assisted suicide and his voice was denied. It was not until he attempted to do it himself that he was listened to. In her essay, Spivak argues that you cannot bring people out

of the subaltern by saving them, you must help them be free to save themselves (1988, p.292). Camilla wants to save Will by protecting him, by changing his mind but she is unable to. In line with Spivak's writings Will cannot be saved by any amount of good actions of others, he can only be saved by having his own agency recognised.

Camilla's relationship with Will is difficult in the novel. Will becoming more vulnerable brings about a return to a relationship similar to that of a mother and small child. However, while some of the aspects of this are necessary it cannot become a reality as Will resents the idea. Camilla must care for Will but only from a distance, through hiring carers such as Nathan and Louisa. Will has mentally and emotionally outgrown the need for such an intimate relationship with Camilla even though he physically needs it again. Although it is different for Camilla, for her the part of Will that needs caring will always be there:

It's just that the thing you never understand about being a mother, until you are one, is that it is not the grown man... You see all the people he has ever been all rolled up into one. I looked at Will and I saw the baby I held in my arms, dewily besotted, unable to believe that I had created another human being. I saw the toddler, reaching for my hand, the schoolboy weeping tears of fury after being bullied by some other child. I saw the vulnerabilities, the love, the history. That's what he was asking me to extinguish – the small child as well as the man – all that love, all that history' (p.141).

Camilla in one way enjoyed having Will back but she could see his frustration:

I heard him and could well imagine what he had been like in those business meetings, the career that had made him rich and arrogant. He was a man who was used to being heard, after all. He couldn't bear it that in some way I had the power to dictate his future, that I had somehow become mother again (p.141).

She did at times use this new-found power over him; 'it's an unfair advantage, being able to walk away from a man in a wheelchair' (p.140). Additionally, when she spoke for him when first meeting Louisa much to Will's disdain 'I'm here mother. You don't have to talk across me. My brain isn't paralysed. Yet' (p.41). However, in the end she gave her son what he needed to be free; to have his own voice. She sacrificed her child, her perception as a good mother and even her family to help her son out of subalternity. *Me Before You* highlights the sacrifices

of Louisa, Steven and Georgina but perhaps the most complete sacrifice is that of Camilla who loses everything (Steven and Camilla do indeed separate after Will's death and Camilla also leaves her job due to the public backlash (p.475)). She is portrayed as the mother figure willing to sacrifice everything for her child (much in contrast to her husband who will be discussed in the next section). In Spivak's essay, the woman died to have her voice heard, Will also tried to die to have his voice heard. Spivak examines how suicide has been understood in a number of different societies and notes that in one instance suicide was allowed for women if their husband has died as she recounts 'kill yourself on your husband's pyre now, and you may kill your female body' (Spivak p.118). It is understood that a woman may not be able to carry on after the death of her husband and that her fate is tied to his. Camilla's fate is tied to her sons. Will's attempted suicide allowed him to break through to his parents and eventually got his wish. Camilla's does not die yet she somewhat completes the sacrifice Spivak discusses. She loves everything due to the death of a man in the family. To allow Will to die Camilla loses her child, her job, the respect of her community and her marriage. Camilla sacrifices her voice to help her son have his heard.

In this section, the difficult decision for a parent of protecting a child with a disability versus allowing them to make their own decisions has been discussed. While the situations of Nate and Camilla were quite different, the characters were linked in their challenges of making decisions that would give their children what they need as opposed to what they want them to have. The intersectionality of disability and childhood makes these decisions more difficult as the parental need to protect is amplified. The following section will continue to explore the effect disability has on the parent child relationship by looking at the spouses of Camilla and Nate.

5.3 Disability and Giving Space

The previous section examined instances in the novels where parents struggled to allow their children have their voices heard due to a sense of parental protection. This section will analyse examples of parents from the primary texts who did give their children more

freedom. It will investigate the relationship between Isabel (Nate's wife) and her son August in *Wonder* and between Steven (Camilla's husband) and his son Will in *Me Before You*. Isabel and Steven both attempt to create a separation from their children in the novels albeit for very different reasons. Throughout this section, these characters' sense of identity in relation to their children will be explored as well as their relationship with their sons. The difficulty in maintaining their own identity while caring for their children in the texts will also be explored. Continuing on from the previous section the work of Spivak will continue to be used to investigate these issues.

Spivak asks the question as to whether the subaltern can speak and further asks what the elite can do to prevent 'the continuing construction of the subaltern' (p.294). Spivak notes that the only way to break subalternity is for the subaltern to free themselves and that the elite should 'work for the... subaltern' (1992, p.47) not do the work for them. This is something Isabel and Charles attempt to do for their children by giving them freedom. The parents in these texts struggle to help their children have a voice. They sometimes do so by sacrificing their own voices. In the argument between Isabel and Nate mentioned in section 5.2, Isabel tries to convince her family that August needs to attend mainstream school as her work home-schooling him is no longer sufficient nor in his best interests. 'I just think you need to learn more than I can teach you' (p.18). Isabel wants August to have the same opportunities as other children his age. She doesn't want his disability to limit his social development by keeping him home-schooled. Isabel tries to convince August that it is a good idea 'you know how bad I am at fractions' (p.19), 'it would be good for you Auggie' (p.22). However, Isabel's decision is not solely focused on the good of her son. In caring for August, Isabel has struggled to maintain her own voice. Early in the book August notes that 'Mom homeschools me. She used to be a children's-book illustrator... I haven't seen her draw anything in a long time. I think she's too busy taking care of me and Via' (p.13). Unlike Nate, Isabel tries to be brave for August. August realised this when he is about to leave for a tour of the new school when he sees his mother 'I looked at Mom's face, and that's when I realized she was just as nervous as I was' (p.29). Isabel wanted August to go to school for his own sake and for hers. However, when August struggles against the decision she becomes remorseful feeling she is punishing August by trying to do something for herself. 'After my tour of the school, Mom and Dad had

reversed sides on whether I should go or not' (p.48). Hehir noted (p.4) that disability often becomes an overwhelming focus for both a child with a disability in their early years and for their parents. While Nate is shown as a caring parent, Isabel as a stay at home mother takes on the brunt of this responsibility. Raising August had become a large part of her identity. She needed August to move on so he could develop his voice and she could reclaim hers. Isabel is not subaltern in the same way Spivak described, but in having disability in the family she struggles to maintain her own voice. However, her sacrifice does seem to allow August the freedom to move forward with his education and lose some of his subalternity.

Isabel's relationships with the rest of her family also suffer due to her care of August. Arguments with Nate have already been discussed; however, their relationship is by far the strongest of any parents in the primary texts and are the only set of parents who stay together. Additionally, Isabel always finds it difficult to offer enough attention to her daughter Via. Stalker and Connors noted, while citing a number of additional studies, that 'some parents perceive their non-disabled children as more mature and independent than they might otherwise be (Glendinning, 1983) or more altruistic and responsible (Tozer, 1996)' (2004, p.220). This is stating that parents perceive these traits not that siblings necessarily have any of these them. Via writes that 'mom and Dad would always say I was the most understanding little girl in the world' (p.101). Being told this is a compliment but also places pressure upon her. Via would have to try and live up to this moniker. When August was young both Isabel and Nate spent a lot of time caring for him as he was very sick. This was a lot of time lost with Via who was largely cared for by her grandmother. The relationship between Isabel and Via suffered because of this. From Via's descriptions of August's early years to the example of Isabel leaving in the middle of a mother-daughter day to help August (p.134), August's disability has always made it difficult for Isabel to find time for Via. In the middle of an argument overheard by August, Via and Isabel have the following exchange:

[Via:] "You screamed first! Just leave me alone, okay? You've been really good about leaving me alone my whole life, so why you choose high school to suddenly be interested I have no idea..."

Then I don't know what Mom answered because it all got very quiet (p.255).

It is likely Isabel does not respond to Via's statement because she knows there is some truth in it. Via might be the 'most understanding little girl in the world' but she still needed her mother. Isabel was willing to self-sacrifice for August but she hadn't realised the extent to which this hurt her daughter. The time spent focused on disability took time away from maintaining the other relationships within the family. Balancing being a mother of a child with a disability while also being a mother to another child is something Isabel struggles with throughout the book. Isabel and her family manage to work through many of these issues within the novel which cannot be said about the family units in the other primary texts.

In *Me Before You*, Will's disability doesn't break his family apart, instead it holds together a dysfunctional family. Will had moved out before acquiring disability and did not have a particularly close relationship with his family since. His sister had moved to Australia. His parents Steven and Camilla were in a marriage which was falling and apart and Steven was dating another woman. In the 1970's, before the word was considered outdated, McCormack had written that 'a handicapped child makes a handicapped family' (1978, p. 12). The notion of whether a child with a disability creates a family with a disability is explored in all four of the texts as family interactions always have a large focus. In the other three novels disability does cause strife in the family life of the characters. However, the structure of *Me Before You* is different. For the Traynor family disability seems to be more a physical manifestation of a troubled and crumbling family unit, perhaps specifically Camila and Steven's marriage. As Will struggles through living with his disability, seeking ending his life as his way to happiness, Camila and Steven struggle to maintain the remnants of their marriage as Steven himself wishes for Will's death to allow them to move onward. The character of Steven in the novel is both challenging and difficult to relate to. As the agency of these characters are examined and the effect disability has upon this agency, Steven is affected by it yet it is difficult to feel sympathy for him as even though to tries to grant his son's wish to die, arguably releasing from his position as subaltern by supporting his having his voice heard, it is for very selfish reasons.

To again quote Spivak a person who is subaltern is 'a person without lines of social mobility' (Spivak 1988, p.98). Even before Spivak, Chakrabarty notes that a main aim of subaltern studies was 'to make the subaltern the maker of his own destiny' (2000, p.24). The ability or indeed inability to have agency in your position in life is a central aspect of subalternity. The notion of social mobility is presented as very important to the Traynor family. Will is very upset because of the limitations of where he can go and how he is seen due to the perception of his disability. Steven, Will's father, also becomes trapped due to Will's disability. Steven loves his son. However, in the novel Steven is portrayed as a difficult and sometimes challenging character as he admits to the reader he is only staying with his wife and family because of Will's position and would otherwise leave to be with another woman. Steven's turn to have the narrative voice in the novel is relatively short (pp.381-387) and much of that is spent furthering the narrative. Steven is given only a page and a half of the almost five-hundred-page narrative to discuss his affair and feeling of being trapped. He recounts his evening with Della, the woman he is dating. They talk about Will and the holiday he will be going on as the both refuse to say the things they want.

Poor Della. I could see her fighting her instinctive urge to ask me about our future – to consider how this unexpected development might affect it – but I didn't suppose she ever would. Not until this was all resolved (p.386).

Steven is obviously struggling with his position. The only way he can move forward would be for his son to die. He had planned to leave Camilla for Della shortly before Will's accident. He wants this and believes Della wants it too.

In some respects, she might legitimately have hoped for an end to it all. It was Will's accident that had so curtailed our plans for a life together, after all. She must have secretly hoped that my responsibilities towards Will would one day end so that I could be free (p.386).

It is hard to consider Steven as a subaltern; a wealthy man in good health who suffers no prejudice. What the novel seems to do here is highlight that disability affects everyone it touches in different ways. It can be difficult to feel sorry for Steven but he is also trapped due to disability.

It might have been easy for Moyes to place Steven as an antagonist in the novel. While he might be a difficult character to relate to, she attempts to offer a balanced view of him. Steven does admit his son's death would offer him a level of freedom but he is not proud of himself for thinking this.

The only way I would ever be able to leave my family was if Will decided, after all, that he was still determined to go to this infernal place in Switzerland. I knew it, and Camilla knew it. Even if neither of us would admit it to ourselves. Only on my son's death would I be free to live the life of my choosing (p.386).

Before this section is seen, Steven's view on the situation is already shown to be different to Camilla's. He seems quicker to accept Will's request to go to Dignitas, an organisation for assisted suicide which Louisa angrily describes as the 'place where people commit suicide' (p.154). 'I wouldn't get your hopes up' (p.139) Steven tells Camilla in relation to Will changing his mind. 'I'm just being realistic' Steven argues to which Camilla responds 'you sound ... you sound like you're already expecting it to happen'. 'I know my son' (p.139) Steven answers. Whether this response is pragmatic or something else, considering his affair, is difficult to tell. Little of Steven's character is revealed making him difficult to truly hate or feel sympathy for. The purpose of his character in the novel seems to be highlighting the struggles of the family unit. Steven is trapped in a marriage he doesn't want to be in. Camilla is trapped in a marriage with a man she knows doesn't love her. The novel presents Camilla and Steven as trapped in their roles as parents. Steven has put his role as parent as priority and won't allow any changes that will affect that. It is difficult to understand whether Steven's fear is of pushing Will over the edge or of the social backlash he would receive if he left his family in this situation but whatever it is, he is stuck. His social mobility has been removed. His future depends on Will. Only by allowing Will to live the life of his choosing can he live the life of his.

Steven and Isabel are very different characters but also share a number of similarities. Both parents want to fulfil their children's needs in an effort to reclaim their own voices. Now, while this means very different things (going to school vs assisted suicide) there are similar motives. Isabel feels overwhelmed by home-schooling August and wants her freedom. Steven wants to leave his family and feels like he cannot do this while Will is alive. In very different

ways both novels are presenting the same argument; the parents of children with disabilities lose some of their freedom because of their children. While these characters cannot be considered subaltern, they are presented as having attained some of the elements of subalternity through their association with disability. They struggle to have their own voice and to have social mobility. They feel trapped. The writers have chosen to highlight the disadvantages having a child with a disability can have on a family unit. The following sections will examine families where one parent has left due to the stress of disability in the family.

5.4 Single Parent with a Child with a Disability

In the following two sections the representation of separated parents of a child with a disability will be explored in the primary texts. This section will discuss Ed Boone, Christopher's father, in *TCI* and Elsa, Trevor's mother, in *TRFOC*. Both of these characters have been left by their partners to be the sole carers of their child. The life of a single parent of a child with a disability is seen in these novels as very difficult. This section will examine these characters using the writings of Edward Said on othering, both in relation to how these characters are seen to struggle to connect with their children and are othered by other characters. Both Trevor and Christopher need full time assistance and so both Ed and Elsa have a large portion of their lives dedicated to the care of their sons. As seen in *Me Before You*, these novels also choose focus a lot on the strain that having a child with a disability can cause on a family unit.

Said's *Orientalism* deals with the notion of the Other with particular focus on western society's (the Occident) view of eastern society (the Orient). Said writes that 'the relationship between Occident and Orient is a relationship of power, of domination, of varying degrees of a complex hegemony (p.5). These power dynamics can be enforced in numerous and many of them can be subtle including keeping knowledge from groups or limiting opportunities with the reasoning of protecting someone. Chapter four of this thesis argued that a similar relationship is represented in the novels between those with a disability and those without. A prominent site of this notion of power struggle in the texts is in the relationship between

Christopher and his father. Ed Boone has been the sole carer for his son for a number of years. Ed often struggles to care for and connect with Christopher. The power dynamic between Ed and Christopher in the novel changes regularly. Ed does care greatly for Christopher and often tries to adapt to his view of life. Christopher's more rigid outlook makes this a necessity. For example, Ed will make Christopher's meals to his liking 'the supper was baked beans and broccoli and two slices of ham and they were laid out on the plate so that they were not touching' (p.62). Ed does not challenge Christopher on this and accepts it. Ed also accepts that Christopher does not like to be touched and respects this even when it is difficult for him. Christopher recalls that when his father collected him from the jail cell:

Father was standing in the corridor. He held up his right hand and spread his fingers out in a fan. I held up my left hand and spread my fingers out in a fan and we made our fingers and thumbs touch each other. We do this because sometimes Father wants to give me a hug, but I do not like hugging people so we do this instead, and it means that he loves me (p.21).

Ed recognises Christopher's differences and for the most part respects them.

Sinclair writes that this understanding and openness to difference is necessary in building a relationship with a child with ASD and something that many parents struggle with. Sinclair notes:

Push for the things your expectations tell you are normal, and you'll find frustration, disappointment, resentment, maybe even rage and hatred. Approach respectfully, without preconceptions, and with openness to learning new things, and you'll find a world you could never have imagined (p.17).

Ed has recognised Christopher's different ways of seeing the world and has an openness around it that lets them develop their relationship. However, while there is a level of respect toward Christopher in many of their day-to-day interactions the notion of power and domination do still occur in various ways. When Ed's wife chose to leave her family, he chose not to tell Christopher the truth. Instead of explaining the situation to Christopher he told him his mother had died; 'father said she had died of a heart attack '(p.36). This portrays a different dynamic. Now Ed doesn't trust Christopher, he is keeping information from him. Said writes that production of knowledge is a source of 'power' (p.9). This is an idea echoed in the

work of many writers such as Machiavelli's *The Prince* (1988) in his teachings of how to lead a nation and in Foucault's *Discipline and Punish* (1995). Chakrabarty noted that Subaltern studies analysed dominant power structures through 'an interrogation of the relationship between power and knowledge' (2000, p.15).

Foucault in particular argues in *Discipline and Punish* that knowledge could be used to control and alter behaviour. In the discussion of prisons and prisoners he writes:

The most important thing was that this control and transformation of behaviour were accompanied - both as a condition and as a consequence - by the development of a knowledge of the individuals (1995, p.125).

The more knowledge you have about a person the more power you have over them. Arguably the opposite is then true, the less knowledge the less power. It is in this major lie about his mother's life that the relationship between Christopher and Ed becomes closer to these power structures of Orientalism, Machiavellianism and those seen in Foucault's discussions on control. Ed is controlling Christopher's truth, his understanding of his own family life and producing false knowledge as he believes Christopher does not have the tools necessary to cope with the truth. Ed's actions can be seen as an act of protection toward his son but it is also in essence an act of control. Ed cannot handle the truth himself and so will not let Christopher know it either even though the truth he gives Christopher is much more damaging. Instead of telling Christopher his mother moved out he tells her she has died and hides letters Christopher's mother is sending him (p.143). He is controlling Christopher's correspondence and relationships with family members and believes he was right to do so; 'I did it for your good, Christopher' (p.143). While Ed's own story is portrayed as quite tragic, a single parent who is struggling under immense pressure, his behaviour toward Christopher is still abusive. This is particularly unfortunate as Ed is arguably the best central father figure in the primary texts other than Nate in *Wonder*. While Ed does have positive qualities much of it is overridden by his lies and omissions.

Ed is portrayed in the novel through the eyes of his son Christopher. Ed is also interestingly othered by Christopher who often finds him strange and illogical:

Father got up in the morning he always put his trousers on before he put his socks on and it wasn't logical but he always did it that way, because he liked things in a nice order, too. Also whenever he went upstairs he went up two at a time, always starting with his right foot (p.31).

Ed's portrayal is limited as it focuses on the elements that Christopher wants to focus on. Said argues writes that 'too often literature and culture are presumed to be politically, even historically innocent' (p.27). Additionally, Benedict Anderson noted that the novel was used to 're-present' (1983, p.25) ideas and re-structure them from a different perspective. While Christopher tells us he never lies (p.37) he still could be seen as an unreliable narrator. Additionally, the things Christopher chooses to write about and focus on tell a certain kind of story. The section mentioned above about the care his father put into preparing his dinner is only mentioned fleetingly. Many of the things Ed does for his son may not be highlighted in the novel as Christopher does not consider them important. Much of the patience and effort Ed puts into his relationship with his son may go unnoticed. However, it can be argued that these fleeting mentions are supposed to be enough to inform the reader of Ed's character. To return to Ciocia's reading of the text, they believe many readers will engage with this book from a 'position of superiority' (p.330). The reader is expected to know more than Christopher and to fill in these blanks themselves. Therefore, while Christopher is narrator and should have a level of power over his father, even this is lost as the reader will look past his narration. The struggle for power over the narrative voice and the 'creation of knowledge' as Said (p.94) has put it is even made into a plot point as Ed finds Christopher's book and attempts to throw it away. Additionally, he attempts to ban Christopher from continuing to write and in doing so tries to strip Christopher of his voice and his ability to tell his own story (p.104). The relationship between Ed and Christopher is a struggle between protection and truth. For all that Ed does for Christopher and the care he shows him, control is a prominent part of their narrative, an unhealthy feature created because Ed doesn't trust his son to be capable of handling the truth.

Elsa, Trevor's mother in *TRFOC* has her representation heavily skewed by Ben's narrative perspective. The novel is seen through the eyes of Ben, Trevor's carer. Through much of the book Ben views Elsa as Other, arguably through the perspective of disability. Ben places his own parental insecurities and issues onto Elsa. He does not see Elsa as she is but as he wants

her to be. Garland-Thompson writes that 'to look at the way we look at disability, I elaborate a taxonomy of four primary visual rhetorics of disability. They are the wondrous, the sentimental, the exotic, and the realistic' (2002, p.58). The manner in which disabled is being framed by the viewer can greatly alter the perception of the character with each of Garland-Thompson's rhetorics capturing different elements of disability representation. These ways of framing disability are not limited to the character but by association also sometimes family members. Elsa is seen at various times through all four of these lenses by Ben. For example, he exoticises her character as being the parent he could not. Ben writes a description of Elsa:

Elsa ought to wear a cape. She runs the farm sixteen hour a day, makes dinner, cleans house and still finds quality time for her son. She sleeps about three hours a night, and even then, she's up every half hour to turn Trev (p.7).

As Ben has lost his own children, in an accident for which he was partly to blame, he is obsessed with the standard of parent Elsa is. He looks at her ability with wonder 'Elsa is made of impressive metal' (p.26). As his perspective constantly switches back from his modern-day interactions with Elsa and Trev and flashbacks to time spent with his family, sentimentality also plays a role. In Elsa and Trevor, he sees the family he used to have viewing them as a model family unit and Elsa a model mother figure. Garland-Thompson's realistic visual rhetoric is seen in the difficulty of her day to day work. While Ben is fascinated with Elsa much of the praise he gives her is deserved. Through the realistic lens Ben also feels closer to Elsa, he feels attracted to her caring nature and begins to believe he could be part of this family. Finally, the exotic comes into play. Ben falls for Elsa, or at least for the image of Elsa. 'I'm convinced I could love her, with her sad clear eyes, her starched work shirts, and the scent of timothy and manure that trails in her wake' (p.26). Ben also convinces himself that she wants him too. 'She likes me. She wants me to stick around. And who knows, maybe not just for Trev's sake' (p.26). Ben exoticises Elsa's caring nature. Elsa does not accept Ben's advances 'I seize her about the waist with both hands and pull her toward me. Instantly, the world turns to ice as Elsa tears herself free of my clutches, glowering' (p.27). Elsa's role in the novel is limited to mother and perspective partner. She does not feature in a large chunk of the novel as she does not join Ben and Trevor on their road trip. Therefore, her character is very limited. While she is removed from the narrative due to the necessity of the road trip, the novel also removes her

completely when she is no longer a romantic possibility for Ben or a necessary mother figure for Trevor. In this way she is seen as expendable outside these two roles.

Although her relationship with Ben is difficult throughout, Elsa's relationship with her son is seen as very strong, at least from Ben's perspective. Elsa is very protective of Trevor. This could be seen to be overprotective at times:

"I fucking hate those waffles. They taste like cardboard." [Trevor]

"For real?" [Ben]

"My mom makes me eat them. They're healthy as shit" (p.29).

However, overall their relationship seems positive. When Trevor is very unwell it is only his mother he wants:

"Do you want any water or anything?"

"No. Could you get my mom?"

"I can turn you."

"I just want to talk to my mom," he says, unable or unwilling to mask his impatience. "Could you get her? Please" (p.68).

This protectiveness and care is the main element seen in their relationship (arguably due to the reasons in the above paragraph about how the narrative voice views Elsa). Elsa seems to be understanding toward Trevor 'you can only push him so far before he starts pushing back' (p.26). Unlike the often-strained relationship between Ed and Christopher, Elsa and Trevor are much closer, partially out of necessity due to the amount of time they need to spend with each other. Elsa and Trevor are close and are safe in their home, however there is arguably a fear of leaving this safe space which is exasperated by the introduction of Trevor and Ben's road trip. Said writes that:

A group of people living on a few acres of land will set up boundaries between their land and its immediate surroundings and the territory beyond, which they call "the land of the barbarians" (p.54).

Trevor and Elsa have become afraid of the outside world, afraid of anyone who wasn't in their small two-person tribe. In the beginning of the book Trevor feared going anywhere that he wasn't used to. While Ben helps him work on this to the point where Trevor is willing to go

on this trip the prospect of him leaving his safe space and indeed without his mother petrifies Elsa. She argues with Ben over the idea:

“Tell me, then,” says Elsa. “What you were thinking when you cooked up this trip? And just when were you planning to tell me about it? Or were you just planning on leaving while I was in Bend and not telling me at all?”

“I guess I was thinking it’s something he needs to do,” I [Ben] lie.

Elsa clamps her eyes shut and breathes deeply. Calmly, she proceeds. “What gives you the right to decide what my son needs? (p.114).

If Trevor leaves, Elsa would not be there to protect him, he won’t be in his safe place and outside of their safe place is the land of the unknown, ‘the land of the barbarians’. Elsa initially fires Ben over this. However, as Elsa is defined as a character by her ability to sacrifice for her son, she does so once again by changing her mind and allowing Trevor to make his own decision (p.130). Elsa’s role is that of mother, once she is relieved of this position she is relieved of her position in the text.

It is somewhat surprising to find within *TCI* a major representation of a father figure as the main carer of a child with a disability. The mother figure taking this role, as seen in *TRFOC*, is much more common. LJB Hayes (2017) has noted in a large scale investigation into the care system in Britain that there are ‘time-worn sexist assumptions about women’s propensity for care work in domestic spaces’ (p.56) and that the media and indeed government structures reinforce the image of female family carers as ‘cheap [if not free] nurses’ (p.56). Elsa’s story is not an uncommon one. Women are still expected to fulfil caring roles and having a child with a disability can often mean the end of a career for a woman. Hayes (p.57) notes that even when there are a male and female parent available, due to the cost of care and the gender pay gap it is much more common for the woman to give her up job and take on a greater responsibility for care, often receiving little assistance in the act. This was further seen in *Wonder* when Isabella as opposed to her husband Nate quit her job to raise August. Elsa’s struggles even more as she is expected to work full time while also fulfilling a lot of Trevor’s needs. Even when Ben is working with Trevor there are instances where Trevor still wants his mother to carry out the labour associated with his care, for example, when he is sick he will

not let Ben help at all. Furthermore, Ben notes he spends 'forty to sixty hours a week with Trev' (p.7) Elsa still has to fill the role of carer the rest of the week after spending those forty to sixty hours running a farm. While Ed has to endure a similar situation, in reality it is much more common for this unpaid labour to be filled by a female family member.

Ed and Elsa are both defined in relation to their children. Little of their characters are given outside of their role as parent. While the relationships with their children vary between the texts, due to the type of disability present, both novels highlight the immense difficulty of raising a child with a disability especially as a single parent. It was also disability that caused the breakdown of their marriages. The novels have represented disability as toxic to the family unit. These characters are also seen as othered and are treated differently due to their association with disability, for example, Ben's obsession with Elsa. While the relationship between the parents and their children can be considered othered at times when protectiveness becomes domineering, both parents are shown as very caring toward their sons. The relationships are not poor but are constantly seen as a struggle, rarely allowing for positive moments.

5.5 Leaving a Child with a Disability

The previous section examined the struggles of Ed and Elsa who have to raise their children with a disability on their own. This section will examine their former partners Judy and Bob both of whom left their families as they were unable to cope with their children's disability. Both of these characters are largely represented in the novels by their act of leaving their families and the aftermath this causes. For Bob, his role in the novel is of a character trying to make up for wrongdoings and rebuild a relationship with his family. For Judy, it is a more complex depiction as, after leaving her family, her son is wrongly informed that she has died. Her passing becomes a mystery element within the novel until it is revealed that Ed fabricated her death. Judy and Bob are both often seen as outsiders, no longer part of the core family

group. Their relationships with their children are seen as difficult both before and after they leave and the novels once again focus on the difficulty and purposed tragedy of having a child with a disability.

Judy's representation for much of the novel is one that is controlled by her ex-husband Ed. This representation corresponds with Said's qualifications for something to be considered as Orientalism as will be shown here. Firstly, Said's qualification that 'ideas, cultures, and histories cannot seriously be understood or studied without their force, or more precisely their configurations of power, also being studied (p.5) can be applied to this situation. Judy leaves her family as she needed space for herself. However, Ed does not reveal the truth to Christopher. Interestingly, what the heartbroken Ed initially tells Christopher is that his mother is in hospital and that 'she has a problem... a problem with her heart' (p.29). The inferential meanings here are blatant. Ed twists the truth. He challenges Judy's love for her family by questioning her heart, her love for her family, all while lying to Christopher. Ed allows Christopher to believe his mother had been dying in hospital for weeks without letting him see her:

Mother died two weeks later. I had not been into hospital to see her but Father had taken in lots of food from Marks and Spencer's. He said that she had been looking OK and seemed to be getting better. She had sent me lots of love and had my Get Well card on the table beside her bed. Father said that she liked it very much (p.35).

While Christopher does not seem to react poorly to this, it does have an effect on him as he becomes very distressed when finding his mother's letters. Yet, he also tries to care for his father in this situation 'Father said, "I'm sorry, Christopher, I'm really sorry." But it wasn't his fault' (p.37). The position Ed takes comes from a place of anger and mourning. He has lost his wife. His wife left him for their neighbour and he has to raise their son alone. He feels she is dead to them as a family and makes his feelings Christopher's reality. When Judy could no longer be his wife and Christopher's mother in the way he wanted her to be, she ceased to exist. While Ed was suffering during this period and had endured a trauma, the scale of the lie created trauma in itself for both Judy and Christopher. While Judy's leaving was a power move, Ed held the power in the aftermath and he twisted reality to what he wanted it to be.

Another of Said's qualifications is that 'it would be wrong to conclude that the Orient was essentially an idea, or a creation with no corresponding reality' (p.5). Judy did leave her family. When Ed said Judy had a problem with her heart and that she was gone, he believed both of those things were true. The family unit struggled throughout Christopher's life and Judy arguably struggled most of all. The relationship between Judy and Christopher attempts to show the reality of the emotional distress a parent with a child with a disability can be in. Christopher notes that when he was younger, what he deems as his 'behavioural problems' (p.59), made his relationship with his mother difficult. 'Mother would say, "Jesus, Christopher, I am seriously considering putting you in a home," or Mother would say, "You are going to drive me into an early grave"' (p.60). The second quote being especially difficult in hindsight as Christopher was led to believe his mother died young of a heart attack. In Judy's letters to Christopher, she tells her side of the story. She tells of the stress she was under and how she didn't know how to take care of Christopher. In one particular letter (pp.133-138), she goes into great depth on the subject:

I was not a very good mother, Christopher. Maybe if things had been different, maybe if you'd been different, I might have been better at it. But that's just the way things turned out. I'm not like your father. Your father is a much more patient person. He just gets on with things and if things upset him he doesn't let it show. But that's not the way I am and there's nothing I can do to change that (p.133).

She continues to tell a story about being unable to help Christopher when having a sensory overload at a mall and just crying when getting home, then arguing with Ed and eventually hitting him. Judy also writes that:

Christopher, I never meant to hurt you. I thought that what I was doing was the best for all of us. I hope it is. And I want you to know that this is not your fault. I used to have dreams that everything would get better (p.137).

Judy's actions are different to those of Bob for instance, who will be discussed later in this section. Judy didn't leave because of an idea about disability. Judy left because she was unable to deal with the very real situation she was in.

The overlapping power dynamics of Orientalism and disability representation can be seen affecting Christopher's whole family as lies and assumptions have severely damaged the relationships between Ed, Judy and Christopher. Said's third and final qualification is 'never to assume that the structure of Orientalism is nothing more than a structure of lies or of myths which, were the truth about them to be told, would simply blow away' (p.5). When the truth is revealed about Judy to Christopher and indeed when they meet once again everything is not immediately fixed. The problems that were there before, the problems Ed's lies were built upon, still remained. When Christopher wants to stay with his mother, she receives immense pressure from both her new partner and from Ed. Christopher and his mother begin arguing:

And Mother said, "Christopher, I am just about holding this together. But I am this close to losing it, all right? So just give me some --"

Then she stopped talking and she put her hand over her mouth and she stood up and went out of the room (p.250).

Judy is still unable to be the mother Christopher needs all the time. In the end, Judy and Ed manage to come to an understanding and shared custody of Christopher (p.266). Judy's representation by Ed was twisted but their relationship had been put under a pressure that neither were truly able to handle. Throughout the novel living with a child with an intellectual disability is represented as being very difficult. Neither Ed nor Judy are made out to be villains in the text. The novels may be seen to be attempting to highlight the lack of supports available for parents in similar situations although this perspective isn't often very overt.

While the character of Bob has a similar history to Judy, a parent who left his family due to being unable to cope with having a child with a disability the characters are very different. Ben writes that Bob 'ran off when he [Trevor] was three years old, two months after he was diagnosed' (p.7). While Judy spent years raising her son and would eventually succumb to stress, Bob seemed to leave much earlier, and based his decision somewhat on the idea of disability as opposed to the reality, highlighting the danger of negative representation. While little is featured in the novel about Trevor's early years with his parents this seems to be what happened. Said writes that 'Orientalism depends for its strategy on this flexible positional superiority' (p.7) arguing that even with relationships change the Orientalist maintains the

upper-hand. Koppers argues that in relation to cultural representation and the connection with the centre that 'the mobility and choice open to the centre is not open to the centre's 'others'' (2003, p.54). Both Koppers and Said argue that the centre has the upper hand and that the Other, in this instance those with a disability are often at a disadvantage. The action of leaving his family was a show of power. Bob would overcome disability by leaving it. This view of disability is talked about in depth in Sinclair's article *Don't Mourn For Us* (1993). Here Sinclair discusses parents' reactions to having a child with a disability, in his case autism but it seems relevant in this example also. 'Parents often report that learning their child is autistic was the most traumatic thing that ever happened to them' (p.15). Bob seemed so traumatised by learning of Trevor's diagnosis that he actually could not handle raising him. Sinclair continues; 'but this grief does not stem from the child's autism in itself. It is grief over the loss of the normal child the parents had hoped and expected to have' (p.15). This may explain Bob's experiences. Bob lamented the loss of a healthy child. However, when Trevor grew up to be very intellectually, if not physically, capable Bob attempted to reinsert himself into his son's life. Throughout the novel, Bob is often described as weak or even pathetic and looked down upon by Elsa and Trevor. Though as the book progresses there is also a sympathetic feeling created toward him, most likely by the narrative voice of Ben who is still struggling after believing to have failed his own family. However, in opposition to this interpretation Said's notion of 'flexible positional superiority' comes into play. Bob leaves his family when they need him most, later in life he tries to make himself feel small so they will forgive him. Bob is always trying to be the one in control even though he does it in an unconventional manner. He believes he should be forgiven and will not leave Elsa and Trevor alone until he achieves this.

In the previous section it was mentioned that for Elsa and Trevor other people were like the 'barbarians' (p.54) Said wrote about. As the small family of two tries to protect itself, Bob becomes one of the barbarians, an outsider now rejected by the family. Neither Elsa nor Trevor are seen as particularly interested in having Bob around. While Ben feels sorry for him at times, he also notes a number of instances where Bob is selfish in his attempts to reconnect. He often calls Trevor even though it is widely known the Trevor has immense

difficulty answering and using a phone (p.37). Ben also describes an unexpected trip Bob took to see Trevor:

Before we go feeling sorry for Bob, who flew nearly halfway across the country to make an appearance at the bedside of his ailing son, let's talk about Bob's tactical errors. Number one: flying halfway across the country uninvited (nay, conspicuously discouraged), not to mention totally without warning, is just the sort of flight decision that got Bob in trouble in the first place. Moreover, showing up on the doorstep at 7:50 a.m., five hours before Trev's customary waking time, demonstrates not only a lack of consideration but a complete disregard for the order and routine that Trev stands for (p.75).

Trevor refuses to see him and asks his mother to tell him to come back later. He does and Trevor again refuses to see him (p.79). Ben's opening line of 'before we go feeling sorry for Bob' is an important line in analysing Bob's character. While he at first seems to be suffering or mistreated, his brings much of it upon himself. Trevor's feelings toward his father are not presented as being manipulated by the other parent, as Christopher's were about his mother. Bob seems to have created his own problems. He left when he wanted to leave and he is trying to force himself back in now that he has decided he wants to be part of their life. Bob may have become the barbarian but he believes he will eventually get welcomed back in. For a large section of the novel Bob attempted to this by forcing himself into the family unit through ill-thought-out plans. However, as the novel progresses Bob does improve and comes up with ideas such as sending Trevor comedic postcards, a method of communication that benefits his son more than himself.

The portrayals of Bob and Judy once again show disability breaking a family unit apart. Although they leave for different reasons, Judy leaves due to being unable to cope with her son's disability while Bob leaves due to being unable to cope with the idea of his son's disability, disability and disability representation are the prime factors. While both portrayals offer positive discussions on the necessity of more parental support and the danger of disability representation neither of these ideas are portrayed well and disability is largely seen as a burden. These characters find it hard to connect to their children and disability is seen as a division. In both books, all members of the family suffer because of having a child with a disability.

5.6 Siblings and Identity

To move on from parental figures the following section will examine the representation of siblings in the primary texts. As Christopher in *TCI* and Trevor in *TRFOC* do not have siblings the focus will instead be on *Me Before You* and *Wonder*. The depictions of Will's sister Georgina and August's sister Via will be discussed as will their relationships with their siblings. The writings of Hall and Taylor will be revisited to examine identity in relation to Via who often discusses in the book her relationship with disability. The character of Georgina and her relationship with Will will be examined using Anderson's *Imagined Communities*. The two sister characters offer very different interpretations as Via writes about growing up with a sibling with a disability and Georgina reacts to her sibling acquiring a disability later in life. While Via is quite a central character and Georgina's role is kept quite minimal both still offer interesting views on the role of sibling.

This chapter opened with the following quote from the Via in *Wonder* 'I'm always going to be the sister of a kid with a birth defect: that's not the issue. I just don't always want to be defined that way' (Palacio, p.113). This highlights the effect disability has on not only a child with a disability but also their family. In one short statement Via captures much of the problems August and the other protagonists have with disability being an overriding identity marker. Via loves August but she struggles with how her connection with him affects her life. Growing up as August's sibling effected Via greatly. Stuart Hall writes that:

Perhaps instead of thinking of identity as an already accomplished fact, which the new cultural practices then represent, we should think, instead, of identity as a 'production', which is never complete, always in process, and always constituted within, not outside, representation (p.222).

Via own self-perception has been linked to August ever since she was born. 'August is the Sun. Me and Mom and Dad are planets orbiting the Sun' (p.101). While she was cared for by her parents and grandmother Via did place herself as secondary in her family unit throughout her early years. Hames (2008), writes about siblings' views on have a brother or sister with a

disability (albeit his focus was largely around intellectual disability). He argues that while many originally thought that having a child with a disability had a very negative effect on siblings, this is no longer considered true. While citing additional sources Hames notes that 'more recent reviews have identified that this is generally not the case (Stoneman 2005) and any negative effects are often only minor (Rossiter & Sharpe 2001) (p.491)'. Via is portrayed as being well-adjusted and living a happy life. However, she still does struggle with separating her own identity from August. Growing up she was August's sister first and Via second even within her own family.

Via's struggles continued as people outside of her family also often seemed more interested in August or how August looked than they did her. Taylor writes that:

The thesis is that our identity is partly shaped by recognition or its absence, often by the misrecognition of others, and so a person or group of people can suffer real damage, real distortion, if the people or society around them mirror back to them a confining or demeaning or contemptible picture of themselves (p.25).

As seen in chapter three August struggled greatly with feelings of misrecognition. This happens to his sister also. As seen in the above paragraph Via's parents sometimes see her predominantly in relation to her brother and attribute traits to her that may not be true. Via struggles with this while at home. However, Via not only worries that she is considered second best in her family but that this will spread to other areas of her life. This lack of attention proves to be difficult for Via as she struggles with being seen only through the lens of her brother. She has accepted the belief that his needs are more important than hers:

I'm used to the way this universe works. I've never minded it because it's all I've ever known. I've always understood that August is special and has special needs (p.101).

By seeing August as the special sibling Via accepts her place as the non-special sibling. When her parents compliment her patience with her brother she refuses to accept the compliment and instead states 'I understood there was no point in complaining' (p.101). This fear of misrecognition and feeling of always being in the footsteps of her brother has already spread to her friend group as one of her closest friends Miranda often seemed more interested in August than her. Via believed Miranda sometimes cared for August more than she did herself

writing that out of herself and her two best friends; ‘Miranda had almost always been the sweetest to August, hugging him and playing with him long after Ella and I had moved on to playing something else’ (p.115). Hames noted (p.497) that siblings sometimes have a difficult time telling friends about their siblings with a disability and that in some instances of their study when certain children in their class found out the siblings themselves were bullied for it. Via doesn’t endure any bullying but she is terrified of having people care more about her brother. August is already the sun that Via must orbit in her family life, she doesn’t want this to become her public life also.

Taylor discusses how identity can function in the intimate sphere, how identity is viewed internally and in relation to significant others and in the public sphere where identity is continually understood in relation to the larger world:

And so the discourse of recognition has become familiar to us, on two levels: First, in the intimate sphere, where we understand the formation of identity and the self as taking place in a continuing dialogue and struggle with significant others. And then in the public sphere, where a politics of equal recognition has come to play a bigger and bigger role (Taylor 1994, p.37).

This clash between the public and private sphere is something that influences a lot of Via’s narrative in the novel. As the story progresses Via is about to start a new school. Via feels like her identity in her home is static and lesser than she would like it to be, however the possibilities of creating a new identity in a new school are exciting for her. She writes about her last school that ‘what I always loved most about middle school was that it was separate and different from home. I could go there and be Olivia Pullman—not Via, which is my name at home’ (p.112). But she goes on to say that as more people learned of August, as he came to schools plays and events, this freedom lessened. At the thought of her new school she writes that ‘the best thing about high school is that hardly anybody knows me at all’ (p.113). By that she is of course implying that nobody knows August either. Via wants the freedom to be herself. She feels she is dragged down by her association with disability. However, this new freedom comes at a cost as she avoids talking about her brother and attempts to stop him visiting the school, which causes her great distress as she explains to her boyfriend Justin:

It's just been so nice being in a new school where nobody knows about him, you know? nobody's whispering about it behind my back. it's just been so nice, Justin. but if he comes to the play, then everyone will talk about it, everyone will know.... i don't know why i'm feeling like this.... i swear i've never been embarrassed by him before (p.240).

Via is punishing herself for being embarrassed about August. However, she isn't really embarrassed about him, she hates the way people treat her family when they know. Hames wrote that in his study of 11-14-year-old children with a sibling with a disability (Via is 15, close to the age range) 'the majority had started a new school... and were still very cautious about telling new friends about their brother or sister' (p.498). This seems to be common here, but at least in Via's case it should not be interpreted as embarrassment in this depiction but of fear of how they Via herself will be perceived.

This fear of being placed second is part of Via's family life, of her school life and even part of her friend group. When Via begins dating Justin she fears what he will think. Justin writes that 'she didn't tell me about august until our third date' (p.224). Then after Justin meets August Via gets very nervous. 'So, what did you think? She asks me nervously the second we're inside her room. Are you shocked?' (P.224). Justin tries to comfort her, and while he is a little shocked, he doesn't really mind. Via gives another glance into growing up with August when she tells Justin:

When i was little, she says, there were lots of kids who never came back for a second playdate. i mean, lots of kids. i even had friends who wouldn't come to my birthdays because he would be there. they never actually told me this, but it would get back to me. some people just don't know how to deal with auggie, you know? (P.225).

Taylor notes that 'nonrecognition or misrecognition can inflict harm, can be a form of oppression, imprisoning someone in a false, distorted, and reduced mode of being' (p.25). Via grew up being afraid to bring anyone home and literally losing friends because of how August looked. It scared her into being able to think she couldn't create meaningful relationships without sacrificing her family. The 'the deep cultural prejudices against disability that they had to endure from an early age' (p.4) that Hehir writes about children with disabilities, was something Via had to endure also. However, in Justin, Via finds someone who looks past this.

Not only does he not care about how August looks he puts Via first and is understanding about what she has been through. Via feels like she doesn't deserve to talk about her issues because they don't compare to what August has gone through (p.240). But Justin tries to understand, 'you've dealt with a lot your whole life' (p.240). Justin cares for Via and does his best to understand and help her through her struggles. Taylor writes about 'nonrecognition or misrecognition' inflicting harm. Justin recognising Via's struggles is a major step in their relationship. It is a positive depiction of helping someone in Via's position. Justin doesn't fix everything; he just listens and sees Via for who she is.

Via doesn't only suffer from the social stigma of being associated with disability. She herself also carries an invisible disability:

In August's case, the doctors were able to identify one of the "single nucleotide deletion mutations" that made war on his face. The weird thing is, though you'd never know it from looking at them: both my parents carry that mutant gene. And I carry it, too (p.127).

Via has the same genetics August had. She fears this in terms of having children:

If I have children, there's a one-in-two chance that I will pass on the defective gene to them. That doesn't mean they'll look like August, but they'll carry the gene that got double dosed in August and helped make him the way he is (p.129).

Via does not want this to happen to the extent that at 15 years old she has already decided against having children. 'Countless babies who'll never be born, like mine' (p.130). Via doesn't want her children to endure what August has had to endure. This is from her own experience of living with him and not from any vague misconception of disability. Justin notes that Via 'she wants to be a scientist. a geneticist, of all things. she wants to find cures for people like her brother, i guess' (p.226). Justin is only half right here. Via may want to become a geneticist to help August but also to help herself. One of the reasons Via is often very caring and understanding of August is she knows it very easily could have been her. She could have been the one who went through all of what August endured. Her identity is linked to August's disability because her social interactions make it so, but also because she carries the same genes.

The relationship Via has with August is difficult but overall positive. For Via, August is her brother first and she writes that most of the time she doesn't even take heed of how he looks.

I never used to see August the way other people saw him. I knew he didn't look exactly normal, but I really didn't understand why strangers seemed so shocked when they saw him (p.105).

Via said she never understood why others stared until she came home from visiting her grandmother for four weeks:

For this tiny fraction of a moment I saw him not the way I've always seen him, but the way other people see him. It was only a flash, an instant while he was hugging me, so happy that I was home, but it surprised me because I'd never seen him like that before. And I'd never felt what I was feeling before, either: a feeling I hated myself for having the moment I had it. But as he was kissing me with all his heart, all I could see was the drool coming down his chin. And suddenly there I was, like all those people who would stare or look away.

Horrified. Sickened. Scared (p.106).

This moment helped Via understand how others saw August but it didn't really affect their relationship. Via is an older sister; she is protective but also willing to push August when he needs it in ways others won't. While Via hates feelings of 'misrecognition' she also refuses to judge August by his disability. When August wants to quit school, and it is believed his parents may let him if he very upset, Via is the one who is strict with him:

The point is we all have to put up with the bad days. Now, unless you want to be treated like a baby the rest of your life, or like a kid with special needs, you just have to suck it up and go (p.139).

While the quote is insulting toward people with special needs, the sentiment is positive. Via won't pity August and she won't let him pity himself. She wants him to push forward because she feels August as a person is able to. Via's relationship with August is an honest one, arguably the most honest relationship he has. While Via struggles with social stigma and unfortunately time lost with parents, her relationship with August is strong. Her suffering is not caused by August's disability but rather its perception and arguably lack of supports for her family.

The relationship between Via and August is very different to that of Will and Georgina. Georgina's role in *Me Before You* is strange. Will's sister has moved abroad and has little to do with Will's life. However, when learning of Will's decision about travelling for assisted suicide she is understandably upset and angry, but also controlling. Anderson's discussion on imagined communities examines the connections between large groups such as the nation. Although strange it can be argued that the relationship between siblings Will and Georgina can fit into the notion of an imagined community. Anderson argues that a community should be judged by 'the style' (p.6) of how it is created rather than how realistic it is. Georgina's relationship with her brother was distant before the introduction of his disability, afterward it seemed Georgina reimagined the structure of their family. Having little interaction for a seemingly large number of years Georgina feels like she should have control over Will's actions. Anderson writes about the paradoxes of nationality. These paradoxes seem to also apply to the sibling relationship between Georgina and Will after his disability. These paradoxes apply to the distinction Georgina seems to make between what her family was before Will's accident and what it is now. The first paradox Anderson notes is 'the objective modernity of nations to the historian's eye vs. their subjective antiquity in the eyes of nationalists' (p.5). While Georgina is focusing on family, she is ignoring the fact that her family is unfortunately quite fractured. Her relationship to the family is weak, especially since moving away. Her place in the novel is limited to such an extent that her character was removed completely in the movie adaptation of the novel. Georgina seems to be less of a fully developed figure but rather a roughly written 'Family Member No.3' character to enhance the tragedy of the situation.

Georgina is furious when learning about Will's decision and immediately flies home to England. She argues with her mother and with Will about the decision. When she finds them resisting her she responds to her mother:

I do care about him, Mummy. I do. He's my brother and I love him. But I can't bear it. I can't bear even the thought of it. He's wrong to ask, and you're wrong to consider it. And it's not just his own life he will destroy if you go ahead with this (p.134).

This sentiment brings up a number of issues and also a nod to the other two of Anderson's paradoxes of nationality. Those being:

The formal universality of nationality as a sociocultural concept - in the modern world everyone can, should, will 'have' a nationality, as he or she 'has' a gender - vs. the irremediable particularity of its concrete manifestations (p.5).

and the 'political' power of nationalisms vs. their philosophical poverty and even incoherence' (p.5). In her response, Georgina makes use of the family titles of brother and mummy to try and sway opinion. She uses the universality of family, that she is a daughter and Will is a brother and that these roles are important and unifying. However, this is challenged by her defensive language which brings us to the final paradox of political power vs philosophical poverty. Georgina's words are powerful and her plea heart-breaking as she uses family titles to try and push her point. But this connection she is citing is undermined by the fact that she has to argue that she does in fact care about Will and she does in fact love him. Having to say and prove these things doesn't give the image of a strong family unit that Georgina is trying to portray. Anderson argues that when identity 'it cannot be 'remembered', must be narrated' (p.204). Georgina is trying to explain her relationship to her family as it is not remembered as being that way.

As the novel progresses Georgina chooses her independence and career over her brother. Georgina reveals she cannot go on holiday with Will and Louisa:

'I can't. You know I start my new job in two weeks. I won't be able to come over to England again for a bit once I've started.' 'You're going back to Australia?' 'Don't sound so surprised. I did tell you this was just a visit.' 'I just thought that ... given ... given recent events, you might want to stay here a bit longer.' Camilla Traynor stared at her daughter in a way she never stared at Will, no matter how rude he was to her. 'It's a really good job, Mummy. It's the one I've been working towards for the last two years.' She glanced over at her father. 'I can't put my whole life on hold just because of Will's mental state.' There was a long silence. 'This isn't fair. If it was me in the chair, would you have asked Will to put all his plans on hold?' Mrs Traynor didn't look at her daughter. I glanced down at my list, reading and rereading the first paragraph. 'I have a life too, you know.' It came out like a protest (p.166).

In this paragraph *Me Before You* puts forward its own paradox. Georgina is arguing she must have her own life, an important issue that was discussed in relation to Via. However, she believes she should not have to change her life for her family, yet, believes Will should change his for her. The relationship between Will and Georgina seems to crumble on a foundation that seemed to be already rocky. The character of Georgina isn't portrayed as a terrible person and the tragedy of the situation makes some of her decisions understandable. However, her inconsistency and comparatively small role makes her depiction much less fruitful for analysis and also much less believable than that of Via. Georgina is shown to suffer and her role is seen to enhance tragedy but does not seem to add a lot to the narrative otherwise. Georgina imagines being part of a loving cohesive family unit, but this image is false and seems to be a gut reaction to Will's decisions. Anderson writes that "all profound changes in consciousness, by their very nature, bring with them characteristic amnesias" (p.204). He argues that in dealing with large-scaling change the part is often forgotten and this seems to happen in this case. Georgina in dealing with Will's disability has forgotten the nature of her family's relationships with each other.

The characters of Via and Georgina are very different. One seems a genuine attempt to understand the life of a sibling with a disability while the other seems to be somewhat of a plot device. Both sides do highlight the struggles of having disability in the family but while *Me Before You* only shows tragedy, *Wonder* tries to present a more balanced, leaning toward positive, perspective. The relationship between August and Via is shown as sometimes difficult but overall positive. It allows an in-depth look at a character with a sibling with a disability might be like (even though again it is not coming from real life experience by the writer and is still a fictional account). It is interesting that out of the four primary texts only one shows includes a well-structured sibling relationship with a child with a disability. It may well be that creating the feelings of difference and isolation for a character is more difficult when they have a sibling. The inclusion of Via brought a new level of meaning to the character of August that may not exist in the other texts. While Via struggled with identity there are a lot of positives associated with her relationship with August also.

5.7 Carer as Narrative Voice

Throughout, this chapter has examined the portrayal of family members of a character with a disability in the texts. This section will move to explore the depiction of the relationship between a character with a disability and their carer in the novels. It will particularly focus on the relationship between Ben and Trevor in *TRFOC* and the relationship between Louisa and Will in *Me Before You*. As carers can often be seen as the advocate or voice of the care, language can be seen as a vital element of this relationship. The writings of Ngũgĩ and Achebe will be revisited to examine how language can be used as a way of enforcing power. The notion of voice is also an important aspect in these relationships, as in both texts it is the carer (Ben and Louisa) and not the characters with a disability (Trevor and Will) who are the primary narrative voices of the texts.

The relationship between Louisa and Will is difficult in its early stages and quickly evolves into a power struggle. Louisa through her position as carer has an element of power over Will which he dislikes. Will uses language and culture to try and claim a dominant position in the relationship.

‘I don’t like films with subtitles.’ ‘That’s like saying you don’t like films with actors in them. Don’t be ridiculous. What is it you don’t like? The fact that you’re required to read something as well as watch something?’ ‘I just don’t really like foreign films.’ ‘Everything after Local Bloody Hero has been a foreign film. D’you think Hollywood is a suburb of Birmingham?’ (p.83)

Will would often critique Louisa on what he believed was her lack of cultural knowledge and lack of ambition. Louisa when noting the things Will enjoyed writes; ‘making me read books or magazines, and then talk about them. Knowledge is power, Clark, he would say’ (p.286). Will’s attitude to Louisa is often condescending. He treats her as inferior someone bereft of all the cultural knowledge that is so valued in his part of society. In lieu of physical abilities Will uses language to punish Louisa. ‘Language is a handy whipping boy to summon and belabor when we have failed in some serious way’ (Achebe 2009, p.102). To punish her not for anything she has or hasn’t done, but to punish her as she is his carer, the physical

manifestation of his loss of abilities and opportunities. However, strangely, Will and Louisa built their relationship on this foundation and Louisa begins to enjoy the music, movies and books that Will forces her to watch. Additionally, Will in his insults becomes more comfortable with Louisa as he feels a superiority. Though, the reason this can work in the novel is that no matter how much Will insults or demeans Louisa he is still never truly seen as the dominant character.

The story of Will's death is not actually Will's story. It is Louisa's story. Louisa is the predominant narrative voice in the novel. Additionally, the book served as a launching point for a book series focused on Louisa. 'To control a people's culture is to control their tools of self-definition in relationship to others' (Ngũgĩ 1986, p.16). Ngũgĩ argues that this method of control takes two forms for colonisers. The first form is undervaluing people's culture in relation to aspects such as 'art, dances... literatures' (p.16). This seems to be the form of control Will has attempted to enforce as seen in the last paragraph. While Will might seem to control some of Louisa's cultural identity on a surface level it is truly Louisa who is in control. She takes care of Will. She does for him many of things he is unable to do himself. While Will might demand he and Louisa watch a certain kind of film she is the one who will get up and put it on. Ngũgĩ notes the second method of taking this control is by 'the domination of a people's language' (p.16). While he was focusing on colonial languages vs native language he begins the argument with the pretence of taking 'language as communication (p.16). Louisa has a lot of control over how the reader perceives Will, she is his representative both as his caregiver and as the narrator. Even within the narrative of Will ordering Louisa around it is still truly Louisa who is succeeding here as it was her goal, and indeed her job, to get Will to open up to her. 'What am I here for?' Lou asks Nathan, 'Try to cheer him up a little' (p.44). Even in exerting dominance Will is losing. As the novel progresses Louisa also manages to change Will's perspective on what he can and cannot do since acquiring a disability. Tragically Will's only true victory is in his unwillingness to have his mind changed about travelling to Dignitas. Even in this example Louisa helped Will and helped convince others of his decision. Louisa is truly the one in control. She decides which of Will's orders to give in to. She chooses which stories about working with him she tells the reader. How Will's character is represented

is dominated by his caregiver, by his advocate. Although Louisa is an employee of Will's family, she is in charge.

Louisa in her role as caregiver manages to evolve and strengthen her relationship with Will by allowing him to feel strong and confident again. In allowing him to try and better her, by his own standards, she gives him purpose. Ngũgĩ writes that:

'The choice of language and the use to which language is put is central to a people's definition of themselves in relation to their natural and social environment, indeed in relation to the entire universe' (1986, p.4).

Will's interactions with Louisa allow him to change his self-definition. It allows him to feel better about himself. This can be seen also in his relationship with Nathan. While Nathan does care for a lot of Will's physical and medical needs he is also a friend figure. Louisa notes in her list of things Will likes to do that one of them is:

Being a bloke. Especially with Nathan. Occasionally, before the evening routine, they would go and sit at the end of the garden and Nathan would crack open a couple of beers. Sometimes I heard them discussing rugby, or joking about some woman they had seen on the television, and it wouldn't sound like Will at all (p.287).

Being a caregiver in this instance involves a more holistic approach as both Nathan and Louisa offer him a sense of normalcy, a sense of forgetting about his limitations. Out of the list of things Louisa writes that Will likes, two of the main ones are just being with her and Nathan. They offer him an opportunity to express himself, to laugh and chat about things that are not his health or his future. This is something Will doesn't feel he can do with anyone else. Louisa's role as carer is to help Will find his voice but also to try and change it. She wants him to have a strong sense of self in a way that will change his mind on dying.

Throughout the course of the novel Will and Louisa's relationship changes. Louisa begins challenging Will more often:

So how is it okay for you to offer an opinion on every single thing I say or do, and yet nobody else gets to say anything at all?' 'Go on, then, Louisa Clark. Give me your opinions (p.125).

As they begin to respect each other, their relationship changes from professional to romantic, from carer and caree to boyfriend and girlfriend. When Louisa realises that their relationship is changing 'I like Will a lot' (p.371) she wants to stop being his carer. 'You can't be both. You can't be carer and ...' (p.372). Louisa tries to change their relationship but she never really stops being Will's carer. 'But he needs me' (p.379) Louisa says as she breaks up with her boyfriend for Will. However, to return to Ngũgĩ's quote that language is central to a people's definition, it may be that the word carer never actually really defined Louisa and Will's relationship. Her job was to build a relationship with him and to try and change his perspective. She did care for him but the limitations of the word carer caused Louisa much grief as their connection evolved. As she had been given a certain title she felt as if she had betrayed herself and indeed her 'social environment' (Ngũgĩ 1986, p.4) when the title no longer fit her role. As Louisa transitions into this new role she becomes less controlling of Will and eventually learns to accept his decision. She also argues that Will's biggest struggle was not losing his mobility but his autonomy, his agency.

I trust Will to know what is right for him, and because what has been the worst thing for him has been losing the ability to make a single decision, to do a single thing for himself (p.460).

Spivak's quote that 'you don't give the subaltern voice. You work for the bloody subaltern, you work against subalternity' (1992, p.47) is relevant to the evolution of Louisa and Will's relationship. Louisa stopped trying to give Will a voice. She dropped her role as carer as she finally gave Will what he wanted, someone who listened and helped. For Louisa, being given a title was too limiting to her experiences. Although Nathan seemed to better balance the two sides coming to terms with Will's situation at an earlier time:

If he doesn't, then by forcing him to carry on, you, me – no matter how much we love him – we become just another shitty bunch of people taking away his choices (p.401).

The novel highlights that the same labels do not work for everyone.

A changing relationship between carer and caree also featured in *TRFOC*. Ben took on the role of carer to Trevor at the beginning of the novel but as the book progressed, he became more of a friend character. Both books seem to put forward the idea that categorising people associated with those with disabilities is limiting on the real-life relationship. The novel opens with Ben discussing his training as a caregiver and how the role of caring for someone is explained in 'dozens of helpful mnemonics to help facilitate effective caregiving' (p.1) such as ALOHA (P.2) standing for 'Ask Listen Observe Help Ask Again' and PRO meaning 'Professional Reliable and Objective' (p.8). Objective in this sense means that Ben believes he doesn't need to share any of his personal life with Trevor and that their relationship should be solely professional. Achebe writes that 'we play politics with language, and in doing so conceal the reality and the complexity of our situations from ourselves' (2009, p.102). Achebe argues that language is often played with to avoid the difficulty in situations. Mnemonics are a simplified way of achieving this, of making the challenge of defining the role of carer straightforward. Koppers notes that 'disability experience shifts with time' but for many 'being disabled means being fixed [in time]' (2003, p.8). These mnemonics are a linguistic way of doing this of maintaining and controlling a correct way of interacting with disability. The words and mnemonics that Ben was given about how to be a good carer do not allow for the complexities of working with a real person and of having to build a relationship with them. However, this objectivity that Ben speaks about slowly breaks down throughout the novel as he spends more time with Trevor. The title of the book itself reflects this *The Revised Fundamentals of Caregiving*. Ben, through his time working with Trevor, revises these tools he is given in his class as they often fail in reality. It is interesting to note that in the film adaptation of the book the title was changed to *The Fundamentals of Caring* arguably losing some of the complexity of the story and the changes Ben goes through as a caregiver.

In a somewhat similar fashion to Will and Louisa's relationship, due to Trevor's limited mobility, language and communication play a large role in their relationship. The thesis has already discussed how Trevor uses sexually explicit language about woman to try and seem more mature and break an image that infantilises him. It is interesting how Ben responds to this. Ben engages with this language and uses it in response to Trevor. As Louisa gave Will what he wanted out of their relationship Ben does the same. 'I'd give her a Gorilla Mask'

states Trevor 'I'd give her a Bulgarian Gas Mask' (p.9) responds Ben. Trevor is trying to achieve something in his use of language and Ben helps him achieve this by responding in the manner he deems appropriate. Achebe argues that language 'seems so natural that [people] rarely give much thought to it' (1989, p.128). This is not true for Trevor and Ben at the beginning of their relationship. Words are carefully chosen to show dominance and to allow dominance to be shown. As the book progresses Trevor becomes more confident in himself and in his relationship with Ben and this language gradually fades away. Word choice seems to become less important. It becomes more natural, more akin to Achebe's declaration. The book shows that language is only natural when your expression is not challenged and when a character is more confident in their identity. When Trevor was challenged and uncertain, he needed to plan his words as a way to rise up to this challenge and Ben needed to respond appropriately. For Ben, as with Louisa, his role as carer was much more than meeting physical needs.

As their relationship evolves Ben challenges Trevor more often. At the beginning of the book Ben followed the rules of caregiving he had been given:

Sometimes I want to let Trev have it. Aren't you tired of doing the same ten things over and over! I want to say. The waffles, the Weather Channel, the mall and the matinee on Thursday... But of course, I never do these things, or say these things (p.8).

As Trevor grows in confidence Ben feels like he can challenge him more. Ngũgĩ writes that language 'is both a means of communication and a carrier of culture' (1986, p.13). Ben wants language to be used for more than just communication for Trevor he wants to use to help create a different way of life. Ben wants to challenge Trevor and expand his world. He does this by planning the fake road to try and get Trevor to think about the world outside of his routine, to think about a life outside his routine. Ben writes that it is an 'exercise in hope' (p.19). When Ngũgĩ calls language a carrier of culture he is stating that it is an active process of keeping something alive and strong. Ben adapts this idea, language used here through the planning of the road trip, is exercising, maintaining hope and a larger world view. Hehir discusses the 'low expectations' (2002, p.18) that plague people with disabilities. All four texts highlight the problems with low expectations and highlight the benefits of challenging them even when they are held by the character with a disability themselves. Ben challenges

Trevor's low expectations about himself but there seems to be an element of control in his seemingly benevolent actions. Ben is frustrated by Trevor when he doesn't push himself forward. This frustration is arguably not really about Trevor. Ben believes himself to have failed as a parent and his children have passed away. He believes Trevor is wasting his life, wasting opportunities his children will never have. He wants Trevor to have the best life he can but it is Ben who decides what that means. Additionally, Ben himself has endured a tragedy and is suffering from low self-esteem. If he can fix Trevor it will be a success for him.

Another common feature between *Me Before You* and *TRFOC* is that it is really the carer not the character with a disability who is the narrative voice and the main protagonist. *Me Before You* is Louisa's story not Will's and *TRFOC* is Ben's story, not Trevor's. While Trevor has his own personality, character arc and development in the novel it is always connected to Ben's development. Ben tells the story by alternating between his time with Trevor, his past life with his family and his personal life. Much of it is to highlight how different events affected Ben and how he has evolved throughout. From this perspective Trevor falls back into the 'Tiny Tim' character trope of a character defined by their need for help and by how they can help someone by allowing them to be charitable. Trevor and Ben help each other as Ben grows as a character as much if not more than Trevor throughout the novel. However, because so much of the narrative is about Ben it seems one-sided. Ben tries to fix Trevor in an attempt to fix himself. In similar fashion to Louisa, Ben gets to choose what elements of Trevor's story to tell the reader due to being in control of the narration. Once again, the advocate of the person with the disability becomes the all controlling voice. While the narratives of both novels seem to try and highlight the humanity and kindness of carers, the presentation and form of these stories goes against this message. 'Language, like any other human invention, can be abused, can be turned from its original purpose into something useless or even deadly' (Achebe 1989, p.133). Narratives that were meant to highlight how caregivers help to give voice to people in their care instead show carers speaking for the people they are working with. This goes against Spivak argument that you do not 'give' (Spivak 1992, p.47) the subaltern a voice, yet this is what is happening here the narrators are framing the characters with disabilities which they are working with and speaking for them, choosing what parts of their story to tell the reader.

When analysing the relationship between Will and Louisa it is interesting to take into account the genre of the novel being a romance. Ria Cheyne argues that disability studies has often ignored romance novels even though they are some of the most popular forms of literature (2017, p.201). Cheyne aligns herself with the Romance Writers of America's definition of what a romance novel is. She defines it as having a central love story which is the focus of the main plot as well as including an emotionally satisfying and optimistic ending. The relationship between Will and Louisa is a main focus of the text. Additionally, while the ending may not at first seem optimistic, it is emotionally satisfying as it builds to the emotional crescendo of Will's death providing a narratively fulfilling story. Louisa's story does end optimistically as she begins in journey into the rest of her series of books without Will as she goes to explore 'the whole of Paris' (p.481) in the final lines of the text. To return to the 'narrative prosthesis' (2000, p.49). idea of Snyder and Mitchell, where disability acts as a way of pushing forward the narrative, Will serves as both the love interest for Louisa and also the springboard for the rest of her story. To expand on this idea in relation to Cheyne's writing she discusses, while building on the work of Patricia Puccinelli that in romance novels disabled character often have the 'yardstick quality' (p.208) where they are used as a way to help readers assess others characters by examining how they interact with them. This can be seen explicitly in *Me Before You* as the narrative structure of the book resolves around numerous characters discussing their lives in relation to Will. On a large scale this is also the case for Louisa. Her interactions with Will are a way for the reader to assess whether they want to invest in the character both in relation to Will and beyond this in subsequent novels. Will is a test for Louisa. This could be arguably true for Ben in *TRFOC* too as Trevor is his test of whether he can redeem himself as a positive character after his traumatic past. Louisa and Ben are using their role as caregivers to enhance their own narratives.

The representation of carers in the texts are complex and often portray juxtaposed images. Louisa and Ben are shown to try and help remove the limitations of Will and Trevor's disabilities but are often shown to be selfish in their intentions. Will and Trevor both benefit greatly from their relationships with their carers but their stories are not the focus of the novels, it is the development of Louisa and Ben that are the main narratives. Like Tiny Tim

helps Scrooge change himself in 'A Christmas Carol', Wil and Trevor help Louisa and Ben become better people. This is especially troublesome in *Me Before You* as the novel launches a subsequent series of books about Louisa. In *TRFOC*, Ben and Trevor help each other though it still seems one-sided. Language use in these relationships is seen as very important as verbal power struggle occur at different times throughout the texts. Language is power in these examples and although it is represented as switching from side to side, the carers always have the most powerful voice as they narrate the story to the reader.

5.8 Conclusion

This section explored the representations of parents, siblings and carers through the lens of both postcolonialism and disability studies. It can be seen throughout this chapter the most of these relationships were depicted as quite negative. In the case of the parents, two of the four sets of parents had separated due to their child's disability at the beginning of the texts (*TCI* and *TRFOC*). Another set of parents separate by the end of the novel in *Me Before You*. Will's sister is also seen to struggle greatly. *Wonder* is the only book that seems somewhat positive in its presentation of a family unit. While August's parents and sister suffer, they still value each other and disability is not seen to have damaged their cohesiveness as a family unit to as much a degree as the other texts. Issues with voice and language arose as characters with disabilities and their family members often had their voices ignored. Family members were also affected socially due to being associated with disability. Identity issues were seen prominently in family members as they struggled with having their identity primarily associated with their role in the family. It was also shown that parents struggled to connect with their children, perhaps seen as most challenging in *TCI*. Overall, the family unit was seen to be affected quite negatively by having a child with a disability in it in all four texts.

The representation of carers seemed to clash in both form and content. The books tried to showcase carers helping the people whom they worked with. However, while ensuring their voices were heard they often went against this as they were the main narrators and controlled the stories of the people they worked with. In conclusion, while family relationships were

usually well developed, in general having a child or sibling with a disability in the texts is almost always depicted as negative and difficult. The depictions of carers usually saw them as more important than the person they were caring for and made the characters with a disability a part of their journey forward instead of them having their own voice or story.

Conclusion

Throughout this thesis it has been seen that these novels, which have often been deemed authentic and positive (Letcher 2010), are actually in many ways problematic in their representation of disability. The novels can be seen to follow negative trends of overcoming disability and sacrificing character depth to be inspirational. The fact that these texts are written by normate writers has been challenged and the problems that occur from this have been discussed. Overall, postcolonial and disability theory has been used to breakdown disability representation in these contemporary texts, identifying power dynamics, interesting ways of using language and their depictions of otherness. The novels highlight a lot of issues of otherness and oppression that people with disabilities are likely to experience. However, the texts are also often problematic in themselves. For example, as seen in chapter one, they highlight the struggles of having one's voice be heard, however, the novels themselves are an act of one community speaking on behalf of another, normate writers telling the story of disability.

Chapter two examined a number of representations of language and communication within the novels. The language used to describe the characters often prove quite harmful. Christopher in TCI argues that language is insufficient for describing his experiences, challenging titles such as 'special needs' and highlighting the limitations of the word. Christopher also describes his struggles understanding the cultural associations of language and finds face-to-face conversation difficult. Achebe writes that speech 'seems so natural that [people] rarely give much thought to it' (1989, p.128). The challenges that Christopher faces are not a struggle many people would consider. August and Christopher also highlight their difficulties with word associations and how people connect them with cultural representations of disability. For example, August often gets associated to negative figures such as 'Freddy Krueger. E.T. ... Mutant' (Palacio, p.97), 'orc' (p.247), 'Gollum' (p.312) and 'Darth Sidious' (p.59). Palacio attempts to highlight the importance of language and how much cultural weight a word can carry as well as the struggles of self-expression that can be caused by societal expectations. Overall, the novels seem to showcase the insufficient power

of language to accurately label people or experiences and the negative ramifications of its failed attempts. Interestingly the novels themselves also take part in this. As *Wonder* uses quotes comparing it to *TCI* on the cover, it is using vague associations for describing disability identity. Additionally, while *Wonder* highlights how media figures can become damaging caricatures of disability it could be argued that novels themselves are creating new caricatures that may become damaging themselves. This highlights a regular issue of the books attempting to challenge damaging media trends toward disability representation while unconsciously following them.

Chapter three continued the exploration of associations and identity by examining grouping using Anderson's *Imagined Communities*. Anderson's writing on grouping and identity helped highlight the damaging effects of labelling large-scale groups of people and how a dominant descriptor such as 'people with disabilities' can limit self-expression. These limitations can create further negative feelings for a character as seen in the writing of Hall and Taylor. The binary idea of being either in or outside of a community meant many of the characters felt trapped. Additionally, when Will's position in *Me Before You* changed later in life from normate to disabled, he was unable to accept it as he believed the divide between communities too big to cross. The educational community as seen in the school lives of August and Christopher proved interesting example of the difficulties in focusing on the divisions of community and what it can do to a character's identity. August is seen as different to his classmates in his mainstream classroom and has to go through a number of challenging and difficult situations before he is accepted by those around him. Alternatively, Christopher attends a special school and he rejects his classmates as he feels no connection to them. Christopher also struggles to get access to mainstream education. Not comfortably fitting into either community, Christopher gets lost in the periphery. The novels highlight the struggles of being forced into a social category. Many of the characters lash out at these situations and end up hating those who they are associated with. For example, Trevor himself using the word 'retard' to describe his new carer (p.127), Christopher complaining how the other kids in his class are 'stupid' (p.56) and Will can literally not live with the idea of being associated with disability. The novels argue that being treated poorly because of disability create negative feelings towards others with disabilities. Characters are taught to learn to hate themselves

(‘why do I have to be so ugly’ (p.76) – August to his mother) and others with a disability instead of the people or systems oppressing them.

Chapter four further explored this idea of division and othering. Said’s writing in *Orientalism* highlighted the difficulties that can be experienced when a character’s identity is rejected by those around them. Koppers also discusses the damage that was done as characters were forced to play the role of ‘character with a disability’ and the limitations this had on their self-expression which was strengthened by Said’s discussion on performance and othering. Often characters are forced to accept that they will be treated as helpless and expected to act as such. Both Trevor and August have internalised this treatment at the beginning of their respective stories and struggle to break this idea. The difficulty of identity expression seen in chapter three does not just limit these characters it changes them as they sometimes accept the characteristics the world gives them. It was also argued that these novels can be damaging in relation to narrative perspective. Ciocia argued that the way the first-person narration is structured in *TCI* intentionally infantilises Christopher to the reader. This could arguably be assigned to *Wonder* too, as the reader is positioned as more intelligent and more advanced than the character with a disability. These characters are only meant to be seen as equals by very young readers. Older readers may experience the books differently as they see the mistakes Christopher, for example, makes before he realises it himself. This changes Christopher from a heroic detective character to a somewhat tragic childlike figure. Eric Chen offered an interesting exploration into how literature can help create understanding of disability which tied into Said’s argument that the power of literary and media representations helped create and maintain images of the Orient. He also noted the most influential work was often created by Occident writers. The fact that these novels are not written by writers with disabilities does bring up an issue with authenticity. Chen’s writings on *TCI* highlighted that an outside force studying a group may be able to see what goes into a person’s head and what comes out but they will never may able to experience what happens in the middle. These books cannot be a way of seeing into the mind of a person with a disability. They can only ever be an imagining of what a writer believes it might be like to have a disability. This may not necessarily have to be a bad thing, however, when these novels are

as influential, especially in educational settings, therefore this needs to be given careful consideration.

Chapter five changed the focus of study from the characters with a disability to the depictions of their caregivers and family members. There was an investigation in carers, parents and siblings. The ramifications of disability on a support network can be physical, financial and also social. To repeat the quote that opened the chapter from August's sister Via 'I'm always going to be the sister of a kid with a birth defect: that's not the issue. I just don't always want to be defined that way' (Palacio, p.113). This sentence highlights so many of the issues that the characters with disabilities themselves are seen as experiencing. The sibling relationship is seen to take a toll on Via. In *Me Before You*, Will's decision about assisted suicide is something his sister Georgina struggles with greatly. However, as Georgina has moved away from home she does not play a big part in Will's life after his disability. Via is really the only example of sibling representation. She is depicted as struggling at times but overall having a very positive and healthy relationship with her brother. Although August's disability does seem to put a strain on her relationship with her parents. The caregivers seen in *Me Before You* and *TRFOC* are shown in texts of fulfilling not just the physical needs of those they are working with but also their social needs. Ben and Nathan become close friends to Trevor and Will. Louisa even becomes romantically involved with Will. In the beginning of *TRFOC* Ben details some of his training in being a carer and one of the rules highlighted is to maintain a professional relationship. However, this never seems to happen in the books. Trevor and Will seem to benefit tremendously from more personal relationships with their carers as they are often the only people who treat them as people. However, as these carers are the main narrators of the stories they often become the protagonists and Will and Trevor become Tiny Tim like figures existing more to enhance the stories of someone else. Giving the narrative voice to the carers also takes it away from the characters who have a disability.

In *TCI*, *Wonder* and *TRFOC* the parents have either broken up or on the verge of breaking up over the stress of having a child with a disability. Disability is shown as detrimental to the family unit. Although the actual relationships with their children vary greatly, the effects on

the parent's relationship and their own health is more often seen as extremely negative. *Wonder* is the only text that showcases a positive family unit featuring disability as August's parents do at times struggle but lean on each other to help support the family. However, even here, snippets are shown of the sacrifices made as August's Mother had to give up her job and much of her social life to care for August and home-school him for many years. Family members and caregivers are sometimes seen as experiencing difficulties and associated with disability through association. They are also often used to offer a more accessible voice to the reader for understanding disability. For example, Louisa's perspective is used in *Me Before You*, to showcase how difficult Will's life is as she first tries to transverse footpaths with him. The representation of family members as well as caregivers and the social reach of disability was quite a central point in these texts. There is room for further research to be done especially in relation to the large focus given on the suffering of parents and the destruction of the family unit due to disability in many of these novels.

While postcolonial theory has been helpful throughout this thesis in understanding the power dynamics of representing a minority group it did have its drawbacks. It was difficult to maintain a nuanced approach to disability in relation to postcolonial theory at times and other theorists were needed to help bridge the gap. While postcolonial theory is helpful in problematizing disability, using postcolonial theory more so as part of a broader use of cultural studies may help improve nuanced readings. There are a number of avenues this thesis has opened up for further research. It has highlighted a number of problems present in these popular texts. It has touched on issues with representation of the effects of disability on the family unit which needs further exploration. Certain areas that were not focused on that should be in future work is the gender issue that a majority of texts about characters with disabilities seem to be male focused. Future work into this project will hopefully incorporate more voices of people with disabilities, by studying creative work by disabled writers and hopefully finding collaboration opportunities with academics who identify as having a disability. Overall, this thesis has highlighted that these texts are often problematic in their depictions and in their authenticity even though some have become cultural institutions in their influence in contemporary media. Part of this blame can be both on the writers but arguably some of it may be on us as readers and critics also. The academic and

critical community have at times either ignored these texts or unfairly praised them. This research has hopefully added to the conversation about how literature about disability is treated both by writers in how they approach these characters and by readers and academics in critical approaches to disability. Mark Haddon, TCI's own novelist, has discussed his worries about how his work has been used:

'It is used as a textbook for social workers, and for policemen, which is something I heard recently. I never meant it to be a textbook' (Singh 2015).

These novels are pieces of fiction; however, these stories have had too much expertise attributed to them.

Bibliography

Primary Texts

Burnett, R. (2016) *The Fundamentals of Caring*, California: Netflix.

Chbosky, S. (2017) *Wonder*, California: Lionsgate.

Evison, J. (2012) *The Revised Fundamentals of Caregiving*, New York: Algonquin Books of Chapel Hill.

Haddon, M. (2003) *The Curious Incident of The Dog in The Night-Time*, London: Random House.

Moyes, J. (2012) *Me Before You*, UK: Penguin Books.

Palacio, R.J. (2012) *Wonder*, London: Transworld Publishers.

Palacio, R.J. (2017) *We're All Wonders*, London: Puffin Books.

Sharrock, T. (2016) *Me Before You*, California: Warner Bros. Pictures.

Stephens, S. (2012) *The Curious Incident of The Dog in The Night-Time*, London: Methuen Drama.

Secondary Texts

Achebe, C. (1989) *Hopes and Impediments Selected Essays*, New York: Doubleday.

Achebe, C. (2009) *The Education of a British-Protected Child*, London: Penguin Classics.

Alaniz, J. (2014) *Death, Disability, and the Superhero: The Silver Age and Beyond*, Mississippi: The University Press of Mississippi.

Anderson, B. (1983) *Imagined Communities Reflections on the Origin and Spread of Nationalism*, London: Verso.

Annamma, S. (2018) *The Pedagogy of Pathologization Dis/abled Girls of Color in the School-prison Nexus*, New York, Routledge.

Aronson, J. (2000) *Sound and Fury*, California: Next Wave Films.

Ashcroft, B., Griffiths, G. and Tiffin, H. (2003) *The Empire Writes Back* (2nd ed.). London: Routledge.

Ashcroft, B., Griffiths, G. and Tiffin, H. (2006) *The Post-Colonial Studies Reader*, Oxford: Routledge.

Barker, C. (2011) *Postcolonial Fiction and Disability Exceptional Children, Metaphor and Materiality*, UK: Palgrave Macmillan.

Bhabha, H. K. (1994) *The Location of Culture*, London; Routledge.

Bloom, E. (2016) *The Wireless Past Anglo-Irish Writers and the BBC, 1931–1968*, Oxford: Oxford University Press.

Bourdieu, P. (1996) *Distinction A social Critique of the Judgement of Taste*, Massachusetts: Harvard University Press.

Bourke, A. (2001) *The Burning of Bridget Cleary: A True Story*, Pennsylvania: Penguin Books.

Canguilhem, G. (1978) *The Normal and the Pathological* trans. Fawcett, C. & Cohen, R. (1991) New York: Zone Books.

- Chatterjee, P. (1986) *Nationalist Thought and the Colonial World: A Derivative Discourse*, London: Zed Books for United Nations University.
- Chen, E. (2005) *Mirror Mind: Penetrating Autism's Enigma*, Singapore: Self-published.
- Chen, M. (2012) *Animacies: Biopolitics, Racial Mattering, and Queer Affect*, Durham, NC: Duke University Press.
- Cobb-Roberts, D., Dorn, S. & Shircliffe, B. eds. (2006) *Schools as Imagined Communities The Creation of Identity, Meaning, and Conflict in U.S. History*, New York: Palgrave Macmillan.
- Collin, L. (2016) *Sanctuary*, Ireland: Eclipse Pictures.
- Connors, S. (2013) 'I Try to Remember Who I Am and Who I Am Not' in Thomas, P. L. (ed) *Science Fiction and Speculative Fiction: Challenging Genres*, Netherlands: Sense Publishers.
- Conrad, P. (2007) *The Medicalization of Society*, Baltimore: Johns Hopkins University Press.
- Couser, G. (2009) *Signifying Bodies: Disability in Contemporary Life Writing*, Michigan: University of Michigan Press.
- Crosby, C. (2016) *A Body Undone Living on After Great Pain*, New York: New York University Press.
- Darwin, C. (1869) *On the Origin of Species by Means of Natural Selection: Or the Preservation of Favoured Races in the Struggle for Life*, New York: Appleton.
- Davis, L. (1995) *Enforcing Normalcy Disability, Deafness, and the Body*, London: Verso.
- De Saussure, F. (1966) *Course in General Linguistics*, eds. Bally, C. & Sechehaye, A. New York: McGraw-Hill Book Co.
- Dickens, C. (2003) *A Christmas Carol and Other Christmas Writings*, London: Penguin.
- Doyle, A.C (1894) *The Memoirs of Sherlock Holmes*, UK: George Newnes.
- Doyle, A.C (1986) *A Study in Scarlet*, New York: Amereon Limited.
- Drevner, T. (2010) *Loving Lampposts*, California: Cinema Libre Studio.
- Ellis, K. (2016) *Disability Media Work Opportunities and Obstacles*, New York: Palgrave Pivot.

- Ellis, K., Garland-Thompson, R., Kent, M. & Robertson, R. Eds (2019) *Manifestos for the Future of Critical Disability Studies Volume 1*, New York: Routledge.
- Foucault, M. (1980) *Power/Knowledge Selected Interviews and Other Writings 1972-1977*, New York: Pantheon Books.
- Foucault, M. (1995) *Discipline and Punish The Birth of the Prison*, New York: Vintage Books.
- Garland-Thompson, R. (1997) *Extraordinary Bodies; Figuring Physical Disability in American Culture and Literature*, New York: Columbia University Press.
- Gellner, E. (1983) *Nations and Nationalism*, Oxford: Blackwell.
- Gleeson, S. (2019) *Constellations*, Ireland: Pan Macmillan.
- Glendinning C. (1983) *Unshared Care: Parents and their disabled siblings*, London: Routledge and Kegan Paul.
- Gramsci, A. (1971) *Selections from the Prison Notebooks*, Hoare, Q. and Smith, G. Trans. And Ed. London: Lawrence and Wishart.
- Grimm, J. Grimm, W. (1972) *The Complete Grimm's Fairy Tales*, New York: Pantheon Books.
- Hackford, T. (2004) *Ray*, United States: Universal Pictures.
- Hall, A. (2012) *Disability and Modern Fiction Faulkner, Morrison, Coetzee and the Nobel Prize for Literature*, England: Palgrave Macmillan.
- Hallström, L (1994) *What's Eating Gilbert Grape*, Los Angeles: Paramount Pictures.
- Hayes, L. (2017) *Stories of Care: A Labour of Law Gender and Class at Work*, U.K.: Palgrave Macmillan.
- Jacobs, W. and Jones, J. (1985) *The Comic Book Heroes: From the Silver Age to the Present*, New York: Crown.
- Kershner, I. (1980) *The Empire Strikes Back*, United States: 20th Century Fox.
- Kevles, D. (1985) *In the Name of Eugenics: Genetics and the Uses of Human Heredity*, New York: Alfred A. Knopf.

- Kipling, R. (1994) *The Collected Poems of Rudyard Kipling*, United Kingdom: Wordsworth Editions Ltd.
- Kuppers, P. (2003) *Disability and Contemporary Performance: Bodies on Edge*, New York: Routledge.
- Kuppers, P. (2011) *Disability Culture and Community Performance Find a Strange and Twisted Shape*, Hampshire: Palgrave Macmillan.
- Kuppers, P. (2014) *Studying Disability Arts and Culture: An Introduction*, Hampshire: Palgrave Macmillan.
- Lacan, J. (1968) *The Language of the Self: The Function of Language in Psychoanalysis*, Baltimore: Johns Hopkins Press.
- Levinson, B. (1988) *Rain Man*, California: MGM/UA Communications.
- Linton, S. (1998) *Claiming Disability: Knowledge and Identity*, New York: NYU Press.
- Lodge, D. Wood, N. eds. (2000) *Modern Criticism and Theory A Reader*, England: Pearson Education Limited.
- Longmore, P. (2003) *Why I Burned My Book and Other Essays on Disability*, Pennsylvania: Temple University Press.
- Ludden, D. (2002) *Reading Subaltern Studies: Critical History, Contested Meaning and the Globalization of South Asia*, London: Anthem Press.
- Lucas, G. (1977) *Star Wars*, United States: Lucas Film Ltd.
- Machiavelli (1988) *The Prince*, Cambridge: Cambridge University Press.
- MacMurphy, H. (1926) *The Almosts: A Study of the Feeble-Minded*, Boston: Houghton Mifflin.
- Marsh, J. (2014) *The Theory of Everything*, UK: Universal Pictures.
- Matsumoto, D. (2009) *The Cambridge Dictionary of Psychology*, Cambridge: Cambridge University Press.

- McCormack M. (1978) *A Mentally Handicapped Child in the Family*, London: Constable.
- McEwan, C. (2009) *Postcolonialism and Development*, New York: Routledge.
- Mitchell, D. and Snyder, S (2000) *Narrative Prosthesis: Disability and the Dependency of Discourse*, Michigan: University of Michigan Press.
- Morris, D. (2002) *Peopewatching*, London: Vintage Books.
- Morrison, T. (1993) *Playing in the Dark: Whiteness and the Literary Imagination*, New York: Vintage.
- Mossman, M. (2009) *Disability, Representation and The Body in Irish Writing 1800-1922*, England, Palgrave Macmillan.
- Moyes, J. (2015) *After You*, UK: Penguin Books.
- Moyes, J. (2018) *Still Me*, UK: Penguin Books.
- Paur, J. (2017) *The Right to Maim Debility, Capacity, Disability*, London: Duke University Press.
- Puccinelli, P. (1995) *Yardsticks: Retarded Characters and Their Role in Fiction*, New York: Peter Lang.
- Said, E. (1978) *Orientalism*, New York: Pantheon Books.
- Schmiesing, A. (2014) *Disability, Deformity, and Disease in the Grimms' Fairy Tales*, Michigan: Wayne State University Press.
- Seton-Watson, H. (1977) *Nations and States. An Enquiry into the Origins of Nations and the Politics of Nationalism*, Colorado: Westview Press.
- Shapiro, J. (1994) *No Pity: People with Disabilities Forging a New Civil Rights Movement*, New York: Broadway Books.
- Shelley, M. (1869) *Frankenstein; or, The Modern Prometheus*, Boston: Sever, Francis, & Company.
- Sheridan, J. (1989) *My Left Foot*, London: Palace Pictures.

Stevenson, R. (2008) *Strange Case of Dr Jekyll and Mr Hyde and Other Tales*, Oxford: OUP Oxford.

Stiker, H. (1997) *A History of Disability*, Trans. Sayers, W. Ann Arbor: University of Michigan Press.

Todorov, T. (1993) *On Human Diversity, Nationalism, Racism, and Exoticism in French Thought*, Porter, C. Trans. Massachusetts: Harvard University Press.

Tolkien, J.R.R (1994) *The Lord of The Rings*, New York: Harper Collins.

Wa Thiong'o, Ngũgĩ. (1986) *Decolonising the Mind*, England: James Currey Ltd.

Whitaker, S. (2013) *Intellectual Disability: An Inability to Cope with an Intellectually Demanding World*, England: Palgrave Macmillan.

Woolf, V. (1948) *The Moment, and Other Essays*, California: Harcourt Brace.

Young, R. (2003) *Postcolonialism A Very Short Introduction*, Oxford: Oxford University Press.

Book Chapters, Secondary Articles, Newspapers, Etc

Achebe, C. (1965) 'English and the African Writer', *Transition*, No. 18 (1965), pp. 27-30, Indiana: Indiana University Press.

Adams, R. (2013) 'Disability Studies Now', *American Literary History*, 25(2), 495–507.

Adams, R. Reiss, B. Serlin, D. (2015) 'Introduction' in Adams, R. Reiss, B. Serlin, D. (eds) *Keywords for Disability Studies*, New York: New York University Press.

Baynton, D. (1998) 'Language Matters: Handicapping An Affliction', Disability History Museum, available at: <https://www.disabilitymuseum.org/dhm/edu/essay.html?id=30> [Accessed 27/05/2020].

Baynton, D. (2001) 'Disability and the justification of Inequality in American History', Longmore, P. & Umansky, L. (Eds), *The New Disability History: American perspectives*, pp. 33–57, New York: New York University Press.

Bogdan, R. Biklen, D. (1977) 'Handicapism', *Social Policy* 7, March/April, pp.14-19.

Bogdan, R. Biklen, D. (2013) 'Handicapism' in Wappett, M. Arndt, K. (eds.) *Foundations of Disability Studies* New York: Palgrave Macmillan.

Bowker, N and Tuffin, K. (2002) 'Disability Discourses for Online Identities', in *Disability and Society*, Vol. 17, No. 3, pp.327-344, London: Carfax publishing.

Breeden, L. (2012) 'Transformative Occupation in Practice: Changing Media Images and Lives of People with Disabilities' in *Occupation, Participation and Health* 32.

Burch, S. and Nielson, K (2015) 'History' in Adams, R. Reiss, B. Serlin, D. (eds) *Keywords for Disability Studies*, New York: New York University Press.

Burks-Abbott, G. (2008) 'Mark Haddon's Popularity and Other Curious Incidents in My life as an Autistic' in Osteen, M. (ed) *Autism and Representation*, New York: Routledge.

Butler, J. (1990) *Gender Trouble Feminism and the Subversion of Identity*, New York: Routledge.

Chakrabarty, D. (2000) 'Subaltern Studies and Postcolonial Historiography', *Nepantla: Views from South*, Volume 1, Issue 1, pp. 9-32, North Carolina: Duke University Press.

Chataika, T. (2012) 'Disability, Development and Postcolonialism' in Goodley, D., Hughes, B. & Davis, L (eds) *Disability and Social Theory New Developments and Directions*, U.K.: Palgrave Macmillan.

Cheyne, R. (2017) 'Disability Studies Reads the Romance Sexuality, Prejudice, and the Happily-Ever-After in the Work of Mary Balogh' in Waldschmidt, A., Berressem, H. & Ingwersen, M. (eds) *Culture – Theory – Disability Encounters between Disability Studies and Cultural Studies*, Germany: Transcript Verlag.

Ciocia, S. (2009) 'Postmodern Investigations: The Case of Christopher Boone in The Curious Incident of the Dog in the Night-time', in *Children's Literature in Education*, 40, pp.320–332, Germany: Springer Science + Business Media.

Connor, D. and Ferri, B. (2013) 'Historicizing Dis/Ability: Creating Normalcy. Containing Difference' in Wappett, M. Arndt, K. (eds.) *Foundations of Disability Studies* New York: Palgrave Macmillan.

Coombs, D. & Mayans, M. (2015) 'Insider or Outsider? Using Young Adult Literature and Experiential Learning to Understand the Other' in *The ALAN Review*, Fall 2015, Volume 43, Number 3, New York: National Council of Teachers of English.

Crenshaw, K., Ocen, P., & Nanda, J. (2015). 'Black girls matter: Pushed out, overpoliced, and underprotected', Available at:

www.atlanticphilanthropies.org/app/uploads/2015/09/BlackGirlsMatter_Report.pdf

Accessed [14/11/2020].

DasGupta,S (2015) 'Medicalization', in Adams, R. Reiss, B. Serlin, D. (eds) *Keywords for Disability Studies*, New York: New York University Press.

Dave (2006) 'The Curiously Irresistible Literary Debut of Mark Haddon', *Powells.com*, 10/10/2006 Available: <https://www.powells.com/post/interviews/the-curiously-irresistible-literary-debut-of-mark-haddon> Accessed [06/12/2019].

Davis, L. (2006) 'Constructing Normalcy: The Bell Curve, The Novel, and the Invention of the Disabled Body in the Nineteenth Century' In Davis, L. (Ed.). *The Disability Studies Reader* (pp. 3–16). New York: Taylor and Francis.

Donnelly, J. (2007) 'The Relative Universality of Human Rights', *Human Rights Quarterly*, Vol. 29, No. 2, pp. 281-306, Maryland: John Hopkins University Press.

Dorn, S. (2006) 'Imagined Communities and Special Education' in Cobb-Roberts, D., Dorn, S. & Shircliffe, B. eds. (2006) *Schools as Imagined Communities The Creation of Identity, Meaning, and Conflict in U.S. History*, New York: Palgrave Macmillan.

Ezard, J. (2003) 'Curious incident of writer's literary hat trick', *The Guardian*, 13/11/2003, available:

<https://www.theguardian.com/uk/2003/nov/13/books.whitbreadbookawards2003>

[Accessed 06/02/2020].

Gabbard, D. (2015) 'Human' in Adams, R. Reiss, B. Serlin, D. (eds) *Keywords for Disability Studies*, New York: New York University Press.

Garcia, A. (2013) *Critical Foundations in Young Adult Literature*, Netherlands: Sense Publishers.

Galvin, R. (2003) 'The Making of the Disabled Identity: A Linguistic Analysis of Marginalisation', *Disability Studies Quarterly*, Spring, Volume 23, No. 2, pp. 149-178, Ohio: The Ohio State University Libraries.

Garland-Thompson, R. (2000) 'Seeing the Disabled: Visual Rhetorics of Popular Disability Photography', P. Longmore and L. Umansky, eds. *The New Disability History American Perspectives* pp.335-374, New York: New York University Press.

Garland-Thompson, R. (2002) 'The Politics of Staring: Visual Rhetorics of Disability in Popular Photography', Snyder, S, Brueggemann and Garland-Thompson, R. eds., *Disability Studies: Enabling the Humanities*, pp.56-75 New York: Modern Language Association of America.

Garland-Thompson, R. (2005) 'Feminist Disability Studies', *Signs*, Vol. 30, No.2, pp.1557-1587, Chicago, The University of Chicago Press.

Garland-Thomson, R. (2012) 'The Case for Conserving Disability', *Journal of Bioethical Inquiry*, pp.339-355, Netherlands: Springer Netherlands.

Ghai, A. (2012) 'Engaging with Disability with Postcolonial Theory in Goodley', D., Hughes, B. & Davis, L (eds) *Disability and Social Theory New Developments and Directions*, U.K.: Palgrave Macmillan.

Gilchrist, H. (2012) Jojo Moyes Red Chat, Red Online, 19/10/2012, Available: <https://www.redonline.co.uk/red-women/red-chat/a511090/jojo-moyes/> Accessed [12/11/2020].

Gilmore, J. (2012) 'Assisted Living', *The New York Times*, 07/09/2012, available: <https://www.nytimes.com/2012/09/09/books/review/the-revised-fundamentals-of-caregiving-by-jonathan-evison.html> [Accessed 12/02/2020].

Goldberg, H. (2016) 'Why Some Disability Rights Activists Are Protesting 'Me Before You'', Self.com, 26/05/2016, Available: <https://www.self.com/story/why-some-disability-rights-activists-are-protesting-me-before-you>, Accessed [15/05/2020].

Green, M. (2011) 'Rethinking the subaltern and the question of censorship in Gramsci's Prison Notebooks' in *Postcolonial Studies*, Vol. 14, No. 4, pp. 387-404, New York: Routledge.

Guarisco, M. & Freeman, L. (2015) 'The Wonder of Empathy: Using Palacio's Novel to Teach Perspective Taking' in *The ALAN Review*, Fall 2015, Volume 43, Number 3, New York: National Council of Teachers of English.

Guglielmi, J. (2017) 'Julia Roberts Urges Fans to 'Choose Kind' in an Effort to Combat Bullying', *People.com*, 08/11 2017. Available: <https://people.com/movies/julia-roberts-anti-bullying-charity-wonder/> Accessed [14/11/2019].

Hall, S. (1990) 'Cultural Identity and Diaspora', in Rutherford, J. Ed. *Identity: Community, Culture, Difference*, pp.222-237, London: Lawrence & Wishart.

Hames, A. (2008) 'Siblings' Understanding of Learning Disability: A Longitudinal Study', *Journal of Applied Research in Intellectual Disabilities* 21, pp.491–501, Newcastle: Blackwell Publishing Ltd.

- Hehir, T. (2002) 'Eliminating Ableism in Education', *Harvard Educational Review* Vol. 72 No. 1.
- Higgins, C. (2019) 'Mark Haddon: 'Curious Incident was like a gold-plated ball and chain'', *The Guardian*, 04/05/2019, Available: <https://www.theguardian.com/books/2019/may/04/mark-haddon-interview> [Accessed 06/02/2020].
- Jakobson, R. (1960) 'Linguistics and Poetics', in Sebeok, T. *Style in Language*, Cambridge: MIT Press pp.350-377.
- Johnstone, C. J. (2004) 'Disability and identity: personal constructions and formalized supports', *Disability Studies Quarterly*, 24(4). Available: <http://dsq-sds.org/article/view/880/1055> Accessed (14/11/2019).
- Jones, J. (2006) 'Bold, Graphic but Bad Art', *The Guardian*, 16/03/2006.
- Kuppers, P. (2008) 'Dancing Autism: The Curious Incident of the Dog in the Night-time and Bedlam', *Text and Performance Quarterly*, 28:1-2, 192-205.
- Lee, S. (1963) *Tales of Suspense*, Vol.1, #39, New York City: Marvel Comics.
- Lee, S. and Ditko, S (1963) *Strange Tales*, Vol. 1, #115, New York City: Marvel Comics.
- Lee, S. and Everett, B. (1964) *Daredevil*, Vol.1, #1, New York City: Marvel Comics.
- Lee, S. and Kirby, J. (1962) *Journey into Mystery*, Vol 1, #83, New York City: Marvel Comics.
- Lee, S. and Kirby, J. (1963) *X-Men*, Vol.1, #1, New York City: Marvel Comics.
- Letcher, M. (2010) 'Off the Shelves: Autism in Young Adult Literature' in *The English Journal*, Vol. 100, No. 2, pp. 113-116, New York: National Council of Teachers of English.
- Longmore, P. K. (1985) 'A note on language and social identity of disabled people', *American Behavioural Scientist*, 28(3), 419-423.
- Louai, E.H. (2012) 'Retracing the concept of the subaltern from Gramsci to Spivak: Historical developments and new applications', *African Journal of History and Culture (AJHC)* Vol. 4(1), pp. 4-8, Academic Journals; Nigeria.

Margolis, H. and Shapiro, A. (1987) 'Countering Negative Images of Disability in Classical Literature', *The English Journal*, Vol. 76, No. 3, pp. 18-22, New York: National Council of Teachers of English.

Maughan, S. (2012) 'New Anti-Bullying Campaign Lauds the 'Wonder' of Being Kind', PublishersWeekly.com, 05/31/2012, Available: <https://www.publishersweekly.com/pw/by-topic/childrens/childrens-industry-news/article/52173-new-anti-bullying-campaign-lauds-the-wonder-of-being-kind.html> Accessed [15/05/2020].

McRae, J. (2007) Introduction to Walsh, C. 'Schema Poetics and Crossover Fiction' in Lambrou, M. and Peter Stockwell, P. (Eds.), *Contemporary Stylistics* (pp. 106–117). London: Continuum.

Mee, C. (2006) 'Introduction to a Summer Evening in Des Moines', in Lewis, V. (ed) *Beyond Victims and Villains: Contemporary Plays by Disabled Playwrights*, New York: Theatre Communications Group.

Merriam-Webster Dictionary (2018) Quadriplegic, Available at www.merriam-webster.com/dictionary/quadriplegic, [Accessed 27/09/2018].

Miller, J. (1964) 'Translators Note' in Lacan, J. *The Four Fundamental Concepts of Psychoanalysis*, New York: W.W. Norton & Company, Inc.

Mitchell, D. and Snyder, S (2019) 'Low-level agency Disability, oppression and alternative genres of the human' in Ellis, K., Garland-Thompson, R., Kent, M. & Robertson, R. Eds (2019) *Manifestos for the Future of Critical Disability Studies* Volume 1, New York: Routledge.

Mouland, B. (2005) 'Nelson Looks Down as Statue of Disabled Mother is Unveiled in the Rain', *The Daily Mail*, 16/09/2005.

Noll, S. and Trent, J.W. (2004) 'Introduction', in Noll, S. and Trent, J.W. (eds), *Mental Retardation in America: A Historical Reader*, New York: New York University Press.

NPR Staff (2013) 'How One Unkind Moment Gave Way To 'Wonder'', National Public Radio, 12/09/2013, available: <https://www.npr.org/2013/09/12/221005752/how-one-unkind-moment-gave-way-to-wonder> [Accessed 27/04/2020].

Omi, M, and Winant, H. (1994) 'Racial Formations', in Omi, M, AND Winant, H. eds. *Racial Formation in the United States : From the 1960s to the 1990s*, pp.3-13, Taylor and Francis: Oxford.

Penrose, W. (2015) 'The Discourse of Disability in Ancient Greece', in *Classical World*, Volume 108, Number 4, pp.499-523, Maryland: John Hopkins University Press.

Pilkington, E. (2012) 'The Ashley treatment: 'Her life is as good as we can possibly make it'', *The Guardian*, 15/03/2012, Available:

<https://www.theguardian.com/society/2012/mar/15/ashley-treatment-email-exchange>

Accessed [15/11/2019].

Prentice, C. (1997) 'Born in a Marvellous Year?: The Child in Colonial and Postcolonial New Zealand Literature', *New Literatures Review*, 33, pp.65-80.

Pritchard, S. (2016) 'The Readers' Editor On... Portraying Disability', *The Guardian*, 29/05/2016, available:

https://www.theguardian.com/commentisfree/2016/may/28/readers-editor-attitudes-changing-to-disability?CMP=share_btn_tw [Accessed 14/11/2019].

Professional Development Service for Teachers (2015) *Jcsp library project - Recommended reading document* available: <https://www.pdst.ie/node/5831> [Accessed 16/12/2019].

Quinn, K. (2016) 'Me Before You, starring GoT's Emilia Clarke, is a 'disability snuff movie', say protesters', 06/17/2016, *The Sydney Morning Herald*, Available:

<https://www.smh.com.au/entertainment/movies/me-before-you-starring-gots-emilia-clarke-is-a-disability-snuff-movie-say-protesters-20160616-gpkqim.html>,

Accessed

[15/05/2020].

Raynor, O. and Hayward, K. (2005) 'The Employment of Performers with Disabilities in the Entertainment Industry' California: National Arts and Disability Centre, Available at

<http://artsedge.kennedycenter.org/2009neasummit/pdfs/EmploymentofPerformerswithDisabilities.pdf> [Accessed on 01/02/2020].

Richards, P. (2004) "'Beside Her Sat Her Idiot Child" Families and Developmental Disability in Mid-Nineteenth-Century America' in Noll, S. Trent, J. (eds) *Mental Retardation in America*, New York: New York University Press.

Rodas, J. (2015) 'Identity' in Adams, R. Reiss, B. Serlin, D. (eds) *Keywords for Disability Studies*, New York: New York University Press.

Rodgers, L. (2012) 'How to Win an Oscar', *BBC*, available at

<https://www.bbc.com/news/entertainment-arts-16932374>, [Accessed on 01/02/2020].

Romance Writers of America (2014) 'About the Romance Genre', 19/08/2014, available at https://www.rwa.org/Online/Romance_Genre/About_Romance_Genre.aspx [Accessed on 26/05/2020].

Rossiter L. & Sharpe D. (2001) 'The siblings of individuals with mental retardation: a quantitative integration of the literature', in *Journal of Child and Family Studies* 10, 65–84.

Russo, M (2012) 'Facing Up to It', *The New York Times*, 06/04/2012, available: <https://www.nytimes.com/2012/04/08/books/review/wonder-by-r-j-palacio.html> [Accessed 12/02/2020].

Samuels, E. (2002) 'Critical Divides: Judith Butler's Body Theory and the Question of Disability', *NWSA Journal*, Volume 14, Number 3, Fall 2002, pp.58-76, Maryland: John Hopkins University Press.

Sherry, M. (2007) '(Post)colonising Disability' in *Wagadu* Volume 4, Summer 2007.

Shinn, C. (2014) 'Disability is not Just a Metaphor', *The Atlantic*, Available at <https://www.theatlantic.com/entertainment/archive/2014/07/why-disabled-characters-are-never-played-by-disabled-actors/374822/>, [Accessed on 01/02/2020].

Siebers, T. (2013) 'Disability, Pain, and the Politics of Minority Identity' in Wappett, M. Arndt, K. (eds.) *Foundations of Disability Studies* New York: Palgrave Macmillan.

Silentmiaow (2007) 'In My Language', Available:

<https://www.youtube.com/watch?v=JnylM1hI2jc> [Accessed on 29/02/2020].

Simon, R. (2005) 'Alison Lapper, the New Icon of Trafalgar Square', *The Evening Standard*, 15/09/2005.

Sinclair, J. (1993) 'Don't Mourn For Us', in Bascom, J. ed. *Loud Hands: Autistic People, Speaking* Washington D.C: Autistic Self Advocacy Network. pp.15-21.

Singh, A. (2015) 'Mark Haddon - don't use Curious Incident... as an autism "textbook"', *Telegraph*, 08/06/2015, Available:

<https://www.telegraph.co.uk/culture/culturenews/9311242/Mark-Haddon-dont-use-Curious-Incident...-as-an-autism-textbook.html> [Accessed 14/11/2019].

Snyder, S and Mitchell, D. (2007) 'Disability Haunting in American Poetics', *Journal of Disability Studies* 1, pp.1-12.

Spivak, G. (1988) 'Can the Subaltern Speak?' in Nelson, C. and Grossberg, L. (eds.) *Marxism and the Interpretation of Culture*, pp. 271 –313, Urbana, IL: University of Illinois Press.

Spivak, G. (1990). *The Post-Colonial Critic: Interviews, Strategies, Dialogues* (edited by S. Harasym). New York: Routledge.

Spivak, G. (1992) 'Interview with Gayatri Chakravorty Spivak: New Nation Writers Conference in South Africa', Interview by Leon De Kock, *ARIEL: A Review of International English Literature*, 23:3, Maryland: The Johns Hopkins University Press.

Stalker, K. and Connors, C. (2004) 'Children's Perceptions of Their Disabled Siblings: 'She's Different but it's Normal for Us'', in *Children & Society Volume 18* (2004), pp. 218–230, London: National Children's Bureau.

Steffens, D. (2012) 'Me Before You, By Jojo Moyes Listen and learn from an odd couple', *The Independent*, 08/01/2012, available <https://www.independent.co.uk/arts-entertainment/books/reviews/me-before-you-by-jojo-moyes-6286458.html> [Accessed 12/02/2020].

Stoneman Z. (2005) 'Siblings of children with disabilities: research themes' *Mental Retardation* 43, 339–350.

Taylor, M. C. (1994) 'The Politics of Recognition' in Gutmann, A. *Multiculturalism Examining the Politics of Recognition*, pp.25-74, New Jersey: Princeton University Press.

Titchkosky, T. (2015) 'Normal' in Adams, R. Reiss, B. Serlin, D. (eds) *Keywords for Disability Studies*, New York: New York University Press.

Tozer R. (1996) 'My brother's keeper?' Sustaining sibling support' in *Health and Social Care in the Community* 4(3): 177–181.

Wa Thiong'o, Ngũgĩ. (2013) 'My Encounters with Chinua Achebe', in *Journal of Asian and African Studies*, 48(6), pp.760–762.

Wallace, J. (1994) 'De-Scribing the Water-Babies: "The Child" in Post-Colonial Theory' in Tiffin, C. and Lawson, A. (eds) *De-Scribing Empire: Post-Colonialism and Textuality*, London: Routledge.

Wappett, M. Arndt, K. (2013) 'Foreword' in Wappett, M. Arndt, K. (eds.) *Foundations of Disability Studies* New York: Palgrave Macmillan.

Wendell, S. (2001) "Unhealthy Disabled: Treating Chronic Illnesses as Disabilities." *Hypatia* 16, no. 4: 17–33.

Woodburn, D. and Kopic, K. (2016)' The Ruderman White Paper on Employment of Actors with Disabilities in Television', *The Ruderman Family Foundation* Available at http://www.rudermanfoundation.org/wp-content/uploads/2016/07/TV-White-Paper_7-1-003.pdf, [Accessed on 01/02/2020].