

LUP - Faculty of Education

Pernille Rømoen

Master's Thesis

Developing Critical Literacy through Disability Studies:

A critical analysis of disability in *The Secret Garden* and *Wonder*

Lektorutdanning i Språkfag

Spring 2023

Acknowledgments

First and foremost, I have to thank my supervisor Rebecca Sioned Davies. Without her invaluable patience and knowledge, this endeavour would not have been possible. Thank you for keeping me on track and being a constant reminder that I actually have to hand something in if I want any feedback.

I am also grateful to my classmates and the endless hours we have spent in the library this semester, for all their help, tips, and moral support. I am even more grateful for the hour-long breaks we had trying to stay sane during this venture.

This thesis marks the end of my time as a student and there are so many people who have been an inspiration and support to me and that have made my time as a student enjoyable and fun.

Thank you.

Abstract

This thesis seeks to explore how the use of young adult fiction can increase awareness of the hegemonic discourse of an able-bodied society by demonstrating critical literacy through a disability studies-based reading of Frances Hodgson Burnett's The Secret Garden (1911) and R. J. Palacio's Wonder (2012). The aim of the thesis is to demonstrate that the use of young adult fiction with disabled protagonists can further pupils' thinking and meaning-making process. There is a general lack of conversation about disability and therefore, reading disability narratives contributes to bringing awareness to an underrepresented minority. The analysis of The Secret Garden and Wonder highlights the different attitudes people have about disability and the way disability is treated by an ableist society that sees disabled people as an Other. Teaching literature through a disability studies lens encourages critical awareness of the socio-cultural aspects that dictate society's attitudes toward disability as well as contributing to the pupils' understanding of the core value "human dignity". These novels were chosen because they were written 100 years apart and portray disabled people through two opposing models of disability. This allows pupils to compare the development of societal attitudes toward disability through common tropes such as "disability as metaphor" and "disability as something monstrous".

Sammendrag

Denne masteroppgaven utforsker hvordan skjønnlitteratur for ungdom kan øke bevisstheten om den hegemoniske diskursen til et funkofobisk (ableist) samfunn ved å demonstrere critical literacy gjennom en disability studies-basert analyse av Frances Hodgson Burnett sin The Secret Garden (1911) og R. J. Palacio sin Wonder (2012). Målet med oppgaven er å vise at bruken av skjønnlitteratur med funksjonshemmede protagonister kan fremme elevers tankeog meningsskapende prosess. Det er en generell mangel på samtaler rundt funksjonshemning og derfor vil lesing av fortellinger med funksjonshemmede personer bidra til bevisstgjøringen av en underrepresentert minoritet. Analysen av The Secret Garden og Wonder fremhever de ulike holdningene folk har om funksjonshemming og måten funksjonshemning blir behandlet av et funkofobisk samfunn som ser på funksjonshemmede mennesker som en Andre. Litteraturundervisning gjennom en disability studies-linse oppmuntrer til kritisk bevissthet rundt de sosiokulturelle aspektene som dikterer samfunnets holdninger til funksjonshemning, samt bidrar til elevenes forståelse av kjerneverdien «menneskeverdet». Jeg valgte The Secret Garden og Wonder fordi de ble skrevet med 100 års mellomrom og fremstiller funksjonshemmede personer gjennom to motstridende funksjonshemningsmodeller. Denne framstillingen lar elevene sammenligne utviklingen av samfunnsmessige holdninger til funksjonshemning gjennom vanlige troper som "funksjonshemning som metafor" og "funksjonshemning som noe uhyrlig".

Table of contents

1.	Introduction	1
	1.1 Disability Studies and Critical Literacy	4
2.	Theory	11
	2.1 Disability Studies	11
	2.1.1 Medical Model	14
	2.1.2 Social Model	15
	2.2 Disability and Literature	18
	2.3 Disability and Language	25
3.	Critical Reading of Young Adult Fiction	26
	3.1 Products of Their Time (the Medical and Social Model)	32
	3.2 Language of Disability	43
	3.3 Hereditary Illnesses and the Fear of Contagion	50
	3.4 Appearance and Staring	53
	3.5 The Able-Bodied in a Disability Narrative	63
4.	Conclusion	66
Re	eferences	69

1. Introduction

The purpose of this dissertation is to explore how the use of young adult fiction can increase awareness of the hegemonic discourse of an able-bodied society. This will be done by demonstrating critical literacy through a disability studies based reading of *The Secret Garden* (1911) and *Wonder* (2012). I will argue that an awareness of how English language cultural productions can create social attitudes will help pupils develop a broader social consciousness, as is required by the core curriculum. Teaching literature through a disability studies lens encourages critical awareness of the socio-cultural aspects that dictate society's attitudes toward disability.

LK20 is fully implemented as of spring 2023 as the newly revised Norwegian curriculum. With its arrival, LK20 brought with it a multitude of fresh possibilities and changes. The new curriculum opened up opportunities for more individual interpretation by teachers under broad topics. The Norwegian school system allows freedom of method which essentially means that, even though the aims are the same for all, every teacher can choose how they want to achieve these aims. As LK20 has broad and open aims, teachers have considerable leeway as to how they want to structure their classes to best fit their group of pupils. As a teacher you have a responsibility to help your pupils reach the competence aims stated in the curriculum of the relevant subject as well as the values and principles stated in the core curriculum. "The core curriculum describes the fundamental approach that shall direct the pedagogical practice in all lower and secondary education and training" (Ministry of Education and Research, 2017, p. 3). The purpose of the core curriculum is to guide teachers to give pupils the necessary tools to learn about the world and to develop as a human. There are six core values within the Core Curriculum that a "school shall base its practice" on, these values originate from the Education Act and express values upon which the Norwegian society is built (Ministry of Education and Research, 2017, p. 6). These values are "human dignity", "identity and cultural diversity", "critical thinking and ethical awareness", "the joy of creating, engagement and the urge to explore", "respect for nature and environmental awareness", and "democracy and participation", and they work as the foundation of all teaching.

The core value "human dignity" focuses on equality and differences. Through "human dignity", issues such as human rights, equality, discrimination, and humanity are raised as an important part of the pupils' schooling. Human dignity is recognised "when teachers show care for the pupils and acknowledge each individual" (Ministry of Education and Research, 2017, p. 6). The English subject has, along with all other subjects, a responsibility to safeguard these values and make them apparent to the pupils. Disability is an important topic within human dignity, yet disability is not specifically mentioned in either the core curriculum or the curriculum in English¹ There are several mentions of difference throughout both the core curriculum and curriculum in English and how important it is to learn to respect people different from yourself. Both curricula explicitly mention ethnic minorities such as the Sami, Jews, Kvens/Norwegian Finns, Forest Finns, Roma, and Romani people/Tatar, as well as mentioning cultural and linguistic differences, and differences of religion and belief. However, the curricula fail to mention disability as a way of being "different". Disability is often an overlooked area of equality and intercultural competence, thus making it an even more important topic to explore. It should be mentioned that sign language is included in the core curriculum under "identity and cultural diversity", and that "Norwegian sign language is also recognised as a language in its own right in Norway" (Ministry of Education and Research, 2017, p. 7). One sentence is used to acknowledge sign language as a legitimate language, yet it is placed under "identity and cultural diversity", a section with a main focus on ethnic and cultural minorities. Still, disability can be a distinct cultural identity that disabled people feel affiliated with.

In a country where society has become more concerned with diversity and how important it is to make minorities feel welcomed and seen, it feels like one minority is often left out or forgotten. Disabled people, a minority found in every country, are seldom included in the conversation about diversity. Linda Ware argues that "disability is a long overdue conversation among critical theorists, pedagogues, and educationalists who fail to recognise disability as a cultural signifier; nor do they include disability as a meaningful category of oppression" (Ware, 2001, p. 112). This lack of disability as a topic of conversation is visible in various of my teacher training textbooks from different syllabi that have diversity

¹ It is worth mentioning that my focus is on disability as a social issue, rather than pedagogical help with those with specific disabilities (PPT).

(mangfold) as a focus. Westrheim & Tolo (2014) Kompetanse for Mangfold, a textbook dedicated to diversity in school fails to include disability in the narrative. In the book's preface, it is specified that "everyone is provided a place at school, regardless of outside interests, social background, gender, religion, or ethnicity" (Westrheim & Tolo, 2014, p. 5). In a way, disabled people are included under these categories, as disabled people come from different social backgrounds, and have different genders and religions. Nevertheless, it can be assumed that that was not a conscious decision when the book was written. There is one mention of disability in the whole book; in chapter five, written by Elisabeth Eide, discrimination as a term is discussed and she mentions §135A of the penal code that is "against discrimination based on ethnicity, religion, gender/sexual orientation, or reduced functional ability" (Westrheim & Tolo, 2014, p. 158). Even though disability is - through reference to the penal code – placed together with ethnicity, religion, and gender, which are all topics discussed in the textbook, disability is failed to be recognised as a topic worth discussing in a book about diversity. Juliet Munden and Christina Sandhaug, in their book Engelsk for secondary school (2017), a textbook used in several of the teacher training programmes at the university, has dedicated five of its 506 pages to "teens with special needs" (Munden & Sandhaug, 2017, pp. 38-42). The special needs mentioned are ADHD (ADD), dyslexia, blind pupils, and deaf pupils, and each section covers some generalised information about the disability. The section opens with "in this section we consider pupils with specific challenges" (Munden & Sandhaug, 2017, p. 38), with no indication that other types of challenges exist, giving the impression of a homogenous society where there are only four ways of being disabled. However, it should be addressed that there is a great focus on inclusive teaching methods for pupils with special needs. It is important to differentiate between inclusive teaching methods and teaching the social aspects of disability, such as the value of disabled people in society, and unconscious biases, and challenges they might face. While there is a lot of focus on the former, there is a shortage of the latter, which is the focus of this thesis. Two other syllabus textbooks about diversity that have no mentions of disability are Ulikhet og fellesskap (2020) by Sigrun Sand, and Å være lærer i en mangfoldig skole (2018) by Espen Schjetne & Thor-André Skerfsrud. Across four textbooks from teacher training program syllabi, it appears as though the only diversity that exists is cultural diversity, which encompasses different cultures and religions. This is of course not true, as disability is a meaningful topic to all. Linda Ware together with Tom Painting, a veteran language arts teacher, developed a curriculum unit that had an aim to promote understanding of disability. Tom expressed to Ware that he did not feel qualified to teach about disability

and that it was somebody else's job (Ware, 2001, p. 120). The issue with this statement, an attitude many will resonate with, is that this is exactly the job of an educator; to stay updated on cultural issues in order to best provide our pupils with up-to-date information. It is a teacher's responsibility to seek information and become educated. "If teacher educators accept the challenge of reimagining disability, we must begin by problematising disability through a cultural lens" (Ware, 2001, p. 120), which is where disability studies come into the picture. It is this idea, that disability is not a topic worth exploring by the general population, that disability studies actively tries to change by highlighting the social and cultural significance of disability. Disability studies tries to do to disability what postcolonial theory and race theory do, making us more aware of invisible cultural and systemic biases and challenges.

1.1 Disability Studies and Critical Literacy

The field of disability studies focuses on how the world views disability "in the context of culture, society, and politics" (Rice, 2018). Even though disability is something that exists within all cultures, every culture treats disability differently through politics, language, legal adjustments, civil infrastructures, and other areas of society. The core value of Human dignity, and intercultural competence, can be an entryway into teaching pupils the different ways one minority group is viewed and treated across different cultures. Disability studies intersects with the curriculum aims of human dignity and intercultural competence in a shared focus on human rights, equality and discrimination. Critical literacy is an important skill highlighted in LK20 and necessary for pupils to master if they are to challenge established social and cultural narratives. Critical literacy in the English subject requires a sensitivity to how language and culture create a socio-political perception of minority groups. Disability studies can, therefore, give pupils insight into how society uses language and specific narratives to frame disability in a certain light. Disabled people often face everyday challenges non-disabled people are unaware of. Non-disabled people might not even think about some of the challenges disabled people have to face, as these challenges might be so far from their reality that it is never something they have had to consider before. Intercultural competence can therefore be useful in understanding different ways of living and acknowledging that different does not necessarily equate to worse than what you are used to yourself. Intercultural competence can also help make people see what the majority can do to help a minority feel like an accepted, appreciated, and integral part of society. It is stated in

the curriculum in English (ENG01-04) that learning about different cultures and ways of living can help "promote curiosity and engagement and help to prevent prejudice" (Ministry of Education and Research, 2019, p. 2). Through intercultural competence you gain insight into cultures other than your own, encouraging understanding of other ways of living, which in turn creates a reflective, open-minded youth.

Disability studies explores the socio-cultural treatment of disability as a whole: what it means to be disabled in a society where non-disabled people are the norm and to challenge the hegemonic established views of an able-bodied world (Cheyne, 2019, p. 12). Disability is not an exception of being but rather an individual experience with as much subject validity as the able-bodied experience. As a minority, disabled people share several of the same experiences other minorities have and continue to face, where discrimination and ostracization are at the top of the list. There is, however, one crucial difference between disability and other minorities: anyone can become disabled. Disability is a reality anyone might have to face on a personal level, either through birth, sickness, or an accident. A person cannot wake up one morning and suddenly have a different ethnicity than when they went to bed, but they can wake up and have become paralysed during the night. As disability is a reality anyone might have to face, disability studies also aims to achieve the recognition that disability, regardless of a person's disability status, is an important topic for all people (Cheyne, 2019, p. 12). It is important to note that "disabled people" is not a term all people with impairments agree with, as some might prefer other terms. What is most important to remember when talking about, or with, disabled people is to listen to how people talk about themselves and conform to their narrative. By acknowledging that different people prefer different terms and by complying with their preferred terms, you give legitimacy to disabled people as individuals. While the social model uses "disabled people", some people prefer people-first language (person with a disability), placing the person first and the disability second. Throughout this thesis, I will be using the term "disabled people" as I am analysing literature from the social disability studies perspective. That said, if I am referring to a specific person or group who uses people-first language or another preferred term I will use their preferred term.

People are products of where they grew up; you learn the values of the society that surrounds you, which in turn shapes your values and beliefs. This concept was termed "cultural mediation" by Lev Vygotsky. Cultural mediation is also a reflection of the shared knowledge of a culture. A child learns from their parents and friends, who have learnt their knowledge from their parents and friends, which turns into a society of people with shared knowledge. Literary texts are a part of cultural mediation and are often reflections of the society in which they were produced. Thus, it becomes possible to become aware of and learn the values held by different societies and from different time periods through reading novels. Historical literature can show us where ingrained perceptions and beliefs might be rooted. The education system also plays an important role in the distribution of shared knowledge through set values that the education system is obliged to follow. Through teaching the core values of the core curriculum "school shall base its practice on the values in the objectives clause of the Education Act, "the objectives of education and training", consists of seven objectives the Norwegian education system must incorporate in its education and training:

Education and training must be based on fundamental values in Christian and humanist heritage and traditions, such as respect for human dignity and nature, on intellectual freedom, charity, forgiveness, equality and solidarity, values that also appear in different religions and beliefs and are rooted in human rights.

Education and training must help increase the knowledge and understanding of the national cultural heritage and our common international cultural traditions (Education Act, 1998, §1-1).

These two statements illustrate the ideal of shared values and knowledge of the Norwegian society that are expected for all people to learn and share. This idea of shared knowledge would also include attitudes toward disabled people and disability as a whole. Following this, I believe one way of teaching human dignity and intercultural competence is through young adult fiction, specifically young adult fiction which focuses on disability. At the same time, it is also possible to follow the development of attitudes by reading two novels from different time periods and analysing how these topics are addressed in the different books before comparing the two. Based on the information presented above, this dissertation examines two English language novels suitable for young adult readers: *The Secret Garden* (1911/2011) written by Frances Hodgson Burnett and *Wonder* (2012) written by R. J. Palacio. Both

represent disabled characters, however, while one is written in the early 20th century, and set in England, the other is a contemporary novel set in the USA. This demonstrates shared attitudes and values about disability in diverse societies, as well as differences. When critically reading novels and becoming aware of how they reflect cultural attitudes to disability, pupils will be made aware of their own unconscious attitudes and language, both when using English and having a more clear-eyed view of their mother tongue.

Critical literacy is a skill that is important to have when reading texts. Critical literacy does not have one single definition, however, there are some main aspects or ideas that are recurring. Critical literacy can be viewed as the study of language in the sense that language holds power; you try to look beyond the words written to find embedded meanings and motives (Alford, 2019, p. 7). This means having a critical perspective in meetings with texts, to question the text and its perspective and intention. Jennifer Alford (2019) captures the essence of critical literacy: "The interest for critical literacy is how texts work, what texts do to us, and how we can manage the ways in which they seek to work." (p. 7). Critical literacy is important to English as an Additional Language (EAL) learners, especially when reading texts. As an EAL learner, you often read texts set in a different environment than you are familiar with. Therefore, to fully grasp the content of the text, an understanding of the sociocultural context and the structures of meaning behind the basic sense of the words are necessary.

Frances Hodgson Burnett's *The Secret Garden* and R. J. Palacio's *Wonder* can through a disability studies lens be used in the upper-secondary classroom to teach the core value "human dignity" while developing the skill of critical thinking. *The Secret Garden* and *Wonder* are written 100 years apart, and both books have main characters with physical disabilities. Colin Craven, in Burnett's novel, is wheelchair-bound and believed to have progressive curvature of the spine and August Pullman, in Palacio's novel, has multiple genetic mutations that has left his face disfigured. Critically reading these novels through a disability studies framework can help uncover how disability has been used as a trope in the 1900s and how older tropes still influence social attitudes and beliefs. Choosing novels from two different time periods was a deliberate choice, as this allows a comparison of historical

and current points of view as well as exploring the changes in disability representation over time. Literature can act as a great tool for making pupils conscious of their own sets of values and engaging critical awareness. Christian Carlsen argues that "fictional texts challenge readers to explore different identities and perspectives on life" (Carlsen, 2020, p. 210). Reading fiction encourages you to explore different identities and perspectives that you might not be familiar with, or completely relate to. Exploring different identities might help develop a person's capacity to understand the people around them (Carlsen, 2020, p. 210). By understanding the characters and the choices they make, you develop your ability to understand people different from yourself and build empathy. This in turn can shape a person's attitudes and social beliefs. However, the pupils need to be critical in meetings with texts and certain narratives. They should be aware of when a narrative represents an outdated or prejudiced view such as that encountered in The Secret Garden, where a little girl has become "yellow" and "disagreeable" due to her colonial upbringing in India, it should be questioned. A modern reader should question that perspective and note that it reflects a hegemonic narrative that was common for the time. It is worth pointing out that both novels are written by able-bodied women and therefore do not represent a subjective experience of disability, but that can be explored as products of their cultural context in their treatment of disability.

Literature has the ability to tell the story of anyone, anywhere, bringing both known and unknown people, cultures, and societies to life. Pupils are supposed to learn about other cultures and countries during their education, but you cannot always go to these places or bring them into the classroom. Literature, however, opens up this opportunity, bringing authentic cultural expressions into the classrooms. A lot of classrooms in Norway are multicultural, with pupils whom all have their own identities, and an inclusive education system is necessary to be a successful education system. Literature can act as one of the stepping stones to achieving an inclusive classroom by reading inclusive texts by authors from all over the world. Texts about different kinds of people with different backgrounds, religions, sexualities, abilities, and challenges, encourages empathy and representation (Murty et al., 2021, p. 170). For some pupils, these texts will be about them, in the sense that they can recognise themselves in the text, while for other pupils it will offer an opportunity to learn about people and cultures other than themselves. Timothy Lintner (2011) writes about the importance of representation in literature, not only the representation of different cultures and ethnicities but also representation through "exceptionalities". Exceptionalities can include impairments and disabilities of any kind (p. 201). He further writes about how reading inclusive literature can help challenge stereotypes and develop empathy and understanding regardless of your own situation. For the non-disabled pupils, they might develop more understanding of people with disabilities and some of the challenges they might face, while the disabled pupils see people like themselves struggling with relatable issues and through these narratives get recognition. This in turn advocates "for the development of positive student attitudes toward and an ultimate acceptance of all students through the use of children's literature" (Lintner, 2011, p. 201). When pupils meet with unfamiliar topics and themes it can broaden their horizons and understanding of other people and cultures. Additionally, this knowledge might lead to the deconstruction of the "us" versus "them" narrative (Monobe & Son, 2014, p. 74), as pupils gain an understanding of other people and cultures, they might recognise that we are all people and not inherently different. Diverse and inclusive texts can help pupils gain knowledge of topics central to LK20. Using these types of texts is a way to promote human dignity, while additionally having the pupils learn about their own attitudes, perceptions, and beliefs (Murty et al., 2021, p. 172).

As stated in the English subject curriculum, the subject is especially important when it comes to the development of intercultural understanding and identity development (Ministry of Education and Research, 2019, p. 2). Under "Relevance and central values" in the English subject curriculum, it says intercultural competence helps with understanding that there are different ways of living and that, "[t]he subject shall develop the pupils' understanding that their views of the world are culture-dependent. This can open for new ways to interpret the world, promote curiosity and engagement and to help prevent prejudice" (Ministry of Education and Research, 2019, p. 2). This ties together with the notion of shared knowledge. Just as attitudes toward disabled people and disability are culturally dependent, so are the pupil's views. Therefore, incorporating intercultural competence (IC) into teaching in the EAL classroom when reading literature is crucial, especially as most literature used in an EAL classroom will be literature from another culture than that of the pupils. The pupils will, through literature, meet with both known and foreign cultures and to fully understand these stories the pupils will have to understand the culture in which the story is set and how it affects the story and its characters. Intercultural competence helps make the pupils aware that culture – including negative aspects like prejudice – is related to language, and that they need

to be more cautious when using their second language than their first language because they will be less conscious of cultural signification. This will also help them look more objectively at their own culturally-defined perceptions. Learning about other cultures can help the pupils become aware of differences and their own biases, which in turn promotes human dignity and the ability to respect and understand each other across different cultures. Intercultural competence is again mentioned under the core element "working with texts in English" where it says that, through working with different types of texts, "the pupils will develop intercultural competence enabling them to deal with different ways of living, ways of thinking and communication patterns" (Ministry of Education and Research, 2019, p. 3). Intercultural competence is essential in developing culturally conscious pupils.

2. Theory

2.1 Disability Studies

The focus of this thesis is to investigate how young adult literature can be used in the uppersecondary classroom to teach about disability. In order to have a strong socio-cultural understanding of disability, knowledge of disability studies as a discipline is essential for teachers to have. Disability studies is a research field "that views disability in the context of culture, society, and politics rather than through the lens of medicine or psychology" (Rice, 2018). Disability studies aims to shed light on the cultural position disability has, what it means to be disabled, the social context, and to challenge the hegemonic able-bodied views of the world. It is stated in the Curriculum in English that, through working with texts in English:

the pupils will develop intercultural competence enabling them to deal with different ways of living, ways of thinking and communication patterns. They shall build the foundation for seeing their own identity and others' identities in a multilingual and multicultural context. (Ministry of Education and Research, 2019, p. 2)

Intercultural competence is necessary to learn as the disabled community is a cultural community, with its own discourse, and disability is not just a medical diagnosis. Another goal of disability studies is to achieve recognition of the fact that disability is an important, meaningful topic to all people, regardless of a person's disability status (Cheyne, 2019, p. 12).

"Many believe that disabled people already won their rights. In much the same way that racism is believed to have been resolved by civil rights legislations" (Ware, 2001, p. 108). Even though this statement is in an American setting, it can be argued that it is relevant in a Norwegian setting as well. There are many legal protections for disabled citizens in Norway, such as the "Anti-Discrimination and Accessibility Act", the "Convention on the Rights of Persons with Disabilities", and § 4-6 of the "Working Environment Act". There are also organisations whose sole focus is fighting against discrimination and helping people who experience it. The "Anti-Discrimination Tribunal" is an independent, neutral organisation that offers free-of-charge services "to parties who wish to have a complaint heard by the Anti-

Discrimination Tribunal" (Diskrimineringsnemda, n.d.). Another organisation focused on discrimination is the 'Equality and Anti-Discrimination Ombud' which "fight[s] for those who are unfairly treated and discriminated against" (Likestillings- og diskrimineringsombudet, n.d.). Although there are all these protections for disabled citizens in place, unconscious biases and cultural norms which affect individuals are still present. Time and time again, instances of discrimination against disabled people occur. This fall, an article outlining such a case was published in VG. Gry Hege, who is missing both her arms and legs, was refused a renewal of her handicap-parking permit, as she was told she could always find another pharmacy with better parking, or shop at a time with less traffic so that she could park closer to the store (Sviggum, 2022). Thomas Myhre, who is in a wheelchair and commutes to work twice a week, has experienced being left behind or forgotten by the train on several occasions. The excuses given to him are that the lift needed to bring him on board takes too long to use for them to be able to pick him up and stay on time, if the lift even works, which he claims is a 50-50 chance (Rønhovde, 2023). Then there is Remi André, who has cerebral palsy, whom it took six years of applying before he managed to get a job. Remi André is a highly qualified man who has started his own business, worked as a taxi driver and has a trade certificate in computer science, yet he struggled to get a job. Even if it was never stated as a reason, he believes it is because of his diagnosis and the fact that he uses a wheelchair that he was rejected every time (Hafsaas, 2022). As a last effort, Katrine Bjørnsen, his supervisor from NAV, published on her Facebook an advertisement requesting anyone to contact her if they had any work for Remi. The advertisement got a lot of attention and today Remi works at Haukeland University Hospital. The Head of Section, Silje Greve Gangdal, explained that the hospital did not have to make any adjustments for Remi's wheelchair. "All he needs is a quality chair, as we all do" (Hafsaas, 2022). Through these three people, it is clear that the Norwegian society still maintains an unconscious belief that it is disabled people's job to adapt to society and not society that should accommodate disabled people.

On an international and historical level, WWI and WWII helped carry disabilities out into the light, bringing with them a greater understanding of disabled people (Murray, 2018, p. 91; Quayson, 2007, p. 10). The number of war heroes who became disabled from the wars forced people to acknowledge disabilities, both physical and mental. Rehabilitation centres were built and diagnoses such as shell shock syndrome gained recognition and understanding (Quayson, 2007, p. 10). The predecessor to the Paralympics started in 1948 as a sporting

competition for British World War II veterans with spinal cord injuries (The Editors of Encyclopaedia Britannica, 2023). The Paralympics contributed greatly in changing the attitudes to disability by lifting disabled people out from the shadows they had been hidden away in and out into the spotlight for people to celebrate. The focus of the sporting competition is to celebrate what disabled bodies can achieve rather than mourning what they cannot. Although the two World Wars contributed to a more widespread acceptance of disabled people, the attitudes to birth defects were not the same as those who had been wounded in battle. Those who became wounded in battle were seen as heroes, as they had sacrificed everything to protect their countries and defeat evil, unlike those who were born with birth defects, who were seen as less and "broken" individuals one should be ashamed of. Even though the two world wars contributed to a wider acceptance of disability, it would still take many years before disability studies as a field would emerge and continue changing attitudes for the better.

Disability studies is a broad field and important to include in educational contexts, as it spans social sciences and humanities. It is also relevant to education both through the curriculum in English and the core value section of the core curriculum. Equality and solidarity are important key concepts of the Norwegian educational system, and thus inclusive discussions and lessons are necessary to achieve a more complete view of Norwegian society and the world. As a field, disability studies started to gain recognition from the 1980s onwards (Hall, 2016, p. 19). Rachel Adams (2013) notes that disability historian Paul Longmore divides disability studies into two waves. The first wave "involved a struggle for civil rights that culminated in the landmark 1990 Americans with Disabilities Act. The next comprised the search for collective identity and creation of a disability culture" (p. 496). Adams further notes that even as Longmore was writing this theory, the second wave was entering a third wave, where key debates within the disability studies field surfaced (Adams, 2013, p. 496). One of these debates surrounds the separation made by the social model between "disability" and "impairment", which will be explained in section 2.1.2. Even though disability studies was not a recognised field until the 1980s, different models of disability existed long before this time. The two models that have gotten the most attention are the medical model and the social model. The medical model describes people who have disabilities whereas the social model talks of people who *are* disabled. These models exist to both define what disability is and to understand how disability is viewed in society (Dirth & Branscombe, 2017, p. 414).

Disability models aid in furthering our understanding of the bigger picture of the position of disability in society. They highlight the issues disabled people face and how they can be addressed. The social model uses the term "disabled people" instead of "people with disabilities" in a bid to step further away from the medical model. Using "people with disabilities" can be connected to the medical mindset that a disability is something you have within you and something that you can get rid of, undermining the identity of someone who is disabled. Whereas "disabled people" acknowledges the disabled identity and that people are disabled by society (Retief & Letšosa, 2018, p. 4). Longmore suggests that disability theory is moving beyond the social model, as it is far from perfect. The main issue with the social model is that it solely focuses on society's role in disabling people with impairments, fully disregarding the health struggles that come with impairments. Other weaknesses of the social model include the separation between "disability" and "impairment" which can be said to overlook people with cognitive and invisible impairments, and the notion that it is possible to accommodate all impairments, which is not possible. The shortcomings of the social model "disables disability studies" (Osteen, 2008, as cited in Hall, 2016, p. 26) in a way. Because of the weaknesses of the social model, there is a need for new approaches and ideas (Hall, 2016, pp. 26-27). This does not mean we should disregard the social model completely but look to it and the medical model and take from them what works and what does not. This way a more nuanced model can emerge, and voice issues the other models have failed to recognise, to fit continuously-changing societies.

2.1.1 Medical Model

The medical model arose simultaneously with the advancement of medicine in the mid-1800s and onwards (Retief & Letšosa, 2018, p. 2). As medicine became more advanced, it was now possible to treat previously fatal ailments, and a broader understanding of different diseases and ailments allowed more people to get treatments to help in their recovery. The medical model treats disability as a disease that needs to be cured and rehabilitated, always branding disability as something negative. Because disabled people are understood through their diagnosis, and medicine is there to either cure someone or better their quality of life, the model indicates that having a disability places you as inferior to nondisabled people. (Dirth & Branscombe, 2017, p. 415; Leduc, 2020, p. 36). Disability is viewed as something outside the norm, placing disabled people outside society, as something "other" and in need of

"correcting". The medical model is behind negatively loaded terminology such as "invalid", "cripple", "spastic", and "retarded" (Retief & Letšosa, 2018, p. 3). The use of these medical terms to insult or other groups and individuals illustrates how disabilities have been seen as something bad which needs to be fixed. However, every culture has different words describing disabilities and disabled people, and it is, therefore, important to remember that a word which is accepted terminology in one country might be an offensive slur in another. This is especially important for an English teacher in Norway, who have a responsibility to make pupils aware of different terminology and the different meanings they can have².

Through the medical model, people have been removed from the public sphere and seen separately from society: there is nothing wrong with society, the model claims, it is the person that has to be fixed, and that is a problem which the disabled person has to solve themselves (Dirth & Branscombe, 2017, pp. 414–415; Leduc, 2020, p. 37; Retief & Letšosa, 2018, p. 3). Because disability is seen as something to be cured, something out of the ordinary, society does not have to change and accommodate disabled people. Amanda Leduc notes, "There is an assumption that there is only one way of moving through the world – one way of walking, one way of seeing, one way of smell and touch" consequently disability falls outside this sense of "normal", painting disability as "almost always the villain" (Leduc, 2020, p. 37). A major issue with this model of disability as a disease is that many disabled people do not consider themselves sick (Retief & Letšosa, 2018, p. 3). As an illustration, a person missing a limb is not necessarily sick: you can be completely healthy while missing an arm or a leg, as it is not something that can be cured or fixed. An alternative to the limited approach of the medical model is to address the rigid social structures that disadvantage people who do not fit within the "norm".

2.1.2 Social Model

The social model stresses that a person has an impairment, but it is society that disables people (Cheyne, 2019, p. 13). The social model of disability arose in the 1960s-70s as a response to the medical model and stands in opposition to some of its central ideas and beliefs

² Seen an example of this under section 3.2 – Lizzo changes the lyrics in her song GRRRLS due to offensive language.

(Dirth & Branscombe, 2017, p. 415; Leduc, 2020, p. 43). Through the lens of the social model, disability is no longer viewed as a disease or seen separately from society; disability is now placed within the public sphere. Focusing more on the role society plays, the social model normalises disability more than the medical model does. Impairments are no longer classified as something that needs to be fixed or cured, rather, having an impairment is an acceptable way of being. The Union of Physically Impaired Against Segregation (UPIAS), established in 1972, was a disability rights organisation in the UK and has been a major force behind the social model (Shakespeare, 2021, p. 17). It was through UPIAS' work and principles that the social model emerged as a competing model to the medical model which had been the dominating force in understanding disability. A key difference between the medical and social model is the distinction UPIAS makes between disability and impairment:

Impairment: lacking part of or all of a limb, or having a defective limb, organ or mechanism of the body.

Disability: the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from participation in the mainstream of social activities. (Barnes & Mercer, 2003, as cited in Hall, 2016, p. 21).

Through UPIAS, impairment is defined as what most people think of when they hear disability and being disabled is no longer a purely medical issue. Disability becomes the responsibility of society, not a battle to be fought alone. Because the social model differentiates disability and impairment, it is possible to have this separation between being disabled and having an impairment. Tom Shakespeare (2021) identifies three main benefits of the social model: "effective *politically* in building the social movement of disabled people [...] effective *instrumentally* in the liberation of disabled people [...] effective *psychologically* in improving the self-esteem of disabled people and building a positive sense of collective identity" (p. 19). These benefits cover both an individual level and a societal level, strengthening a collective identity while holding society accountable for its prejudices against disabled people.

However, there are some weaknesses of the social model that must be mentioned. Primarily, the distinction between impairment and disability might be the model's biggest strength, yet it

is also its largest weakness. In UPIAS's definition of disability "physical impairment" is used for people with impairments. This way of defining disability only as something physical can be excluding of people with cognitive and invisible impairments (Retief & Letšosa, 2018, p. 4). Phrased in this way, it sounds like people with cognitive and invisible impairments cannot be disabled and are thus excluded from the disabled narrative. This can lead to the undermining of an entire group of people facing the same obstacles as those with physical impairments. Additionally, the separation between impairment and disability is not always as clear and easy to define as this model indicates (Shakespeare, 2021, p. 21). The way impairment is presented as unproblematic, that an impairment just "is" in a sense, implies having an impairment is never a hindrance. The social model often ignores the painful realities of impairments and neglects the importance impairments have in many disabled people's lives (Retief & Letšosa, 2018, p. 5; Shakespeare, 2021, p. 20). Many people with impairments live with chronic pain or a high risk of illness that will never fully go away. Therefore, no matter how accessible society becomes, impairments can, and will, be a hindrance to some people. The social model fails to recognise this reality that many disabled people live with. Whereas the medical model only blames the impairment, the social model ignores the medical aspects of impairment and entirely blames society for disabling people. Another weakness of the social model lies in the concept of a barrier-free society (Shakespeare, 2021, p. 21). This concept involves making all platforms and places accessible to all people regardless of impairment. It is a positive ideal, but, impossible to obtain. There are parts of the world that will be inaccessible to a lot of disabled people. Mountains and historical buildings will be inaccessible to wheelchair users and people with challenges walking, and blind people will never be able to see the northern lights. People with different impairments often prefer different and contradictory arrangements which fit their individual impairment the best, making it difficult or nearly impossible to make all arenas of society accessible to all (Shakespeare, 2021, p. 21). Where wheelchair users would prefer ramps, someone who is visually impaired might prefer stairs. The sheer variation of impairments makes it challenging to accommodate all the different needs that would have to be accounted for. For a teacher, it could prove challenging to pre-emptively accommodate all needs without being specifically asked to because of the vast variation of needs. The challenges of a barrierfree society would also apply in a school setting. Something that could be a potential solution could be the teacher asking all their pupils at the beginning of a new school year what kinds of accommodations they require, and from then on, the teacher would consider that when planning future lessons.

2.2 Disability and Literature

As expressions of cultural attitudes and values, literary texts can provide a way into sociocultural examinations of disability representation. Ato Quayson (2007) explains that "literature representations of disability are not merely reflecting disability; they are refractions of that reality, with varying emphases of both an aesthetic and ethical kind" (p. 36). What Quayson is essentially saying is that literature is not mimetic of reality but rather porous. Even though literature reminds us of reality, it is a reflection; and just as images are distorted by water, reality is distorted by literature. This distorted representation of disability through literature is potentially made harmful precisely because literature is often mistaken for reality, and that negative depictions of disability and disabled people in literature will therefore be perceived as reality. Thus, society will perceive disability in that same negative manner as presented through literature. Quayson (2007) outlines nine categories of representations of disability one encounter in literature:

1. Disability as null set and/or moral test 2. Disability as the interface with otherness (race, class and social identity) 3. Disability as articulation of disjuncture between thematic and narrative vectors 4. Disability as moral deficit/evil 5. Disability as epiphany 6. Disability as signifier of ritual insight 7. Disability as inarticulable and enigmatic tragic insight 8. Disability as hermeneutical impasse 9. Disability as normality (p. 52)

These categories vary across genres and can also be combined into new categories. A text can represent disability both as the interface of otherness and as moral deficit/evil. An especially common representation of disability in older literature is disability as metaphor. Through this metaphor disabilities become "a textual device that, precisely because of the way in which it reconfigures what disability means, ultimately has little to say about the actual lives experienced by those with disabilities." (Barker & Murray, 2018, pp. 2–3). When disability is a metaphor, the disability often symbolises an inner turmoil of that character, a punishment for something the character has done, or an external symptom of a moral failing. Disability as metaphor often "acts as a form of ethical background to the actions of other characters, or as a means of testing or enhancing their moral standing" (Quayson, 2007, p. 36). As a metaphor, it is less about the disability and more about what that character must do to redeem themselves. In *Moby-Dick; or; The Whale* Captain Ahab's missing leg is not a commentary on the

suffering of a disabled captain in a society that favours the full-limbed, it is rather a symbol of his unstable state of mind (Barker & Murray, 2018, p. 2). He is given a disability to physically depict his inner state of mind, to strengthen exactly how mad he is and to what lengths he is willing to go to get what he most desires. When disability is used as a metaphor, it dehumanises disabled people and takes away the actual struggles impairments can cause. Disability as a metaphor is held in contempt by disability scholars as it misrepresents the reality of disability. Disability as metaphor "tend[s] to depict disability as either a source of pity or threat" (Hall, 2016, p. 36). This is a one-dimensional way of representing disability and does not give a nuanced understanding of disabled identity. However, some scholars argue that instead of completely rejecting disability as metaphor, it should be engaged with critically (Hall, 2016, p. 38). Engaging with these narratives can further understandings of how disability-as-metaphor shape and have shaped how disability is viewed and treated in literature and society. As people's understanding of disabilities and the challenges disabled people face increase change might be easier achieved. This is why literary depictions of disability should be used in teaching English.

"For centuries, fictional narratives have used outer difference to telegraph inner monstrosity" (Grue, 2023). This quote highlights a common literary trope, where depictions of disability is disability as something monstrous. Elizabeth Wheeler (2013) calls this "the monster model", a model within disability studies which identifies cultural constructions of disabled people as monsters (p. 345). In literature and film, disability and monstrosity go hand in hand as seen depicted through characters such as Darth Vader and Darth Sidious, Voldemort, the Joker, and even morally good characters like Quasimodo. The monstrous disability is often depicted either as the villain's facial disfiguration or the hero who must break the curse that disables them. The correlation between disabilities and monstrosity goes back hundreds of years up until today seen in all kinds of literature. The monster model is closely related to disability as a metaphor. Where disability as a metaphor depicts disability either as a source of pity or threat, the monster model almost solely plays off disability as a threat to "normal" civilisation. Wheeler explains that the monster model as a depiction of disability uses appearance to portray a character's intention or inner flaws, mirroring what is often seen when disability is used as a metaphor. Jan Grue, a wheelchair-bound Norwegian writer, academic, and actor argues that disability as something monstrous "provides not only a shorthand for separating good characters and bad, but explains their motivation and narrative function" (Grue, 2023).

Grue further explains that "sometimes, this connection between embodiment and motivation is made fully explicit" (Grue, 2023). For Colin this connection is indeed made fully explicit, his appearance and poor health are his main driving force and the reason he is such a sour child when first introduced to the reader, as will be elaborated on in chapter 3. The fairy tales we grew up with, seemingly vacant of disabled characters, are filled with scarred individuals, or people cursed into monstrous beings. Beast from "Beauty and the Beast", in both the original and Disney's version, has been cursed to have a deformed, beast-like appearance, isolating him from society. The Little Mermaid has her voice taken away and walking feels like walking on knives, the prince in "The Frog Prince" has been turned into an ugly frog, and the ugly duckling did not find happiness until he also found beauty. The morally good usually end up breaking their curse and getting their happy ending after getting their beauty back. The villains of these stories, although seldom cursed, also have monstrous appearances. Scar from "The Lion King", the witch from "Hansel and Gretel", Rumpelstiltskin, Cinderella's stepsisters, Shere Khan, Captain Hook, and even Snow White's stepmother, who is a beautiful woman, turns herself into an ugly hag to poison Snow White. The shared commonality between these villains is some sort of undesirable physical feature to symbolise their evil nature. Because fairy tales usually have a strong allegorical aspect, they tend to use disability as a metaphor for moral failings or problems to be overcome. This in turn portrays a mindset close to the medical model, that disability is something bad and needs to be overcome. It should be noted that the fairy tales such as Cinderella, Snow White, Peter Pan, and the Jungle Book are originally from different cultures, time periods, and languages, and are a commentary on the society that they were written. However, in fairy tales where the protagonist has to overcome hardships or break a curse, Leduc (2020) notes, it is never society that changes, it is always the protagonist who undergoes a transformation (p. 41). She goes on to explain that "in fairy tales, the transformation of the individual relies on fairies and magic or the gods – because it is understood that society itself can't (and indeed won't) improve" (Leduc, 2020, p. 42). This idea that nothing changes unless with the help of magic strengthens the belief that society will not accommodate the individual.

Fairy tales is not the only genre that relies on looks and impairments to visually represent good and bad as horror also frequently employs this technique. Horror relies on fear and discomfort and often portrays the monstrous evil character you are supposed to fear or the disabled victim whom you are supposed to fear *for* (Cheyne, 2019, pp. 27–28). The horror

genre, understood in a broad sense, has created an abundance of iconic villains such as Pennywise, Captain Ahab, Ghost Face, the girl from the Ring, Pinhead, Freddy Krueger, and Michael Myers. All these villains have monstrous appearances to scare the protagonists and the audience. The problem with horror is not that it tries to create a fearful response, but how disability is used for that effect (Cheyne, 2019, pp. 32–33). Horror uses an already established idea that disability is something negative and the thought of being disabled is something to fear. However, in relying on negative associations of disability, horror reinforces this idea and contributes to the ostracization of disabled people. Through both fairy tales and horror, disability is used as a trope which draws on and reinforces disability as undesirable. Literature teaches us that beauty equals good and ugly equals evil, disabilities are to be either feared or pitied (Leduc, 2020, p. 102), and only with the help of magic can we dream of defeating disabilities

These repeated depictions of disability as negative begin to create an expectation of this trope in literature and film. Lois Keith (2001) says we have learned five things from disability in Victorian literature:

(1) there is nothing good about being disabled; (2) disabled people have to learn the same qualities of submissive behaviour that women have always had to learn: patience, cheerfulness and making the best of things; (3) impairments can be punishment for bad behaviour, for evil thoughts or for not being a good enough person; (4) although disabled people should be pitied rather than punished, they can never be accepted; and (5) the impairment is curable. If you want it enough, if you love yourself enough (but not more than you love others), if you believe in God enough, you will be cured (p. 7).

What is made clear from this is that nothing good comes from being disabled. The only thing to strive for as a disabled person is to find a cure to their ailments, be that of body or soul. Impairments are not something to be accepted nor celebrated as part of one's identity, or a valid state of being for anyone. Keith also writes that "from the 1850s, up until very recently [...], there were only two possible ways for writers to resolve the problem of their character's inability to walk: cure or death" (Keith, 2001, p. 5). Stuart Murray (2018) further explores this attitude of cure or death as the only acceptable outcome for a disabled character, through the

furious response of a disabled child's mother to the play *Kill Me Now* (pp. 101-102). The play, written by Brad Fraser, ran at the Park Theatre in London between February and March 2015 (Murray, 2018, p. 101).

In *Kill Me Now*, father Joey gives up a promising career as a writer to look after his disabled son Jake, who has spinal stenosis. In a dramatic twist, Joey develops a disability himself and, unable to face a future of seeming hardship, commits suicide (Murray, 2018, p. 101).

Critic Dea Birkett, and mother of a disabled child, wrote in the British *Guardian* a furious response to the play expressing her disgust at the ableism of this play. She is unable to fathom why the theatre, "which is supposed to be about creativity", cannot imagine what it is like to be the parent of a disabled child (Birkett, 2015). She writes that the play is, however, true to the perception of the able-bodied society whose worst fear is disability, yet also pities disabled people. Birkett also criticizes the lack of disabled actors, as there are none in the play, and that non-disabled actors playing disabled people "love to squirm, startle and speak as if they were drunk" (Birkett, 2015), giving an unrealistic picture of what the life of a family with disabilities is like. Kill Me Now portrays being disabled as such an undesirable state of being that a "rather dead than disabled" attitude is reinforced as an accepted way of thinking and expressing oneself for nondisabled people. "When the audience gives a standing ovation, they're applauding this prejudice" (Birkett, 2015). Murray (2018) writes that through Birkett's article she expresses "an assertion of presence and a refusal to be subsumed in Fraser's narrative of pity and tragedy" (Murray, 2018, p. 102). Birkett is fighting against the hegemonical able-bodied society by refusing her child to be wrongly represented and celebrated through popular culture.

Although there is literature which represents disabled people as part of society, the manner in which they have historically been represented is harmful. Therefore, these harmful representations must be explicitly addressed when these texts are used in the classroom, to avoid replicating those negative significations. Teaching critical readings of these texts will allow the pupils to be critical of all representations they encounter, and not, unconsciously replicate these assumptions and attitudes. As previously discussed, disability is more often than not portrayed as something undesirable and evil. If the protagonist is disabled, they go on

a spiritual journey to better themselves as people and rid themselves of any impairments, often with the help of magic (Leduc, 2020, pp. 38–41). Disabled characters are however not always cured of their impairments, even if they belong on the side of the protagonist. Yet these instances often seem to only happen if the disabled character has a minor role in the story: where they function as a tool for the protagonist to become a better person. These characters seem to only exist to further the development of the protagonist and therefore their only character trait is being disabled. This portrayal of disability is one-dimensional and indicates that a disabled person is nothing more than their disability. A more insidious version of this trope is disability as literal evil: the disfigured villain. The villain became disfigured in one way or another to visually symbolise their inner callousness. Villains like these are found in horror, fairy tales, Disney movies, and popular tv-shows such as Stranger Things. It is important to note that this is not a historical representation, but a contemporary one that needs to be actively rooted out. In addition to the manner in which disability is depicted, the language used about disabilities and disabled people holds influence as well.

Disability is often associated with either weakness or exceptional strength. Disability as a weakness portrayed through language will be explored in section 2.3. On the opposite side, you have disabled people as super-humans: people that are so brave, and so inspirational because they are "managing to get up in the morning and remember [their] own name[s]" (Young, 2014, p. 2). This phenomenon was dubbed "inspiration porn" by disability activist Stella Young in 2012 (Leduc, 2020, p. 58). Inspiration porn is something most people are familiar with without being aware of the fact that they are. As a phenomenon, it depicts disabled people overcoming various obstacles in their lives: something as simple as walking, or something extraordinary, such as winning Olympic gold. While acknowledging the benefits of positive depictions of disability, Stella Young explains that she uses the word "porn" deliberately as it "objectif[ies] one group of people for the benefit of another group of people" (Young, 2014, p. 2), which in this case is the objectification of disabled people for the benefit (inspiration) of non-disabled people. The able-bodied society sees the disabled body as less, and therefore the bar is lowered for disabled people since "no one challenges those born with 'challenges'" (Leduc, 2020, p. 58). Thus, "when the disabled person meets the expectation of this new, lowered bar, they are cheered and congratulated" (Leduc, 2020, p. 58; Young, 2014, p. 2). Jan Grue (2016), explores the problem of inspiration porn with a focus on Young and her definition. He explains how inspiration porn "obscures structural and systemic causes of

disability" (Grue, 2016, p. 840). These depictions are often a narrow representation of disability: a visible impairment that can be "replaced" by medical intervention or technology (Grue, 2016, p. 847), and gives the image that an impairment is not something that holds one back, as there are alternatives that can make your life, almost, "normal" again. This one-dimensional depiction of disability as something visible and easy to fix (as long as you have money and resources to achieve this), undermines the diversity of disabled people, "and make[s] people with hidden impairments and chronic illnesses even more marginalised than they already are" (Grue, 2016, p. 847).

"The only disability in life is a bad attitude" can often be heard or seen in the context of inspiration porn, a narrative especially seen in older literature. The idea that if you try hard enough, and work hard enough, you will magically not be disabled anymore is an idea central to the medical model of disability. Young counters this by saying:

[T]he reason that that's bullshit is because it's just not true, because of the social model of disability. No amount of smiling at a flight of stairs has ever made it turn into a ramp. Never. [Laughter and applause] Smiling at a television screen isn't going to make closed captions appear for people who are deaf. No amount of standing in the middle of a bookshop and radiating a positive attitude is going to turn all those books into braille. It's just not going to happen (Young, 2014, p. 3).

By directly mentioning the social model of disability, Young argues that disability is caused by institutional structures. She is holding society accountable for disabling people. Hence, the logic behind "the only disability in life is a bad attitude" does not hold up, as it undermines the complex reality of living with an impairment. This directly correlates with Grue's (2016) depiction of the false image inspiration porn provides: one where disabled people can do anything. He argues that this is untrue, and that disabled people are limited by their bodies and the world, just as non-disabled people are (Grue, 2016, p. 856). What would instead be desirable, is positive depictions of disability that do not objectify disabled people, and that celebrate human achievement while at the same time acknowledging the reality of having an impairment or chronic illness. Inspiration porn does not allow people to acknowledge the less positive experiences of being disabled as well as depicting an able-bodied world in which disabled people are an othered metaphor for triumph over adversity.

2.3 Disability and Language

Inspiration porn relates disability with exceptional strength, while on the opposite end, there is an association between disability and weakness as portrayed through language. Through the language used, disability is often related to weakness. This weakness can be expressed through playground insults, the way you describe a person or an object, or how you refer to illness. "The fundamental problem lies not with the words used to describe the characters, but with the attitudes ascribed to him" (Grue, 2023). Words are never just words; language always exists within a cultural understanding that leaves room for connotations and incorporates personal feelings from the recipients. The words and phrases connected to walking illustrate how negatively charged language depicts words used about challenges with walking, something Keith (2001) writes about. "Words which relate to difficulties with walking and standing have taken on negative associations - bent, crooked, crippled, stooped, hunchbacked [...] – whereas those connected with walking are positive: straight, upright, firm, erect" (Keith, 2001, p. 22). She further talks about expressions which promote the ability to walk: "'standing on our own two feet', 'putting our best foot forward', 'keeping one step ahead', 'walking tall' [and] 'taking it in our stride'" (Keith, 2001, p. 22). To add to this, "standing up for yourself" is another common expression she does not mention. All these expressions and words subconsciously promote ableism. "Bit by bit, the language we use reinforces the idea of disability as a thing of weakness, making the disabled person into something weak, someone less." (Leduc, 2020, p. 220). Through this narrative, weakness is always something negative, even though weaknesses are human and something all people have. Closely related to language is the concept of "discourse", which relates language to power. Those who have power in society - in our case able-bodied people - inscribe their subjectivity as the "norm" and those who do not fit this subjectivity become Othered. Controlling the discourse amounts to control of how the world is perceived. This creates low self-esteem amongst the Othered because one can only express humanity through a language that Others oneself. By using "language that reinforces this viewpoint [that the disabled body is bad] – even if it's unconsciously – you participate in a world that seeks to further entrench disabled exclusion (Leduc, 2020, p. 221). In other words, the representation of minorities is vital for creating a strong sense of self. An author cannot place a random disabled character into their story and call it a day. Both how the character is represented and the language used are crucial to a true and just representation of disability and the disabled identity.

3. Critical Reading of Young Adult Fiction

Young adult novels, Frances Hodgson Burnett's The Secret Garden (1911) and R. J. Palacio's Wonder (2012) are books which have immense potential for use in the classroom. Both novels approach disability in an engaging way, challenging pupils to think creatively and critically about disability, as long as they are guided through a critical approach: through the lens of disability studies. Teaching these novels can prove difficult, as the understandings and attitudes toward disability are constantly changing. The Secret Garden was first published in 1911 and *Wonder* was first published in 2012. With one hundred years apart, the novels portray disability in two greatly different ways: one telling the story of change within the body and the other change in society. Both novels begin by presenting their protagonists as different, as an Other, and both immediately begin by throwing their protagonists into unfamiliar environments. This transition becomes heightened as the protagonists have, until this point, been living otherwise shielded lives: one by always getting her will and the other by being home-schooled. Critically reading these novels opens up opportunities to discuss values and attitudes society holds that are widely accepted as the truth. Read through a disability-studies lens, both novels place their protagonists within the monster model, or as "freaks". The appearance of Mary, Colin, and August are all so "horrid" that it serves as a main topic of conversation. *Wonder*, however, steps away from this as an acceptable model and turns the monster back into a boy. Neither of the texts are perfect regarding political message or the way they portray disability, but they should not be ignored because of this. Just as Hall (2016) argues that disability as metaphor should be critically engaged with rather than rejected, these novels should be critically engaged with as well. Flawed narratives offer the opportunity to question why society is the way it is and why we have the attitudes we do. Therefore, exploring how disability is portrayed and treated in these novels allows the teacher to introduce the pupils to the important concept that fiction serves a purpose beyond entertainment. When reading The Secret Garden and Wonder through a disability-studies lens it is unavoidable not to recontextualise and question the ideologies we perceive as truths. Critically reading these novels can help us challenge the "assumption that there is only one way of moving through the world – one way of walking, one way of seeing, one way of smell and touch" (Leduc, 2020, p. 37).

Just over a hundred years old, *The Secret Garden* was written and published long before disability studies had become a recognised field. The novel demonstrates some of the social attitudes outlined in the theory section and shows how these historical beliefs have become culturally entrenched in a way that a reader unfamiliar with disability studies would not be aware of. Burnett wrote The Secret Garden during a time of great medical advancements when the general view on illness was changing. Previously fatal ailments were now something that could be cured, and thus cure became an attainable goal for people. General treatment and rehabilitation also saw changes which helped the general public health. The attitudes toward illness that were developed alongside the medical advancements are now attitudes recognised as the ones seen in the medical model. The Secret Garden is mainly set in Yorkshire, England, and is written through a third-person omniscient point of view. The narrator is an unknown entity and therefore appears objective. Hence, it can be understood that through the third-person point of view, the reader is presented with the assumed shared cultural attitudes of the early 1900s England. The protagonist, Mary Lennox, is an unloved child living in British-Raj India with her neglectful parents and is solely raised by her Ayah. Her parents are British: her father works for the English Government and her mother, who never wanted anything to do with Mary, is a known beauty who only likes attending parties. Mary is a spoilt, sour, young girl who likes no one and is liked by no one. At the beginning of the novel, a cholera epidemic kills her parents, leaving her an unwanted orphan. After Mary is found alone at her house by some British soldiers, she is sent to Misselthwaite Manor in England to live with Mr Archibald Craven, her uncle. Mary finds Misselthwaite Manor, which lies isolated on the Yorkshire Moors, a gloomy place.

Our introduction to Misselthwaite Manor as a gloomy place, filled with secrets and locked rooms, introduces the gothic elements of the novel to the reader. *The Secret Garden* has several elements typical of the genre. The gothic elements have strong connotations to the dark and mysterious, with frequent appearances of dreadful monsters (Kilgour, 2013, p. 3). As a response to the strict confinement of the Enlightenment, the gothic monster often takes the shape of man: the man who does not fit the narrow requirements to be orderly, rational, and healthy. These monsters are often exiled and locked away because society has branded them freaks of nature (Anolik, 2014, p. 2). Not fitting into the strict image of what a man is, Colin takes on the role of the monster early on in the novel, locked away in his room separated from society as a shameful family secret. Mr Craven mirrors his son in that he too is perceived as a

monster. The first thing Mary learns of her uncle is that he has a crooked back that made him disagreeable and that he is away most of the time. Even when he is not away, her uncle locks himself in the West Wing, not to be disturbed by anyone. Having a crooked back places Mr Craven on the outside of society, and he also isolates himself from the outside-world by locking himself in his study and travelling to faraway places. When Mary arrives at Misselthwaite she finds the manor and moor dark, vast, and filled with secrets, and she sometimes even hears the cries of a child coming from inside the house. The servants deny this, blaming it on the wuthering wind. The wailing, of course, turns out to be Colin miserable and alone in his dark room. A stark contrast between Victorian ideals, still held by society in the early 20th century, and the Gothic is the ideal about the home. Victorian ideals of the "Angle of the house" is contrasted by the gothic idea that "the home is a prison, in which the helpless female is at the mercy of ominous patriarchal authorities" (Kilgour, 2013, p. 9). The domestic sphere as a prison is seen through Colin who is locked away in his home at the mercy of his own father. The gothic elements of The Secret Garden play an important role in the novel's depiction of disability. When human difference is seen as something monstrous, disability becomes frightfully inhuman and something that needs to be hidden away from view. However, some progressive movements within the Gothic genre recognise humanity within the monster (Anolik, 2014, p. 2). This humanity is granted to Colin, who with the help of Mary and Dickon, breaks free from the domestic sphere he has been locked away in and transforms from monster to human. Colin's transformation, which is only possible by casting away any notions of disability, shows that is still something unwanted and negative at the end of the novel. Further discussion of the depiction of disability in The Secret Garden will be explored in the upcoming sections. Maggie Kilgour in her book The Rise of the Gothic Novel (2013) explains that "in general, the gothic has been associated with a rebellion against a constraining neoclassical aesthetic ideal of order and unity, in order to recover a suppressed primitive and barbaric imaginative freedom" (p. 3). These are elements found in *The Secret* Garden, a story of two children rebelling against the constraints of the adult world through the innocent imagination that only children have.

Colin is not the only one to undergo a transformation and breaking free of the constraints of adult supervision. Mary, who is most disagreeable herself, undergoes a transformation after arriving at the Manor. As no one is there to tend to her and she spends most of her time by herself, she is forced to use her imagination for the first time in her life, something that leads

to her transformation at the Manor. Slowly but surely, Mary becomes healthier with the help of exercise and fresh air. She is later introduced to Dickon, a moorland boy who is her maid Martha's brother, and Colin, Mr Craven's "invalid" boy. The three of them nurture a secret garden, that has been locked away for the last ten years, back to life. By restoring the garden, Mary and Colin are nurtured back to life together with the garden, transforming themselves into healthy young children. *The Secret Garden* is, ultimately, a story about healing, growing up, friendship, disability, loneliness, and the power of thoughts. Through positive thinking, wishing for better health and a lot of determination, Mary and Colin overcome their negative outlook on life, healing their bodies in the process.

Since The Secret Garden was published, attitudes about disabilities have changed and there is generally a greater understanding of both visible and invisible disabilities. Just as The Secret *Garden* offers insight into how disabilities were viewed at the beginning of the 20th century, Wonder does the same for the 21st century. Wonder is set in a modern society that, despite the turn of a new century, holds on to values common to the early 19th century. These are values and attitudes that are often felt by minorities. Wonder is the story of August Pullman and the people closest to him as he starts school for the first time. August is a ten-year-old boy living in Manhattan together with his mom, dad, and older sister Olivia (Via). He has Treacher Collins syndrome that has left his face disfigured, and we join him through various struggles and joys in a society that treats him differently than everyone else. These struggles take the shape of bullying, Othering, ostracizing, struggles with making friends and fitting in, disability, and surviving fifth grade. However, despite his daily struggles, and sometimes the wish to give up, August pushes on with the help of his friends and family, and manages to finish fifth grade "and that's not easy, even if you're not me" (Palacio, 2013, p. 306). Wonder is written through a first-person point of view, where August functions as the narrator for most of the novel. Other perspectives than that of August are provided through other narrators: Via, Summer, Jack, Justin, and Miranda. The effect of having August as the main narrator is that a subjective voice is given to the minority. This challenges the able-bodied subjectivity that is the "norm" and the point of view we are used to seeing, which in turn can prevent the Othering that often comes with the single story. Having multiple narrators shed light on the struggles and joys of his friends and family as people involved in August's life and contextualises him as part of society. By switching between narrators, Wonder provides more than a single story, and as such also provides a nuanced picture of what it is to live with disabilities experienced by both disabled and non-disabled people. Through the different narrators, the reader can learn about their attitudes to disability as their point of view allows the reader to access their inner thoughts and experiences. The shift of narrators offers a nuanced perspective of the struggles a disabled person faces both first-hand by August and second-hand by his friends and family. Palacio's choice of including the perspective of other people than August gives insight into the society that rejects August. Wheeler argues that the function of having multiple narrators changes the appeal of the novel from one "on the individual strivings of the main characters [to one] on a vision of a community transforming itself" (Wheeler, 2013, p. 338). *Wonder* is not a story about a single disabled boy, but a story about a community that learns to accept all people regardless of ability. August's narration provides the reader with an "outside-looking-in" perspective, while the other narrators provide an "inside-looking-out" perspective, where the "inside" is the hegemonic able-bodied perspective. Via, on the one hand, has most of her life had a foot both on the inside and the outside, while narrators such as Summer and Jack have always been on the inside but after befriending August experienced what it is like being on the outside.

Together The Secret Garden and Wonder display disability in literature through the Medical and Social model of disability and illustrate how disability in literature, and therefore in society, has changed over the years. Illustrating two contrasting ways of approaching disability is the main reason I chose these novels. The Secret Garden portrays values often deemed old-fashioned or out-of-date that we unfortunately still see in today's society. While some of these are still illustrated in Wonder, the novel portrays the shifted values that are more commonly seen today. Reading older literature and comparing it with modern literature presents the opportunity to explore values held by the society of that time and how those values have changed and in turn shaped today's society. Critically reading these novels in the classroom makes pupils more aware of these attitudes and their outdated roots. Engaging with novels that can be placed within the Medical model and Social model respectively will also provide a more complete picture of disability studies as a whole than reading only one novel would achieve. While neither novel is perfect, "there is significant pedagogical worth in teaching novels that leave important political interpretation open to ambiguity, but the teacher's guidance of students through such novels becomes crucial" (Meyer & Wender, 2016, p. 92). Both The Secret Garden and Wonder challenge popular perceptions of disability, offering great tools to be used in developing critical literacy. Reading these novels will help

enable pupils to see that culture creates responses to disability and help to confront their own subconscious biases.

3.1 Products of Their Time (the Medical and Social Model)

Burnett's depiction of disability in The Secret Garden could have been influenced by the improvement and understanding of illness, or a metaphor for the weakness of aristocratic lines compared to healthy working-class characters. It could also be a commentary on the negative influence of the Empire on the "healthy" British native or a commentary on society in combination with the general public attitude toward illness through disabled children. Or it could be all of the above. Peter Hunt writes in the introduction of The Secret Garden how the novel "is now widely recognised as a densely symbolic novel, drawing together and challenging established ideas of the Romantic child, Victorian child-rearing and cultural values, empire and religion – and of women's and children's fiction." (Burnett, 2011, p. vii). Through her novel, Burnett challenged established ideas of her time, writing a novel which set itself apart from a lot of literature of the late 1800s. She does this by challenging gendered expectations with both Mary and Colin. When first introduced, Colin is a feeble, sickly child, more commonly associated with girls and women at the time. But unlike his predecessors, the saintly females, Colin is not a saint: he is a spoilt, wilful young boy, a parody of "these longsuffering, too-good-for-this-world characters" (Burnett, 2011, p. xix). Colin assumes the role traditionally given to girls. Mary has similarities and differences to other girls in fiction "like Jane Eyre and Anne Shirley she is a disruptive orphan – but unlike her predecessors for whom home is a key symbol, Mary does not even know where hers is" (Burnett, 2011, p. xii). Mary is an orphan, something which is often encountered in the literature of the late 1800s- early 1900s. She is a psychologically damaged girl with no home, making her not as cheerful as her American counterparts,. Mary and Colin are for the most part left to themselves, only tended to when given food or when they see fit. Mrs Sowerby, the mother of twelve children, encourages the children to be mostly left to their own devices. She says it is healthy for them and promotes growth and helps develop their imagination. "In many ways [The Secret *Garden*] is the opposite of the 'girl's book' of a hundred years before, when adult influence and interference were seen as beneficial" (Burnett, 2011, p. ix). That is not to say the novel is perfect in this regard, as when it comes to disability, the novel ticks off almost all the boxes of the damaging medical model. One of the novel's main themes is healing: healing of body and healing of mind. Both Mary and Colin have weak bodies and are disagreeable, ugly-looking children when we are first introduced to them. Slowly but surely after arriving at Misselthwaite, Mary's health, appearance, and manners improve, and after she meets Colin,

his health, appearance, and manners improve as well. With a combination of exercise, fresh air, a hearty diet, and liberty from adult supervision, both of them are healthy, fat children at the end of the novel, cured of their illnesses and disabilities. Cure as the end goal is central in the medical model and evident throughout the novel. When they are sick and frail, Mary and Colin are disliked children with bad temperaments, but as soon they become healthier, other people find them more agreeable. The correlation between health and acceptance is undeniable. Society in *The Secret Garden* is not accepting of disability, which is evident through Colin being hidden away as a family's shameful secret. As the medical model sees disability as the issue, it is the sick children who have to change to be accepted into society, not the other way around. The only adult character to change is Mr Craven himself, who is also disabled.

Wonder was published one century after *The Secret Garden* and reflects the social development away from a medical model. Wonder is a story about disability as experienced by both disabled- and non-disabled people and illustrates disability through the social model. The biggest change from the medical model to the social model was the belief that disability, or impairment, is no longer seen as something that needs fixing. There was never a question from Auggie's family that he is lesser than them only because he is seen as different by society. Fir instance, when his parents argue about Auggie starting school, it is not about whether Auggie is capable or not, it is about him surviving the unavoidable attention he will get. His father describes sending him to school as a "lamb to the slaughter" (Palacio, 2013, p. 10). This metaphor paints August as an innocent, which he is, that is being targeted by the danger that is society, a danger that then needs to change for August to be safe. August has never faced "the outside world" the same way he will need to when attending school; therefore, his father argues that August is not properly equipped to deal with the adversity he will inevitably face at school. His parents are well aware that society will treat their son differently and wish to shield him from harm, as any parents would. However, by shielding August from the negative gaze of other people, they are unconsciously contributing to the Othering of their child. August's parents shielding him from society can be drawn as a parallel to the hiding away of Colin. Although the intention behind hiding their child is different in the two novels, the result of this action is the same: a child Othered by their own parent(s). By wanting to keep August at home, they are separating him from society, thus allowing society to go unchallenged and unchanged. This narrative plays more toward a

medical model of disability, than it does to a social one, as the social model emphasises that society has to be held responsible and accommodate disability. However, it is people's potential treatment of August that makes his parents question if attending school is the right choice for August, supporting the idea that it is society that disables people, which is central to the social model. Later on, August's parents change their minds about having August attend school. They want him to have the same opportunities other children his age have as his mom no longer feels she is qualified to teach him (Palacio, 2013, pp. 10–11). Being home-schooled would give August less opportunities, something his parents wish to prevent, refusing to let societal prejudice toward disabled people dictate their son's life. Their refusal to conform to the notion that disability is something that has to be hidden away fits with the discourse of the social model of disability. What might be even more important is that, in the end, it is up to August whether he wants to attend school or not, and that he can even quit whenever he wants (Palacio, 2013, p. 114). Leaving the final decision to Auggie, even though he is a child, gives him agency, and it validates that his experience is unique and not something his parents are fully able to understand.

In the first sentence of Wonder, August states that he is not an ordinary ten-year-old kid even though he does ordinary things (Palacio, 2013, p. 3). He has given this quite a lot of thought when he further reflects on why this is. "Here's what I think: the only reason I'm not ordinary is that no one else sees me that way." (Palacio, 2013, p. 3). It if were not for society, August Pullman would describe himself as an ordinary kid. Auggie is not held back by his impairments, but he is seen as disabled by society. August states from the beginning of his story, that he portrays himself in terms of the social model. This does not, however, mean that August does not have any challenges when it comes to his impairments. He has had a lot of medical interventions throughout his childhood, several of which were needed to save his life. Although Palacio acknowledges August's medical struggles, it is mostly in a sense that it all belongs to the past and that today the only struggle August has is an unaccepting society. Not acknowledging the painful reality of living with impairments, undermines disabled people. This is something the social model is critiqued for, by solely focusing on society's role in disabling people it ignores the reality of impairments. Palacio is contributing to the idea the social model highlights: society is the only challenge disabled people face. Wonder can then be used as an illustration that there is a need for a new disability model that holds society accountable for disabling people while at the same time allowing people with impairments to

have medical and other struggles related to their impairment, which is not necessarily something that can be fixed. Wheeler (2013) argues that "[p]art of the book's artistry lies in the way R. J. Palacio rings changes on three competing models of disability: the social model, the individual or medical model, and what I am calling the monster model" (p. 336). She further explains how Wonder starts with the medical model before moving to the social model. This shift is shown through August entering the public sphere by attending school for the first time. Up until fifth grade, August has been home-schooled by his mom, which represents the medical model. By being home-schooled August has lived a sheltered life outside the public sphere, a life where his medical problems have been between him, his parents, and his doctors. Attending Beecher Prep symbolises August's entry into the public sphere where we are introduced to the disabling nature of society toward people who are seen as different. August has had 27 surgeries in his ten young years, which is why he was homeschooled. For most of his life, August has been confined "to the isolation of the medical model. But this is just the backstory. For August's entry into fifth grade, the novel steers right into the social model of disability and stays there" (Wheeler, 2013, p. 339). The individual, in this case August was traditionally expected to isolate themselves from society and find a cure for their ailment with the help of medical professionals. August is now no longer seen as the problem, but as a person disabled by an able-bodied society that only believes there is one way of living and moving around in the world. Even though Wheeler praises Palacio in her portrayal of disability, this does not mean that it is a perfect portrayal of disability. Wheeler is simply praising Wonder for achieving a much more realistic depiction of disability than a lot of novels have done before. Palacio has not written a utopia or dystopia where all people have the same values and attitudes toward others, she has written a story with characters from different social backgrounds who have different values and beliefs. This diversity of characters from different social backgrounds, portrayed through August's peers, elevates Wonder in its representation of different attitudes toward disability.

Abbye Meyer and Emily Wender (2016) are, however, critical of *Wonder*'s disability representation. In their chapter "Teaching and Reading *Wonder* and *Marcelo in the Real World* with Critical Eyes" they argue that in "*Wonder*, a text that works tirelessly to humanize its disabled character through kindness and sympathy, disability is explicitly denied, rather than embraced" (Meyer & Wender, 2016, p. 82). Their main argument is that none of August's friends end up celebrating his disability: they only get used to his face. This is a

rather simplistic view of *Wonder*. Even though Jack and Summer both reassure the reader that you get used to Auggie's face, they further explain that it was neither pity nor obligation that made them keep hanging out with him, but it was his personality. Summer explains "I don't really feel sorry for him anymore. [...] that's not why I keep sitting down with him. I keep sitting down with him because he is fun" (Palacio, 2013, p. 120). While Jack explains that he was initially only friendly to August:

because Mr. Tushman asked me to be especially nice and all. But now I would choose to hang out with him. [...] if all the guys in fifth grade were lined up against the wall and I got to choose anyone I wanted to hang out with, I would choose August. (Palacio, 2013, pp. 142–143)

Their initial reason to approach August was not in any way celebratory of disability, yet, after getting to know him they stuck by him. They see August for more than his disability; they see him as a person. Although *Wonder* is written by an adult, the main characters are all 10 year-old children and Palacio has written them as such for child readers to enjoy. Children are not as critically aware as adults, and through the choices made by Jack and Summer, the reader then has the opportunity to question and reflect on these choices. Learning is a process and Jack and Summer have only just had their eyes opened to disability and the challenges that entail. *Wonder* is not a perfect portrayal of disability as it ignores the often painful reality of impairments, but when it comes to disability as caused by society Palacio has captured the essence of this in her novel.

In her email to Mr Tushman, following an event where Jack punched Julian in the mouth, Mrs Albans, Julian's mother, expresses a mindset closer to the medical model than the social model. She writes that she is concerned that giving the children the task to "befriend" the new child with special needs at the start of the year was too much for the young souls to handle, and she also points out that Beecher Prep is not an "inclusion school" (Palacio, 2013, p. 162). What Mrs Albans is saying is that she believes that August, because he is different, does not belong in their school and that he should attend a school for "kids with special needs". She wants to remove August from the public sphere and place him in a place where she does not have to deal with August's disability. Through Mrs Albans, Palacio illustrates attitudes toward disability that are closely aligned to the medical model, attitudes we also see in *The Secret Garden*. Mrs Albans wants August to be separated from society, hidden away in a sense. This

is the same treatment we see Colin being subjected to by his father. Mrs Albans is a great character to illustrate the attitudes people have against disabled people and the challenges they face when stepping into the public sphere. Mr Tushman on the other hand is the complete opposite of Mrs Albans. In his reply to Mrs Albans he is rather straightforward and forces the narrative back to the social model:

As for your other concerns regarding our new student August, please note that he does not have special needs. He is neither disabled, handicapped, nor developmentally delayed in any way, so there was no reason to assume anyone would take issue with his admittance to Beecher Prep – whether it is an inclusion school or not. (Palacio, 2013, p. 163).

In his email, Mr Tushman makes it clear that August does not have any special needs as a consequence of his impairments, and if he did, there would be nothing wrong with him attending the school as August passed the application process and he is an extremely good student. Not only does Mr Tushman defend August by refusing to let him be defined by his impairment, but he also brings disability back into the public sphere by making it clear that he does not tolerate ableism. Even though the school is not an inclusion school does not mean disabled people are not allowed to attend Beecher Prep, August or any other child with an impairment has the same requirements and chance of getting accepted to the school as any able-bodied child would. Mr Tushman's reply is, however, ambiguous. Even though his reply is clearly in August's defence, it could also be understood to be Othering of pupils who might have more serious impairments. In his reply, Mr Tushman, firmly states that August is "not disabled" nor has "any special needs", and, therefore, Mrs Albans need not worry that August will cause any disturbances that will negatively affect the other pupils. What his reply could indicate is, that if August's impairments were more serious, then there would have been something the parents could take an issue with. By this, Mr Tushman accepts Mrs Albans' social view that was August more impaired, he should be in another school. In Mr Tushman's defence, the way he phrases himself could also be a direct response to please Mrs Albans. Mrs Albans makes it very clear in her email to Mr Tushman what her views on disability are, and being an influential parent of the school board, Mr Tushman might have wanted to avoid any unnecessary arguing about August's attendance to Beecher Prep. Thus he adopts Mrs Albans' framing of disability, writing an answer in a manner she would have to accept, and by doing so he is undermining the reality of impairments. Through Mr Tushman, Palacio is illustrating a person that is trying to include a disabled person, something he is partly successful with, but

in doing so he is at the same time Othering disability and enforcing the idea that disability is something negative. Whether Palacio is deliberately representing Mr Tushman's attitudes as acceptable, or if she is accidentally using the discourse of medical disability in a context where she is trying to reinforce the social model, is difficult to discern. Seen from the perspective of a teacher using this novel in the classroom, it is important ot not loose sight of the effect this narrative might have a child reader. Within the children's novel, Mr Tushman represents a sort of ultimate authority. He is an adult, as well as the principal of the school August attends. This creates a skewed power relation, giving him power over the pupils at Beecher Prep both as an adult and also in literal power in the sense that he can expel and punish the pupils. As a voice of authority, younger readers are more prone to accept everything Mr Tushman says without questioning his views and attitudes. Mr Tushman serves as the voice of a changing community; wherein he acts as the intermediary between August and the society that seeks to expel him. A character like Mr Tushman is a good example of why critical thinking is such an important skill for pupils to have. Even though Mr Tushman is a character with authority, this does not mean his actions should go unchallenged.

One of the weaknesses of the social model is that it entirely blames society for disabling people and by doing so often ignores the painful realities of impairments. Although Wonder can be viewed through the social model of disability, it might not entirely fit either. Alice Hall (2016), through Longmore's three waves of disability studies, writes about the need for a new disability model; that the field has come to a point where it has moved past the social model. This move away from the social model is also reflected in Wonder. Wonder embraces disability as society's responsibility while also exploring, to a degree, the pains August experiences through his impairments. August has health risks associated with his disability regardless of how accessible society becomes, which will never affect able-bodied people. Wonder represents a collaboration between doctors and society, drawing on the strengths of the medical model by taking August's health issues seriously, at the same time as holding society accountable for disabling people. Even though Wonder does not disregard August's health struggles, it does not execute the treatment of the topic perfectly either. Almost all of August's health struggles are mentioned as something that they have moved past. It is as though Wonder presents August as someone who is as healthy as he will ever be, and the novel explores the next chapter of his life; a chapter where it is time to challenge society. August's physical health will be explored more in-depth later in this chapter. As a whole,

Wonder draws on the strengths of the medical and the social model, which could indicate the move into a third wave: a move beyond the social model which holds society accountable for disabling people while at the same time acknowledging the reality of having impairments. However, it would be difficult to say for certain, as there is no new model yet established.

The influence of the medical model in The Secret Garden is much more pronounced than in *Wonder*, demonstrating the shift in social attitudes. The presence of doctors is one key difference between the two novels. In The Secret Garden, Doctor Craven, Mr Craven's brother, has an active role in the story and is one of the characters to make frequent appearances throughout the novel, while in *Wonder* doctors play more of a background role. From the moment Colin was born, doctors have had an opinion of his health, concerned he would become a hunchback like his father. One doctor put Colin in a brace, while another took it off scolding the first doctor that Colin got too much medicine and too little discipline (Burnett, 2011, p. 102). Colin is convinced he is dying because of all the whispers from the servants and Dr Craven. His mind has become polluted by the diagnosis of the doctor, and as a result Colin has lost any hope of living. Dr Craven has constantly reminded Colin of his mortality throughout his life, and that that he must not forget that he is ill, when all Colin needs is joy (Burnett, 2011, p. 108). Colin's ill health is a conversation between the doctor, himself, and his household, and not an issue for people outside his household to concern themselves with. This idea that disability is something to be dealt with in private is something the medical model has a firm belief in. Through a medical-model lens, the doctor is the highest authority and not something to be challenged by ordinary folk. No one, except for the children, questions Dr Craven and his advice to young Colin. During a time when medicine was rapidly evolving, the word of the doctor was the truth. In a society where the medical authority is left unchallenged, what the doctor says and believes becomes the truth, and thus little to no change in general opinion will occur. As a result, the medical model is allowed to thrive. If the doctor tells you that you are in need of fixing, that you are broken as a result of an impairment, that is what you will believe and the attitude you will adopt. This is what also occurs in The Secret Garden, where the doctor expresses that there is something wrong with Colin, that he needs fixing, hence, Colin adopts this way of thinking. Being disabled is looked at by the doctor as something unacceptable and in turn, everyone else will also see disability this way. With being cured seen as the only acceptable way of being a member of society, Colin is left with only two possible outcomes: cure or death.

The doctors in Wonder contrast the harsh doctor portrayed in The Secret Garden, as there is never a question between cure or death in Wonder. Most of the doctors in Wonder are only mentioned as part of August's past surgeries and hospital visits. The doctors have played their part in August's story: they have bettered his quality of life with life-saving and lifeimproving surgeries, and during all these surgeries there has never been a question of a cure. The doctors' aim was never to cure August of his impairments, as his impairments are not something any doctor could cure, and that is acceptable. The doctors have done what they can for Auggie and now it is up to him to overcome any challenges he might face connected to his impairments. It is problematic, however, that August's health struggles are presented as almost entirely belonging to the past. While it is true that moving forward, August will not have as many surgeries as he has had in the past, that does not mean he is no longer impaired. Even with the help of medicine, there will be times when August is held back by his impairments. Although most of the health issues connected to Treacher-Collins syndrome will be treated in infancy, children born with the syndrome will require long-term monitoring. According to the NHS, people born with Treacher-Collins syndrome will not typically require more surgeries after their mid-twenties (Great Ormond Street Hospital, 2019). This would mean that, at ten years old, August's health journey is far from over. Palacio glossing over this fact mirrors the social model, which ignores the struggles of living with impairments in favour of solely blaming society for disabling people. The only doctor we encounter during the novel is an ear doctor August has to see when it is revealed during his annual check-up that his hearing has considerably declined. At first, August resists help from the doctor, he does not want the massive hearing aids that make him look like Lobot, a character from Star Wars. The doctor is patient and kind toward August, and he takes time to explain every step of the way so that August has full insight into his own medical journey. The doctor even responds to Auggie's Star Wars reference, relating the hearing aid to something August is familiar with. The second the hearing aid is turned on, everything becomes "bright" (Palacio, 2013, pp. 211–215). When Auggie realises how much the hearing aids better his hearing and shuts out all the noise, it outweighs his fear of looking different. Instead of shunning his disability, he embraces the medical advances which help him overcome his difficulties. Palacio does not portray medicine as an evil, even though Wonder is written within a social model of disability. Medicine and doctors are there to help people who need it without trying

to make people something they are not. It is a harmony between health and acknowledging individual identity.

Contrasting this, August's sister Via presents us with a more negative side of medicine. Via is describing what August looks like and what the different surgeries have done to change his face to a more "normal-looking" face. She is not describing his appearance in a condescending manner; she is describing him as she would any other face that has undergone changes. Via does not have an issue with what August looks like, but there is one aspect of her brother she does have an issue with. August tends to shut other people out and not verbally express how he feels and what he thinks. Via loves her brother and wants to be a part of his life, therefore, wishing he would express himself more:

I wish he would tell me how he feels. He used to be easier to read before the surgeries. You knew that when his eyes squinted, he was happy. When his mouth went straight, he was being mischievous. When his cheeks trembled, he was about to cry. He looks better now, no doubt about that, but the signs we used to gauge his moods are all gone. There are new ones, of course. Mom and Dad can read every single one. But I'm having trouble keeping up. And there's a part of me that doesn't want to keep trying: why can't he just say what he's feeling like everyone else? He doesn't have a trache tube in his mouth anymore that keeps him from talking. His jaw's not wired shut. He's ten years old. He can use his words. (Palacio, 2013, pp. 89–90).

What Via is describing here is that August's face has been altered by surgeries to such a degree that it has become stiff and hard to read. Most of August's surgeries have been life-saving or life-improving yet, through Via, it is hinted that some of August's surgeries have been purely cosmetic to "improve" his appearance, making him look more "normal". This could be a comment made by Palacio that August felt the pressure from society to "look like everyone else" and therefore had plastic surgeries that were not strictly necessary but done to please society and to look as close to "normal" as possible. These are surgeries that, if living in a perfect world which did not discriminate against disabled people, August could have been spared, and he would not have felt the pressure to look like everybody else. Via concludes her train of thought, "I think: we've all spent so much time trying to make August think he's normal that he actually thinks he is normal. And the problem is, he's not" (Palacio, 2013, p. 90). Via is explaining that they have a family discourse that does not Other August, but when

he ultimately encounters the outside social discourse, in which he is Othered, he is going to find it more shocking and upsetting because he has been taught he is "normal" by his family.

Via's role in *Wonder* is an important one. She is a supportive sister that wants what is best for her little brother, even though his diagnoses have made her play second fiddle her whole life. She is a voice of reason within the family that is stuck between the family discourse and the outside social discourse. Because she walks both worlds, she is able to see problems her parents have not thought of. Because her family has always shielded August from the outside world, Via is concerned that he has not been adequately equipped to meet with society. What she expresses might be an earnest wish for her brother to survive in a world that does not view him as an equal. August's parents have always adapted activities and plans to best suit August and his whims. "August is the Sun. Me and Mom and Dad are planets orbiting the Sun" (Palacio, 2013, p. 82). As August has mostly only been around close family who knows how to read him and who have adapted to fit August's narrative, he has never had to adapt himself to other people, and Via is concerned about this. August can not expect everyone to always adapt to him, as that is not how the world works. In order to survive the outside world, he needs to express his needs if he wants them met. He has to be an active participant in his own life, especially when he is seen as different by everyone else. In a perfect world disabled people would not have to fight every day for society to take them into consideration, yet, all people, regardless of disability status, have to voice their needs in order for other people to meet them. People are not able to read minds and thus do not automatically know what other people need. A person who is seen as different or foreign to other people, makes it harder for the majority to meet the needs of the minority, especially if the minority does not voice their needs. August is, to many of the people in his life, the first disabled person they have had a meaningful relationship with, and he has challenges non-disabled people never have had to consider. It is not August's job to educate people about disability, but he does have a responsibility to include himself in the narrative. Refusing to be over-looked forces people to acknowledge his existence and his needs and, to be able to do that, August has to 'say what he's feeling like everyone else'.

3.2 Language of Disability

A key reason for using literary texts in English to teach about disability is because language signifies certain models of disability. As stated in section 2.3, the people with power control the discourse which dictate how different groups of people are represented through language. Therefore, examining the language used in literary texts can reveal seemingly hidden attitudes towards people in the text. These attitudes or models of disability are not only visible through slurs but also unconsciously negative connotations. Making pupils aware of the power language holds is an important step in developing critical thinking. Words are never simply just words; language holds associations and arouses feelings in the recipient. Two words seemingly describing the same thing or person can invoke vastly different emotions because of the associations with that word. "Terrorists" and "freedom fighters" can be used to describe the same group of people yet are two contrasting narratives. 'Terrorists'' tell of a group of bad people using violence to invoke fear in other people, while "freedom fighters" are a brave group of people fighting to free an area or people from evil. Journalists and authors are experts in using language to spread their agenda. The problem with language lies not only with the words used to describe something but with the connotations to that word. Grue (2023) argues that:

Language is powerful, but never on its own. It is entwined with politics, culture and history. If we change old words for new ones, but do nothing to change the context, we leave the job half done [...] Politely calling a Bond villain a 'differently abled person' does nothing to undo the link between their embodiment and their villainy. (Grue, 2023)

Critical literacy and discourse analysis highlight the power connected to language, and looking beyond the words written on a page to understand the full meaning of a text. The people with power control the discourse, hence controlling how the world is perceived through the language we use. Therefore, to fully grasp texts, you need to have an understanding of the society and culture in which the text has been created.

Language as something culturally dependant is an important topic to discuss in the EAL classroom, as the pupils will encounter texts from various cultures. Different cultures use different terminology about the same things, and some words that are seen as slurs in some

countries might be acceptable in others. In the summer of 2022, after Lizzo released her song GRRRLS as part of her upcoming album Special, she faced a lot of criticism because the song contained the word "spazz" or "spaz". The full line was: "Do you see this shit? I'ma spazz" (Genius, 2022). In the context of the song, Lizzo used the word to indicate losing control. People criticised her use of the word as it is a derogatory term used about and toward disabled people, specifically people with cerebral palsy. The public called for her to change the lyric, which Lizzo responded to by changing the lyrics from "I'ma spazz" to "Hold me back". She addressed the issue on her Instagram, posting an apology where she explained that she "never want[s] to promote derogatory language", and as an influential person, she is "dedicated to being part of the change I've been waiting to see in the world" (Victor, 2022). She further explained that as a fat, black woman in America, she has experienced being on the receiving end of hurtful language, and "overstand³ the power words can have (whether intentionally or in my case, unintentionally)" (Victor, 2022). The term is an extremely offensive slur in the UK, but in America, it is not always seen as a derogatory term, and is often used to describe losing control or being clumsy (as Lizzo used it). However, as an influential singer, with fans from all over the world, her words hold a power that she must be conscious of if she does not wish to hurt other people. Lizzo listened to the people criticising her choice of words, educating her that it is an offensive slur used about disabled people, and changed accordingly. As an American, Lizzo seemed unaware of the negative connotations connected to the word, and thus in using it hurt a whole group of people. This example illustrates the importance of understanding language in a cultural setting. Had Lizzo been British, she would most likely have been aware that the word is offensive and not used it in her song.

As well as being culturally dependant, language is also in constant change. In the EAL classroom, you are bound to encounter older texts, texts that have been written anywhere from 10 years ago to 500 years ago. Language awareness is necessary when reading older books, as they can contain outdated language that can change the meaning of the text if read in a modern setting. Working with Shakespeare, for example, is not a straightforward task. Most of the language used in his plays is unintelligible for someone unfamiliar with the way he wrote. Reading older texts requires practice, both in translating words no longer used and understanding when a word has a different meaning in the text than what is used today. While

³ In this case, I believe Lizzo used the word 'overstand' in place of 'understand' as a colloquial way to express that she does more than understand the power words can have as she has experienced it herself

some terms stay unchanged for decades, others change over just a couple of years. The Secret Garden is just over 100 years old and some of the terms used in the novel to describe people or their actions have a different meaning today than when they were written. Reading this novel without being aware of outdated language can alter the story from how it was originally intended to be perceived. When Mary first meets Ben Weatherstaff, the gardener, he asks her if she is the "little wench from India" (Burnett, 2011, p. 31). "Wench" is an old-fashioned word that has several meanings. It could mean a young girl (as it does in this case), a female servant, or a woman of low class. However, "wench" is sometimes used in modern settings often as an insult directed at women. Calling someone a wench today is almost the same as calling them a "bitch". Ben continuously refers to Mary as a wench throughout the novel, and pupils reading this today could think Ben is mean toward Mary, while in reality he is only calling her a little girl. Language awareness is important as language changes over time and is culturally dependant. This could be even more true when reading about minorities. It is often the case that the books written about minorities have been written by the majority, which would affect the language used about the minority. It is not until more recent times minorities have been able to, or at least are trying to, change the one story told by the majority. Disabled narratives written in a hegemonic able-bodied discourse are bound to affect how disability is represented through language.

Mary, Colin, and August all experience different types of name-calling and offensive language used about them. The language used toward Mary and especially Colin is more related to their abilities through different adjectives and nouns, while August is often compared to pop-culture monsters and villains. While neither of these ways of addressing the children are good, the people addressing Mary and Colin rarely do it in a purposefully hurtful way, whereas the name-calling toward August is meant as insults. When the housekeeper Mrs Medlock first sees Mary she exclaims "My word! she's a plain little piece of goods!" (Burnett, 2011, p. 12). This interaction illustrates the nature of most of the name-calling toward Mary and Colin throughout the novel: they are not as much name-calling as observations by others expressed out loud. Although the intention behind these interactions does not come from a place of malice, it does not change the fact that the language they use are reinforcing the idea that disability is something bad and unwanted. Throughout the novel Colin is called "invalid", "cripple", and "crooked" multiple times and it is not until Ben Weatherstaff discovers the children in the secret garden and asks Colin if he is not the cripple boy with a crooked back and crooked legs that Colin expresses his resentment in being called a cripple (Burnett, 2011, p. 158). Ben calling Colin a cripple to Colin's face is a turning point in the novel. After this accusation, Colin stands up for the first time and for the next few pages he is described with words such as "straight", "upright", and "tall", not only describing his physical condition but with a moral implication as well (Keith, 2001, p. 137). Through the language used to describe Colin standing up for the first time, it is confirmed that Colin is as good and dependable as any other man. Both before and after his transformation the language used to describe Colin illustrates the argument Lois Keith (2001) makes that "words which relate to difficulties walking and standing have taken on negative associations [...] whereas those connected with walking are positive" (p. 22). The language used to describe Colin as a healthy boy can be argued to be more problematic than the language used about him when people thought he was disabled. During the time when Mary and Colin are hiding Colin's improving health from the adults at Misselthwaite Manor, Dr Craven notices that Colin's appearance and features have improved greatly. "In fact as an imitation of a boy who was a confirmed invalid he was a disgraceful sight" (Burnett, 2011, p. 183). In essence, it says that someone who is disabled cannot be healthy. Colin even describes himself as finally being "a real boy" after his transformation (Burnett, 2011, p. 187). These notions that being disabled makes you unhealthy or that you are not a "real" boy if you are disabled, convey the idea that a disabled life is a lesser life. Coupled with the fact Colin is "hidden" away as a shameful family secret, The Secret Garden uses language that reinforces negative attitudes toward disability and reading these kinds of narratives without language awareness or knowledge about disability studies can leave the reader with simplistic and harmful ideas about disability.

Unlike Colin, towards whom people are never intentionally mean, August is on the receiving end of a lot of name-calling by other children. There is never a question about the intention behind the things August is called by other children: Orc, rat boy, freak, shrunken head, monster, Freddy Krueger, E.T., and mutant are some of the names August is called. Julian, the school bully, draws a comparison between Darth Sidious from Star Wars to August, even going as far as dressing up as Darth Sidious on Halloween to taunt August (Palacio, 2013, pp. 76–77). Most of the names thrown at August are pop-culture characters that are either known for being hideous, evil, or both. Wheeler (2013) argues that Palacio engages with the monster model in order to destroy it (p. 345). The monster model, as outlined in section 2.2, depicts disabled people as monsters and uses appearance to portray a character's intention or inner flaws. August is called the names of monsters who are rooted in the monster model; monsters whose appearance portrays their inner flaws and evil nature. By drawing comparisons between August and these characters, they are subconsciously indicating that August's appearance is a reflection of his inner state of mind, painting August as the villain. When children look at August, "grotesque figures from popular culture emerge in their subconscious" (Wheeler, 2013, p. 345). The bullies in Wonder use language as weapons, and they use names they know will hurt. This is where the language use differs between The Secret Garden and Wonder. While the language used in The Secret Garden is not meant to hurt Colin, it still associates disability with negative traits. The bullies in Wonder call August these names precisely because of the associations these names evoke. However, unlike these monsters, August's appearance is not a reflection of any underlying evil, which is apparent to the reader or anyone that spends any time with him. Although August is nothing like these monsters, the monster model continues to be present until the novel's climax. During a school trip, August and Jack stumbles upon six older children from another school, and when these children notice August's face they react in horror and disgust calling August every name they can think of: Gollum, Alien, orc, Freddie Kreuger. As August and Jack try to leave, the situation escalates and ends with August losing his hearing aids and getting bruised and battered (Palacio, 2013, pp. 265–270). Through this encounter, August learns how violent and hateful the mindset of the monster model can become. After the incident, August is naturally shaken and describes how he sees the faces of the older kids every time he closes his eyes. "The look of total horror on the girl's face when she first saw me. The way the kid with the flashlight, Eddie, looked at me as he talked to me, like he hated me" (Palacio, 2013, p. 274). Palacio is turning the horror discourse back on the bullies: they are the truly frightening ones because they are cruel. This encounter crushes the "logic" behind the monster model, since appearance has nothing to do with character. The readers have, from early on in the novel, known that a "monstrous" appearance does not equate to evil, and through the older kids in the forest, it is revealed that the real monsters do not have physical features that reveal any inner callousness.

It is not only negative depictions of disability that can be harmful for disabled people, as seemingly positive depictions can have a negative impact on the perception people have of disability. "Inspiration porn" is a depiction of disabled people overcoming various obstacles in their lives in a simplistic objectifying way, in order to serve as inspiration to non-disabled people. Paired with the attitude that "the only disability in life is a bad attitude" these ways of presenting disability can foster harmful pictures about what disability is and undermine the struggles disabled people face. *The Secret Garden* and *Wonder* both display aspects of inspiration porn to various degrees. The central premise of *The Secret Garden* is the idea that through exercise and positive thinking, anything is possible. After Mary found Colin and helped him start his road to healing, Colin started to have a brighter outlook on life and changed his attitude toward life.

That night Colin slept without once awakening, and when he opened his eyes in the morning he lay still and smiled without knowing it – smiled because he felt so curiously comfortable. It was actually nice to be awake, and he turned over and stretched his limbs luxuriously. He felt as if tight strings which had held him had loosened themselves and let go. (Burnett, 2011, p. 139)

The tight strings that have loosened not only represent that he is physically getting better but also represent the heavy mental toll Colin has been under starting to lift. *The Secret Garden* portrays disability as curable, as something you can overcome with a positive attitude, which showcases ideas central to the medical model. Burnett has written an inspiring story about two unhealthy children that manage to transform themselves into happy, healthy children by having a positive view on life, and just as with inspiration porn, it undermines the lived reality of disability.

Wheeler (2013) argues that *Wonder* moves slightly close to some of these inspirational tropes and clichés, and that "part of the book's appeal lies in an old-fashioned inspirational discourse in which the hero achieves success through individual striving rather than social change" (p. 337). The inspirational feature of *Wonder* is best seen in the final moments of the novel during graduation. August is awarded the most prestigious award the school bestows, the Henry Ward Beecher medal. A medal "to honor students who have been notable or exemplary in certain areas throughout the school year" (Palacio, 2013, p. 303). While presenting the award, Mr Tushman talks about "kindness", "courage", "friendship" and how one can measure these qualities: an answer they, fortunately, have: "Greatness [...] lies not in being strong, but in the right use of strength [...] He is the greatest [...] whose strength carries up the most hearts by the attraction of his own" (Palacio, 2013, p. 304). At first, August cannot understand why he is awarded this medal but quickly admits that he knows 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" (Palacio, 2013, p. 306)

August is awarded the Henry Ward Beecher medal because his presence and resilience throughout the school year were such an inspiration to the non-disabled people at the school that they feel the need to congratulate him. Society expects less from disabled people and, therefore, lowers the bar for them. "When the disabled person meets the expectation of this new, lowered bar, they are cheered and congratulated" (Leduc, 2020, p. 58; Young, 2014, p. 2). However, Auggie receiving the medal can also be read as a stepping-stone toward change. August is being publicly acknowledged not only by his peers but the entire school and parents. A whole community is ready to welcome and accept August as a part of society. Wheeler (2013) argues that "the subtle character development in Wonder goes much deeper than those plot devices, to show the complex struggles of building disability community. Wonder earns its happy ending" (p. 338), which I agree with. Wonder touches upon some tropes and clichés that we could go without, but despite this manages to portray the disabling nature of society toward those with impairments. The award is a fine line between inspiration porn and change and can be dependent on the way you read it. It is important to acknowledge that both ways of interpreting are present, which makes this scene in particular so important to question and have conversations about in the classroom.

3.3 Hereditary Illnesses and the Fear of Contagion

Disability described as something contagious is found in both The Secret Garden and Wonder, yet unfolds in completely different ways. In Wonder, it is dealt with in terms of genetics, whereas in The Secret Garden, there is an implication of inherited sin. Mr Craven's hunchback is believed to be hereditary which has led to Colin being bedridden his whole life. After Mary's parents died of cholera, she is sent to live with her uncle, Mr Craven, in Yorkshire. The first thing she is told about her uncle, whom her parents never spoke to her about, is that he "got a crooked back [...] that set him wrong" (Burnett, 2011, p. 15). Mary does not meet her uncle until she has been at the Manor for quite some time, and when she first meets him she observes "that the man in the chair was not so much a hunchback as a man with high rather, crooked shoulders, and he had black hair streaked with white" (Burnett, 2011, p. 84). Later, when Mary and Colin meet for the first time, Colin is constantly telling her that he is ill and will die even though Mary cannot see anything wrong with him other than his pale, thin face. When Mary asks Martha about what is wrong with Colin, she admits that no one knows for certain, but that Mr Craven "went off his head when Colin was born" and would not even look at the baby. He exclaimed the child would be a hunchback like himself and would be better off dead (Burnett, 2011, p. 101). Throughout his childhood, Colin has been sick with fevers, colds, coughs, and even typhoid, but survived all the same, yet, he has been cooped up in his room for ten years all because of his father's fear of having a disabled child. Colin's fate was decided for him: he was to die or grow up to become a cripple, which is a fate worse than death. The attitude of Mr Craven and a select of other characters caring for Colin display a "rather dead than disabled" attitude. The thought of Colin growing up to become disabled is unthinkable, as disability is seen as an unacceptable way of living. This mindset has been transferred to Colin, and he has become so afraid of growing up to become a hunchback that he dares not sit up and is constantly checking his body for lumps. "If he should feel a lump coming he should go crazy and scream himself to death" (Burnett, 2011, p. 116). It is not until Mary furiously shouts at Colin during one of his tantrums that he starts believing he can live, as Colin has never been contradicted in all his life and has grown spoilt and rotten from this, and the adults have grown frightened of his temper. Left alone with his thoughts and fears, Colin has imagined himself as disabled his whole life until he has become disabled by the thought of it. Mary, who was just as spoilt as Colin when she first arrived, does not fear Colin's tantrums, but instead she contradicts Colin's fears and in doing

so shatters the bubble he has been living in. For the first time in his life, Colin Craven dares to hope and is not burdened by his father's fear. It is important to critically read a "rather dead than disabled" narrative where hereditary illnesses are seen as a fate worse than death. Pupils reading this narrative without questioning Mr Craven can adopt his way of thinking, that having a disabled child is worse than not having a child at all. Hereditary illnesses as a fear has to be questioned by the reader to not adopt harmful stereotypes themselves.

While disability as something heredity is a fear in *The Secret Garden*, it is a fact in *Wonder*. There is no medical explanation for either Mr Craven or Colin's disability, but in Wonder, we are given a specific explanation by Via of Auggie's condition. In the chapters "Genetics 101" and "The Punnett Square" Via gives a detailed explanation of the genetic mutations that came together to make August look the way he does. Unlike Colin, August's disability is represented as perfectly natural and not something to fear. However, while no one expressed out loud any fear that August's disability will be the end of him or that he is better off dead than disabled, Via does not want any children. Via explains the chances of her and Auggie passing on the defective genes to their children if they ever have them. In short, there is a one in four chance her kids will get the gene and look like August if she marries someone with the same defective gene (Palacio, 2013, p. 107). Via does not give a reason as to why she does not intend to have any children, but it is clear it is related to August's condition. It is impossible to determine exactly why this is, but there are some possible explanations. As August's older sister, Via has witnessed his health struggles and been there for all his surgerie:, she knows what physical pains living with this condition causes. Her not wanting to have children can be as simple as her not wanting anyone to go through all the pain her brother has been through. Via has also witnessed to the emotional pain of being rejected by society as well as experiencing it herself. Via has no issues with being the sister of a child with birth defects, but she does not "always want[s] to be defined that way" (Palacio, 2013, p. 91). Living in a society that marvels at anything "out-of-the-ordinary" causes an emotional toll on the family, as Via has lived with this most of her life, it might not be something she wishes on her children. Not wanting children could of course be a combination of these. Unlike Mr Craven in The Secret Garden, Via's fear is not aimed toward disability as something lesser, her fear is linked to society's reaction. Via has seen how society treats disability, and with the pains that already come with impairments, her decision to not have children might be her way of protecting her potential children from pain.

Despite of the hereditary nature of August's impairments, he is treated as contagious by some of the other pupils. There is a game amongst the pupils called 'The Plague' which started at the beginning of the school year. Summer is the first to tell us about the Plague. There is not much to the game, as the only rule is that if you touch August you have 30 seconds to wash your hands before you catch the Plague (Palacio, 2013, p. 120). The Plague is so well established amongst August's peers that it is one of the main reasons no one wants to talk with or play with August. They fear that they might accidentally bump into him and lose the game. When Jack first returns to school after the incident where he punched Julian, he is avoided by everyone. He compares his experience with the Plague and when he says this to Auggie and Summer, Auggie admits that he knows about the game. Although he did not know that it was called the Plague, August always imagined it was like "the Cheese Touch", a similar game found in the Diary of a Wimpy Kid (Palacio, 2013, p. 178). The whole idea surrounding the Plague portrays attitudes toward disability closer to the ones found in the Secret Garden than the ones generally seen in Wonder. The whole principle of any game is to win, which is good, and avoid losing, which is bad. Because catching the Plague is seen as losing, a connection that disability is something bad and unwanted is made clear. Although the children do not actually believe that they will catch a plague if they touch August, as they know it is not contagious, the meaning and intention behind the game speak volumes. August's peers represent society, and they view August as something different and undesirable, believing that August's life is something worth less than their own lives. Toward the end of the novel, no one is playing the Plague anymore and they see August as he is and not as his disability. The evolution of the Plague illustrates how the school changes as a society. At the beginning of the school year, almost all the pupils were in on the game, showing that society saw August as something belonging on the outside. While at the end of the school year, no one plays it anymore, showing that society has changed and no longer treats August as an outsider. The fear of contagion as seen in both The Secret Garden and Wonder reflects the society when the novels were written. In The Secret Garden the fear in itself never goes away, as Colin is the one to change, while in Wonder, the people around August are the ones to change in the end, accepting August for who he is.

3.4 Appearance and Staring

Appearances and staring hold great weight in both novels and are something Colin and August struggle with. Colin, Mr Craven, and August all have visible disabilities, and their appearances are often at the centre of attention as a result of this. Although Mary is not disabled, she is of poor health when she first arrives at Misselthwaite Manor, and her appearance, as with Colin and August, is often a topic of conversation. Mary, Colin, and August experience name-calling directly connected to their outward appearance. *The Secret Garden* established from its first sentence that appearance is an important topic in the novel. The first thing we learn about Mary Lennox is that she is not good-looking.

When Mary Lennox was sent to Misselthwaite Manor to live with her uncle everybody said she was the most disagreeable-looking child ever seen. It was true, too. She had a little thin face and a little thin body, thin light hair and a sour expression. Her hair was yellow, and her face was yellow because she had been born in India and had always been ill in one way or another. [...] when she was a sickly, fretful, ugly little baby she was kept out of the way, and when she became a sickly, fretful, toddling thing she was kept out of the way also. [...] by the time she was six years old she was as tyrannical and selfish a little pig as ever lived. (Burnett, 2011, p. 5)

Mary's appearance is a constantly addressed topic by everyone around her, including herself, and as the novel progresses, Mary transforms from an ugly, selfish child, to a pretty, wellbehaved child. It becomes clear through the descriptions of Mary that her appearance is a reflection of her inner state of being. *The Secret Garden* uses disability as a metaphor, symbolising inner turmoil and moral failing in Mary, Colin, and Mr Craven. Although the two main characters are disabled, *The Secret Garden* is not a story about disability but a story about morality and growth through the use of disability. Barker & Murray (2018), and Quayson (2007) write about how disability as a metaphor is problematic. Disability as a metaphor undermines the disabled identity and uses disability as an accessory with no concern for what harm this type of representation can do. Mary never expresses directly that she is bothered by her appearance, but she proudly declares to Dickon that she is getting fatter every day after he remarked that she has grown stronger and looks different than she did when she first arrived at Misselthwaite (Burnett, 2011, p. 119). Mary might have never thought about or cared much about her appearance, but after losing both her parents and being sent to Misselthwaite, where she knows no one and everything is foreign, she learns a lot about herself and that for other people to like her, she needs to change. Mary, therefore, celebrates her changing appearance as it symbolises that she is becoming a better and healthier child.

Colin contrasts Mary by being obsessed with his appearance. Colin's appearance, just as with Mary's, is a recurring topic and reflects his inner turmoil. It functions as an easily recognised marker for the reader to determine his morality, but unlike Mary, he is tormented by the thought that he might look different. When Mary first stumbles upon Colin, she describes him as having a "sharp, delicate face the colour of ivory and he seemed to have eyes too big for it. He had also a lot of hair which tumbled over his forehead in heavy locks and made his thin face seem smaller" (Burnett, 2011, pp. 90–91). The way Mary describes Colin's features is rather feminine, as traits such as "a delicate face with big eyes" are traits often seen as desirable in women. When used on the boy Colin however, they are used to describe a sickly child. This is a deliberate choice by Burnett as explained by Peter Hunt. Burnett uses Colin as "a parody of these long-suffering, too-good-for-this-world characters: spoiled, wilful, and male – not really suffering from a spinal problem" (Burnett, 2011, p. xix). During their first encounter, Colin tells Mary that he has not been locked up but chooses to stay in his room as he does not want people to look at him. He used to be brought to the seaside when he was younger but refuses to go any longer because he cannot stand the staring of other people (Burnett, 2011, p. 92). Although this is not completely wrong, Colin being hidden away like a shameful family secret his father wants to keep away from the outside world tells the reader that it is not completely Colin's choice to stay hidden. Colin tells Mary that the servants are not allowed to talk about him, and when Mary tells Martha that she knows about Colin she becomes terrified that she will lose her job. Colin is such a well-kept secret that even Ben Weatherstaff, who has worked at the Manor since before Colin was born, does not know what he looks like. Colin believes he is in control because he has bought into that discourse about himself that it is better for him to stay hidden from the world. It is this discourse that has made Colin so afraid of people looking at him, and this fear that makes him stand up for the first time. When Ben Weatherstaff discovers the children in the secret garden, he yells at Mary, angry at her for being in the secret garden which is supposed to be locked up. As he discovers Colin and realises who he is, Ben is bewildered, as he does not understand how Colin can be there in the garden since he is "th' poor cripple" (Burnett, 2011, p. 158). Ben reacts in this way because he has only been able to rely on the rumours he has heard and the social assumption that the disabled child should be shut away out of sight. Hearing this, Colin

shouts back that he is not a cripple, confusing Ben even more, and prompting him to ask if Colin does not have a crooked back and crooked legs, as those are the rumours Ben has heard. Colin has been called several things, but he has never been accused of having crooked legs. This makes him fly into a rage which gives him the strength and determination to prove the old gardener wrong, enabling Colin to stand up (Burnett, 2011, pp. 158–159). When Colin first entered the secret garden with Mary and Dickon, he pledged that he would live forever. Colin has found the will to live, which is something he has never dared before. And so, when Ben asks if Colin has crooked legs, he is insinuating that Colin is less of a boy. Colin who has always been ashamed of his appearance, confronts Ben, demanding that he look at him and challenging him to say it to his face again that he has crooked legs. Colin managed to stand up, presumably for the first time in years, to prove to Ben that he is not disabled. In essence, with the help of Mary, Dickon, and fresh air, Colin gained the strength he has lacked all these years to prove that he is not less than anyone else. Colin has spent most of his life waiting for death because he has been told by everyone around him that he is better off dead than disabled. Therefore, when Colin finally decides to live, he stands up when Ben confronts him, as there is nothing worse than being accused of being "a cripple" in Colin's eyes. Colin is only able to insist on being looked at because he is not crippled, saying that had he actually been disabled he would not have challenged Ben to look at him. Although this is a personal victory for Colin and the others, The Secret Garden's portrayal of disability remains problematic.

Mr Craven is known as a hunchback before he is known as a human. His appearance, as with Mary and Colin's, is a topic of conversation. The first thing Mary learns about her uncle, whom she had never heard about before is that he is a hunchback. During Mary's first meeting with Mr Craven, she is more concerned with his face than his crooked shoulders. He looks miserable, and his "black eyes seemed as if they scarcely saw her, as if they were seeing something else, and he could hardly keep his thoughts upon her" (Burnett, 2011, pp. 84–85). Through Mary's observations, it seems as if Mr Craven is not so much a hunchback as he is emotionally haggard. Toward the end of the novel, Mr Craven is away travelling around Europe and we get an insight into his character, where we learn that he is a troubled man who has, since the death of his wife, struggled mentally.

He had let his soul fill itself with blackness and refused obstinately to allow any rift of light to pierce through [...] When he travelled about, darkness so brooded over him

that the sight of him was a wrong done to other people because it was as if he poisoned the air about him with gloom. Most strangers thought he must be either half mad or a man with some hidden crime on his soul. (Burnett, 2011, p. 200).

Mr Craven "poisoning the air around him with gloom" relates to the fear of contagion discussed in section 3.3. He is so filled with darkness and gloom that people believe he is a dangerous man "with some hidden crime on his soul" (Burnett, 2011, p. 200). Just as with Mary and Colin, Mr Craven's looks are a reflection of his inner turmoil; playing toward disability as something monstrous. After the death of his wife, Mr Craven was swallowed up by grief, neglecting his home and responsibilities as a father. Mr Craven is showing signs of depression, and the treatment of the disability that is mental illness is fear, as people fear him due to his disability.

Mr Craven's change in appearance is different to the one of the children. Where Mary and Colin's appearances gradually change for the better through exercise, fresh air, and development in character, Mr Craven's change is solely due to Colin proclaiming that he will "live forever and ever and ever!" (Burnett, 2011, p. 201). Mary and Colin are active participants in their change, and Colin, through unknown forces of nature is the one who makes his father better. "Magic" as an element in their change from unhealthy and sour to healthy and straight people touches on the notion of inspiration porn. Through dedication and positive thinking anything is possible. With a "the only disability in life is a bad attitude"attitude and through having a more positive outlook on life Colin and his father are quick to recover their health. There is another difference between Mr Craven and the children, as unlike them, Mr Craven is still disabled at the end of the novel. Presumably at least, as there is no mention of his crooked back after his mental change. It is noted, however, by the servants at the Manor, when Mr Craven comes back, that he looks better than before (Burnett, 2011, p. 206). Mr Craven still being a hunchback while the children rid themselves completely of their ailments, might be because the children started their journey of healing before Mr Craven did. Mary started her journey through Martha and Ben Weatherstaff, before becoming an active participant herself. Colin started his journey to better health through Mary before he actively worked to better himself. Hence, Mr Craven might be in the starting phase of his change through the indirect help of Colin, and his appearance might have changed further if the novel continued. Even so, the connection between appearance, disability, and inner state of mind is apparent in The Secret Garden.

August is similar to Colin in the sense that he too is concerned with his appearance to the point that it affects his daily life. However, while Colin changes his appearance to defy the world, August learns to accept himself as he is. Our first introduction to August contrasts that of Mary and Colin. August does not provide us with a description of his appearance, and instead explains that he is no ordinary kid, even though he enjoys doing things other ordinary kids do. The reason he knows that he is different is that "ordinary kids don't make other ordinary kids run away screaming in playgrounds. I know ordinary kids don't get stared at wherever they go" (Palacio, 2013, p. 3). August deliberately refuses to describe what he looks like to the readers. There could be a couple of reasons for Palacio's choice not to describe August's appearance. The first reason could be that because this is August's story, Palacio wants to give the readers the "humanity" of the character before the physical description. As the purpose of the book is to get the readers to look beyond surface appearance, describing what August looks like would defeat this purpose. August has been stared at his whole life and through this book, Palacio has given August the power to decide who gets to stare and when. The only problem with this is that what you look like is a part of who you are and by refusing to acknowledge this, Palacio is refusing a part of who August is. This leads me to the other reason Palacio might have chosen not to disclose his appearance. Because this is a story of growth and the building of a disability community, August has yet to accept himself, something he is unaware of. August says that he is used to how people stare and that he has gotten good at pretending not to see, but time and time again throughout the novel, we are shown that the stares do bother him. All August wishes is to look ordinary, but the fact is he is not ordinary, at least not seen as such by society. August has adopted society's attitudes toward himself. Society brands August as different, something out of the ordinary, and as a result, August adopts these ideas. He tries to disappear into the background, trying to not be seen. He even avoids having his picture taken.

I stopped letting anyone take pictures of me a while ago. [...] I have an aversion to having my picture taken. [...] I couldn't get out of being part of the class picture. Ugh. The photographer looked like he'd just sucked on a lemon when he saw me. I'm sure he thought I ruined the picture. I was one of the ones in the front, sitting down. I didn't smile, not that anyone could tell if I had. (Palacio, 2013, p. 70)

August has Othered himself to a point where he believes his presence in a picture ruins it for other people. He holds the belief that he is different and undesirable based on people's

reaction toward him, and consequently makes an effort to avoid causing any inconvenience. This is where the similarities between August and Colin end. Colin changes himself to fit into a society that has rejected him, and it is not until after this change that Colin is able to fully accept himself. August, on the other hand, goes through a different change, a change of perception. His year attending fifth grade taught August to accept himself as he is. It also taught him that it is not he that should adapt to fit into society, it is society that should accommodate him. This growth is illustrated toward the end of the novel in the chapter "Pictures". This is after graduation and everyone is hugging and kissing August after he won the Henry War Beecher medal.

Everyone started taking pictures of me and pulling out their Flips, and then Dad got me, Summer, and Jack together for a group shot. We put our arms around each other's shoulders, and for the first time I can remember, I wasn't even thinking about my face. I was just smiling a big fat happy smile for all the different cameras clicking away at me. (Palacio, 2013, p. 307).

August no longer minds people taking his picture, he happily lets people photograph him. August has learnt to take up space and to be unapologetically himself. During the class picture, August points out that he did not smile, and because of the way his mouth is shaped, no one would even see the difference if he did smile. This contrasts the end of the novel where August is happily posing for graduation pictures smiling a 'big fat happy smile', no longer bothered about what others might think. He knows he is smiling and that is good enough.

August and Colin share a similar journey handling stares. At the beginning of the novels they both struggle with people staring at them, not knowing entirely how to react, but as the stories progress they grow more confident and start challenging the people staring at them. What differentiates their experience is that Colin is more extreme in his methods than August. As discussed earlier in this section, Colin is so terrified at being looked at at the beginning of the novel that he has locked himself inside his room, only later to loudly challenge Ben to look at him, demanding Ben's gaze on him. However, this demand is to disprove the narrative of him as a cripple, rather than to force the world to be accepting of disability. August, on the other hand, has a softer, more quiet approach to staring. Rosemarie Garland-Thomson, one of the biggest names within disability studies and activism, explores the complexity of staring in her

book *Staring: How We Look.* Staring is a natural response that all people participate in. Staring is a question at the same time as a response. When people see something unexpected they stare because they want more information. "We stare when ordinary seeing fails, when we want to know more" (Garland-Thomson, 2009, p. 3). It is this, sometimes involuntary, action August has to face every time he leaves his house. Because August is seen as different by society, it is only natural that he experiences more stares than most, which is something he is painfully aware of. During August's first visit to Beecher Prep, we get insight into how aware August is of all the stares he receives. During his first meeting with a staff member of Beecher Prep, August notices her response to his face:

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. (Palacio, 2013, p. 17)

Mrs Garcia makes an involutory facial reaction to seeing something unexpected, which is August's face, yet quickly recovers her composure. The only issue is that August is so used to being stared at, that he is able to pick up on the tiniest facial reactions of the starer. A few moments later, when August is shown around school by three other pupils, August shows us again how adept he is at noticing stares:

I noticed Julian staring at me out of the corner of his eye. This is something I see people do a lot with me. They think I don't know they're staring, but I can tell from the way their heads are tilted. (Palacio, 2013, p. 27)

In both of these instances, which happen early in the novel, August pretends not to see the stares and retreats. Staring is an interaction between two people, the starer and the "staree", who both have options regarding how to proceed with the interaction. Being stared at demands a response: the staree can either lock eyes with the starer or avoid a confrontation, while the starer can either advance or retreat (Garland-Thomson, 2009, pp. 3–4). Staring can invoke a vast variety of emotions and reactions and is often a power-relationship where one submits to the other. At the beginning of their stories, Colin and August both allow the starer to hold power over them by avoiding a confrontation and leaving the starer unchallenged. Letting stares go unchallenged teaches us that staring is an acceptable action to do when encountering something unexpected. This in turn is allowing society to go unchallenged in its treatment of disability, which suggests that disability is something shameful that should be hidden away.

From early on in *Wonder*, August keeps on insisting that he is used to the stares and that it does not bother him even though it is obvious to the reader that the stares do bother him. During the first day of school, August rushes to his classroom with his head down to avoid any eye contact. He still gets stared at however, but he insists it is fine and that he is used to it. This also occurs when his new teacher notices him for the first time, August keeps on insisting it is fine, he is used to it (Palacio, 2013, pp. 37–38). He also let his hair grow long to block out the stares. But when it is time for lunch, August is no longer able to lie to himself. He notices that a lot of people are staring at him and talking about him to their friends and August has to admit "I thought I was used to those kinds of stares by now, but I guess I wasn't" (Palacio, 2013, p. 50). August's entry into society was harder than he initially thought, as he did not think the stares would bother him as much as they do. Although he knows most of the stares do not come from a place of malice but rather a place of curiosity, the constant reminder that he is different affects him (Palacio, 2013, p. 62). Excessive staring is an issue disabled people often have to deal with, especially those with extraordinary bodies. Because staring is most often triggered by seeing something unexpected, people with physical features that are not deemed "normal" make "easy targets" for staring. When people with stareable bodies enter the public eye, their public presence expands the range of bodies we expect to see, and the visual landscape enlarges (Garland-Thomson, 2009, p. 9). The solution to staring, according to Garland-Thomson, is as simple as exposure. If staring is caused by something unexpected, then exposing people of different types of bodies will makes different bodies normal. Palacio demonstrates that staring is countered by exposure to a greater range of appearances in the chapter "September" (pp. 61-62) by representing the class becoming "used" to August's appearance. August explains how it took his class one week to get used to his face, two weeks for the other children in his grade, and a month for the rest of the children in school (Palacio, 2013, p. 62). Palacio thus demonstrates Garland-Thomson's argument that exposure expands the visual landscape of people, as time passes August becomes less stareable for the children at Beecher Prep

"Stareable people have a good deal of work to do to assert their own dignity or avoid an uncomfortable scene" (Garland-Thomson, 2009, p. 84). At only 10 years old, August has not yet developed a strategy to handle excessive staring from a large group of people. Having been home-schooled until now, he has not been in many situations where this has been a necessary skill to have. During one of the school fairs, August explains the difference between the occasional stare, which he does have strategies to handle, and excessive staring, which he does not have a sustainable strategy for:

Anyway, it's not that I care that people react to me. Like I've said a gazillion times: I'm used to that by now. I don't let it bother me. It's like when you go outside and it's drizzling a little. You don't put on boots for a drizzle. You don't even open your umbrella. You walk through it and barely notice your hair getting wet.

But when it's a huge gym full of parents, the drizzle becomes like this total hurricane. Everyone's eyes hit you like a wall of water. (Palacio, 2013, p. 207)

August's battle against the stares is a never-ending fight. It does not matter how many people get used to his face, as there will always be a time or a place he is introduced to a new group of people that is not used to his appearance and the whole cycle of expanding the visual landscape starts over. A few stares here and there are not enough to bother August, but the constant wave of stares make August feel like he is drowning. Figuring out what strategies are best to use to cope with staring, is a process of trial and error. It takes time and experience for the staree to find what is best for them (Garland-Thomson, 2009, p. 88). Due to his parents' efforts to protect him, August, who is only 10 years old, has had limited exposure to the public sphere and therefore lacks the necessary experience to cope with the unwanted attention from others. Another issue August has to face is that most of his starers are children like himself, and Garland-Thomson points out that children are a different story than adults, as children are not fully socialised and their stares do not follow the same logic as with adults (Garland-Thomson, 2009, pp. 88–89). However, there is evidence that August is learning different techniques for handling the stares throughout the novel. During his first meeting with Jack, who later becomes his best friend, Jack stares at August as he and a couple of other pupils are showing August around the school. "[A]s I passed by, he looked me right in the face, kind of daring me to look back at him, which I did. Then I actually smiled. [...] And he smiled back" (Palacio, 2013, pp. 29-30). In this interaction, instead of pretending not to notice the stare, August stares back, and in doing that he takes some of the power back from the starer, which Jack respects. "Refusing to wilt under another's stare is a way to insist on one's dignity and worth" (Garland-Thomson, 2009, p. 86). August's stare-down with Jack develops into a positive encounter between the two, where August establishes his own worth as an equal to Jack. This interaction allows a mutual relationship to form between the two boys. Challenging the starer as August does here, shows August refusing to be treated as a

spectacle or as an object for people to stare at to their hearts' content. He is reclaiming his subjectivity against the Othering nature of staring.

3.5 The Able-Bodied in a Disability Narrative

The Secret Garden and Wonder are stories about disability written by non-disabled people. R. J. Palacio and Frances Hodgson Burnett are both able-bodied women who, through their novels, portray the life of disabled children living in a hegemonical able-bodied society. Because neither Burnett nor Palacio are disabled, they represent the experience of the ablebodied society. Even though Palacio portrays disability through the social model, both she and Burnett write from the experience of the able-bodied, which will influence the portrayal of disability in their novels. This is something to be aware of when critically reading and teaching these novels, as their able-bodied experience will leave its mark on the narrative. Jack Will is one of the narrators in Wonder and August's best friend. He functions as a standin for the able-bodied reader. Through Jack, able-bodied pupils are able to recognise their own experience in meeting with disability. Jack first approached August because Mr Tushman had asked him and two other pupils to show him around school. After that, Jack quickly grows fond of August, as August is "a really cool dude" (Palacio, 2013, p. 142). However, by being friends with August, Jack experiences what it is like to be Othered, thus acquiring a "next-to" identity. Befriending someone with a minority identity that you do not have yourself can teach you a great deal about their experiences and how society treats them (Wheeler, 2013, p. 343). As a result of his friendship with August, Jack is starting to make his way into the disability community through their shared experiences. While walking together with August through the hallways, Jack experiences what it is like being stared at in the same way August does; but since Jack not being used to being stared at, has to learn how to handle the stares. At first, Jack pretends not to notice the stares, then he portrays anger toward the starer, and lastly he and August plan their "revenge" on the starer by using humour about the situation (Palacio, 2013, pp. 63-64). Jack and August are bonding over shared experiences by trying to laugh at society's treatment of disability. Wheeler writes that "a new anger at society's treatment of people with disabilities is a sign that one may be coming into the community (Wheeler, 2013, p. 343). Jack is making his way into the disability community.

The transition from being "normal" to being Othered by the society that has always treated him like one of its own was not a painless transition for Jack. Until he met August, Jack did not have any experience with the disability discourse, and slowly being rejected by the discourse he has always been a part of was not something Jack found easy. Jack demonstrates some human, but cruel, behaviour and the reader get to see his regret over this and identify with it. This is exemplified during Halloween, where Jack adopts a "rather dead than disabled" attitude in order to be accepted by Julian and the other guys. August changed his Halloween costume at the last second and because of this, no one recognises him. He listens in on a conversation between Julian, dressed as Darth Sidious, and two mummies, one of whom we learn later is Jack. They say mean things about August, such as that he looks like Darth Sidious, a shrunken head and so on.

"'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.'

'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.' (Palacio, 2013, p. 77)

Jack, who is the second mummy in the extract above, expresses a "rather dead than disabled" attitude, saying a life such as August's is a worse fate than death. Jack's betrayal is rooted in a wish to be accepted by the majority; to feel "normal" again. This wish to be "normal" is also the reason Jack did not sit with August on the first day at school (Palacio, 2013, p. 175). Jack is struggling with his transition into the disability community and is showing some instances where he is rejecting it. It is neither easy nor pleasant to go from being accepted by the discourse to being rejected. Through Jack, Palacio illustrates difficulties able-bodied people might face when meeting disability. Wheeler writes that "Jack's temporary adoption of 'better dead than disabled' is an honest attempt to grapple with the cruelties of an ableist world" (Wheeler, 2013, p. 347). The reason Jack's betrayal hurts August more than any of the bullying Julian has ever done is not only because August thought of Jack as a friend, but because Jack had felt what it was like to be stared at, and what it is like to be treated differently. August and Jack had bonded over shared experiences and Jack had adopted a next-to identity, thus when Jack portrayed a "rather dead than disabled" attitude, it was almost as if August had been rejected by one of his own; someone who was a part of the disabled community and knew of all the pain that entailed. Fortunately, Jack and August's friendship does not end on a bad note.

Palacio redeems Jack later in the novel, allowing him to display regret and a willingness to atone. Following the event that took place during Halloween, Jack is confused as to why

August is no longer speaking to him and it takes a while before he learns that August heard what he said about wanting to kill himself rather than looking like August. Jack instantly portrays regret and disgust in his own behaviour, ending up punching Julian right in the mouth. When making it up with August, Jack flips the narrative from "rather dead than disabled" into "rather dead than mean" indicating that "cruelty is the real disability" (Wheeler, 2013, p. 348). By flipping the "rather dead than disabled" narrative on its head Palacio is moving close to "the only disability is life is a bad attitude", only, she is also flipping this expression back on able-bodied people. If cruelty is the real disability, then it is true that the only disability in life is a bad attitude, which is the bad attitude of society toward people with impairments. Palacio is illustrating the main focus of the social model of disability, which is that it is society that disables people. Jack punching Julian in the mouth is a public rejection of the hegemonical able-bodied society and the consequences of this had Julian turn almost the entire grade against Jack. None of the boys are talking to Jack anymore, and they are all ignoring him and walking away from him. During lunch, August and Summer invite Jack to sit with them as his usual table does not want him. Jack finds this whole ordeal strange and says: "'It just feels so weird,' I said, ' not to have people talking to you, pretending you don't even exist.' Auggie started smiling. 'Ya think?' he said sarcastically. 'Welcome to my world'" (Palacio, 2013, p. 176). Jack is experiencing what it feels like to be invisible and unacknowledged by the people around him. Being overlooked as if invisible is a common experience for those seen as different by the majority. "Those who are different are blocked out by society that insists that only the norm exists" (Anolik, 2014, p. 9). August, who is used to this kind of treatment welcomes Jack back into his world of disability discrimination, forgiving him for earlier rejecting August, while at the same time redeeming Jack. Palacio illustrates some of the struggles able-bodied people might have in meeting with disability and through Jack the pupils can recognise themselves in the process. August and Jack's friendship illustrates the complex struggles of building a disability community. Wonder catches the reality "most children with disabilities experience: a circle of able-bodied people at home and in school united through their experiences with disability and ableist prejudice" (Wheeler, 2013, p. 338).

4. Conclusion

The aim of this thesis has been to explore how the use of young adult fiction can increase awareness of the hegemonic discourse of an able-bodied society in the upper secondary classroom. This was done by demonstrating critical literacy through a disability studies-based reading of Frances Hodgson Burnett's The Secret Garden (1911) and R. J. Palacio's *Wonder* (2012). More precisely, I have argued that an awareness of how English language cultural productions create social attitudes that will help pupils develop broader social consciousness as required by the core curriculum. Teaching literature through a disability studies lens encourages critical awareness of the socio-cultural aspects that dictate society's attitudes toward disability.

There is a lack of conversation about disability in both education and by society in general, and this thesis is an attempt at filling that gap, if only a little. With a focus on the core value "human dignity" and critical literacy, I have shown how young adult fiction can be used to develop these skills. Reading fiction encourages you to explore different identities and perceptions that you might not be familiar with or completely relate to. Critical literacy is an important skill to have when reading literature as it helps uncover unconscious attitudes and perceptions the pupils might have, broadening their social consciousness as well as revealing the embedded meanings and motives of the text. You want the pupils to question the intention of the text and not blindly agree with outdated and prejudiced narratives. Critical literacy requires a sensitivity to how language and culture create socio-political perceptions of minority groups. Language and specific narratives used by society contribute to how disability is framed and understood. As stated in the theory section, the field of disability studies focuses on how the world views disability in the context of culture, society, and politics. There are two main models within disability studies: the medical model and the social model. The medical model describes people who have disabilities and view disability as something negative in need of a cure, while the social model describes people who are disabled by the hegemonical able-bodied society. Through literature, as cultural mediation of the society in which it was written, attitudes toward disability can be revealed. Reading historical literature can show us where ingrained perceptions and beliefs are rooted.

The Secret Garden and Wonder were chosen because they portray the two different models while at the same time having similarities. Exploring how disability is portrayed and treated in these novels opens up the opportunity to discuss values and attitudes held by society that are widely accepted as the truth and the development of these attitudes over time. Both novels capture the essence of disability studies: what it means to be disabled in a society where ablebodied is the norm. However, the attitudes toward disability are quite different. Even though both novels are about change, The Secret Garden is about the change of body to fit into an ableist society, while Wonder is about the change of a community that learns to accept disability. The Secret Garden shares attitudes toward disability central to the medical model. Colin's disability is seen as an illness that has to be cured, in the sense that being disabled is not an option. Colin and Mary change to be accepted into the society that previously saw them as an Other, allowing attitudes toward disability to go unchallenged. Wonder contrasts this by portraying attitudes central to the social model. The novel moves from the isolation of the medical model to the social model and stays there. August goes on a journey of selfacceptance while the community around him learns to accommodate and accept disability. Because Wonder is firmly placed within the social model it also portrays the weaknesses of the model. By solely focusing on society's role in disabling August, Wonder ignores the reality of living with an impairment.

The analysis has revealed that by comparing two fictional novels written 100 years apart, the different time periods influence the perception and representation of disability. By addressing tropes and shared themes in the novels, young adult fiction can help pupils not only develop an understanding of the socio-cultural context of disability but also their own attitudes and perception through developing critical literacy. Both novels engage with some of the same tropes and attitudes, and by comparing the two novels to each other, I found how Burnett and Palacio engage with these in different ways. Disability as something monstrous, "rather dead than disabled", and "the only disability in life is a bad attitude" are all tropes and attitudes found in both novels. Where Burnett portrays these attitudes as acceptable to have toward disability, Palacio engages with these attitudes in order to destroy them. Even though neither The Secret Garden nor Wonder are perfect representations of disability, "faulty" narratives have value and should be critically engaged with and challenged. Engaging with these narratives can further understandings of how representations of disability have shaped how disability is viewed and treated by society. As for why pupils should read disability

narratives like Burnett's and Palacio's, that is because the novels can provide the pupils with necessary insight which will develop their critical literacy.

As this thesis is fully theoretical, an aspect that would have strengthened the thesis further would have been a practice-based study of the novels. A practice-based study with The Secret Garden and Wonder has the potential to reveal both the advantages and challenges of this study. This would provide a detailed report of the outcome of the process. The chosen novels have been used to illustrate how disability narratives can develop critical literacy in upper secondary pupils while teaching "human dignity" at the same time. As LK20 was only fully implemented as of spring 2023 and there is a lack of disability awareness, more time and research are needed to fully study the educational potential of these novels. Another idea for further research would be to use fiction written by a disabled person. Burnett and Palacio are both able-bodied women and represent the experience of the able-bodied society. Thus, using fiction by someone who is disabled would provide the experience and narrative of the disability narratives contribute to spreading awareness of the systemic discrimination toward disabled people and can help bring change.

References

- Adams, R. (2013). Disability Studies Now. American Literary History, 25(2), 495–507.
- Alford, J. (2019). Critical Literacy with Adolescent English Language Learners: Exploring Policy and Practice in Global Contexts. Taylor & Francis Group. http://ebookcentral.proquest.com/lib/hilhmr-ebooks/detail.action?docID=6524203
- Anolik, R. B. (2014). Introduction: Diagnosing Demons: Creating and Disabling the Discourse of Difference in the Gothic Text. In Ruth Bienstock Anolik, *Demons of the Body and Mind: Essays on Disability in Gothic Literature*. McFarland.
- Barker, C., & Murray, S. (2018). Introduction: On Reading Disability in Literature. In C.Barker & S. Murray (Eds.), *The Cambridge Companion to Literature and Disability*.
- Birkett, D. (2015, February 26). Why can't theatre imagine what it's really like to be the parent of a disabled child? *The Guardian*.
 <u>https://www.theguardian.com/commentisfree/2015/feb/26/theatre-parent-disabled-child-kill-me-now</u>
- Burnett, F. H. (2011). The secret garden. University Press.
- Carlsen, C. (2020). Reading literature. In C. Carlsen, M. Dypedahl, & S. H. Iversen, *Teaching and learning English* (2nd edition.). Cappelen Damm akademisk.
- Cheyne, R. (2019). *Disability, Literature, Genre: Representation and Affect in Contemporary Fiction*. Liverpool University Press. <u>https://doi.org/10.2307/j.ctvsn3pp7</u>
- Dirth, T. P., & Branscombe, N. R. (2017). Disability Models Affect Disability Policy Support through Awareness of Structural Discrimination. *Journal of Social Issues*, 73(2), 413– 442. <u>https://doi.org/10.1111/josi.12224</u>
- Diskrimineringsnemda. (n.d.). *Diskrimineringsnemda*. https://www.diskrimineringsnemnda.no/spr%C3%A5k/5451
- Education Act. (1998). Act relating to Primary and Secondary Education and Training (LOV-1998-07-17-61). Lovdata. <u>https://lovdata.no/dokument/NLE/lov/1998-07-17-61</u>
- Garland-Thomson, R. (2009). *Staring: How We Look*. Oxford University Press, Incorporated. http://ebookcentral.proquest.com/lib/hilhmr-ebooks/detail.action?docID=430868

Genius. (2022). Grrrls. Genius. https://genius.com/Lizzo-grrrls-lyrics

- Great Ormond Street Hospital. (2019). *Treacher-Collins syndrome*. Great Ormond Street Hospital. <u>https://www.gosh.nhs.uk/conditions-and-treatments/conditions-we-</u> <u>treat/treacher-collins-syndrome/</u>
- Grue, J. (2016). The problem with inspiration porn: A tentative definition and a provisional critique. *Disability & Society*, *31*(6), 838–849. https://doi.org/10.1080/09687599.2016.1205473
- Grue, J. (2023, March 14). The disabled villain: Why sensitivity reading can't kill off this ugly trope. *The Guardian*. <u>https://www.theguardian.com/news/2023/mar/14/the-disabled-villain-why-sensitivity-reading-cant-kill-off-this-ugly-trope</u>
- Hafsaas, S. L. (2022, June 12). *Remi (27) har cerebral parese og har søkt jobber i seks år*. NRK. <u>https://www.nrk.no/vestland/remi-_27_-har-cerebral-parese-og-har-sokt-jobber-</u> <u>i-seks-ar-1.15997230</u>
- Hall, A. (2016). Literature and disability. Routledge, Taylor & Francis Group.
- Keith, L. (2001). *Take up thy bed and walk: Death, disability and cure in classic fiction for girls*. The Women's Press.
- Kilgour, M. (2013). The Rise of the Gothic Novel. Routledge.
- Leduc, A. (2020). *Disfigured: On Fairy Tales, Disability, and Making Space*. Coach House Books.
- Likestillings- og diskrimineringsombudet. (n.d.). *Om ombudet*. Likestillings- og diskrimineringsombudet. <u>https://www.ldo.no/ombudet-og-samfunnet/om-ombudet/</u>
- Lintner, T. (2011). Using "Exceptional" Children's Literature to Promote Character Education in Elementary Social Studies Classrooms. *The Social Studies*, 102(5), 200–203. <u>https://doi.org/10.1080/00377996.2010.550955</u>
- Meyer, A., & Wender, E. (2016). Teaching and Reading Wonder and Marcelo in the Real World with Critical Eyes. In *Lessons in Disability: Essays on Teaching with Young Adult Literature* (pp. 72–99). McFarland.
- Ministry of Education and Research. (2017). *Core curriculum values and principles for primary and secondary education*. Laid down by Royal Decree. The National Curriculum for the Knowledge Promotion 2020; regjeringen.no. <u>https://www.regjeringen.no/contentassets/53d21ea2bc3a4202b86b83cfe82da93e/core-</u> *curriculum.pdf*

- Ministry of Education and Research. (2019). *Curriculum in English (ENG01-04)*. Established as regulations. The National curriculum for the Knowledge Promotion 2020. https://www.udir.no/lk20/eng01-04?lang=eng
- Monobe, G., & Son, E. H. (2014). Using Children's Literature and Drama to Explore Children's Lives in the Context of Global Conflicts. *The Social Studies*, 105(2), 69– 74. https://doi.org/10.1080/00377996.2013.820164
- Munden, J., & Sandhaug, C. (2017). Engelsk for secondary school. Gyldendal akademisk.
- Murray, S. (2018). The Ambiguities of Inclusion Disability in Contemporary Literature. In C.
 Barker & S. Murray (Eds.), *The Cambridge Companion to Literature and Disability* (pp. 90–103). Cambridge University Press.
- Murty, L., Sinar, B., Williams, G., Pande-Rolfsen, M. S., Normann, A., & Vicary, T. (2021).
 Reading for everyone. In G. Williams & A. Normann, *Literature for the English* classroom: Theory into practice (Second edition.). Fagbokforlaget.
- Palacio, R. J. (2013). Wonder. Corgi Books.
- Quayson, A. (2007). *Aesthetic nervousness: Disability and the crisis of representation*. Columbia University Press.
- Retief, M., & Letšosa, R. (2018). Models of disability: A brief overview. HTS Teologiese Studies / Theological Studies, 74(1), Article 1. https://www.ajol.info/index.php/hts/article/view/177914
- Rice, N. E. (2018). Disability Studies. In *Encyclopædia Britannica*. https://www.britannica.com/topic/disability-studies
- Rønhovde, H. (2023, February 14). *Thomas blir ofte glemt igjen på toget*. NRK. <u>https://www.nrk.no/osloogviken/rullestolbruker-thomas-_24_-opplever-store-utfordringer-som-togpendler-hos-vy-1.16272511</u>
- Shakespeare, T. (2021). The Social Model of Disability. In L. J. Davis (Ed.), *The Disability Studies Reader* (pp. 16–24). Taylor & Francis Group.
 <u>http://ebookcentral.proquest.com/lib/hilhmr-ebooks/detail.action?docID=6469110</u>
- Sviggum, S. K. (2022, September 12). Gry Hege (51) mangler armer og bein—Fikk avslag på handikapparkering. *VG*. <u>https://www.vg.no/i/dwOXWo</u>
- The Editors of Encyclopaedia Britannica. (2023). Paralympic Games. In *Encyclopaedia Britannica*. <u>https://www.britannica.com/sports/Paralympic-Games</u>

- Victor, D. (2022, June 14). Lizzo's Lyric Offended Fans. She Changed It, and They Forgave. *The New York Times*. <u>https://www.nytimes.com/2022/06/14/arts/music/lizzo-lyrics-grrrls.html</u>
- Ware, L. (2001). Writing, Identity, and the Other: Dare We Do Disability Studies? *Journal of Teacher Education*, 52(2), 107–123. <u>https://doi.org/10.1177/0022487101052002003</u>
- Westrheim, K., & Tolo, A. (2014). Kompetanse for mangfold: Om skolens utfordringer i det flerkulturelle Norge. Fagbokforl. <u>https://www.nb.no/search?q=oaiid:"oai:nb.bibsys.no:991415983604702202"&mediaty</u> <u>pe=bøker</u>
- Wheeler, E. A. (2013). No Monsters in This Fairy Tale: Wonder and the New Children's Literature. *Children's Literature Association Quarterly*, 38(3), 335–350. https://doi.org/10.1353/chq.2013.0044
- Young, S. (2014). I'm not your inspiration, Thank you very much. <u>https://humber.ca/makingaccessiblemedia/modules/01/transript/I'm_Not%20_Your_In</u> <u>spirations_transcript.pdf</u>