

It is Okay to Not be Okay: Reading S.C. Megale's *This is Not a Love Scene* and Lottie Mill's, "The Changeling"

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Abstract: It is undeniable that narratives read and heard by young people in their formative years are capable of shaping their thoughts quite unlike anything else. Regrettably, disabled people are highly underrepresented in literature, especially those written for children and young adults. Moreover, representations of disabled characters often fall into one of the many stereotypical categories, or narrative tropes. For instance, a common disability trope is that of a pitiful victim, a disturbing villain, a helpless innocent, or a brave over-comer (Nario-Redmond 3). This dominant narrative causes the viewing of disability, both by people with and without disability as undesirable and inferior. In her seminal essay, "Mirrors, Windows, and Sliding Glass Doors" (1990), Rudine Sims Bishop explains that books serve as "mirrors" when readers see themselves represented in the pages; "windows" when they enable readers to gain understanding and empathy for the experiences, lives and cultures of other people; and "sliding glass doors," when readers feel transported into the world of the book and feel empathy for the characters. Stressing on the importance of correct representation, Toliver explains how "broken mirrors" (2) may reflect inauthentic representation of marginalized people which can be internalised by readers. S.C. The paper examines how Megale's *This is Not a Love Scene* (2019) and Lottie Mill's short story, "The Changeling" (2020) challenge stereotypical tropes for disabled characters, expose systemic ableism and promote a positive disabled identity.

Key Words: Disability, disability studies, disabled writer, representation, young adult literature, ableism.

1. INTRODUCTION:

We are told stories from a very young age. Seeing ourselves represented in some ways, observing ourselves in the experiences of the characters give us a sense of being included and being understood. This seems even more significant for children and young adults. At the same time, learning about perspectives apart from our own builds up knowledge and creates empathy. It is undeniable that narratives read and heard by young people in their formative years are capable of shaping their thoughts quite unlike anything else. Regrettably, disabled people are highly underrepresented in literature, especially those written for children and young adults. Even the narratives that include disabled characters often give an invalidating portrayal of disability. In the past few years, focus on the importance of accurate representation of individuals have expanded. The aim of this paper is to critically analyse the representation of disability experience as depicted in S.C. Megale's *This is Not a Love Scene* (2019) and Lottie Mill's, "The Changeling" (2020), both of which belong to the genre of young adult literature, and both works written by disabled writers.

2. LITERATURE REVIEW:

"The Changeling":

Lottie Mills has won the BBC Young Writers' Award 2020 for her short story "The Changeling." The story will be published by in 2024 as part of a collection of short stories by Lottie Mills titled *Monstrum*. The "Changeling" tells a story about a girl who is born with a physical disfigurement that look like wings. While fairy tale inspired, the story is situated in a modern-day environment, with coming-of-age framework. The short story traces Rowan's experience with her misshapen body and depicts a detrimental influence of ableism on her young mind. It tells of her changing attitude towards her disability, beginning with her contentment with being who she is as a child, her difficult preadolescent experience with her disability and her eventual "unapologetic" acceptance of her difference. *Oneworld* Publisher Juliet Mabey comments of Lottie, "Her writing is original and poignant and challenges us to look beyond our own boundaries and life experiences" (Comerford).

This is Not a Love Scene:

A disabled writer herself, S.C. Megale's *This is Not a Love Scene* tells the story about the realities and fantasies of being a teenager living with a disability. Maeve is an eighteen-year-old girl in a wheelchair looking for love and having a passion to become a film maker. She is an honest and funny teen who positively identifies as a girl with muscular dystrophy. Through her everyday experience, Maeve points out the shortcomings in her environment that makes it difficult for a person in wheelchair to get around. She confronts a number of ableist ideas and situations and yet, she maintains an atypical attitude and response for a disabled literary character. Kirkus review calls it a story that features "a strong, sexually confident disabled female character" which is worth a zoom in (Kirkus).

3. METHODOLOGY:

The paper approaches disability as both a biological factor as well as a social construct. According to World Health Organization (2022), "disability results from the interaction between individuals with a health condition, such as cerebral palsy, down syndrome and depression, with personal and environmental factors including negative attitudes, inaccessible transportation and public buildings, and limited social support" (para. 2). This definition acknowledges the importance of context, individual experiences, disability type, accessibility, and different types of oppression as disabling factors. It implies that the conditions of the body or mind can be debilitating, and at the same time, environments, social expectations, public policies and non-disabled attitudes can be disabling factors. Disability in itself must be understood a complex experience that includes various conditions. Critical disability studies (CDS) perceives disability as a socially constructed "historical, social, political, and cultural phenomenon" (Bialka 143) including diverse traits such as short-term or long-term, and invisible or visible conditions. Disability experience also varies across body, gender, age, socioeconomic status, cultures, and so on. In fact, disabled lives and experiences are as diverse as non-disabled lives and experiences (Markotić 3). This approach also understands that, now and again, other conditions and barriers can be more disabling than the actual disability. In other words, adversities faced by disabled people are most often because of negative attitudes, prejudice, social stigmatization, exclusion, structural inaccessibility and institutional or legal barriers more than a direct result of their disability. And so, rather than individual perseverance, a significant social change is needed for the situation of disability to improve in a society (Barnes et al. 165).

4. DISCUSSION & ANALYSIS:

Disabled characters have sparsely appeared in literary texts for years and the portrayal is most often from a deficit perspective that reinforce negative stereotypes. Depiction of characters with disability often follow stereotypical tropes such as pathetic victim, avenging villain, courageous protagonist, freaks or harmless innocent characters (Markotić 5). We see examples in well-known literary works such as the hunchbacked King Richard III of Shakespeare, Victor Hugo's Quasimono, the saccharine Tiny Tim of *The Christmas Carol* (1843), the one-legged "mad" Captain Ahab in *Moby Dick* (1851), the vindictive and deformed Captain Hook in *Peter Pan* (1904), or the courageous Colin Craven in *The Secret Garden* (1911). Narrative tropes also usually include either a "super cripp" story line that involves a disabled person who achieves exceptional accomplishment in spite of the adversities they face, serving as an inspiration to others, or "the myth of a cure," which follows the storyline of a disabled character who dies at the end or is cured of their disability by the end of the narrative (Schalk 72). Within these narratives, disabled protagonists are viewed as exceptionally brave, courageous, and noble for "cop(ing) with what 'normal' people would find too difficult or overwhelming to handle" (Markotić 4). Conventional narratives have mostly shown disability as "something to be cured, eliminated, fixed, or overcome, and depict life with a disability as tragic, pitiable, and burdensome" (Baglieri & Lalvani 2). This dominant view results in disabled people as well as non-disabled people perceiving disability as inferior and undesirable. Disability can be perceived as "a social status that incites both hostile and benevolent forms of prejudice" and a "group that provokes stereotypes of incompetence and dependency, and behaviours that range from staring and unwanted assistance to abandonment, dehumanization, and hate crimes" (3). These beliefs and prejudices clearly form the basis of ableist ideology.

The term ableism has emerged from the social rights movements within disabled communities of the 1960s and 70s and is historically linked with disability prejudice (Albrecht). Even though specific definition of ableism varies, it is generally understood as the prejudice, discrimination, stereotyping, and oppression of people with disabilities. Nario-Redmond labels the different components of ableism in what he calls the ABCs of ableism: "affective emotions or attitudinal reactions; behavioural actions/practices; and cognitive beliefs/stereotypes that go beyond general negativity" (6). Ableism includes negative prejudices, hostility towards the disabled person as well as "positive ableism" which can manifest in the form of benevolent ableism (Nario-Redmond et al. 729) which can be identified as "pity, paternalistic protection, and unprovoked praise" for disabled people (729). Ableism results in disabled people being "excluded, ignored, misunderstood, rejected, dismissed, avoided, pitied, envied, objectified, dehumanized, manipulated, shamed, mocked, stereotyped, overprotected, condescended to, and/or provided with unwanted help" (739).

Written by disabled authors, “The Changeling” and *This is Not a Love Scene* address deficit views of disability while pointing out the challenges faced by a disabled person in an ableist society. The stories, while displaying the societal biases and limited perspective towards disability, largely focus on the positive attitude of the protagonists towards their disabilities. *This is Not a Love Scene*, using a first-person narrative traces the life and experiences of a teen living with disability, with which the author herself is familiar. The novel, while maintaining a positive view towards disability, explicitly addresses society’s deficit views of disabled bodies. Maeve does not like that she is considered less than in the society because of her disability. She calls out the pervasive exclusion and stigmatization, as well as the sentimental objectification of disabled bodies as “abuse of the disabled” (Megale 2, 63). The book dispels the belief that disability must be cured or eliminated for the disabled person to be viewed normal, or in other words, the book rejects the myth of cure, and the need to overcome the impairment. Maeve’s doctor, Dr. Clayton affirms, “there’s no treatment” and “cure wasn’t even on the table” (90) for her condition. Breaking the focus on Maeve’s disability, the Doctor is more concerned on treating her lung problems, which is often a source of worry, frustration and anger for her. The book also normalizes the reality of living with disability as Maeve and her doctor discusses her ability to have a typical teenage experience such as exploring her physical desires with her new romantic interest.

The novel, while emphasizing Maeve’s positive acceptance of her disability, displays several instances that points out the lack of accommodation for disabled bodies in an ableist society. For example, Maeve comments on the height of typical secretariat counter as she attempts to reach a clipboard with her “weak” arm, and her arm falls “like a trapeze artist who missed his swing mid-air” (32). This necessitates proud Maeve to ask help from the secretary, who is now full of apology, displaying “offensive” (32) pity. In another instance, Maeve, going to the movies finds, as “usual,” that “two able-bodied people,” are sitting in the only two seats that are wheelchair accessible in the theatre (64). Maeve comments that such instances “happened a lot” because nondisabled people never expect “disabled people to come and take fun out of disabled spots” (64). Another example of lack of accessibility for disabled people happens when Maeve visits the town ice cream parlour with her friends. While her friends are getting ice creams, Maeve has to wait for them at the bottom of the steps with her service dog because there is no wheelchair accessible entrance, not even a “ramp into a sketchy back entrance” (74-75). The minority and social models of disability stress society’s contribution to, and shaping of disability through discrimination, prejudice, lack of accommodation and inaccessibility (Longmore 25). *This is Not a Love Scene* highlights systemic ableism which a non-disabled reader may not have previously thought about. And while acknowledging the various physical challenges she has to tackle every day in a world that is built for convenience of non-disabled bodies, Maeve always takes pride in what she is capable of. She calls it “abuse of the disabled” (Megale 2,63) when a non-disabled person steps out of their way thinking that she needs “help when just sitting somewhere doing nothing” (111) because the intent entails that she is perceived as incompetent and in need of pity. The novel undermines the narrative trope of “super cripp” as well as the “myth of cure.” Maeve is a normal teenager with normal teenage problem. She is okay with her disability, and does not feel inferior being disabled, she however, believes that she will be able to do more for herself if her physical and social environments were more accommodating to wheelchair.

In a news article of Newnham College, University of Cambridge, reporting Lottie’s winning the “BBC Young Writers’ Award 2020,” the young writer explains her inspiration for “The Changeling,”

As a disabled person, my stories are quite often preoccupied with ideas of otherhood, based around characters who are outcast from their society in some way or another...I really wanted to write a story which would show the strengths of disabled people or people who are ‘othered’ in some way, rather than portraying them as disadvantaged and in need of ‘fixing’ as so many stories do.”

And in an article for *The Bookseller*, she writes the purpose of her endeavour in writing stories, “As a disabled person, I have so often been frustrated with how outsiderhood, and especially disability, has been misrepresented in fiction. I hope that my collection will subvert these ingrained narratives, and serve as a celebration of difference” (Commerford).

In like manner, “The Changeling” depicts a positive view of disability, dispelling the various misrepresentations of disability in fiction. The very opening of the story presses the notion that disability is devalued in society because of the assumption that it is “better for a child to walk than roll, speak than sign, read print than read Braille, spell independently than use a spell-check, and hang out with non-disabled kids as opposed to other disabled kids” (Hehir 3). The story begins with a comment, “there were no flowers when Rowan was born, it was nothing personal, I don’t think,” suggesting that Rowan’s birth is not celebrated by the world. The mother points out the attitude of society towards disability, which is to look at it with fear, “a deep paralytic fear, which nobody could never quite explain” (Mills 00.38-00.42 secs). And because disability is seen as something that needs to be cured, and because life with disability is seen as an un-preferred state of existence, tragic and pitiable, the medical experts are quick in their attempt to fix Rowan’s deformity. Even before she feels her mother’s touch, the baby is already familiar with the rubber gloves of the doctors

who perform tests and scans on her new-born body in order to find means of curing her disability. While the doctors are trying to fix her abnormality, the mother catches sight of the baby's gaze and feels as if the baby is accusing them of wrong doing. Perhaps, the new-born baby, unable to give her consent and her tiny brain untainted by society's influence, finds nothing wrong with having a disabled body. Her mother too, comments that Rowan's disability is not her primary concern, only an afterthought. Strongly dismissing the myth of cure, the narrator mentions that Rowan's protruding bones cannot be operated on because they are not made of "the rubbery tumorous flesh (they) anticipated, but pure sinew and bone" (2:45). They are "rock solid, permanent" and as Rowan herself, "unapologetic for their existence" (2:54 - 3:00). The story also depicts Rowan's changing attitude towards her disability. As a child, she is perfectly fine with the protrusion in both her shoulder blades. One time, a boy in the playground points out that she has wings and mocks them by flapping his arms. Then everybody in the playground turn to look at her. The child Rowan, as if approving the comparison of her deformity with wings, says "yes," and laughs at the boy's imitative flapping. People's fascination with Rowan's "wings" increases and they start to call her a "real life fairy" (4:51). Their fascination then turns in to curiosity and swarms of reporters constantly follow her at home, school and park. Rowan never talks about how she feels about the public obsession with her, but on her twelfth birthday, she takes a kitchen knife and tries to cut off the lumps on her back. Maybe because the ableist fixation on her physical difference gets to her as she gets older, the positive attitude Rowan feels towards her disability as a child turns into a source of "agony" (5:56) in her preadolescent years, and living with her, her mother feels a constant "cold, nameless grief" (6:19). In her teenage years, Rowan begins to develop a sort of resolve. Though her body crumbles under the weight of the wings, though she can barely walk and her skin bruise at the touch, her mind remains "determinedly fixed on some invisible horizon" (6:41-6:42). And though she maintains her playful and charming personality, her mind has "flown somewhere distant" (7:07). Her eyes fill with an "aching nostalgia" (7:17), and without giving a reason, she tells her mother that she could not stay. On her eighteenth birthday, her mother finds her room empty, it seems she has flown out the window of her room. Literally and figuratively, Rowan has left her nest to be out in the world to be on her own. The short story ends with a remark that Rowan is unchanged, and "flying at last, like she was meant to," with wings "wide and resplendent," and "her sepia eyes twinkling with laughter" (8:18 - 8:22). Though there were no flowers the day the disabled girl was born, she is now "always draped, head to toe in flowers" (8: 23 - 8:26). The world may not celebrate the disabled girl, but she drapes herself with strength, beauty and positivity. Her disability needs no fixing, she is happy and content with life, and competent to live alone.

5. CONCLUSION & RECOMMENDATIONS:

Disability can be considered as the largest marginalized group in the world, and in each marginalized groups, there are disabled people. It is a unique condition in the sense that people can enter and leave the experience of being disabled at any point in life. According to Nario-Redmond, this "open enrolment" of disability explains why "ableism has been such a contentious topic, even among the experts who study stereotyping and prejudice" (4). Chodorow explains that devaluing disability and privileging ability is so pervasive that ableism becomes a "permissible prejudice" (para. 2), which allows ableism to operate "below our cultural radar and remains socially acceptable" (Derby 106). This can result in the disabled person internalizing ableist ideas and view their own lives as "tragic," "defective," and "in need of cure" (Nario-Redmond et al. 727). "The Changeling" and *This is Not a Love Scene* both demonstrate the ways in which ableism operate under the social radar. It caused embarrassment and shame for Maeve and almost result in Rowan's death. This kind of ableism as described by scholars of Critical Disability Studies, which operates under the radar is seen in even highly celebrated and popular young adult literatures featuring disabled main characters such as T.V. Padma's *A Time to Dance* (2004) and Francis X. Stork's *Marcelo in the Real World* (2009). Though the books may authentically represent disabled experience, the protagonists both change in some major way or recover from their disability by the end of the novels, reinforcing the idea that people with disabilities must overcome their limitations. "The Changeling" and *This is Not a Love Scene* on the other hand, dispel stereotypical tropes and ableist analogies. Rowan' does not need to be fixed to be metaphorically adorned with beautiful flowers, and unlike the "super cripp" protagonists of many books with disabled characters, Maeve remains unapologetically ordinary.

Rudine Sims Bishop stresses that children use books to reflect on their own lives as well as see into the lives of others and "When children cannot find themselves reflected in the books they read, or when the images they see are distorted, negative, or laughable, they learn a powerful lesson about how they are devalued in the society of which they are a part" (Bishop 1). She explains that books serve as "mirrors" when readers see themselves represented in the pages; "windows" when they enable readers to gain understanding and empathy for the experiences, lives and cultures of other people; and "sliding glass doors," when readers feel transported into the world of the book and feel empathy for the characters. Emphasizing the importance of correct representation, Toliver explains how "broken mirrors" (2) may reflect inauthentic representation of marginalized people which can be internalised by readers.

It is the hope of the paper that it brings to light how ableism may appear in literature and hopefully influence our reading and understanding of disability experience. It may also help us identify problematic tropes and ableist metaphors. It hopes to show, through disability representation by disabled authors and disabled protagonists that, it is perfectly okay to not be okay, whether physically or mentally. Disability is not the singular defining factor of a person. As written words have the power to shape a society's idea of normalcy, authentic and positive representation of disability in literature will hopefully help young readers with disability to internalize the notion that being disabled is not inherently bad, and that it is a diverse and extensive identity marker.

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