



Understanding Identity and Disability in the Middle-grade Novel *Caleb and Kit* by Beth Vrabel

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Abstract

Children's literature has long been associated with key ideologies and morals for children. Through literary themes, children will learn how to perceive themselves and their surroundings. Beth Vrabel's book Caleb and Kit (2017), which features Caleb as a kid with cystic fibrosis, explores identity and disability, two important themes in this children's literature. These two important themes are analysed using Critical Discourse Analysis (CDA) with critical sociocultural approach by Moje and Lewis (2007) to examine identity in literature and disability model's framework to analyse disability representations and the relation to the protagonist's identity. This study portrays a child's experience with disability by examining the main character's words, actions, and interactions, revealing how both condition and environment alter identity and relationships throughout time. The study finds that the portrayal of disability is multidimensional, shifting as the narrative progresses, emphasizing the dynamic aspect of the character's experiences. Two popular disability models, medical and social, are utilized to investigate the various aspects of disability experience, as reflected in the characters and narrative. Long-standing criticisms of these two paradigms are included in the story, impacting how the characters see disability. This study suggests that both disability models operate best when used together as a full framework for critically analyzing the constructions of disability identity in children's literature and assisting the reader in understanding this issue in their surroundings.

Keywords: Identity; Disability; Children's literature; Caleb and Kit

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Introduction

Children's books are particular kinds of literature that play a significant role in building childhood. This type of literature is used for different purposes. Some are "good"

time pass-the-time activities; others are "good" for learning literacy; still, others are "good" for developing general (or particular) social attitudes; "good" for handling issues or coping with problems; "good" for reading in that "literary" way that is a small part of the

adult culture; or “good” for handling racism, and many books perform multiple of these actions (Hunt, 2016). Drawing on the fact that one of the aims of children’s literature is to help children deal with concerns or cope with challenges, it is important to address critical issues so that children can reflect on their environment. According to research published on the Horn Book Website (2021) by the Cooperative Children’s Book Centre, just 3.4% of novels include a disabled main character. This indicates that, among all the diverse themes, the disability topic is underrepresented. This overlooks the crucial role of literature in depicting disability as it not only documents disability but also shapes attitudes toward it (Hall, 2016). This is especially important in the case of children’s literature because children can obtain alternative perspective on appreciating and respecting individual differences and the significance of being aware of the problems that affect people with disabilities (Kurtts & Gavigan, 2017). In other words, disability theme is important in children’s literature because it can help children develop appreciation for diversity and individual differences in their surroundings. For disabled children, it can foster a sense of belonging and lead to an empowerment.

Numerous scholars have sought to evaluate disability representation in children’s literature. Curwood’s (2013) analysis, using socio-critical approach to literary analysis, depicts how young adult literature portrays disability characters realistically from the first-person perspective and suggests how this literature should be read and used by teachers to promote disability awareness. Sugiarto (2020) identifies problematic representations in children’s books and short stories through literary analysis. Freeman (2020) critically examines the discourse on disabilities in contemporary young adult literature and how it affects the reader’s identity. Faeth (2021) further analyses how literature has conceptualized disability by embracing the character’s complexity through discourse analysis and disability theory. Finally, a study by Roshini and Rajasekaran (2022) examines the differences in the portrayal of disability in two children’s literature *Heidi* by Johanna Spyri and *Rules* by Roshini Lord, respectively

from nineteenth century and twenty-first century. The study found the totally different depiction between the two literature, disability depiction in nineteenth-century novels is tragically pessimistic, while disability representation in twenty-first-century novels is more inclusive and realistic.

All of the aforementioned studies agree on going beyond the surface level analysis of literature. They employ a critical approach such as discourse analysis and literary analysis to analyze how the pattern, stereotype, and ideologies of disability is portrayed in children and young adult literature. Across the board, these studies also advocate for literature that portrays disability in a way that is inclusive, realistic, and empathetic. This study extends the previous studies by combining 3 critical approaches: Critical discourse analysis, sociocultural approach to literacy research, and disability framework to investigate disability in children’s literature “Caleb and Kit” that is nominated for Cybils award for fostering inclusive representation. The methods and the selected text are what set this research apart from the previous studies. In contrast to earlier research that mostly uses one critical approach, this study combines three analytical techniques to offer a more thorough and multifaceted analysis. Furthermore, although a large portion of the literature currently in publication examines a wide variety of texts, this study focuses exclusively on award-nominated works that claim to promote inclusivity, critically evaluating whether or not they actually support realistic and sympathetic representations of disability. This study aims to investigate whether the novel’s language, context, and narrative effectively advance inclusive ideals, particularly in works nominated for their portrayal of disabled characters and their complexity. To explore this, the study addresses two main questions: first, how can the theories of Critical Discourse Analysis (CDA), critical sociocultural methods, and disability frameworks provide insights into the portrayal of disability in the novel? Second, how does the novel engage with and promote disability models to depict the experiences and identity of a child with a disability as well as societal attitudes toward disability?

Methodology

This study examines the issue of disability in the middle-grade novel *Caleb and Kit* by Beth Vrabel using three theories: Critical Discourse Analysis, a Sociocultural Approach, and a Disability Framework. This novel is a finalist for Cybils Award in 2017, which recognizes books that promote diversity, inclusivity, and a realistic portrayal of children and teenagers. This book features a main character that has a disability and the story is told from the first-person point of view. Inclusive literature that wins or is nominated for such awards typically receives widespread attention and has a considerable influence on public opinion. As a result, the goal of this research is to determine how the novel shows inclusivity in its representation of disabilities, as well as how the book promotes understanding, challenges preconceptions, and aligns with the principles emphasized by the award.

This study uses Critical Discourse Analysis (CDA) to investigate the novel's underlying ideology and meaning, especially regarding disability depictions. CDA is used in this study because it provides a framework for investigating how language and narrative structures reflect societal attitudes regarding disability. This approach allows for a more in-depth understanding of how the novel constructs conceptualizations of disability by examining the words and phrases used to describe the disabled characters as the main protagonist, his experiences, and his interactions with family, friends, and the larger community.

Drawing on van Dijk's 2001 approach, the CDA was applied in Glenn's (2008) and Curwood's articles (2012), in which the text was read three times and coded to ensure that meanings were derived from each text and not artificially bridged by the researcher. During the first reading, the text is read to gain a broad understanding of the plot, characters, and themes. During the second reading, the text is critically analysed and coded for key themes: identity and disability. During the third reading, specific textual evidence that supported the themes and verified that the themes are present within the novel is noted.

Critical sociocultural theory (Moje and Lewis, 2007), cited by (Curwood, 2013), is an approach to critical literacy that analyses identity, power, and agency that are fundamental in learning and literacy practices. The theory is used to highlight identity development and moment of agency and power in the novel *Caleb and Kit*, which comprises the following questions:

- Which character embodies or expresses a disability?
- How does the author integrate disability into the storyline? Is it evident in the character's thoughts, words, or actions?
- How does disability shape the character's identity? What other factors come into play as the character makes (and remakes) his or her identity?
- How does the character's disability impact the way other characters perceive or respond to him or her?
- Who has power? How does that change as the plot develops?
- How does the setting of the novel influence characters' identities?
- For a character with a disability, where are the moments for agency within the story?

Considering these questions is crucial as a guide for in-depth literature analysis, as it provides insight into how authors build narratives about disability and represent disability. These inquiries will reveal how identity, agency, and power operate in literary literature as works that promotes inclusive representations.

Finally, disability framework is used to understand the concept of disability in the novel and how it will shape the reader's understanding and attitudes toward disability. Two disability models are used to analyse disability in this novel. The first one is medical model that considers disability a result of impairment of physical functions and structures, including the mind. It can be caused by illness, injury, or health problems (Forhan, 2009). The second one is social model that views disability as a consequence of the environment that creates barriers for people to engage fully in society (Preston, 2010).

Results and Discussion

The analysis is divided into two sections. The first explores identity in the novel using CDA and sociocultural approach. The next section examines two disability models as a fundamental foundation for viewing constructions of disability in a society represented in the book. The most prominent disability models, namely the medical and social models, are explored to understand the formation of disability and the crucial identity of the character with a disability.

1. The Identity in *Caleb and Kit*

In the novel, the main character Caleb serves as a character that embodies disability since he has cystic fibrosis (CF), a progressive illness that limits him in his activities at home and school. This type of disability is also referred to as invisible disability since the impairment is not visible to others. This disability is evident in Caleb's descriptions of himself, his dialogue with others, and his actions reacting to his own and others' views of his impairment. The novel portrays how disability is Caleb's salient identity at the start of the narrative, with details of his disease and how he believes his brother is wonderful because he does not have the condition. There are numerous descriptions of how his lungs function from his own point of view and how he fails to be taken seriously in the sport. As the story progresses, his identity will be redefined as Caleb encounters new friends and situations. In the novel, identity is reflected through discourse in the narrative in which Caleb describes himself and his dialogues with other characters.

a. Caleb's Identity at Home and School

At the start of the narrative, Caleb's identity is significantly shaped by his disability, much as if his entire existence revolves around it. It is evident through how Caleb frequently portrays himself as weak and vulnerable, two characteristics that are associated with him. It can be seen through this excerpt from the novel where Caleb tries to guess Kit's impression of him.

I knew why. I didn't look like a twelve-year-old. I was sort of like Chris Evans at the beginning of the first Captain America movie—the part before the scientist gave Steve Rogers the elixir of super serum and he was just frail looking and scrawny. I'm too short and way too skinny for my age. I'm so used to the air fighting its way out of me that sometimes I forget to close my mouth when I breathe; Patrick says it makes me look like a toddler with my stomach puffed out and mouth hanging open. (Vrabel, 2017, p. 17).

The excerpt above suggests that Caleb sees his condition as a tragedy of not looking like any other 12-year-old child. His physical characteristics are related to fragility and weakness with the choice of words such as short, skinny, frail-looking, scrawny, etc. Caleb describes himself with the phrase "too small and too thin" for his age, implying a comparison or a perception of being less than what youngsters his age should be. As someone with CF, it is hard for Caleb to breathe because of the sticky mucus in his lung. Caleb portrays his troubled respiratory system with the words "fighting its way out of me", which signifies a struggle. The fact that he said, "I'm so used" implies that this condition has been stuck with him all his life. This description implies that disability becomes salient in his identity since he has to mention it when describing himself or trying to see himself through the eye of others. When thinking about himself, he focuses on his distinct physical appearance, health problems, and respiratory challenges.

Moreover, these descriptions reflect Caleb's negative identity as he visualises himself as the pre-serum Captain America, which Chris Evans plays. Before being given a super serum, the character was skinny and had several health problems similar to Caleb. Pre-serum Captain America serves as Caleb's reference as he associates himself with pre-serum Captain America when describing himself. This reference then signifies his identity relating to his disability, which aligns with the impressions of weakness.

Regarding his identity, Caleb receives two different views from his parents: while his

mother accepts the disability, his father does not. This is an important factor in how the character's identity is reflected in the novel because people typically internalise their perspectives through direct interaction with their significant others (Harry Stack Sullivan & Mullahy, 2013), who are important to them. Significant others typically include family, close friends, or community members. For the case of disabled children, they are more likely to be dependent on their parents; hence their views toward themselves are likely to be shaped by their parents. In Caleb's case, although his mother is the significant other that accepts Caleb's disability, it seems that by acting overprotective, she reinforces the stigma and the societal perspective toward disability. It can be seen in the passage below; Caleb's mother emphasises his impairment through her protective attitude.

"And I have more concerns than the typical nervous mommy. My son has cystic fibrosis, which means he needs quite a bit more attention than simply being around someone who is CPR certified, although that is certainly lovely. Caleb's lungs are filled with thick, sticky mucus and easily become infected. He's going to cough a lot—and that's a good thing. The not coughing is when we need to be concerned. He also has to eat all of his lunch." (Vrabel, 2017, p. 47)

His disability makes his mother perceive him as a kid that "needs quite a deal of attention," making Caleb feel different. Caleb responds uncomfortably, saying, "I'm twelve years old. I can tell her what I need." (Vrabel, 2017). According to Bîrneanu et al. (2016), disability often causes parents to be overprotective, to the point of overlooking the child's true needs. Instead, they are projecting what they believe is best for the children. As a result, the child is perceived as reliant, which leads to debilitating rather than enabling. In the novel, the protective attitude from his mother even emphasises the normalcy narrative in which Caleb does not fit the other 12-year-old.

Along with his mother's protective attitude, Caleb's father, who resents his illness, also has an impact on his identity. Caleb's

father pushes him to be like a normal twelve-year-old boy, despite his disability. This reactions to children's disability might be seen as advocacy, setting high expectations, or rejecting stigmatizing labels (Lalvani, 2015). According to Rosalyn Benjamin Darling (2013), Children who are unable to live up to their parent's expectations are less likely to think highly of themselves. It is more likely for children with disabilities to struggle to be the ideal children their parents envision, perhaps resulting in lower self-esteem. This is apparent from Caleb and his father's relationship, as seen in the dialogue below when they talk about Caleb's behavior.

He, too, scooted forward. "Caleb, listen to me. You're old enough to understand that you are not the center of the universe. Man up. Your brother never had any trouble being a decent human being. Time for you to do the same." (Vrabel, 2017, p. 207)

The dialogue above shows how Caleb's father pushes him to be the ideal kid. By comparing him to his brother, a kid with no illness or disability, Caleb's father expects and pressures Caleb to be normal and ideal. The opposing treatment Caleb gets from his parents as his significant others causes Caleb going through a dilemma about what identity he should acquire and what actions he should take regarding his disability. However, one evident thing is that both parents emphasise the feeling of difference in Caleb, resulting in him viewing his identity more negatively.

In the novel, Caleb also receives both special facilities and treatment in school. His class has air conditioner to accommodate Caleb's condition. However, it become a backlash for Caleb because he felt different because of this, even some of his friends make fun of Caleb. This shows despite an increase in inclusive schooling practices, negative attitudes about disability and their adverse effect on the social, emotional, and intellectual development of children with disabilities persist (Mueller, 2019).

Caleb seldom participates in sports since everyone believes he is too fragile to play properly. The excerpt below shows how Caleb is not treated fairly in sports.

*His hands were still curled into fists.
"Why'd you tackle him?"
"It's football," Jett countered.
"It's Caleb," Brad spit back.
Instantly I was ice-water cold. I stepped
back. Twice. Then I turned and strode off
the field. (Vrabel, 2017, p.28)*

The excerpt above indicates that when Caleb's best friend, Brad, says: "that's Caleb," it is more than just a name; it also indicates that Caleb's disability is encoded in his name. In this dialogue, Caleb is stunned because he does not expect even his best friend to pity him by seeing disability in his name and confirming that he should get special treatment because of his disability. This reaction shows that Caleb as a disabled kid, has trouble getting fairness in his life; it is always a pity or patronised reaction from other people. After this encounter, when Brad tries to explain that he is just trying to help Caleb, he realises that all this time, people have treated him based on his disabilities or abilities. It causes a negative sense of identity in which he feels inferior. He feels that disability always comes first in his life, both from other people perspective and his own perspective. His disability makes Caleb's school friends perceive him as weaker, and he should not be taken seriously in sports. This strengthens Caleb's belief that he is excluded, different, and more vulnerable than his friends.

The analysis of language used to represent the disabled character's perplexity, despair, and interactions indicates how the novel's discourse challenges the stigma associated with disability, which is perceived as simply one element. This study demonstrates that, in addition to internal issues, external circumstances can influence a character's disability-related identity. This study verifies previous research by Faeth (2021), which discovered how environmental changes can impair people by restricting their ability to participate. Because surroundings can quickly change from accessible to disabling, categorizing a situation as "disabling" or "non-disabling" is challenging. This is evident in the use of Critical Discourse Analysis (CDA) to examine word choices in the main character's descriptions, which often carry negative and

weakening connotations of his disability. Additionally, dialogues with other characters reveal instances of discrimination, further emphasizing how society beliefs influence the formation of disability. Many instances in the novel that force Caleb to positions as disabled, both from his family and his friends at school. The combination of protective attitudes from his mother and friends, as well as a sense of alienation from his father, makes disability become his primary identity. His family and friends influence him to view his disability as a defect. He internalises his isolated sentiments as an odd twelve-year-old that does not belong to any group, resulting in low self-esteem. As a result, at the beginning of the novel, Caleb's identity toward his disability at home and school is shameful or negative.

b. When Caleb Meets Kit: Identity Transformation

Identity is not static; instead, it is an ongoing process (Bogaerts et al., 2018). In this novel, Caleb goes through several process to navigate his experience living with chronic illness.

In the book *Disability and Identity Negotiating Self in a Changing Society* (2019), Strauss (1962) introduced the concept of turning points to describe situations during which individuals are exposed to new significant others. This situation involves learning new roles and, often, acquiring new identities. When Caleb meets Kit, a girl who lives in the home inside the Daviss, his identity begins to transform. Kit served as Caleb's turning point or his new significant other, and he may gain a new perceptive and identity from her. When Caleb first meets Kit, he is anxious about what Kit would think of him, but it turns out that Kit does not perceive Caleb any differently and makes his disability something to identify him with. This is evident from the excerpt above:

"You don't understand," I mumbled. I hadn't exactly told Kit about having CF. I coughed a lot during the day, but she didn't mention it or say anything about the pills I swallowed with lunch. I liked that about her. She treated me like I was normal, just like her. (Vrabel, 2017, p.105)

At home with his family and at school with his school friends, Caleb internalises a negative value about his own identity that he believes centres around his impairment. Living a protected and limited life, Caleb, who has reached a rebellion phase, begins to search for freedom. His encounter with Kit gives him the freedom and adventure he has been looking for. They live in quite the opposite household in which Caleb is overly protected, and Kit has no parental supervision. The friendship with Kit encourages Caleb to be more confident, believing he is a person first before his disability. With Kit, Caleb feels liberated and welcomed as someone different from his life. By spending time with Kit, he redefines his identity in which he does not associate disability as a part of his identity anymore because Kit does not recognise it as a part of himself. He also gains more control over his life by wanting to conduct the tasks independently.

However, the friendship requires deception, such as lying to Caleb's parents, in which he spends time with Kit instead of going to the summer camp. Eventually, there comes a point where they are being denial about Caleb's conditions. The way Kit is into fairytales and imagination leads to deceiving the reality that they are facing. For example, Kit believes that Caleb simply lives in the wrong society, which makes him disabled. This leads to Caleb's realisation that living by denying the reality led to danger. In the case of his illness, ignoring his disability harms his health because Caleb often engages in unsafe activities for CF people, like getting pushed into the river and running intensely during his playtime with Kit. Caleb's friendship with Kit feels deliberating at first, but eventually, it also causes bad consequences in Caleb's condition and perceptions toward himself.

The story ends with Caleb becoming self-realized and choosing mature decisions for himself. After Kit is rescued from his abusive mom and sent to another place, Caleb and Kit are separated. Despite returning to his normal life, where he has to be surrounded by protective people, Caleb decides to be critical of his society regarding how he perceives his identity and disability. Referring back to the guiding questions by Moje and Lewis (2007),

the moment of agency occurred when Caleb narrates, "I'd like to say the whole cafeteria quieted as I walked in, waiting to see where I'd sit, but the truth is, no one seemed to notice." (Vrabel, 2017, p.179). Caleb used to feel very limited and concerned about his disability and that everything he does will be noticeable to people because of how different he is. Ultimately, it shows that Caleb realises he does not have to focus on his disability. He decided to stop positioning himself in the spotlight or see the difference in himself.

Furthermore, there is a dialogue with his classmate Shelly in which she asks Caleb, "no one put you up to this?" when Caleb sits next to her during lunch. Caleb responds, "No, I wouldn't do that"." besides, I do what I want" (Vrabel, 2017, p. 254). Caleb's response signifies the agency and power that Caleb has. Caleb now decides for himself; he will not let anyone dictate or control his life.

The sociocultural approach considers the broader societal and cultural contexts that influence how disability and identity are represented in a text. As demonstrated by Curwood (2013) in his study, this approach revealed how narratives can take readers on a journey of self-discovery through the eyes of the characters. Similarly, in the selected novel, a comparable journey unfolds. At the beginning of the story, the main character's identity is largely shaped and controlled by external forces, such as parents and friends, who hold power over how the character perceives themselves and their place in the world.

As the narrative progresses, however, we witness a significant shift in the character's identity. Gradually, the character begins to take ownership of their identity, moving away from external definitions imposed by others to a more self-defined sense of self. This transformation highlights the evolving dynamics of power and agency within the character's life, reflecting a deeper exploration of identity and self-acceptance.

2. Image of Disability: Disability Models in Caleb and Kit

There are two prominent models of disability: the medical and social models (Faeth, 2021). The medical model conceptualises disability as a tragedy or problem within a person's body or mind that medical professionals should attempt to solve (Beaudry, 2016). It defines disability by focusing on the biological differences and impairment of people with disabilities. The social model of disability, on the other hand, distinguishes between impairment and disability, defining disability as a disadvantage caused by a disparity between a body and its social environment (Goering, 2015). It sees disability as a societal construct rather than individual condition (Lukins et al., 2023). In short, it views disability as something caused by society.

Disability models contribute to a more inclusive and accurate understanding of disability within the literature context. Although individuals think, feel, and understand disability in unique ways, models help explain collective perspectives and, often, the policies and practices they inform (Ladau, 2021). In this case, we can gain understanding of how Caleb's disability is perceived throughout the novel both by himself and by his environment. Medical and social model of disability are featured throughout the novel and are important in understanding how disability as a component of Caleb's identity is developed. This novel also offers some critics of viewing disability through the medical and social models separately from the narrative and Caleb's character

This novel engages with both the medical model and the social model of disability through the lexical choices, the novel addresses impairment and the idea of "fixing" as part of the characters' experiences, reflecting the medical model. For example, the narrative digs into the main character's physical problems and efforts to "be normal" by undergoing procedures. However, the narrative does not revolve only around disability as a personal struggle to overcome. It uses the social model of disability to represent outer hurdles, rejection, and

discrimination in the character's environment. It underlines how societal attitudes, discriminatory practices, and physical inaccessibility cause the challenges that the characters. The complexities of disability are shown in this novel by the integration of these two models.

a. The Medical Model

According to the medical model of disability, disability is considered to be a result of impairment of physical functions and structures, including the mind. It can be caused by illness, injury, or health problems (Forhan, 2009). Disability, both mental and physical, is considered a condition that must be medically treated for people to participate in society (Brandon & Pritchard, 2011; Forhan, 2009; B. A. Marks, 2000). This normative viewpoint implies that persons are regarded as disabled because they are unable to perform in the same way that supposedly normal person does (Mitra, 2006; Roush & Sharby, 2011.) This model also generally addresses disability via a deficit lens (Connor & Olander, 2020), concentrating on what a disabled person "cannot" achieve rather than their strengths and talents. Medical paradigm may be seen in this excerpt from the novel.

They had just found out their kid had cystic fibrosis. Their minds were probably stuck on phrases like stunted growth and frequent hospitalisations and, most especially, shortened lifespan. I remember the gut punch I felt the first time I googled CF and read: Patients who live until adulthood have a median predicted survival age of forty. When we left an hour later, I still heard crying from the baby's room. But it wasn't from the baby. By the way, I had barely grown half an inch. (Vrabel, 2017, p.59)

Caleb's perception of himself and his condition is consistent with the medical paradigm. First and foremost, the terminology he uses to explain cystic fibrosis and its effects is precisely medical, using terms such as stunted growth, hospitalisation, and survival age. This lens actually allows Caleb to understand and become aware of his condition that is impacting his daily life. However,

medical model causes our main character to let his deficits become the major emphasis in himself as stated in the last line of the excerpt above, "I had barely grown half an inch.". It shows how Caleb allowed disability to be the major emphasis in himself by focusing how he did not get taller physically rather than his other development as an individual.

In the medical model, treatment for people with impairments is focused on eradicating or correcting the problem (Bingham et al., 2013; Forhan, 2009). This model emphasises medical experts to fix the impairment. In this novel, this element of the medical model is shown through the passage below.

Maybe someday doctors will figure a way to fix that whacked-out gene and my body will stop being a mucus factory. Until then, I have to take my meds and wear this vest. All that rumbling helps break up the mucus. The nebuliser medicine I breathe in makes my lungs open up a little. Then I cough out the gunk. The whole thing, I realise, is kind of gross. (Vrabel, 2017, pp. 61-62)

From the excerpt above, Caleb's projection toward his disability, which pertains to the medical model, influences how he views his body. "Maybe someday physicians will figure out a method to correct that messed-up gene and my body will cease being a mucus factory," he says, expressing his wish that his body would return to normal. The medical model posits that the primary objective is to restore physiological or functional systems to a state as close to "normal" as feasible. In this paradigm, individuals with disabilities are expected to listen to the recommendations of medical experts, as the model frames disabilities primarily as internal impairments that require external interventions for effective treatment (Shyman, 2016). This is clear from the line, "Until then, I must take my medicines and wear this vest."

This novel implies critics to the medical approach that highlights isolation, stigma, and poor self-esteem toward people with disabilities (Hogan, 2019). The focus of Caleb's attention on his inadequacies and struggles rather than his strengths demonstrate the

model's detrimental impact. As mentioned in the previous excerpt, it reflects his low self-esteem.

Furthermore, the medical model of disability regards disability as an impairment that must be addressed to function normally. The medical model implies that the disabled person's autonomy is restricted owing to the impairment; hence, if medical practitioners are unable to heal or rehabilitate the individual, they are seen as having a limited ability to engage in society. As a result, a person's impairment may, in some instances, hinder participation, leading to social exclusion (Bunburry, 2109). This aspect is demonstrated in this work via this excerpt:

*"I know." I shrugged, fighting to keep my voice neutral. "Always wondered why no one ever tackled me."
Brad didn't say anything. He just breathed out long and slow when I stopped striding off the field. "It's not like it's a rule or anything," Brad said. "The guys, we just try not to knock you around too much. (Vrabel, 2017, p. 29)*

Caleb was playing football with his pals in the excerpt above, but he gained the "special" treatment since his friends did not take him seriously in the game by not tackling him. Caleb feels alienated and pitied due to his disability, which prevents him from feeling confident when participating in sports like the other kids

b. The Social Model

According to Shakespeare's article (2001) in Disability Study Reader (Davis, 2016), the social model demonstrates that the problems disabled people face are the result of social oppression and exclusion, not their individual deficits. Caleb's perception of himself as different, as seen in the first excerpt in which Caleb says that "I knew why. I didn't look like a twelve-year-old" (Vrabel, 2017, p. 17), is also impacted by the social model of disability since he judges himself based on the prejudices and labels that others have assigned to him. Negative stereotypes, discrimination, and oppression serve as barriers to environmental change and full inclusion (APA). Caleb is

disabled because others have always commented that he does not look like a typical twelve-year-old boy as a kid at the camp said, "Caleb's shorter than the fourth grader in front of him.". He is disabled because people around him always label him as someone who needs special attention, making him feel different and uncomfortable.

One key element of the social model is that society has to remove all physical and psychological barriers for disabled people. The special facility that Caleb has as a result of his disability is one example in this novel that apply this model. This story illustrates the social model through Caleb's facility, showing how a society must create facilities for disabled people to provide a more inclusive environment, like Caleb's classroom has an air conditioner to keep the air from getting too humid, which could harm his lungs. It is also reflected in his interaction with Kit when she said that he should be able to do what he wants because, all this time, his mother has decided all of Caleb's decisions and identity.

Another key element is that the social model places the moral responsibility on society to remove the burdens which have been imposed and to enable disabled people to participate (Davis, 2016). From this perspective, addressing disability is to change the environment and society rather than people with disabilities. The social model is reflected in the way that Kit blames society for Caleb's disability. This enhances Caleb's self-esteem because he finally finds someone who does not see the deficits in himself but in society. Caleb's friendship with Kit feels empowering initially, but eventually, it leads to a disadvantage for Caleb regarding his identity, which will be explained next.

Despite the seemingly positive impacts of the social model, this model also has drawbacks. Tom Shakespeare, an English Sociologist, has emphasised in his article titled *The Social Model of Disability* (2001) that one of the flaws of the social model is that it regards disability as being conditioned solely by social factors without considering the person's impairment. This is a gap because both impairment and social factors render a

person disabled. The interplay of Caleb and Kit exemplifies this.

"I'm sick. It's all right. Maybe they'll find a cure. I mean, I'm better than I was."

I shoved my hands in my pockets and glanced toward the trail leading back home "You're not sick!" she yelled, but she already was a yard away, stomping to the side of the stream and scanning the woods. She dried her face angrily with her palms. "We just need to find the right place. They owe us, Caleb. They owe me!" (Vrabel, 2017, p. 242)

From the excerpt above, there is a conflict between Caleb and Kit. When Caleb realises that he can no longer live in a fairytale or imagination where he has to ignore his disability, he decides to make Kit understand of his illness. However, we can see that Kit dismissed Caleb's condition, claiming that he does not have the illness and is simply in the wrong place. Kit represents people that subscribe to the society model and think the social factor is the only cause of disability. When Kit says, "We just need to find the right place," Kit tells Caleb that he has been living in the wrong place where decisions are made for him by either his best friends or his family, including whether he has a disability or not. This portrays how the social model often neglects impairment as an important aspect of disabled individuals, especially those whose impairment causes chronic pain, like Caleb's case. In the sense of identities, neglecting impairments leads to a problem where disabled people struggle to present themselves.

Beth Vrabel's (2017) book *Caleb and Kit* exemplifies how children's literature engages and promotes disability models. The reader can observe from Caleb's character that both his body and his environment cause his impairment. As a cystic fibrosis child, his awareness of his own illness reflects the medical paradigm of disability. Furthermore, the oppression and discrimination he receives from others around Caleb demonstrate that disability is a representation of other people's prejudices toward a person with a disability which is the key principle in the social model of disability. Furthermore, by providing a

critique of both models proves that disability is detrimental when viewed from only one separate model because models of disability are detrimental when social and medical models are not two viewpoints that should be separated, forcing individuals to utilize just one when evaluating disability (Gallagher et al., 2014).

Conclusion

This article examines two fundamental concerns in children's literature, identity, and disability, utilizing a nominated novel known for encouraging inclusiveness. The study used Critical Discourse Analysis (CDA) to demonstrate how the author's initial language choices for the protagonist reflect the significant influence of his illness on his identity in a variety of social contexts. This is obvious in the protagonist's speech, behavior, and relationships with others. Caleb characterizes his identity at the beginning of the narratives in terms of how his disease affects him, which tends to be negative. He is also regularly wounded when people notice how different he is; those around him also talk to him about his disability, making him feel isolated. The sociocultural method investigates how societal norms, cultural expectations, and power dynamics influence the portrayal of disability and identity in a book. This study found that external elements, such as the opinions of friends and parents, initially shape the protagonist's identity. As the novel progresses, the protagonist acquires agency and redefines his own identity, asserting more control over how he sees himself. This method highlights how the book confronts stigma by portraying identity and disability as fluid rather than fixed. The novel engages with medical and social models through the lexical choices and the narrative that focuses not only on overcoming the disability but also on drawing attention to the barriers in the environment that cause Caleb to be disabled. These barriers are contextual and often linked to society's lack of understanding. It implies that the author is trying to craft such narratives so that the reader can identify the perceived causes of disability and understand that none of the models is sufficient in its way. In doing so, the narrative advocates for a more

nuanced understanding of disability that goes beyond conventional paradigms.

A detailed analysis of the protagonist's changing identity and the interaction between medical and social theories of disability in the book is made possible by the integration of Critical Discourse Analysis, the disability framework, and the sociocultural approach in this study. Caleb's complexity as a character is highlighted by this view, which also highlights how his disability can either be a major aspect of his identity or one of many factors shaped by societal and environmental influences. The complexity of the character's experiences and identity aligns with the award's claim of fostering inclusive portrayal. By portraying a dynamic character who experiences discrimination, frustration, and anger, the text reflects the nuanced reality of disability. This also supports previous research emphasizing the need for children's literature to depict characters with depth, challenging stereotypes and promoting greater understanding. These representations contribute to the broader discussion on disability identity, reinforcing the importance of authentic and multifaceted portrayals. Such portrayals allow for a richer exploration of how disability intersects with personal and social identity, moving beyond simplistic or one-dimensional narratives. Future research could build on this foundation by investigating varied literary works, employing other discourse strategies, and incorporating recent disability models to understand further how contemporary literature, which has also won awards, depicts disability and identity. This continued exploration can further enhance the conversation around representation in literature and its impact on both readers and society.

References

- Beaudry, J.-S. (2016). Beyond (models of) disability? *Journal of Medicine and Philosophy*, 41(2), 210–228.
<https://doi.org/10.1093/jmp/jhv06>

- Bîrneanu, A. G., Alexiu, T. M., Baciu, E., Sandvin, J. T., & Fylling, I. (2016). The Role and Influence of Family and Community Relations on the Disabled Persons' Labor Market Status: Perspectives of Disabled Individuals and Family Members. *Revista de Asistență Socială*, 57–80.
- Bothwell, J. (2011). *Portraying Disability in the Modern Novel: Identity, Subjectivity, and Power*. [Master's thesis, Athabasca University].
- Brandon, T., & Pritchard, G. (2011). "Being fat": a conceptual analysis using three models of disability. *Disability & Society*, 26(1), 79–92.
<https://doi.org/10.1080/09687599.2011.529669>
- Bunbury, S. (2019). Unconscious Bias and the Medical model: How the Social Model May Hold the Key to Transformative Thinking about Disability Discrimination. *International Journal of Discrimination and the Law*, 19(1), 26–47.
<https://doi.org/10.1177/1358229118820742>
- Connor, D., & Olander, L. (2020). Influence of Medical and Social Perspectives of Disability on Models of Inclusive Education in the United States. *Oxford Research Encyclopedia of Education*.
<https://doi.org/10.1093/acrefore/9780190264093.013.1244>
- Curwood, J. S. (2012). Redefining Normal: A Critical Analysis of (Dis)ability in Young Adult Literature. *Children's Literature in Education*, 44(1), 15–28.
<https://doi.org/10.1007/s10583-012-9177-0>
- Darling, R. B. (2013). *Disability and Identity: Negotiating Self in a Changing Society*. New York: Lynne Rienner Publishers.
- Davis, L. J. (2016). *The disability studies reader*. Routledge, An Imprint Of The Taylor & Francis Group.
- Faeth, E. M. (2021). Agency, Power, and Disability: A Textual Analysis of The Silence Between Us. *Children's Literature in Education*, 52(4), 433–448.
<https://doi.org/10.1007/s10583-021-09453-w>
- Forhan, M. (2009). An analysis of disability models and the application of the ICF to obesity. *Disability and Rehabilitation*, 31(16), 1382–1388.
<https://doi.org/10.1080/09638280802572981>
- Goering, S. (2015). Rethinking Disability: the Social Model of Disability and Chronic Disease. *Current Reviews in Musculoskeletal Medicine*, 8(2), 134–138.
<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4596173/>
- Gallagher, D. J., Connor, D. J., & Ferri, B. A. (2014). Beyond the far too incessant schism: special education and the social model of disability. *International Journal of Inclusive Education*, 18(11), 1120–1142.
<https://doi.org/10.1080/13603116.2013.875599>
- Freeman, D. (2020). *(Dis)Ability Discourse And The Mediation Of Disabled Identity In Young Adult Literature And Television* (Master's Thesis). Illinois State University, Illinois.
- Haegele, J. A., & Hodge, S. (2016). Disability Discourse: Overview and Critiques of the Medical and Social Models. *Quest*, 68(2), 193–206.
<https://doi.org/10.1080/00336297.2016.1143849>
- Hall, A. (2015). *Literature and Disability*. London: Routledge.
- Harry Stack Sullivan, & Mullahy, P. (2013). *Conceptions of Modern Psychiatry*. W. W. Norton and Company, Inc.
- Hogan, A. J. (2019). Social and medical models of disability and mental health: evolution and renewal. *Canadian Medical Association Journal*, 191(1), E16–E18.
<https://doi.org/10.1503/cmaj.181008>
- Hunt, P., & G, S. (2014). *International companion encyclopedia of children's literature*. London: Routledge.
- Kingsbury, M. (2021, April 28). The Current State of Disability Representation in Children's Books. *BOOK RIOT*. Retrieved from BOOK RIOT website:
<https://bookriot.com/disability-representation-in-childrens-books/>
- Kurtts, S. A., & Gavigan, K. W. (2017). Understanding (dis)abilities through children's literature. *Education Libraries*, 31(3), 23.
<https://doi.org/10.26443/el.v31i3.259>

- Ladau, E. (2021). *Demystifying disability: What to know, what to say, and how to be an ally*. Ten Speed Press.
- Lalvani, P. (2015). Disability, Stigma and Otherness: Perspectives of Parents and Teachers. *International Journal of Disability, Development and Education*, 62(4), 379–393.
<https://doi.org/10.1080/1034912x.2015.1029877>
- Lewis, C., Enciso, P., & Moje, E. B. (2007). *Reframing sociocultural research on literacy: identity, agency, and power*. Routledge.
- Lukins, J., Naima Bhana Lopez, Mary Rose Sallesse, & Andresen, J. (2023). Fostering Inclusive Dispositions: Integrating Disability Studies in Teacher Education. *Journal of Special Education Preparation*, 3(3), 4–15.
<https://doi.org/10.33043/josep.3.3.4-15>
- Marks, B. A. (2000). Jumping Through Hoops and Walking on Egg Shells or Discrimination, Hazing, and Abuse of Students with Disabilities? *Journal of Nursing Education*, 39(5), 205–210.
<https://doi.org/10.3928/0148-4834-20000501-05>
- Mitra, S. (2006). The Capability Approach and Disability. *Journal of Disability Policy Studies*, 16(4), 236–247.
<https://doi.org/10.1177/10442073060160040501>
- Mueller, C. (2019). Adolescent understandings of disability labels and social stigma in school. *International Journal of Qualitative Studies in Education*, 32(3), 263–281.
<https://doi.org/10.1080/09518398.2019.1576940>
- Rieger, A., & McGrail, E. (2015). Exploring Children's Literature With Authentic Representations of Disability. *Kappa Delta Pi Record*, 51(1), 18–23.
<https://doi.org/10.1080/00228958.2015.988560>
- R, Roshini., & V, Rajasekaran. (2022). More Than an Invalid: A Comparative Study Addressing Disability Portrayal in Children's Fiction. *Theory and Practice in Language Studies*, 12(3), 551–557.
<https://doi.org/10.17507/tpls.1203.15>
- Roush, S. E., & Sharby, N. (2011). *Disability Reconsidered: The Paradox of Physical Therapy*. *Physical Therapy*, 91(12), 1715–1727.
<https://doi.org/10.2522/ptj.20100389>
- Moje, E. B. (2004). Powerful spaces: Tracing the out-of-school literacy spaces of Latino/a youth. In K. Leander & M. Sheehy (Eds.), *Spacematters: Assertions Of space in literacy practice and research*. New York: Peter Lang
- Shyman, E. (2016). The Reinforcement of Ableism: Normality, the Medical Model of Disability, and Humanism in Applied Behavior Analysis and ASD. *Intellectual and Developmental Disabilities*, 54(5), 366–376. <https://doi.org/10.1352/1934-9556-54.5.366>
- Sugiarto, T. (2020). Reading Disability in Indonesian Children's Literature. *Indonesian Journal of English Language Studies (IJELS)*, 6(1), 25–34.
<https://doi.org/10.24071/ijels.v6i1.2693>
- Preston, D. L. (2010). Finding difference: Nemo and friends opening the door to disability theory. *The English Journal*, 100(2), 56–60.
<https://www.jstor.org/stable/25790036>