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Cripistemological Concerns in Ellie Terry's Forget Me Not

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Abstract
The academic field of Disability studies muses over the rights and representations of disabled individuals and has shown prolific growth in the last decade. Disability studies perceive disability as a social construct, integrating with it the ideas of culture, religion, gender, race and sexuality. The application of an intersectional framework to study disability led to the formation of crip-theory, catering to the need for authentic representation otherwise known as cripistemological representations. Cripistemological representations further enhances the scholarship on disability especially intellectual disability which is convoluted and perplexing in nature.
The novel, ***Forget Me Not,*** by Ellie Terry, a semi-autobiographical novel unfolds Terry's journey as a neurodiverse person through the character of Calliope. It stresses upon the need for self-expression as a disabled individual. This research paper focusses on the portrayal of Tourette's Syndrome, an intellectual disorder and the need for cripistemological representations as found in the novel ***Forget Me Not*** by Ellie Terry. Adopting the library research methodology the article will explore the adversities encountered by an intellectually disabled individual and their effort to mask while constructing their personal identity.

Keywords: Tourette Syndrome, Epistemic Injustice, Cripistemology, Intellectual Disability, Shame and Crip Theory.

Disability is a medically derived term which essentially refers to certain types of human variation, that are physical, intellectual or sensory and has the ability to constrict an individual's daily life. Disabled individuals possess significant impairments with regard to anatomy or behaviour. These characteristic features mark them as 'deviant' for they deviate from what society considers to be 'normal' or 'normate'. Individuals who do not adhere to these normative constructs are labelled as defective individuals. Until the earlier part of twentieth century, disability was perceived through the medical model formulated by the psychiatrist Dr. Thomas Szasz in the 1950s.
The medical model of disability as theorised by [1] Thomas Szasz (1960) sees disability as a defect that must be cured or eliminated for the disabled individual to live life to its full capacity (p. 115). [2] According to Diana Misipa and Paul Juma (2023) the medical model of disability sees disability as an inherent quality in an individual with physical or mental impairment (p. 233). It views disabled

individuals as a failure for they do not fit the social paradigm set by the able-bodied people. These narratives portray disability as a negative identity. Later, during the mid-twentieth century, followed by the disability rights movement, several social theorists came forward to break the disability narratives and bring forth better representations for the disabled. The complex nature of impairments unveiled diverse theories and narratives which then emerged into an academic field named disability studies.

Disability studies aims to identify, transform and deconstruct stereotypical disability narratives, thus reconstructing the identity of a disabled individual by giving disability a positive outlook. Disability studies perceives disability as a social construct, integrating with it the ideas of culture, religion, gender, race and sexuality. It strives to depict disability from a multifaceted point of view giving every disabled individual an opportunity to express themselves. The idea of looking at disability as a social oppression rather than a defect made people realise that acceptance of disability is not oriented towards the individual but towards the society. This narrative brought about liberation among the disabled community.

Disability studies endeavours to treat disabled individuals as humans with differences rather than an object of study. [3] As Rosemarie Garland-Thomson (1997) states, disability studies have helped to move disability from the applied fields of medicine, social work, rehabilitation and aided in its birth as a new genre in identity studies (p. 257). Decades of study and theorisation has brought about significant shifts in social, political, intellectual and ideological ways through which an impaired individual is viewed or criticised. At present disability studies has branched into an interdisciplinary field known as Critical Disability Studies.

Critical Disability Studies goes beyond the social model of disability. [4] According to H. Meekosa (2009) critical disability studies tends to encompass the psychological, cultural, discursive and carnal factors that affect disability (p. 50). Critical disability studies rely on intersectionality to analyse the complex ways in which gender, sexuality, race, power, social status, ability and politics converge together to define a disabled individual. The application of an intersectional framework to study disability later led to the formation of crip-theory. The word crip theory was first coined by Robert McRuer in the year 2006 in his work ***Crip Theory: Cultural Signs of Queerness and Disability.***

Crip-theory is a branch of critical disability studies which views disability through the lens of queer theory. The term crip or crippled like the word queer defines a subgroup of people who are under-represented on account of their diverse nature. Crip theory adopts the word crip from the derogatory vocabulary and refines it through epistemological representation of the disabled. [5] Martin Söder (2009) asserts that disability is not a physical ailment but a product of an oppressive and discriminatory society. Crip theory views disabled person as an exemplar of knowledge (p. 68). It stresses on the adaptive nature of knowledge and the need for authentic representation. These representations are known as cripistemological representations.

Cripistemology refers to the idea where the disabled individual tells their own story in their space and time. [6] Thorneycroft (2024) defines cripistemology as redefining and getting to know disability through disability experiences as understood by the disability communities (p. 103). These portrayals could help people break negative stereotypes and improve the quality of life for disabled individual. Cripistemology directly challenges the mainstream society that often misunderstands or monetises disability. It amplifies the voices of the disabled over scientific or medical narratives. It also provides a safer space for the intellectually disabled communities to voice out their struggles, aspirations and desires.

Cripistemology challenges the ideas of medical epistemology. It challenges normative assumptions about who can be a 'knower', what counts as knowledge and how knowledge is formed and transmitted. In a world that is predominantly shaped by ableist, capitalist and colonial epistemologies, cripistemology becomes not only a methodological intervention but an ethical necessity. The knowledge thus generated asserts the fact that the perspectives of the disabled are crucial for understanding disability. It adduces the idea that what is considered as an "objective" truth is often a reflection of a dominant ideology rather than a universal fact.

Cripistemology aligns with the social model and its more radical extension, the political/relational model, which sees disability as constructed by the interplay of body, environment and sociopolitical systems. [7] Cripistemology as Robert McRuer (2006) states emerges from Crip Theory which questions the order of things and the reason as to how and why it is constructed and naturalized in a particular order (p. 2). It presents how disability is embedded in a complex economic, social and cultural structure and the ways through which it could be changed. These features could help enhance the scholarship on disability especially intellectual disability which are convoluted and perplexing in nature.

This research article aims to explore the need for cripistemology through analysing intellectual disability, precisely Tourette syndrome as portrayed in Ellie Terrry's novel ***Forget Me Not.*** It attempts to highlight the need for cripistemological portrayals and its consequential role in proscribing epistemic injustice. It intends to stress upon the adaptive nature of knowledge and the need to eschew fixed categories of viewing a person with intellectual disability. It strives to shed light on the negative stereotypes associated with Tourette syndrome and its negative impact on the victim. This research paper endeavours to ascertain the adversity an intellectually disabled individual faces while constructing their personal identity and the ensuing need for masking.

The novel ***Forget Me Not*** by Ellie Terry is a semi-autobiographical novel that narrates the childhood of Calliope Snow, a 13-year-old girl who suffers from Tourette syndrome, anxiety and OCD. The novel begins with Calliope packing up her luggage for the tenth time as her mother's relationship has once again failed. Calliope's disorder paired along with the anxiety that she experiences from continued changing of schools worsens her condition. It causes a shadow of instability in her life, which arouses her yearning for permanence. This frequent shifting adds on to the already tense relationship between the mother and child. Her mother's emotional instability often forces Calliope to hide her discomfort instead of voicing them out. Terry presents the complicated relationship between a mother and an intellectually disabled child through Calliope and her mother.

Calliope's mother's act of clipping Calliope's hair to conceal her Tourette syndrome exhibits her insensitivity towards Calliope's disorder. Her mother's inability to acknowledge her daughter's disorder causes their relationship to be strained. Her continued urge to cloak Calliope's disorder stresses her belief that concealing it can make her look normal and it could prevent her daughter from being excluded by the society. The idea that cloaking the disorder could make their child normal is a common misconception among parents of children with intellectual disability. Concealment and secrecy, which she uses to protect her child from social stigma starts to weigh on Calliope. Calliope's mother's indifference towards her daughter's medical condition emphasises the need for a broader understanding of neurological disorders.

Terry ventures into the topic of friendship along with focussing on the mother-child relationship. Calliope starts to attend the Black Ridge International school at the age of thirteen. At school she tries to hide her disorder from her classmates, fearing rejection. Her struggles to mask her disorder and blend in,

agitates her, which evokes her tics. This leads to her disorder being discovered by her peers resulting in her being bullied and ridiculed by them. She then meets the school president Jisong who is a central character in the novel. Jisong is attracted to Calliope but finds it hard to stand up for her in public, fearing condemnation.

The friendship between Calliope and Jisong is strained at times by internal and external pressures. This serves as a narrative lens through which Terry examines how young people negotiate difference, acceptance and moral courage. Terry in her novel ***Forget Me Not*** advocates the social model of disability, which states that disability arises from systemic barriers and social exclusion rather than inherent impairment. Terry challenges the stereotypical depictions of disabled individuals by positioning Calliope as a complex, intelligent and emotionally rich character. She centres neurodiversity as a source of narrative rather than a peripheral dialogue. Terry offers both an intimate portrayal of life with a neurological disability and a broader commentary on the challenges of social conformity.

The novel ***Forget Me Not*** is an example of cripistemological writing for, Terry herself suffers from Tourette syndrome and OCD. Cripistemology developed as a response against Western medicine and ableist theories of knowledge on disability. It encourages people to look beyond the dominant ways of knowing disability. It challenges the negative stereotypes associated with a disorder for stigmas inflicting greater harm on the victims rather than the disorder. This could be witnessed in the case of Calliope. The stereotypes that surround Tourette syndrome affects Calliope than the disorder. Calliope suffers more because of misunderstandings associated with Tourette syndrome and her inability to express herself rather than the disability.

Calliope's mother and her doctor both try to suppress and prevent her from speaking out about her disorder. They fear that she might be cornered as a patient of Tourette syndrome as that is always associated with violence and verbal abuse. Calliope's psychiatrist Dr. Flager advises her to hide her disorder:

That if he were me,
he wouldn't go around telling everybody,
because Tourette's is a very
misunderstood
disorder (2017, p. 152)

Tourette syndrome, that often expresses difficulties with communication is truly is one among the most misunderstood disorder. Individuals with Tourette syndrome has always been associated with violent outbursts, improper behaviour and verbal abuse. The negative portrayal of Tourette syndrome in movies and television bring about the misconception that people with this disorder are savage and aggressive. These stereotypes, true to some extent could not be considered as a frame with which every individual with Tourette syndrome should be judged.

Dr. Oliver Sacks wrote notes about his first patient Ray in 1997 where he described Ray as someone with an "urgent killer instinct", as a person who would have violent outbursts and primitive impulses and urges. Calliope suffers from Tourette syndrome just like Ray, but she does not exhibit the same symptoms as him. Calliope shows some primitive impulses such as making faces or weird noises during conversations but never indulges herself in acts of violence towards anyone. [8] Dr. Oliver Sacks (2011) in his work ***A Man Who Mistook his Wife for a Hat*** affirms that although there are hundreds of individuals who suffer from Tourette syndrome no two affected individuals would have the same

symptoms (p. 92). This clearly highlights the idea that despite the disorder being the same, the symptoms exhibited by the individuals would drastically vary.

The arbitrary nature of Tourette syndrome is a primary reason for it to be misunderstood. It also makes it difficult to fit the disorder into a medical framework thus resulting in it being overlooked or covered. Individuals with Tourette syndrome are often asked to mask the symptoms and treat it as a minor inconvenience rather than a disability. Calliope's mother instructs her to control her "instincts" and "act normal." She is made to believe that her disorder which is incorrigible in nature is nothing but an embarrassment or nuisance that could be cured through strong will.

Calliope's sufferings are related to her inability to express herself. [9] Catherine Prendergast (2001) in her work ***On the Rhetorics of Mental Disability*** states that a mentally disabled individual could very well be considered as a rhetorically individual (p. 57). Calliope's neurological condition which is accompanied by vocal tics prevents her from expressing herself. While her condition restricts her, the years of bullying, social stigmas and anxiety also plays a vital role in voicing out her discomfort. Calliope's inability to express and the lack of credible narratives leads her to be oppressed by society. The cause of Calliope's distress lies in the society which considers itself as an agent of epistemic justice.

Cripistemology extends the concept of crip theory into the realm of knowledge production. It raises the question of who a 'knower' is, which could help fight epistemic injustice. Epistemic injustice according to [10] Miranda Friker (2007) refers to an injustice caused to an individual by someone particularly in their capacity as a knower (p. 1). Epistemic injustice occurs when an individual or a group of people are deprived of their right because there are no existing narratives or collective understanding to properly make sense of their social experiences. This oppresses the marginalised people and results in them not having their own identity. The varying nature of intellectual disability and the lack of lived narratives lead the intellectually disabled individuals towards epistemic injustice.

Calliope's Tourette syndrome propel her towards epistemic injustice and marginalisation. She is deprived of her basic right to speak because of the existing narratives that surround her disorder. Her doctor constantly advises her to remain unseen, for he believes that people with Tourette syndrome would never be tolerated in a society which always condemns difference. Calliope's Tourette syndrome marks her as unreliable in the eyes of her family and peers. Calliope's mother in her authority of a knower restricts Calliope's right over her own bodily autonomy. This is seen when she chops off Calliope's hair which was, "the only thing I've [Calliope] ever liked" (2017, p. 5) about herself. Epistemic injustice transcending beyond an individual's free will, seeps into their identity too affecting their formation.

Calliope consciously tries to mask her disorder especially after adolescence. This is the period where the idea of 'I' and 'Me' starts to emerge. The word 'Me' here represents the socialised aspect of the self which is formed with relation to social interactions. The formation of 'me' plays a key role in shaping the 'I' which represents the spontaneous, creative and unpredictable aspect of the self. The concept of 'I' and 'me' which constitute the self, is a dynamic interplay between social conformity and personal agency. The notion of 'me' enables one to approach or address oneself from a standpoint of 'collectivity'. The American philosopher George Herbert Mead, famously called this as the 'generalized other'.

The generalized other unfolds the internalised attitudes, expectations, values and norms of the society in general. The 'generalized other' as defined by [11] Herbert Blumer (2004) refers to the abstract 'other' who embodies what is common to a particular section or class of acting human beings. It precisely

embodies in itself the organized group activity common to a class of social settings (p. 60). The generalised other becomes a reference point that helps an individual to figure out how to behave in various situations. Calliope's continued mobility from one place to another results in her being exposed to new groups with ewer and varied expectations. This results in her transformation into a fragile and conditioned self, often anticipating rejection.

Calliope's idea of 'me' is a manifestation of others' perception of her. It does not describe her rather it points out Calliope's social self built upon the gazes of others who were often shrouded in malice and hatred. Her socially shaped 'me' laden with negative responses suppress her 'I', the spontaneous self. Calliope learns to minimise her presence by curbing her free expressions so that she could disappear. Calliope's 'I', the authentic self, longs for validation of her social self 'me', shaped by years of misunderstanding and social stigma that forced her to hide from the society. Her conscious self is not absent but is constrained by Calliope because she fears judgement. The state of imbalance between the 'I' and 'me' makes it impossible for Calliope to form an identity leading to her fragmented identity.

The predominant concept that creates the self is the attitude of others towards an individual and how they feel the world perceives them. [12] Charles Horton Cooley's (1983) concept of the '*looking-glass self*' claims that every individual develops a concept of self, based on how they imagine others see them (p. 154). This being the case bullying becomes a detrimental cause to identity formation owing to its negative impact on the self. The repeated reception of hostile messages such as insults, exclusion or physical intimidation becomes internalised as part of an individual's 'me'. These constant negative reactions could lead an individual to view themselves as someone who is inherently flawed, inferior and undeserving. Over a period of time, such appraisals may manifest in low self-esteem, social withdrawal and internalised shame, which disrupts the natural development of a balanced self-concept.

The primary factor that disrupts the identity formation is bullying which is often experienced by individuals who have cognitive impairments. Calliope's articulation is disrupted by vocal tics that are characterised by croaking sounds. This makes her a target of bullying and she is made to sit near a trashcan, being labelled as a freak. These constant criticisms slowly limit her interactions with the society. When communication with the outside world gets diminished, neurodiverse individuals like Calliope realise that internalisation of socially acceptable behaviour and etiquette is difficult. Their inability to fit themselves in the societal roles makes them a victim of disdain and criticism.

Individuals with neurodiversity later develop a camouflaged version of 'me' that helps them blend with others. This masked version of 'me' is a socially acceptable mask designed to conform to the external expectations without corresponding to the individual's internal experiences. Masking, as defined by [13] Sonny Jane Wise (2023) in her recent book ***We are all Neurodiverse***, refers to the action or process of suppressing or hiding an individual's personal traits, natural behaviours and responses while simultaneously adopting a set of perfectly crafted traits and behaviours in order to fit in or survive in a group (p. 16). Masking or camouflaging was initially found prevalent among individuals with autism but at present it is used as a coping mechanism by several neurodivergent individuals. Masking could be defined as a strategy through which intellectually disabled individuals suppress their behaviour consciously or unconsciously to blend in with the society.

Intellectual disability, unlike physical disability is hard to decipher and is often asymptomatic. This results in most affected individuals actively hiding their disorder. When Calliope's mother is about to introduce Calliope to her boyfriend, she instructs her, "don't tell anyone about your _____" (2017, p. 26). Her mother's struggle to utter the word Tourette reflects her fear of the disorder. This makes

Calliope believe that only through masking will she will be able to lead a normal life with friends and family:

Now my Tourette's
is harder to hide
but I have to try
if I want to make friends (2017, p. 20)

The constant reminders from the people around her makes Calliope believe that disguising her disorder is the only way to be socially accepted. This pushes her to consciously conceal her symptoms.

Masking could be seen as a social survival strategy used by people in situations where neurodiversity is not understood or welcomed. In his book ***Unmasking Autism*** as [14] Devon Price (2022) states that the main goal of camouflaging is to avoid being detected as a disabled individual (p. 102). Camouflaging could be considered as one of the most tiring and emotionally consuming activities that has been practiced by many individuals with different neurological disorder. Tourette's syndrome as characterised by [15] Sacks (2013), is a disorder where the patient exhibits a torrent of emotions driven through passion and excitement. It amplifies the primal and instinctual behaviour in the affected individual (p. 9). This being the case it gets even more difficult to hide. The idea of being forced to mask Tourette syndrome is similar to depriving the affected individual of their freedom or birthright.

Neurodivergent individuals opt for masking mainly because of the negative stereotypes that commonly surround the disorder. [16] Tom Shakespeare (2016) in ***The Social Model of Disability*** is of the opinion that the sufferings faced by an impaired individual has less to do with disorder than with fear, ignorance and prejudice. These negative emotions and criticisms make the experience appear worse than it actually is (p. 201). Calliope fears that when people get to know about her disorder, they might treat her differently because of the misconceptions associated with it.

Calliope apprehends that the moment people get to know about her disorder they might distance themselves from her fearing weird behaviour of cursing or spitting on them as is normally portrayed in the movies. Stereotypes do not just shape other's opinion about Calliope but also shapes her own opinion of herself. The fear of judgement forces her to hide her disorder which in turn triggers her anxiety and worsens her symptoms. Shame is another prominent emotion that forces an individual with intellectual disorder to mask their disability along with fear.

The feeling of shame begins to take root when Calliope starts to find that she is different from people around her and that she is the 'other'. Her experience with shame begins when she becomes aware of the fact that her body behaves in ways that she cannot fully control and that her motor and vocal tics make her visibly different from her peers. This difference often subjects her to ridicule or rejection. Calliope's feeling of shame does not stop with sadness or embarrassment but leads to internalised rejection. Calliope not only feels bad about her tics but also begins to feel that she is flawed, which is central to the psychology of shame. The more she feels' the more she tries to hide: "I try to keep the tics inside/ to hide the parts of me / that make me different" (2017, p. 9). This reflects how shame pushes Calliope towards concealment, forcing her to suppress not just her tics but also her authentic self.

Calliope's constant shift from one city to another because of her mother's failed relationships solidifies her sense of fear and shame. Every move means starting anew but it also means that she should start to conceal herself more and make sure that no one finds her true self. Calliope's anxiety about being found makes her tics become more visible. This shows how shame gets embedded in the victim's mind as a constant internal pressure. Calliope's life experiences show how shame is not just a response to

ridicule but a prominent emotion that shapes one's identity, behaviour and self-worth. All these changes at the end of the novel when Calliope comes forward to express and define herself.

Calliope does not shy away from others as she enters her new school, instead she combats it by explaining her condition to her classmates:

"I have a neurological disorder
called Tourette syndrome.
Maybe you've heard of it?
Sometimes I make faces or noises
that I don't mean to make.
So... if you happen to hear me croak like a frog,
just ignore me, okay?" (2017, p. 324)

Calliope's cripistemological narrative as the victim and the knower helps her find a place in the society. Shame, identity crisis, bullying and social exclusion faced by a neurodiverse person could be attributed to the stereotypes and lack of understanding that surround them. The misrepresentation and generalisation of neurodiverse individuals in the movies does not cease with them being misunderstood, but it extends to the active limitation of their access to opportunity, belonging and self-worth. These misconceptions also lead to their needs being unmet or overlooked. It pressurises people with intellectual disability to resolve to masking which prevents them from getting the required diagnoses and treatment. These problems could be combatted through spreading awareness about neurological disorders and through proper representations.

Accurate representation is paramount to disabled individuals for representation does more than simply providing visibility. It changes the way in which individuals perceive themselves and the others look at them. When disability is absent or misrepresented in stories or movies, disabled people may feel invisible or mischaracterised. Representation thereby acts as models and mirrors. When people with disabilities are portrayed in diverse roles it helps them reimagine who they are and what they can be. At present, despite better representation of disabled individuals in literature and movies, stereotypes still tend to prevail. The existing portrayals of disabled individuals often rely on stereotyped representations where these individuals are portrayed as objects of pity, source of inspiration or villains. This situation could be changed by providing representation which are written or articulated by disabled people themselves.

Terry relies on cripistemological portrayal to express the life of an intellectually disabled individual. Terry does not present Calliope as a timid, emotionally weak and unstable character who lacks knowledge, as seen in popular narratives. She is rather shown as someone whose understanding of the world is deeply rooted in her emotions, sensory perceptions and intuitive reactions. Her collection of rocks, her interest in constellations along with her acute awareness of other people's moods presents Calliope as a young girl who values relationships, knowledge and stability. Terry's portrayal of Calliope breaks the existing stereotypes that revolve around an individual who is affected by Tourette syndrome.

erry applies dual narrative technique where she uses verse for Calliope and prose for Jisong. This narration creates a clear division between the existing normative narratives and the narrative of a person with intellectual disorder. Jisong's prose is more conventional, linear and socially grounded. It reflects his role as a young man who is tries to navigate peer expectations and uphold the normative behaviour. Calliope's verse on the other hand contradicts traditional narrative. Her poems are lyrical, drawing on metaphor, memory and emotional insight rather than plot or dialogue-driven exposition. This contrast

exhibits the difference between the way in which a person with intellectual disability and an ableist person perceive the world.

The dual narrative technique stresses on the importance as to why cripistemological portrayals are important. It ascertains how the thought process of an intellectually disabled individual is different from an able-bodied person. [17] Irene Rose (2008) states that cripistemological narratives to fight against the pathologisation of difference tries to connect with the affected and the people surrounding them in an emotional level (p. 46). Thus, cripistemology is not an optional subfield within disability studies but it is a foundational reimagining of how knowledge is constructed; who is seen as a knower and what it means to understand the world from embodied, relational and often marginalised perspectives.

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