

Understanding Disability: A Study of Sharon M Draper's *Out Of My Mind*

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ABSTRACT

*This paper endeavours to demonstrate, how application of contemporary ideas about disability to recent literary writings that portray children, give new dimensions to the idea of disability. It provides the experiences faced by the children with disabilities within the contexts of family and society with special reference to the contemporary fiction *Out Of My Mind* by Sharon M Draper.*

Key Words: Disability, contemporary children's fiction.

Disability is often seen as a disadvantage which does not allow a person to do certain tasks or actions which are part of everyday life. Ronald J Berger in *Introducing Disability Studies* discusses about different approaches to disability that can be traced back to the early perspectives of society and culture. The "moral model" of disability which prevailed till the 18th century mainly looked at disability as a disgrace, and there were many cultures which regarded it as a result of a curse. In the Old Testament, for instance, disability is seen as a consequence of the disabled people or their forefathers' actions or sins. This model is historically the oldest, and is less prevalent today. The "medical model" of disability emerged in the 1980's. This model saw disability as sickness or defect which can be cured through medicines. It basically projected disability as "impairment" which resulted in the loss of subjectivity of the disabled individual.

The emergence of Disability Studies challenged these attributions to the people with disabilities. It is an interdisciplinary approach which examines the nature and consequence of disability as a construct of the society. It projects the "social model" of disability, first suggested by Paul Hunt an American social activist. Disability Studies tries to bridge the gap between "impairment" and "disability". Impairment means the physiological condition that involves lack of physical, sensory or cognitive function, while disability is seen as the result of this impairment and of societal reaction which does not enable a person to perform a particular task personally or socially (5).

The social model of disability analyses the disadvantages and restrictions which people with disabilities face and says that disability cannot be reduced to the idea of "physical impairment", rather it is an outcome of society's attitudes towards them and the excluding mentality of the mainstream, because it lives in a "mirage of being normal" (Davis 28). This approach challenges and questions the "ableism" of society that subjects people with disabilities to face "othering" (Berger 14). It also deals with questions like "who defines disability and for what purpose" which will ultimately "unmask the web of social ideals, institutional structures and government policies" that will affect the lives of people with disabilities" (Wendell 23; Linton 10).

According to Berger, the social model of disability did not reject the medical involvement which would improve the person's ability to cope with their lives (15). It "criticizes the widespread belief of society that having a well-defined body and mind decides the worth of a human being" (Siebers 45). Just like sexism or racism, ableism also creates a binary of "normal" and "abnormal" and it projects the ideology of the former category. Tobin Siebers in his book *Disability Theory* argues that this ableism in the society is taken for granted and it remains unconscious and invisible to most people. Siebers also argues, "People with disabilities want to be able to . . . live with their disability, to come to know their body, to accept what it can do, and to keep doing what they can for as long as they can. They do not want to feel dominated by people on whom they depend for help, and they want to be able to imagine themselves in a world without feeling ashamed" (69). Lennard J. Davis in *Disability Studies Reader* opines: "...the "problem" is not the person with disabilities; the problem is the way that normalcy is constructed to create the "problem" of the disabled person" (1). This approach to disability explains the need of the society to become more inclusive as well.

The select primary text comes under the larger and widening area of children's literature. Rubin and Watson comment that in early children's literature negative characters or antagonists were often portrayed as having some deformities and were seen as evil characters (60). For example, the ugliness of the evil sisters in the fairy tale "Cinderella" echoes their deformity in one sense. The same kind of idea can be seen in the portrayal of Captain Hook, the antagonist in J. M.

Barrie's play *Peter Pan*. Captain Hook has a deformed hand. Sauron in the high fantasy text *The Lord of the Ring* by J. R. R Tolkien has monstrous eyes. Similarly, Lord Voldemort, the character in Rowling's Young Adult Fantasy series *Harry Potter*, the powerful wizard of all time, lacks a proper nose and this feature projects him as "disabled". These texts in a way create a binary whereby protagonist or central characters are good and normal, while the antagonists or the negative characters are those who are "disabled", and which distinguishes them from the rest. All these characters were looked upon with negativity and with the notion of not being "normal" as well. The *Adventures of Pinocchio* by Italian writer Carlo Collodi shows another trajectory of disability, where Pinocchio has a long nose. Even though Pinocchio is the protagonist, not a negative character like the above-mentioned examples, the long nose occurred to him as a punishment when he started lying. It is suggestive of teaching morality to children showcasing that if you lie, your nose will grow long. Here also disability is attributed as something negative.

Contemporary children's fiction shows a development in portraying the disabilities, especially of children. In these fictional texts, the influence of "social model of disability" can be seen. These writers choose to criticize the ableistic attitude of the society through their writings. For example, *Wonder* (2012) by R.J Palacio portrays the life of a ten year old boy named August Pullman who has Mandibulo facial dystosis. The text makes the readers relate to the troubled protagonist and his experiences in the context of family and society. It also shows a society in transition which has become more inclusive. *Mocking Bird* (2010) by Kathryn Erskine's portrays the world of Caitlin, who has Asperger Syndrome who is preoccupied with drawing and dictionaries. The entire novel is narrated from her perspectives, and through her the readers are able to see how the society treats her and her disability. Lynda Mullaly Hunt's novel *Fish in a tree* (2015) is another fiction which comes under this category. It explores the life of a girl called Ally who has dyslexia and who is smart in her own way. Hunt questions the attitude of the society by the idea that "if you judge a fish by its ability to climb a tree, it will live its life believing it is stupid" (154). The novel shows that everybody is smart in different ways. All these texts try to empower children who face this kind of problem in their lives.

In this framework, this paper analyses Sharon Mill Draper's *Out of My Mind* which was published in 2010. The novel features an eleven-year-old girl named Melody Brooks who is born with cerebral palsy. Her body is restricted to a wheel chair, because of her disability. It is difficult for her to move her hands and body. The story goes through her experience with her parents, and the world around. She is extremely brilliant and has a "photographic memory" (13). Melody's parents Chuck Brooks and Diane Brooks, along with her neighbour Mrs. Violet who is encouraging and supportive, become her strength. She goes to Spaulding Street Elementary school to get the education that she needs. In the school, she faces discrimination when the children with disabilities are made to sit along with the "normal children". In the course of time, Melody with the help of her personal mentor Catherine comes to know about a speaking machine, through which she can speak. When she gets this machine, her communication becomes lot more easy than before. Because of her brilliance, she is able to take part in a quiz competition and with the help of Melody her school wins in the preliminary level. For the final round, which is set in Washington, the teammates and the teacher deliberately avoid her which makes her quite depressed. But she rises to fight back, and the novel ends with an optimistic note where Melody tries to write her autobiography on a computer with her thumb.

The entire novel is narrated from Melody's point of view. The author uses Stream of Consciousness technique, where Melody tells her story through the thoughts in her head and it becomes the voice of someone who cannot speak. No alternate perspectives are given and through her thoughts the readers come to understand the attitudes of the people surrounding her. By giving voice to Melody, who has cerebral palsy, the writer is making her the centre of the narrative and emphasizes on her attitude towards her disability. Melody sees herself as "ridiculously smart" (13). Since she perceives herself as able, normal and even smarter than the society, it is right to give her a voice than to choose a second person or a third person narrative to narrate her story. It helps her react against the society which sees her as an abnormal child, and thus allows her to question the ableism of the society. It is also to enhance the writer's ideology to support Melody and to make the readers rethink about their mentality towards disabled people.

The disability of the protagonist Melody which limits her from engaging in different tasks is Cerebral Palsy. It is one of the three most common lifelong developmental disabilities, the other two being autism and mental retardation, as first described by William Little in the 1840's. Simon Stevens in the medical journal *Developmental Medicine & Child Neurology* defines cerebral palsy as:

A group of disorders of the development of movement and posture, causing activity limitation that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain... The motor disorders of cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or by a seizure disorder (9).

The major symptoms include: stiff muscles and exaggerated reflexes, lack of muscle coordination, trouble in walking, difficulty with sucking or eating, delays in speech development or difficulty in speaking and so on. Some children with cerebral palsy also have "cognitive impairment" which affects their intelligence. In other cases, the children have extreme intelligence and memory, but because of the trouble in their body movement it becomes difficult for them to express their potential. The protagonist Melody belongs to the latter group where her intelligent mind is housed in a disabled body.

The text also provides some amount of details about her disability. When friends ask about her problem, she says that she has "spastic bilateral quadriplegia, also known as cerebral palsy. It limits my body, not my mind"(168). The text shows her inability to move or speak the way she wishes to. She says in another instance, "It's like I live in a cage with no door and no key" (38). She is pregnant with her thoughts and her body does not allow her to speak. It is difficult for her to even hold a spoon or a pencil. She is strapped into a wheel chair and she could move only with the help of it. Her inability to ask for what she wishes is clearly shown through the line "so both my dog and I get what they give us" (69). But she says that she is glad that she can at least move her thumbs, and she is happy and lively in her state of being. There are no instances in the novel where she complains about her inabilities. Melody, through her life, also challenges the people who have everything but are not satisfied with what they have. It raises the question of who really is "normal"?

The source of comfort and encouragement for Melody are her parents Chuck Brooks and Diane Brooks. Neither are they ashamed of Melody being their child, nor do they try to keep her inside the house. Both of them do not try to make her "normal", instead talk to her through her kind of baby talks and special vocabulary. Melody remembers her dad singing songs and reading books for her. His words "you can do it" (10) were a great source of encouragement in her childhood. Melody's mother Diane believes that her child is unique with her own talents and intelligence. Even though her parents weep, they try to keep her strong. The neighbour Mrs.Violet, whom Melody calls Mrs.V becomes another source of comfort which she grows. Mrs. V is the one who takes care of Melody when her parents are away from home. She sees Melody as a normal child who is very intelligent and prepares for the quiz competition as well. She also helps her add words in the vocabulary and in a way help her function better by accepting the way she is. In one instant Mrs.V says to Melody: "People love you because you're Melody, not because of what you can or cannot do"(281). She acts as a second mother to Melody, who is supportive and sees Melody as capable of anything.

Through different characters, the novel shows the ableism of the society which assumes people with disabilities to be "abnormal" or "inferior" and sees themselves as "normal" and "superior". It also reveals how the medical field often fails to recognize the uniqueness and talents these disabled children have. Society usually judges from their perception of normality. When Melody's mother Diane takes her to Dr.Hugely, he judges her ability based on his medical view point. Melody's inability to talk or move, or the unique ways in which she is talented, becomes a problem for the doctor. His attitude displays the "medical model" of disability in which her disability is seen as medical sickness which can be cured through medicine. For him her subjectivity is lost. He thinks that in medicine, she has cerebral palsy and because of that she is not normal. When he emphasises on her disability and tells her mother "She has cerebral palsy, Mrs. Brooks", Diane attacks him by saying "But a person is so much more than the name of a diagnosis on a chart" (23) and highlights Melody's identity outside "medical model".

Spaulding Street Elementary School, where Melody starts her schooling becomes the place where she has to mingle with other people in society. She says how other students call their bus “special needs” bus and she is admitted to a special program. The use of “special” itself becomes problematic because it looks at these children as “abnormal”. Melody shows how her classmates are different and talented in their own ways. For instance about a girl named Maria, who has Down syndrome, Melody states that Maria has the special ability to understand people, and consider their feelings. Melody also talks about Willy Williams who has extreme knowledge about baseball. Some of the teachers who teach in the “special program” do not recognize their needs. Melody explains an incident where a teacher named Mrs. Billups makes these children listen to the same trivial songs repeatedly and how Melody and her friends hate that. This reveals the teacher’s attitude towards these children with disabilities. Just because she does not consider these children as normal but sees them as “retarded”, she could not do what they really want. There is a kind of binary here where in the teacher assumes that Melody and her classmates are not capable of thinking normally.

The discrimination and othering faced by the children with disabilities are exposed when they are made to sit with the so called “normal” children in the “inclusion classes”. The other children look down upon the “special group” and make them think that they are not empowered. Society’s ableism constantly makes the children with disabilities to think of what they lack not of what they have. The text raises the question “what is normal?”(90). This false construct by the society leads to the mistreatment of Melody. The society refuses to accept her for who she is. The inclusion classes thus become not truly inclusive, but keep some children separate. When Melody won the quiz in the class, no one believes her capability other than her personal teacher Catherine. So, the society makes her disabled by not accepting her talents. Melody’s inclusion to the quiz team becomes a problem for the others because they do not see her as an ordinary girl who has extreme intelligence. Giving reward to the child with disability, which is a common trope in disability narratives (Solis, 1), can be seen in this novel as well. During the TV show, Melody becomes the centre of attraction and everyone’s focus was on her. Melody herself says: “Our Team hasn’t done anything special. They don’t need to. They have me”(205). For the final quiz competition, which is set in Washington, her team mates and teacher deliberately avoid her and think that she may not be able to reach the airport as soon as others can. The ideology of ability is clearly shown by giving preference to the able bodies over Melody.

In contrast Melody’s gratitude can be understood through her gifting of card to Mrs. Violet and her personal mentor Catherine. Her kindness is visible when she tries her best to save the fish Ollie, and in another instant where she saves her younger sister Penny from an accident. It leads to the idea that sometimes what the so called “normal” people lack, the disabled children have. The speaking machine which Melody finds for herself depicts the need for technology and medicine to help the disabled children to live their lives better. She uses the speaking machine to empower herself. But in spite of that, the society disempowers and marginalises her. Her assertion of identity and aspiration to fight her life can be seen in the ending of the novel where she chooses to write her autobiography on the computer with her thumb. “This is going to take a while. So much is stuffed inside my mind. I have lots to say and just one thumb to say it with”(294). She stays within the society and resists, and does not accept society’s ableism.

The novel helps the readers to watch the society through the eyes of a disabled child. The text does not criticize everyone in the society. Through the character Mrs. Violet who sees Melody as “normal” and helps her to achieve her dreams, Rose who chooses to sit with Melody in the inclusion classes, the novel illustrate that not everyone in the society is ableistic. But it mainly questions the widespread belief that having an able body determines the intelligence of a person through the character Melody. Melody’s disability thus becomes “social construction” rather than her “physical impairment”.

Draper’s novel empowers children with disabilities, and helps them to face their life in a positive outlook. In Harper Lee’s novel *To Kill a Mocking Bird*, Atticus says to Scout: “You never really understand a person until you consider things from his point of view... Until you climb inside of his skin and walk around in it” (30). The novel provides a chance to get into the disabled children’s

shoes, and understand how they feel. It also upholds the ideology of the writer who deliberately questions the ableism of the society which sees disabled people as inferior. Katherine Paterson in *Theory into Practice* opines: “The aim of the writer is, like Michelangelo’s, to chip away at the block of marble to reveal the statue within it” (325). Draper’s novel thus helps the readers to identify the hidden ableism that might be otherwise non-critically assumed to be a part of life. It projects the need for the society to be more inclusive and accept everyone irrespective of their differences.

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