

**Recasting Societal Perception towards Disabilities: An Analysis of
Progeria in Selected Works**

**Dissertation Submitted to the University of Kerala in partial fulfilment of
the requirements for the Degree of Masters of Arts in
English Language and Literature**

**University of Kerala
Thiruvananthapuram**

2022

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Preface

In every society, disabled people are ostracised as a result of the lack of voice and agency for disabled communities. However, with the rise of disability rights movements, a new perspective on the rights and amenities available to people with disabilities has emerged.

Disability studies, a distinctly an interdisciplinary field of study, works in public policy, education, and medicine as well as the humanities and social sciences addressing prejudicial notions about disability which result in the marginalisation of those with disabilities. As a result, it can be said that disability studies are a specialised field that aims to change the prejudiced view of society towards disability by presenting a new perspective on it.

This project titled “Recasting Societal Perception towards Disabilities: An Analysis of Progeria in Selected Works” aims to dismantle the created, inaccurate perception of disability by changing how disabled bodies are portrayed in institutional and conceptional frameworks in order to establish a pluralistic world of abilities. The project is divided into four chapters. The first chapter of the project examines how the ideas of disabilities portrayed, highlighting how Hayley Okines overcomes her disability and defies all social conventions in her novel *Old Before Times*. The second chapter shows how movies have an adverse effect on how society perceives disability, which is seen as abnormal or as something to be feared. In the conclusion for the sake of destigmatising disability here it aims to redefine the societal perception of disability.

Chapter One

Introduction

Sharu says, “I’m privileged among the disabled people’s community to a certain extent, but I’m not much privileged in the ablest society” (*Cultural Studies*)

Who else be perfect, even the world itself is imperfect? When perfection is required for an individual to be accepted into society’s normative standards, individuals are pretend to be normal. According to the societal norms of perfection, a perfect body is one that is free of abnormalities or it should be proportionate to the gauges of beauty standards. But in this world, it is believed that more than 500 million people worldwide suffer from some sort of physical, sensory, or mental disabilities and their lives are frequently complicated by social and physical barriers which limit their ability to fully participate in society. Therefore, it can be claimed that society has the power to either improve or exacerbate a person’s disability.

In the past, people with disabilities were stigmatized and thought of as having only their own problems. However, studies on developmental disabilities have changed how people view the concept of disability. The disability study is an interdisciplinary branch of research, which has a significant emphasis on the humanities and social science and investigates disability from the perspectives of culture, society, and politics rather than from medical or psychiatric perspective. This area of study questions that paradigm and offers an alternative perspective on disability from contemporary society as well as from many cultures and historical eras, challenging the use of the term disability to denote a gap from the standard in

the later disciplines in an effort to bring the impaired closer to the recognized norm. Disability studies aim to increase the understanding of disability, comprehending how it manifests in the society, and advocates for social change for those who have disabilities.

Disability studies considers disability is not just a medical condition, but as a political construction and a cultural identity. Disability is not only a collection of mental or physical impairments; it is also the result of interactions between the physical, cultural and political environments, which shape how diverse capacities are perceived and experienced. Disability studies see people with disabilities as not as a mere object of gaze but acknowledge producers, contributors and creators (Kaboor *JP Journals*)

When tracing the origin of disability, it can be traced back to the disability movement in the west during the late 1960s. They are greatly influenced by the movements of other marginalized community. The activist focuses on changing the ways of understanding the disability. At that time the definition of disability was based on the personal medical problem to political one. Disability is much more than that it has a lot to do in relation to society.

According to the disability right activist, disability is not a problem with the individual but with the society, as they create hindrance to those individuals. They are against the medical model of disability which considers the disabled person has the problem and not the society. People before the emergence of disability movement when the medical model was in power, they used to be subjected to medical diagnosis and treatment. It resulted in the feeling of pity.

Even today there is the influence of medical model in certain kinds of charity activities. In this context it is necessary to understand the meaning and definition of disability. Disability is commonly defined by dictionaries as a disadvantage or deficit, particularly a physical or mental impediment that limits one's capacity to perform routine tasks; something that prevents capacities or disqualifies. The term "disability" is a broad phrase that describes a physical and mental ailment that is thought to have a significant medical impact. For people with disabilities, the medicalization of disability has had a wide range of negative effects.

Though they still have an impact on conventional understanding, for a very long time, the only way to describe disability was through the use of diagnostic categories, medical definitions attempt to divide individuals based on biomedical conditions. These definitions had their roots in the biological deterministic perspective of human variation. This "medicalization" of disability depicts human diversity as an outlier, a pathological condition, a shortcoming and most importantly, as a burden and a tragedy for the individual. The medical model of disability sees it as a pathological impairment of a body system or function. Disability studies created its own theoretical framework in response to these misconceptions about disability.

People's attitude towards disability is influenced by the way they think about it. Everyone has a unique perspective on disability; these viewpoints can be divided into three broad categories: moral, medical and social model theory of disability. Disability studies mainly encompass three models. The first one is the moral model, which holds that a person's disability affects their karma, character, behavior and views, as well as their family. From this vantage point,

a disability may be connected to stigma, shame and guilt particularly if it is perceived as an indicator of wrongdoing (Olkin *American Psychology Association*).

On the other hand, disability can be seen as representations of fortitude, bravery and faith. For instance, a religious individual can believe that God chose them to have a disability as a result of their faith in them. Disability may occasionally be seen as proud reminder of conquering hardship in life. The moral model is commonly portrayed in the media and is widely used around the world. In movies they are portrayed as evil or someone who goes beyond human levels to accomplish their goals.

The influence of moral model of disability also can be seen even in the most celebrated mythological texts where certain portrayals of people with disability can be seen. They are presented as either strong, cunning or crafty characters or as beggars who are in terrible suffering and poverty. Ashtavarka, who was born to a Brahmin family, was excellent in learning Vedas and other sacred texts at a very young age, but unfortunately, he was born with a disability and was mocked by other intellectuals at king Janaka's court.

Hindu mythologies ignore women with disabilities completely. An excellent illustration may be found in a tale from the Karthik Poornima, in which Lord Vishnu declines to wed Lakshmi's disfigured older sister, claiming that there is no space for disabled persons in heaven. Then the sister is wed to a peepal tree as a substitute.

The other model is the disability social model theory which was developed in opposition to the conventional paradigm. It is a predicated notion that disability is not a result of physical deficit but rather than social

functioning and exclusion. The social paradigm holds that people are not to blame for their disability. The social model theory of disability advances this notion. It is based on the distinction between impairment and disability, as well as between those who are not. This model is crucial to the liberation of people with disabilities. The goal is to eliminate any barriers that disabled individuals may encounter. The social model also aims to influence how the general population uses individuals with disability. The social model erases a variety of false beliefs prejudices in people's thought. The social model views a person's disability as a component of their identity, much like their colour, ethnicity, gender etc.

According to this view point, a person's disability results from an environment that is inappropriate for them both physically and socially. It is said that not the disability, but this environment is what generates the limitations and hurdles. According this viewpoint, rather than focusing on those who have disabilities, the best method is to treat disability is to alter the environment and society.

The disability study theorist asserts that barriers erected by society that prevent disabled individuals from full participation in society are what produced the disparities that disabled people must contend with. The aim of disability studies is to destigmatize disability. However, disability studies examine how physical, mental, or physiological disabilities are defined and how they affect people, with the ultimate goal of minimizing all forms of prejudice and discrimination; it examines disability from medical, legal, and cultural perspective.

This project is concerned with the disability called progeria. The term Progeria has a Greek origin from the word's "pro" meaning "before" or "premature" and "geras" meaning "oldage" and is described as a rare, fatal, "premature aging syndrome" which causes disabilities in early childhood. It is caused by a tiny spelling mistake in the DNA sequence. The gene responsible for Progeria is called LMNA (pronounced "lamin-a"). The LMNA mutation causes the gene to produce an abnormal LMNA protein called Progerin in kids with Progeria.

Progeria is classified into two types- Hutchinson Gilford Progeria Syndrome, which has its onset in early childhood and Werner Syndrome (adult progeria) which occurs later in life. Fortunately, the intellect of children with progeria is unaffected, despite the physical changes in their young bodies. Its symptoms include growth failure, loss of body fat and hair, skin changes, stiffness of joints, hip dislocation, atherosclerosis, cardiovascular diseases and stroke. (*The Progeria Handbook*).

According to Dr. William C Sheil in *Webster's New World Medical Dictionary*, "Progeria is a rare genetic disorder that causes children to age prematurely. It is characterized by dwarfism, baldness, pinched nose, small face and small jaw relative to the head size, delayed tooth formation, and aged looking skin, diminution of fat beneath the skin, stiff joints and premature atherosclerosis. It is due to a single- letter "misspelling" in a gene on chromosome 1 that codes for lamin A, a protein that is a key component of the membrane surrounding the cell's nucleus" (Sheil *The Progeria Handbook*)

Children with Progeria die of stroke or cardiovascular arrest at an average age of 13 years. Statistics data suggest that it affects approximately 1

in 20 million people. Progeria Research Foundation was established in 1999 in US by the parents of a child with progeria, Drs. Leslie Gordon and Scott Berns. It is the only nonprofit organization worldwide which is dedicatedly working for finding treatments and cure for progeria. According to PRF there are approximately 200 to 250 children living with HGPS worldwide at any given time, of which 60 are from India. Progeria affects both sexes and all races equally. Since it a very rare medical condition very less medical research has been done to support and address the Progeria kids. Very less work and research has been done in the media representation of Progeria, which is noticeably underdeveloped. In order to understand HGPS holistically, as well as the real condition this gap should be addressed. The present study accomplishes this by interrogating representation of Progeria in four selected films and one life writing.

Representation is incredibly important for people who are outside the norm because it allows them to create an identity for themselves in an environment that so often ignore their existence. When it comes to the representation of disability in literature, it is clear that we need to redefine that norm. Specifically, by interrogating representation of Progeria in the films like *The Curious Case of Benjamin Button*, *Ratsasan*, *Jack*, *The Aurora Encounter* the researcher also examine how they are represented in a life writing of Hayley Okines' *Old Before My Time*. In the film *The Curious Case of Benjamin Button* centers on Benjamin Button who suffer from a rare ageing condition, where he ages backwards. The film *Ratsasan* tells the story of a brave police officer who tracks down a psycho serial killer murdering school

girls. The film gives us a strawman villain in the form of an Anglo-Indian young man who has Progeria.

Films are considered as the very powerful medium that can either encourage or shatter how people feel about themselves and other people around them. Contemporary society is very much influenced by the media and its representation. People from all walks of life; deserve to see their stories being portrayed on the big screen. Representation of disability in the fictional characters has a great impact on society's views on individuals with disabilities in the everyday lives.

In 'The Disabled Person in Society: A Historical Perspective', Ramon Puig and Stephen Von Tetzchner puts it in as "Disabled people have always had a place in the society, but a place that the abled-bodied community prescribed for them. Mainly the roles given to disabled people had negative characteristics. Deaf people were considered as a special case as per Roman law. Occasionally, a disability was linked to a special ability. For example, special skills were attributed to the blind people, with regards to poetry and music, and "seeing in to future". In old Greece, Rome and Egypt disabled people were attributed to rejection as well as socialization. In one extreme, the person with impairment could be the expression of evil, and in the other extreme, a hierophant. The focus did change, with the rise of Christianity. People who were sick, crippled, blind or deaf were considered as objects of Charity and people who are mentally retarded as "innocent". In the 19th Century with the wave of positivism it led to a new emphasis" (Puig *The Disabled person in society*)

Children with disability have a rooted lifelong effect on their physical, mental and emotional health as well as their social situation. Childhood is one of the most sensitive time periods, where most of the development takes place. Children with disabilities are one of the most deprecated and dismissed groups in the society. They are often victims of daily marginalization in the form of negative attitudes, lack of adequate policies and legislation. They are always denied their rights to healthcare, education and even survival. Majority of these children, are often likely to be among the poorest groups of the society. Their disabilities often place them at a higher risk of physical abuse and often they are barred from receiving proper nutrition or care they need in emergencies.

Annie Segarra is a disabled American artist, and activist for LGBT and disability rights. She has been successful in advocating accessibility, body positivity, and media representation of marginalized communities. She argues that mainstream movie characters with disabilities are either portrayed as being tragic and depressed, or they exist only to further the narrative of the main character. She also cites several examples including *Me Before You* and *The Ringer* which shows disability with a negative effect. While there are some films like *Avatar* and the *X-Men series*, that feature disabilities in a positive representation, where the audience too is amazed and feels compassion towards these characters.

Life Writing may be the most powerful and accessible tool in the literary genres for the marginalized groups. It requires less literary expertise and more real-life experiences, unlike fiction or drama. One such work is *Old Before My Time* by Hayley Okines that takes the readers through more

realistic and encouraging journey of a 13- year old teenager, who is born with Progeria. Hayley Okines (3 December 1997- 2 April 2015) was an English author and activist who had extremely rare genetic disorder Progeria. Throughout her life she actively campaigned raising awareness regarding the rare genetic disorder. Even though she died at a very early age of 17, she inspired many with her incredible message and story. The readers get driven by the positivity that is reflected by Hayley and her mom Kerry on her unusual life experiences. *Old Before My Time* traces the life of Hayley Okines, who lived her entire life with a severe genetic disorder (Progeria). It is inspiring life writing where she portrays the challenges she and her mother faced, the positive and the negative influences she had in her life. Regardless of her age she has been a genius in writing her disability so effectively, that the readers get a real picture about a disabled person and disability.

She can be considered to be a white dove ensnared in a thorny bush fiercely stretches her wings and soars over the sky like the Phoenix rising from the ashes. The transformation from a Dove to a phoenix is not as easy as we think, it needs arduous effort to undertake such journey in her life, and even at the face adversity she exuberantly reverberates the joviality in life. Even though she is well aware of how severe her disability is, she doesn't let it bother her since she assumes it will go away as she ages and her progeria disappears. According to her teacher Mrs. Haines, she worked hard to retain everything she had learned. She never felt like she had disability as she thought of herself as normal and ordinary as everyone else. She becomes liked by other students of her age because of her upbeat personality. She consistently made an effort to bring out the best in people.

When she first started going to school, she was worried about her. As her self-consciousness increased, she refused to leave the house without a hat on her bald head. She believes that she shouldn't be burdened by internal inconsistencies. But as the years went by, Hayley's progeria started to show. She becomes slimmer, and now she is referred to as a sack of bones. The loss of hair was the most visible indication of change, but she mindfully ignores it. Her days are short and every day is bliss. She had sleepless nights and endless days where she was endured by the extreme pain and difficulties. Even lives become worsen and harder, she was enthralled by her own hopes for the future.

Films portray disability differently than book. The way that people with disabilities are portrayed in movies affects how society views them generally. Film is regarded as one of the most expressive forms of media since it appeals to people's senses on all levels. As an influential medium, it particularly appeals to our senses of sight and sound, allowing us to experience and feel the emotions, sensations and thoughts of the characters being portrayed. Hence, it is evident that films had a significant impact on people.

Films frequently have a tendency to fictionalize stories and add embellishments to suit the tastes of the audience. Films frequently depict crippled individuals as a source of sympathy or even humor. Sometimes, they are even depicted as something to be feared, it makes changes in how others view disabilities and those who are disabled. They are treated as an alien or an extraterrestrial being.

The most noteworthy aspect of these films is how they treat their characters, note that they have protagonists with disabilities. In addition to being stereotyped, people with disabilities are not accurately represented in the media. The victim, a figure who is portrayed as a helpless object of sympathy or pity, is probably the most prevalent stereotype of people with disabilities. The character being portrayed as a hero who shows himself by overcoming his infirmity is the second most popular kind of stereotyping, and the third is labeling him as a villain.

The way disability is perceived by the society is one of the major concerns of this project. Books and movies both played a significant role in influencing how society views people with disability. A person with disability is typically shown in books and novels in entirely different ways, but in autobiographies like Hayley Okines *Old Before My Times*, there it presents the true tale of a person with disability which reflects the problems, pain and challenges she and her family faced. She never cursed her abnormalities instead; she referred to them as special. She overcame all of her physical challenges and overcame them to achieve success in her life. Others who battle with their disability seem to find motivation in it.

In movies, disabilities are often portrayed negatively. Either they portray cripple people as pitiful in order to arouse sympathy in the audience, or they portray them as terrifying monsters in order to attain blockbuster success. Therefore, it cannot be assert that movies depict real life stories of individuals with disability and this would have a negative effect on the audience because they would fear those people whenever they see them with their menacing look.

Hence, this project attempts to reveal how society views disability and how it is portrayed in the book Hayley Okine's *Old Before My Times* and in selected movies and thereby, recasting the attitude of society towards people with disability. The chapters in the project are divided into four. The first chapter of the project highlights the origin and evolution of disability studies. The second chapter analyze how the concept of disability is presented, highlighting how Hayley Okines in her book *Old Before My Times* overcomes her disability and disproves all societal norms. She asserted that she had faith in herself and said "I am the same as everyone else deep down, wearer all fallible". The third chapter demonstrates how films present disabled people and it is noted that films exert a negative impact on how society views disability, which is viewed as abnormal or as something to be feared. In the conclusion for the sake of destigmatizing disability, the project aims to redefine the societal perceptions of disabilities, with a hope that this study would inspires people to give up on their perfection to accept the flaws and improve their imperfections, because everyone is perfectly imperfect.

It is believed that people with disability and their surroundings determine their level of disability. Disabled people have endured unfair treatment for many years. They have been viewed as ridiculous and pathetic or non-human and malevolent. Even some people mistakenly believe that disability is God's punishment. This attitude will change when one tries to understand oneself with them and everyone should understand that nobody is born bad but it's the society which "makes" or "breaks" an individual.

Chapter Two

Piling up the Ray of Hope to Live

Hayley Leanne Okines, a prolific author and campaigner, was born on 3 December 1997; she had the incredibly rare condition progeria. She is well known for raising awareness regarding of the illness among the public.

Hayley participated in a treatment trial that exceeded doctor's expectations, for her anticipated lifespan, despite the fact that progeria patients only lived up to the age of 13. At the age of 17, she passed away on April 2, 2015. Her mother, Kerry and co-author Okines, released her autobiography, *Old Before My Times*, in 2012. It was her first and only book, which detailed her upbringing and progeria battles. Her second well-known novel, *Young at Heart*, chronicled her disability battle and adolescent years filled with passions.

The story of Okines, who had progeria in her entire life, is told in the book *Old Before My Time*. She and her mother, Kerry, portray their struggles as well as the positive and negative influences they had on their lives in this amazing novel. The book follows Hayley as she travels the world and meets her pop idols Kylie, Girls Aloud, and Justin Bieber, as well as her delight and heartbreak as she loses her best friend to the syndrome at the age of 11. She candidly discusses her expectations for the future and her positive outlook towards her ground breaking drug trials in America as she approaches the age of 13, which is the usual life expectancy for a child with progeria.

In the opening of the book, Okines explicitly states that she considers herself "unique". She considers herself as special. Hayley comes across as someone who is really optimistic about her situation. She views having

progeria as an ability and is pleased of the person she has become despite having a serious illness, she thinks that she was one in eight million because her disease was so uncommon. She had been the subject of numerous TV shows because she was so unique, and when strangers approached her and ask whether they have seen her on television, she had to smile and be courteous.

People with disabilities frequently encounter presumptions of all types from society or the so- called normal people. But Hayley appears to refute these presumptions. The disabled individual believes that their disability is their end and the worst possible fate a person might experience. People frequently ask Hayley whether she wishes she didn't have progeria; she always responds with a resounding "no". According to Hayley she would still prefer to have progeria to not having it. Hayley is conceived that she is identical to everyone else.

The novel is divided into thirty-three chapters, of which some are written by her mother Kerry, and some are coloured by Hayley. She enjoys her life and seeks happiness through her constant participation in all the activities and world tour. The work clearly shows what it actually means to be living with progeria and how hard it is for the parents to keep counting each day as a blessing. Hayley's mother, Kerry, is equally strong as Hayley. She had taught a naughty trick to deflect the unwanted attention of anyone who stared at her for too long. She seems to be a very polite and emotionally strong person who wouldn't mind if these people had spoken to her instead of giving her long stares. She is ready to give them what little knowledge she has about progeria. When Hayley was taken out in her wheel chair, she was always aware that strangers were staring at her, and she would simply respond by sticking her

tongue out, causing the starrer to quickly look away and move on. She is like every 2- year-old naughty and timid girl, even though she looks old.

This mischievous act gave them both a wicked sense of satisfaction to watch their embarrassment. Both Kerry and her husband are working very hard for Hayley to make her special at every moment. Very soon after her diagnosis, Mark and Kerry agreed that they would never shield her from the public gaze, and that meant appearing in the media. The media took Hayley's photographs and she often interviewed along with her parents. The local paper storied Hayley's progeria story and very soon calls from news agencies, women's magazines, television companies, radio stations, and all were waiting exclusively to have access to Hayley's amazing story.

People started to donate money, gift and were also offered world trips. Hayley's condition was spread through newsrooms around the world, from Germany to Japan. Hayley was four when her story was shown in a series of extraordinary people documentaries titled, *The Girl Who Is Older Than Her Mother*, which showed Hayley's diagnosis to her first day at school. Kerry also shares her experience of sending Hayley to school for the first time and it turned out well, she was warmly welcomed and had made many friends, except for negative comments, Kerry states:

I remember how at the end of the day she had run to meet Mark and me waving a paper plate covered with glue and strands of black wool and crayoned eyes and mouth. 'This is Stacey', she announced handing her artwork to Mark. (Hayley 75)

It is usual for a mother to be concerned about a child's school life if her child is different from other kids of her age. Kerry in one of the chapters

says, “Her personality and childhood innocence had protected her so far but her insurances on covering her head in public made me think another child had said something to her” (80) and she also states that, having no hair has never seemed to bother her until she started school, Now she refuses to go out without her bandana. Kerry was satisfied that the school would do everything they could to protect Hayley from cruel name-calling.

From chapter seven “No Hair, No Nits” Hayley takes her story further. She says that she didn’t mind that she didn’t have much hair because she knew she had progeria. A cameraman had asked her whether she minded having no hair and she said, “It doesn’t worry me. One day someone said to me if you had a wish what would you wish for, she said she wants nits because other people have hair so they can get nits, but she didn’t (84). She also talked about her friend Erin who has severe Eczema.

I wanted Erin to be my friend because she was different like me, but she was bigger. When I played hide and seek in school, I couldn’t catch the other kids because they are too fast, but Erin didn’t run away. She has always stood by me because that’s what best friends do. (86-87)

Hayley feels that living with progeria is hard because people treat you like a baby. She can be seen as any other frustrated teenager, who wants to shout at them, ‘I am not a baby’. As she ages, Hayley is feeling more comfortable sharing secrets and things to Jane who also loves her, because she didn’t want to worry Kerry. She also talks about her ‘special bond’ she shared with her grandparents. Kerry also remembers the instance when Hayley was born, a nurse turned to her grandmother and said ‘You would think she was a

princess'. To which she replied, 'She is a princess to me'. It seems Nanna and Pops were the most important people in Hayley's life and she was the center of their world.

She accomplished her dream of meeting the renowned personalities and receiving an award, which was like her dream come true moment. For Kerry when she discovered Hayley had been nominated for an award at the women's own Children of Courage Awards in 2002. Prince Charles would be presenting ten children with medals for their bravery. Hayley was being honored for her understanding courage having been nominated by readers of Women's Own Magazine, who had followed her life through magazine features. When she was walking into the Abbey she met many celebrities and it was very positive and emotional response from their side. Burly East Enders actor Ross Kemp sweat give her a hug, Pop star Billie Peter gave her a kiss, and Veteran comedian Sir Norman Wisdom tickled her bald head. When actress Suranne Jones laid her eyes on Hayley's cherry face, she was so overcome with emotion and started to cry. Hayley can be seen as a very sweet and stubborn girl, who asked Prince Charles for an autograph even though she was told by his manager that he didn't like to give autographs.

The instances from the chapter seven: "No Hair, no Nits", gives a clear picture of Haley who, despite her abnormalities, made an effort to bring positivity and likeness to life, striving to realize her dream before succumbing to death, though she never want to lose her hope as she enjoys life to the fullest. She says she didn't mind that she didn't have much hair because she knew she had progeria. A cameraman had asked her whether she minded having no hair and she said, "It doesn't worry me. One day someone said to

me if you had a wish what would you wish for. I said nits. Because other people have hair, they can get nits and I don't (84). She also talks about her friend Erin who discovered Hayley had been nominated for an award at the Women's Own Children of Courage Awards in 2002. Prince Charles would be presenting ten children with medals for their bravery. Hayley was being honored for her understanding courage having been nominated by readers of Women's Own magazine, who had followed her life through magazine features. When she was walking into the Abbey she met many celebrities and it was a very positive and emotional response from their side. *Burly East Enders* actor Ross Kemp swept Hayley off her feet and give her a big hug; pop star Billie Piper gave her a kiss and veteran comedian Sir Norman Wisdom tickled her bald head. When actress Suranne Jones laid her eyes on Hayley's Cherry face, she was so overcome with emotion she started to cry. Hayley can be seen as a very sweet and stubborn girl, who asks Prince Charles for an autograph even though she was told by his manager that he didn't like giving autographs.

And at that point she broke the Cardinal rule and asked, 'Can I have your autograph, please?' Her cheeky smile won over the royal guest who replied, 'Only if I have yours.' Hayley scribbled her name on a piece of paper and give it to the Future king of England and he returned the favor. (131)

During her course of life, she had met many celebrities like popstar Kylie Minogue, Justin Bieber, Steve Irwin and many others. James documentary filmmaker also shadowed her second documentary *The Girl Who Is Older Than Her Grandmother*. In 2004, Hayley had another of her wishes

granted when she met the Crocodile Hunter Steve Irwin. He had also visited her and handed her free tickets to the zoo and the Port Lympne Wild animal's park, where she had an extra ordinary experience of meeting the gorillas, crocodiles and the black rhinos.

In chapter 15: "Being Famous Can Be Annoying", she states that, "The Best thing about progeria is that I get to go to really cool places and meet cool people." Hayley's relationship with her brother Louis and sister Ruby is very much evident. Like in any relationship, sibling rivalry was not a new thing. Hayley states it as such:

I was not pleased when my brother Louis was born. I had to share my bedroom with him and he would wake me up in middle of the night crying. When my sister Ruby was born, I was happy. I wanted a sister to play with and I knew when she was old enough, we could share our dolls and clothes. When I was little, I had lots of Bratz dolls and I would let Ruby play with them and I would do her makeup. (175)

She claims that she and Ruby had a weird relationship, sometimes they hated each other and other times they are best friends. They also argued like any other siblings and at the end asked each other whether they are best friends. Also, they are very open with Hayley's condition and they also share their opinions. Louis is the one who worries that he is the smallest in his class and frequently complains about it to Hayley to which she responds very positively and said that she is the littlest in the whole school. Hayley is a very patient girl who knows how to accept herself the way she is and never feel bad about it.

Like any other kids of her age Hayley too likes to wear beautiful clothes. She also feels jealous of Ruby many a times, because she has really nice clothes. She is also very happy about Ruby and Louis' health and says, "I don't feel jealous of Ruby and Louis' health. "If I didn't have progeria, I would not get to do cool stuff and meet really cool people" (192). Even though these siblings fight with each other, but at the next moment they are one soul and two bodies. Maddie was one of her best friends who had progeria. Her death was one of the most traumatic things that Hayley overcame. Because of her age she didn't know the meaning of 'death' and later on she has a very positive attitude towards Maddie's death and is comfortable with it. Also, Hayley's condolence speech at Maddie's funeral was very emotional and positive, "Maddie, I love you lots and always. I'm sorry we had a fight. Thank you for being my best friend and sister. Hope you had a safe journey. See you in heaven" (192).

In chapter 20 "Hope for Hayley" brings in hope for Hayley, her family as well as for many other progeria kids. In 2003 Dr. Leslie and a team of scientists in America had had been trying to find the cause of progeria in order to work on a cure. They also found that Lamina A protein- Progerin is a defective and unstable protein that cause children to age premature in which there are more than 8 million children around the world were affected by it. They selected a total of 15 children, including Hayley, were invited to take part in the drug trial, which is a hope to extend the lives for progeria kids. Hayley during her treatments was very cooperative with her doctors and patiently went through each and every phase of it, with a hope to live longer. Her parents were very worried about the drug trial and how it would turn out.

Kerry was like, “I know it’s a risk because the drugs have never been used on progeria children before. It’s a risk I’m willing to take. We have no choice”(192).

Hayley’s hope for growing hair and growing tall is very visible in the chapter: “I’m Gonna Grow Hair”. She seems very excited to have long hair like other teenagers of her age. She readily took all the pills and underwent several treatments; including needles which she hated the most, only with the hope to grow tall and grow hair. She even had dream that she grew in to a beautiful girl. “In my dream I took the drug and woke up and really had long hair and was really tall. I looked like my sister Ruby. It was cool time. When I woke up, I remember thinking, that’s what’s going to happen; your hair is going to grow. But I knew it wouldn’t happen overnight” (209-210). Hayley started checking herself in front of the mirror each day and she felt the drug hadn’t worked out quite like she wished. But gradually found that little eyebrows are growing. She even imagined that if she gets eyelashes, she can put mascara on them, she also felt taller, since she has been taking the drugs.

The teachers at school have been very supportive of Hayley and her progeria throughout her school life. They have held special events and cake base to raise awareness and money for Hayley’s charity. When Hayley reached High school, it seems she hated going to school, because everyone seemed really big and she was really tiny. But many of her school friends supported her. If someone is staring at her they say, ‘Stop staring! Leave her alone.’ Hayley showed great maturity when her parents decided to get divorced. She also found that they were much happier staying away from each other.

When Hayley was 13, she was a typical teenager who loves shopping and sleepovers. She was very active in social network sites Face book and Twitter and had thousands of virtual friends all over the world. She used to receive thousands of messages on Hayley's website. Once there came across a rumor that Hayley passed away. When Hayley found out about the rumor she responded as, "That's Ok, I've read that Justin Bieber has died six times" (197). She has also received many ignorant and hurtful comments like, 'Why that girl got a bald head? Or 'That girl looks so weird'. The most terrible message received on the Face book page: 'Your child looks like an alien and I'm an alien mother from space. I'm going to come down and take my baby' to which Kerry boldly responded as, "Your pathetic boy, take a good look at yourself in the mirror before you criticize other people" (197). Kerry and Mark have proved to a wonderful and supportive parent for Hayley, making her each moment cheerful. People with disabilities are often trolled on social media. Throughout the novel a reader gets a positive response, except for a very few negative comments. The books follow Hayley's inspirational journey and her struggles trying to cope up with the condition.

The story narrates the pain and the suffering of a thirteen -year-old girl. She developed into a powerful advocate for those with progeria, who have got a fewer chances of survival. Progeria patients are believed to have lived an average life expectancy of thirteen year. Even in this story it is evident that Hayley never sheds her hope to live. She overcome her fate while spreading happiness to everyone she encounters. She is special in so many ways. She removed all her obstacles through her own effort. Within the confines of the four walls of the hospital room, she created her own colourful world. She

never loses her hope because she is the mentor of her own life. She emphasized the value of life. Since nobody in the world is perfect, anything can happen to anyone which has the potential to change our lives.

Chapter Three

Normalcy in Disguise

Growing up with disability is a form of life. To understand this life form, it is necessary to acknowledge that disability is a social and cultural construct which reflects a society's policy and practice towards people with disabilities (Oliver 1986). Such policies and practices of being made by able-bodied majority vary from country to country. Such policies and practices have changed during the recent years typically from segregation of disabled people to non-segregation, and from their dependence towards independence. Disability has its own effect on the society as well as on the person who is disabled. The disabled person gets more conscious and tries to find answer to the question "Who am I?" and there develops the notion of "Self-concept". According to Roy Baumeister, self-concept is "The individual's belief about himself or herself, including the person's attributes and who and what the self is." Self-concept is a very controversial and complex term that is related to several other constructs like self-esteem, self-images, self-efficacy, and self-concept awareness.

Disabled people are distinguished from non-disabled people. Disabled people are an oppressed group, and often non-disabled people and organizations-such as professionals and charities-are the causes which contributed to that oppression. Michael Oliver argues that the social model is a useful tool rather than a theory, idea or concept". The social model demonstrates that the problems disabled people face is the result of social oppression and exclusion, not their individual deficit.

The social model has been effective psychologically in improving the self-esteem of disabled people and building a positive sense of collective identity. The focus is on the individual, and on her limitations of body and brain. Lack of self-esteem and self-confidence is a major obstacle to disabled people participating in society. The social model has the power to change the perception of disabled people. The problem of disability is relocated from the individual, to the barriers and attitudes which disabled her. It is not the disabled person who is to blame, but society.

People with disabilities were viewed as tragic, unique or cunning in some way. They were not allowed to work, mix with others or travel and many were placed in asylums. Ingstad and Reynolds claims that media representation of disability often relates to insanity and evil. This is evident in such things as super hero movies, where the bad character is often portrayed as physically deformed or mentally unstable.

One of the films that have been taken for the present study is film that is *Ratsasan*. It is a 2008 psychological thriller film directed by Ram Kumar. The film features Vishnu, Amala Paul and Saravanan. The film was ranked at 2nd in the IMDb Top Indian Movies of the year 2018. The film revolves around the story of an inspiring police officer, who tracks down a serial killer murdering school girls. The film's menacing villain Christopher is considered as one of the most terrifying characters in Kollywood. The title of the film *Ratsasan* itself means 'demon' in the literal sense. If an image from *Ratsasan* crawls in to the eyeballs and gnaws at the brain, it's this one: a serial killer loom over to a petrified little girl, with a hammer in his hand. The character of Christopher affects the viewers by bringing in the feelings of disgust and fear,

more than sympathy or pity. He is shown as an Anglo-Indian teenage boy who suffers from Werner Syndrome, where he looks very old for his age, like his mother Mary who is a magician. The reason behind his psychopath brutal nature is substantiated by his disability. Even though his mother knew he would never be accepted by his friends or society, she takes a lot of effort to make him 'fit' with other children of his age, she introduces him in school through magic show'. Even though the students were delighted by Mary's magic, they were refraining from accepting or making friends with Christopher. The only person who accepted Christopher was Sophia. Christopher found solace only in Sophia other than his mother. He misunderstands her friendship for love and when he confesses his love to her, Sophia is shocked at the beginning and later on when he starts pestering her, she feels disgusted to confront him. Another striking scene is where, he pleads before her to accept his love and after many failing attempts to make him understand, she tells him he was impotent and she hands him various books on genetics. She also explains him about his hormonal condition. The conversation goes on as:

CHRISTOPHER: I am normal.

SOPHIA: No, Christopher! Don't make me say it!

CHRISTOPHER: Sophia, please be with me forever.

SOPHIA: You are not fit for marriage, you are impotent. Please don't follow me in the name of love, marriage or friendship.

(Ratsasan 1:55:14)

The same night he goes in front of the mirror, starts talking and weeping about his condition and how others hated him. With great struggle

Mary convinced him that he will become the great magician. In order to boost his self-esteem and to come up his “drawbacks”, she styled him up a bit. But when he reaches school, he is shattered when everyone calls him “impotent”. He considers Sophia responsible for this and brutally kills her. He goes on killing many school girls brutally. Also, the psycho character is seen showing many stunts and martial arts in the film, which is not at all practical in real condition. The psycho serial killer is feared by the entire city, due to his extraordinary brutal way of killing, a detailed description is given regarding the way in how he kills the girls. The doctor who conducted the autopsy of one of the girls says, “I guess, the killer doesn’t know what pain is! Black heart! He drilled out her eyes, then broke her teeth and uprooted her hair patch by patch. On top of that, he has scarred all over body with knife. He did this all while the girl was alive. This man is suffering from “Antisocial Personality Disorder” with aggression and deviant behavior, in short a “Psycho”. All these details regarding the psycho evoke a feeling of fear, disgust among the viewers. It would have been a different scenario all together, if the character of Christopher was a “normal” person. But by adding a special disability to Christopher, the image of a psycho killer has greatly shifted from a “normal person” to a “disabled one”. Now whenever the word “psycho” is heard, naturally the image of Christopher with a hammer in his hands comes in. Due to this misrepresentation, the way a society looks or confront can be greatly affected. People will have a fear while talking or when getting closer to such people.

Music creates mood and there is a connection between music and an emotional event. In film, music plays a major role to influence the audience to

empathize and sympathies with the character and to understand the mood state of an actor. The horrifying and disturbing background music throughout the entire film was composed by M. Ghibran. This haunting Melody, in its orchestral version, runs through the entire film, punctuating, accentuating and underlying the mood of the lead character that is Christopher, dealing with a psychological problem and a town gone coward. It also has a very negative impact on the viewers.

Next movie that has been taken for the present study is a 1986 Science-fiction named *The Aurora Encounter* directed by Jim McCullough and written by Melody Brooke and Jim McCullough. The film is based on the Aurora, Texas, UFO incident. The film stars Jack Elam, Mickey Hays, Peter Brown, Carol Bagdasarian and Dottie West. The plot centers around a benevolent extraterrestrial (alien) visits a small town of Texas in the 19th century. A number of locals are scared by the sighting of the UFO. One woman also shoots at the tiny alien who peeps in to her house. The alien then joins a drunkard Charlie Hawkins to play checkers. As the plot moves further, we can see the aliens befriend three children. School teacher Miss Peebles, writes the story on the alien, which attracts the attention of the state governor who sends a ranger to investigate and kill the extraterrestrial.

There are many science-fiction movies which have shown aliens since decades. The main thing that differentiates *Aurora Encounter* from the others is that it uses a human with progeria as its alien, instead of person in a costume. Now to some this might seem like giving a child with a rare condition the chance to act and to others it may seem like exploitation. The character of the alien is played by progeria-sufferer Mickey Hays who either

was forced to play in the movie by his parents or is really just not a good actor. Throughout the film Mickey seems to be out of place and his emotions seem very limited. May be because of his condition, he seemed very low and disinterested. Each and every scene where Mickey makes an entry seem like he is not at all enjoying.

The scene where Elam and the Alien play checkers together and get drunk too lack emotions. The alien gets drunk and is visibly intoxicated as he gets back into his spaceship. In the movie we can see he also rescues three school girls from falling into the cave. Towards the end it is shown that the people come to know about the alien and the Governor orders to shoot him down. Finally, when he is shot by the governor's henchman, he attempts to fly back in his spaceship but unfortunately crashes. The editing is so tight and confusing that one cannot tell what's going on. The music and the background color of the movie failed to create an emotional impact and failed to show the seriousness of many situations in the plot.

Hays brought worldwide attention to progeria when he carried out his role in the movie *The Aurora encounter* and in 1987, he made an appearance in Kirby documentary *I am not a freak*. The disabled-ness of the visitor seems even more pronounce when the spaceship is shown. It looks like a grey, clunky, old Ford Pinto without wheels, and it wobbles side to side. Throughout the film his unnamed character is represented as mute and has no dialogues. When the three school children meet the cute alien for the first time, they are very much shocked and startled, ending up in a loud scream. But later on, they are carried away by his friendly behavior, and accept him

the way he looks. Mickey Hay is considered to be one of the longest survivors of Progeria.

Jack is a 1996 American comedy- drama film starring Robin Williams and directed by Francis Ford Coppola. William plays the role of Jack Powell, a ten-year-old boy caught in the body of a forty-year-old man. Jack is shown as a boy who ages four times faster than normal as a result of Werner Syndrome, a form of progeria. In the film when the baby is diagnosed with an extreme form of Werner Syndrome by Dr. Lin, he colloquially explains his condition by rendering him “sick as frick”. The word ‘frick’ is very offensive and is similar to damn.

Till the age of ten, Jack is giving home tutorial by his tutor, Lawrence Woodruff. He is shown extremely childish, as he only socialized with his parents and his tutors. Later on, when his tutor convinces his parents about sending him to public school, his parents was initially balk, for fear Jack could be emotionally hurt. When he first attends school, he is exploited and bullied by other kids. He later on wins their hearts by winning the basketball competition and eventually gets those adult magazines and other such items. As time goes by, other kids try to find the kid trapped inside the body of a 40-year-old man and he gets accepted by them. The film carries a negative impact as it failed to balance the comedy with the seriousness of the plot. The purpose of this film is not evident that is, whether it is made for adults because it has so much of melodrama. Also, it fails to give an education or awareness regarding the condition. It focuses much on the juvenile kid humor, like when Jack is playing with the other kids in the tree house or they are farting, which seems very much immature. Many of the scenes failed to show its seriousness, like

the part where Jack got a mini heart attack and falls down the stair, it was shown as a funny scene, instead of having an emotional impact. The background sound of the scene too was very much improper and did not fit the seriousness, resulting the viewers to laugh.

Even though Jack is a ten-year-old, he is being played like a kindergartener, there lies the difference most of the ten-year-old boy don't sleep with adults by giving a lame reason they had a bad dream. Another notable scene is where he is introduced to his school principal as:

Principal: How would you like to see your classroom?

Jack: Yes.

Principal: A little louder.

Jack: Yes

Principal: Louder Jack.

Jack: Yesses. (*Jack 1:15:35*)

In this scene he screams out very loud, this is not normal response of a ten-year-old. Another awkward scene is when Jack asks to his teacher (Jennifer Lopez) for a ball night party. It was very weird for her, to make him understand he is just ten-year-old and it won't be right for her to hang out with him. Even though he tries hard to convince her, at the end he feels rejected and runs out crying like an immature six or seven-year-old kid.

Jack: Do you mind going to the dance with me?

Miss Marques: Jack, you don't want to go with me. I'm an old lady.

Jack: But that's why I can't go with the girls my age because I look so much older than them.

Miss Marques: Jack, you are still a young man here up. I know
I look closer to your age than the other girls in class. (1:20:14)

When we come to the end of this phase of our life, we find ourselves trying to remember the good times and trying to forget the bad times. We find ourselves thinking about the future, we start worrying what I am going to do, where I am going to be in ten years. I say to you, hey look at me please don't worry so much because in the end none of us are very long on this earth. Life is fleeting and if you are ever distressed cast your eyes to the summer sky, the stars are strung across the velvety night, when a shooting star streaks through, when he gobbles down the floor with minor heart attack, his mother thinks that it is best for him to be taught at home. He gets in to an argument with his mother and runs away to a night club. There he ends up in to a terrible fight with another man. As the plot proceed further, he is depicted as sitting alone at home, not going to school, neither does he talks to his friends. At the end when he finally comes to school all his friends and Miss. Marques cheer him up.

Then the film takes a seven years skip, and the scenes follows Jacks convocation day, where he also gives a speech. He almost looks like an eighty-year-old man, very weak and frail. As Jack goes on as such, "I'm cool, I don't have very much times the blackness turning night in today, make a wish, think of me, make your life spectacular"(1:45:20). So, he frights off with his friends in a car and what happen after that is not shown in the film, whether his life goes on or he dies or if he makes anything of his life. The purpose of the film was comedy rather than focusing on the syndrome. It also failed to evoke an emotional attachment to the character Jack.

The Curious Case of Benjamin Button is a 2008 American fantasy romantic drama film directed by David Fincher. The story line is believed to be inspired by F.Scott Fitzgerald's short story. The film stars Brad Pitt and Cate Blanchett and portrays their extraordinary love. The plot centers on Benjamin who is born with a very rare genetic disorder where he looks like an old man in his 90s. Since the film is a fictional fantasy, here Benjamin is shown aging backwards and various instances where disability is strongly represented is analyzed in this study. Talking about the title, the word 'curious' which can also mean odd. In the literal sense Benjamin's case is curious, as he ages backwards over the course of life. In the beginning Benjamin starts his life by looking like a normal baby except for his wrinkled skin and his appearance of an old person. Benjamin's father Mr. Thomas Button is another notable figure of high social and economic status in the society. He was not ready to accept the baby who looked too weird (or may be ugly) and eagerly wanted to get rid of it. It seems like he even attempts to throw the baby in to the river (9:57). Later when he sees the police officer, he quickly leaves the baby on the steps leading to New Orleans boarding house for the elderly, where Queenie, accepts him and raises as her own child. We can see a domination of yellow color, in a scene where the baby is being abandoned. It can either represent baby's innocence or Thomas Button's madness. An important sound in the scene is baby's crying, which may signify innocent baby's assault. This brings in a negative impact among the viewers.

When Queenie sees the baby on the door steps, she is startled by the view and she exclaims as "Poor Baby, it's for sure nobody wanted to keep it. Come on, baby" (12:05). She also says to the little baby as such "you are as

ugly as an old pot, but you are still a child of God” (12:07) Benjamin cries like any other baby, but after a closer examination by the doctor he says to

Queenie as:

DOCTOR: He show all the deterioration, the infirmities, not of a newborn, but of a man well in his 80’s on his way to the grave.

QUEENIE: Is he dying?

DOCTOR: His body is failing him before his life’s begin...There Are place for unwanted babies like these, Queenie...Queenie, some creatures aren’t meant to survive.

(15:27)

In this scene’s usage of the word ‘creature’ shows that the baby is not even given the consideration of a human being. Another instance is when Queenie introduces the baby to the old people in the old age home, an old woman reacts as such God in Heaven. She feels that the baby looks just like her ex-husband. Queenie’s husband also makes her understand that it is not right to keep the baby, by claiming that “it may not be even humankind.” The music too that is being played in the background evokes a sense of pity and sympathy among the viewers. Benjamin baby face evokes the feeling of ‘disgust’.

The film takes a leap of six year and the face of Benjamin should normally be of a six-year old. He’s sitting on a wheel chair now...small, shrunken with age, legs and hands crippled with arthritis... Eyeglasses are just one addition. Another instance is where Benjamin is curious and peeps down the street watching kids of his age (may be 7) sitting on his wheelchair. As

soon as he tries to move a step ahead, his mother pulls him back angrily shouting “Benjamin! That is dangerous. Come back over here.” The only reason behind her resistance is her fear of Benjamin being bullied by other children. Another instance takes place Scene 41, in church tent with a Negro preacher, Benjamin and Queenie. Queenie tells the preacher to pray for Benjamin and the conversation goes on as such:

PREACHER: (at Benjamin) And what’s this old man’s irradiation?

QUEENIE: He’s got the devil on his back...trying to ride him in to his grave before his time...(25:30)

This indicates that his mother believes that, he is suffering because of his sins. The music in many scenes are very silent and pleasant, it might be focusing on the helplessness of Benjamin. The colours in the movies are very dull, might be trying to showcase Benjamin’s similar dry state of mind. In the church tent scene, we can see when Benjamin gets up from his wheelchair and one crippled leg at a time, hobbles across the stage. The people urge him with loud string of “Hallelujahs...!”.

In scene 60 it can be seen that Daisy wakes him at midnight and they enjoy their secret under a table with a small lit candle and she realizes that he is not as old as he looks and their conversation goes as such:

BENJAMIN: I’m younger than I look.

DAISY: You don’t seem like an old person... like my grandma... Are you sick?

BENJAMIN: I heard Tizzy and my mother whisper. They said I Was going to die soon. But I fooled them so far.

DAISY: You are different than anybody I have ever met. You are odd. (52:12)

Throughout the movie, the strong bond between Queenie and Benjamin is very evident. They understand each other without even saying a word. After being silent for many years one night a very touching chat goes on between them:

QUEENIE: You are a different child...a man child. People aren't going to understand how different you are.

BENJAMIN: What's wrong with me, Mother? (55:04)

Here it is very evident that the concept of 'Self-image' pops in. Benjamin starts becoming conscious of how he is being perceived by others. He feels disgusted by the way people look at him. Throughout the movie, there is continuous transformation in body image of Benjamin, where he spends much of his "elderly" boyhood in a wheelchair or on crutches, but gradually sheds the disabilities of advanced age as he reaches childhood.

The circle of life is an important theme and a determinant factor of character's identity. From the beginning till the middle half of the film the character of Benjamin is seen with a sense of pity and then suddenly the audience feels proud and mesmerized by the looks of a 25-28-year-old. Almost every character in the film has clear identities. There is Daisy who is the dancer, there is Queenie as a mother figure, there is someone who teaches Benjamin music, someone who is a swimmer, someone who is continuously struck by lightning, etc. All the characters have a determined identity, except for Benjamin, who has no identity. Throughout the film we can see Benjamin's changing careers such as sailor, repair man, security guard, etc.

The struggle of Benjamin leads us to the main idea of the film. It does not matter whether you live your life forwards or backwards, what matters is how you live it.

Benjamin had a totally different perspective towards life in the film. He was very optimistic and appreciated every struggles of his life. The only thing that differentiates Benjamin from others is his outer appearance. He does not have an old perception towards life while he looks old; neither has he had childlike perception while his appearance gets younger. He is totally different from how the society perceives him. There are many scenes which have both bright and dark areas. This preference maybe to create the mental situation of Benjamin: uncertainty, suspense, desperation, alienation.

In this film the character Benjamin is been given an image of a “Superhero”. But in reality, such people celebrate and enjoy being “different”. Disability is considering to be a viable identity variable to be recognized, acknowledged and celebrated. A person need not be shown as a hero, pathetic, a criminal psycho identity, instead he/she should be able to acknowledge his/his difference and celebrate it. Scholars of Disability studies suggest that disability is the ultimate category of abjection, or arguing that everyone is actually all disabled. This evokes the idea that disability is just an add-on to the regular suspects of identity politics- race, class, gender and sexuality. However, the danger if universalizing disability, or ratcheting up its importance, is that disability is played as a trump card, neutralized or seen as a transcendent. For people with disabilities, the experience of operation is undercut, they are situated knowledge’s ignored. Yet it is worth paying cautious attention to the way’s disability is used to stigmatize almost all

“minority” groups, how such groups often distance themselves from disability without challenging its derogatory entailments, thus reifying them, and how norms circulate, affect everyone enforced by everyone. Through the film the disabled person is give the image of a “super hero”, such identities shift the focus away from disability. Such misrepresentations often silence the actual disabled experience and fractures the community, harming instead of helping.

When examining these films, it is clear that the narrative they present is misleading and too dramatic. The disabled person is portrayed in these movies as an alien, monster or weird. People who are watching these films get negative effects as a result of the negative characterisation and narrative. Furthermore, it will mentally and emotionally devastate those with disabilities.

Chapter Four

Conclusion

Different people have various perspectives on the issue of disability. In the family and other social institutions, the person with disability is viewed as an object of sympathy or pity and is often left alone or shunned. People keep distance from the disabled and view them as outsiders. Developmental disability is influenced by a person's personalities as well as how society views and encourages them. This will depend on how the person feels about their own disability, how they feel about other individuals with disabilities and other members of society, as well as how society feels about them.

A disabled person who is stigmatized because of the bad perception of society and this would in turn create anxiety and irritation among disabled people. This attitude and behaviors of society bring a violent and aggressive nature among disabled people. This forced them to be more conscious about their disability rather than their abilities and they become vulnerable.

An individual's physical and mental capabilities have an impact on his or her social status and position. According to a number of studies, religious and cultural beliefs have a significant influence on how non-disabled people perceive, feel about and behave towards people with all kinds of disabilities. The conduct and treatment of the society and family in which he or she lives, as well as the individual's personal attitude toward his or her disability, have a significant impact on the overall development of the individual. In India, people with disabilities are more negatively impacted by the societal attitudes that are displayed toward them in all facets of society than by their actual

infirmities. For disabled people societal attitudes and behaviors lead to extra difficulties.

People with disability would not be considered worthy of respect and are still under the pressure to elicit an emotional response from society, whether it is the image that inspires inspiration. This ongoing pressure highlights how society views individuals with disabilities as undeserving of inclusion in a world designed for abled ones, which exacerbates the discrimination these people already experience. We discover that the word “disability” is defined as something as a lack in human life and also society has a preconceived notion that persons with disability are less competent to care for themselves, as they are always dependent of others. Society always puts obstacles to those individuals and makes them less competent. Individuals with disability are not given the same social, economic, and educational opportunities. Even Medias present those disabled ones as weak and ostracized because they encounter prejudice in every aspect of life.

People with disabilities would be expected to self-heal, if science is unable to treat them, in other words it can be said that, those with disabilities would need to work harder to show that they merit the funding from these charitable groups. Hence it is believed that in order to prove their worthiness, they need to excel in their life. It is because society expects that person with disabilities should fit into societal structures for being a part of them rather than creating structures that fit into the lives of a person with disabilities.

Disability, though as old as the origin of Homo sapiens, has passed off without attracting critical social inquiry. With the spread of Darwinian ideas on evolution and the survival of the fittest, physical and intellectual deficiency

in humans, however, acquired social connotations giving ground to medical interventions. Objectifying the “body”, the medical professionals diagnosed the differences as “deficiencies” and “defective bodies” and mind as “dangerous” and “threatening” to the rest of society. Disability is perceived as a threat to social progress and people with severe disabilities are classified as mutants, subjecting them to corrections ranging from segregations to sterilization. Even when considering the attitude of family is again crucial to the disabled individuals. The reality is that parents exhibit a kind of rejection to the child who is born out of this disability. They possess self pity, guilt feeling and withdrawal. The parents stress level increased to the point where they reject their disabled child.

Social attitudes prior to twentieth century reflected the idea that people with disabilities were unwell, imperfect, and abnormal. These people were viewed as an object of terror and sympathy by society as a whole for many years. The prevailing belief is that these people needed to rely on welfare or charitable groups because they are unable to participate in or contribute to society. Institutions are created by state and municipal administrative bodies to shelter people with disabilities starting in the late 1800s. These facilities are typically constructed outside the towns. Social views encouraged this segregated managerial approach. Sadly, isolating oneself from society just serves to further stigmatize people.

Numerous studies have examined the effects of various attitudes. The multidimensional evaluation of people that goes into attitudes about disabilities can be either positive or negative, or it can be both. In contrast to negative attitudes, this may encourage low expectations, discrimination and

marginalization. Positive attitude may foster inclusion and acceptance by family, friends, and employers. Research has shown that healthcare professionals' negative attitudes are a barrier to people with disabilities participating in activities like physical activity, fitness and educational settings. To be more precise, given the current state of the world and the importance of attitudes, the public needs to be reminded to review and promote their attitudes towards people with disabilities. Nothing is more important for the welfare of people with disabilities than public acceptance and support.

Disability studies examine how physical, mental, or psychological disabilities are defined and how they affect people. With the ultimate goal of minimizing all forms of prejudice and discrimination, it examines disability from medical, legal, and cultural perspective. Disability studies in literature have ignited a new stream of thoughts in reader and viewers worldwide. Even though there came up many disabilities works in the realm of world literature, the disability aspect of it was never the primary concern. This project investigates how disability is depicted in the films as well as in life writing and also aims to recast new definition to disability by maintaining a positive attitude of society in perceiving a person with disability.

The works which are discussed in the project are the films like *The Curious Case of Benjamin Button*, *Ratsasan*, *The Aurora Encounter*, *Jack* and Hayley Okines book *Old Before My Time*. In all these films, the disability aspect has lost its rawness and reality. Disability is not the matter of concern; it has just been used as the backdrop. These misrepresentations can cause more trouble to the disabled community, instead of helping them to accept the

reality. The visuals or the images formed by the film always leave a greater impact on the society and it prompts the abled community to treat the disabled community in a harsh way. Through these films, the society itself is building the identity of a disabled community, rather letting them fix it on their own. Stereotype influences the people without disabilities react to those people with disabilities. For example, some stereotypes of disabled people portray them as being: pitiable and pathetic, sinister or evil, tragic but brave, laughable, outcasts, non-sexual and incapable of fully practicing in everyday life.

While watching these films, it affects the audience in many different ways. Films have shown positive as well as negative aspects which affect the mindset of the society in viewing disability and those people who are disabled, or a balance between both these affects with lot of fictional elements. On the other hand, while reading life writing, it evokes mainly positive affect among the readers, carrying the reality and its purity.

The beginning we discussed how films portrays disability chapters and finds that the film having positive affect as well as negative effects. Many scenes, shots, dialogues have been noted which created an affect among the viewers. Also, a critical study has been done of the characterization as well as on the aspect of identity. Since the concern of disability, was something revolving around these central characters, it was important to make an analysis of the construct of their self. It looked in detail the concept of disability which is depicted in these works. It also tries to discuss many concepts like self-concept, self-esteem, and self-efficacy and social model. The chapters gradually advance to the identity of the disabled.

Identity involves the recognition of the self. It is not static, but it constantly changes in accordance to the political, cultural, social and historical events. The project primarily focuses on the concept of identity and defines it's as a concept that evolves from the social construction of disability. It discusses in detail the social construction of disability that creates an identity for a disabled person solely from the expectations of a group of people who are considered as able-bodied. It also tries to explore the concept of "Who am I?" The chapters go on with the social identity which is imposed on the disabled making them a marginalized section. The marginalization slowly advances to the creation of the disabled as the other. The society constructs a normalcy, considers the other as the abnormal.

The perception of disability is brought in the chapters. It discusses how disability is portrayed in the selected works as it reflects the way the particular disability is perceived by the readers as well as viewers. The chapters broadly look in detail how disability is depicted in the selected works.

It is observed that life writing has been able to picture the reality with least fictional elements. Still it has been able to move the readers which determine the success of the writing. It has been able to wipe off the typical stereotypes attributed to the disabled community to some extent. The young writer has left the reader surprised with her courage and her optimistic view towards life. Hayley is an inspiration to many who feel down. It has also received a review on Okines described Okines as "Hayley possesses one of the strongest lives forces we have encountered".

Disability writing is necessary in redefining the existing conceptions about disability which is greatly affected by social perceptions and

constructions of an abled Society. This project has taken such powerful writing that has various implications on disability and will be able to change society's attitude towards them. Most of the times disabled people are misunderstood by the society and hence they are often excluded from abled society. The removal of physical, communicational and attitudinal barriers is necessary for the inclusion of the disabled people in the society. Every human being is different in their own way. The society must be able to accept disabled community with their unique differences. It is the fundamental right of an individual to live independently in the community regardless of their disability.

Inclusion, and all-encompassing practice, ensures that people of differing abilities visibility and palpably belong to, are engaged in, and actively connected to the goals and objectives of the worldwide society, as opposed to be labeled as "other" among a "typically developed" individual. Disability in India is a very complex issue it overlaps with the other difficulty such as low literacy and employment rates, widespread social stigma and poverty. Children with disabilities are five times more likely to be out of school than the average child. Disabled adults are more likely to be unemployed, and families with a disabled member are often worse off than average.

It is observed from the evidences an experience of the life of people with disabilities that when the obstacles in their inclusion to the society are removed and when such individuals are empowered to fully participate in societal activities, the whole society of disabled people are benefited. A more accommodative space is needed for the disabled to bring them into the

forefront of the society. When we say society, it is inclusive of the disabled community as well, the existence of barriers for them is determinant to the whole society.

Governments should give special care to make sure that people with disabilities get equal opportunities as the others and the regulations and the laws that are brought in should be inclusive for the disabled people as well. We must work relentlessly to bring together various stakeholders and funding Agencies, corporations, and NGOs to create truly inclusive employment opportunities for the disabled community. Science and technology innovations and assistive devices and tools can go a long way to help them acquire the skills, education, and training they need to become employable and empowered. Legislation is main area that can help fight discrimination and oppression. The Equality Act 2010 enforces a duty on employers to make adaptations that will aid disabled people in the work place. This act also makes it illegal to treat people differently because of their disability.

Individuals can show care for the disabled children by spending time with them. It is a great thing to bring some light to the dark world. Every area can organize a special play-group and other children should accept their disabled friends and play with them. Article 24 of the UN Convention on the Rights of Persons with Disabilities stipulate that countries must take steps to ensure that persons with disabilities access an inclusive, quality and free primary and secondary education on an equal basis with others in the communities in which they live.

Human without humanity is just an animal. It is the humanitarian qualities of understanding, love and compassion which give man the nobility.

Human are naturally born imperfect. The only true disability is the inability to accept and respect differences. Accepting a person with a disability must never be out of pity or charity.

However, it is important to say that, over time and between cultures, the idea of disability is gradually altered. Indian society's level of consciousness has increased to the point where people with disabilities are now seen as humans. This would be a better situation than in the past. Attitudes and perceptions of society towards people with disabilities has changed with time, and this change has also seen in their terminology that is being used for disabled people, from "crippled" to "handicapped" to physically challenged changed to "people with disability".

The origin of disability rights movements in India in the early 1990s has identified people with disabilities as not as a recipient but as participants in the nation's development process. The emergence of several local and governmental organizations has also helped to raise awareness of the sensitive and concerning needs of people with disabilities. The most significant action is to modify society's perception of those with disabilities, so that those without disabilities are not less aware of their needs and sympathetic to their plight. As a result, the society will be able to create an inclusive atmosphere and a culture that values and respects people with disabilities.

One of the most crucial steps to develop a positive attitude toward persons with disabilities is to abolish the closet and secretive mentality of society by sensitizing and empathizing with the persons without any kind of disability. The creation of an inclusive environment and culture of concern will nurture the confidence and self-esteem of persons with disabilities. The

development of an accepting environment and a caring culture will boost the self-esteem of people with disabilities. This would bring the notion that we must all recognize that people with disabilities are an essential component of human diversity and have equal right to our respect.

The study of disability in literature is still-relevant today because it enables people who are physically or intellectually challenged to integrate into society, establish their equality, and raise their self-esteem. Therefore, it would be worthwhile to pursue additional investigation. A greater grasp and understanding of disability-related issues help to give a clear understanding about those who are disabled, which invokes a fellow feeling and compassion rather than pity for those who are disabled.

World health organization (2001) defines disability as an umbrella term, incorporating many aspects of body impairments, activity limitations, and participant restrictions. They acknowledge that disability as the result of negative interactions between an individual's disability and the physical and social environment in which he or she lives.

The feeling of sympathy and empathy are critical for the development of social behavior, social competence and moral reasoning. Empathy is the ability to feel and understand another person's emotional state or condition through emotional matching and affect sharing. Sympathy is an emotional response to another person's troublesome situation, typically expressed as feelings of pity, sorrow, or concern for the other people.

Family plays a significant role in shaping children's belief and attitude toward others. Parenting styles and children's attachment styles may determine the child's future attitude toward individuals with disabilities.

Importantly, there is an intricate interplay between parental factors and children personality factors.

Human rights education can also be an important tool for combating stigma and the resulting discrimination experienced by persons with disabilities. By developing national human rights education plans and by ensuring that human rights education takes place in schools, children are able to understand disability rights, which can be used to address specific harmful beliefs that may be held within our society.

Along with shifts in societal attitudes, the vocabulary used to characterize people with disabilities has also changed. The words like “idiot”, “imbecile” and “moron” are very outdated. The words mentally retarded and disabled have taken their place. The emphasis should now on the person. People with disabilities desire acceptance for their strengths rather than their limitations. Instead of using the word “disabled”, some people prefer the phrase “differently abled”.

It is very strange to find that a man’s physical impairments are what define him as disabled. Then what about individuals who have infirmities in mind, pointing not to any pathological circumstances, but those infirmities brought on by our own incapacity to deal with our flaws.

Hence in the present predicament, it is important to consider who is disabled, whether it’s a person with physical disabilities or someone who has a flawless physique but a weak mind. It is difficult to blame someone who is physically disabled with their limitations and restrictions. We often believed that we are flawless human beings with all the necessary skills to complete any task. We have a lot of struggles to get through in our society, and every

now and then, some of them bravely get beyond a variety of mental and physical hurdles but some of them still struggles and give up without even taking a try. Therefore, it has nothing to do with the defects in the body. As a result, not everyone who is disabled is deemed to be disabled and not everyone who is not affected is necessarily believed to be capable.

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