Chapter I

Introduction

Disability is a ubiquitous human experience prevailing across the globe since time immemorial. The term 'disability' refers to a condition where an individual might experience limitations or difficulties while managing their daily activities.

Disability as a state can affect an individual unexpectedly by having temporary or permanent consequences. A medical condition that affects body or mind can create barriers for an individual to actively participate in his/her physical activities. Impairments or conditions that are physical, mental, cognitive, and developmental that is congenital/acquired are silently suffered by many who are also subjected to oppression and discrimination. The general impacts caused due to impairments might not be the same for every individual. It affects each person in a different and unexplainable manner.

Disability as a term frequently addresses a single community but not every individual even with the same impairment follows similar patterns in their condition.

Studies document that fifteen per cent of the world's population is afflicted by some sorts of impairments that are acquired by birth or accident. Types of disabilities that are commonly found can be categorised under visual, hearing, locomotor, and mental impairments, cerebral palsy, learning disabilities that includes, dysgraphia, dyslexia, Attention Deficit and Hyperactivity Disorder (ADHD), speech and language disabilities among others. The most mentioned causes of disability are associated with instances such as lack of care received by the mother during pregnancy, hereditary, poor hygiene and sanitation, natural or man-made disasters, unpredicted accidents, malnutrition, congenital diseases, and much more. Some medical conditions are prenatal and there can be various reasons that act as a cause to prenatal disabilities.

Genetic factors, embryonic or fetal developmental accidents, lack of nutrition, traumatic exposures, or diseases that the mother has contracted during pregnancy can result in prenatal disabilities.

Birth defect that is commonly referred to as congenital disorder or congenital anomaly is a health condition that is present in a child at the time of his/her birth. It can be inherited due to multiple reasons or environmental factors. It has the ability to affect the physical, intellectual, or developmental factors in a growing child. Such conditions are categorised as structural disorders and functional disorders. Structural disorders commonly affect the shape of a body part while functional disorders have an impact over the proper functioning of physical organs. It also includes degenerative and metabolic imbalances that affect the developmental growth of a child. Side effects from medications, infections, poorly maintained food habits, alcohol consumption, or smoking during pregnancy can induce risk factors affecting the child's future. Certain defects can be identified during scanning or prenatal tests and the treatments to such conditions can vary depending on the individual. Proper health care with a balanced diet and regular medical consultations can limit the cause of prenatal disabilities.

Apart from congenital conditions, impairments also result from traffic or workspace accidents. Recently, many individuals are being severely affected with permanent or temporary impairments due to road accidents. According to World Health Organization, 1.3 million of world's population lose their lives to accident each year and many are affected with fatal injuries. Workplace accidents according to the International Labour Organization are reported to be more than 337 million, among which 2.3 million deaths are mentioned. Inhaling poisonous gases, human or animal attacks, insect bites, slips and falls from staircase, pavements, swimming

pools, and traffic collision becomes the reason for multiple fatalities whose lives are affected unexpectedly.

The aerial spraying of endosulfan in the cashew plantations of Kasaragod, a northernmost district in Kerala had caused severe health hazards, and ailments including skin irritations, reproductive, developmental, and physical impairments in human beings and animals. Due to this, many children suffer from various health disorders and calves were born with deformed limbs. Radioactive waste from uranium mines had affected nearly fifty thousand people in Jadugoda, a village in Jharkhand. Evidences of skeletal fluorosis due to contaminated water are commonly seen in people who belong to the Kutch coast in Gujarat, and various other states of India such as Rajasthan, Karnataka, Assam, and Bihar. The aforementioned tragedies are few among the documented causes of impairments in India.

While understanding disability, it is important to know the past, present, and future perspectives about the concept of disability. A historical analysis on disability sheds light on how people were treated differently throughout history. Unfair and inhumane practices on individuals who have impairments highlight the crucial situations that they were placed in because of their condition. The stories narrated by the Greek philosopher, Plutarch reveal that in ancient Greece, children who were born with impairments were killed and abandoned in the woods. The elders of the age believed that it was better to end the life of a child who is born with impairments as they cannot serve in the military to protect their country. History also provides information regarding the healing sanctuary of Asclepius at Epidaurus that had permanent stone ramps which enabled access for the mobility impaired individuals. It proves that at least in few places, people with impairments were acknowledged and

respected as the difficulties they endure during visiting temples and sanctuaries were taken into consideration while designing its architecture.

During the medieval period, disability was considered as a condition that was caused by demons. It was also regarded as a punishment to the sins committed in their past life. Lack of income and financial support often persuaded them to resort to begging but a few were privileged to get the care and attention rendered by the monks. Almshouses can be regarded as a supportive system that provided help for the elders and individuals who had impairments. Europe witnessed changes during the Age of Enlightenment as it had a more supportive and scientific approach towards individuals with impairments. But their living condition worsened during the nineteenth century as it was the period of industrialisation. Poverty affected the lives of many who were not able to afford their daily living as well as medications. This was an age of oppression and the physically impaired were neglected by all means.

In United States, adults who had physical impairments joined the workspace to fill the vacancies of soldiers who had to battle in World War II. It was the Civil Rights movement that emerged during the 1960's and 1970's that provided a favourable living condition for the individuals who had impairments. This was followed by the introduction of educational laws which consequently improved the conditions of educational institutions. An Act for the relief of sick and disabled seamen (1798), The Community Mental Health Act (1963), Architectural Barriers Act (1968), Education for All Handicapped Children Act (1975 to 1990), Civil Rights of Institutionalized Persons Act (1980), and Medicaid are the few acts and policies that had significantly improved the lives of individuals with impairments. Consequently the disrespectful attitudes towards the physically impaired individuals changed as the society became more accepting and progressive than their ancestors. Recognising

them without discrimination eventually helped them to be successful without holding traces of self-doubt.

In Africa, the individuals who had impairments and were born to wealthy families got the privileges of having good treatment facilities and health care assistance.

The situation of the economically weaker class was the same irrespective of their nationalities. They struggled to receive even the basic amenities of life. The UN statistics states that there are around six hundred million people throughout the world who have impairments and among whom eighty million are citizens of Africa. The social stigma and marginalization makes them prefer to collect alms as a sole option for survival.

Sources from The World Health Organization indicate that ten to fifteen percent of Africa's population who have impairments are children. The Apartheid era had introduced special schools for children who experienced difficulties in their mobility or other sorts of impairments including hearing, intellectual, and visual impairments. Racial discrimination prevailed all over Africa and in these schools children who belonged to the African ethnicity had to undergo many difficulties. Due to racial differences, these children were barred from equally gaining the resources that were provided by the school authorities.

Asia and the Pacific, cover sixty percent of the six hundred million people residing in different geographical locations with impairments of various types.

Their concerns and needs were not properly attended or served. Poverty strikes as their enemy that delimits them from receiving any achievement and prosperity. Living amidst the adversities of financial imbalances, they are often left neglected from the mainstream society. Historical records claim that children who have impairments were not given proper education and women had to experience attitudes of injustice from all spheres of life. From the census reports of 2011, it is understood that

26.8 million people with different kinds of impairments reside in India. The world health survey conducted by the World Health Organization between the years 2002 to 2004 reports that twenty-five percent of Indian inhabitants experience difficulties that are congenital or acquired.

The early Indian society viewed disability as a punishment that an individual had to suffer as a result to the negative deeds that he/she did in his/her previous life. In most cases, individuals with impairments were considered as a burden to the family. The society never failed to express their sympathy when a child is born with any impairment. This was followed by conversations where they discuss about the difficulties that the family will have to face while bringing up a child who is born with impairments. They were often denied of the basic opportunities that includes education, employment, or care by the mainstream society. During 1800's, disability was considered as a problem that was caused due to a disease or accident including trauma and other medical conditions. The emergence of medical model of disability established the concept of treatment and sustained medical care as demanded by the health professionals depending on the individual's physical condition.

Recently, disability was connected with environmental and social factors that act as barriers which restrict an individual with impairment to actively participate and gain access to the public services. The social model of disability highlights the social expectations and constructions that paves way to make the life of physically impaired more difficult. Within the Indian subcontinent, the amount of attention provided to the concerns of the individuals with physical and mental impairments is a rare phenomenon. The first legislation that advocates the rights for the disabled was initiated only during the 49th year of Independence. The passing of Rights of Persons with Disabilities (Equal opportunities, Protection of Rights and Full Participation) Act 1995, popularly known

as the 'disability law' or the 'PWD Act' served as an example of the disability rights movement. On 16th December, 2016 the Parliment of India passed a much more effective and comprehensive disability rights law which is the Rights of Persons with Disability Act (2016). The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act (1999), Rehabilitation Council of India Act (1992) are few Acts that were passed in India for the welfare of individuals with impairments.

Every Indian citizen holds various documents such as voter identification card, or driving licence, whereas an individual with impairment has to be certified with a disability identification card. Unique ID for Persons with Disabilities is a national database that is implemented for delivering the rightful benefits that the government offers to make the lives of physically impaired individuals better. Disability Rights activist, Anita Ghai mentions that the benefits that are provided with the help of disability certificate might vary from state to state. People with permanent impairments have allowances and stipends based on their condition. The Disability Certificate acts as a proof of their status to avail the grants/benefits/rights and other facilities that the state and central government offers. Along with stipends and pension, it also helps them to get access to concessions during travel. To obtain this certificate, the individual should prove that he/she is an Indian citizen. The medical board should approve that the person's disability status is forty per cent or above. Submission of the aforementioned documents will help them avail the certificate.

Disability studies emerged as an academic research during 1980's. It was first established in the US, UK, and Canada. The main purpose of the study is to analyse disability through the lens of historical, cultural, social, political, and legal values rather than through medical and psychological approach. It voices out the pervasive

discrimination that affected the lives of many individuals who suffer from impairments and work towards attaining the rights that will help to improve the quality of their life. The roots of disability studies are associated with the Disability Rights Movement that emerged in the 1960s. The Union of the Physically Impaired against Segregation (UPIAS) was formed in 1972 in the United Kingdom for addressing the civil rights issues for the individuals with impairments. UPIAS motivated an academic network of theorists and practitioners of disability studies in the US who formed a community in 1982. It was known as the Section for the Study of Chronic Illness, Impairment, and Disability of the Social Science Association and in the year 1986, the committee was renamed as the Society for Disability Studies. The chief founders of this non-profit organisation are Nora Groce, Daryl Evans, Steve Hey, Gary Kiger, Irving Kenneth Zola, John Seidel, and Jessica Scheer.

Records prove that India has the largest number of individuals with impairments after China. 18.49 to 21.92 millions of individuals in India suffer from impairments of different types. It was only recently that disability studies as an academic inquiry to explore the social models of disability in India originated. It helps the society to rectify their misconceptions on disability. The works of Bhargavi Davar, Amita Dhanda, Renu Addlakha, and Anita Ghai, try to portray the hidden and painful realities of the disabled experience. Disability Studies as a research field in India is not well established as it is in the west. Disability is an emerging genre that deserves more attention. Ghai mentions that it is very hard to find someone who works on disability studies because of the historical myopia towards the subject. Disability is always connected with ignorance and invisibility, and disability studies as an area of research should emerge to fight against the stigmas that are connected to it. An academic understanding that focuses on the history, tradition, culture, experiences, and

expectations of individuals with impairments will help the society to eradicate their negative perceptive of disability.

Depiction of disability differs through ages. Disability in ancient times according to Hindu culture is associated with a disease that emphasises on the importance of cure. Rig Veda is one of the earliest sources to understand disability. It is associated with the idea of cure by the Ashvins, the semi-divine medical twins. Hymns in Rig Veda define how Ashvins can give sight to a visually impaired individual and how a mobility impaired individual can walk. It also mentions the story of Queen Vishpala who uses iron prosthesis when she loses her leg in a battle. Elements of disability are also visible in India's two greatest epics, the *Mahabharata* and the *Ramayana*. In the postcolonial Indian English Literature, a snippet view of disability can be seen in the novels such as *Clear Light of Day* (1980) by Anita Desai, *Midnight's Children* (1981) by Salman Rushdie, *Animal's People* (2007) by Indra Sinha, et cetera.

It is difficult to find works that are based on disability within Indian English Fiction, though there are novels that feature characters who have impairments. Frequently such characters are sidelined from the main narratives. A few novels are *Sepia Leaves* (2006) by Amandeep Sandhu, *Em and the Big Hoom* (2012) by Jerry Pinto, *An Upbeat Story* (2018) by Manjula Padmanabhan, and books that features children who have impairments includes *Flute in the Forest* (2010) by Leela Gour Broome, and *Unbroken* (2017) by Nandhika Nambi. *Naseema: The Incredible Story* (2005) by Naseema Hurzuk, *As the Soul Flies* (2007) by Yasmin Sawhney, *One Little Finger* (2011) by Malini Chib, *The Other Senses* (2012) by Preeti Monga, *No Looking Back* (2014) by Shivani Gupta, and *River of Time* (2017) by Jeeja Ghosh are autobiographical writings on disability that narrates the powerful stories of the

hardships experienced by them while they tried to triumph over the social injustices caused due to their impairments.

This research is a critical study that focuses on the excruciating experiences of physically impaired individuals within the Indian context. The novels selected for conducting this research are Simply Nanju (2016) by Zainab Sulaiman, A Time to Dance (2014) by Padma Venkatraman, Family Life (2001) by Akhil Sharma, and Trying to Grow (1990) by Firdaus Kanga. The hypothesis is that if the stereotypical views and biased attitudes towards people with impairments are eradicated, it can improve the quality of their living experience and if information about their legal rights is properly communicated, then the families of individuals with physical impairments can get access to their rightful benefits. The main objective of this research is to analyse and highlight the derogatory and dogmatic social structure that attempts to degrade the individuals who have impairments. By emphasizing these human rights violations, the thesis tries to establish a politically appropriate understanding of the disabled experience. It also provides a clear view about their path of transformation for progression. Narratives about disability within Indian context serve as a foundation to understand the cultural influence, power politics, and identity formation of an individual with impairments in the current scenario.

While deciphering the concept of disability for a better understanding of the same, the researcher found the following materials and this helped in recognising the need to vocalise the various issues that center around this.

Iwona Filipczak in her article "Disability, Illness and Cultural Belonging in Akhil Sharma's *Family Life*" traces how disability or illness is connected with immigration and culture.

A. Shahul Hameed in his article "Between Exclusion and Inclusion: Representation of Disability in Firdaus Kanga's *Trying to Grow*" discusses about the representation of disability in Post-independence Indian English Fiction by focusing on the difficulties experienced by the protagonist due to his impairment.

R. Bhattacherjee in his research article "Trying to Grow out of Stereotypes:

The Representation of Disability, Sexuality, and the "Modern" Disability Subjectivity
in Firdaus Kanga's novel" presents the representation of disability and difference in
privileges based on gender, caste, and class.

Moncy Mathew in her article "The New Parsi: A Study of Firdaus Kanga's Trying to Grow" has analysed the lost glory of the prominence of Parsi Community in the Post-independent India.

Since there are only limited research done on the disability aspects on the novels chosen for research, the researcher felt the need to study and respond to this imperative facet.

David T. Mitchell and Sharon L. Synder's *Narrative Prosthesis: Disability* and the Dependencies of Discourse (2000), and Disability Theory by Tobin Siebers (2008) have enabled the researcher to learn more about disability and the issues that are experienced by physically impaired individuals.

Albert Bandura's *Social Learning Theory* (1977), Urie Bronfenbrenner's *The Ecology of Human Development: Experiments by Nature and Design* (1979), and *Childhood and Society* (1950) by Erik H. Erikson have contributed significantly in this research to understand the developmental patterns and the influence of the society in an individual's life.

Anita Ghai's *Disability in South Asia: Knowledge and Experience* (2018), and *Rethinking Disability in India* (2015), Renu Addlakha's *Contemporary Perspectives on Disability in India* (2011), and G. N. Karna's *Disability Studies in India: Retrospects and Prospects* (2001) have helped the researcher to get insights about the disability experience in India.

Indian-born American author Padma Venkatraman was born on 13th November, 1969 in Chennai, Tamilnadu. Venkatraman later moved to the United States to continue her higher education and holds a doctoral degree in the field of Oceanography. She pursued her postdoctoral degree in Environmental Engineering and also served as a chief scientist in research vessels in Germany. Venkatraman had also taken the position of head at Inwoods Small School and handled oceanography for the students of University of Rhode Island. It was later that she recognised her passion towards writing and produced few notable literary works such as Climbing the Stairs (2008), Island's End (2011), A Time to Dance (2014), The Bridge Home (2019), and Born Behind Bars (2021). Venkatraman has also written few non-fiction books entitled as Women Mathematician (2008) and Double Stars: The Story of Caroline Herschel (2007). She was honoured with many awards including the Julia Ward Howe Award for Young Readers, South Asia Book Award, SCBWI Magazine Merit Award for Nonfiction, ASTAL RI Book of the Year Award, Paterson Prize, Best Book for Young Adults, Outstanding Book for Young People with Disabilities, and much more. She was also the finalist for India New England's Woman of the Year Award in the year 2009.

Venkatraman started her writing career in the year 2008 with the publication of the novel *Climbing the Stairs*. The story was identified by many and received successful reviews and awards. The novel can be regarded as a historical fiction that depicts the aftermath of World War II and revolves around the life of Vidya, a fifteen

year old girl who struggles to achieve her identity. Venkatraman's next novel *Island's End* is set in an island where the protagonist Uido was enthralled about her fascination in becoming the spiritual head of her tribe. It contains elements and influences of Venkatraman's time spent at Andaman Islands where she had met the natives who survived the Tsunami of the year 2004. The publication of her third novel *A Time to Dance* reveals a change in her writing style. Working on the issues of disability, the novel projects the hardships that are encountered by individuals with impairments.

Set within an Indian background, the novel, *The Bridge Home* represents the lives of children who are homeless. Viji and her sister Rukku, decide to leave home as their father is very abusive. They seek shelter under an abandoned bridge where they find two other children with whom they share a good bond. The negative aspects of dysfunctional families and the depressive stages that the children had to undergo to survive is the main theme of the novel. Her latest work *Born Behind Bars* was written based on an article that she had read on the internet. The article was about a man sharing his personal story about being born behind bars as his mother was pregnant while she was in jail. Kabir, the protagonist of the novel was born in the prison as his mother was jailed for a crime that she had not committed. Being behind the bars restricted him from knowing the outside world. The plot proceeds to provide informations of Kabir remarkably striving to survive. Venkatraman through her novels has always tried to provide a visual depiction where the readers can associate the hardships endured by each character especially children.

Padma Venkatraman's *A Time to Dance* was inspired from one of her earliest memories of Shoba Sharma who had danced for her brother's wedding ceremony.

During the time, she was a little girl who eventually became a performer and dance teacher despite suffering a serious physical injury. Hence, *A Time to Dance* is a

dedication to the brave and courageous individuals that have proved through their life that struggles and hurdles can follow one's way but neither is powerful enough to stop one from one's aim. Venkatraman has also expressed her gratitude towards Savitri Rajan who had taught her carnatic music to which bharatanatyam dance was set and to T. Krishnamacharaya from whom she learnt the art of yoga and Vedic chanting. Published in 2014, the novel narrates the story of young Veda and an accident that follows, which squashes her dreams. Admiring the posture of a statue of Lord Shiva during a visit to the temple, Veda realised her innate passion that has bloomed and made her recognise that dance is all what she needed. Her obsession towards dance was not approved by her mother; who felt that dance is not a good choice for a middle-class girl as it is not career oriented. But the support and acceptance rendered by her father and grandmother was fair enough for Veda.

Veda's mother always hoped that her daughter would excel in mathematics and science subjects though she had expressed her interest towards dance. Veda practiced consistently with the help of her dance master Uday as she wanted to be the title winner of an upcoming dance competition. She followed his instructions to be a meticulous dancer and her movements were graceful with a high degree of precision. After the competition, the voice of the judges echoed through the microphone that announced Ms. Veda Venkat as the winner for her flawless impressions and skilful mastery over her body. But what awaited Veda on her way back from the competition was a highly distressing situation that shattered the balance of her life. The van in which Veda was travelling rampaged down the pot-holed road and all that she could remember was the headlights of the opposite vehicle that flashed at them. The driver lost his control over the vehicle and thus the accident occurred.

At the hospital, the health professionals consoled her and revealed the truth that the doctors had to amputate her right leg below the knee. The thought of not being able to dance again made her question her very existence. She was consoled by Dr. Murali, who introduced her to Mr. James (Jim) who was conducting a research on cost-effective prostheses. Veda was partially relieved when the doctors promised her that she will be able to dance again using her prosthetic leg. The novel also depicts the financial struggles that the family had to manage while dealing with the medical expenses, whereas, Veda was undergoing pain and shame due to the humiliation that was imposed on her by the society. The novel broadcasts the living conditions of individuals with impairments and the oddities that they were exposed to because of their physical condition. Veda was able to rise high with the support gained from her grandmother, father, and friends but not every child is privileged enough to gain such care and love.

Akhil Sharma is an Indian-American writer born on July 22, 1971 in Delhi, India. He later immigrated to the US at the age of eight. He pursued his studies from New Jersey and later became an Assistant Professor in Creative Writing at Rutgers University, Newark. In the year 2000, Sharma entered into the space of literariness with the publication of his debut novel *An Obedient Father*. The novel helped him win the Hemingway Foundation/PEN Award (2001) and Whiting Award (2001). The novel is set in the year 1991, when the Indian Prime Minister, Rajeev Gandhi was assassinated. It further describes a dysfunctional family where the protagonist Ram Karan lives with his widowed daughter and granddaughter, collecting bribes. He has also penned few short stories such as *The Blue Umbrella Man* (1990), *Mother and Son* (2007), *We Didn't Like Him* (2013), *A Life of Adventure and Delight* (2016), et cetera.

Sharma was awarded with the New York Times Ten Best Books of the Year (2014), Folio Prize Winner (2015), the International Dublin Literary Award (2016),

and DSC Prize for South Asian Literature Short List (2016) for his second novel *Family Life*. Published in 2001, the novelist has taken instances from his personal life to deploy the character Birju. Sharma's teenage brother Anoop had an accident while swimming and that caused severe damage to his brain. As a result of this he was no longer able to walk, talk, or roll over in his sleep. He stayed in the hospital for two years when their parents decided to bring him home. The novel is based on the difficulties that the family underwent physically, emotionally, and financially. Sharma took twelve and a half years to complete the novel and he felt that he could be more truthful while writing his experiences as a fiction than a memoir.

Family Life depicts the lives of the Mishra family through the narrator Ajay, who is the youngest member of the family. He provides a detailed account of events that forced them to change their perspectives towards life. It is a story of two brothers who emigrated from India to the U.S. due to their father's profession. They were leading a very normal and contented life with no regrets or worries. While trying to adjust and adapt to their new life in New York, tragedy struck as a diving accident left one brother, Birju severely brain damaged. It shows the importance of love and togetherness while taking care of loved ones while they are sick. The Mishra family stood together while looking after Birju though the financial constraints had often created misunderstandings among his parents. While Birju's mother was always hopeful in her son's recovery, Mr. Mishra was often pointlessly cynical in his approaches. The novel depicts Indian culture and its views on disability. After the accident, the family was avoided by their relatives but the plot also provides instances where the Mishra family was treated with respect by strangers who knock at their door for receiving blessings from the parents who are taking care of a physically impaired child. Sharma delightfully expresses that fighting hard to protect one's

family is the best investment that one could make. The whole plot revolves around their struggles while managing to provide the best for their ailing son.

Zainab Sulaiman served as a special school educator in Bangalore and *Simply Nanju* published in 2016 is her only novel. She is a highly dedicated and goal-oriented Human Resources professional, currently working with Zeven Sports India Private Limited. Sulaiman had earlier worked with the Association of People with Disability in Bangalore, and as a volunteer teacher and fundraiser in non-profit sectors. Sulaiman's novel *Simply Nanju* was a result of her services in the field of teaching, volunteering, and fund raising for various NGOs and schools for children with impairments. These experiences opened her to the world where children despite their difficulties participated actively in their school activities. They focused on their abilities rather than their physical conditions.

Simply Nanju is set in a school which was specially designed for children with physical impairments. The story takes the readers through an alley of adventures and challenges that Nanjegowda (Nanju) and his classmates experience in an educational institution. Inappropriate attitudes of the non-teaching staff often cause them humiliation. The story exemplifies diversity and each child in the novel has a background history that is very sensitive. To make the plot more interesting, Sulaiman has brought in an investigation which the children plan strategically to find the culprit behind the missing notebooks of the class topper. The issues experienced by children who use wheelchairs, the lack of accessibility in public spaces, terminologies that degrades their physical condition, the shame imposed on them because of their inability to follow the bathroom etiquettes are the other prominent concerns raised by Sulaiman.

Firdaus Kanga was born with osteogenesis imperfecta, a condition which is commonly referred as brittle bones. He had a difficult childhood as his condition gave him multiple fractures for which the pain was unexplainable. Born in 1960, in Mumbai, Kanga was home-schooled until his fourth grade and he later joined the Campion School in Mumbai. His novel *Trying to Grow* depicts his own journey of dealing with brittle bones. Kanga currently residing in London has also tried his expertise in the field of acting. Kanga through his works wanted to preserve his past and writing helped him to sail to a distant land of fancy and imagination. *Trying to Grow* received international attention and the novel is translated into many languages. It was later produced as a movie entitled as *Sixth Happiness* (1997) in which Kanga starred as well as wrote the screenplay. *Heaven on Wheels* is a travelogue authored by Kanga in the year 1990 and the plot unravels his experiences in UK where he met Stephen Hawking.

Published in 1990, *Trying to Grow* details the reality of disability, culture, and sexuality. He has tried to break the social taboos and cultural beliefs that are connected with the concept of disability. The protagonist Daryus was born with osteogenesis imperfecta, a condition in which he can never grow taller than four feet. Throughout the novel Daryus is referred as Brit, a name suggested by his elder sister while she was informed about his condition. His sister Dolly was his good friend and she was willing to sacrifice her own happiness for being with him during his hard times. He was constantly supported by his family and they were ready to take any measures that were suggested to them as a cure to brittle bones. They simultaneously made sure that Brit was leading his life in the best possible way and they assured that he learns to stay independent during their absence. As Kanga had personally walked through the same terrain, the intensity of the character's pain is well projected.

The complications experienced by Brit while being in a relationship, society's outlook towards disability, statements that degrade his physical existence, witnessing the fear of parents who were worried about his condition and future, architectural barriers that has made his social life difficult are all pictured with utmost care and detail by the author. The crudities practiced by the medical practitioners and attendants who helped Sera, mother of Brit to deliver him are also described in detail. When a child is born with impairment, the society tends to ignore him/her and feels reluctant to invite such a child with a welcoming heart. Brit along with his family was never bothered about the pitiful statements delivered by the society. Kanga by implying wit and humour has sarcastically highlighted the Indian tradition that holds certain beliefs regarding disability as a subject. Brit was often considered as a victim and the society pities the entire family for the hardships that they have to undergo while taking care of him. *Trying to Grow* is a fictional representation of the dark realities that the members who have physical impairments experience along with their family members.

There is always delight, ecstasy, and excitement while formulating something new as it may bring progress in the lives of many to lead a better life. Likewise, a theory or concept is introduced to study, interpret, and understand literature with all its essence and deeper meanings. It refers to the methods that are derived to analyse a literary text from multiple interpretive perspectives. The thesis primarily concentrates on the ideas initiated by Tobin Siebers in his book *Disability Theory* (2008) to understand the realities of disabled experience. Psychosocial theory propounded by Erik H. Erikson provides ample opportunities to understand the developmental patterns and psychological changes that occur in an individual according to their living circumstances. An individual is bound to change his/her characteristics, thought

process, actions, personality, and attitudes according to their development. Resisting the dominant social constructions over disability through actions taken at the right time is exemplified through this study. Anita Ghai's vision on disability as mentioned in her text *Rethinking Disability in India* (2015) provides details of social exclusion and stigma that are attached to individuals who are mobility-impaired in India.

Tobin Siebers (1953-2015) was the Professor of English Language and
Literature, Professor of Art and Design at the University of Michigan, V.L. Parrington
Collegiate Professor, and co-chair of the University's initiative on Disability Studies.
His major publications are *The Mirror of Medusa* (1983), *The Romantic Fantastic*(1984), *The Ethics of Criticism* (1988), *Morals and Stories* (1992), *Cold War*Criticism and the Politics of Skepticism (1993), *The Subject and Other Subjects:*On Ethical, Aesthetic, and Political Identity (1998), Among Men (1998), Disability
Theory (2008), and Disability Aesthetics (2010). He sought to discover a solution to
reverse the negative connotations, derogatory attitudes, social meanings,
terminologies, and the stigmas that are attached to disability. He believed that while
living in a progressive and democratic scenario, it is not politically correct to
disparage an individual for his/her physical condition. His writings analyse the
representation of disability in literature, arts, architecture, and social structures to
instil in his readers new insights to think anew about bodies in public places.

The article *My Withered Limb* by Siebers published in 1998 provides a glimpse of his own experiences while dealing with disability. He recalls of having contracted with poliomyelitis at the age of two. The year 1955, witnessed 40,000 cases of polio, leaving two hundred children with varied forms of paralysis in USA. Siebers considered him to be the luckiest among his acquaintances as his lungs and arms were intact, and only one of his legs was affected. He describes how difficult it

is to stay impaired in a country like America where one's image and body is prioritised. The disabled were ridiculed and barred from gatherings with pitiful looks and Siebers identifies that people like him are always crushed to solitude. Every individual with impairment is subjected to face such discriminations at least once in their lifetime. Siebers describes how the physically impaired individuals were treated in different parts of the world. He points out that in ancient Greece, they were left to die on the cold mountain hillsides, in Africa the individuals with impairments were food for the beasts and people were thrown into a well in European countries.

Towards the end, he had realised that his disability or physical condition is an inextricable part of his existence and by accepting it, he is accepting himself.

Heart-rending experiences due to his physical condition prompted him to write his well acclaimed book *Disability Theory*. Published in 2008, his work analyses the heights of social oppression that are imposed on individuals with various impairments. Siebers primarily discusses the three interlocking agendas in his book *Disability Theory*. The first agenda is to analyse the potential of disability studies to transform the basic assumptions that the society holds about the concept of disability, its meaning, identity, social injustice, and politics. Siebers wanted to theorise the emerging field of disability studies by connecting its core issues with theorists who are specialised in adjacent fields such as cultural studies, literary theory, gender studies, queer theory, and critical race studies. Secondly, he wanted to have an extended discussion of the broad means by which disability identity is specified as a representational category that projects the hardships experienced by individuals with impairments. A debate on disability issues is an approach that enables the theorists to spread the realities of disability. Thirdly, the book theorises disability as a minority identity. Recently, disability has been categorised as a minority identity where their

issues must not be regarded as a personal misfortune but as a product of social injustice. Siebers wanted to bring changes to the existing social misconceptions that treat disability as a disease. He aims to accumulate the narratives, myths, stereotypes, and ideas about disability to make the readers probe into their own feelings of ability and disability.

This research mainly identifies the issues experienced by physically impaired individuals through the two aspects articulated by Siebers. At first, the thesis tries to identify the reasons as to why individuals with impairments are excluded by the dominant social structure. Siebers voices his concerns about the damages that are inflicted by the society on people who have impairments. History produces evidences of marginalisation that are initiated by the manipulative sources that are in power. Siebers fights against such oppressive structures and prejudicial representations to put an end to their practices. He dreams of a space where people with impairments are respected and treated equally so that they will have a chance of leading their life to the fullest. He wants to raise consciousness in the readers regarding their plight and the society should recognise and take responsibility for their terrible actions.

Siebers points out that, individuals with impairments will lead themselves to isolation if they are not willing to share their stories to the world. He believes in fighting for their rights rather than living in a state of denial. It helps them to resist the negative representations created by the political constructions. The modern scenario should bring changes by properly representing individuals with impairments in a public sphere. The world should slowly conceive the concept of not labelling the disabled bodies as defective. Social prejudices have set certain expectations regarding the behavioural attitudes of the individuals with impairments. Siebers mentions that the society expects the disabled to be helpless and inferior. One should not measure a

person's capability by his/her ability to function. Such ideologies repress disability and considers able-bodied as normative to define humanbeings. Siebers has personally experienced statements that convey the message that people with impairments should maintain distance from the able-bodied as society considers them 'ugly'. Siebers gently reminds,

Some of you have disabilities. Some of you do not. Most of you will someday. That is the reality of the human mind and body. Remember what you already know about people with disabilities, so the knowledge will be useful to you when you join us. The blind do not lead the blind. The lame do not want to walk alone. We do not love only our kind or ourselves. You others are our caregivers—and we can be yours, if you let us. We of the tender organs are not narcissists. (52)

In the second aspect, he unlocks the difficulties that are experienced by the physically impaired due to the architectural barriers. Restricting the freedom of an individual to have free access to public spaces is an example of human rights violation. Siebers questions the authority for not taking into consideration their predicaments to lead comfortable lives. The individuals with impairments also have their rights. He concludes by stating, "A society with a universally accessible built environment and laws designed to offer equal protection to all people would produce far fewer disabled citizens in the future" (Siebers 190).

German born American psychologist, Erik Homberger Erikson has dedicated his life on understanding human minds and the changes an individual might undergo at various stages of his/her life. His quest towards identity inspired him to coin the term 'Identity Crisis'. It was his own life experiences that encouraged him to originate

this concept. Erikson's mother, Karla Abrahamsen was estranged from his biological father, Valdemar Isidor Salomonsen when she had conceived him. She later moved to Karlsruhe, where she married Theodor Homberger. Erikson believed that Homberger was his father until his late childhood and it was difficult for him to accept the truth when his parents revealed his biological father. He was officially adopted by Homberger in the year 1911, and Erikson who was born as Erik Salomonsen changed his name to Erik Homberger Erikson. It was these experiences that prompted him to write on identity confusion.

Erikson spent his later years as an artist wandering in many places along with his doubts and questions regarding his biological father. During one of his voyages to Vienna as a tutor, Erikson was fortunate to meet Anna Freud who inspired him to study psychoanalysis. After years of learning, he was able to link psychology with anthropology as he discovered that while an individual grows, his/her thoughts, feelings, and actions will be deeply influenced from his/her cultural or social upbringing. In his finest analytical work *Childhood and Society*, published in 1950, Erikson studied the developmental stages that are present in human beings. He was also honoured with Pulitzer Prize for his work *Gandhi's Truth on the origins of Militant Nonviolence* (1969). *The Life Cycle Completed: A Review* (1982) and *Vital Involvement in Old Age* (1986) are some of his later works.

Erikson in his theory of psychosocial development has divided the life cycle into eight stages. The stages like infancy, adolescence, and old age is further categorised into eight different stages where he describes the changes that occur during the development of an individual both physically and psychologically. The first stage as defined by Erikson is 'Basic Trust vs. Basic Mistrust'. This stage begins from the time a child is born until the baby turns one year old. The basic trust

in a child will be first created in his/her unconscious mind based on the maternal care that he/she receives. The first social achievement seen in children is when they are willing to let go of their mother and be comfortable in others presence. Here 'trust' is the confidence attained by a child to believe in his/her surroundings. 'Mistrust' arises in the subconscious mind of children when they fail to achieve the 'basic trust'. A growing child deserves the attention and love of his/her parents as childhood experiences are the base that will act as the psychological pillar of an individual's future deeds.

The second stage 'Autonomy vs. Shame and Doubt' occurs between the ages of one and three. Here, a child tries to be 'autonomous' by learning new activities such as speaking, reading, and writing. They might also hold opinions on what they should wear or eat. Their tiny attempts to walk alone without any elderly assistance can also be witnessed by the parents. The children should not be criticised or discouraged when they fail in any of their activities as it can affect their young minds that results in 'shame and doubt'. The third stage 'Initiative vs. Guilt' is seen between the age group of three and five. This is a stage when the child begins interacting with other children of the same age group at his/her school. This helps to improve the communication skills in a growing child. Children of this age will be full of doubts as their young minds always have a thirst for knowledge. According to Erikson, 'initiative' occurs when children try to learn and be a part of new activities. They might experience feelings of 'guilt' if they fail to complete a task that they have initiated.

The fourth stage, 'Industry vs. Inferiority' occurs during the ages of five and twelve. Children during this stage will be filled with enthusiasm, passion, creativity, and exuberant imagination. They try to participate in activities which till then were done with parental assistance or guidance. Excelling at school, at games, and other activities will be their priority. Gaining appreciation from teachers encourages them to

be 'industrious'. If their talents are left unrecognised, children may feel inferior or sceptical in their own skills thus failing to move forward towards their potential goals. The fifth stage, 'Identity vs. Role Confusion', is generally seen in children who are between the ages of thirteen and nineteen. Here, a child steps into adolescence with the advent of puberty. In this stage of growing up, their perspective towards life begins to revolutionize. Children during this time struggle to establish their 'identity' as part of leading an independent life. The greatest risk that an individual experiences during this stage is 'role confusion'. Young minds are not strong enough to bear the pain of failure during their struggle towards achievement, so they should equip their minds to adopt and adapt to any situation that adulthood offers them.

According to the sixth stage as defined by Erikson, people belonging to the age group of twenty and thirty-nine, will be dealing with the stages of 'Intimacy vs. Isolation'. This is a stage when adults prepare themselves to take up challenges and focus on their career and life. Individuals will also show interest to get involved in a serious relationship or commitment. Avoiding these emotions due to the fear of ego and loss is also seen in adults during this stage. The counterpart of 'intimacy' is 'isolation' where they prefer to move away from the forces or people whose presence they feel might be a danger to them. Erikson states, such disturbing thoughts will affect the individuals in various ways including their character and mind that are entangled with isolation or depression; and if an individual manages to succeed this stage then a sense of security is attained.

'Generativity vs. Stagnation' takes place during the ages of forty and sixtyfour. 'Generativity' is initiated in an individual who gives importance to provide
proper guidance to the next generation. Their main priority is to be a part of social
activities that leads to expansion and growth. Failing to be a supportive member of the

family especially as a parent generates stagnation in adults, thus resulting in dejection. The last and eighth stage according to Erikson is 'Ego Integrity vs. Despair' which affects individuals who belongs to the age group of sixty-five and above. This is when a person steps into his/her retirement life. 'Ego integrity' happens when a person had accepted his/her life in its full glory by mesmerising their past which had victories and defeats. People who have faced many rejections and failures in life, during their last days will regret by contemplating on their lack of ability in leading a successful life. This leads to the stage of 'despair' when people feel that they do not have another chance to live again to rectify the mistakes that they have committed. Individuals who wish to establish their integrity must have worked hard while they were healthy and young.

Anita Ghai born on 23rd October, 1958 currently works as a professor at School of Humanities Studies, Ambedkar University, New Delhi. Prior to that, Ghai has been an Associate Professor in the Department of Psychology in Jesus and Mary College, University of Delhi. She advocated the disability rights in India and had also rendered her voice in the areas of rights to education, gender, health, and sexuality. Ghai has also served as the former President of the Indian Association for Women's Studies. She was affected with poliomyelitis at the age of two and her own life experiences being a resident in India as an individual with impairment motivated her to conduct a research in the field of disability by chiefly focusing on the issues of India's disabled women. To impart her understanding and knowledge on disability, Ghai has authored few books on the same theme. Her writings include, (*Dis*) *Embodied Form: Issues of Disabled Women* (2003), *Rethinking Disability in India* (2015), *Disability in South Asia: Knowledge and Experience* (2018), and has coauthored *The Mentally Handicapped: Prediction of the Work Performance* along with Anima Sen.

Ghai reports that social responses to disability had affected the community across the world. "Within the dominant Indian cultural ethos, labels such as 'disability', 'handicap', 'crippled', 'blind', and 'deaf' are used synonymously" (Ghai xix). Associating impairments as a defect or flaw is a commonly seen notion. Ghai recalls, how as a child she was allowed to share her room with her male cousins, as the society desexualise girls who have impairments. She also asserts the fact that in India, lack of accessibility is a crucial phenomenon that has affected the lives of many. Ghai has also fought against for the inaccessibility to public restrooms and considers it as a failure from the side of the government and private sector constructions. She states, women including her are reluctant to drink water while they go out due to this issue and as a result to which many women suffer from kidney stones. Ghai narrates an incident when she was forced to crawl on a tarmac by the staff members of Air India, a flag carrier airline of India at the Indira Gandhi Airport, New Delhi in the year 2016. She felt embarrassed when the airlines denied her allegations when she reported them for their failure to provide a wheelchair by violating the Director General of Civil Aviation Guidelines. These are a few of her experiences that persuaded her to turn into an activist in the later years.

Ghai primarily shares her experiences of growing up with impairment through her text *Rethinking Disability in India*. It helps the readers to understand the vivid realities of being mobility-impaired in India and its relationship with cure. Ghai states that though her body had gone through a lot of difficulties when she contracted polio, was affected by breast cancer, and had experiences of stroke and heart surgeries, she decided to resist her fears by never giving up on hope. Her findings on the cultural stereotypes and it functionalities are well portrayed in the chapter 'Conversations

about disability: The Cultural Landscape'. It briefs about the perceptions of disability by the Indian society. Ghai quotes,

The point is not that one culture makes people do or think this and another that but that ideas are informed by and in cultures and cultures are partial expressions of a world in which the dualities of domination/subordination, superiority/inferiority and normality/abnormality are relentlessly reinforced and legitimized. (22-23)

Cultural forces that interfere in social attitudes are not restricted to India alone. Ghai has underscored the various meanings and terms that the Indian community has derived to define disability. The meaning differs based on the cultural practices and geographical locations. Few people consider disability as a punishment that is caused due to an individual's past transgressions. In India such belief is commonly referred as 'karma'. Some believe that suffering is inevitable and others connect to disability as a result to an individual's evil doings.

Ghai wants to deconstruct the meaning of such stereotypical approaches while understanding and portraying disability. In every culture people have formulated a set of rules that define reasons for the cause of disability. She states that it is critical to understand that our actions do not create any pre-determined future reactions. In the notion of resisting disability, Indian families are willing to choose any medium that is sold in the name of cure. Parents are ready to rely on anything or anybody who claim to save their children. Ghai remembers her parents taking her to temples, tantric priests, and faith healers to cure polio. Practising supernatural methods and sorcery projects the faith that the society has on magical spells that utilises external forces or evil spirits to produce aberrant effects in the world. The society constantly reminded

them that being disabled is equal to being defective and it is such statements that influence the family to practice unusual medications. Ghai was personally involved in such activities and so was Firdaus Kanga. Families visit such medical practitioners with ardent belief and unquestioned devotion in their miraculous powers. Kanga has depicted the presence of supernatural healers in his work *Trying to Grow* through which the readers are enlightened with the strange rituals and practices that individuals with impairments are forced to do.

Ghai mentions that the term 'handicapped' is derived from the phrase 'cap in hand', thus indicating the notion that individuals with impairments needs charity to move forward in their life. The society views them as incapable of leading an independent life. The terms 'disabled' and 'handicapped' are synonymously used within Indian scenario. Terms such as lame, blind, crippled, imbecile, disabled, deaf, dumb, mentally retarded according to Ghai are linguistic stereotyping of individuals with impairments. The book also focuses on issues experienced by individuals with impairments due to poverty, lack of education, and employment. Poverty prevails everywhere and physically impaired individuals are the most vulnerable among them. She mentions that social exclusion is also a cause of poverty as they are not fortunate enough to have equal and economical benefits. The society considers the impairment of an individual as a disability that restricts that person from gaining opportunities. This concept frightens the employers and they are reluctant to offer jobs to individuals with impairments.

Ghai also highlights the discrimination faced by students at educational institutions. Children should be provided with quality education and the practice of inclusive education opens opportunities for them to lead their academic life with dignity. A welcoming school community where students are provided with awareness

of disability is an important criterion. Right from childhood, issues of disability should be discussed in classrooms as this might act as a stepping stone to avoid discrimination among the future generations. The PWD Act has introduced rules that should be followed by educational institutions. According to the Act, all children with impairments are to be given free education, books, uniform, study materials, transport facilities, and should also have the liberty to study in a barrier-free environment. Ghai believes, through her findings and disability studies in general, the readers will think critically about disability as well as the discrimination that affects such marginalised communities.

The thesis focuses on the stigmatic constructions of disability and how individuals with impairments are marginalised as helpless victims who are weak, dependent, or vulnerable. The thesis unravels the underlying patterns of oppression that are associated with disability. The second chapter, "Understanding Realities of Disability" addresses the social imbalances and architectural barriers that are confronted by individuals with impairments. It tries to ascertain a paradigm shift from the currently practiced ideologies through the critical viewpoints of Tobin Siebers as articulated in his book *Disability Theory*. The chapter elucidates the sufferings of physically impaired individuals by studying the social meanings, marginalisation, and architectural barriers that are experienced by them. The third chapter, "Transformation for Progression" tracks the theoretical framework developed by Erik H. Erikson to provide the importance of social interaction and identity formation. It reviews the developmental patterns and struggles that an individual experiences at each stage of his/her life. The fourth chapter, "Indian Perspectives of Disability" provides the unique nature of disabled experience within the Indian context through the findings of Anita Ghai as elucidated in *Rethinking Disability in India*. Chapter five, "Narrative

Constructions of Disability" examines the narrative techniques employed by the authors while creating characters who experience physical impairments. The last chapter, "Summation" encapsulates the major arguments that are presented in the preceding chapters.

The chapter lays forth the findings and possible solutions that the research has obtained while analysing the selected novels. A 'Case Study' has been carried out to authenticate the study.