

**UNDERSTANDING INDIAN EXPERIENCE OF DISABILITY WITH
REFERENCE TO SELECT AUTOBIOGRAPHS OF PERSONS
WITH DISABILITIES**

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DECLARATION

I hereby declare that the thesis entitled **UNDERSTANDING INDIAN EXPERIENCE OF DISABILITY WITH REFERENCE TO SELECT AUTOBIOGRAPHIES OF PERSONS WITH DISABILITIES** completed and written by me has not previously formed the basis for the award of any Degree or Diploma or other similar title of this or any other university or examining body.

Place: Kolhapur

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CERTIFICATE

This is to certify that the thesis entitled **UNDERSTANDING INDIAN EXPERIENCE OF DISABILITY WITH REFERENCE TO SELECT AUTOBIOGRAPHIES OF PERSONS WITH DISABILITIES** which is being submitted herewith for the award of the Degree of Doctor of Philosophy in English under the Faculty of Humanities of Shivaji University, Kolhapur is the result of the original research work completed by Trupti Pandurang Gawade under my supervision and guidance and to the best of my knowledge and belief the work embodied in this thesis has not formed earlier the basis for the award of any degree of similar title of this or any other University or Examining Body.

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Dr. M. S. Vaswani

Research Guide

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Chapter I

INTRODUCTION

Introduction:

The society excludes many people on the basis of class, gender, religion, race, caste, creed, color, nationality, ethnicity and disability all over the world. These people are still struggling to get fundamental rights. The reasons of their exclusion from the mainstream society may be different, but the intension of their struggle is same i.e. to get equal treatment in the society like other human beings.

In reality, these categories of the people should be accepted as part of human variation. But they are often excluded due to their different characteristics which are not considered as normal by the majority of people in the society. Indeed, the exclusion of particular group is likely to break down people's hopes and aspirations. Likewise, it may be weaken the foundation of the nation because each person's contribution is valuable in the process of national development.

As mentioned earlier, the people with disabilities is also one of the groups of people which is excluded from the society. For long, their basic needs have been overlooked because they are considered as unwanted members of the society. Although some awareness programs regarding disability related-issues have continuously been carrying out at global level for the last five decades, still the expected change is not found in their situation especially in developing countries.

One thing is to be noted that almost 500 million people of the world population are estimated to be disabled in one or other way. In fact, the majority of world's disabled population lives in developing countries

like India where they live in miserable condition due to the lack of access in essential services like education, employment, transportation, information, rehabilitation, accommodation and medical care. The fact is that developing countries are economically backward, so they are unable to provide even the basic facilities to their citizens including persons with disabilities. Hence, the persons with disabilities are often confronted with various difficulties while surviving in such condition. Needless to say that disability related experiences of such people in developing countries may be very different from developed countries like USA, UK and Australia. Therefore, the focus of present research is only on the Indian experience of disability. The researcher has chosen six Indian autobiographies to understand the experience of disability in India.

The main purpose of choosing the genre, 'autobiography' to understand the experience of disability is that autobiography is more reliable source of information about social conditions than other forms of literature like poetry, drama and novel. In reality, autobiography is non-fictional work which always brings faithful representation of reality without showing imaginary characters, events and incidents. Therefore, this genre can be helped to comprehend the real lives of persons with disabilities after reading their autobiographies. Another reason for choosing autobiographies for present research is that in fiction, disabled characters are generally portrayed in negative manner by some authors in their literary work. Charlotte Bronte's *Jane Eyre* (1847), Charles Dicken's *Cricket on the Harth* (1990) are best examples of this. Even in films, they are portrayed as pitiable, miserable or strange characters. The recent movie called '*Kabil*' in Hindi language is fine example of it. Therefore, autobiography is better platform for persons with disabilities to describe the real picture of their lives, which is probably invisible to the society.

Indeed, writing autobiography is the act of self-revelation in which the person brings out some essential facts of his/her life. Although, the author oneself is the focus of the autobiography, it also throws light on the people and events that the author has known or witnessed. In short, there is truthful representation of both individual's life as well as contemporary society. Therefore, an autobiography can be an important source to understand the society in which the author has lived.

Some writers of autobiographies use this genre to expose the blemishes of society in which they have lived. They also use it to protest against the socio-economic and political exploitation and discrimination. In 1980s and 90s, Dalit autobiographical writers emerged on literary scene and raised their voice against exploitation and discrimination. These autobiographies are an important part of dalit discourse. Autobiographies of Shankarrao Kharat, Prof. P E Sonkamle, Baburao Bagul, Daya Pavar, Sharankumar Limbale, Keshav Meshram, Lakshman Mane, Kishor Shantabai Kale, Lakshman Gaiakwad, Madhav Kondwilkar, Dadasaheb More, Kumud Pavale, and Shantabai Kamle have triggered outrage and feelings of social inequality and injustice.

These Dalit autobiographies have been extensively studied, but autobiographies of persons with disabilities have not attracted attention of research scholars. The persons with disabilities are also marginalized and disempowered like Dalits. They are not only marginalized from the social economic, cultural and political activities but also from the research agendas. Therefore, to fill the research gap, the present researcher is attempting to scrutinize select autobiographies of Indian persons with disabilities. These autobiographies are as follows:

1. *Face to Face* (1957) by Ved Mehta
2. *Lights Out* (2014) by L. Subramani
3. *The Other Senses* (2012) by Preeti Monga
4. *No Looking Back* (2014) by Shivani Gupta
5. *One Little Finger* (2010) by Malini Chib
6. *Deaf in Delhi* (2006) by Madan Vasishta

Autobiography as a Genre:

The word ‘Autobiography’ is derived from three different constituent parts- ‘autos’ ‘bios’ and ‘graphein’. The word ‘auto’ means ‘self’, ‘bio’ means ‘life’ and ‘graph’ means ‘to write’. When these three different parts come together, the word ‘autobiography’ is formed. Thus, the whole word ‘autobiography’ means the life-story which is written by person herself/himself. The following definitions will help to clarify the meaning of autobiography.

M. H. Abrams defines autobiography as “a biography written by the subject about himself or herself.” (22). The Oxford English-English-Hindi Dictionary also defines autobiography as "the story of a person’s life written by that person” (79). According to Stephen Shapiro, autobiography is “an art of perspective, an art of juxtaposed perspectives: the present commenting upon the past, the past commenting upon the present. It is an art of contrast and integration” (119). The above definitions show that the main goal of autobiography is to reveal the reality of person’s life. Most importantly, autobiography is the only tool of providing most reliable information about human personality to the

readers. In other words, it is a fine medium for autobiographer to bring some essential facts of his/her life in front of world.

Autobiography significantly opens the platform of self-revelation to autobiographer. Indeed, the act of self-revelation is human and natural phenomenon. It depends upon the thought process of man. However, autobiography is the only genre through which person can freely express his/her life experiences. Its main purpose is to reveal the person's life. D. G. Naik says:

“Autobiography is a work entirely devoted to this purpose—the purpose of revealing the inner self or the personality of the individual writer. Autobiography, therefore, should be the most popular and satisfying form of literary art” (12).

Briefly stated, it is very simple and suitable form used by the author to express his/her personality.

The fact is that innumerable theories are established on other literary forms like poetry, drama and novel. For instance: from Aristotle's *Poetics* (335 BC) to E. M. Foster's *Aspects of the Novel* (1927) reminds that critics and scholars are interested in these forms excluding non-fictional work like autobiography. They perhaps consider that autobiography is not a significant form of literature. In this context, Shapiro points out that, “They are wrong to exclude autobiography from the realm of literature because it is not “imagination” or does not refer to a fictional or invented world” (423). Like Shapiro, many other critics also think that imagination is the only base of other literary forms except autobiographical writing. Hence, they do not agree to accept it as a form of literature. But here one thing is to be noted that every writer has to take great efforts while expressing himself/herself in any form or genre of

literature whether it comes under fictional or nonfictional category. Therefore, it is true to say that autobiography is also a worthy form of literature, even though it was neglected by earlier critics.

On the other hand, few critics believe that autobiography uses the narrative style of fiction. However, it comes under the category of fiction which includes novel and short story. In this point of view, Alfred Kazin explicates:

“...autobiographical writing, even when it assumes the mask of sincerity and pretends to be the absolute truth, can be as fictional as the wildest fantasy. ... it is just another way of telling a story, it tells another kind of story, and it uses fact as a strategy” (213).

In reality, each literary form has its own specialty and characteristic-features. Although some features of these forms are similar with each other, it doesn't mean that they are same. For instance: the narrative style or structure of autobiography is similar to fiction but still it has its own special characteristic-features. Although the narrative style or structure of autobiography is same with fiction, the autobiographer focuses on the actual lived moments of his/her life instead of using imaginary events and incidents. Furthermore, he/she also tries to divide his/her life story into several periods or chapters and gives it an artistic shape. It means that autobiographer tries to present real characters, events and incidents in his/her autobiography.

The subject matter of autobiography is related with human mind and nature. It often focuses on various traits of human personality and its psychological development. In other words, the autobiographer is unique and special part of autobiography. It is expected that he/she should be

sincere and frank narrator of his/her life. Along with some good qualities, he/she has an ability to talk of his/her weaknesses also. In other words, the true autobiographer honestly tries to reveal both positive and negative sides of his/her personality. In this context, D. G. Naik explains “The real autobiographer is such an artist then; there is no reason why should be insincere, dishonest, and unfaithful to facts” (38). Thus autobiographer is seen as true and faithful narrator of his or her life story.

In the last few decades, the genre, ‘autobiography’ has become very popular. Many people from different caste, creed, gender, race and religion including persons with disabilities have started to write their autobiographies. It is the only platform for them to write something about their lives. The readers from different age groups also show their too much interest in reading different autobiographical books of these people. They believe that such books provide an authentic information about person’s life. In fact, they visit great personalities and their aspirations while reading autobiographical books. Along with entertainment, such books provide enthusiasm and positivity to the people of all age groups. In short, autobiography naturally creates an ever-lasting impact on the mind of readers.

Importance of Autobiography to Understand the Experience of Disability:

As described earlier, autobiography is fine medium of self-expression. It brings more essential facts of person’s life. Most importantly, it gives truthful and reliable information than other forms of literature like poetry, drama and novel. Although the author uses ornamental language to create effectiveness, there is no place for imagination. Another thing is that it is more authentic than biography as

well. The reason behind that the experiences of life described by person himself are more effective and reliable than others. However, the person himself/herself can bring all the crucial aspects of his/her life by writing autobiography. The most important advantage of this genre is that the society can understand the problems of diverse people after reading their autobiographies because it is generally assumed that whatever is written in autobiography is true.

Like other marginalized groups of people including dalits, women and queers, some persons with disabilities also take initiative to write their autobiographies to express themselves. They use this platform to describe their own experiences of life that is somewhat different from the life of other average people. Due to this self-revelation, the harsh reality of their lives comes out in the world. It reflects not only the life of single disabled person but also of those who are facing the same reality of life. In reality, the society may be unaware about what type of life they live, what are their problems, what are their sufferings and how do they cope up with that? But their autobiographies help to get the answers of these questions. In short, the true voices of people with disabilities can be heard by reading their autobiographies. However, autobiographies of persons with disabilities are most important to understand the experience of disabled people.

Biographical Sketches of Authors:

1. Ved Mehta

Ved Prakash Mehata, an Indian novelist and journalist, was born on 21 March, 1934 in Lahor, British India. He belongs to a Punjabi Hindu family. His mother, Shanti Mehta was house wife and his father, Amolak Ram Mehata was doctor in public health service in Punjab. He lost his

eyesight at the age of three and half due to the cerebrospinal meningitis, a kind of serious infection that can damage the optic nerve responsible for sight, resulting in partial or total blindness. After that, his parents sent him to the Dadar School for the Blind in Bombay where he learned certain skills of independence.

As his father recognized that there was no future for blind in India, he sent him to America for education. The author was very much impressed by America where he could live normal and independent life. Along with excellent education, he enjoyed the freedom of movement and a complete sense of self-reliance that he couldn't enjoy in India. He also went to England for his further achievements. While living in America and England, he was influenced by the writings of various well-known writers like T. S. Eliot, James Joyce, Johann Goethe etc. In the meantime, his writing career also flourished and he became prolific writer later on. Now Mehta is successful author of twenty-seven books including fiction and non-fiction.

His first book is *Face to face*, an autobiography which was published in 1957. His other literary works are- *Walking the Indian Streets* (1960), *Fly and the Fly-Bottle: Encounters with British Intellectuals* (1962), *The New Theologian* (1966), *Delinquent Chacha* (1966), *Portrait of India* (1970), *John Is Easy to Please: Encounters with the Written and Spoken Word* (1971), *Daddyji* (1972), *Mahatma Gandhi and His Apostle* (1977), *The New India* (1978), *A Family Affair: India Under Tree Prime Ministers* (1982), *A Ved Mehta Reader: The Craft of the Essay* (1998), and *All for Love* (2002).

2. Lakshmi Subramani

Lakshmi Subramani is currently working as a senior sub-editor in Bangalore. He has written his autobiography entitled *Lights Out* which

was published in 2014. This book describes his fighting for living normal life in spite of having progressive blindness. At the age of eighteen, he completely lost his eyesight due to the Retinitis Pigmentosa, a genetic disorder which affects the retina. Since then, he started experiencing gradual and incurable condition leading to complete blindness. Although, he became visually impaired later on in his life, he had been suffering from retinal disorder since his childhood.

Because of his serious condition of progressive blindness, he was often experiencing unexpected blurriness. His eyes were suddenly getting blur while walking or cycling. With the experience of sudden and recurrent haziness, he started losing his self-confidence frequently. He wanted to live free from sudden and recurrent haziness, but it would never happen due to the problem of deteriorating condition of his eyes.

3. Preeti Monga

Preeti Monga was born in Amritsar in 1959 in middle class Sikh family. She is one of the India's disability rights activists. She is the founder of Silver Linings, a non-profitable organization that works for inclusion and empowerment of blind children and women. She lost her eyesight due to the reaction of Smallpox vaccine given few days after her birth, which made an allergic infection in her eyes. Thereafter, she developed Retinitis Pigmentosa that caused to the deterioration of her functional eyesight. When she was in 8th class, she was expelled from regular school because of the frequent complaints of her teachers about school performance. Therefore, her parents decided to admit her in a blind school of Delhi. But as they found that school was not in good condition, they didn't leave her alone there. Despite having poor education, she made her career in many other arenas by taking huge hard

efforts. Instead of giving up in her bad times, she proved herself by achieving grand success in life.

Being visually impaired, she has devoted herself to work for well-being of other visually impaired or disabled. She worked at various levels that may not be possible for able bodied person either. She is a well-known corporate trainer, a fitness consultant, a successful business woman, a trauma counselor, a trained coach and a PR profession. Along with this, she is one of the most inspiring motivational speakers. She motivates saying: “It is only one life we all have, I want all of us to live it to its best!” She is the author of two books that are *The Other Senses* and *Flight Without Sight*. *The Other Senses* is the first part of her autobiography, published in 2012 and *Flight Without Sight* is the second part published in 2017. These two books are true witness of her hard struggle in life.

For her achievement, she has won some prestigious awards including- The State Award for the Exceptional Achievement in Entrepreneurship in 2015, The National Award for the Empowerment of Persons with Disabilities in 2013, The National Women Excellence Award in 2010, The Red and White Bravery Silver Award in 1999, The Vocational Service Award in 1996, The Manav Sewa Award in 1995 and many more.

4. Shivani Gupta

Shivani Gupta is the founder of Non-governmental Organization called ‘AccessAbility’ and one of the India’s best-known access consultants. She has spent most of her professional life in working towards improving accessibility of public spaces for persons with disabilities. Her famous motto is “Access=Ability”. She has completed

her hotel management, architecture and inclusive management degrees from well-known institutes in India and foreign countries.

She has written her autobiography entitled '*No Looking Back*' which is published in 2014. In this book, she has described true story of her life in which she unfortunately faces overwhelming odds. She meets with an accident twice in her life. In these two accidents, she loses everything including hopes desires and aspirations in her life. Despite of having too much troubles in life, she tries to keep herself stable in every situation.

After becoming disabled, she devoted her life in helping to make environment accessible for persons with disabilities in India. For her achievement, she has been endowed with following honors and awards- the Helen Keller Award (2008), the CavinKare Ability Mystery Award (2008), the Neerja Bhanot Award (2004), the National Role Model Award (2004), the Red and White Social Bravery Award (1999) and the Sulabh International Women of the Year Award (1996).

5. Malini Chib

Malini Chib is one of the India's disability rights activist and writer. She suffers from severe disabling condition called Cerebral Palsy which is congenital disorder affected person's muscle movement and coordination. This physical condition makes her to use wheelchair lifetime. She learns how to type with her one little finger by sitting in a wheelchair. Despite of having such severe condition, she has successfully done her two International master degrees in Gender Studies and Library Science and Information Management in London.

She is the founder and co-chairperson of Able Disabled All People Together (ADAPT), through which she is actively working for the well-

being of other disabled people like her. For her contribution in the disability sector, she has been honored with National Award for the empowerment of persons with disabilities from the Indian Ministry of Social Justice and Empowerment in 2011. Likewise, on the occasion of World Cerebral Palsy Day, she was honored with the first global Cerebral Palsy Day Award in 2017 for ensuring the rights of disabled people.

She unfolds her life experiences in autobiography entitled *One Little Finger* (2010). The Indian film named *Margarita with a Straw* (2014) is somewhat based on her life. It is in Hindi language film directed by Malini's cousin, Sonali Bose. The main role is played by Kalki Koechlin, French actress and writer who appears as teenager with cerebral palsy.

6. Madan Vasishta

Madan Vasishta was born in a village called Gagret, in Northern India, in 1941. After the two weeks of high typhoid fever and the mumps, Madan became deaf at the age of eleven. It was very hard for him and his parents to accept the truth of his sudden transformation from normal into abnormal hearing world. Due to his deafness, he stopped going to school from the middle of sixth standard and started working in the field as farmer. At the same time, he started studying at home with the help of his cousins.

After his matriculation, he moved to Delhi and joined All India Federation of Deaf where he came in contact with other deaf people who had used to speak in sign language. Once he had got chance to go to Gallaudet University, in Washington DC, where he did his B.A. in History and Psychology, M. A. in Deaf Education and Ph. D. in Special Education Administration. Later on, he worked as a teacher, researcher,

principal, program evaluator and retired as superintendent from New Mexico School for the Deaf in 2000.

He has written his autobiography which is divided into two parts that are *Deaf in Delhi* and *Deaf in DC*. His *Deaf in Delhi* was published in 2006, in which he has shared his own experiences of disability in India. Afterwards, he wrote the second part of his autobiography entitled *Deaf in DC* which was published in 2010. In this book, he explores his personal experiences of disability in Washington DC.

Review of Relevant Literature:

The researchers and scientists have always been interested in the study of disability, but they have viewed disability through the lens of doctors or service providers. Disability is considered a personal medical condition, rather than a social issue. However, the social model of disability challenges this orientation. According to the eminent disability scholars such as Vic Finkelstein, Mike Oliver and Colin Barnes, the source of a person's impairment is in her or his medical condition, but the source of disability is in society.

Jane Campbell and Mike Oliver in *Disability Politics* have traced emergence and survival of the disability movement in Britain. Scot Danforth and Susan L. Gabel have edited a volume on *Vital Questions Facing Disability Studies in Education*. David T. Mitchell and Sharon L. Snyder have edited a volume on *Disability Theory*. Alice Hall in *Disability and Modern Fiction* has examined the depiction of disability in modern fiction.

Rajesh Verma and Pragya Verma in *Disability Perspective in Rehabilitation* have examined National and International Scenario in

rehabilitation. G. N. Karna in *Disability Studies in India Retrospect's And Prospects* has significantly traced the academic development of Disability Studies in India.

In his essay, 'The Autobiographical Artist', Jai Arjun Singh provides glimpses of Ved Mehta's literary insights containing the touch of autobiographical elements. If one reads his essay thoroughly, the due focus could be found on *Face to Face* which is his first book published in 1957. It tries to describe his whole life story in very short and precise language. Maya Jaggi's article "Sight Unseen" (2001) describes that Ved Mehta's *Face to Face* is a record of his life, which contains his experiences in both India and western countries. Margalit Fox's article in The New York Times focuses on Ved Mehta's autobiography, *Face to Face* along with his other fictional and non-fictional works. In the article, "Ved Mehta: Painter of Words", Ziya Us Salam gave reference of his autobiography, '*Face to Face*' while discussing the facts of his life.

The Penguin India has written an article on 12th April, 2014 entitled "Inspirational Stories from Real Life Heroes" on four books of inspirational stories which include *No Looking Back* by Shivani Gupta and *Face to face* by Ved Mehta. It shows Shivani Gupta's *No Looking Back* is a heart touching story of Shivani's life which is full of challenges and indignities. This article again talks about Ved Mehta's *Face to Face*, an autobiography which tells a story of a man who became blind at the age of four. Other two books mentioned in this articles are *Courage Beyond Compare* by Sanjay Sharma and Medini Sharma and *This Star Won't Go Out* by Esther Grace Earl. In fact, this article brings an overview of these four books. It tries to introduce such invisible faces to the readers who may be unknown to these well-known figures.

“Lights Out- A true story of a man’s descent into blindness by L Subramani” is a book review written by Privy Trifles where she expresses her views about L. Subramani’s *Lights Out* (2014). In this article, she admires the man who fought against his disability to strive for normalcy and transform his weaknesses into greatest strengths. In her article “I am prone to mistakes too”, Sangeetha Devi Dundoo has also done critical assessment of L. Subramani’s book *Lights Out*. She has denied the notion that disabled are too weak.

Ambica Gulati glimpses on Preeti Monga’s struggle in her article “Through Your Eyes Only”. She appreciates Preeti’s hard journey of life which is described by Preeti in her two books *The Other Senses* and *Flight Without Sight*. “A Sight To Behold” is blog written by Shelvin Sebastian on Preeti Monga’s life, in which he unfolds the secret of her success that is her faith in her own abilities and hard work. S. Gokul’s article entitled “Understanding the Relations of Religion and Disability: A Study of Preeti Monga’s *The Other Senses* and Nalseema Hurzuk’s *The Incredible Story*” studies the relations of disability and religion with the help of two Indian disabled women’s life narratives such as *The Other Senses* and *The Incredible Story*. This article examines how the life narratives challenge against the stereotypical notions of the society.

In the article, “Ability Unlimited” Budhaditya Bhattacharya critically writes about Shivani Gupta’s autobiography *No Looking Back* (2014). He explains how social and material environment hinders the persons with mobility disabilities like Shivani Gupta. Binjal Shah’s “Two accidents, a wheelchair and a National award from APJ Abdul Kalam: Shivani Gupta’s heroic tale” highlights various stages and calamities in Shivani Gupta’s life.

In his research paper “One Little Finger: An Outcry for Inclusive Society” Vishal Singh brings critical analysis of Malini Chib’s autobiography *One Little Finger* (2010). Singh tries to shed light on Chib’s heroic battle against stereotypical and stigmatised notions of Indian society. Along with this, he briefly compares Indian and western attitude towards disability, which is significantly reflected in Chib’s autobiography. Ramya Kannan has appreciated Malini Chib’s arduous journey of life in her article “An Arduous Journey” (2011). She points out that it is very hard to survive in an indifference society for the people like Chib, who always struggle to live meaningful and independent life.

“Deconstructing the Medical Model of Disability: A Review of Malini Chib’s Autobiography *One Little Finger*” is a research paper written by Sharada Devi who attempts to analyse Malini Chib’s *One Little Finger* in relation to the concept of disability and its various approaches. “Activist and author Malini Chib: Yes She Can!” is an article written by DNA, which is about her life. It slightly talks her book, *One Little Finger* which has inspired to all who have read it. The Times of India has published article on Malini Chib entitled “Activist-author honoured with global cerebral palsy award”, which mainly discusses about her global Cerebral Palsy Day Award. But it has also given reference of her autobiography and its film adaptation in Hindi language. “With 2 masters & book, she’s defeated disability” is Shreya Chowdhury’s article discusses Malini Chib’s successful journey of life despite of having severe disabling condition with reference to her autobiographical book ‘*One Little Finger*’. Renu Addlakha wrote book review on Malini Chib’s *One Little Finger* in which she briefly gives some ideas about the journey of her challenging life.

Trudy Suggs' in her article "Deaf in Delhi offers Rare Perspective of Being Deaf in India" discusses the first part of Madan Vasishta's autobiography named as *Deaf in Delhi* which is a story of man who became deaf at the age of eleven. It rightly points out that due to the poverty, there is very little hope of future for the deaf people in India.

This short review of relevant literature demonstrates that the autobiographies of persons with disabilities in India have not yet been studied in the light of disability perspective.

Significance of the Present Study:

Literary theories and modes of interpretation are generally appreciative of class, race, and gender, but disability is largely ignored as category of analysis. Disability is generally considered as an abnormality or deviation, rather than a human variation, like race, sex and religion.

The autobiographies of persons with disabilities are generally read as a source of inspiration. The experiences of authors are regarded as personal and the readers sympathise with the authors and draw inspiration. However, the social, political and legal issues raised in these autobiographies are overlooked. The present study aims to analyse and interpret the authors' experience of disability from social, economic, political and psychological perspectives.

Further, understanding of disability is dominated by European and American experience and this is applied as a universal norm. However, the experience of disability in India is complicated by poverty, gender, caste and community.

The present study will take into consideration all these factors which make the experience of disability in India unique and perhaps worse.

Hypothesis of the Study:

The experience of disability in India is complicated by poverty, gender, caste and community. This experience may be unique to India. The autobiographies of the persons with disabilities narrate this unique experience. This narration is also a form of protest against the social attitude towards disability.

Aims and Objectives of the Study:

In the light of above hypothesis the aims and objectives of the present study are as follows:

- To draw theoretical framework of Disability Studies.
- To analyze the select autobiographies in the light of Indian Experience of Disability.
- To highlight inaccessibility and other social issues like discrimination and injustice against disable persons.
- To create awareness among people to remove negative attitude towards disability and persons with disabilities.

Scope and Limitations of the Study:

The present research work focuses on six autobiographies of Indian persons with disabilities to find out Indian experience of disability. It tries to discuss the various problems of persons with disabilities within Indian

context. With the help of these autobiographies, the researcher seeks to explore the social issues regarding disability.

Research Methodology:

The researcher has selected six Indian autobiographies of persons with disabilities. The theory of Indian Experience of Disability will be studied thoroughly. The historic and contemporary attitude of Indian society to disability will be studied. The available interviews of the authors will be analyzed to supplement the information available in their autobiographies. The analytical, interpretative and evaluative methods will be used for the present research work.

Chapter Scheme:

The chapter scheme of the study is as follows:

❖ Chapter I : Introduction

- Introduction
- Autobiography as a genre
- Importance of Autobiography to Understand the Experience of Disability
- Biographical Sketches of the Authors
- Review of the Relevant Literature
- Significance of the Study
- Hypothesis of the Study
- Aims and Objectives of the Study
- Scope and limitation of the Study

- Research Methodology
 - Chapter Scheme
-
- ❖ **Chapter II:** Disability Studies: A Theoretical Framework
 - ❖ **Chapter III:** Autobiographies of Visually Impaired
 - ❖ **Chapter IV:** Autobiographies of Wheelchair Users
 - ❖ **Chapter V:** Autobiography of Hearing Impaired
 - ❖ **Chapter VI:** Conclusion.

Chapter II

A Theoretical Framework

Introduction:

In the present chapter, a modest attempt is made to prepare a theoretical framework of Disability Studies which critically examines the concept of disability thoroughly. The theory of disability studies helps to understand past and present representation of disability. After formulating the theory of disability studies, this chapter focuses on Indian experience of disability which is different from western experience of disability. The main point i.e. Indian experience of disability contains other sub-points with proper explanations. It includes- disability rights movement in India, disability studies in India, the present scenario of disability in India, disability status in urban and rural India, specified categories of disability in India, rights of disabled people in India, problems of disabled people in India and experience of women with disabilities in India. The researcher has chosen six Indian autobiographies of persons with disabilities for analysis in order to study the Indian experience of disability.

Disability Rights Movement:

Disability Rights Movement was significantly influenced by the civil rights and women's rights movements which began in the United States during the 1960s and 1970s. It came into reality when the people suffering from disabilities noticed their disability in the same socio-political sense as blacks and women viewed their race and gender respectively. However, they decided to come together and fight for their own rights. Consequently, after the great contribution of various groups and their organizations in America, the Disability Rights Movement came

into existence in the 1980s. This movement always seeks to fight for equal rights and opportunities for persons with disabilities. The most popular slogan of this movement is ‘Nothing about us without us’ which is used at international level.

Disability Studies:

The evolution of disability studies as separate academic discipline began with the disability rights movement which started during the 1980s and 1990s. Just like racial studies and women studies which emerged through the civil rights movement and women rights movement respectively, disability studies also came out of the disability rights movement. After the 1970s, the world-wide growing social and political movements of disabled people have tremendously influenced the study of disability. Later on, the concept of disability was introduced in various western universities or academic institutions for teaching and doing research. Many academicians and social activists of diverse profession are attracted towards this newly emerging area of knowledge. Like gender studies and cultural studies, disability studies has also developed as a separate academic discipline in various parts of the world.

Definition of Disability Studies:

Disability studies has significantly emerged as distinct academic discipline which critically examines meaning and nature of disability. It also examines various definitions of disability proposed by various experts and scholars from different parts of the world. Along with diverse approaches to disability, it studies various types, causes and consequences of disability. G. N. Karna defines disability studies:

“as a discipline which reformulates the study of disability by perceiving the problem of disability as a social phenomenon, social

construct, metaphor and culture, thereby suggesting minority group approach to its study” (250).

According to Simi Linton:

“Disability studies takes for its subject matter not simply the variations that exist in human behavior, appearance, functioning, sensory acuity, and cognitive processing but, more crucially, the meaning we make of those variations. The field explores the critical divisions our society makes in creating the normal versus the pathological, the insider versus the outsider, or the competent citizen versus the ward of the state. It is an interdisciplinary field based on a sociopolitical analysis of disability and informed both by the knowledge base and methodologies used in the traditional liberal arts, and by conceptualizations and approaches developed in areas of the new scholarship. Disability studies has emerged as a logical base for examination of the construction and the initiatives undertaken by the disability rights movement have resulted in new paradigms used to understand disability as a social, political, and cultural phenomenon” (02).

The above definitions show that disability studies explains the changing dimensions of social attitude towards disability through the different historical periods. It primarily offers an in-depth explanation of treatment which is given by the society to disabled people from past and present years. In other words, its main task is to observe historical as well as contemporary scenario of disability. It widely focuses on a social, political, cultural and historical representation of disability. Most

importantly, it also focuses on intersectional or interdisciplinary study of disability.

Disability has historically been conceptualized as biological or individual problem, but after recasting the disability as civil rights issue, disability studies, a new academic discipline, has reframed the concept of disability in a social relationship or context. According to Rosemarie Garland-Thomson, “Disability studies views the condition of having a disability as a social relationship characterized by discrimination and oppression rather than as a personal misfortune or individual inadequacy” (01). The social approach to disability is central to the field of disability studies. It states that the main source of disability is rooted in society, but not in medical condition of particular individual. It means, the problem of disability does not reside in individual’s medical condition, but it resides in social disabling environment that restricts individuals with impairments from full integration in society. Disability studies thinks that individual’s impairment is universal human condition that may not be avoided all the time. Hence, it should be accepted as a part of human variation.

Feminist Disability Studies:

The ethnicity, race, class and caste have extensively been studied, but the concept of disability is omitted in the realm of feminism. Hence, feminist disability studies significantly concentrates on the relationship between feminism and disability. It arises through the notion of disabled women’s exclusion in the women’s movement. Needless to say that feminism always talks about the objectification of female body and conventional roles of women, but women with disabilities have been excluded from the feminist agenda. Renu Addlakha explicates, “While

the invisibility of women with disabilities in the male dominated disability movement is, to some extent, understandable, their absence from the women's movement cannot be so easily overlooked" (223). It shows that omission of disability from the theory of feminism is not acceptable. Hence, the feminist disability studies tries to focus on this issue. According to Rosemarie Garland-Thomas, "Feminist Disability Studies also seeks to correct traditional feminism, which sometimes ignores, misrepresents, or conflict with disabilities" (05).

It is well-known fact that in the patriarchal society, women with disabilities are more oppressed than normal women. They face double discrimination of being women and disabled. Generally, women in such society perform conventional roles like managing household chores and taking care of children and family. But women with disabilities are considered as incapable of performing these roles. Furthermore, such women are considered as physically unattractive and sexually undesirable. This is because their physical appearance may not fit in the cultural idea of beautiful body. Hence such women are often rejected in the marriage proposals on the basis of their disabilities. Due to such traditional expectations, they remain isolated for lifetime. Rosemarie Garland-Thomason rightly points out that "Feminist Disability Studies emphasizes changing public policy and cultural institutions rather than viewing the problems of disabled women as residing in their own supposedly inferior bodies" (05). Just as social approach states that disability resides in social structure, but not in person's biological condition, the feminist disability studies steps forward with the same impression that the issues regarding disabled women reside in cultural institutions instead of inferior bodies of disabled women. The feminists usually talk against the female foeticide, but the use of genetic screening

technology for aborting foetuses with abnormalities is not discussed in their female foetuses debate.

The Concept of Disability:

Disability is an indispensable part of human experience because it is quite natural phenomenon. Like diverse colors, genders and heights of people, it is also one of the parts of human diversity which cannot be separated from human beings. In fact, diversity is found everywhere in nature. For instance: one can find it within trees, flowers, fruits, birds and animals, although it may or may not be noticed. However, it can rightly be said that like other living beings, “heterogeneity among the human beings in various sphere is also normal” (Malkar & Sarker, 88). But the people may never think about that with this perspective. So they always hesitate to accept such heterogeneity or diversity among human beings.

The divergence is also found within disability because it includes various categories. One can find that some disabilities are visible and some of them are invisible. Its causes and effects are also different because some disabilities are congenital and many of them are acquired later in life. Likewise, “some disabilities are static while others are progressive” (Karna, 33) in nature. Diversity is also seen among the persons with disabilities because each person with disability may suffer from different disability. Such persons with different disabilities are found all over the world. Most importantly, divergence among persons with disabilities is also dependent upon the severity of each impairment. One can find that the degree or severity of each impairment varies from person to person, although some persons suffer from the same disability. Thereby “some people with impairment of mobility can commute in certain situations, whereas others cannot” (Karna, 33). In short,

divergence within disability and persons with disabilities depends upon the category and severity of individual's impairment.

Disability is an unpredictable thing because it can affect anybody, at any time or any stage of his/her life. In fact, it is present everywhere in the world. So it is true to say that this is not just problem of one country but of the whole world. In this context, Peter Coleridge says, "Disability is an issue that touches us all. It is not only, or even mainly, associated with poverty: disability can affect anybody of any background, in any country at any time" (06). It shows that having any kind of disability is a fact of human existence. It was present in past, is seen in present and will remain in future. Even though some disabilities are preventable by taking precautions and proper care, it is impossible to eliminate it completely from the social milieu. According to Karna, "human life has ever been marred by the ravages of natural disasters, hereditary as well as birth defects and accidents—causing disability of one sort or the other to many people" (Karna, 68). It means that there are various factors related with human life. So it is difficult to avoid the influence of disability every time.

It is said that unlike other categories involving gender, religion, race, caste, creed and color, disability is a fluid concept because it involves many multifaceted aspects. For instance, some disabilities are inherent and some of them are accidental or acquired later on with aging. In fact, some disabilities appear sporadically, others are constant in nature and some of them are life-long. In addition to that some disabilities are visible whereas others are hidden or invisible. Here Alice Hall rightly clears that "a person can become disabled suddenly, temporarily, and at any time in their lives. Disabilities can be invisible and most disabilities are acquired over the course of a lifetime rather than from birth" (06).

Most importantly, some disabilities can be controlled or cured by proper medical treatment, but many of them remain lifetime.

Definitions of Disability:

Disability is a complex term because it has multifaceted aspects. Although it is difficult to define, many scholars seek to define it in their own ways. Mamata Rao defines:

“Disability is the disadvantage or restriction of activity caused by a society which takes little or no account of people who have impairments and thus excludes them from mainstream activities” (173).

According to Merriam Webster Dictionary, disability is

“a physical, mental, cognitive, or developmental condition that impairs, interferes with, or limits a person’s ability to engage in certain tasks or actions or participate in typical daily activities and interactions” (<https://www.merriam-webster.com>>).

Disability Discrimination Act (DDA) 1995 defines person with disability as

“a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities” (01).

The above definitions show that disability is physical, mental, intellectual or developmental condition that makes more difficult for person to perform certain activities. In other words, it is a condition in

which person cannot cope up with other non-disabled person while doing something due to his /her physical or mental limitations.

Sometimes the terms ‘impairment’ and ‘handicap’ are interchangeably used for ‘disability’, but these terms have different meanings. An international classification of impairment, disability and handicap has been made by the World Health Organization (WHO) in 1980 to differentiate the meanings of these three terms.

Impairment: It means “any loss or abnormality of psychological, physiological or anatomical structure or function” (47).

Disability: It is “any restriction or lack (restricting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being” (143).

Handicap: It is a “disadvantage for a given individual, resulting from an impairment or disability, which limits or prevents the fulfilment of the role that is normal (depending on age, sex and social and cultural factors), for that individual” (183).

The above definitions show that impairment is defective biological structure. Disability is an interaction between impaired person and disabling social environment. And handicap is the result of both person’s impairment and disability. For instance: If a person has walking impairment, it directly affects person’s mobility power. Due to the disabling social environment, he/she cannot participate in mainstream society. As a result, he/she cannot avail the same things like others.

Approaches to Disability:

Many international scholars and bodies have tried to define the concept of disability, but there is no single definition which carries the

whole sense of disability. The reason behind that it has undergone considerable changes and modifications due to its heterogeneous nature. Subsequently, many approaches to disability have also been developed with new frameworks of how society views disability.

1. Religious Approach to Disability:

Religious approach is the oldest approach to disability. According to this approach, there are many religious causes significantly related to disability. Indeed, each religion has perceived the fact of disability in different way. One can find that no single religious text has sought to define it with scientific and broad manners. The Hindu doctrine of Karma Phala also reveals the Indian ideology of disability which mainly states that “disability is sought to be linked with the retribution for the sins committed by individuals in the past” (Karna, 71). It means, having any kind of disability is considered as God’s punishment for sin or crime that may have committed by either individuals or their parents or ancestors in the present or previous birth. Along with this, another prevalent cause of disability especially in Indian society is that having a lack of faith in God. The contemporary scholars and experts have rejected this approach to disability considering disability is not curse or punishment from God.

2. Medical Approach to Disability:

After the mid-18th century, the religious approach to disability was gradually replaced by the medical approach to disability. The medical approach to disability primarily refused the theological ideas of religious approach. Since the drastic change in the field of medical science, disability has been considered as nothing else but medical issue. Hence, this approach mainly thinks that disability as a defect within the individual. It means that the person himself/herself is responsible for

his/her inability to participate in society because of his/her biological condition or health problem which can be cured or eliminated completely by proper medical treatment or surgery. Therefore, it is prime responsibility of medical science to diagnose the defect within individual and give proper treatment accordingly. Briefly stated, the main objective of this approach is to make the disabled persons able or normal as soon as possible by providing them required medical treatment. However, the limitation of this approach is that it fails to support the persons who have severe or permanent impairments which may not be cured by any treatment. However, it is right to say that the persons with severe or permanent impairments get failure in this system. Additionally, this approach does not take into account the social attitude towards disability which is the main cause of exclusion of persons with disabilities from all spheres of life.

Most important thing is to be noted that this approach asserts disability as a ‘personal problem or tragedy’ rather than social responsibility. So it is also referred as the ‘personal tragedy’ approach of disability. It is considered as personal tragedy because this approach thinks disability “as a deficit residing in the individual; they refused to see disability as a pathology or to treat it as a problem that is necessarily in need of cure, rehabilitation or concealment” (Hall, 21). In this view, the role of persons with disabilities remains passive recipients of medical care rather than active participants of society. This approach implies charity approach to disability considering disabled people as needy and requiring welfare measures. Briefly stated, this model does not adequately capture the phenomenon of disability.

3. Social Approach to Disability:

The phrase ‘social approach to disability’ is coined by Michael Oliver, a British disability rights activist in 1983. This social approach to disability shows its reaction against medical approach to disability which tries to explain the problem of disability through the lens of medical science. After the emergence of this approach, the issue of disability has been seen as social problem rather than medical or individual problem. According to this model, disability comes after impaired person’s interaction with disabling environment. In this context, Insa Klasing explicates “disabling environments prevent the participation of disabled people in all walks of life due to badly designed buildings or inaccessible transport” (32). It shows that disabled people are physically disabled, but the society makes them more disabled by not providing them proper resources.

Along with this, negative attitude of the society also tends to exclude them from various mainstream activities. Klasing further elaborates that “Life is made difficult not so much by the individual’s medical condition, but mainly by a hostile physical and social environment which excludes disabled people from all spheres of village life” (30). It means that persons with disabilities suffer more from social disabling condition than their medical condition. Indeed, it is not possible to avoid the influence of disability every time, but the society can remove attitudinal and environmental barriers that exclude disabled people from all spheres of life. The limitation of this approach is that it excludes the issues of cognitive impairments like Autism or learning disabilities. In short, this approach only correlates social environments with individual’s physical impairments without considering cognitive disabilities.

4. Human Rights Based Approach to Disability:

In the last few decades, there has been a rapid expansion in legal conceptions. Since then, the facts of human life are significantly scrutinized through the legal aspects. Hence, the phenomena of disability is also seen with the lens of legal perspective. As a consequence, human rights-based approach of disability came into reality. This approach predominantly deals with the human rights of disabled people. The persons with disabilities are entitled to the same rights enjoyed by non-disabled citizens. The Americans with Disabilities Act has first time put forward this approach to disability in 1990. This approach is an improvement over the social model of disability, which sees disability as human rights issue. Like non-disabled people, disabled people have also right to enjoy civil and political as well as economic, social, and cultural rights in order to live life with dignified manner. David Johnstone describes:

“It has only been in recent years that the discourse around disability has turned to a consideration of human rights. Human rights, in their turn, have been influence by the growing strength of the disability movement and the emerging self-confidence of disabled people. A rights-based discourse spreads the dimensions of disablement to include civil, political, economic, social, cultural and environmental obligations” (23).

This approach focuses on the empowerment of disabled people rather than providing charity or welfare measures to them. In short, this approach views disabled people as subjects, not as objects.

Thus, these four predominant approaches have been adopted to describe the phenomenon of disability. They bring some changes within the perceptions of disability framework. Briefly stated, they represent some different observations and try to describe disability within a specific system, time and culture.

Nature of Disability:

As discussed earlier, disability is physical, mental, intellectual and sensory impairment. It may be permanent or temporary in nature. Likewise, there are diverse categories of disability in which some disabilities are curable and some of them are incurable in nature. Likewise, permanent disabilities cannot be cured by medicines, therapies or surgeries. For instance: some disabilities like blindness, deafness or dumbness may not be cured by any treatment. Whereas temporary disabilities like broken limbs can be cured by proper medical treatments like medicine therapies and surgeries.

Types of Disability:

Visible disability and invisible disability are the two types of disability.

1. Visible Disabilities:

Visible disabilities cannot be hidden because they are obvious to others. Hence, one can easily identify a person whether he/she is disabled or not by his/her physical appearance. For instance: the person who has walking impairment can be easily identify by others at first sight.

2. Invisible Disabilities:

Invisible disabilities are not immediately obvious to others. Hence, they have also been called as hidden disabilities. For instance: disabilities like deafness and dumbness are considered as invisible disabilities because it is very difficult to recognize a person who suffer from such disabilities by his/her appearance at first glance.

Some disabilities like mental disabilities are invisible to others but its symptoms are visible which are usually reflected through the behavior of person who suffer from such type of disabilities.

Causes of Disabilities:

There are two main causes of disability: natural causes of disability and man-made causes.

1. Natural Causes of Disability:

The old age is considered as one of the natural causes of disability. It is a natural process which may come in every human beings life if s/he lives long life. Such old age people have their own problems. They go through the various old age ailments including diabetes, deafness, cataract, rheumatics, asthma, weakness, dental problem, walking problem and unstable mental state. Such type of ailments badly affect their power of mobility which is required to work independently. Along with old age, various diseases are also the causes of disability. Some diseases come for short time but their impacts may remain for long time or permanent. For instance: leprosy cured person generally suffers from extreme physical deformities. Hence, its impact remain permanent, although it seems to be cured.

Consanguinity is also one of the main causes of disability, which reduces genetic variations in a group which may significantly protect

against the expression of recessive genes that can lead to congenital or genetic disorders. Some disabilities like Down Syndrome come naturally because they are inherited. The natural disasters including earthquake, fire, tsunami, famine, storm and landslide are also natural causes of disability. Such natural calamities often occur in various parts of the world by which many people are killed, but most of them are severely injured and become disabled permanently.

2. Man Made Causes of Disability:

Poverty and disability go hand in hand because both are cause and consequence of each other. Due to poverty, it is very difficult for people to get proper nutrition and physical care which may give rise to many disabilities. The most important thing is that most of disabilities are preventable if the poverty is reduced. Malnutrition is closely associated with poverty, which causes certain disabling conditions. Illiteracy about the proper knowledge of physical care also causes many disabilities. Another man-made reason of disability is road accidents.

People can be severely injured and become disabled in wars and civil conflicts. There are many chances of bomb attacking in wars. Along with wars, many people become disabled due to the civil conflicts. Especially, in India people from different communities, castes, creeds, and religions live together. There can be some disputes among them on various issues that may lead to civil conflicts.

Now a day's technology is an inseparable part of human life that makes the things easy. But, excessive use of technology may be harmful for health. For instance: constant use of mobile creates a lot of vision problems among people. DJ is a device that produces a lot of noise which can weaken the hearing capacity. Industrialization is also important cause

of disability because it increases pollution which may lead to the numerous health issues.

The Experience of Disability:

Disability is an inescapable part of human diversity which is found in every corner of the world. Although it is a global reality, the experience of disability varies from person to person, society to society, place to place, country to country and culture to culture. The reason behind that every individual with disability has different family background which may lead to different experience. For instance: some disabled people belong to rich families, but many of them have poor family background. The family members of all disabled individuals may be supportive. But many of them receive little or no assistance from their family.

The experience of disability varies from society to society as well. It depends upon what type of treatment society gives to its disabled people. It also varies from country to country because each country has different social and cultural background. In addition to that the experience of disabled people who live in developed countries is also different from those who live in developing countries in terms of getting resources. For instance: along with all the other problems, the problem of accessibility is severely faced by the people living with disabilities in developing countries. Even this experience can be different in country itself. For instance: the experience of disabled people who live in rural areas is different from their urban counterparts. In fact, “the experience of disability today in any country is likely to be very different from the experience of disability in that country a hundred years ago” (Klasing,

38). During the last few decades, each country has been trying to ameliorate the condition of their disabled population.

Another important thing is that every individual with distinct disability has to face different challenges and problems in their lives. For instance: in the case of education, the problems faced by visually impaired persons are different from wheelchair users. Their experience pertaining to education is completely different. Just as, inaccessible reading materials create obstacle in the way of persons with visual impairments whereas inaccessible school buildings are big hindrances in the way of all wheelchair users. Even if, their experience of disability is different from each other, they have to undergo the same sufferings of exclusion from the regular schools. Indeed, each person with different disability has to acquire different kind of skills and techniques to tackle the various situations of their life.

Western Experiences of Disability:

The ideas of bodily perfection in ancient times are reflected through the mythical stories of that period. The well-known story in Greek mythology tells that:

“The only physically flawed God in the Greek pantheon was Hephaestus who was born lame to Zeus and Hera. Hera practiced a form of infanticide by ‘casting him out of heaven’ whereupon he was rescued by Aphrodite, the Goddess of Love” (Karna, 69).

The above description reminds that body should be in perfect form. If one can lose bodily perfection, he/she has to face the harsh reality of life like Hephaestus.

Christian ideology is generally considered as cornerstone of western civilization. In spite of that, it speaks out against disability and disabled persons. It separates body and spirit from each other assuming that “The body is, however, meant to house the spirit, so that we are supposed to be consider our bodies as a temple that must be sanctified” (Karna, 69). As per the Christian belief system, the occurrences of diseases are not treated as natural but as moral failure or imperfection.

Even in the holy Bible, there are numerous allusions to the images of disability which represent disability as an evil. The Old Testament reveals that “blindness, leprosy and other disabling diseases are punishment for blasphemous behavior” (Karna, 71). The New Testament also links disability with sin which can be forgiven by God. Hence, many churches in the modern society are opened to get rid of that sin. In the middle ages, the grotesque ideas about disability were significant. During that age, disabled people were associated with the court jesters as well as the Christian fools which were used for the purpose of entertainment.

After that, freak shows were prevalent in European and American cultures. Disabled people were the professional performers of freak show in which exotic or deformed humans as well as animals were exhibited for public amusement. Due to the problem of their education and employment, their families also sent them to participate in that show to earn money. Although, freak show was a commercial and profitable business for their employers, its main purpose was to amuse or entertain the audiences. The people used to attend such shows to see the varieties of freaks with curiosity. In short, it was a big business of “presenting human oddities for amusement and profit” (Bogdon, 510). In reality, the freaks were misused under the name of profit and amusement because the presentation of such shows was always exaggerated with extraordinary

physical abnormalities in order to attract huge audiences. But that led to create negative impact of freaks identity which was misrepresented in front of world. Therefore, the people also saw them as an object of amusement but nothing more than that.

Even though, freak show was very popular in European and American culture for many centuries, it was ended in the early 20th century after the medicalization of human abnormalities. Gradually, the people in western countries like USA, UK and Canada also began to accept human abnormalities as a part of human diversity. So, the present experience of disability in western countries is better than India because most of things are accessible for persons with disabilities.

Indian Experience of Disability:

One can find that the present understanding of disability in India is dominated by European and American experience of disability. This experience is applied as a universal norm. The present research work seeks to understand the unique experience of disability in India because Indian experience of disability is complicated by poverty, gender, caste and community. Another fact is that India is one of the developing countries where people with disabilities get limited resources, facilities and opportunities. So, it is obvious that the experience of disability in India is different as compare to developed countries like USA, UK and European countries where they get adequate resources and facilities to lead normal life. Even though "...no country in the world has solved the problem of integrating all its disabled citizens into active social and economic life" (Sugaritha and Madeswaran, 2), the condition of persons with disabilities in developed country may be much better than developing countries.

Disability Rights Movement in India:

After the establishment of disability rights movement in America in the 1980s, the whole world became aware about the rights of persons with disabilities. The evolution of this movement in India can be traced back in the early part of 1990s. It emerged after the people suffering from disabilities started demanding their rights. There were various groups and the organizations from different parts of country supporting them. As a result, three legislations that are- Rehabilitation Council of India Act of 1992, Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act of 1995 and National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability Act of 1999 were subsequently enacted by the government of India for persons with disabilities. After that, Indian government adopted the United Nations Convention on the Rights of Persons with Disabilities in 2007. Then the government came up with the new act i.e. the Rights of Persons with Disabilities in 2016.

Disability Studies in India:

After the success of disability rights movement, several universities and academic institutions in various countries have given scope for the researchers to work on this newly emerging field. For the last five decades, many researchers from diverse professions have been studying the multiple aspects of disability all over the world. But the fact is that the field of disability studies is unfortunately ignored in the curriculum of universities and academic institutions in India. So far, very few Indian researchers from humanities, social sciences and other disciplines have been attracted to this topic. As far as literature is concerned, there is very

little research which has been done on disability as compare to other branches of humanities and social sciences.

Historical Representation of Disability in India:

Even though, the experience of disability varies from country to country, the history of disability in India somewhat resembles western history. Bhat states “during a ‘pre-historic’ time, many tribes killed off people who were deemed physically unfit to survive in the world” (Anand, 43). In traditional societies, there was a religious meaning attached to the occurrence of disability. It is said that occurrence of any kind of impairment was considered god’s punishment for one’s sin in the previous or present life.

According to Karma theory “Disability was considered the result of ‘wrong actions’ in one’s past life or the present one’ (Anand, 44). Such type of views regarding disability are still prevalent in Indian society. In reality, the Karma theory deprives disabled people from their inherent rights to lead independent life. During the medieval period, disability had been linked with supernatural factors. In the modern era, many supernatural and superstitious beliefs were gradually replaced by rational and secular thinking of people due to progress in medical science and later on the social approach has been linked to disability. Likewise, in the postmodern era, the issue of disability relates to the human rights approach.

The historical representation of disability in India is significantly reflected through the fictional characters with disabilities depicted by the authors in their literary work of arts. The disabled characters are represented in negative manners by some authors. They mostly appeared as evil, weak, ugly, fool, exotic and abnormal by nature. In this context,

Anita Ghai argues: “in the epics Mahabharata and Ramayana, many characters with disabilities are presented in a negative light” (Anand, 44-45). For instance: Dhritrashtra, the blind king of Kuru Kingdom in Mahabharata, who had been deprived of his throne on the account of his blindness. Even though he was eldest son, his younger brother Pandu was made the king. The characters Shakuni, an orthopedically disabled, in Mahabharata and Manthara, a dwarf woman in Ramayana are also represented negatively.

The Present Scenario in India:

Although the situation of persons with disabilities has finally begun to change, the history witnesses that having a disability meant something much worse and socially outcaste. Due to the global concern of disability, the United Nations has formulated many schemes and policies for the betterment of persons with disabilities. As a part of signatory of United Nations, Indian government also has come forward with the range of policies to ameliorate their condition. Even if they are still facing the enormous problems in their path, the significant progress has been continuously occurring in their lives due to some anti-discriminatory laws that can increase their participation in society.

The change in the situation of disabled people is gradually reflecting through the recent terminologies used for disabled people as ‘disabled’, ‘persons with disabilities’, ‘differently abled’ and ‘persons with special needs’ instead of ‘crippled’, ‘handicap’ or ‘defective’. Thus, many abusive and objectionable words from colloquial language are replaced by sophisticated verbal expressions. In the present scenario, persons with disabilities are viewed as persons with a wide range of abilities. Despite their abnormalities, they are also human beings with all

social, economic, emotional, physical, political, intellectual and cultural needs with other non-disabled people.

Disability Status in Urban and Rural India:

To understand the Indian experience of disability, it is necessary to focus on rural areas “Because disabled people in rural India are a silent and invisible group in spite of their significant numbers” (Klasing, 26). It is estimated that about 80 percent of total Indian disabled population lives in rural area, whereas remaining 20 percent live in urban area. Actually, there is huge gulf between the population of disabled who live in rural and urban areas. Needless to say that the condition of disabled people in urban areas is better than disabled people in rural areas. Even today the basic facilities are beyond the reach for those disabled people who live in urban India. Hence, they are often deprived of their basic rights.

In particular, each person wants to be independent in life. The people with disabilities have also the most common desire to do everything independently as other non-disabled people. But it never happens in the case of persons with disabilities due to their functional limitations. In reality, they feel humiliated by the sense of dependency even doing the simplest daily activities like walking, bathing or eating. Their dependency can be mitigated significantly by providing them proper education, employment, assistive devices and medical assistance. But, it is beyond the reach for those people with disabilities who live in rural India.

There is need to provide them various benefits such as education facilities, medical facilities, accommodation facilities, rehabilitation facilities, self-employment policy, pension schemes, reservation in education and employment for their welfare. Now-a-days the

Government, NGO's and other private institutes try to provide them these facilities but the rate of beneficiaries is very low because disabled people in rural area may not be aware about these schemes.

Specified Categories of Disability in India:

The entire magnitude of disability in India can be enormous. India has largest population of disabled people possibly after China. The National Sample Survey (NSS) of India conducted 76th round survey program on disability during July to December, 2018. It is estimated that 2.2 per cent which means around 30 million people of total population are disabled in India. It has been considered all the specified categories of disability stated in the Rights of Persons with Disabilities Act of 2016.

There are various categories of disability by which the persons with disabilities come under the protection of concern laws. The Persons with Disabilities Act of 1995 has listed seven categories of disability including "Blindness, Low-vision, Leprosy (cured), Hearing impairment, Locomotors disability, Mental retardation and Mental illness" (Singh and Mehmi, 12). Meanwhile, there was growing public awareness of some more disabilities. The Rights of Persons with Disabilities Act of 2016 classifies twenty-one disabilities including above seven. These twenty-one disabilities comprise in five main categories. They are as follows:

1. Physical disability:

Physical disabilities limit the person's functioning, mobility, dexterity and stamina while doing something. It includes four major categories of disability: locomotor disability, visual impairment, hearing impairment and speech and language disability.

A. Locomotor disability:

In this type of disabilities, it is very difficult for person to move from one place to another due to the afflictions of musculoskeletal or nervous system. It includes ‘Leprosy cured person’, ‘Cerebral palsy’, ‘Dwarfism’, ‘Muscular Dystrophy’ and ‘Acid attack victims’.

B. Visual impairment:

It includes person who cannot see at all or has blurred vision even with the help of spectacles. But person who has proper vision in one eye will not be treated as ‘visually impaired’.

C. Hearing impairment:

As a person of this category cannot hear anything or can hear only loud sound, he/she will be considered as hearing impaired. In other words, person of this category suffers from ‘deafness’ or ‘hard of hearing’. Along with visual impairment, hearing impairment is also included in the category of sensory disabilities.

D. Speech and Language Disability:

“Speech and language” disability comes due to the organic or neurological condition. A dumb person is included in this category. Similarly, a person will be considered as having speech disability, if his/her speech is not understood by the listeners of normal comprehensive and hearing condition.

2. Intellectual disability:

It is a condition in which persons of below average intelligence or mental ability are included. It includes both ‘specific learning disabilities’ and ‘autism spectrum disorder’. The conditions of dyslexia, dysgraphia,

dyscalculia, dyspraxia and developmental aphasia are included in learning disabilities.

3. Mental disabilities:

Mental disabilities are also known as ‘mental illnesses’ or ‘mental disorders’ in which a person has abnormal thoughts, emotions, behaviors, perceptions and relationships with others. If someone lacks comprehension appropriate to his/her age, he/she will be called as ‘mentally disabled’ or ‘mentally retarded’. Depression, bipolar disorder, schizophrenia, dementia are the causes of mental disabilities.

4. Other disabilities:

It includes two types of conditions such as chronic neurological conditions and blood disorder.

A. Chronic Neurological Condition:

It includes ‘multiple sclerosis’ and ‘parkinson's disease’. These two categories are associated with nervous system of person. In multiple sclerosis, person’s nerve cells in the brain and spinal cord are seriously damaged. Parkinson’s disability is a progressive disease that affects the central nervous system of person. It creates cardinal symptoms like muscular rigidity, tremor, slowness of movement and postural instability.

B. Blood Disorder:

It comprises three categories of disability such as ‘Haemophilia’, ‘Thalassemia’, and ‘Sickle cell disease’. ‘Haemophilia’ means the loss of normal ability of blood clotting which may cause fatal bleeding. ‘Thalassemia’ results an excessive destruction of red blood cells and hemoglobin in which transport of oxygen from the lungs to other parts of

the body is hampered. 'Sickle cell disease' is a hemolytic disorder caused by the destruction of red blood cells.

5. Multiple Disabilities:

In the category of multiple disabilities, the person suffers from more than one of the above stated disabilities. For instance: If the person has hearing impairment, he cannot develop his speaking ability. It affects his overall communicative and developmental activities.

Human rights of persons with disabilities in India:

The human history shows that from the man's first existence in this universe till the 20th century, there was no provision for persons with disabilities. But first time in the human history various provisions are made for them at international and national levels after the second half of the 20th century. Actually, these provisions have originated from the needs of people who became severely disabled in World War II.

Although Indian constitution has not made specific provisions for persons with disabilities, Article 14 mainly talks about that each person is equal before the law. However, the principle 'everyone is equal before the law' applies to the persons with disabilities like others because they are also human beings. Therefore, it is completely barred to discriminate or exclude someone on the ground of disability. They have the same rights that other people enjoy. Despite that they need some special rights for their overall developments. However, like other nations, Indian government has subsequently made some separate provisions to remove the barriers in their ways.

1. The Mental Health Act of 1987:

The aim of this act is to protect the rights of persons who suffer from mental illness. It directs Central and State Authorities to provide mental health facilities and services for them. To regulate their mental illness, they have to be admitted at Psychiatric hospitals or nursing homes. The presence of these persons may be dangerous for the society. However, it is necessary to protect society from the presence of such persons. Another most important thing is that it is illegal and unconstitutional to send non-criminal mentally ill persons to jail.

2. The Rehabilitation Council Act of India (RCI) of 1992:

Its main focus is to provide rehabilitation facilities for persons with disabilities. It includes training for their encouragement and motivation. It also promotes the research in rehabilitation field.

3. The Persons with Disability Act of 1995:

The Persons with Disabilities (Equal Opportunities Protection of Rights and Full Participation) Act, 1995 was passed by Parliament in December, 1995 and came into force on February 7, 1996. The prime objective of this legislation is to provide barrier free environment which helps to stop any kind of discrimination against the persons with disabilities and integrate them into mainstream society. It enacts the rights of disabled in relation to their education, employment, non-discrimination, and social security.

4. National Trust Act of 1999:

National Trust Act is also known as National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act of 1999. This act endeavors to take care of the persons

with the categories of Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities. This act mandates to arrange the welfare programs for them.

5. National Policy for Persons with Disabilities (2006):

It was formulated when it was realized that persons with disabilities are also valuable human resources of country like other citizens. This is mainly focused on rehabilitation of persons with disabilities. Along with this, it also focuses on barrier free environment, social security, and research.

6. Rights of Persons with Disabilities Act of 2016:

The RPWD act has identified twenty-one different types of disability including earlier seven that are mentioned in Persons with disabilities Act of 1995. Its main focus is on the provision of accessibility for persons with disabilities.

Even after so many provisions by the Indian government, disabled people especially in rural India are facing enormous problems. This is because such provisions are only seen on the papers, but the proper implementation is not done by the government.

Various Problems Faced by Persons with Disabilities in India:

In India, the persons with disabilities are most disadvantaged or socially marginalized group of people who do not have access to the basic social services and resources. Hence, they have to face enormous problems regarding education, employment, transportation system, rehabilitation and many more to survive in this condition. All their problems regarding their disability are interlinked with each other. For instance: due to the inaccessible school buildings and materials, persons

with disabilities are deprived of education and without acquiring proper education they cannot get employment. However, to understand the experiences of persons with disabilities in India, it is necessary to study their problems. Those problems are given below:

1. Education:

As far as education is concerned, the ratio of students with disabilities in India is very low as compare to non-disabled students. If the students with disabilities want to take education, a lot of obstacles come in their ways. Mostly, their parents think that giving education to disabled child is a waste of time, money and energy because there is no “point of investing in education for a child who is “not normal” (Klasing, 31). Sometimes, they cannot afford to send their child in school because they have other expenditures of that child including frequent and expensive medical treatments like surgeries and therapies. Furthermore, such children require special aids and appliances to perform their daily tasks and the cost of these instruments are very high. Another thing is that each disabled child may not belong to the rich family. In some cases, those who are disabled but rich may not have a big problem in accessing education, whereas those who are disabled but poor may suffer a lot even to get basic education. Likewise, it is not possible for each disabled child to get education in special schools. If they are admitted in the mainstream schools, they face a lot of problems because such schools are very poor in case of accessibility.

Generally, the ramps or elevators are absent in regular schools. Furthermore, toilets are also not accessible for them. The entrances of doors are mostly narrow. Hence, it is very problematic for those children who have physical disability. Most unfortunate thing is that these schools do not show any kind of interest to modify the infrastructure. In the case

of others students who have hearing, seeing or learning impairments, there are no special teachers and teaching aids to facilitate the problems of their learning. Klasing also says that "...children who were mentally slow, or speech and hearing impaired, or blind, felt isolated and marginalized in the course of teaching" (12). It is true to say that the mainstream schools never fulfil the needs of disabled students as per their requirements. Hence, such students always feel isolated in such schools. Briefly stated, in the absence of supportive equipment, trained teachers and educational settings make children with disabilities lag behind other normal children. As a result, they do not realize their full potential.

Thus, the students with disabilities need accessible school environment. Along with this, they need accessible school materials and facilities including teaching curriculum, textbooks and computers. They need special teachers and appliances for learning too. But the mainstream schools are unable to provide these things to them. However, they need to take the help of special schools where they can get individual support, barrier free environment, trained teachers and necessary equipment. But, such special schools are mostly located in urban areas and majority of disabled population live in urban areas in India. The people in rural area are unaware about such special schools. But the special schools sometimes refuse to admit the students with extensive physical disabilities.

2. Employment:

Unemployment is a big obstacle in the way of persons with disabilities because there are limited job opportunities available for them. Indian Government's the Persons with Disability Act of 1995 guarantees three percent of job opportunities for them in public and private sectors. Only having such kind of reservation in job opportunities is not enough.

But they need barrier free environment at their workplace, which enables them to work equally with non-disabled people. Even today, very few buildings and premises are accessible for them in India. For instance: most of buildings have number of floors without lifts and ramps that they can use. But they have to take help of others to carry them up from one floor to another. The entrances of such buildings and toilets are very small in which wheelchair users cannot enter. Besides that toilets have no bars that are essential to hold on them for stability. Mostly, the people with mobility disabilities face the problems of moving in such type of inaccessible buildings and premises.

The first and foremost reason of their exclusion in the placement is that employers have some prejudices and misperceptions against them. However, the employers may think that such persons are incapable or have no potential to manage work. Hence, they are always reluctant to employ them at the workplace. The fact is that the employers have no right to discriminate against persons with disabilities on the basis of physical abnormalities during the process of their placement. In fact, physical restrictions can be mitigated by making suitable modification in environment at workplace.

3. Transportation:

The poor accessibility in transportation system stops people with mobility impairment to go out of their homes. One can find that various platforms, roads, buses, trains, airports and places are still inaccessible in India, so that it is very difficult for them to travel or reach at their workplace. Sugirtha and Madeswaran also illustrate that “The transportation problem is one of the major issues facing the disabled.

Without a customized transportation system, many disabled who will otherwise be able to join workforce will be confined to their homes” (05).

Especially, persons with mobility disabilities always suffer on the account of inaccessible transportation system. For instance: public service vehicles do not have wide entrances for the wheelchair users. They are built with staircases at the entrance, so that wheelchair users cannot enter or exit without help of others. The public service operators probably think that waiting for wheelchair user while entering and getting off the bus is also wasting of their time. Persons with mobility impairment are often abused and mistreated by both operators and public as well. In some cases, the priorities are not given to the persons with disabilities, even though many seats are reserved for them. In a rush, they can be shoved aside by able-bodied people who may sometimes ignore the presence of disabled person. The reality is that all wheelchair users’ economic condition may not be good, so that it is not affordable for all of them to travel in private vehicles all the times.

Now a day’s both public and private transportation is completely inaccessible for visually impaired person. Pedestrian paths are not available everywhere for them. Even crossing the roads is very difficult thing because there is no arrangement of sound system while indicating the signal through lights. In such situation, it is impossible to understand when they have to stop and cross the roads. It short, mainstream facilities are not designed on the basis of inclusion but exclusion of disabled people.

4. Accessibility:

The word ‘accessibility’ means approachability of anything that person wants to achieve without encountering barriers. The Cambridge

Dictionary defines accessibility as “the fact of being able to be reached or obtained easily”. It shows that accessibility brings necessary benefits to all its users. Although the general meaning of this word refers to the access of services or other things that can be used by everyone, it is often used to describe facilities or services that assist persons with disabilities because most of the things or places are inaccessible to them while they are accessible to persons without disabilities. The fact is that their needs are not taken into consideration while building or developing things for others. As a result, they cannot participate fully or equally in the mainstream society with other people.

India is very poor in the case of providing accessibility to its disabled population. Hence, disabled people in India are always confronted with various problems due to the lack of physical accessibility. It prevents them from participating fully in social activities like non-disabled people. The public and private buildings are mostly inaccessible. For instance: the ramps and elevators are not seen anywhere in these buildings. The toilets are also not accessible. Even the parking services of such buildings are inaccessible for them.

Most of the time, the students with disabilities are not enrolled in regular schools due to the lack of accessible buildings and study material. Furthermore, having required qualification, knowledge and talent at disabled people, the employers never give them opportunities to work because they do not want to restore the structure of their buildings. As noted earlier, inaccessible platforms, roads, buses, trains, airports, buildings, places, toilets and parking services deprive disabled people to work independently. Actually, it is responsibility of society to make the things accessible.

5. Accessibility of Information:

It is true that today's world is based on information technology. That information must be accessible for everyone including persons with disabilities because

“Accessibility allows individuals with disabilities to have use of information and services that is equal or equivalent to the use enjoyed by everyone else. Accessibility to information and communication technologies (ICTs) encompasses issues of both physical and intellectual disabilities” (Jaeger and Bowman, 70).

Nowadays, the devices like computers and mobiles are the main sources of getting any information. Hence, such devices must be accessible for persons with disabilities. Even though such devices are accessible, many websites are not accessible for them. Therefore, they cannot reach at proper information which may be valuable for them. Even online transactions are not yet possible for visually impaired people because of inaccessibility in e-banking services. In addition to that ATM are also not accessible for them. Overall, it seems that the needs of these people are not taken into consideration while developing new technologies.

6. Aids and Appliances:

Aids and appliances play a crucial role in compensating the loss of particular body part or function. So, some aids and appliances are specially created for the persons with disabilities, which assist them to improve the qualities of their life. There is availability of various appliances such as crutches, calipers, prostheses, tricycles and wheelchairs for physical movements, Braille writing machines,

dictaphones, CD players, tape recorders and special mobility aids like cane for visually impaired, low vision aids for low vision and hearing aids for hearing impairment. Such aids or appliances help to mitigate the severity of their physical impairments. But many surveys in India revealed that most of the aids and appliances are of poor quality. Furthermore, due to the lack of training, many people with disabilities fail to use or handle them. More often, these aids are not suited to local conditions and the repairing centers are also not available.

7. Health/Medical Services:

Disabled people frequently need specific medical treatment and care. But, it is sometimes very difficult for them to manage the cost of their treatments and medicines because all disabled people's economic condition may not be good. The Indian government spends some amount on the health of disabled people, but that expenditure is insufficient compared to the actual costs of their treatment. Most often, the medical services provided by the government to disabled population are beyond the reach for those who live in villages. Furthermore, other professional therapists, physicians and surgeons in India are few in number and most of them are settled in big cities. It is impossible for disabled villagers to get the required treatment at the initial stage.

Government healthcare services are very poor in quality. Especially, the Primary Health Centers are the cornerstone of the rural healthcare system, but they are not wholly accessible for people with disabilities even today. Along with environmental barriers, they find that these centers have shortage of staff including special doctors, trained workers and supplies. Likewise, these health centers never distribute aids and appliances which are really essential for them. Additionally, they never offer physiotherapy or counseling to them either. Even the district-

level hospitals do not take into account the special needs and requirements of persons with disabilities. The lack of awareness on the part of disabled people keeps them away from seeking medical help at several levels. For instance: most of the disabled people especially in rural India are unaware about the dates of medical camps which are sometimes near to them.

8. Rehabilitation:

According to The Persons with Disabilities Act of 1995, “Rehabilitation” refers to a process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric or social functional levels” (03). The above description shows rehabilitation plays important role in the life of persons with disabilities. It teaches them how to survive in this world. It is the process of integrating disabled people into mainstream society. It covers diverse areas including social, educational, occupational, physical or psychological rehabilitations. Many rehabilitation centers are available in India. But rehabilitative services are concentrated only in urban areas and not in rural areas. Most of disabled population is unaware about these centers due to lack of knowledge.

9. Reasonable Accommodation:

The provision of reasonable accommodation for persons with disabilities is crucial to perform essential functions efficiently and productively. Indeed, not all the individual with disabilities required accommodation. It depends upon the nature of that individual’s disability. In fact, each person with disability does not require the same accommodation. It varies person to person because each disabled person may have different disability. Although some people suffer from same

disabilities, they may require different accommodation because the severity of each individual's impairment can be different.

10. Social Security:

The state has to arrange social security programs for the welfare of its citizens to improve their standard of living. Although it is responsibility of each state to protect their basic human rights, Indian states have failed to protect its disabled population from many adversaries like poverty, illiteracy and unemployment. This is because many provisions are made for the full social security of disabled people, but they are not implemented properly. So they always feel insecure about their lives.

11. Integration:

Generally, disabled are separated from the society because of the negative attitude of the people who may think that disabled people cannot contribute anything due to the lack of their ability. But, integration is always required for the welfare of society because division of the society into various minorities groups is not good for any society. In addition to that such division of society never help to achieve the main goal of that concerned society. It is said that the fingers of hand are not equal, but the roles of each finger are important while doing any kind of work successfully. In that way, the role of disabled people is also important in the process of national development. Hence, it is prime responsibility of policy makers who design and implement development programs to encourage the process of inclusion of disabled people in the mainstream society like others.

12. Negative Attitude of Society:

In Indian society, the persons with disabilities are still facing attitudinal barriers including prejudices, misconceptions and stereotypes. These negative attitudes and beliefs can result in stigma by which persons with disabilities are excluded and segregated from the society. Actually, people have lack of knowledge and awareness about the occurrence of disability and its implications in future. This ignorance also leads to stigma. Rohwerder explains that “the lack of understanding and awareness regarding the causes of disabilities and their resulting characteristics is a key factor in the stigma experienced by persons with disabilities” (2). It clears that inadequate knowledge and awareness regarding disability and disabled people create negative attitude among people.

13. Social Exclusion:

Social exclusion means not giving equal opportunities or resources to any individual by the majority of people in the society while participating in common activities. The society excludes many people from social, economic, cultural and political activities. According to Levitas et al.:

Social Exclusion involves the lack or denial of resources, rights, goods and the inability to participate in the normal relationships and activities, available to the majority of people in a society, whether in economic, social, cultural or political arenas (9).

The concept of social exclusion was first used by Renee Lenoir, the then French State Secretary of Social Action in 1774. He used this term to describe a wide range of excluded people which include aged, poor,

suicidal, physical or mental disabled and other socially marginalized groups of people.

Persons with disabilities are largely dispossessed social group of people than other marginalized groups of people in India. They are always hidden behind the walls at home by their families due to some stereotypical opinions and misconceptions about disability. As a consequence, they lead their life in isolation, loneliness and silence. They remain invisible, unnoticed and voiceless, in spite of their significant number. They are rarely seen in schools, workplaces, streets, markets, theaters, factories, temples, churches, buses, weddings or playgrounds.

They have not been given chance in political decision-making. “Unlike other minority and caste groups, disabled people have not yet established themselves as special interest group in state or national politics” (Klasing, 24). They are absent from both state and national level political agendas. “The lack of political representation may translate into a lack of policies and programmes targeted towards the excluded” (Klasing, 34). In some cases, political exclusion may impact their access to social services like health and education.

After studying these problems, it is cleared that persons with disabilities in India lead very challenging life. They often get limited resources and opportunities to participate in mainstream society. Along with disabling environment, they face attitudinal barriers in their ways.

The Experience of Disabled Women in India:

Despite all the above discussed problems, disabled women face some additional problems on the basis of gender inequality. Hence, in order to understand Indian experience of disability, it is necessary to

understand the problems of disabled women in India. The problems of disabled women are as follows:

1. Societal Role:

The role of disabled women in social life depends upon the tradition and culture of concerned society. In Indian society, many superstitions are still prevalent in the mind of people about disabled girls or women, so that they have limited opportunities to participate in community life. For instance: disabled women's presence is usually considered as inauspicious on the occasion of community celebrations and gatherings. "Even their presence in a family can hamper the marriage prospects of their siblings significantly" (S. Datta, 36). As a consequence, they confine themselves in their parental homes. This leads them to live under the feelings of isolation, loneliness and low self-esteem.

The idea of education for women is usually considered as unnecessary waste of time, energy and money in male dominant society like India. In such condition, the prejudice against educating disabled girls or women is even stronger. Many surveys revealed that disabled women in rural areas face even harsher discrimination while taking education compared to their urban counterparts. According to Klasing, "No school had ramps or special toilet facilities for its disabled students, making education a daily struggle especially for physically disabled girls" (12). Having limited and unequal access of participation in education, disabled women have little chances of participating in employment. Statistical data reveals that disabled women are often denied the access to employment due to the negative attitude of the employers. Even if disabled women find job opportunities, they earn lowest wages compared to disabled men and non-disabled women.

2. Double Discrimination:

Double discrimination means discrimination against person on the basis of more than one ground. Generally, the social status of women varies from culture to culture or tradition to tradition of country in which they live. It is well-known fact that women have low status especially in Indian patriarchal society. Since women face discrimination due to gender bias, women with disabilities face two fold discrimination of being both women and disabled. “Women with disabilities are marginalized within an already marginalized group” (Morgan, 23). Likewise, due to the poverty, some disabled women face triple disadvantages. “Being a women, origin in a poor family and suffering from a disability constitute triple disadvantages in maintaining existence” (Datta and Datta, 15). In addition to that if such women belong to any lower caste, then they will have to face multiple segregations in society. Briefly stated, due to their gender, impairment, poverty and caste, disabled women face multiple forms of oppression in India.

3. Marriage Problem:

In Indian society where the marriages are mostly arranged by elders rather than individual choices. Disabled women are completely ignored in marriage negotiations between two families. Hence, they have less chances of getting suitable marriage partners due to their impairments. As a result, they are mostly married off by their families with wrong persons who are already married or too much older than them. Klasings also describes the situation of rural women with disabilities that “Most were forced to marry in highly unequal situations, as second wives to older men, widowers or divorced men” (15).

The most unfortunate thing is that women's physical endowments are primary important factors in Indian societies while determining their social value or status. Their chances of getting married and having sexual partnership also depend on their physical appearances which disabled women don't have. In short, strong emphasis on the physical appearance of women creates negative image of disabled women. It is widely accepted that disabled men can marry non-disabled women but disabled women cannot marry non-disabled men because disabled women are perceived as those who are unable to perform their traditional roles of wife, mother and home maker due to their impairments. But, there are numerous disabled women who have proved that they can handle extra challenges in their marital life while managing official duties.

4. Misconceptions:

Women are generally expected to perform traditional role of looking after household duties. Unlike non-disabled women, disabled women are usually considered as incapable of fulfilling sexual, reproductive and maternal roles. Hence, disabled women do not have the same life options that are being performed by non-disabled women in the form of marriage, motherhood, and care taker of their families. Because, it is common belief that if disabled women cannot take care of themselves, then how they can take care of their family and children which requires physical strength and mobility. This belief is strong in the case of women with mental disabilities.

Another misconception is that mother's impairment can be inherited by her children. People have fear that disabled women will produce defective children. But, the fact is that majority of impairments are not hereditary or congenital. This fear in the mind of people makes severe discrimination against disabled women especially those who have

mental disabilities. So, disabled women who are born with disabilities remain unmarried for lifetime. If they become disabled after their marriage, they are abandoned or divorced by their husbands. There are very few cases in which disabled women remarry.

5. Sexual Abuse:

All over the world, girls or women with disabilities are frequently affected by the violence like sexual abuse. The most horrible thing is heard that "...in Africa, there is a myth that having sex with virgin can cure a person of HIV/AIDS. Women and girls with disabilities are targeted for rape, because they are presumed to be asexual and thus they are virgins" (Sowmya, 264). Such type of abuses have happened not only in Africa but also in various parts of the world. It is reported that girls or women with disabilities in rural India are mainly treated "...as unpaid domestic labour and sexual objects, and suffered high levels of physical and psychological domestic abuse, sometimes even desertion" (Klasing, 15). Especially girls or women who have mental or intellectual disabilities frequently go through sexual abuses. It is also reported that the number of sexual abuse is highest in women or girls with hearing and speech impairments because the culprits take advantage of the fact that such victims are unable to communicate the crime to others. But the judicial system is unable to protect them from such cruelties.

6. Forced Sterilization:

"Forced sterilization is the process of permanently ending someone's ability to reproduce without his or her consent" (Kumar, 228). Especially, girls with mental retardation are forcefully sterilized by the doctors as per the demands of their parents. Klasing also points out that "Girls with disabilities, particularly those who are mentally challenged,

were found to suffer from routine sexual abuse and unwanted pregnancies” (15). Instead of forced sterilization to avoid future complications like unwanted pregnancies, it is necessary to eradicate the problem of sexual abuse from the society.

After studying the condition of disabled people in India, it shows that there is still lack of awareness found among people about nature, causes and consequences of disability. The preceding theoretical framework of disability studies will be applied to the analysis of autobiographies of persons with disabilities to understand the experience of disability in India.

Chapter III

Autobiographies of Visually Impaired

1. *Face to Face* by Ved Mehta

Ved Mehta was a prolific writer and journalist. He started his career as writer by writing his autobiography entitled *Face to Face* which was published in 1957. Later on, he wrote twenty-seven fictional and non-fictional books. Most importantly, he worked for the magazine called *The New Yorker* as a staff writer for many years. Through his writing, he tried to introduce many things about India to the American readers. Margalit Fox says that Mr. Mehta was widely considered the 20th-century writer most responsible for introducing American readers to India” (www.nytimes.com). While describing about the simplicity of his writing, Ian Jack said that “His essays were clear and informal, and always rooted in the concrete and the particular” (<https://www.theguardian.com>).

The book '*Face to face*' is about the life of author who became blind at the age of three and half due to the problem of Meningitis which is a kind of serious infection that can damage the optic nerve responsible for sight, resulting in partial or total blindness. In this book, he mainly focuses on his childhood memories in India and early education at a School for the Blind in Arkansas. It is divided into three parts that contain twenty-seven chapters with different names. The name of first part is 'India and Home' which comprises first ten chapters. The second part entitled 'Pakistan and Transition' contains next eight chapters and the part third 'America and Education' includes last nine chapters. The whole story of this book moves around author's struggle for education which is the basic right of every individual including disabled people. He faced a

lot of problems like inaccessibility and negative attitude of people because India had little provisions for blind at his time.

He was born on 21st March, 1934 in British India and died on 9th January 2021 in New York City at the age of 86. His father was a doctor in the Public Health service and mother was house wife. At the age of three and a half, Mehta started suffering from the prolonged sickness i.e. Meningitis. During this sickness, he lost his eye sight and became visually impaired for lifetime. As he lost his sense of eyesight, he started living with his other four senses. He describes:

I started living in a universe where it was not the flood of sunshine streaming through the nursery window or the colors of the rainbow, a sunset or a full moon that mattered, but the feel of the sun against the skin, the slow drizzling sound of the spattering rain, the fell of the air just before the coming of the quiet night, the smell of the stubble grass on a warm morning (Mehta, 03).

It shows that the problem of his eyesight transformed him to live in the world of four senses. It is difficult for anyone to live in the absence of one of the senses, but Mehta had to accept the new situation of his life and developed different techniques to observe things with other four senses.

His father was a trained doctor but he could not save his son's eye sight. His wide medical experience had made him to accept the truth that his son would be blind for the rest of his life. Once his father declared that "But now, by fate or by the will of God, blindness had struck not only a child of the well-to-do, but that of an excellently trained doctor, who found his training in this instance useless" (04). It is true that

disability can affect anyone at any time. It never sees the background of any person. Initially, it was hard for Mehta's family especially for his parents, his three sisters and brother to accept the truth of his blindness. But they could not deny the reality.

Author's father was a rational man and he had always scientific explanation about everything. Whereas his mother had faith in conventional beliefs and practices. This was because of their coming from different background. His father was a trained doctor who travelled abroad extensively. He was influenced by the western ideas and cultures. But his mother belonged to a large middle-class religious family. She was brought up in the strict discipline of a very conventional Indian home. She could not go to school after passing her eighth class which was considered good education at that time. From that time until her marriage, she devoted herself to cooking, sewing and caring of her younger sisters and brothers. Mehta thinks "While these skills trained her to be an excellent mother, they did not prepare her to cope rationally with an unfamiliar tragedy such as blindness" (07). So, her irrational thinking made her to believe in some superstitious causes behind her son's blindness.

It was difficult for his mother to accept that her son's sight would never return. She wanted him to be cured at any cost. She firmly believed his blindness as tragedy which came due to the past misdeeds. Once she called the family pandit at her home for consultation. The pandit started examining the lines of author's palm but he could not explain their problem. He suggested her to consult other pandits. Thereafter, she took consultation of some other pandits. According to the author, "Although their analyses and remedies differed considerably, they all agreed that by doing penance for her sins, my mother could improve my chance of

regaining sight” (05). It means that most of these pandits were talking about sin that was committed by his mother in the previous birth and now she had to do penance to restore the sight of her son. So, they prescribed various methods including prayers and necessary rituals to get rid of that. Most interestingly, even if his father would scorn such methods, his mother performed them secretly.

Along with these methods, religious counsel was taken in the form of series of visits to Bakims, physicians who followed the Greek or Unani medicine. Author says that “These quacks prescribed all types of concocted drops to put in his eyes” (05). His mother followed such non-scientific methods in the hope that his blindness could be cured. Once his father returned home unexpectedly and saw the author was crying loudly because his mother was administering the drops into his eyes. He became furious as he saw the repulsive act of his mother. He strictly forbade her to make the visits of hakims and the purchase of surmas. After that, his mother stopped visiting the hakims but she continued to apply the surmas to his eyes until he was eleven.

His father completed his education in public health in the University of London in England. After that, he took a job in newly created Public Health Department as Municipal Health Officer. Because of having such strong base of education and job status, he perfectly knew the importance of education. Most importantly, his strong determination to give high education to all of his children was quite natural. But he soon realized that it was difficult in the case of author because there are very few schools for blind in India at that time. Therefore, he decided to send him abroad for education. In reality, after author’s blindness, his father determined that at any cost he would give him better education like his other children. Once the author accidentally came upon his father’s diary in

which he had written that “I will sell my soul to give him the highest education possible” (62). Until then, his father never hesitated to take hard efforts to provide him better education.

Meanwhile, his father tried to read all available literature on blindness. He found that “almost all India’s blind people had turned to begging for their livelihood, or had become owners of *Pan* and *Biri* shops and spent their days rolling nuts and condiments in a betel leaf or tobacco in a cigarette paper” (10-11). It shows that there was no scope for personal growth for blind people in India at that time. Consequently, such people turned towards begging or spent their lives in small shops. But the author’s father didn’t want such future for his son.

His father started corresponding with many prominent educational authorities to ask their advice. But concerned authorities gave him negative response by saying “For the blind, educational facilities and personnel were limited, and often the schools became semi-asylums with all ages grouped together in classes without any gradation system” (11). Briefly stated, getting education was difficult thing for blind in India. The reason behind that, the regular schools could not consider their special needs and on the other hand the special schools also provided them limited opportunities to take education.

At the age of five, his parents sent him to Dadar School for the Blind in Bombay where Dr. R. M. Halder was principal who promised them to take special care of their son. In the first class, he spent his time looking over stuffed animals and birds to get their images in mind. He also learned how to count with the help of abacus. Thereafter, he made rapid progress in arithmetic class and correctly associating the names and shapes of birds and animals. Along with academic progress, he learnt

personal adjustment and discipline. Most importantly, he learnt to do everything independently. In his second year at school, he had begun to learn multiplication and division on an arithmetic slate. He had also started reading and writing Braille in English. Likewise, he spent his spare time to take care of his own little plot of land where he planted vegetables as everyone else. He describes “I continued my studies at the school for another year and a half and within two and a half years I had absorbed all the school had to offer” (25). Indeed, Dadar School and Bombay gave him scope for overall improvement in very early days of his life. He liked Dadar School so much but the climate didn’t suit him. So, he was sick a good part of time.

Mr. Halder, the principal of Dadar School, encouraged the author as he expressed his wish to go to America for education. He tried to contact Dr. Ferrell who was the director of Perkins Institute on his behalf. But the reply of Mr. Ferrell ruined the dreams of his immediate visit to America. He strongly recommended that he should not leave his home environment in such early age. According to him, “...his experience with those coming from the East at an early age to study in the Western world indicated that there was a grave risk of becoming total misfits in Eastern as well as in Western cultures” (25). Thereafter, Mr. Halder suggested his father that no immediate provision could be made for author to go abroad for education because in his opinion he should spend early days of his life with family instead of staying in boarding school.

Thereafter, his father learnt about Emerson Institute at Lahor. Like Dadar School, Emerson Institute also gave vocational training which might help to rehabilitate the students who got admission there. In fact, there was no gradation system with regular classes like other schools. The author says “Their education followed no system of gradation by classes,

and even if it had, the education would have ceased by the fifth grade because of the lack of funds to engage qualified teachers, who are so scarce everywhere” (78). It shows that very few institutes were trying to work for blind people at that time. But due to the lack of funds, such institutes were suffering from inadequate resources. So, they could not work properly and effectively.

The fact is that India is one of the developing countries where most of the people still live in poverty. In such condition, very little attention is given to special needs of disabled people. The author’s father knew “The blind in India have no future, for in a country ridden with starvation and poverty, little attention can be paid to those with special problems” (78). It shows that the society is not aware about the special needs of disabled people.

As his father had observed that in India the most of blind people were musician, he hired a tutor, Pandit Hukum Chand to teach music to his son. Panditji came three times in a week in the afternoon to give him lessons in music. But he had to discontinue his classes as his family left Lahor and shifted to Bombay as refugees after the partition of India. His parents had not been able to bring anything with them from Lahor except their summer clothes. They left everything there.

Meanwhile, his family again shifted from Bombay to Delhi and then to Simla for their safety. Sometimes he felt frustrated as he saw his parents and siblings were busy in their works and he alone would not do anything. In Lahore, at least he was engaged by his music teacher. But here in Shimla he could not do anything. His musical instruments were left behind in Lahore. He tells “All my musical instruments, *table*, *tambura*, *sitar* and harmonium had left behind, and no teacher here could

add to my progress” (149). Along with these musical instruments, he left his few Braille books in Lahore. Furthermore, his electric transformers and carpentry tools were gone. So, he had to pass few months in the state of inaction.

Once his father heard about Sir Clutha Mackenzie, a totally blind Englishman who was directing St. Dunstan’s Hostel for the war-blinded in Dehradun. Sir Mackenzie was first blind person that his father had ever met and was impressed by his learning and abilities. St. Dunstan’s Centre was only for war-blinded people. So, the author had little chance to get admission there. But, after requesting the concerned authority, his father was able to admit the author at St. Dunstan’s Centre which was considered as best training center for the blind in India.

The author found that St. Dunstan’s Centre was a beautiful place. He says “The classroom atmosphere was as wholesome as that of the huge compound with its scores of lichee trees” (151). He tried to learn all the things whole heartedly. His teacher, Mr. Cameron spent ample time to teach him language and typing. Likewise, Mr. Advani, another teacher, taught him grade-two Braille, the more complex Braille which includes contractions and abbreviations. He expresses that “My stay in Dehra Dun was not only fruitful but happy” (151). The reason behind that he was allowed to take out Braille books and magazines to read from their small library. Most importantly, he learnt the value of doing things independently. But the St. Dunstan’s had given him only eight months’ opportunity to stay there and sent him back home considering he had learnt all St. Dunstan’s had to offer him.

Once he had an interview with Mr. Baldwin, a representative of a large American corporation. Unfortunately, he performed very poorly in

that interview. Mr. Baldwin found that he had poor language skill and educational foundation. So, the author again lost his hope of going to America. He wrote a long letter to Pandit Neharu about their losses in Pakistan, his search for education and his growing frustration. Pandit Nehru expressed “Why do you want to leave home and go to places where no one will take care of you? You can get all the education you need here, by going to schools for the seeing children” (157). But the author felt too discouraged to tell him that he had tried to approach in seven schools where the teachers showed their incapability to handle blind students and they seemed fearful that the students like him would disrupt the routine of their classes.

The author had strong desire to go abroad for education but couldn't find the right way. He himself had lost few opportunities to go there for one or other reason. So, he felt frustrated. But his father often tried to give him hope by saying

“I will stand behind you, and you will go to England or America even if you have no financial assistance, or as far as that goes, no admission. Don't forget, child that I myself went to England without promise of admission. Once you are there, they won't send you back” (156).

His father encouraged him by telling his own example of going to England and making excellent career, although he had no assurance of admission at the initial stage. These encouraging words of his father again created new hope of going abroad.

The author kept trying, once he wrote a letter to Arkansas School for the Blind and expressed his wish for getting admission in their school. It was unexpected for him but he received letter of acceptance from them.

Finally, his dream of going to America for education came true. He was very much impressed by America where he could live normal and independent life like others. Along with excellent education, he enjoyed the freedom of movement and a complete sense of self-reliance that he couldn't enjoy in India. He writes "All these things my own country had not been able to do, because I was blind" (303). It is clear that his hopes and aspirations were not fulfilled while living in his own country because of his blindness. He thinks "In India I will not only have to surrender my freedom of movement, but may have to join the thousands of students with liberal-arts degrees who sit day after day in a park because there is no job to be had" (303). So, he thought that he took right decision to leave India and went to America where he got the chance to prove himself despite his blindness.

He found that most of the things like roads, transportation services were accessible for visually impaired in America. But In India, inaccessible public places especially roads restrict visually impaired people from moving independently. Indeed, the visually impaired people need audio signals, guiding blocks and warning blocks on the required places to navigate or cross the roads safely. But these things are not found on Indian roads. Most importantly, pedestrian are not given first priority while walking on or crossing the roads. So, it is very dangerous especially for visually impaired in terms of safety. The author describes "...in India there were no red and green lights, no regulated traffic laws comparable to America, and the erratic tonga men, bicyclers or ox carts could not be expected to look after the interests of a pedestrian, especially a blind one" (256). It shows that traffic rules are strictly followed by the public in America. So the blind people can go anywhere independently.

In the epilogue, he has cleared that he was going to Oxford University after completing his graduation for his further achievements. His teachers in Arkansas school encouraged him to go there. While living in America and England, he was influenced by the writings of various well-known writers like Plato, T. S. Eliot, James Joyce, Johann Goethe etc. In the meantime, his writing career also flourished and he became prolific writer.

He decided to spend two years in Oxford before making his way to India. But he was doubtful about this decision. He thought "...whether I was dreading returning to India because I had become too Americanized, whether this postponement of two years might not ultimately result in my returning to America to live" (306). He had strong love for India but he would like to live in America where he was already fascinated by so many things including education, accessibility and positive attitude of people towards disabled. So, he had hope to enjoy American life again.

Overall, Ved Mehta's impression about India in terms of education, accessibility, people's attitude was not so good as compared to America. However, he considered that America was his own home. He says "...for now America is as much my home as any place is in this foot-loose world" (309). Briefly stated, he felt much more comfortable to live in America than in India in every aspects of life.

2. *Lights Out* by L. Subramani

Lakshmi Subramani was born in 1973, in Tamil Brahmin family, in Madras. Presently, he is working as senior sub-editor with Deccan Herald in Bangalore. His autobiography entitled '*Lights Out: A True Story of a Man's Descent into Blindness*' is a real story of his life. Since the early age of his life, he had been suffering from Retinitis Pigmentosa, a genetic disorder which affects the retina. Being a patient of Retinitis Pigmentosa, he was experiencing the debilitating process of going blind which often demoralized him. In the book review, Privy Trifles writes "Lights out shows with painful clarity the debilitating process of going blind and the agonizingly bewildering effect it had on him" (www.privitriflies.co.in). Indeed, it is a physical, mental and psychological journey of author who was mainly experiencing the progressive blindness and the way it affects him and his family.

This book comprises twelve chapters with different names. It starts with the chapter named 'A Trip to the Doctor' in which he describes his frequent visits to the Dr. Rakesh's clinic for his eye treatment. In reality, he had been suffering from the eyes problem since his childhood. At the age of five, he had to fix the thick black spectacles frame over his nose permanently. However, he was used to visit Dr. Rakesh's clinic to check up his eyes or change the glasses accordingly.

Once he went to his clinic for routine checkup. He noticed the great anxiety on the face of Dr. Rakesh while examining his eyes with ophthalmoscope. He had perhaps found something wrong in his eyes than usual. After doing few more tests on his eyes, it was clear that he had detected the problem of retinal disorder. In fact, he was blind at the age of

eighteen but he had been suffering from retinal disorder since his childhood.

It is true that the whole family gets disturbed when one of its members suffers from some kind of disability. The author's family which included his parents and three siblings, became restless after hearing the news of his approaching blindness. His father was running a family business and his mother was a house wife. He had three siblings named Lakshmi, Arjun and Eshwar. Lakshmi was nine-years-older than him. Likewise, Arjun was three years and Eshwar was four years younger than him. Every one of his family supported him in the critical journey of life.

If a child acquires a disability, it's very hard for his/her parents to make themselves stable. At the initial stage, the parents who have disabled child, need mental support especially from relatives and friends. The same thing happened with the author's parents who felt devastated as they heard the news of their son who was going blind over the period of time. His father called his siblings for getting comfort and support. Along with the parents, his whole extended family were disturbed by getting this news. Uncle Raman, his father's brother who was doctor by profession, came to console author's parents. After seeing the reports which were given by Dr. Rakesh, he didn't believe his nephew's progressive deterioration of vision. He thought that the reports perhaps showed wrong results. However, he decided to take the advice of other doctors to confirm whether the diagnosis was right or wrong.

Meanwhile, the author observed how it was difficult for him to mix up in non-disabled students in the school. He was losing his confidence as other non-disabled students were calling him by the nickname 'four eyes'

in the school on the account of his wearing of spectacle. Indeed, nobody likes nicknames that indicate their physical deformities.

He found that the non-disabled students showed their unwillingness to include disabled students in their group while playing or doing other school activities because they thought that disabled students were not fit for those activities. He felt isolated in his school. He always wanted to be a part of the group of playing boys, but never dared to go on the ground. Because he was embarrassed by his first experience when he was not chosen in the team by other boys. He narrates “I was the only one left standing, alone, not chosen, with absolutely no one wanting me in their team” (Subramani, 06). It was really humiliating for him. Even Mr. Simi, their physical education teacher, suggested all of them to take him in, but no one wanted him in their team because he wore spectacles.

He was excluded from most of the activities on the account of his wearing of spectacles. But at the same time he was aware that the wearing of glasses was more valuable for him than the urge of running around with other boys. Even the elders in his family always restricted him from doing most of the activities saying ‘Don’t run around and break your glasses!’.... ‘Don’t walk alone at night!’, ‘Don’t chase after your brother!’ (07). As a result, he hated the spectacle even if he had no other option. But he sometimes thought that the glasses made him look intellectual and attractive rather than the object of weakness or impairment.

Each disabled person has to go through the physical suffering on the account of their impairments. The author thought that no one can understand his sufferings except the person who went through the same sufferings. He described his pains in the words of that “The pain is

continuous, unrelenting, and it almost pushes me to the threshold of tolerance” (10). Even in the clinic, he found other patients whose tears were rolling down from their cheeks due to the liquid poured into their eyes. He also describes that “I knew what it feels like when the liquid is poured into the eyes—the burning sensation—as if acid has touched its sensitive surface” (08). He understood their sufferings because he was also going through the same sufferings like them.

After hearing the news of his progressive blindness, the relatives came to console his family and some of the pious among them suggested to his mother that “...prostrating before god, begging for his mercy with tearful eyes, would help us find a way out” (31). Even his family believed that the answers of such problems could be found after praying the God for the act of purification that removed sins. His mother didn’t want to lose any chance of trying to find his cure. Hence, along with the medical treatment, she started using non-scientific methods in the hope of his cure. She met a number of miracle workers, astrologers, healers who all claimed to have knowledge of the past sins and remedies to get rid of their effects.

Once his uncle told his mother about a tantrik whom he knew personally. He had got his appointment at evening with great difficulty. The author saw the images of Goddess ‘Durga’ in his home. After looking at him, that tantrik declared “This boy is the victim of curse” (39-40). He further continued “He dragged with him the effects of a very bad curse from his previous birth. He’s very impure! We have to cleanse him and make him worthy of the Goddess’s blessings” (40). Thus, he was trying to relate his present condition with the effect of curse from his last birth. However, he suggested them to conduct three ‘homas’ for him, so that he would come out of that curse. Afterwards, he gave a long sheet of

paper on which he had written the names of all the ingredients to perform these homas. But the expenditure of these Homas was not affordable for his family because of their low income.

Few days later, they went to visit an alternative healer who also possessed divine spirit. The author saw that healer was worshiping Devi Upasaka in his house. After looking at the author, he suddenly fell down on the floor and started doing the movements like snake. His wife explained what he was trying to show with his gestures. She declared by confirming with him that this boy had 'Naga Dosha'. It means that he was carrying impurity within him because he had hurt a snake in some way. So, he suggested them that "You must take him on a pilgrimage to Nattarasankotai, a shrine located near Madurai. Also offer a pair of silver eyes to the Goddess. This will cleanse him of his Naga Dosha" (42). After all, he observed one thing common among those godmen to whom he visited so far that they all were seen him as the product of impurity which led him to born with imperfection. Nobody was talking about his defective gene which was the real cause of his trouble. In reality, they were cheating people under the name of different Gods and Goddesses. But still his family did not stop visiting the parlours of godmen and astrologers because they desperately wanted him cure.

His mother took him to the pilgrimage of Nattarasankottai, Samayapuram, Chidambaram and a few other shrines where he had to perform various rituals. It was a plan of one month in which they had to cover different temples. In reality, the transport, medical expenses and fees of different godmen impacted their family savings. His family business had many partners, so it was difficult for them to manage it. But his mother juggled with whatever money she had.

Afterwards, his mother took him to meet another therapist who assured them saying “I can work on this. This should be curable” (44). In fact, he had never given direct treatment before to Retinal Pigmentosa in his practice, but he was familiar with the symptoms. In this therapy, the author had to consume a bagful of obnoxious medicines. He wrote “Every day, I force myself to swallow them, if not for my own comfort, at least for mother’s sake” (45). Thus, there were number of tonics and powders that he forced himself to swallow only for his mother’s sake.

They went to Chidambaram to meet an astrologer whose predictions were absolutely correct. That astrologer asked his birth details in order to see his horoscope. As he closely studied the squares representing the planetary positions, he declared “There’s something wrong with this boy’s eyes” (53). Even he reeled out the details of his past that he had been using spectacles since childhood. His mother and Uncle were surprised by his amazing accuracy about his past. They were told that his serious eye problem would disappear soon and he would lead a normal life. They were happy with the prophecy of that astrologer. The author asked his mother to stop dragging him to such places because he knew the reality of his condition which was explained by Dr. Rakesh.

Raman Uncle again suggested to take second opinion of other ophthalmologist about his eyes. He helped them to get an appointment at one of the city’s best eyes hospitals. A young female doctor of that hospital diagnosed that the author had all the symptoms of night blindness which was one of the symptoms of RP. The opinion of this doctor proved whatever Dr. Rakesh had diagnosed earlier was right. It was really a setback for his mother and others in the family. They did everything including allopathic, spiritual, cosmic or alternative medicines, but it did not help. Their trips to godmen, astrologers and

others took too much time. So, the author had to miss the school for a long time. Consequently, it affected his overall performance in the school.

He wanted to live normal life but he suffered a lot due to the momentary lapse of his eyesight. However, the fear that he was going blind soon haunted his mind wherever he went. Once he was riding a bicycle for going to theatre to watch a movie with his friends. Suddenly, he felt discomfort due to the reflection of bright afternoon light. As his regular exercise, he blinked the eyes many times to clear up the vision but still he continued to see nothing. He describes his fear:

“My pulse quickens, heart pounds, and sweat streams down my forehead. I want to shut out that one thought which seems to flicker like a danger signal: Have I gone blind?... Have I?... Have I!” (60).

The first time he realized what blindness is. He wanted to share this incident especially with his mother to get rid of fear but he stooped himself because he didn't want to see his mother's meaningless efforts to treat the condition.

Another incident made him to realize how the eyes are important to live normal life. Once he fell down in empty corridor in the school while descending the flight of stairs. His books and notebooks were scattered across the stairway. His spectacle flew off and crashed into the railing. He didn't understand what he had done to deserve this all. It made him to remember that it was really the result of some unknown sin as many people and godmen seemed to suggest. He thought that the eyes are most important than any other part of body. He says “... I would have probably bartered an arm or a leg to retain my eyes because I do realize their

importance” (68). Indeed, he became helpless due to his momentary lapse of eyesight.

After that incident, his mother took him to Dr. Rakesh who was the only person who could fully comprehend the complexity of his eyes condition. Dr. Rakesh scientifically explained them the present condition of his retina which had a dark blue spots scattered across the retina’s red region. Such dark blue spots decayed the light sensing cells that were most necessary while functioning of eyes. This is all because of “The defective gene prevents blood and oxygen from reaching these light-detecting cells and triggers a slow process of blindness” (71). The first time he realized that the real cause of his retinal disorder was not related to the sin of his previous birth but the defective gene.

Dr. Rakesh disclosed a strong possibility of having this condition was consanguinity which is also one of the important causes of disability. He explained consanguinity in scientific language that “It’s a kind of genetic similarity usually found between a closely related male and a female. An identical weaker gene in them could possibly express itself as a disability in the offspring” (72). The author thought that although his parents felt guilt for contributing such weaker gene now, they would not be confused hereafter with the sin that astrologers talking about all the times. In reality, at the time of his parent’s wedding, no one had thought that the marriage within genetic proximity would prove to be something problematic. Even today, it is a common practice in many regions of India to fix marriages within blood relations for familial bonding. In fact, the people are not yet aware about the fact that such marriages are one of the causes of genetic defects. Hence, due to the consanguinity, many people in India are probably affected by the genetic defects like Retinal Pigmentosa. His mother now became aware about the results of intra-

family marriages. However, she wouldn't even think of settling her children's marriages within the relatives.

Many incidents described by the author in this book show the attitude of Indian people toward disability and disabled people. When the news of his progressive blindness spread everywhere, he had to face more and more undue attention from the people while walking on the road. Some people stared at him differently. Some of them had pretended to show sympathy toward him but that was only for curiosity or contempt. He remembered incident in the vegetable market where he went to bring tomatoes for his mother. As he saw most of the tomatoes were raw and he asked about that, the shopkeeper reacted rudely "They are not raw. Look properly—or are you really going blind" (76). Even at the barbershop, he had been asked if he was really going blind. Actually, he was annoyed by constant questions from the strangers. Such unexpected questions from the people revealed their attitude towards disability.

He thought that once he had a brilliant future ahead of him. But now his status was being a worthless boy due to his impending blindness. He didn't understand why people thought that a person who was going blind must be useless. Instead of supporting the person with disability and his/her family, they showed such insensitivity towards them. Even in the family gatherings, there was only discussion about his condition. He felt "my place in the family's list of promising children to occupy an altogether new status-the most unfortunate one" (79). Not all of his relatives but few of them were genuinely concerned about his condition. They visited them with holy ashes and kumkums from temples. They also came with some therapy techniques. Some of them had suggested recipes with vegetables that could have a healing effect. His mother started including healing foods in daily cooking especially green vegetables to

improve eyesight. He was fed up with swallowing mixture of milk and drumstick flowers or crape jasmine regularly. After drinking these herbal concoctions, the taste unbearably lingered on his tongue for long time.

The fear of going blind in future remained in his mind. Once in the corridor of school, he saw the boy whose eyes were completely white. Actually, he was blind. His face was attractive but his blind eyes made him so unattractive, strange and unusual. The whole picture of that boy threatened him. He thought that “The boy is both a peek into my future and embodiment of my present fear” (83-84). His heart was started sinking by the fear of becoming like that boy in the future. He tried a lot but couldn't overcome his deeply rooted fear.

He did various temple visits and appointments with therapists. He remembered his last visit to Tirupati where he had to wash his body in the intolerably cold waters of the temple tank at 3 am to perform some rituals. Then, along with other fifty devotees, he sprawled on the cold granite of the temple corridor and started to roll on the floor. Even he bartered his hair in return for God's blessings. In this context, he points out “I've stuck to my side of the bargain, and now can only hope that God sticks to his” (96). In reality, he was annoyed by countless temple visits and performing various rituals. Now he realized that such visits were nothing but waste of time and money. Even such visits affected the result of his exam. He failed in the exam. He knew that marks cannot decide his future but he was regretting losing one year of his life. In the meantime, the family friend Mr. JRK made him stable in this situation. He encouraged saying “You've just failed in the exam, not in life. Try taking this as a stepping stone towards success” (98-99). He also added “Failure can sometimes be helpful,’ ‘It makes you take a step back and get a fresh perspective on life” (99). These words gave him courage to

move forward. The author found that there were very few people like Mr. JRK supported him in his critical condition except his family.

His mind was suppressed by the fear of haziness. Sometimes his fear reflected in the dreams at night. Once he saw the dreadful dream which was about a boy who wore a large pair of dark glasses and was holding a white stick in his hand while walking on the busy street. He was scared terribly. But after waking up, he realized that the boy whom he had seen in his dream was he himself. He said “I am not sure if the enemy is blindness or my fear of this uncertainty” (112). Because the fear of going blind was more dominant in his mind than the actual condition of his blindness.

Along with family, it is responsibility of teachers to understand the problems of disabled students. But it never happens especially in regular schools. The author shares one of his school experiences that his vision started to blur after writing few lines from the top of the board because of the sunlight ricocheting from the entrance of the door. He wanted to do the exercise which was taught by one of his therapists to relax the eyeballs. So, he slumped on his desk and covered his eyes with the palms. But his exercise was interrupted by the teacher who thought that he was sleeping. He was hurt by the words of teacher who said “If I’m not wrong, aren’t you a detainee from last year? For how long do you want to warm these benches?” (118). As punishment from the teacher, he remained standing for the rest of the class and copied from the board. It was really difficult for him to explain his haziness which often came at the most unexpected movements.

His mind was filled with fear whenever his eyes started getting blur while walking. In such situation, he had to discontinue his walking and

blink many times for clearing his eyes. The obscurity of his eyesight was sudden. He describes it “my condition is such that to me a mirage looks like a stream and a stream seems as faint as a mirage” (120). However, most of the time he didn’t understand how to handle the situation. One day his eyes were getting blur while boarding the bus which suddenly started to move. So, the growing distance between him and the bus made it difficult to step on the footboard. At that time, he was close to colliding with a cyclist riding in the wrong direction.

The author was persistently disturbed on the account of haziness of his eyes. His vision started diminishing day by day, even after taking proper care. Once his uncle gave him a bicycle to go to post office to post few of his letters. While riding the bicycle, his eyes suddenly became blur for long time. His grip on the bicycle’s handlebar slicked and he reeled on his left side. He felt incapable of handling the traffic. So, he parked the bicycle in a corner and tried to settle down his nerves. After this incident, his uncle decided to take him to a pilgrimage. Actually, he didn’t understand which thing either his blindness or recent bicycle incident had prompted his uncle to join the forthcoming Sabarimala trip with him. But he was not interested to attend such trips anymore.

He didn’t like his mother’s thinking that miracle would save his eyes. Once she was praying for the positive results of his test while Dr. Rakesh checking his eyes. Her expectations became true when Dr. Rakesh told the news that he didn’t see a lot of dark spots spreading across his retinas. The author didn’t understand whether stability of his retina was really the result of bitter pills and liquids or the various rituals performed on the cold granite floors of the temple. Whatever it was, but the fact was that the immediate threat of his blindness had dissipated. Everyone in his family became happy with this news. He described the

ambience of his home after hearing the good news “Incessant smiles have now replaced the usual, anxious frowns. Now, every day the radio is turned on for music. Ma’s evening coffee is tasty again and I see her praying fervently before God, thanking the supreme force in the only way she knows” (131). It shows that everyone in his family seemed to be happy as they heard about the stable condition of his eyesight. Everyone in his home started praying to thank God.

Considering this happened by god’s grace, his uncle suggested that this was the proper time to take him to Sabarimala pilgrimage. Actually, the author wanted to prepare for his first year’s final exam because he had a good chance to reach among the top rankers. But his mother firmly declared that he had to go on that pilgrimage to honor her prayers. This trip would have ended in three or four days, but his uncle had scheduled a longer trip covering many temples across the southern states. So, it took about forty days. The experience of that trip was unforgettable because his tress, fear and anguish simply faded away in the company of beautiful nature. He expressed his gratitude partly for the magical sight and partly for the mystery that life had become. But the fear of blindness again came in his mind. And he asked himself “Would I be seeing more of these mesmerizing images or was this some kind of a finale before the lights went out forever?” (136). It seems that wherever he went through, the fear followed him like a shadow.

In the last chapter named ‘The Descent Begins’, he describes his memories of September 1990. He was not blind yet but still fighting with the obscurity more acute than earlier. As walking with the chaos, he had to rely on the familiarity which was a kind of mental picture of his surroundings to navigate instead of eyes. He thought that while passing the road, he was not worried about injuries but the repeated question of

riders who asked “don’t you have eyes?” (140). It made him upset every time. Everyone in the family was happy after the good news from Dr. Rakesh earlier but “the obscurity returned with a vengeance, freezing me in the middle of the chaos and dreadfully closer to moving vehicles” (141). Different therapies were turning out well but the blur was occurring with alarming frequency which reinforced the fear that he was not quite out of it.

The fear always lingered in his mind because he thought that sudden and prolonged lapse of vision might cause a nasty collision with vehicle. Once his vision started blurring in the middle of the street. So, he didn’t understand where to move exactly. When he moved backward to avoid a direct collision with auto rickshaw, there were two bicycles turning around the corner behind the auto. He describes “I freeze when I feel the rear-view mirror of the auto rickshaw brush against my shoulder and the front tyre of one of the cycles roll over my left foot” (144). His eyes were closed and the tears were rolling down from the cheeks. After opening the eyes, he found a crowd gathered around him. The thought of an accident scared him terribly. But he soon realized that he hadn’t fallen down or met with accident. The cyclist had applied brakes and took him to the corner of the road. This incident shows that it was all nothing but the fear of his mind.

At the initial stage, he had problem of seeing in daylight and he could see at night. But his heart started sinking when he experienced the disturbances of seeing at night for the first time. So, he thought that his vision was probably going downhill. He again asked the causes of his sudden lapses of vision to Dr. Rakesh who explained him “The photo receptor cells which sense light begin to decay for a person with RP, resulting in disturbances in vision” (146). Now it had become challenge

for him to walk through the congested lanes around his home also. He no longer felt confident and enthusiastic to walk.

Due to the problem of his eyesight, he had to face many horrible incidents in the life. Once his mother sent him alone to one of the godmen's house where he found Maari Amman's images displayed in different postures. While returning to his home, he stood alone at the deserted bus stop and waited for the bus. After waiting for some time, he eagerly got in the bus without checking its final destination. Asking the way to the station from a fellow passenger, he entered at a desolate street hoping that he was going towards the right place. In the meantime, he heard the voice of man who came near to him and asked him for help. As that man started speaking, the unpleasant smell of local liquor started lingering around him. He strongly felt that he could be in danger. It was difficult for him to escape from that heavily drunken man. He wanted to go to the suburban station but he came to the wrong way because the road suggested by the drunkard was nothing but a narrow, muddy trail that runs parallel to the railway tracks where he heard the electrical train's whistle that pierced the silence. He climbed up some steps thinking that must be a station. But he again turned into panic when an odour similar to that drunken man who assailed him at down the street. Before he could do anything, someone grabbed his wrist and pulled him into a crowded place. After blinking his eyes to adjust in the bright light to see better, he saw a liquor shop. He was rescued from the next unpredictable crisis and managed somehow to return home.

His vision was deteriorating more rapidly than earlier. The objects around him were getting blur with every passing day. He thought that to live with decaying vision is more dangerous than complete blindness. While facing such horrible reality of life that his vision was obscured by

the smoky blur or the flashes every time, he often lived under the fear and shame. He felt humiliated before his peers and classmates. He describes “I feel I don’t have a choice because I have an eyes condition that is unlikely to give me a blissful death, or, at least, swifter blindness” (153). It shows that he was living life without choice. He didn’t want to live life that he was living presently. Instead he would like to die or go blind completely.

Thus, this book seeks to describe his long and torturous battle with approaching blindness. The end of this book is a very pessimistic one. As his vision started deteriorating day by day, his confidence level also declined. He himself said “I am seventeen and still have the best part of life ahead, but I feel old and defeated with each ‘incident’ chipping away my confidence” (156). This was because the battle with failing vision was now getting more and more difficult for him than anything else. He didn’t think that his blindness was likely to be a blessing for him. Instead he thought that everything was better than blindness.

3 The Other Senses by Preeti Monga

Preeti Monga was born on 22nd April, 1959 in Simla, in Sikh family. She is the founder of Silver Linings, a non-profit organization that works for inclusion and empowerment of blind children and women. Being a visually impaired since her childhood, she has devoted herself to work for the well-being of other visually impaired or disabled people. Most importantly, she has very dynamic personality. Despite of blindness, she has led various roles as social worker, disability activist, aerobics instructor, entrepreneur, consultant, counsellor, author and many more throughout her life. She won many prestigious awards such as National Award for Empowerment of Persons with Disabilities from the President of India, Red and White Bravery Award and Rajiv Gandhi Manav Seva Award for her other valuable contribution to society.

The Other Senses is her autobiographical book published in 2012. It contains sixty-seven sections without names but each section shows its number in Braille script. The story of this book is about the life of Preeti Monga who lost her vision in childhood. S. Gokul describes “This book is about how being a woman she managed her childhood with a disability, her adolescent days as a young woman and how she molds herself with the disability as a successful person today” (32). Being a woman and visually impaired, she had to suffer social rejection and discrimination, but she never gave up. Even in so much troubles, she found different ways to become successful.

She was the first-born child of her parents. So she was brought up with a great care and adoration. Her mother’s name was Mohini who did her graduation in bachelor degree and she took up the role of house wife. Her father’s name was Charanjit who had completed his bachelor degree

in science. When Preeti Monga was seven or eight years old, her parents came to know about her approaching blindness. It was very depressing thing for them.

Thereafter, her parents took her to the several eyes specialists to see what was wrong with her eyes. She had to undergo different tests in the hospital. Ignoring her loud protest, the countless drops of atropine were forcefully dropped into her eyes at the time of test. She describes “No matter how much I cried or pleaded, nothing seemed to release me from painful injections and petrifying examinations” (Monga, 24). As a child, she didn’t really understand what is blindness and its serious impacts in future. So whenever she was taken to eyes specialist, her only concern was that she should not be recommended spectacles. However, only to avoid spectacles, she was trying to misguide the doctors when they were repeatedly asking her about the clarity of glasses.

Innumerable trips to doctors for in-depth consultation with the most competent doctor revealed that both the optic nerves of her eyes were partially paralyzed for unknown reasons and no treatment was still available anywhere in the world. After becoming disabled, everything had changed for her. She started experiencing the changing attitude of people around her as they heard about her disability. They looked at her with pity and compassion. She describes “Friends, teachers, and neighbours, all looked at me with pity; I seemed to have been transformed into a strange pitiful object to be handled with extra consideration or simply left alone!” (28). She was completely taken aback by this type of attitude of people. She also found that her friends didn’t come to call her to join them at playtime. They sent her back home by giving some excuses if she dared to go out herself to join them. She writes “I was completely bewildered and felt guilty for some unknown

crime I had committed” (27). She didn’t want to live such dull and sad life. All people had changed except her parents and her brother. In her interview with Ria Das, she says “Outside my home, however, and in school, I faced social rejection, shame, sadness and fear” (<https://www.shethepeople>). So she was really happy for that one blessing.

Along with her eyesight, she had lost her right to be like everyone else. As she realized that her life was never going to be the same again, she decided to do something in her life because she didn’t want to go on like this. She expresses that “Never mind what they all make me feel, I just can’t just sit around sulking and depressed, waiting for life to get back to normal, when nothing at all is wrong with me” (Monga, 28). She decided to live life by ignoring the attitude that surrounded her.

She shared her one more experience that shows negative attitude of the people who were much closed to her earlier. Once she was suffering from fever along with angry red rashes after the inoculation of smallpox vaccine which was given by visiting doctor to all the students in her school. Due to her problem of skin disorder, no one wanted to have her around. Some of her friends had broken their friendship with her because they didn’t wish to come in the contact of such skin disease at all. Her mother repeatedly attempted to convince her friends regarding the non-infectious nature of her skin disorder but it prove unsuccessful. During that period, she was left alone because she herself was most uncomfortable with her condition and felt more comfortable indoors. She felt “So tragically imprisoned and deeply saddened, I spent most of my time alone, feeling like a bird that had lost its wings and yet could not abandon a longing to fly” (30). She was utterly crushed under the feelings of discomfort and loneliness. In fact, this skin disease stayed for the next

forty years with her. Sometimes she was bedridden for as long as six months as a consequences of severely infected and painful sores. For such long period, she had to depend on others while eating food and using the washroom too.

Her family was shifted from Agartala to Delhi where she had got the place in Loreto Convent, Delhi. At the time of admission, her parents told Sister Clare, the Principal of the school, about her vision impairment and they might need to make few adjustments in the school for their daughter's sake. Thereafter, Preeti Monga got complete cooperation in her school. All the teachers were helpful and cooperative in nature. She elaborates "At school, the teachers were not only great teachers but also wonderful human beings..." (43). Along with teachers, the classmates were always ready to help her whenever she needed something. But the change came in her life after the transfer of Sister Clare from that school. She was expelled from the school by the new Principal. After the exclusion from the formal education "Everything seemed to have come to a full stop: no school, no studies, no play, no friends, and nothing to look forward to" (45). So she was left alone once again.

She realized that the regular schools were not willing to admit her due to her visual impairment. Therefore, the school for blind was the only option to complete her education. A couple of days later, she accompanied her parents to only school for blind girls in Delhi. But, her wish of going to school remained unfulfilled forever because her parents disagreed with the condition of staying her compulsory in the hostel of that school which was in poor condition.

She decided to make her career in music. So she enrolled as a distance-learning student for the Visharad, a six years diploma course in Indian classical music, in the Gandharva Maha Vidhyalaya which is one of the India's finest music institutes. After the enrolment, she started taking music lessons from Mr. P. D. Saptarashi, a well-known violinist. In the final year of her diploma, her Guruji could no longer come to teach her due to his illness. Therefore, she was placed under the guidance of Mr. Narendra Nath Ghosh who was also a well-known radio artist. Her present Guruji expected a perfect performance from her while practicing but she failed to do that. He made her realize that she didn't possess a natural ear for music. So her dream of learning music was shattered. She saw many cases of blind persons who were bestowed with the ear for music but she was not. She blames "When God takes away a person's eyesight, he makes an unfailing gift of an ear for music. ...if He had decided not to gift me an ear for music, why did He plant such dream in my mind" (52). She didn't understand what she had done to deserve so much failure in life.

She thought that she was constant source of worry and concern to her parents. So, she decided at least to avoid creating a situation of greater pain and grief for them. She diverted her mind on the other major but unnoticed activities at home. Thereafter, she started spending most of her time to help mother in the house hold chores like cooking, dusting, ironing, cleaning and watering the plants. She had also mastered the skill of making their beds, setting and keeping their room tidy, especially on the days when their housemaid went on leave. Her parents kept a distance learning option before her to resume schooling. But she was not interested in studying subjects that would not be helpful her in practical

usage. In fact, she would prefer to get married and raise a family instead of doing that.

Fortunately, with the help of magnifying glasses, she could read some printed material in controlled environment. Now she was enjoying the reading of different books independently. Her mother gave her a book of Denise Robbins' *The Leopard in The Snow*, a romantic story. After reading that story, she became pleasantly conscious of her youthful womanhood and began paying attention to her appearance.

At the time of morning walk, she suppressed her sorrow after seeing a large number of enthusiastic students from renowned universities like JNU. It evoked a desire to be a student herself in her mind. She thought that the prospect of a university education was entirely out of question for her because of her blindness. So, she desperately felt being incomplete.

Her nature was very fantastic and enthusiastic. She always endeavored to learn something new despite her blindness. She had found way of communicating independently in a legible script with the help of portable typewriter which her Daddy had brought from the US. Soon she became a master in the skill of typing. As she went to Calcutta at her Aunt Frauke's home, she learnt swimming at the Calcutta Swimming Club under the guidance of Mr. Kerna.

At the time of living in Calcutta, she heard about dating first time. She had been associated with doctors from patient's standpoint and so much enamored with doctors. So she didn't miss the chance to make friendship with a medical student whose name was Govind. She wanted to continue dating with him but their relationship was ended very soon. She found that he hardly uttered more than a few words throughout the

one and a half hour of their meeting. She didn't want such monotonous man as a life partner.

As she described earlier, her friends left her alone when they heard about her disability. But she didn't see such attitude in the nature of her dearest childhood friend, Madhumita from Agartala, who now coincidentally moved into her neighborhood in Delhi. Madhumita was pursuing her graduation from Delhi University. She would often take her along to the college festivals and other social events. She proudly introduced her to the college mates without feeling ashamed of bringing along a blind girl as her friend. The normal people were generally hesitant to proclaim any association with persons with disabilities, but Preeti never felt this with Madhumita.

Her only ambition was to marry and settle down in life. According to her, that was the best option left in her hand. But she suffered a lot in that process on the account of her disability. It was a trend in Indian society to marry off the daughter of family as soon as possible, she wondered why her turn had not come. Therefore, she promptly decided to look one herself rather than waiting for someone to find a husband. She felt that she herself could choose correct life partner as she had an exact picture of her life partner in the mind. She seriously started looking for her prospective life partner everywhere in her neighborhoods, relatives and friends by putting aside her predetermined conditions regarding partner's appearance and profession. Meanwhile, she discovered the 'Pen Pal' column in Sun magazine that helped to seek a friend. She found a friend named Narendra who was from Madras and started writing letters to him. Narendra gave her positive response even after hearing about the problem of her disability.

Meanwhile, her family shifted from Delhi to Goa as her father had accepted an offer to serve as chief engineer with the state electricity department. Preeti was pleased as she got the letter from Narendra who was coming to Goa to meet her. Few days after their first meeting, she asked him about the future of their relationship. But she got the negative response from him just as “Well, I am not sure...whenever my father brings up the matter of my marriage, I will definitely suggest your name, and if he approves of you, I will definitely marry you!” (83). She was hurt by his audacity to dare such expression towards the girl that he claimed to love so much.

Once a proposal of marriage arrived for her from a relative in Chandigarh. The prospective bridegroom was a Sikh air force officer who was looking for a second wife. In fact, he was ready to accept her with disability. Preeti was also happy with this relation because the man who didn't see her but willing to marry her as he was fully aware of her disability. Their wedding would be scheduled within few months. But her sweet dream of new life crashed when the matter of their marriage took an unexpected turn. The dejection and despair both engulfed her when she heard the prospective bridegroom was going to marry another woman at the same time in Patiala. She didn't understand why he had deceived her as she never asked him to marry her but he himself intended to marry her.

In Goa, a general manager of a five star hotel offered her to work in the hotel. She spent two days of her job very happily. But on the second evening general manager of the hotel requested her parents not to send her to the hotel anymore because the employees of the hotel had gone on a strike due to her ad-hoc appointment. This was the most shocking thing for her. In fact, she was being denied the basic right to live

in this world on the account of her blindness. She felt “I was not snatching anything from anyone, I meant no harm, and only wished to live with dignity” (89). Her simple urge was that to live with dignity as everyone else. In reality, she possessed different skills including cooking, knitting, housekeeping, swimming, reading and writing. She also had an excellent conversation skill that she could hold with anyone without hesitation. But still she felt that no one wanted to share this world with her because she is blind.

Her family moved to Delhi from Goa. She heard about the National Open School, a special distance learning institution for school dropouts. Her parents also succeeded in convincing her to acquire some formal education. Although, this idea didn't attract her, she decided to give class 10th examination. She also went to the Blind Relief Association (BRA), a school for blind boys to confirm whether she could learn a vocation. The principal who himself was blind, advised her to learn braille to read and write independently.

Once her grandfather had advertised in the matrimonial section of the Sunday newspaper for her. Actually, he didn't mention her disability intending to inform them at the time of their coming to see her. But the prospective groom and his relatives sprinted out of her home as they heard about her blindness. Even none of them had shown any courtesy to see her. She tells “Thankfully, I never had to go on display, but it was certainly a nerve shattering experience to watch prospective grooms and their relatives sprint out our home when they learnt of my impaired vision” (93). It shows that disabled women are not usually preferred for marriage in Indian society.

Meanwhile Keith, who was regular visitor of her home, fell in love with Preeti despite her disability. Preeti was also attracted toward Keith's attractive and handsome personality. She was very happy with this relationship. She thought "The Lord had not allowed any other man to claim my hand...because he had intended this very special man for me" (95). They decided to marry soon but his parents didn't give positive response to their marriage because she was not a Catholic and she was blind too. Keith left his parents' home for their relationship and shifted in one room rented apartment. Considering Preeti would not manage to live with him in one room, Keith himself requested her parents to permit them to live with them after marriage. Preeti's parents also agreed with that decision but she was not happy with this arrangement because she didn't want to put burden upon her parents.

After all, she married the man of her choice. So she was very happy but her happiness didn't last long. On the first night of their wedding, she realized that she married a strange, alcoholic and abusive man. She never ever heard that type of abusive language and strange behavior in her twenty-two years. She says "I could not figure out what had suddenly hit me; everything had been completely enchanting and joyful till a couple of minutes ago; what had so suddenly triggered off such violence in this wonderful individual?" (99). She observed that he went out of control because of drinking too much liquor.

Thereafter, she also found that Keith was doing nothing but spent the rest of the day in front of the television. On the top of that, he drank liquor and tortured her regularly. She realized "With my wedding having changed the course of my life so drastically, my self-esteem and confidence crushed and diminished, I went about life as if in a nightmare!" (101). She was frustrated after marriage. So she felt that she

was better off without husband. After few months of their marriage, she was pleased by the news of her pregnancy. But even in pregnancy, Keith continued to torture her. Fed up with his regular torturing, she attempted to end her life by swallowing half a bottle of rum. Fortunately, it didn't affect her and her infant.

She was not only bearing his physical but also mental torture. He often asked her to bring money from her father for one or other reason. But he never returned them again. Actually, she didn't want to put extra financial burden on her father but still she had no option. She was going with a lot of mental pressure and wanted to share her sorrow with someone. There was no one with whom she could share her pains and troubles. However, most often she would suffer in solitude and silence.

Keith was very careless. He didn't want to take any responsibility. He spent his time with playing carom or going to movie with friends every day. Whereas Preeti spent each day under the tension and guilt of being so helplessly and hopelessly dependent upon her loving family. Many times, she was possessed with the thought of dying in childbirth. But she knew that putting an end to her life would bring unbearable pain to her family, so it was better to remain alive and hope for the best.

She often lived under the fear of his unpredictable outburst and sarcasm. She considered herself fortunate because Keith had accepted her despite of having disability. But after their marriage, Keith often made fun of her blindness. Once he made fun of giving her an empty plate with spoon on it and then asked her to eat that. As she put her hand on the plate searching for the food, he had a hearty laugh. On the top of that, he often call her 'blind bat'. He told her that "You should thank your stars I

married you... don't you all ever forget it" (105). He thought that he had done a great job by marrying disabled woman like her. Till the time of their marriage, she never felt that she was blind because he cared for her a lot and never behaved like that.

Meanwhile, she was bestowed with a baby girl whom she named Fiona and second time a baby boy whom she named Mark. She thought that Keith might be changed after becoming father, but it did never happen. He never took the responsibility of her and children. The major part of his salary went on his own entertainments. She was annoyed by the thought of how she would look after her two children or how much burden she had given to her parents.

He would never allow them to live in peace. While his own wife and children craved for a few movements of love, care and affection, he spent a large part of his time running errand for friends or neighbors and solving the problems of sad and lonely women. If he felt in mood, he would play with his children, if not, he would beat them cruelly. Everything depended upon his mood that could change any time. If he ever did something good for them, it was only for winning the appreciation of outsiders. People were impressed by his goodness. They often appreciated him saying "What a wonderful act of kindness to have married a blind girl" (113). It reflects the tendency of Indian people who are never surprise if the non-disabled woman accept disabled man, but they are surprise if the non-disabled man accept disabled woman as their life partners. The people also thought that Keith was very caring and wonderful man who left his parents' home just in order to look after her entire family. But the reality was that Keith himself decided to live in her parents' home after their marriage. And now he established himself as

ruler of her parents' home but none of them dared to raise any objection just to maintain peace at home.

She realized that Keith was not good as husband or father. He didn't have any love or care for them. He was neither in happiness nor in sorrow with them. She was already depressed by the thought of living a life with total dependency. In addition to that her two children's responsibility also came on her family. So she decided to do something through which she could earn money. She was aware that no one would give her job with just a class ten certificate. She couldn't take music classes. She could take on some typing work but it was too poorly paid even after taking hard efforts. She thought of opening a day care facility for children of working mothers but it was also difficult enough to look after the two of her own.

She knew that if she wanted to live dignified life, she had to become financial contributor first. So the idea of running aerobic classes struck her. She was motivated by Veena Merchant's 'Keep Fit Show'. At first, Veena showed her negative response on the account of her blindness but Preeti convinced her successfully by showing her ability to take up the profession of an aerobics instructor in spite of her blindness. After getting the permission from Veena, she joined the instructor training program. Charlie, the instructor, was teaching both via visual and verbal instructions. If she was unable to follow anything, Veena corrected her physically by pulling and pushing her arm and legs. Thus, she successfully completed her classes. After completing her classes, she started teaching Veena's classes. Soon she had launched her own aerobic classes.

Within three months of launching her own aerobic classes that was called 'Preeti's Keep Fit', she had got both fame and money. Along with that she was transformed into a confident and self-assured woman. Her new found financial freedom and professional success only triggered further negative feeling into her relation with Keith. As years passed her fear and humiliation suddenly transformed into anger. So she retaliated Keith through the open verbal battles. Now she was becoming an aggressive retaliator rather than being impatient all the time.

The entire responsibility of running the home, classes, and the children devolved on her when her Mummy and Daddy went to Ireland and Germany to visit her Uncles for three months. She would take the help of Sandy but he fell seriously ill after the day following of her parent's departure. Meanwhile she could somehow manage the household duties but it was difficult for her to manage the responsibilities outside the home due to her disability. During that period, she took the help of her friends and students instead of her husband. In the toughest journey of life, her friends not only gave her hand but also emotional strength.

At this juncture, she came in contact with other blind people who had greatly inspired her by their talents and achievements. Even she got other opportunities to work. She met Vimal Mohite, director of education at the National Association for the Blind (NAB), who requested her to teach aerobics to the blind children in school. Thereafter, she began teaching aerobics to hundreds of students at the school, which gave her a new and vibrant energy. Now she got the meaning and purpose of her existence. Thereafter, she was drawn into the other activities at the institution like teaching English to the students, counselling parents and other administrative activities under Vimal's expert instruction.

Meanwhile Keith's words and action still continued to hurt and upset her. She wanted to separate from Keith forever in order to get rid of him. Her inner voice told her that it was the proper time to reach at the correct solution to the most painful problem of her life. She described "It was the most wonderful feeling that once I could have Keith out of our lives, we could all live free of dread" (122). She was annoyed with his merciless physical and mental torture. So she wanted to live with peace by letting him out of her life.

Her mother convinced her to give him one opportunity. So she came up with the idea of asking him to take her and the children to his own home because he might be bothered while living with all of them. Even the idea of her own home appealed to Preeti. She herself was not looking her lonely life forever. In fact, she didn't wish to deprive her children of their father's love. So, she agreed to give him another chance. They shifted in their new rented two-room apartment in East Delhi. But within few days, he was back to his way. He again started drinking. He completely ignored the responsibilities of his family. On the top of that once he beat the children mercilessly. She found that her children also felt unhappy and insecure in their home. So she sent them back to her parents' home. As she thought it is unbearable and unsafe to live with him, she also came back and stated living with her parents.

Now she promised herself that she would live the life on their own terms with self-respect and dignity. She suffered an excruciating pain in Keith's company but she took it positively thinking "My marriage to Keith had given me two beautiful children, my own home, and the opportunity to manage life independently" (136). Thereafter, she built up such confidence and capabilities that helped her to move forward. She met innumerable people and grew her knowledge. In the meantime, she

went to Germany to her favorite Aunt Frauke. In Germany, she realized that why she hadn't tried to look beyond the spectrum of growing up, marrying and bringing up the children and waiting for death. The trip to Germany transformed her from battered or frightened into a smart, confident, self-assured and sparkling individual.

Once Mr. Vikram Dutt visited her with an invitation to go to Calcutta for the Disabled People' International Conference as a resource person as expert on aerobics. At first, she was scared by the thought. But her fear vanished when she was greeted by the cheerful voice of other participants. As a resource person, she had the privilege of staying in the luxurious rooms at the Taj Hotel. The overwhelming experience of meeting three hundred persons with various disabilities and their limitless admiration restored her lost confidence and self-esteem. She returned home with scores of friends and she got many offers of employment as well. Mr. Vikram Dutt and Anuradha motivated her to join National Association for the Blind, Delhi to teach aerobic and typing to the blind children at the school. Thus, she joined her very first job with fifteen hundred rupees. At the very first few weeks of working in NAB, she had made loads of new friends. She was for first time aware about a huge world out and so much more could be done. She expresses "I felt like a little bird that that had been let out of her cage and was flitting from branch to branch, and then from tree to tree" (154). After a long time, she felt herself free.

Once she telephoned her old friend Sunil with whom she learnt about her new business about marketing and sales of pickles. Seeing an opportunity of making extra money and keeping in close touch with the man she loved, she showed interest to sale few boxes of pickles. She sold

the boxes to her friends, colleagues, neighbors and people in her locality. Sunil offered her the job of marketing manager in her company.

Their product which had been rejected by the market many times earlier, was prominently displayed without any charge by the relevant outlets because of her innovative ideas and natural selling skills. They decided to market other products like popcorn and papadom under the brand name of 'Preeti'. However, along with pickle, they launched popcorn with her signature as a new product. As their workload increased, they needed more people to help. Therefore, Sunil highly recommended Ashwani, one of his former employees as marketing concern. Ashwani was twenty-six, a young boy with smart and good looking personality. She liked his dedication and meticulous work habit.

Although she was visually impaired, she successfully managed to do all the activities. Her day began at five in the morning with teaching of aerobics before to help kids to get ready for school and readying herself to work. She worked almost twelve to fourteen hours in day. Sunil told her about the special benefits offered by Delhi Financial Corporation for persons with disabilities if she took a loan for business. As she did so, she received the exhilarating partnership in Sunil's business. Meanwhile, she thought that it was proper time to file for a divorce. To find a lawyer and to afford the fees was beyond her reach. So, she took the help of non-profitable organization 'Shakti' or 'Shaktishalini' in this matter.

In the meantime, the bank refused to proceed the loan on her name because she was blind. So, she took this matter to Human Rights Commission who thereafter ordered to issue the loan to her. This was her major victory because henceforth no bank in India could refused a blind client the right to open and operate a current account. Thus, as their

business extended, they launched their products in the neighboring states. Working in streets and markets in the burning heat of summer and freezing cold nights had strengthen her determination. Even though she was working hard, she was still unable to earn enough money to fulfill her and children' needs without her family's help. So, she buried her desire to assist other disables temporarily and to find only partial rendering services like counselling and encouraging disabled people.

It was totally unexpected for her that Sunil was getting married second time with another woman. She wanted to give up the life but she couldn't because she didn't want to see her family again in pain. She thought that she hadn't any right to fulfill the relationship because she was blind. She shared her grief with Ashwani who was also defeated in the game of love at the same time because his girlfriend left him for someone else. Sharing the similar experience with each other made a close bonding between them. Once she declared her true feelings of love towards him. He also accepted her proposal. They decided to marry.

Meanwhile, she was regularly attending court for her divorce which was finally granted. She soon married Ashwani. She finally won the man of her dream to live with love and care. They both were working hard to take Sunil's business forward. But Sunil didn't want to continue her in his business partnership now onwards. He terminated Ashwani's services and instructed him never to enter in his office. She asked Sunil to return her money that the company had borrowed against her name to enable her to leave too. Now they both were jobless.

She went to participate in a fashion show organized by the Ability Foundation. She always dreamt of walking the ramp, so in the form of this fashion show, her dream came true once more. It was fashion

show where the persons with disabilities were to model alongside professional models like Aishwarya Roy. It gave her chance of modeling in another fashion show where the famous Bollywood actor, Rahul Dev was to be her co-model.

The positive changes in her life began to come. Ashwani's parents had reconciled with them. Likewise, she got the excellent news of the allotment of a DDA flat. Their dream of taking flat in the locality of Mayur Vihar came true. Most importantly, both of them had got good job. Her children also completed their education, got jobs and settled in their married life.

She joined her new job in Katha, an NGO working in the field of education and publishing as a public relations and revenue manager. In the office, her co-workers felt inferiority complex due to her efficient performance while working there. She had major disability and low qualification but she performed better than them though they were much qualified and able-bodied. Their resentment was expressed in various forms such as some of them showed unsolicited sympathy to her or few of them tried to find her faults. Likewise, others intentionally ignored her or placed needless obstacles in her way. But she always ignored their ridiculous actions and utilized her working time to best of her ability.

Apart from working at Katha, she continued to work freelance with the disability sector. She had been offered a position with one of north India's most prestigious eye hospitals where she got the opportunity to head the public relations department of Dr. Shroff's Charity Eye Hospital. She was drawn into fund raising, marketing, training trauma counseling and patient relations activities for the hospital.

She also launched her own organization called Silver Linings. She was practicing art of writing and spent the rest of the time expanding the knowledge. Once she conducted a motivational seminar for the corporate employees. After that, she worked as corporate trainer. Now her mission was to inspire, guide and motivate people all over the world. She was first appointed as the Indian coordinator and then nominated as a board member for the Combat Blindness Foundation India, a US based organization, working in the area of avoidable blindness in the developing world.

With the encouragement from her family and friends, she began the journey of this book. Furthermore, she wrote the content of her web site and worked on a story for the Chicken Soup' series in addition to authoring a 'Hot Shot' recipe book in collaboration with Susan Vishwanathan, a scholar and her dear friend. Then, she gave up the job at SCEH and launched a new business venture called Silver Linings HR Solutions Pvt. Ltd., an executive search company.

Thus, her overall journey shows that life was not easy for her. Being a woman and disabled, she herself faced double marginalization in Indian patriarchal society. So she has been working for the empowerment of visually impaired women or girls for many years. In her Interview with Ria Das, she has given the valuable message for all women or girls to become successful that "Women need to understand that we are equal citizens on this globe. We have equal responsibilities and equal rights" (<https://www.shethepeople>). She faced many difficulties in life but she never gave up. By taking hard efforts, she achieved magnificent success in her life.

Chapter IV

Autobiographies of Wheelchair Users

1. *No Looking Back* by Shivani Gupta

No Looking Back is Shivani Gupta's autobiography which was published in 2014. It is divided into five sections with significant titles, including prologue and epilogue. In this book, Shivani Gupta unfolds a true story of her life that inspires thousands of people all over the world. It is unbelievable but twice in her life she met with car accidents by which her dreams and aspirations were shattered completely. In fact, she lost everything that was familiar to her, but still she made herself stable in these situations and resumed her life again.

In the prologue of this book, she has provided some essential information about the background of her life journey. In the background, it is clear that she is going to attend alumni meet of her batch mates of 1991 at the Institute of Hotel Management (IHM), New Delhi. Her caregiver, Ritu is also accompanying her for assistance. She needs assistant because she is a wheelchair user. The venue of their meeting is The Kingdom of Dreams in Gurgaon. As she reaches in her car at the venue, her classmates come and gather around her. She met some of them at her wedding ceremony one and half years ago. But she is meeting many of them after a long time of twenty years.

In the first section entitled 'Rebirth', she has described how she met with first accident at the age of twenty-two while riding in a car on the road with her friends after attending the party at night. In that accident, she survived somehow, but her spinal cord was injured severely,

resulting in permanent disability. As she found that she could no longer walk, she started using wheelchair.

The main story of this book begins with her hospitalization after the first accident. At first, she was admitted to one of the hospitals where she had been diagnosed with a spinal injury. So, she was shifted to the All India Institute of Medical Science (AIIMS) for further treatment. This hospital was considered as one of the best government hospitals in India, but she received very poor treatment in that hospital. It was unbelievable but she had to spend so many hours even to get admitted, although she was in very serious condition. Along with her, many other people like her were waiting to get medical assistance or a hospital bed. She describes “I lay on a stretcher for hours in a dirty and overcrowded corridor, along with so many others, in line to get admitted” (Gupta, 14). In such condition, Shivani felt just like being in hell. Due to the shortage of resources in such government hospitals, patients have to wait for hours in order to get proper treatment.

On the top of that, the hospital was very poor in terms of cleanliness and sanitization. She explains “Flies buzzed around the place and the obnoxiously strong odour of disinfectant overpowered my nose” (14). Likewise, lying on the back, she sometimes found lizards crawling around the roof of dirty room of that hospital. Indeed, it is very disgusting thing that the patients and their relatives have to stay in such unhygienic condition all the time. Briefly stated, health care facilities provided by the government hospitals to people in India are not up to the mark.

Even after staying for many days in the hospital, there was no improvement in her physical condition. In fact, it was getting worse day by day. She developed ‘Tetraplegia’ which is one of the most severe

forms of paralysis that may again lead to the further complications. She soon started suffering from lung infection that was sure to aggravate into a lung failure. The doctors were unable to control her deteriorating condition. According to her, “it was as if they were waiting for my condition to deteriorate, having decided that I was not going to improve even if I survived” (35-36). It means that the doctors were waiting for her condition to deteriorate because they were completely negative about her condition.

Fortunately, she was rescued by Dr. Chahal who was a senior doctor specialized in spinal surgery and a director of impending spinal cord injury center in Delhi. After going through her files, Dr. Chahal realized that she should have been operated as soon as possible after the accident for maximum recovery. But the fact was that due to the lack of attention of doctors in AIIMS, her condition had become more complicated. It took time but her condition improved to some extent by proper treatment and surgery of Dr. Chahal. After spending Two months under the supervision of Dr. Chahal, she was able to sit on a wheelchair. She accepted the wheelchair willingly because it was better than lying on the bed all the time.

She started understanding her condition with the help of Dr. Chahal who created hope of living in her mind. Indeed, Dr. Chahal played a crucial role in her life because he always tried to encourage her by telling the stories of other people who had done very well in life in spite of being tetraplegics. It is true that human being can naturally accept and adjust with each new situation. She tells “It is uncanny how, over time, a human being can adjust to and accept his or her changing circumstances” (40). She also started accepting her condition without any hesitation.

There was nothing that she could visualize in future. Even there was no ambition or aspiration to think about. At this time, she had to relearn simply how to live. Delhi was a capital city of India but no single rehabilitation center was available there. Therefore, she had to go to Pune where the only rehabilitation center available, that was a part of military hospital. At the center, she realized the permanence of her situation after meeting with the people who had been living in a wheelchair for long years. She didn't understand how to react to this realization that she was not going to walk again.

Before the accident, she was living a carefree and relaxed life. As other girls, she had also dreamt of marriage with Sunil, her boyfriend from college, having children and settling down in life. She elaborates “All I really seemed to want, I had realized, was a family— a husband and children, and a life with them” (08). But everything had changed after the accident. She realized that the things were not going to be the same in future. Now she could not even dream of that.

She was confident and independent person earlier. She always liked to handle all of her affairs on her own. She could do whatever she liked without bothering anyone. But after meeting with accident, everything had changed suddenly. Now she had to completely depend on people around her. In reality, her surviving in this accident is like a rebirth which gives her new identity as a disabled. She had no other option but to accept this new identity. Before her accident, she had never even thought about disability. In fact, she never heard anyone in her contact who was disabled. But now she understood what was disability and its implications.

As mentioned earlier, her independent existence had vanished after her accident. She could not walk and work on her own. So, she had to depend on others even for doing simple activities like grooming, toileting, sitting, eating or turning. She got personal caregiver named Putul, a young girl from West Bengal to do these things for her. She first time realized how it was challenging to accept and adjust with personal caregiver. It was difficult to maintain physical and emotional privacy by having a constant company of caregiver every time. But the problem for the disabled people is to spend most of the time in the company of caregiver. According to her, “Having a caregiver also meant goodbye to the privacy that is usually important to maintain one’s sanity. Life with caregiver wasn’t just a compromise on physical privacy but also emotional privacy” (52). It means that there was little space for individual to think about something in a constant forced of someone’s company. But being a disabled there was no other option left. So she accepted this fact by thinking that because of caregiver, at least she was going to stop being dependent on her relatives. At this movement, she missed her mother who would have taken her responsibility, but she passed away some years ago.

As time passed, she accepted and adjusted with the new reality of her life. Most importantly, she understood that her spirit was stronger than her body. Although her body looked so weak outwardly, she felt very strong internally. She realized that despite her impairment, there were a lot of things that she could focus on. In fact, she knew that it was difficult for her to fit in the society where disabled people have low status. Although everything was casual for her earlier, now “Each day was a challenge, with several ups and downs. Each day was like a lifetime of learning and experiencing” (54). It means, as she became

disabled, she started facing new issues and challenges through which she learnt a lot.

A couple of years after her accident, Sunil, her boyfriend, occasionally came to meet her. But as time passed, he stopped visiting altogether. She already knew that there was no place for her in his life any longer because everything had changed after the accident. So, when she received the news of his marriage, five years after her accident, she was not surprised. The reality is that disabled women are not culturally accepted for marriage. In most of the cases, they are abandoned by their partners after becoming disabled. This is all because of the society that expects woman to perform different traditional roles like to take care of her children or family and manage all house hold duties. And the people believe that such house hold duties cannot be managed by disabled women. The same thing happened with Shivani whose boyfriend, Sunil abandoned her after she became disabled.

After the realization that her spirit was stronger than body, she decided to do something that could help to prove her identity. She knew that her acceptance back into society after her disability was not possible. She tried to get a job in a back office of the hotel where she used to work before meeting with an accident, but she was rejected on the account of her disability. Even getting a job anywhere else on the basis of her hotel management degree was not going to be easy for her. So, she decided to restart her life once again with retaining another skill. Meanwhile, one of her friends reminded her skill of painting. Although she could not hold the brush in her hand, she learnt alternative way of holding her brush to get better control over it. Thereafter, she started practicing her painting which provided exercise to her hands. After some days of practice and discarding numerous sheets of paper, she found improvement in her

painting skill. Then, she produced a number of cards with beautiful paintings. Once she had got the chance of displaying and selling her painting cards in a fair of one of the colleges in Delhi. Thereafter, she got chance of displaying and selling them even in various fairs of the charitable organizations.

As she started facing the outside world, she confronted various issues and challenges. Most importantly, transportation became serious problem of her life. While going to display her painting cards in a fair, she first time became aware of inaccessibility of public transportation in India. On that particular day, her friend managed to drop her at college in her father's car. But she noticed that it is difficult task to transfer herself into vehicle. She needed at least two-three people to get in and out of that. Every time she had to take the help of other to do so. So she realized that if the public transportation provided the access, she would have managed to travel on her own without giving trouble to others.

As she got chance of attending other fairs of charitable organizations to display and sell her painting cards, she somehow managed to travel by auto rickshaw to attend these fairs. She comments:

“Travelling in an auto for a tetraplegic with a wheelchair and a personal caregiver was reckless and next to impossible—yet, I did so because that was the cheapest mode of transportation available to me” (70).

It shows that it was very difficult for her to adjust in auto rickshaw while travelling, but she had no other option. She knew that travelling by bus was not feasible for her because there was no way that she could board the bus in her wheelchair. Although it was easy to transfer her into auto rickshaw than the bus, each time going by the private vehicles was

not affordable for her. In fact, almost half of her money that she earned in these fairs was spent on her travelling. She tells “my money went towards my transport and buying more materials for painting” (70). In short, due to the inaccessible public transportation system in India, she had to meet a wide range of challenges as she wanted to go out.

Along with the problem of accessibility, she had to face attitudinal barriers in her life. This is because the attitude of society towards disabled people is not good in India. Once Shivani went to Haridwar for blessings with her family. As she was waiting in the queue to enter the temple at Haridwar, a poor middle-aged woman came to her and handed her a twenty-five-paisa coin assuming that she was a beggar. She didn't understand how to react in this situation. It was really a humiliating experience for her. Generally, the people in India view that disabled people are needy and they live with the charity. She felt bad because people started judging her only on outward appearance instead of her internal qualities. According to her, “Providing me with charity was probably much easier than to try and really understand what I needed” (64). She hated such charitable act of people towards disabled people. She found that the same charity being distributed for persons with disabilities in so many ways in the society. According to her, it is always better to provide them barrier free environment instead of offering any kind of charity.

She observed a kind of condescending behavior of society towards disabled people. She started finding her own opportunities and creating a path for herself by avoiding negative attitude of society. She writes “I could learn to handle and overcome all the problems my disability brought with it, but there was no way I could change society's attitude towards me” (64). It is really difficult task to change the attitude of the

society because society has already stereotypical opinions and misconceptions about disability and disabled people.

Her father returned to India from Nigeria to take care of her after two years of accident. Although he took her responsibility, there were other challenges that awaited her attention. She didn't want to depend on her family any longer. In this situation, painting somehow seemed to be her new profession which gave her confidence and encouragement to face the world. In fact, her painting skill gave her new identity and again brought meaning in her life. Additionally, it also provided her a way to become a self-reliant and gave her strength to push herself beyond her limits. Some charitable organizations gave her opportunities to display and sell her painting cards in their monthly fair through which she started earning small amount of money. Sometime she felt that she was selling her hand-painted cards as her college friends were holding good positions and had promising futures. But still she was happy for doing something productive and remunerative. In reality, it was easy for her to be dependent on her father for the rest of the life, but she didn't want to do that.

Once she got the opportunity to have a solo exhibition for her paintings. During this exhibition, she was appreciated for her work and ability by the people. All the media people took the notice of her creativity. She was interviewed for TV channel. There were articles printed in the newspapers showing "The Flower Girl' who could not hold a brush properly in her hand created delicate watercolour paintings" (70). But she didn't like media's act of highlighting her stories more than art to inspire readers. They were making her paintings to be some kind of superhuman act that required a lot of courage. In reality, she was getting too much attention because she was disabled.

In India, people believe that disabled people can be cured with the divine power. So, she had been told the names of miracle healers available in some village especially by the auto drivers or some other person on the road. But she writes “I could not blame people for sharing these recommendations because a disabled person is generally viewed as someone needing treatment to become ‘normal’” (70). The people didn’t understand that she was not ill but she used wheelchair as mobility aid to overcome her walking difficulty. She took these incidents as amusing.

She was in search of stable profession. Luckily, she got a job in the rehabilitation centre at the India Spinal Injuries Centre in Delhi. Before joining rehabilitation centre, she attended two-months training in Salisbury in UK, which was required to be a peer counsellor. She was very much impressed by the accessibility for persons with disabilities in UK. She had been to other countries in Europe before having disability, but this experience of visiting such developed nation was different in many ways. Earlier she had just noticed the beauty, infrastructure or cleanliness of the places but now she observed how disabled people interact with their environments and society responded to their needs.

In Salisbury, she found that a number of wheelchair users were leading their life with the most regular manner that she had never seen in India where disabled people are confined to their homes or other charitable institution. As she went outside in India, the bystanders were always curious about what had happened to her. She often heard their comments like “Chhi chhi! See, such a young and pretty girl in a wheelchair—who will marry her now?” (76). Such type of remarks made her unhappy but she deliberately tried to avoid them.

As she visited other offices for some work, her physical presence seemed like a burden to people who expected from her to send a representative instead of troubling herself to visit personally. Actually, she wanted to be self-reliant but people made her feel that she was different from others. During her training, she saw the disabled people in Salisbury were doing their chores themselves. Through her training in Salisbury, she understood the true meaning of rehabilitation which taught disabled people how to overcome the obstacles.

For her, one of the most memorable events during that training was a cocktail party which was organized for all the current and ex-patients of the rehab centre in Salisbury. In this party, she was surprised to see the unique relationship of Andrew and Nina. Andrew was one of the patients and Nina was the physiotherapist in the centre. They had met in the hospital and fallen in love during his rehabilitation. It was beyond her imagination that a non-disabled person can fall in love with a disabled person. She never ever saw such kind of relationship in her life. She saw “They seemed so much in love that it was like something out of a fairy tale” (79). It shows that their relationship was so unique. Such type of unique relationship are rarely found in India.

After returning from her training in UK, she joined rehabilitation center where she had got an opportunity to help people struggling with spinal cord injuries. She offered proper information and support to spinal injury survivors about their spinal injury. This was exactly what she was not given at the time of her accident. While doing this job, she met various people with spinal injury from different backgrounds. The rehabilitation center was located in Vasant Kunj and it was not possible to travel up-and-down distance of almost sixty kilometer every day. The

management kindly offered her a room on campus, which was not in good condition but it was better than travelling daily.

Shivani found that along with the transportation services, the places of entertainment are also not accessible for persons with disabilities in India. Once Shivani went to the first multiplex cinema theatre at Delhi to watch Titanic, with her friend Annie and her another colleague at rehabilitation center. It was her first time to go to such newly built multiplex theatre. So she had no idea about its accessibility. As she reached there, she was informed that a wheelchair user can get access only to two out of the four halls. She became furious because she had to sit in one corner of the hall separately accompanied by unknown people while her friends sat somewhere else. The whole plan of watching movie together with her friends remained unsuccessful due to the lack of accessibility in that multiplex.

Before leaving the place, she started screaming at the manager of the multiplex for giving such poor and discriminatory treatment. She wrote a long note in complaint register for receiving such poor service in their multiplex, even after knowing it was completely a waste of time. Most of the time, she had experienced that “Living in India, I was used to having all my complaints ignored” (93). It shows that ignoring the complaints is common practice in India. But this time, she got a call from the senior manager of that multiplex and he expressed his wish to meet her. After their call, the senior manager came at the center to meet her with an apology note on behalf of the owner of that multiplex. At the end of their meeting, he assured her that the authority would certainly look after the issues of improving accessibility in their multiplex for disabled people.

She describes her another horrible experience of visiting the temple of Kanyakumari a couple of years ago with her colleagues from the center. As she reached there, she was not allowed to enter in the temple with her wheelchair considering it was impure. Then, after a great deal of hesitation, she made one of her colleagues to carry her in his arm to get a darshan of Goddess Kanyakumari. She was allowed to take a darshan in this way instead of using wheelchair. She also agreed to do so because she didn't know much about her rights and non-handicapping environment at that time. But it was really injustice to her. Under the name of impurity, she was prohibited from using her wheelchair which is her basic need. As she analyzes such type of past experiences in the present times, she understands that people have no problem with her disability, but they have problem with her wheelchair. The reason behind that they are unable to provide accessibility for the wheelchair users like her. Due to the lack of accessibility and negative attitude of people, many times she was either excluded from the things or she had to take the help of others to do that. She considers that this is one of the most humiliating and embarrassing experiences in her life.

Along with theatres, temples and other places, she had bad experience of the hotels or restaurants in India. As she went to Nainital trip, with her friends from the centre, she found that the hotel which was booked by them was not accessible. They got the rooms on the first floor of the hotel. So she had to be carried all the time. It was difficult to spend two nights in such uncomfortable and inaccessible hotel but she made her mind that it was better than living in the horrible hospital accommodation which was offered her by the authority of spinal centre.

She and her father suffered a lot till the final allotment of a DDA flat that she got on the basis of her disability. They went to concerned

government office in the case of approval, but they were neglected. Thereafter, they met various officers including Lieutenant governor of Delhi regarding the case, but it didn't help. One of the officers openly asked her father to pay him one lakh rupees as bribe to get the work done. But her father refused to do it. As a result, her case was further delayed. As they went to meet the minister of urban affairs, he approved the case and demanded immediate allotment. But their immediate action also took two years for the final implementation. So, when she did get her flat, the cost was double as much as they had made the application. She thought thought "If only we had paid the bribe, we could have saved ourselves a large amount of money by getting an allotment earlier, when the costs were lower!" (127). Just like her, many disabled people do not meet their needs due to such corrupt people in government offices.

While working at Rehabilitation centre, she met Vikas who was an occupational therapist at the spinal centre. At first, they were just casual friends but the trip to Nainital brought them closer. During the trip, she noticed that Vikas was different from her other friends. He was the only person who had not left her alone while others were enjoying trekking or visiting other places that were inaccessible to her wheelchair. She assumed that she would find some excellent friends in this trip but much later she got to know that none of them had really wanted to take her along because she was disabled and was going to be accompanied with her carer. Through this incident, she learnt the hypocrisy of people to whom she thought her real friends. She thought that it was better for her to remain in her own space where the people would not bother her while making a special arrangement for her.

After this incident, she developed a habit of inviting people to her place instead of going out with them. She explains:

“As a disabled person, if my friends exclude me from taking me along for a rock show, a movie or a pub, then I am supposed to understand their difficulty and let go rather than expect them as friends to assist and ensure my inclusion” (101).

It shows that she usually adjusted with the things that excluded her from mainstream society and stopped expecting from the people especially friends to assist for her inclusion.

Over time, intimate relationship developed between Vikas and her. Once she got an invitation to participate in a fifteen days training organized by the United Nations Economic and Social Commission for Asia and Pacific (UN-ESCAP) in Bangkok, Thailand. Vikas also joined her for this training. They attended this training very seriously. It made them realize the importance of non-handicapping environment in the lives of persons with disabilities. They understood that providing accessible environment for disabled people was the most basic right for them to live with same ease and dignity as a non-disabled person. In short, this training created interest in their mind to work on accessibility for persons with disabilities in India.

Vikas decided to do job as occupational therapist in UK, but he had to give the exam to work there. On the occasion of his exam, they again travelled to UK together. After going to UK, they heard about access survey for London Access Guide. In the form of this survey, they got an opportunity to travel Europe for a week with the group of eighteen people. Their stay and food was taken care by the group. It was a novel experience for both of them. Having an access guide in all tourist areas is useful concept. In India, many travel guides are available in the market

but they have lack of information on accessibility for the benefit of disabled travelers like her. They were impressed by this project. They started dreaming to bring the new concept of access guide in India. And after eight years, they had successfully developed their own travel portal called 'Free to Wheel' with access information for places in Delhi.

The last phase of their trip was a journey to Paris and Brussels. Vikas pushed her wheelchair throughout the trip. They found that most of the places in foreign countries were accessible, but she shared her horrible experience when they were going to visit Eiffel Tower. As they got off at the station for Eiffel Tower, they saw a flight of fourteen steps while coming out of the station. They might be not knowing other accessible road and they could not ask anybody due to the problem of communication. So there was no option but to pull her wheelchair up all these steps. At this movement, she started cursing herself for coming to this trip but it was not her fault but this was because of the poor designing of spaces. As Vikas slipped out of his shoes while pulling her up with wheelchair, she was petrified by the thought that:

“My wheelchair could have easily slipped out of his hands at any movement, or he could have lost his balance and both of us would have gone lolling down and hurt ourselves severely, in this country where we couldn't even communicate” (137).

Vikas somehow managed to pull her up alone. But no one around them came to help them and they also did not tried to call anyone for help. She thought that “At least, even if facilities are not accessible in India, people would have come forward to help without even being asked” (137). It is true that not only family members, but strangers also

come forward to help disabled people in India if they need some kind of help. Except this incident, her overall experience of this trip was fascinating.

While working at the rehabilitation centre, she came to realize that there was nothing new to learn there. On the top of that, there was no prospects for any sort of promotion. After the UN-ESCAP training, she identified her area of interest which was to work on accessibility for persons with disabilities. So, she decided to quit the job at the centre. She started looking for another option seriously. Once she went to a job fair organized by a private university which was affiliated to Edexcel, a British company. She decided to do a full-time two years diploma course in architecture technology.

After taking admission, she shifted to a rented house closer to university with her father and Ritu, her new caregiver. Her faculty at the university was most accommodating but no single place in the whole university was accessible for wheelchair except the studio and computer room. There was no other place where she could go, not even the restroom that she needed a lot. So, while attending classes, she had to face the biggest challenge that was to manage her incontinence. But managing incontinence was not easy task for her. She sometimes failed to manage that. She described her plight in the words that:

“As always, my biggest challenge was managing my incontinence. Her bladder training and practice of remaining thirsty and not drinking any liquids for hours together helped me attend my classes. Despite this, there were accidents; on those bad days, I had to leave for home early and miss my classes. These accidents never failed to pull me down. I

would often return home and cry helplessly for not being able to manage” (152).

She suffered a lot due to inaccessible premise of her university but she had no other option but to complete the course anyhow.

Vikas had started his new life with new job in the UK and she was also busy with her new course. Living apart from each other had not affected their relationship. They had started recognizing each other’s importance in their life in greater depth. Even they probably loved each other more than before. They were physically separated but still they were emotionally connected. She says “Without communication with one another, the day seemed incomplete” (152). They both knew the fact that they had no future together because Vikas’s parents would not accept her as their daughter-in-law at any cost. His parents always advised him to stay away from her. Although there was no future of their relation, they loved each other selflessly.

After completing her course in architecture technology, she was looking for higher studies. Meanwhile, she received the Neerja Bhanot Award which was given to a woman who shows exemplary courage and works for the benefit of others in spite of her own trying circumstances. In the same year, she received the National Role Model Award from the Ministry of Social Justice and Empowerment. Having the same dream of working for inclusive environment for persons with disabilities, Vikas and she took admission for a postgraduate programme at the University of Reading in the UK. During this programme, they lived together without any social pressure, which was not possible for them in India. She writes “Both of us made our home with each other, away from the society that forced us to hide our feeling for each other from everyone”

(162). She considered it to be most beautiful time in their lives. This course gave them direction in terms of fulfilling the dream of accessibility. The foundation of their organization called AccessAbility, was an outcome of this.

After completing her postgraduate programme in inclusive environment in UK, she joined a corporate company in Delhi as a Programme Manager in the department of social responsibility. Here, she had to set up the programmes for the company to work towards improving accessibility for people with disabilities in India. So, she was now happy with her perfect job profile in this company. But from the first day of her working, she started facing the issue of accessibility at her workplace. The building where her office was located, had an inaccessible main entrance with ten or twelve steps. There was another entrance which was accessible for wheelchair but that was only for V.I.Ps. Even after requesting the concerned authority, she was not allowed to use that accessible V.I.P entrance. It was really shameful because she was supposed to be a proponent of accessibility but she herself faced the problem of inaccessibility at her workplace.

The similar discrimination on the account of inaccessibility was continuously going on with her in the office. So, she didn't want to continue her work with the organization which had no proper attitude towards its one and only disabled employee. In her interview with Ananya Sarkar, she states that "Unfortunately, disabled people are always looked at as a separate group rather than part of the whole. This leads to odd attitudes of people towards us, inaccessibility, lack of opportunities and ultimately results in discrimination" (<https://www.indianruminations.com>). So she had no other source of income but still she quit her job after ten months. She didn't want to

continue working with the organization where her abilities would not be appreciated. Thereafter, along with their old friends, she and Vikas had formed AccessAbility, their own organization through which they worked for the promotion of inclusive environments in India. For the recognition of their work, she received the Ability Award and the NCEPDP Shell-Helen Keller Award.

It was unbelievable but Vikas's parents suddenly accepted their relationship. They had been aware of her existence and importance in his life. Now the constant fear of losing him was replaced by immeasurable happiness. She thought that it would be a privilege to be a part of his family. Finally, they married on 13th April, 2009. They were happy in their married life. But their happy married life was devastated after four months of their marriage. As they were going to the first family trip with his parents, they suddenly met with major car accident on their way to Manali. The oil tanker hit them hard and they were all injured very seriously.

Soon after the accident, they were taken to a nearby hospital which had lack of resources and facilities. She describes "This was, by far, the most ill-equipped hospital I had ever seen and looked more like a hostel than a hospital" (Gupta, 214). On the top of that, the staff of the hospital took them in reluctantly. In reality, the same situation is found in most of the hospitals in India.

After checking Vikas's father, the doctor declared him dead. She was terribly shocked by this news. She could do nothing but to lie down and wait for what happened next. She articulates:

"Life seemed completely out of control. Our education, our social status, our material possessions had no meaning at that

moment. The situation had taken a charge, and my family and I lay there helplessly” (215).

Afterwards, they were shifted to Sundernagar hospital where their wounds were stapled and again they were recommended to shift at PGI hospital in Chandigarh. Only Papaji’s body was being retained in Sundernagar. The PGI hospital is considered as the pride of Chandigarh, but Shivani was surprised after seeing such disgraceful place with dreadful services and inadequate resources. She saw that the staff of the hospital took them in reluctantly. The emergency ward of that hospital was full of patients and their families. At time of her first accident, she had seen the same scene in the corridor of AIIMS hospital where all the patients were waiting to get in. The worst thing was that the basic care of patients was not taken care. Everything seemed to be unhygienic. She explains “This hospital, however, was worse—the stretcher I was transferred to from the ambulance was soaking wet from the rain” (217). The doctors detected that Vikas had an internal bleeding in his stomach and Mammyji was diagnosed with a head injury and a fractured arm. Shivani had a broken femur, a fractured left hand and a deep gash across her neck.

After doing initial examinations in the PGI hospital, the doctors suggested both Shivani and Mammyji could shift to Delhi but Vikas was not recommended to shift because of the bleeding in his stomach. So, Vikas had to stay back for further treatment in that horrible hospital. They were brought straight to a super specialty hospital in Delhi where they were treated by Dr. Bajaj very carefully.

Shivani was restless in Delhi with the thoughts of Vikas who was still in that dreadful hospital. Mamaji, Vikas’s uncle was taking care of

him. She remembers that the day they got admitted to the hospital was 14th August and the next day was Independence Day, a national holiday. The doctors told Mamaji that Vikas's internal bleeding could be managed by oral medicine. As Mamaji called and passed this news everyone to Delhi, all were happy. But at that time, none of them was aware that this was the worst news they could get. The only reason of putting him on oral medication was that the doctors were not in mood to operate him on their holiday. He was operated on the next day but he was completely out of hand. PGI was famous government hospital in that region. But just like AIIMS, the nursing care in this hospital was very dismal. Even if his condition deteriorated, Vikas was not kept in the ICU before and after his operation. He just laid there on the bed fighting hard to recover. Later on, he developed septicemia that resulted in multiple organ failure. He finally gave up. She describes "Once again, it was the negligence of doctors that took everything away from me" (220). The thing which happened with her some years before, happened with him. The doctors kept assuring them that he would be fine without disclosing the seriousness of the situation until the case was completely gone out of hand.

At the initial stage of injury, the patients should receive proper and quick treatment for their better recovery. But due to the lack of resources and facilities, the patients remain untreatable for long time. Most of the time is wasted in shifting them from one hospital to another because of the scarcity of equipment. At the time of her first accident, Shivani herself suffered due to the poor treatment and negligence of the doctors. And she and her in-laws family went through the same experience at the time of their second accident as well.

Thus, Shivani Gupta tries to portray her life in this book. Her meeting with the serious accidents twice in life shocks the readers. These

two accidents snatched everything that was familiar to her. In the first accident, she lost her independent living due to the spinal cord injury. Over time, she somehow accepted and managed to live with change in her life. But again unexpected turn came in her life. She met with the second accident in which she lost Vikas who was her soul-mate and strong pillar of strength.

She survived both the times, but she was deeply disturbed by the loss of most valuable things in her life. She tried to take everything positively considering there should be a purpose behind her survival in this world. In this context, Binjal Shah states “After all, she wouldn’t have survived two such colossal calamities if she didn’t have a purpose to fulfil in the world” (<https://yourstory.com>). After seeing her great contribution in field of disability sector, one can understand why she had survived even after facing such colossal calamities in her life.

Indeed, the life of Shivani Gupta represents the situation of other disabled people in India. Her first-hand experiences reveal that even today people with disabilities have to face various issues and challenges. Accessibility is the major issue in their life. In reality, India is one of the developing countries and has failed to provide them barrier-free-environment. In her conversation with Aqueel Qureshi, Shivani tells that “Surely the present environment is a witness to the fact that planner and architects are not aware of the issue in India” (<https://www.dnis.org>). It means that the designers or architects are not aware about the needs of persons with disabilities in India.

Along with accessibility, they face issues regarding education, employment, health facilities and many more because the society has not fully accepted them. During her interview with Ananya Sarkar, she tells

that “I think society’s acceptance of persons with disabilities as a part of the human diversity is the main thing that is missing” (<https://www.indianruminations.com>). It is true that the situation has begun to change, but still they are facing many issues.

2. One Little Finger by Malini Chib

Malini Chib is one of the India's disability rights activist and writer. Since her birth, she has been suffering from severe disabling condition called Cerebral Palsy which is congenital disorder affecting muscle movement and co-ordination. Her medical condition forced her to use wheelchair all the time. She has learnt how to type with one little finger which can only work properly except her other body parts. She cannot speak properly due to her lack of speech ability. In such condition, she has completed two International Master Degrees in Women Studies and Library Science and Information Management in London. At the time of her interview with Priyanka Dasgupta, she tells "I educated myself, learnt to type with my one little finger and speak through the Lightwriter" (<https://m.timesofindia.com>). Shreya Chowdhury writes "In late 1998, at the University of London, she was one of the first international students with disability" (<https://m.timesofindia.com>).

She unfolds her life experiences in autobiography entitled *One Little Finger* which was published in 2011. The Indian film named *Margarita with a Straw* (2014) is based on her life. *One Little Finger* is divided into four sections with different names. The first section is entitled 'Roots', in which she covers earlier journey of her life. She discusses the points that are—the real cause of her disability, her parents' decision to go to England, her school days at Cheney in England, coming back to India, breaking down of her parents' relationship and her boarding life at Delarue. 'Growing up' is the second section which consists of four sub-chapters. It focuses on the later journey of her life. She describes her experience in the non-disabled world where she often

faced the problems of inaccessibility and negative attitude of people. The third section is ‘A slice of Freedom’ which seeks to emphasize her journey towards empowerment. She describes how she had successfully completed her two Master’s Degrees and got a job in Bombay. She also illustrates how she had actively started working for the disabled people in India. Fourth section is ‘Reflections’ which mainly focuses on the overall reflection of her life. She elaborates how she had got the chance of revisiting her life while writing this book.

At the very outset, she describes her traumatic birth process. She tells “During the process, the umbilical cord got stuck around my neck, resulting in a lack of oxygen to my brain...” (Chib, 03). In the medical language, this process is called ‘*Anoxia*’, a result of *Hypoxia*. Due to the lack of oxygen to her brain at time of birth, Malini was affected by a severe disabling condition called Cerebral Palsy for lifetime.

The Pediatrician was doubtful whether she would survive. He kept repeating to himself that “*it was a mistake I should have carried out a caesarean...lets see if she survives...I am not sure if she will survive...at the most 72 hours*” (03). But the luck would have it, she survived and entered into the world. She was a beautiful baby and had a fair complexion with a large eyes. Therefore, her Australian nurse called her by the name of ‘Rosebud’ and ‘Princess’.

As time passed, her family noticed that she was not doing much activities like other normal child of her age. She describes “The little effort necessary for sucking the bottle was enough to tire me and I slept all day” (03-04). Her overall activities didn’t seem to be normal. Even after few months, there was no improvement found in her condition. So she was shown to the renowned experts and doctors. Thereafter, various

examinations were carried out by the doctors to find out correct diagnosis. And it was diagnosed that she was affected by Cerebral Palsy. The motor cells of her brain were completely damaged by the lack of Oxygen. Initially, it was difficult for her family, especially for her mother, to accept the fact that her child was not normal.

Indian doctors were pessimistic about her condition. They thought that the damage to her brain was irreversible. Even the further assumption of doctors that Malini was not only physically but also mentally handicapped made her parents more depressed. But later on it was cleared that even though her body was severely disabled, her mental condition was quite normal. The witness of this fact that she was excellent in solving memory games and master mind.

Being physically disabled, she could not enjoyed the same things that other kids could do. She wondered why she could not run, play or explore the surroundings like others. Other children also not understood why she didn't play the usual games with them. They usually left her alone while playing the games.

She was upset because of people's discriminating attitude towards her. In one birthday party, she was depressed as the hostess gave all the kids their going away presents of balloons, hats and whistles but left her alone. The hostess apologized for that but she thought that Malini was unable to play with them because of her present condition. So Malini was left alone during the party as other children went to enjoy. In reality, to remain lonely is a common experience of disabled people. Such type of incidents make them to feel that they are different from others and have no right to enjoy.

Malini was very fortunate to belong to a privileged and well educated family. Her uncle, Samiran, who was a physician at the Royal Post-Graduates Medical School at Hammersmith Hospital, London, told her parents that the Indian doctors didn't know much and were extremely negative about her condition. So he suggested them to go to England for better treatment. Her parents also knew that in the area of medicine and education, England was far superior to India. Therefore, they decided to move there for her treatment. It was not simple decision for them because they had to give up many things including job, home and friends and start all the things again.

In London, Malini was admitted in a special school called Roger Ascham School in Cambridge. Later on, she moved to a school at Cheyne Walk, Chelsea in London. Her parents found that the people in England had more positive attitude towards disabled people than India. They became happy after seeing the result of her IQ test by a well-known psychologist, Agatha Bowley. In this test, she had been given many tasks to complete. The report of her IQ test showed that she was not only normal, but also above average in intelligence. A graphic description commonly used to describe the children like her in England is "an intelligent mind with a disobedient body" (09). It means that one has deformed body but intellectual mind.

Fortunately, she had received very good exposure in both home and school. Her family spent most of the time to teach her normal activities. Her father taught her swimming. She was taught how to read at the age of two by her mother and aunt through a flash card method. Everybody in her family treated her normally and spent their quality time with her. These early years shaped her personality in a proper manner.

At her school Cheney, she received the best treatment from the team of different professionals who came there to deal with the students like her. Cheney was a Teaching Hospital which offered a variety of activities that included physiotherapy, Speech and Occupational therapy, along with education. With love and support from her family and school, she grew stronger.

Malini's mother successfully completed her post-graduate diploma course at the institute of Education, University of London. Later, she became a professional special education teacher and also began to work with mentally handicapped adults at the institute in Balham. It gave her a lot of knowledge about Malini's condition. The decision of her parents to move to England was very fruitful.

Malini's parents wanted to have a second child but they were worried that something would go wrong. Then, under the consultation of Professor Brown, they decided to have second child. After her brother's birth, her parents decided to go to India. So, it was difficult for Malini to leave London because it was the place where she blossomed and she got the stability in excellent management. The most important thing was that in London, she never felt that she was different from others. She experienced that "People here loved and accepted me for what I was" (15). But she knew that there was different situation in India. That's why she didn't want to go to India. She described that "My parents and I did not realize then that a dark period in our lives was approaching, and there were momentous challenges that awaited us in India" (15). It shows that they were going to meet such new challenges in India that they never ever thought.

After returning to India, they often faced the negative attitude of people. She shared her experience in the Children's hospital in India where she went for treatment. The staff members of that hospital would not treat her as a human being. She said "They poked and examined me as if I did not feel any pain" (16). She missed the staff at Cheney, who were so kind and sensitive towards her. In fact, they treated her as a child first, not a handicap child. She writes "I well remember that the Cheyne staff had been so nurturing, friendly, warm, sensitive and egalitarian" (17). She never saw such sensitive staff in India.

It is fact that along with disabled people, their families also suffered from negative social attitude. The same thing happened with Malini and her family. Especially her mother didn't like people's different attitude towards Malini. Malini tells:

"My distress and the trauma of being with people so completely different affected my mother terribly. She had no one to talk to about her grief and became quite distraught. The social attitude towards me affected her badly, and she became isolated with her grief and suffering" (17).

She found that there was no schooling for children with disabilities in India. So, the idea of schooling for the children with multiple disabilities came in her mind. She started a school called 'The center for Special Education' in Bombay. Later on, she subsequently launched Spastic Societies in Calcutta, Delhi, Bangalore and Madras, with the help of her close family members and good friends.

Malini found that education in the Centre for Special Education was a little unsystematic and it seriously hampered her intellectual growth. She had a major problem of communication because of dysarthria, a slow

monosyllabic speech that takes longer time for people like her to communicate. Therefore, she was always imprisoned in her thoughts due to the lack of opportunity to communicate. She thought that if she was in a normal school, it would have been possible for her to interact with normal peers. So, she didn't like the idea of sheltering disabled children in special school where they had no exposure to the outside world. So, she strongly felt that normal environment was necessary for all human being to develop their intelligence and social networking skills.

After returning to India, her parents took divorce. The separation of parents was really a traumatic experience for her. She considered that this was the darkest period of her life. Along with her mother and brother, she had to leave her father's home. So she missed the good time that she had spent with her father. She had many friends of her age in building, but she had to leave them after her parent's separation. She thought that "Perhaps, if we had stayed on there, my life would have been very different. I would have grown-up with normal friends of my own age" (27). She felt bad if she went to school regularly, she would have friends of her age. But the concept of inclusive education was not yet introduced in India. In short, she remained lonely with no school, no friends and no interaction with children of her own age. Meanwhile, her father remarried a wonderful person named Margot Raymond. Her mother also remarried Sathi Alur, a Chartered Accountant, who first came to the Spastic Society to look after its accounts.

Once she got an opportunity to go back to England for education. She also agreed to go back because she realized that the things were too stagnant in Bombay. Furthermore, the negative attitude of people made her and her mother unhappy at every movement. Malini wanted to go away from such monotonous life in Bombay. She explains "I was bored

by the monotony of life in Bombay. The education offered was not challenging enough and the negative attitude of people towards me made me and mother very despondent” (40). She needed a change and wanted to try out something different.

In England, she was admitted in Thomas Delarue, a secondary special school run by the UK Spastics Society for bright A-level students. She found that the school was spread over five acres of land and the premises of that school were fully accessible and wheelchair friendly. Everything was structured and systematic there. The school functioned like a normal secondary school, where all the subjects were taught. The academics of school at Deralue were very hard for her because she had not received much of a formal education before, but she managed everything.

She got an electric wheelchair which helped her to increase the mobility. Now she could move anywhere without others assistance. At first, her life at Deralue, a boarding school was very hard but it helped her to organize the time and build up the confidence. While living in boarding school at Deralue, she remembered the sentence which was written by Abraham Lincoln to his son who was living in boarding school that “The best steel goes through fire” (45). These inspiring words gave her strength all the time. After two years of living in boarding school, she got the General Certificate for Secondary Education which made her eligible to get admission in any college. Her dream of studying with normal students of her age came true when she was admitted in St. Xavier’s Junior College which is one of the prestigious colleges in India. After getting admission in that college, she had worried about whether she would academically cope up with other normal students.

The campus of the college was wheelchair unfriendly, so she faced extreme problems of accessibility. The main building of college comprised of the four floors with two lifts. The first lift was small. It was really hard to adjust her electric wheelchair in it. Therefore, she always had to depend on others while pulling and pushing her wheelchair. Likewise, the second lift was big in size but it was at the far end. In fact, both of these lifts didn't stop at the middle floor of building where the library was situated. So, she couldn't go to the library, although she had strong desire to go there.

On the top of that, there were ledges at the end of each classrooms. She always had to depend on others to overcome these barriers. She thinks "Why do all normal people think that everyone in the world must keep to the norm of the walking pattern, and if one does walk like everyone else, one will be left out of life?" (53). In short, the needs of physically disabled people are generally ignored by architects while constructing the buildings. Hence, they have to depend on others even for doing simple task.

Being a disabled, she had to meet with many embarrassing incidents at the very first day of her college. For instance: as she entered the classroom, the whole class remained silent and paid attention towards her until she was settled on her place. In fact, it was terribly painful for her when all the class started whispering and staring at her as if she entered in the wrong classroom. Another incident was that due to her speech problem, nobody understood her name even after she repeated it many times. The same scene was repeated in every class.

To cope up with the normal students, she had to use different methods and techniques. For answering the questions in the class, she

used cannon communicator, a device for those who have speech impairment. But it took long time. Along with the speech, she had a problem of hand functioning by which she couldn't hold the pen in her hand and write down the notes in classroom. However, her mother came up with new idea that she gave her classmates a pad with a sheet of carbon paper, so that the notes of whole lecture could be covered in that and Malini would get other copy from them. To do so, she had always to depend on her classmates for notes.

Her speech was slow and arduous. Therefore, it was difficult for her to participate in any conversation in the school. Although she had a lot of things to share, it was not possible for her to contribute them quickly at the time of conversation. When she was in the special school, the professionals and others were trained to listen them sympathetically and they would prefer to give extra time for listening to the students like her. But in this regular school, she had a little space to converse with others. So, she was isolated and frustrated by not being able to participate in conversation like other normal peers.

She realized that her feelings were not understood by the normal world. Once the group of her classmates went to see the movie leaving her alone. They might have thought that she would be a trouble for them. She was hurt whenever people treated her as if she had no feelings. People didn't understand that although she had abnormal body, her mind was quite normal like others. She explained that "I knew that I was different and trapped in a dysfunctional body, but did others realize I had a spirit and a mind separate from this body?" (55). She didn't understand how she could tell them that she had the same feelings or desires that every human being has.

In the journey of her self-introspection, a lot of questions touched her heart, “what is normal? Who is normal? Why am I abnormal? Who decides? I cannot speak, I cannot walk; does that make me abnormal?” (56). It was obvious that she was physically disabled but what about her mind that was quite normal. Being a physically disabled, she was fully aware that she was never going to be easily accepted by the so-called normal society. Therefore, she decided to prove herself intellectually.

As she failed in the first unit test of the college, she thought that she had lost the first chance to prove that she was intelligent. But the main reason of her failure was the rote kind of learning in India. The examiners wanted broad and essay type answers. A great deal of efforts was needed to write such long answers. In this style of writing, it was hard for her to remember the exact words given in the textbook. It was difficult task to master over such kind of writing because of her poor speech and poor hand. Another thing was that her writer had to take the strenuous efforts to comprehend her expressionless speech. Therefore, she didn't like education system in India. She said that “...the education system in India teaches students to be like sausage machines rather than thinkers of future” (61). In England, she was trained to conceptualize what she learnt.

In college, she had many friends but no boyfriend. She felt bad because of her disability no one even thought of her. She knew that the boys wanted normal girlfriends rather than disabled girlfriends. She wrote “For the typical boys, it was not acceptable to be seen with a disabled girl-friend. They wanted a ‘normal girlfriend’ on their arm” (59). Many times, she thought that if she had not been disabled, she would have boyfriends like her other normal girl-friends.

Indeed, she liked a normalcy of life. So she never left any chance to feel normal. It's very funny but she secretly felt normal as she saw her name in the blacklist on the account of low attendance, along with her other normal peers in the college. She says "Secretly, I felt normal; I too had been blacklisted like anyone else" (60).

She gave the HSC exam and passed it with good marks. Then she took admission for BA course in the same college. Unlike the HSC classes, her BA classes were held on the third floor where lift could not reach. She requested the management of the college to shift the classes on the floor which was accessible by the lift. But the management shirked its responsibility by saying that the lecturers wanted their classes in certain rooms and the lecturers placed the responsibility with the management. She realized that no one cared about her inconvenience. So, her problem remained unsolved. She points out that "Xavier's was following a good policy in agreeing to admit disabled student, but facilities for accessibility were appalling" (70). It shows, even in education system, many policies are made for the well-being of disabled students but they remain only on paper without implementation.

She wanted to enjoy mainstream activities as others but she was hurt many times due to the negative attitude of the people. She narrates two social events that made her to go into depression. Once she went to Prom Night with the group of her girlfriends only for enjoyment. As the loud music began in the background, she started dancing with her crutches in group. But after a while, one of the organizers didn't allow her to dance with the crutches. She remembered her words "why don't you sit down, you are bound to fall. You can't dance with crutches" (65). So she had to stop dancing unwillingly. Thereafter, she found that her group of friends went to dance with their male friends. But she was left

alone. She felt unhappy because she was no longer a part of them. She always dreamt of man who could see beyond her body. She expresses her feelings:

“I wondered if there would ever be a man in my life. Would a man see beyond my body? Would anyone put their arms around me and dance with me? Would anyone kiss me passionately? Would I ever be needed by a man emotionally or would I always be regarded as a burden for someone to take care of?” (65).

It shows that she wanted a man who could care or love her and accept her as she was. She didn't want to live her life alone.

There was another incident by which she was terribly hurt. She remembered that she visited Nargis' house on the occasion of her birthday. She had been left alone at the table for having a lunch in that birthday party because her friends went to join the crowd. On the top of that she didn't expect from Nargis who openly refused to sit with her and went to join her other friends. In reality, she would like to join them but it was not possible for her to hold the plate and eat with them. She felt very bad as other's enjoyed the lunch in each other's company and she sat and ate in solitude. Thus, these two occasions remained in her mind forever. She tells “It taught me to be a bit distant from my friends, as I seemed to collapse emotionally if they did something which upset me” (67). So she decided to avoid the social gatherings which made her upset.

After her request, Zubin Petit, one of the English lecturers in Xavier's, came to her home to explain T. S. Eliot's *The Wasteland*. In the meantime, they got to know each other and came close through the poem. They found that there were a lot of things similar between them. As a

result, they started enjoying each other's company. Thereafter, Zubin became a part of her family. Even her mother gave him a part time job at the society. She realized that Zubin was the only person from the opposite gender who could handle her extremely well. He was one of those who could understand her speech. She found him to be warm, compassionate and caring.

Meanwhile, she went through the BA exam which was really torturous for her. It was held in the month of May. So, her throat was getting dry dictating long essay type answers. She narrates that:

“The worst thing was that the exam took place in the heat of May, when temperatures soared. My throat got so dry calling out long essay type of answers that I could not speak without sips of water” (74).

This time her each paper was six hours long. The whole process was arduous for both the writer and her. After overcoming such kind of difficulties, she finally completed her BA degree.

She went for Goa trip with her brother Nick and his American friend, Alison. It was the first time Nick had gone with her without family. In fact, that was one of the rare occasions for her to spend time with her own generation. So, she was very excited about the trip. In Goa, they stayed in Erica's boutique at Baga. Erica and her sister Joanne had come to India from South Africa 20 years ago. They were friends of Ranjit, her father.

In her Goa trip, she had to face the problem of toilet accessibility. She was usually comfortable with English toilets instead of Indian style toilet which required good balance. But English toilets were not available there. She explains:

“One has to balance in a squatting position to spend a penny, which is all very well for the rest of humanity who possess good balance, but not an easy task for someone like me, who suffers from ataxia and has limited balance” (78).

It shows that while constructing the buildings, attention is only given to the needs of average people, but the needs of disabled people are not taken in to consideration. It was surprising to discover that in the whole Baga, there was only one public western-style loo which was in the small café on the beach, known as Anthony’s. Due to the small space of that loo, they had to keep wheelchair outside, so that Nick and she could get enough space to fit within it. In short, Goa was not a very friendly place for her wheelchair, but it was possible to enjoy the whole trip because of Nick who handled the wheelchair beautifully.

After her degree, she went to USA for a short visit which was a great learning experience for her. She visited the University town of Berkeley, where she saw amazing accessibility for the wheelchair users. She found that “Every place was accessible, be it a library, museum, restaurant, shop, school, public toilet or theatre, and this facilitated independence” (83). Such wheelchair friendly environment made someone to forget that he/she could not walk. But there was an opposite picture in India where the most of places and buildings were totally inaccessible to the wheelchair users. She was often upset while trying to enter in five star hotels, theatres, art galleries or any other place in India.

In Berkley, she also found that there were several organizations working for the welfare of disabled people. She visited one of the organizations called Centre for Independent Living which trained disabled people on how to manage their life even if they had severe

disabilities. Likewise, there were many disabled people who had charge of heading disability organizations. Another thing she liked most that they themselves hired or fired their personal helpers. In fact, they would prefer to hire outsiders rather than their own family members or friends to assist them. Along with these things, she liked the ideology of disabled people in Berkley. Malini describes:

“They argue that nobody is completely independent. For instance, a normal person would need a carpenter, a plumber or an electrician, perhaps. The disabled, too, are dependent on getting help to enable independent living, so that they can function more efficiently and able to take up employment” (84).

It means no one in this world is completely independent. Even normal people depend on others to meet their daily needs. Just like normal people, disabled people also take the help of other human beings to lead an independent life.

The personal assistants of disabled people come in the form of other human beings to fulfill the needs of walking or doing something. This concept of independence appealed her. She knew that most of the people in society considered them as dependent or helpless because they see their deformities rather than their personal attribution. She rightly points out that “The person within the disabled person is always unnoticed because their physical demands are so immense and often glaring” (85). It means that the society is used to see their disabilities but they never see their abilities. After her trip to Berkley, she decided to get an attendant because she no longer wanted to depend on her family.

After graduation, she decided to do MA. She applied for the course of Publishing in Oxford Polytechnic. Meanwhile, Zubin also went to Oxford for studying Chaucer. After some days, Malini got the acceptance letter from the Oxford Polytechnic for that course. So she was excited to go to London where she was more comfortable than India in all aspect of life. Now her dear friend, Zubin was also there. As she arrived in Oxford, she met Zubin who greeted her with special warmth and affection. She always felt comfortable in his company. Zubin was one of those who understood her speech completely and he managed her and her wheelchair entirely on his own. In fact, she secretly hoped for this relationship where he and she were more than just a friends.

In Oxford, she got disabled friendly room in a student's residence called Pollock House which was located in Pullens Lane in Headington. It was very close to Oxford Polytechnic. In her room, she started living with Maya, her attendant. Maya was fluent in English. Due to her knowledge of English, she soon became a star of Pollock house. Malini observed that it was a good thing for her that Maya was proficient in English which helped her a lot for having an impaired speech, but the people easily ignored her and turned to speak with Maya. She tells "The problem with having a carer who is fluent, as Maya was, is that it was easier for people to ignore me and address the carer instead" (93). Whereas, she felt doubly disabled in the company of her new attendant named Vimla who was not good communicator due to the lack of language skill. She said "With my speech impairment, and Vimla's lack of language skill, it doubly disabled me" (176).

Like the problems of accessibility in the Xavier's, she faced the same problems of accessibility in the Publishing department too. The Publishing Department was up on the flight of stairs, so she had to take

great efforts of walking with Maya if she wanted to visit the department. She had two tutors named Kevlin Smith and Bob Woodlings who had strange attitude towards her. They were a bit confused about how she would finish her course. They could not understand her speech, so Zubin and Navina, her another friend assisted her during tutorials to interpret her speech. There were twenty other students in her class, who were not so helpful. She had to repeatedly ask them for notes. She could not go to the library which was not accessible. In the situation, she missed her classmates at Xavier's, who were helpful in nature and would always lend their notes to her.

As a part of course, she had to go through the mock interview for a job along with other students. Thereafter, she got the job in the publishing house. It was really a good news for her. But there was another news that hurt her terribly. In their routine walk, Zubin told her that he was gay and had partner from Belgium whose name was Bart. She didn't show her emotions right away but she was deeply hurt by this news. She wanted a boyfriend or partner just like her other girlfriends but it would never happen in her case. She expresses "I yearned for all that was normal despite my disabled body" (99). She silently desired for romantic relationship but the problem was that she was disabled girl and no one tried to develop that type of relationship with her. Later on, she heard from a common friend, Helen that "Zubin was also upset and had admitted that had he not been gay, he would have been with me" (99).

After doing Master's Programme, she returned to Bombay where she began working with the recreational club that Zubin and she had started. She had got a job in Bombay Times. But she started facing a lot of issues because the workplace was not wheelchair friendly. The attitude of the people at her workplace was good towards her but they didn't think

in term of her accessibility. She tells that “The attitude of the editor and my colleagues was great, but they did not think about accessibility concerns, which was unfortunate” (104). She found that the canteen was far away from her office, so she could not join her colleagues for tea or lunch. She felt isolated during lunch time. Even toilets in her workplace were not accessible for her. Once she fell from the steps of that toilet and was badly hurt. She also faced the problem of inaccessible transportation service in India. Likewise, the pavements were not wheelchair friendly. The streets had too many potholes. She tells that “The basic problem of working in India was the lack of accessibility” (104). She had to leave the job because of this disabled unfriendly environment.

Meanwhile her mother had got an opportunity to work with the ‘London School of Economics’. Along with her mother, Malini again went back to her favorite place called London. Meanwhile, her mother registered for Ph. D in the Institute of Education, University of London which was situated in Bloomsbury under the guidance of Jenifer Evans. During Ph. D, both her mother and Malini were influenced by the social model of disability which claimed disability was socially constructed.

Malini had a lot of things and experience to share but her poor speech stopped her. Once her mother and she were invited by Professor, Klaus Wedell in a workshop where she found that disabled people who were more disabled than her could communicate independently. But her speech was incoherent and difficult to understand. She felt that it was important to be able to communicate without help of third party. So, she went to Roehampton Hospital in Putney for an assessment of her communication difficulty. She was recommended a smaller and new compact version of communicator that she could carry easily in her handbag. Now it was possible for her to communicate with others.

Instead of manual wheelchair, she started using electric wheelchair which gave her a wonderful feeling of movement and freedom also. Now she was confident to manage the busiest road of London on her own. She explains “With this, I did not feel as if I could not walk. I did not feel helpless. I could slip into shops, chemists, bookshops, restaurants etcetera. Whatever the so called normal person does, I could do” (111). She could go everywhere. In fact, she could change the several buses to meet her friends. She didn’t feel that she could not walk. She could enjoy the feelings of walking in London but that was not possible in India due to the lack of accessibility on the roads or pavements for wheelchair users. She wrote “Moving around outdoors is not an easy task in India” (112). Even though she had an electric wheelchair which was far better than her earlier manual wheelchair, she could not go out in India because of inaccessible roads and buses.

One day Maya left her job as attendant and went to Calcutta where her family lived. It made Malini upset, but she soon made her mind that attendants like Maya should not be a permanent fixture of her life. It made her to realize that she was thirty, but could not achieve much in terms of independence. Her lack of independence became a cause of trouble when her mother was busy in her Ph. D. Her mother was spending most of her time in reading and writing. Therefore, Malini herself began doing every possible thing independently. First time, she took the charge of managing her whole day. After Maya’s departure, Malini felt herself freed instead of being constantly forced to be with someone and having to instruct someone what to do. According to her, “Every human being needs space and time on their, own to develop and think. If a disabled person is constantly with a person and taken care of, she or he is not going to develop into their own person” (115). It is clear that every

human being needs his/her own space in life to think or act. But it is not possible in the case of disabled people who have to live mostly in the company of person who takes care of them.

Malini's parents took a great efforts to teach her most essential and new things intending that she should not be dependent on someone in future. She remembered that her father trained her how to climb stairs with the help of banisters. Even her mother taught her how to access email that revolutionized her life because it was possible for her to communicate with others.

The attitude of the people towards her was good in London. She narrates a good experience in the supermarket while shopping "It was unbelievable how helpful people were. Nobody stared. Nobody asked me rude questions. If she could not reach for things, other shoppers would pass me an items" (121). But her experience was different in India where she had to bear stares of people or answer their unnecessary questions.

Once she made a plan of Paris trip to spend a summer holiday along with her friend, Fiona. All over her journey, she found out that most of the places like airports, hotels, roads, museums or churches were wheelchair friendly. Even the attitude of people toward her was better than in India. In fact, during her trip, she would not feel that she was disabled. So, it remained unique holiday for her.

She got an admission in the Institute of Education for doing the Master's Programme. Although she had got admission, the institute didn't allow her to stay in student's accommodation. The institute was not ready to take her responsibility because she was disabled. In reality, the institute had no specific provisions in term of accommodation or personal

assistance for students with disabilities. She herself found that there were some disabled friendly rooms, but the authority directly suggested her to live in Care Home. She applied for the same flat where her mother stayed in while doing her Ph. D, but the administration was unwilling to give it to her as she had earlier lived there for five years with her mother. Her American friend, Gregg who was the President of Students Union, kept up the lobby on her behalf and brought up the topic of disabled student's accommodation. The lobby helped her and the institute granted her to stay in the same room where she lived during the time of her mother's Ph. D. Although she was granted permission to live there, the institute didn't take the responsibility of her safety. Another problem was that her Master's Programme was one year course which needed a lot of hard work. Therefore, she asked the University authorities to allow her to do it in four years. The authority also supported her by granting her permission.

Her Master's classes began in the evening regularly. She enjoyed these academic days because her tutors and other students of the class had very good attitude toward her. Being influenced with the ideas of inclusive education, her tutors always encouraged her to participate actively in the classroom. Most of the time, they made their classes busy with the interaction on intellectual level that helped her to develop her intellectual sense. She felt that her voice was heard first time throughout her academic journey.

In the initial stage, she faced many issues regarding accessibility in the present institute as well, but the necessary modifications were done by the authority for her in the four years. The most admirable thing was that the authority had made the changes in their infrastructure only for one student who was disabled. She had not found such type of positive

attitude of the authority in the St. Xavier and Oxford Polytechnic where most of the places including classrooms, toilets, library and canteen were not accessible to her. But these places were accessible in the present institute. Now she could go wherever she wanted without any help. She wrote “I spent hours in the library trying to absorb the texts” (140). So her wish to go and spend time in the library was fulfilled because the library of that institute was wheelchair friendly.

The society mainly talks about independence of persons with disabilities, but some people are surprised if they see disabled people do some activities independently. Malini described her two experiences that show the typical attitude of people towards disabled people. The first incident happened in the lift of institute, where a lady surprisingly asked her that “*Are you alone? Where’s your helper?*” (140). But she didn’t give any reply to that lady and went away. Another incident happened in the canteen where she went to have breakfast. As she stood in a long queue, a young man in his thirties came forward and offered his help to her. After a while, a lady companion of that man came there and she was surprised as she saw Malini who was alone. She started talking in very rude language. She repeatedly saying “Someone must be with her. She can’t be on her own. I have worked with these mental people. It can be very dangerous” (142). She went to call the management regarding that. The security guard came with that lady. He was also stating that no one has reported her missing yet. It was really traumatic episode for her. Thus, these two incidents show that the normal people cannot imagine disabled people without helper.

Her present tutors always motivated her to read more on women and disability. After reading she realize that she was also a part of that

society where disabled women faced double discrimination of being both disabled and woman. She confirms:

“Other feminists also suggest that being both disabled and a woman, is a ‘double discrimination’ which means women with disability have to struggle with the oppression of being a woman in a male-dominated society, as well as the oppression of being disabled in a society which is dominated by able-bodied people” (145).

She understood that the disabled women suffer double discrimination because of the cultural expectations of society from women, in which the disabled women could not be fitted at all.

According to her, only to talk about inclusion of disabled women in society is not enough but it is also necessary to think about their physical or emotional needs. She noticed that it was easier for disabled men to get an able-bodied partner, but it is almost impossible for disabled women to get able-bodied partner for marriage. This was because women were culturally expected to do most of the housework alone. The society thought that the tradition roles of women could not be fulfilled by disabled women. She learnt another most important thing that:

“Traditionally, women are only considered to look beautiful and that is it. Most men desire their women to be attractive and beautiful. As far as a disabled woman is concerned, she always gets unnoticed because her body is different” (146).

It shows that disabled women never fixed in the criteria of beautiful body. So they have low demand in the marriage proposals. At first, Malini had a strong desire to have a male partner in her life but she realized that no one could see her as life partner because of her severe

disabling condition. In her interview with Dasgupta, She expresses “I have had a hard time accepting that I’m trapped in a rejected body that is not sexually attractive. But most men look at me as asexual” (<https://m.timesofindia.com>). It was certainly painful for her, but she accepted the reality. As she grew older, her desire to have a partner in life was automatically minimized.

It is considered that disabled are always dependent on family or society. But she thought that “everyone is inter-dependent” (Chib, 149). It is quite natural that all human beings are socially, emotionally, physically, and intellectually dependent on one another. She gave her own family example while her mother was doing Ph. D, they shared the household chores between them. She says “While I did all the outside chores, like the shopping, the laundry, posting letters, she did all the cooking and cleaning of the house” (149). They were inter-dependent. The four years of her Master’s Programme broaden her knowledge and perspective that enriched her life. She felt confident and empowered. She describes “I was, for the first time, able to accept my own identity as a disabled woman, and was proud of being one” (150). She felt proud of being a disabled because it gave her chance to understand the life very closely.

In London, everything was so accessible and the people around her were eager to help her. She was able to master over her the daily chores. She made herself as independent as she could live without her parents. Once she refused her parents to come to India with them even after they were insisting her to come. In fact, she successfully managed to live that weekend in the absence of her parents. Once again she lived alone as her parents went to India for six weeks. Her parents didn’t want to leave her alone this time also, but she thought that it was pointless for to go and

come back. Thereafter, she was completely fine with staying back while her parents travelled. As time progressed, she was glad that her parents could leave her alone at home without worrying about her. She realized how significant her new found independence was.

She always expressed her gratitude towards technology because it played important role in her life. Her electrical wheelchair helped her to increase her mobility power. If it had not existed, she would be confined at home all the time. Even the computer technology made her easy to communicate with others. She said that “Thank goodness for technology for people like me who needed wheelchairs for mobility and computers for communication!” (165). It shows that technology helps to reduce the severity of her disability. It made her capable to handle a wide range of activities independently.

After completing her Master’s programme, working at the Institute’s Library was really ideal for her. She found that all the information was computerized. Anyone could communicate or interact through the internet. She buried herself one year in the library to complete four assignments for her Master’s Programme. She had to do a lot of hard work to complete that because “Each assignment needed an argument which was crucial, a reference to all the current writings on the subjects and a detailed bibliography stating all sources of information” (165). She had to write all these things carefully. Because of the lack of her functioning hand, she had to do all this with one finger. Whatever the people did in an hour, she did it an entire day. Therefore, every day she had to spend a great deal of hours in front of computer.

After the suggestion of her Librarian friend named Gwyneth, she decided to become a Librarian. After searching various institutes and universities, she decided to do her second Master’s course in Library

science at the London Metropolitan, University of North London. The course of Library Science at London Met was a professional one, which concentrated more on management style of functioning within library. She was allotted two rooms flat in the residency known as The Arcade on Holloway Road in Holloway, which was fully accessible. But the only problem was transport because she had to change two buses to get to college.

While travelling by bus, she frequently went through different experiences. Once one of the passengers in the bus started admiring her friend, Varsha as she saw her helping to get into the bus. She said her that 'You are a wonderful person'.... 'God bless you' (170). It shows attitude of people towards disabled people, who believe that if one can help disabled people, he/she would be blessed by the God.

Her both Master's degrees gave her enough confidence. She thought that she would get job but it was not easy for her. She applied for two jobs at the Institute, one was for the post of a Disability Officer and one was for a Cataloguer in the Institute's library. Now she had a good qualification but no experience. Even her speech and limited hand function were the biggest barriers in finding job because most of the jobs needed it. According to her "The actual fact is that employers could see only my disability, not my capability" (174). Even after getting two MA degrees, she didn't get job. So, she felt demotivated.

Then, she started lecturing at the Institute of Education. Her new friend Felicity Armstrong, a prolific writer and academic on Inclusion Education, invited her to deliver lecture for the students of her Institute. She delivered her entire lecture with the help of power point presentation. This experience gave her huge confidence. Thereafter, she started lecturing in India too. Once she had got an opportunity to deliver a lecture

at the Sorbonne University in Paris. Even though she had poor speech, she used power point presentation while delivering the lecture. She liked to deliver lecture, so she would not let the chance of giving lecture anywhere in the world. She observed that the attitude of people towards disabled people gradually began to change. She wrote "...the lecture confirmed that the world was beginning to accept us—they did not look at us as if we had come from Mars!" (180). It is true that the voices of the disabled people have started to be heard in the normal world of people. In fact, the attitude that they are something different or strange, also began to change.

In spite of her two Master's, she didn't get job in London. She realized that most of the jobs needed speech but she lacked that. Fortunately, she had got job as a Senior Event Manager at the Oxford Bookstore in Mumbai. After coming to India for job, she started actively working for the welfare of disabled people in India. She believed that both able and disabled people should come together to build inclusive society where all people were included. So, she started working with the organization called Able Disabled All People Together (ADAPT), that she had earlier formed. Being influenced with foreign accessibility, she thought that such type of accessibility must be there in India for disabled people.

Now she is actively working for the well-being of other disabled people like her. For her contribution in the disability sector, she has been honored with National Award for the empowerment of persons with disabilities from the Indian Ministry of Social Justice and Empowerment in 2011. Furthermore, on the occasion of World Cerebral Palsy Day, she was honored with the first global Cerebral Palsy Day Award in 2017 for ensuring the rights of disabled people.

Chapter V

Autobiography of Hearing Impaired

1. *Deaf in Delhi* Madan Vasishta

Deaf in Delhi is Madan Vashistha's autobiography which was published in 2006. It is the life story of author who became deaf at the age of seven from a bout of mumps and typhoid. After becoming deaf, his life had changed and he had started facing different challenges that he never even imagined. He was excellent in school and wanted to become a doctor, but he had to stop schooling in the middle of sixth standard. His dream of becoming a doctor was shattered. But he was still positive about his life. Within limited exposure for deaf person in mainstream society, he never lost any chance to prove himself. So he later on achieved a huge success in his life. His book, *Deaf in Delhi* helps to know his overall journey of his life through in detail. According to Islam & Jana, "Madan Vasishta's *Deaf in Delhi: A Memoir* (2006) is a remarkable work of literary disability scholarship, informed by the author's sense of pain, struggle, and triumphant march in life" (203). This book is divided into thirty-nine sections with significant titles in which he describes his real experience of deafness while living in India especially in Delhi.

Madan Vasishta was born in 1941, in a village named Gagret in Northern India. He became deaf at the age of eleven. Due to the suffering from two weeks of typhoid and the mumps, he woke up one night with strange feeling of discomfort. He elaborates "My head was full of very loud noises, as if I were standing in a major railroad station. I heard blaring whistles, people yelling, and trains thudding along the tracks" (Vasishta, 01). As he cried loudly, all the members in his joint family

gathered to see him. He realized that he could see their lip movements but no longer heard their voice. So he was taken to their family doctor, who was considered as expert in Ayurveda. But his Ayurvedic medicine could not cure his hearing problem. Afterwards, he was treated by various renowned doctors from different cities, but his deafness could not be cured. Along with scientific treatments, various non-scientific methods were adopted by his family to cure his deafness.

Since long, as many other societies from different countries, there have been some religious superstitions linked to disability and disabled people in Indian society too, where having disability is considered as God's punishment for sins that may have been committed by either individuals or their parents or ancestors in the present or previous birth. Another prevalent misconception about disability is that disabled have no faith in God. Madan Vasishta belonged to a middle class family in Gagret, a farming village. His whole family always tried to defend such type of religious ideas. Bhua Parvati, his father's younger sister, was a very religious woman. The author says "Everything in the world, according to her, happened according to the pre-written will of Rama or Krishna or Vishnu or Shiv—the four major Hindu gods" (15). She strongly believed that his deafness was caused by his lack of respect for God.

The author was influenced by Ramayana and Mahabharata that he read at the age of ten. So he was convinced that neither Rama nor Krishna were faithful gods. Whenever he tried to argue his theory about the gods, Bhua Parvati refused to listen him by covering her ears with palms. She scolded him saying "That is sinful, young boy" She added "Lord Rama will hear you. Do not talk that or He might punish you" (16). According to her belief, his deafness was the result of his mocking of the gods. She

believed that he would regain his hearing as he asked for forgiveness. But the author would refuse to pray and ask for forgiveness for a sin or crime that he had not committed.

Considering his deafness the result of some celestial punishment, he was taken to number of sadhus, miracle healers, temple priests and many more who claimed to have a direct link to gods. At first, he was taken to Gurkha Baba who lived in a cave. Gurkha Baba dressed only in a langoti which resembles thong bikini underwear and his whole body was covered with white ash just like many other holy men in India. Bhua Parvati brought him to their home. The author describes:

“He sat there in front of my bed, erect on a chair with his left foot crossed over his right knee, holding the *trishul* in his right hand. His eyes were very serious, and he did look very graceful—almost holy” (17).

The author had to touch his feet for blessings. Before leaving the place, that Baba gave him white ash in his palm and applied some of it to his forehead. He had to lick that so-called holy ash from his palm and swallow it. As he left, the author got mad at Bhua Parvati. He tried to convince her that Gurkha Baba was nothing but a thug and was leading a nice life by fooling people. According to him, “God does not need a Gurkha as a middle man to help me” he added “If God wants to make me hearing, he would do it without that faker” (18). Here, the author wanted to suggest that if the God existed in the world, he didn’t want such faker as mediator between them.

The second sadhu to whom he was taken was called Mahatma from Andora, a small village two miles from Gagret. He was in the Andora Temple located on the bank of Swan River. He was well-known sadhu

throughout the district. Bhua Parvati took the author to receive the blessings of Mahatma, so that he would be able to hear soon. They touched his feet to receive his blessing. While leaving that place, he told Bhua Parvati that he didn't know when but he would receive his hearing soon. According to the author "it was an open ended and broad answer-anytime between now and whenever" (19). He wanted to comment on his ambiguous prophecy but he had to keep quite because Bhua Parvati had a firm belief that his deafness was caused by his mocking everything religious.

Bhua Parvati took him to other faith healers who professed to have connections with ghosts, goblins and lost souls. The sadhus and Mahatmas to whom he had visited earlier at least practiced from temples and had some kind of legitimacy. But these healers used old tombs, broken down temples or their own houses to run their business. He had visited such places several times, but he has described only one experience that he once decided to visit a Siddh who was plying his trade in Bheekuwal, a village not far from Hoshiarpur. In reality, he never made such plan on his own but this time his interest in movie led him to plan this trip to Bheekuwal which was near cinema house in Hoshiarpur. Before going to cinema house, he reached at the place of that Siddh with his cousin, Ramesh, where they saw a huge crowd of people who came for the blessing. It was apparent that this Siddh didn't provide individual service but bless people in masses. He describes "Since we had walked twenty-three miles in the hot sun for this, we needed to get some ash" (21). So they managed to get some ash in a piece of paper. Then, they went to see movie and returned to their home.

The treatment for his deafness didn't stop with the holy men or miracle workers, but there were other home remedies that were

administered by his family. His elder sister, Brahmi applied milk steam to cure his deafness. She learned this technique from an old lady. During this experiment, many people gathered around to see the miracle, but nothing happen. He tells “The warm steam felt good on my cold ears at first, but soon it became uncomfortable” (24). The trial of this experiment went on for whole month on a daily basis but ended abruptly when his sister returned to her in-laws. This home remedy of his sister was really painful and torturous to him.

Baba Hardev Ram, his grand uncle came up with new idea for his cure. Once he told him to follow him to the well. After reaching there, his uncle leaned on the wooden derrick and said something to the well. Then, he told the author to yell something to the well. The author obliged and yelled a few times. His uncle repeatedly asked him if he could hear himself. But he could not hear anything. The author clears “Perhaps my uncle thought that hearing my echo might cure my deafness” (25). After few tries, his uncle gave up and left the place.

He had to go through another non-scientific experiment that was arranged by his other grand uncle, Baba Khushi Ram. He frequently invited the guy named Sain in his inn. Sain cleaned people’s ears for half a rupee. When he saw the author, He expressed his wish to cure his deafness. Almost thirty people gathered to see how Sain was going to cure his deafness. The author describes “I was nervous as he had laid out a small red doll in front of me. I wondered what was in it, and visions of sharps knives and hot oil were making me uneasy” (27). Then, he slowly and dramatically waxed both of his ears with the tools of his trade. After waxing his ears, he asked one of the young men in attendance to yell into his ear and asked the author if he could hear. But still he could not hear anything.

Once he himself decided to test God. Bua Parvati's ongoing accusation that his deafness was the result of his refusal to believe in God strengthened his resolution. He prayed to God to make him hearing. He conversed privately "If you make me hearing, I will worship you all my life and live like a holy man" (81). He gave him three months to prove his existence. For a three months, he prayed daily after taking his bath. The deadline passed but he didn't regain his hearing. So, he stopped worshipping God from the next day.

Thus, every non-scientific method failed to cure his deafness. The author didn't like these methods but he complied only for the wish of his family. The superstitions regarding the causes of disability are responsible for such unscientific treatments of disabilities. Madan Vasishtha's experiences show that Indian people still believe in superstitious causes of disability and expose the disabled to bizarre treatments. Such treatments cause pain to persons with disabilities and delay the process of their rehabilitation.

Before becoming deaf, he was one of the clever students in his class. He wanted to become doctor but he could not fulfill his dream after becoming deaf. Because his hearing problem stopped him to attend the school. In reality, the regular schools in India have no place for such type of disabled students. As he requested the headmaster of his school, he was given permission to give final examination of his sixth grade. On the very first day of his examination, he realized that everything had changed after his deafness because he could not communicate with people as before. Everyone was talking to each other but no one had patience to communicate with him. He observes that the students walked at a distance from him. Some students never lost opportunity to tease him. He describes "They would stand behind me and make all kind of noise" (30).

In fact, his inability to hear was a part of their amusement. Likewise, his teachers were more sympathetic towards him.

The condition of disabled people in rural India is worse than urban area. In rural areas, they get limited resources and facilities that are usually available in urban areas. Madan Vasishta was living in a small village in northern India. He and his family were not aware of special schools for deaf people. In reality, the special schools of disabled people are usually located in urban areas and most of the people in rural areas are unaware about the availability of special schools.

As he stopped attending school, a lot of time remained in his hands. So, as per his father's wish, he started herding cattle and rest of the time he spent working in farm along with other family servants. His full time farming didn't stop or create obstacle in his education. Even after spending most of his time in working in the farm, he passed the high school examination in first division by doing study on his own at home.

He was dreaming to become a doctor earlier, but now he thought that it would not be possible due to his hearing problem. In fact, he was working in farm after becoming deaf but he didn't want to do farming lifetime. He wanted a glamorous job instead of working in farm all the time. He writes "I wanted a glamorous job. A job for which I wore fancy clothes and shiny shoes, slicked back my hair, and whistled while I worked" (71). He knew that it was not possible for him while living in the rural area like Gagret, where he saw limited opportunities. But still he kept thinking about other jobs. Once the idea of working as truck driver's assistant called 'cleaner' came in his mind. But he stopped thinking as his friend, Tilku who was a driver on his own truck made him aware about this hard and dirty work.

He wanted to do something but he could not get proper direction. In fact, he had only high school education which was not enough for looking any kind of job. Even higher education was not possible for him because none of the colleges was going to admit a deaf person like him. He describes:

“My high school education had not prepared me for any jobs, and I thought you have to be able to hear to work for other people. Higher education was out of the question since I knew none of the colleges in Hoshiarpur were going to admit a deaf person” (81).

It shows that regular schools in India are not given chance of education for disabled students. Such education system closes all the doors of employment opportunities for them in future. In the case of author, he didn't understand what to do with his little education. Once the idea of becoming a sadhu came in his mind. He might have thought that it was easy to become sadhu because it does not require any educational qualification or background. He knew:

“India is a country of sadhus, or holy men. These sadhus come in all shapes and sizes with all kinds of beliefs and degrees. Educationally, they range from being totally illiterate to being scholars” (82).

But he didn't share the idea of becoming sadhu with anyone. Instead he kept it in his mind and waited for right opportunity. Once a mahatma or a great soul passed through his village and stayed a few weeks in their house. The author didn't want to lose this opportunity. So, he expressed his wish of becoming a sadhu and go to Rishikesh with this

sage before his father. But he became more upset as this plan was not accepted by his father.

The government of India provides various schemes and facilities for persons with disabilities for their betterment. Due to poor implementation of laws, persons with disabilities are deprived of various government benefits. Once the author heard from his eldest brother, Narain about a photography school for the deaf in Delhi which was going to provide training in photography and a government law offering scholarships to the physically handicapped. Along with his brother, he went to inquire about that at the office of the vocational rehabilitation department. After going there, they realized that no one in the office knew about this new scheme of scholarships and training programs for the physically handicapped. The head clerk of that office sent them to the director's office for more information. The author observed that the clerks in the director's office were spending their office hours in relaxed manner. These clerks had no concern for people who came there with new hopes and aspirations. According to the author, "None of these clerks knew about this new law that would change the lives of millions of handicapped children in India" (92). In reality, implementing such type of government laws is a part of their job but such employees in government offices often overlook to that. As a result, most of the disabled people remain away from their rights that can bring a huge change in their life.

The drastic change came in the life of author when he was admitted as student in the All India Photography Training Institute for the Deaf (PID) which was located behind All India Federation of the Deaf (AIFD) office at Cannaught Place in New Delhi. There he was registered as an AIFD student. Mr. B. G. Nigam was the general secretary of the AIFD. At first, there were only two students in the classroom named Khurana

and Goel. Few students were admitted later. V. R. Goyle was the only one teacher who spent most of the time in his Photo Studio and less time in the classroom.

After joining PID, he began to learn photography but more than that he began to learn about new world which was different from normal world. Initially, he got confused as he saw people were used to communicate with their hands and fingers with each other. He describes that “The idea that people could communicate with their hands and, worse still, that people could understand this wild flailing of hands and fingers, was just inconceivable to me” (98). Later on, he understood that it was a sign language used by deaf people while communicating with each other.

He became deaf later in his life. At that time, he was seven years old. So he could speak and write in Hindi or English language. He first time came to realize that there were other people who didn't know how to speak or write in any language because they were born with deafness. Therefore, they used sign language as medium of their communication. His lack of signing skills created barrier while communicating with them. So, he decided to learn sign language as soon as possible. Thereafter, he kept practicing this new method of communication which seemed to be very interesting to him. He writes “I was thrilled about the possibility of communicating with this new mode” (100). He became fascinated with this language and within a couple of weeks he was able to fully communicate with his new deaf friends.

One of the reasons he moved to Delhi was the availability of government scholarships for persons with disabilities. He applied for one of the fellowships after getting admission at the PID and was waiting for

approval. After doing inquiry at the office that granted scholarships, it was cleared that he had not received the scholarship as they had never received his application. The author writes “This, in bureaucratic language, means they had either lost it or it was still sitting in some tall pile of files in front of one of those sleeping clerks” (116). It shows that the clerks in government’s offices never do their job carefully, so that many people like him do not meet their needs.

Because of the carelessness of the clerks, he didn’t receive scholarship. He didn’t want to become economic burden on his brother, Narain with whom he lived in Delhi. So, he had no other option but to work somewhere. As he told his predicament to Mr. Nigam, he offered him two part time jobs. First, he was going to work in Mr. Goyle’s studio after school and second, he was going to teach an adult literacy class at night. Mr. Goyle was going to pay him 25 rupees a month and his night class would pay him another 25 rupees. So, he was going to earn 50 rupees per month. He tells “The idea that I was making some money satisfied me, and the opportunities to do professional photography at the studio and be a teacher were much more valuable than any amount of money” (117). He was very happy with this job opportunities that gave him a lot of practical knowledge. Working at the Goyle’s Studio gave him a lot of experience. At first,

“Instead of being behind the counter and dealing with fancy people, I found myself working in the darkroom, washing and drying prints, trimming and retouching them, and then putting them in envelopes with marked order numbers” (121).

In spite of that, he had sometimes got opportunity to work at the counter. Likewise, he had also got the opportunity to take photographs at

weddings, new events and various ceremonies. So, within a few months, he had also developed skills of processing and printing films at the required speed and professional quality. He describes “I could produce professional quality photographs, shoot portraits and action photographs, and deal comfortably with clients” (123). All these new skills gave him a lot of courage and self-confidence.

After joining PID, he heard about deaf clubs where the deaf people met once in a week. But after visiting twice these clubs, he stopped going there. The reason behind that a distinct class system which was related with money bothered him and never encouraged him to visit these places. He found that most of the members came there from wealthy families. He unfolds “My clothes clearly indicated that I was not wealthy, therefore, I did not belong to their group” (124). Actually, he belonged to the rural background and it was clearly reflected in his dressing style and overall personality. So, other members looked him down. He also tells “Despite my wearing pants and coats, I looked like a country bumpkin” (124). As he tried to associate with the poorer members, they didn’t show their interest even to talk with him. Since he was not comfortable with the members of deaf clubs, he stopped attending their meetings.

But the attitude of these people changed little bit as he began to teach the night class. Some of his students introduced him as their teacher to people. In addition, the news that he could read, write and speak in English like hearing people helped to move up in the circle of people. Most importantly, his reputation was strengthened as he became a member and joint secretary of the Deaf and Dumb Association (DDA), which was established by Mr. Nigam and his friends. Now he was invited to join the group of richer members who associated with Mr. Nigam. He writes “The deaf people who used to avoid me were now hovering around

me” (134). So he enjoyed this role as an important member of the deaf community.

Every day he had to spend his time from 7:00 am to 11:00 pm in the classroom, Goyle’s Studio and then, in the night class. There was only Sunday to spend with his family. After becoming joint secretary of DDA, his life became busier than earlier. Now he had to spend his Sunday for DDA. After joining the DDA, he gradually began to learn that the main goal of AIFD was to raise enough money to run the office and pay for Nigam’s annual trip abroad. He illustrates “Each year, Nigam went to another country for the World Federation of the Deaf’s annual conference or some other meeting, and the AIFD paid all the expenses” (134). Everyone in the organization knew how Mr. Nigam used the federation money for his lavish lifestyle and expensive trips, but no one dared to speak against him. One of the income sources of AIFD was the annual Flag Week. During National Flag Week, the deaf people wondered all over the city in groups of three or four to collect donation by selling miniature India flags. The author didn’t like this work but there was no choice. He clears “It bothered me that we all had to go out and beg for paisas so Nigam could make his trip” (136). It means, some organizations in India misuse the money that they collect under the name of welfare. The author didn’t want to let this happen anymore. So, he discussed this issue with his friends but they suggested him to stay quite.

The deaf people always face considerable challenges due to the problem of communication. The main thing is that deafness is an invisible disability which is not easily apparent to all. So in some cases, such people have to prove that they are deaf. Another thing is that there are many deaf people who can talk like hearing people because they became deaf later in their life. So people do not believe in them in certain time.

Once the same thing was happened in the case of the author and his friend, Kesh, as they went to visit Rashtrapati Bhavan's (President's House) garden which was generally open for the public in each March. They saw the president, Dr. Rajendra Prasad who had been sick for a few weeks and being wheeled around in the secure part of the garden. While moving to get closer view of the president, their way were blocked by several policemen assuming that they were trying to assassinate him. They told them that they were deaf and requested him to write on the piece of paper what was their problem. But they didn't believe that they were deaf. Even the author and his friend didn't understand what they expected from them exactly. One of the guys from the crowd transcribed what he was saying "They do not believe you are deaf, and they think you were trying to kill the president" (148). The fact of author's talking like hearing people made them more doubtful about their deafness.

His teacher, Mr. Goyle who was his role model died in road accident. His sudden death affected his school and work. After waiting for few months, Mr. Nigam appointed Mr. Yadhav as teacher but he became more important to Mr. Nigam as a writer because his writing was so good. Soon Mr. Nigam appointed Mr. Lal, another teacher who had never met deaf people before, but he treated all the students as regular people not as deaf one. The author writes "Despite the fact that he had never met a deaf person before, he adapted to us as if he had known us all his life" (150). It shows that there are very few teachers like Mr. Lal in India who treat their disabled students with genuine care and love. Otherwise, there are some other teachers who never show their interest in disabled students.

Author's fluency in signing increased but he felt shy signing in the public. The main reason was that signing was not a common sight in

India at that time. He frequently observed that as he and his friends started signing in the public, the people gave them different and curious look all the time. He expresses “Every time my friends and I signed in public, we drew a crowd of curious onlookers who behaved in a variety of ways” (156). However, to avoid strange look and staring of onlookers, he generally avoided to communicate in sign language.

After finishing his two years at the Photography Institute for the Deaf (PID), he started working full time in the Goyle’s Studio. But Mr. Nigam offered him job as teacher at the PID. He was also settled in his new routine as teacher at PID. A huge change came in his career after getting permanent job as assistant photographer at the National Physical Laboratory in Delhi. For this job, he had to face practical examination in photography and an interview. At first, he thought that he would be kicked out before the interview because he was the only deaf out of all seventy-plus hearing people who came for the same. But he got that job after competing such large number of hearing people who came for that position. He describes:

“That position did much more for me. Slowly I began to realize that deafness was not going to stop me from succeeding in life. All I had to do was to venture out, and I might get a better job than the one I had just gotten” (165).

This position made him to realize that his deafness would not stop him to become successful in life. In short, this gave him confidence.

He became deaf later in his life so he never went to the deaf school before coming to PID. But he learnt horrible deaf stories about deaf schools from his friends who had attended them. His friends told him that the teachers didn’t care about them and didn’t know how to sign. His

dealings with Mr. Nigam had also shown him that deaf people needed to be united against tyranny and manipulation. He specified that “We needed better schools, better organization, and, perhaps, a college for the deaf” (166). He wanted to bring change in the lives of deaf people in India. He also added “I was going to fight the government to get rights and for the deaf” (167). He wanted to take initiative with full force.

Until now, he was just thinking about his career. In fact, the idea of getting married was never in his list. But he soon realized the importance of partner in life and he decided to marry. Thereafter, his marriage was fixed by the family with Nirmala Devi who had been called by her nickname called Nikki. After his engagement, he again resumed his busy life in Delhi.

Now he started working as an assistant photographer for the Indian National Scientific Documentation Centre (INSDOC) a new department of the National Physical Laboratory (NPL). This agency made copies of scientific journals and books for scientists all over India. This was his first experience to work with hearing people. Initially, his coworkers gave him furtive looks and left him alone. Over time, they accepted him as a part of their group. Although communication was always an issue, they adjusted him. One thing was sure that after getting government job, his status had risen in the deaf people.

Although he had got that government job, he was still working for DDA. Once Suraj, a general secretary of DDA assigned him a task of escorting the deaf American woman whose name Hester Bennet, around Delhi. So, the author and his friend, Kesh went to escort that American lady. The reason of his selection was knowledge of English. This task gave him opportunity to learn something about deaf people in America.

The author describes “Hester learned a few Indian signs, and Kesh and I picked up some American sign” (180). She was impressed by author’s English. So, she suggested him to go to Gallaudet.

After getting job at the National Physical Laboratory (NPL), he thought that he was settled for his life. Other deaf people looked at him enviously for having such a well-paid and secure job. None of his friends who had received training at the PID had a job like him. He should have been happy and proud of his job. But he felt restlessness within a couple of years at the NPL. He wanted another job with more responsibility and better salary. He heard that several friends of Bhai Narain worked in private companies and banks where they got high salary.

He learnt about a college for a deaf in America. He had an address of Gallaudet College, which was given by Hester Bennet. He sent applications twice but he could not get any reply. As per the advice of Mr. Nigam, he again wrote application to Dr. Leonard Elstad, the president of Gallaudet College and expressed his desire to take further education in their college. One month later, he received a letter and an application form from the registrar of Gallaudet College. He was told that admission test would be arranged for him through the U.S embassy in New Delhi. Later on, he learnt that Gallaudet did not admit Indian students as their experience with other students from India had not been very good. But Hester Bennet helped him in this instance. After giving admission test, he was waiting for result. Meanwhile, he married Nikki. Being a deaf, thousands of questions crossed his mind just as “Would she be a good wife? Would she be able to learn signs and communicate with me, or would she just write on her palm like the other members of my family?” (198). He thought that his deafness might bother her but it was not like that.

After few months, he received letter of his acceptance from Gallaudet. He could not believe it, but his goal of higher education was going to be fulfilled soon. He got admission but money was a big issue. But he managed it somehow after visiting different government officials. During the process of visa, he had not 'P' Form which was an assurance that he would have full financial support in the currency of the host country. The U. S. embassy could not issue him a visa unless he produced that form issued by Reserve Bank of India. He and his brother, Narain went office to office for that form but no one had paid attention to them. The clerks in those offices wanted a few hundred rupees in a bribe to issue the form. The author explains "For wealthy people, shelling out a few hundred rupees was nothing, and those clerks were used to getting that baksheesh, or tip, as they called it. But for us, that money was difficult to get" (206). He felt glad because his brother's ferociousness made the clerks to forget their bribe.

Unfortunately, his 'P Form' was denied under the criteria of the \$250 donation from Mr. Burnes for books was from a private party. The Indian government considered only government or major university grants not private donations. Regarding this matter, they visited many high positioned people in concerned government offices, but they were neglected. The author describes "Bhai Narain and I visited each of these "high position" people. Some of them refused to see us; others simply expressed their sympathy by telling us that this was not under their jurisdiction" (206). It shows, the people in government offices do not have genuine concern for the needs of common people. They never try to solve their problems. In the meantime, the author's friend, Kesh finally came to rescue him, introducing him to a friend's friend- a judge called Mr. Erady's, the director of the department that issued 'P' Forms. A short

phone call from the judge, his form was accepted. Finally, he got his visa and he went to America for further education.

In the epilogue, he has shared some of his experiences in America. Being a deaf, he observed that in India hearing people had always written to him and he had always responded them with his voice. So he never had to write to express himself. But hearing people in America didn't prefer to write for him. On the top of that they didn't understand his speech. He says "My heavy Gragret accent made my speech unintelligible to the America" (212). Actually, he had never heard English spoken by American people. So he had no idea about their sounds.

As he entered the Gallaudet College, he saw about thirty students who were signing rapidly with each other. He could not understand even single word because he had no idea about American Sign Language. The students in Gallaudet ignored him totally. He felt bad because this never happened in case of him in India. He illustrates "In India, the arrival of a stranger is a big event. A student from another country would have been surrounded by people and questioned about where he was from and what he was doing" (213). His first few attempts to get someone's attention were totally failure. Then, he did succeed in getting attention of one of the male students called Godsay from Florida, who helped him further. He writes about him that "My friend from Florida was very patient guy and fingerspelled words slowly for me wrote on paper to explain things" (214). As time went on, he learnt more American English.

Apart from education, he learnt many more things while living in America. He was first time exploring new culture which was totally different from his own country. In short, his experience of living in America was quite new and different from India in all aspect of life. He

considered himself as lucky to become deaf because he thinks “Deafness did open new doors for me, and I used them to arrive where I am now” (220). Along with many issues and challenges, deafness brought him many opportunities and he took advantage of those opportunities.

After completing his graduation and post-graduation from the Gallaudet University, in America, he did his Ph. D from the same University. Thereafter, he worked as teacher, principal, superintendent in the schools for the deaf in Texas, Illinois and North Carolina. After the retirement, he also started working on Indian Sign Language (ISL), interpreting, and educational research projects in India. Most importantly, he published the first Indian Sign Language (ISL) Dictionary in 1981.

He thought that the provision of Indian Sign Language must be there in mainstream educational system for the inclusion of deaf students. In his conversation with Parvinder Singh, he strongly expresses this ideas. He says “The ideal should be to achieve true inclusion, for instance basic sign language should be made a mandatory part of all teachers training programmes” (<https://www.dnis.org>). It shows that true inclusion of deaf students is possible when it becomes mandatory part of all teacher training programs.

Chapter VI

Conclusion

The present research work aims to understand Indian experience of disability with reference to select autobiographies of persons with disabilities. It comprises six chapters. The first chapter of this study is introduction that consists following points- autobiography as a genre, importance of autobiography to understand the experience of disability, biographical sketches of authors, review of relevant literature, the significance of the study, hypothesis of the study, aims and objectives of the study, scope and limitations of the study, research methodology and chapter scheme. The second chapter is theoretical framework which focuses on the theory of disability Studies. After examining the theory of disability studies, the researcher tries to find out how Indian experience of disability is different from western experience of disability. Third, fourth and fifth chapters are analytical parts of the study. In these chapters, selected autobiographies of persons with disabilities are analyzed to understand Indian experience of disability. After examining and analyzing the select autobiographies of persons with disabilities, certain conclusions are drawn in the sixth chapter that is concluding part of the present research work.

Disability is a global phenomenon because it is present everywhere. Although disability is found in every part of the world, treatment which is received by disabled people can be different from one part to another due to its traditional or cultural variations. So, it is true to say the experience of disability is different from country to country. One can even find that the experience of disability in each country is likely to be very different from the experience of hundred years ago of that

country. In fact, the complete integration of disabled people into society has not yet been achieved in any country in the world, but each country is trying to remove the present barriers in their ways.

Since long, the persons with disabilities have been facing the problems of social negligence, environmental barriers and other major hindrances in their ways. But, after the establishment of disability rights movement at a global level during 1970s, some improvement is found in their condition. In order to improve their status in the society, this movement had undertaken various programs and activities all over the world. Most importantly, disability studies emerged out of the disability rights movement in the late twentieth century. It studies the concept of disability thoroughly. Just like race and gender studies, disability studies is also introduced by many institutes, colleges and universities in their curriculum for doing study or research.

The present understanding of disability is dominated by the experience of America and European countries. And it is used as universal standard. The experience of disability in India is also unique and it is complicated by poverty, caste, gender and community. The reason being that India has different socio-political and cultural background. Furthermore, it is considered one of the developing countries where the experience of disability is different from developed countries like USA and UK in terms of resources and facilities.

The researcher has selected six autobiographies of persons with disabilities to understand Indian experience of disabilities. In the third chapter, the researcher has analyzed three autobiographies of visually impaired persons- *Face to face* by Ved Mehta, *Lights Out* by L. Subramani and *The Other Senses* by Preeti Monga. The fourth chapter

contains the analysis of two autobiographies of wheelchair users- *No Looking Back* by Shivani Gupta and *One Little Finger* by Malini Chib. The fifth chapter seeks to understand experience of deafness with the help of *Deaf in Delhi* by Madan Vasishta. These autobiographies of persons with disabilities significantly help to understand Indian experience of disability through their first-hand experiences.

After analyzing selected autobiographies of persons with disabilities, some findings are detailed in the sixth chapter. These autobiographies reveal that although the persons with disabilities suffer from different impairments like visually, walking or hearing impairments, they commonly recognize with the same identity called 'abnormal'. In fact, the persons with diverse disabilities have to confront with different issues and challenges in their day-to-day life, but they face one common problem i. e. exclusion in the mainstream society. They cannot live their life as other normal beings. Just like other marginalized groups of people, their life experiences are also distinct from other average people

The experiences of these authors remind that every individual with distinct disability has to face different challenges and problems in their lives. For instance: in the case of education, the problems faced by visually impaired persons are different from wheelchair users or hearing impaired persons and vice versa. Just as, inaccessible reading materials create problem for visually impaired persons, inaccessible school buildings and the problem of communication have created big hindrances in the ways of wheelchair users and hearing impaired persons respectively. It means that their experiences pertaining to education are completely different, but they have to undergo the same sufferings of exclusion in the regular schools. Although they have same suffering of exclusion in all spheres of life, each person with diverse disability has to

acquire different kind of skills and techniques to tackle the various situations of their life.

The experiences of these authors also show that disability can affect anyone at any time. It never sees the background of the people. For instance: it is well-known fact that poverty brings disability. But the case of all these authors was different. They belonged to well-to-do family, still they are affected by disability. Some people are born with disabilities and some become disabled later in life, although the causes of their disabilities are different. For instance, Except Malini Chib who was born with Cerebral Palsy, all these authors became disabled later in their life. Ved Mehta, L. Subramani and Preeti Monga became blind at the age of three and half, eighteen and six respectively. Shivani Gupta became physically disabled at the age of twenty-two and Madan Vasishta became deaf at the age of eleven. One can mitigate the influence of disability to some extent by taking proper care and precautions, but it is not possible for anyone to avoid it completely.

It is cleared that some people are born with disabilities and some of them become disabled later in their life. The question of identity is easy for those who are born with disabilities, but it is very difficult for those who acquire disability later in their life. The reason behind that they have to adjust with their new identity and at the same time their families also have to accept new situation. Hence, disabled persons and their families need a vital support and counselling at the initial stages, so that they can easily adjust with the reality of their lives.

These autobiographies reveal that accessibility plays a crucial role in the lives of persons with disabilities to lead normal lives. But persons with disabilities in India face major problems of accessibility. Most of the

places or things like transportation services, parking facilities, roads, platforms, buses, trains and various public or private buildings in India are not accessible for them. For instance: being wheelchair users, Shivani Gupta and Malini Chib face various issues on the account of inaccessibility. In their autobiographies, they have described such awful experiences that reveals how India is poor in terms of providing accessibility in required places for disabled people. The lack of accessibility in various places restricts them from working independently. Every time they have to rely on others help while going out for any work. Accessibility is a basic need of persons with disabilities because it helps them to work or perform independently.

Due to the lack of accessibility in various places, persons with disabilities have to face discrimination every time in society. Shivani Gupta describes her experience in the theatre where she went to see movie with her friends. But she had to sit in one corner separately accompanied by other unknown people while her friends sat somewhere else. At that time, she became furious that the whole plan of watching movie together with her friends remained unsuccessful due to the lack of accessibility in that multiplex. This incident shows that the places of entertainment are also not accessible for persons with disabilities in India. In short, various experiences of all these authors regarding accessibility show that the needs of persons with disabilities are not taken into consideration by the architects or planners while constructing or developing new things.

These autobiographies also reveal that persons with disabilities usually face discriminatory attitude of people in their workplace. Although they have good education, it is very difficult for them to find a job because of the negative attitude of employers who may think that

disabled people cannot work efficiently. Malini Chib had completed her two master's degrees in Publishing Course and Library Science in London, but she faced difficulties in finding job. Once she got a job in Bombay Times but she found that there were a lot of issues of accessibility. Along with inaccessibility on the workplace, wheelchair unfriendly transportation service also forced her to quit job. Shivani Gupta also had to quit her job as Programme Manager in a big corporate company in Delhi on the account of inaccessibility. The main entrance of her office building was inaccessible to her wheelchair. There was another accessible entrance which was only for V.I.Ps. But she was not allowed to use that accessible V.I.P entrance.

The experiences of these authors regarding education show that persons with disabilities in India have to face many problems in education. Most of the time, regular schools are reluctant to admit disabled students. Consequently, poor education affects their employment opportunities. Preeti Monga was expelled from the regular school Loreto Convent, Delhi. So she had to stop her formal education in ninth standard. Later on, she faced various problems while finding a job with this little education. Madan Vasistha also stopped attending school after becoming deaf at the age of eleven because he was facing the major problem of communication. But his passion for education motivated him to study at home and appear for exam in school. He somehow completed his matriculation by studying individually at home. Thereafter, he wanted to take higher education but none of the colleges was going to admit a deaf person like him. He was actually deprived from the basic right of his education on the basis of disability. Being a wheelchair users, Shivani Gupta and Malini Chib faced the problem of physical accessibility in their colleges where they took admission. The premises of the colleges

including library, canteen, washroom, lifts and other many things were inaccessible for their wheelchairs. In this regard, they tried to meet concerned authorities of the college but nothing happened. The fact is that the concerned authorities of such institutes do not want to modify the structure of their buildings for few students who need it. Needless to say that such schools or colleges have no provisions for the students with various disabilities who have special needs in the form of trained teachers, assistive devices, accessible study materials and accessible school buildings. But regular schools in India are unable to fulfill their needs.

Health care is most indispensable part of human life because it is prime need of every human being. But the health care system in India seems to be worse than other countries. Due to the lack of public expenditure, both public and private health care centers in India always struggle with inadequate infrastructural facilities and poor maintenance. There is always shortage of manpower including doctors, trained nurses and paramedical staff to handle overcrowded patients in India. In reality, one can either become permanently disabled or lose the life due to such poor quality of health care facilities. Gupta's autobiography reveals the abysmal condition of health care in India. After her two accidents, she observed that the hospitals, especially government hospitals, in India were poor in terms of maintaining hygiene or cleanliness. Likewise, the patients were not taken care properly by the staff of these hospitals.

Many doctors in these hospitals have negative attitude towards their disabled patients. Being a patient of Cerebral Palsy, Malini Chib's experience of Indian doctors was not so good. The doctors were negative about her condition. They assumed that she was not only physically but also mentally handicapped. This assumption of Indian doctors made her

parents more depress. As they moved to London, they took the proper consultation of doctors about her condition. After doing several tests there, it was cleared that she was not only normal, but also above average in intelligence.

Even today the attitude of Indian people towards disability and disabled people is negative. Disability is generally perceived as a tragedy or loss of individual as well as his/her family. So, along with impairment, disabled people and their family always confront social stigma, prejudice, exclusion, discrimination and negative attitude of people. The society does not understand that disability is nothing but natural phenomenon. It should be accepted as a part of human variation but due to the lack of awareness and knowledge among people about the causes of disability, it is seen as something different or strange.

Since time immemorial, many false assumptions about disability and disabled people are held by society. There are some religious superstitions linked to disability and disabled people in Indian society. Sometimes disability is considered as God's punishment for sins that may have been committed by either individuals or their parents or ancestors in the present or previous birth. Another prevalent misconception about disability is that disabled have no faith in God. Madan Vashista's autobiography reveals some of these superstitions about disability prevalent in Indian society. After becoming deaf, he had to follow some superstitious beliefs and practices that were carried out by his family to cure his deafness. Considering his deafness as the result of some celestial punishment, he was taken to number of sadhus, miracle healers, temple priests who claimed to have a direct link to gods. The treatment for his deafness didn't stop with the holy men or miracle workers but there were

other non-scientific home remedies that were administered by his family. But every non-scientific method failed to cure his deafness.

The same non-scientific methods and practices were carried out by Ved Mehta's mother after his blindness. Her irrational thinking made her to believe in some superstitious causes behind her son's blindness. She took consultation from various Pandits and Hakims. Even if his father scorn such methods, his mother performed them secretly.

L. Subramani's family also believed that his blindness was a result of his sinful act in previous birth and it can be cured by praying to God. Thereafter, his mother started doing various non-scientific treatments in the hope of his cure. She met a number of miracle workers, astrologers, healers who all claimed to have knowledge of the past sins and remedies to get rid of their effects. In reality, superstitions regarding the causes of disability are responsible for such unscientific treatments of disabilities. Such treatments cause pain to persons with disabilities and delay the process of their rehabilitation.

Since long, persons with disabilities have been leading their lives with the charity given by society. Even today non-disabled people think that disabled people are needy and they give charity to disabled people. Shivani Gupta describes one of her most humiliating experiences that she never even imagined. As she was waiting in the queue to enter the temple at Haridwar, a poor middle-aged woman came to her and handed her a twenty-five-paisa coin assuming that she was a beggar. She was surprised by the act of that woman and didn't understand how to react. But she later on understood that disabled people are generally considered as needy and they live on charity which is given by the society through different ways.

This incident reminds that disabled people are still seen as passive recipients rather than active participants or contributors of society.

A significant proportion of disabled population in India resides in rural regions. The condition of disabled people in rural India is worse than urban area. In rural area, they get limited resources and facilities that are usually available in urban areas. Madan Vasishtha was living in a small village in northern India where he had limited exposure. After becoming deaf, he had to stop school in the middle of sixth standard. Thereafter, he spent next ten years of his life working in his family farm as a farmer. He and his family were not aware of special schools for deaf people. There are very few special schools for disabled available in India and most of them are located in urban areas. So most of the people in rural areas are unaware about the availability of special schools.

Some of these authors have bad experience about some people who worked in the government offices. Madan Vasishtha found that the clerks in government offices never do their job sincerely. Once he applied for a fellowships after getting admission in the All India Photography Training Institute for the Deaf in Delhi. He waited long time for approval but he received nothing. After making inquiry at the office that granted scholarships, he was shocked by their response that he had not received the scholarship as they had never received his application. The author expressed the possibilities that either they lost his application or kept it in a big pile of files in front of them. He also experienced that while doing his visa process the clerks in the concerned department wanted a few hundred rupees as bribe to issue 'P' Form which was an assurance that he would have full financial support in the currency of the host country. Actually, the government employees have not genuine concern about the

suffering of common people. They do not show their interest in work until they do not get money as a bribe from the people.

Shivani Gupta and her father also went through the same experience. They suffered a lot till the final allotment of a DDA flat which was given her on the basis of her disability. They went to concerned authority for approval, but they were neglected. Thereafter, they met various officers including Lieutenant governor of Delhi regarding the case but nothing happened. One of the officers openly asked her father to pay him one lakh rupees to get the work done. But her father refused to do it. As a result of it her case was further delayed. As they went to meet the minister of urban affairs, he approved the case and demanded immediate allotment. But still their immediate action also took two years for the final implementation. So when she did get her flat, the cost was double as much as they had made the application. She thought that if they had paid the bribe, they could have saved a large amount of money by getting an allotment earlier when the cost was lower. Thus the experience of Madan Vasishta and Shivani Gupta shows that many disabled people like them may not meet their rights due to such corrupt people in government offices in India.

Some organizations in India misuse the money that they collect in the name of welfare of disabled. For example: while working with the All India federation of the Deaf (AIFD), Madan Vasishta experienced that the members of this federation wandered all over the city in groups of three or four to collect donation by selling miniature India flags. And the general secretary of that organization used the federation money for his lavish lifestyle and expensive trips to foreign countries. Due to such malpractices, disabled people do not meet their genuine needs, although some organizations are established for the wellbeing of disabled people.

Many cultural and traditional beliefs make disabled women's experiences different from non-disabled women. Indeed, disabled women have double disadvantages in Indian patriarchal society. Being a woman and disabled, they usually suffer with two fold discrimination. Because women are expected to perform traditional roles like cooking or taking care of family. So it is assumed that disabled women are unable to perform such household duties. Hence, Indian families never accept disabled woman for marriage. As a result of it, disabled women remain unmarried for lifetime. On the top of that, if they become disabled after their marriage, they are abandoned or divorced by their husbands. Especially in Indian society, there are very few cases in which disabled women remarry.

In her autobiography, Malini Chib expresses her dire need of life partner who could love her beyond her disability. Most of her friends had partners in their college life but no one showed his interest in her. She was serious about her relationship with Zubin, her friend, but she got frustration as he told the fact that he was a gay. Unfortunately, she remained unmarried for lifetime. In the case of Preeti Monga, many times she got rejection in marriage proposal because of her blindness. Finally, she married Keith but she had to leave him to get rid of his daily tortures and remarried Ashwani, who met her at office where she worked. The case of Shivani Gupta is different. She was abandoned by her boyfriend as she became disabled. Although she had tetraplegic condition, Vikas married her. At first, Vikas's parents were not happy with their relationship. But, as they realized her importance in his life, they gave permission for their marriage. So they married after completing ten years of their relationship. Most importantly, they were happy in their married life. But their happy married life was devastated after four months of their

marriage while going to Manali for family trip. In that accident, her husband, Vikas and her father-in-law died. Thereafter, she remained alone without partner.

Almost all of these authors have travelled in western countries like USA, UK and European countries for academic or other reason. Their western experience of disability is better than India. They found that there is better understanding and awareness found among western people about disability and its causes. Most importantly, western people have accepted disability as a part of human variation. So their attitude towards disability and disabled people is not negative. In fact, they usually give priority to special needs of disabled people. These countries provide them better accessibility that helps them to lead normal land independent life like non-disabled people. Both Shivani Gupta and Malini Chib were very much influenced by the wheelchair friendly environment in western countries in which they had lived.

The fact is that disabled children in those countries go to school as their non-disabled peers. Likewise, disabled people earn their own income by doing jobs everywhere like their non-disabled colleagues. In their country, they get required aids and appliances which assist them to work without help of others. They also get proper correctional surgeries and therapies in their countries. In short, disabled people in foreign countries enjoy the same rights enjoyed by non-disabled people. Ved Mehta was very much impressed by America where he could live normal or independent life like other normal beings. He found that most of the places or things like roads, transportation services were accessible for visually impaired in America. But In India, inaccessible public places especially roads restrict visually impaired people like him to move independently. Most importantly, pedestrian are given first priority while

walking on or crossing the roads in America. So, it is better especially for visually impaired in terms of safety. But he never observed these things in India. Indeed, the visually impaired people need audio signals, guiding blocks and warning blocks on the required places to navigate or cross the roads safely. But these things are not found on Indian roads.

Along with excellent education, Ved Mehta enjoyed the freedom of movement and a complete sense of self-reliance that he couldn't enjoy in India. In short, he felt more comfortable to live in America than in India. Malini Chib also felt more comfortable to live in London where she enjoyed wheelchair friendly environment and educated attitude of people everywhere.

Most important thing is that persons with disabilities in India get strong support from their family. Even today some people live in a joint family. Therefore, persons with disability are not only supported by their parents but also other family members or relatives. After becoming disabled, these authors have also got physical or mental support from their family. They all belong to well to do family. Even they get support from other people apart from their family members. Some people voluntarily come to help disabled people without any ulterior motive. But it does not happen in foreign countries. For instance: in their trip to Eiffel Tower, Shivani Gupta and Vikas badly needed the help as they saw fourteen steps while coming out of the metro station. No one around them came to help. Even they had not tried to call anyone for their help because they were in strange country where most of the people speak in French, so they could not communicate with them.

Overall, it is right to say that the life of persons with disabilities in India is more challenging than western countries. Many laws exist for

disabled person but due to the poor implementation of those laws, there is no expected change found in their situation even today. There is need to create awareness among the people about disability and disabled people In India. It will help to change the negative attitude, misconceptions and stereotypical opinions about disability. One of the effective ways to create mass awareness is to introduce concept of disability in schools, colleges and universities. In order to understand the various facets of disability, it should be studied as a separate academic discipline like gender and women's studies. In reality, Indian universities and academic institutions have not yet incorporated disability studies in the curriculum.

Another way to create awareness is to increase the number of trained volunteers in the disability sector so that they can help to change the negative attitude of the society. Social media can also be effectively used to sensitize the people because it can reach a large number of people. Along with this, various seminars, workshops and conferences can also help to create awareness.

One thing is to be noted that the society shows sympathy or pity towards persons with disabilities, but they don't need sympathy and charity. Instead they want such support that they can fully participate in mainstream activities like others. If the family and the society come forward to fulfil their special needs, thousands of disabled persons can be like Stephen Hawkins who has contributed enormously in Physics in spite of having severe locomotor disability.

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**UNDERSTANDING INDIAN EXPERIENCE OF DISABILITY WITH
REFERENCE TO SELECT AUTOBIOGRAPHIES OF PERSONS WITH
DISABILITIES**

A THESIS SUBMITTED TO

SHIVAJI UNIVERSITY, KOLHAPUR

FOR THE DEGREE OF

DOCTOR OF PHILOSOPHY

IN

ENGLISH

UNDER THE FACULTY OF

HUMANITIES

BY

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80-Recommendation

Persons with disabilities is one of the marginalized groups of people. For long, their basic needs have been overlooked. Although some awareness programs regarding disability related-issues have been carried out at global level for the last five decades, still the expected change is not found in their situation especially in developing countries. The majority of world's disabled population lives in developing countries like India where they live in miserable condition due to the lack of access of essential services like education, employment, transportation, information, rehabilitation, accommodation and medical services. The fact is that developing countries are economically backward, so they are unable to provide even the basic facilities to their citizens including persons with disabilities. Hence, the persons with disabilities are often confronted with various difficulties while surviving in such condition. It is obvious that disability related experiences of such people in developing countries are very different from developed countries like USA, UK and European countries.

Persons with disabilities have taken initiative to write their autobiographies to expose the blemishes of the society in which they lived. The autobiographies of Dalit have been extensively studied, but autobiographies of persons with disabilities have not attracted attention of research scholars. They are not only marginalized from the social economic, cultural and political activities but also from the research agendas. Therefore, to fill the research gap, the present researcher is attempting to scrutinize select autobiographies of Indian persons with disabilities. The researcher has selected following autobiographies- *Face to Face* (1957) by Ved Mehta, *Deaf in Delhi* (2006) by Madan Vasishta, *Lights Out* (2014) by L. Subramani, *One Little Finger* (2010) by Malini Chib, *The Other Senses*

(2012) by Preeti Monga, *No Looking Back* (2014) by Shivani Gupta for the present research work. The main purpose of choosing the genre, 'autobiography' to understand the experience of disability is that autobiography provides authentic and reliable information about person's life and social conditions.

Conclusion

These autobiographies reveal that the persons with disabilities in India face the major problem of accessibility because most of the places or things are not accessible for them in India. Along with accessibility, they face the problems regarding education, employment, rehabilitation, medical care, reasonable accommodation and many more. Due to the lack of knowledge and understanding of people regarding the causes of disability, they face the negative attitude of society. Many laws exist for them, but due to the poor implementation of those laws, there is no expected change found in their situation even today. Indeed, there is need to create awareness among the people about disability and disabled people. It will help to remove the negative attitude, misconceptions and stereotypical opinions about disability. One of the effective ways to create mass awareness is to introduce concept of disability in schools, colleges and universities. In order to understand the various facets of disability, it should be studied as a separate academic discipline like gender and women's studies. Another way to create awareness is to increase the number of trained volunteers in the disability sector so that they can help to change the negative attitude of the society. Social media can also be effectively used to sensitize the people because it can reach a large number of people. Along with this, various seminars, workshops and conferences can also help to create awareness.

Summary

Chapter I: Introduction

In this chapter, the researcher attempts to introduce the topic of present research work in brief. It also focuses on the biographical sketches of selected authors. The researcher has chosen autobiographies of persons with disabilities to understand Indian experience of disability. Hence, this chapter tries to study 'autobiography' as genre.

Chapter II: A Theoretical Framework: Disability Studies

In this chapter, the researcher has drawn the theory of disability studies which critically examines the concept of disability thoroughly. This theory also helps to understand the experience of disability. The understanding of disability is dominated by American and European experience of disability. It is considered as universal norm. But Indian experience of disability is also unique and it is complicated by poverty, gender, caste and community. Hence, this chapter also focuses on the Indian experience of disability. To understand the Indian experience of disability, the historical representation of disability, rural and urban experience of disability, specified categories of disability, human rights of persons with disabilities, various problems of persons with disabilities are studied in Indian context.

Chapter III: Autobiographies of Visually Impaired

In this chapter, three autobiographies of visually impaired persons are analyzed. It includes Ved Mehta's *Face to Face*, L. Subramani's *Lights Out* and Preeti Monga's *The Other Senses*. These autobiographies show that the biggest challenge for persons with visually impaired is to navigate around the places without help of others. Besides that they often face the problem of

accessible reading material. Very few books or textbooks are available in Braille script.

Chapter IV: Autobiographies of Wheelchair Users

Two autobiographies of wheelchair users are analyzed in this chapter. Shivani Gupta's *No Looking Back* and Malini Chib's *One Little Finger* shows that the wheelchair users face the major issue of physical accessibility in India because most of the places are inaccessible for them.

Chapter V: Autobiography of Hearing Impaired

In this chapter, the autobiography of hearing impaired person is analyzed. It focuses on Madan Vasishta's *Deaf in Delhi*. After analyzing this autobiography, it is cleared that the persons with hearing impairments face the major problem of communication.

Chapter VII: Conclusion

After analyzing the selected autobiographies of persons with disabilities, certain conclusions are drawn in this chapter.

FUTURE FINDINGS:

The present research work attempts to understand Indian experience of disability with reference to select Indian autobiographies of persons with disabilities. The autobiographies of visually impaired, wheelchair users and hearing impaired person are analyzed to understand Indian experience of disability. In the next research, western experience of disability can be studied through the western autobiographies of persons with disabilities. The experience of disability varies from country to country because each country has different socio-political

and cultural background. Furthermore, the experience of disability in developing countries is different from developed countries in terms of getting resources and facilities. Hence, a comparative study of Indian experience of disability and western experience of disability can also be done. The experience of disability in rural areas is different from urban areas. So the future research can be concentrated on the rural and urban experience of disability separately or it can be compared. Most importantly, various authors have thrown negative light on disabled characters in their fictional writings. Even in films, such disabled characters are portrayed as strange, exotic or pitiable objects. Such fictional works and films can also be studied through the different perspectives.

PART II

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DECLARATION

I hereby declare that the thesis entitled **UNDERSTANDING INDIAN EXPERIENCE OF DISABILITY WITH REFERENCE TO SELECT AUTOBIOGRAPHIES OF PERSONS WITH DISABILITIES** completed and written by me has not previously formed the basis for the award of any Degree or Diploma or other similar title of this or any other university or examining body.

Place: Kolhapur

Date: / /2022

Trupti P. Gawade

Research Student

CERTIFICATE

This is to certify that the thesis entitled **UNDERSTANDING INDIAN EXPERIENCE OF DISABILITY WITH REFERENCE TO SELECT AUTOBIOGRAPHIES OF PERSONS WITH DISABILITIES** which is being submitted herewith for the award of the Degree of Doctor of Philosophy in English under the Faculty of Humanities of Shivaji University, Kolhapur is the result of the original research work completed by Trupti Pandurang Gawade under my supervision and guidance and to the best of my knowledge and belief the work embodied in this thesis has not formed earlier the basis for the award of any degree of similar title of this or any other University or Examining Body.

Place: Kolhapur

Date: / /2022

Dr. M. S. Vaswani

Research Guide

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Research Student

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Chapter I

INTRODUCTION

Introduction:

The society excludes many people on the basis of class, gender, religion, race, caste, creed, color, nationality, ethnicity and disability all over the world. These people are still struggling to get fundamental rights. The reasons of their exclusion from the mainstream society may be different, but the intension of their struggle is same i.e. to get equal treatment in the society like other human beings.

In reality, these categories of the people should be accepted as part of human variation. But they are often excluded due to their different characteristics which are not considered as normal by the majority of people in the society. Indeed, the exclusion of particular group is likely to break down people's hopes and aspirations. Likewise, it may be weaken the foundation of the nation because each person's contribution is valuable in the process of national development.

As mentioned earlier, the people with disabilities is also one of the groups of people which is excluded from the society. For long, their basic needs have been overlooked because they are considered as unwanted members of the society. Although some awareness programs regarding disability related-issues have continuously been carrying out at global level for the last five decades, still the expected change is not found in their situation especially in developing countries.

One thing is to be noted that almost 500 million people of the world population are estimated to be disabled in one or other way. In fact, the majority of world's disabled population lives in developing countries

like India where they live in miserable condition due to the lack of access in essential services like education, employment, transportation, information, rehabilitation, accommodation and medical care. The fact is that developing countries are economically backward, so they are unable to provide even the basic facilities to their citizens including persons with disabilities. Hence, the persons with disabilities are often confronted with various difficulties while surviving in such condition. Needless to say that disability related experiences of such people in developing countries may be very different from developed countries like USA, UK and Australia. Therefore, the focus of present research is only on the Indian experience of disability. The researcher has chosen six Indian autobiographies to understand the experience of disability in India.

The main purpose of choosing the genre, 'autobiography' to understand the experience of disability is that autobiography is more reliable source of information about social conditions than other forms of literature like poetry, drama and novel. In reality, autobiography is non-fictional work which always brings faithful representation of reality without showing imaginary characters, events and incidents. Therefore, this genre can be helped to comprehend the real lives of persons with disabilities after reading their autobiographies. Another reason for choosing autobiographies for present research is that in fiction, disabled characters are generally portrayed in negative manner by some authors in their literary work. Charlotte Bronte's *Jane Eyre* (1847), Charles Dicken's *Cricket on the Harth* (1990) are best examples of this. Even in films, they are portrayed as pitiable, miserable or strange characters. The recent movie called '*Kabil*' in Hindi language is fine example of it. Therefore, autobiography is better platform for persons with disabilities to describe the real picture of their lives, which is probably invisible to the society.

Indeed, writing autobiography is the act of self-revelation in which the person brings out some essential facts of his/her life. Although, the author oneself is the focus of the autobiography, it also throws light on the people and events that the author has known or witnessed. In short, there is truthful representation of both individual's life as well as contemporary society. Therefore, an autobiography can be an important source to understand the society in which the author has lived.

Some writers of autobiographies use this genre to expose the blemishes of society in which they have lived. They also use it to protest against the socio-economic and political exploitation and discrimination. In 1980s and 90s, Dalit autobiographical writers emerged on literary scene and raised their voice against exploitation and discrimination. These autobiographies are an important part of dalit discourse. Autobiographies of Shankarrao Kharat, Prof. P E Sonkamle, Baburao Bagul, Daya Pavar, Sharankumar Limbale, Keshav Meshram, Lakshman Mane, Kishor Shantabai Kale, Lakshman Gaiakwad, Madhav Kondwilkar, Dadasaheb More, Kumud Pavale, and Shantabai Kamle have triggered outrage and feelings of social inequality and injustice.

These Dalit autobiographies have been extensively studied, but autobiographies of persons with disabilities have not attracted attention of research scholars. The persons with disabilities are also marginalized and disempowered like Dalits. They are not only marginalized from the social economic, cultural and political activities but also from the research agendas. Therefore, to fill the research gap, the present researcher is attempting to scrutinize select autobiographies of Indian persons with disabilities. These autobiographies are as follows:

- 1. *Face to Face* (1957) by Ved Mehta**
- 2. *Lights Out* (2014) by L. Subramani**
- 3. *The Other Senses* (2012) by Preeti Monga**
- 4. *No Looking Back* (2014) by Shivani Gupta**
- 5. *One Little Finger* (2010) by Malini Chib**
- 6. *Deaf in Delhi* (2006) by Madan Vasishta**

Autobiography as a Genre:

The word ‘Autobiography’ is derived from three different constituent parts- ‘autos’ ‘bios’ and ‘graphein’. The word ‘auto’ means ‘self’, ‘bio’ means ‘life’ and ‘graph’ means ‘to write’. When these three different parts come together, the word ‘autobiography’ is formed. Thus, the whole word ‘autobiography’ means the life-story which is written by person herself/himself. The following definitions will help to clarify the meaning of autobiography.

M. H. Abrams defines autobiography as “a biography written by the subject about himself or herself.” (22). The Oxford English-English-Hindi Dictionary also defines autobiography as "the story of a person’s life written by that person” (79). According to Stephen Shapiro, autobiography is “an art of perspective, an art of juxtaposed perspectives: the present commenting upon the past, the past commenting upon the present. It is an art of contrast and integration” (119). The above definitions show that the main goal of autobiography is to reveal the reality of person’s life. Most importantly, autobiography is the only tool of providing most reliable information about human personality to the

readers. In other words, it is a fine medium for autobiographer to bring some essential facts of his/her life in front of world.

Autobiography significantly opens the platform of self-revelation to autobiographer. Indeed, the act of self-revelation is human and natural phenomenon. It depends upon the thought process of man. However, autobiography is the only genre through which person can freely express his/her life experiences. Its main purpose is to reveal the person's life. D. G. Naik says:

“Autobiography is a work entirely devoted to this purpose—the purpose of revealing the inner self or the personality of the individual writer. Autobiography, therefore, should be the most popular and satisfying form of literary art” (12).

Briefly stated, it is very simple and suitable form used by the author to express his/her personality.

The fact is that innumerable theories are established on other literary forms like poetry, drama and novel. For instance: from Aristotle's *Poetics* (335 BC) to E. M. Foster's *Aspects of the Novel* (1927) reminds that critics and scholars are interested in these forms excluding non-fictional work like autobiography. They perhaps consider that autobiography is not a significant form of literature. In this context, Shapiro points out that, “They are wrong to exclude autobiography from the realm of literature because it is not “imagination” or does not refer to a fictional or invented world” (423). Like Shapiro, many other critics also think that imagination is the only base of other literary forms except autobiographical writing. Hence, they do not agree to accept it as a form of literature. But here one thing is to be noted that every writer has to take great efforts while expressing himself/herself in any form or genre of

literature whether it comes under fictional or nonfictional category. Therefore, it is true to say that autobiography is also a worthy form of literature, even though it was neglected by earlier critics.

On the other hand, few critics believe that autobiography uses the narrative style of fiction. However, it comes under the category of fiction which includes novel and short story. In this point of view, Alfred Kazin explicates:

“...autobiographical writing, even when it assumes the mask of sincerity and pretends to be the absolute truth, can be as fictional as the wildest fantasy. ... it is just another way of telling a story, it tells another kind of story, and it uses fact as a strategy” (213).

In reality, each literary form has its own specialty and characteristic-features. Although some features of these forms are similar with each other, it doesn't mean that they are same. For instance: the narrative style or structure of autobiography is similar to fiction but still it has its own special characteristic-features. Although the narrative style or structure of autobiography is same with fiction, the autobiographer focuses on the actual lived moments of his/her life instead of using imaginary events and incidents. Furthermore, he/she also tries to divide his/her life story into several periods or chapters and gives it an artistic shape. It means that autobiographer tries to present real characters, events and incidents in his/her autobiography.

The subject matter of autobiography is related with human mind and nature. It often focuses on various traits of human personality and its psychological development. In other words, the autobiographer is unique and special part of autobiography. It is expected that he/she should be

sincere and frank narrator of his/her life. Along with some good qualities, he/she has an ability to talk of his/her weaknesses also. In other words, the true autobiographer honestly tries to reveal both positive and negative sides of his/her personality. In this context, D. G. Naik explains “The real autobiographer is such an artist then; there is no reason why should be insincere, dishonest, and unfaithful to facts” (38). Thus autobiographer is seen as true and faithful narrator of his or her life story.

In the last few decades, the genre, ‘autobiography’ has become very popular. Many people from different caste, creed, gender, race and religion including persons with disabilities have started to write their autobiographies. It is the only platform for them to write something about their lives. The readers from different age groups also show their too much interest in reading different autobiographical books of these people. They believe that such books provide an authentic information about person’s life. In fact, they visit great personalities and their aspirations while reading autobiographical books. Along with entertainment, such books provide enthusiasm and positivity to the people of all age groups. In short, autobiography naturally creates an ever-lasting impact on the mind of readers.

Importance of Autobiography to Understand the Experience of Disability:

As described earlier, autobiography is fine medium of self-expression. It brings more essential facts of person’s life. Most importantly, it gives truthful and reliable information than other forms of literature like poetry, drama and novel. Although the author uses ornamental language to create effectiveness, there is no place for imagination. Another thing is that it is more authentic than biography as

well. The reason behind that the experiences of life described by person himself are more effective and reliable than others. However, the person himself/herself can bring all the crucial aspects of his/her life by writing autobiography. The most important advantage of this genre is that the society can understand the problems of diverse people after reading their autobiographies because it is generally assumed that whatever is written in autobiography is true.

Like other marginalized groups of people including dalits, women and queers, some persons with disabilities also take initiative to write their autobiographies to express themselves. They use this platform to describe their own experiences of life that is somewhat different from the life of other average people. Due to this self-revelation, the harsh reality of their lives comes out in the world. It reflects not only the life of single disabled person but also of those who are facing the same reality of life. In reality, the society may be unaware about what type of life they live, what are their problems, what are their sufferings and how do they cope up with that? But their autobiographies help to get the answers of these questions. In short, the true voices of people with disabilities can be heard by reading their autobiographies. However, autobiographies of persons with disabilities are most important to understand the experience of disabled people.

Biographical Sketches of Authors:

1. Ved Mehta

Ved Prakash Mehata, an Indian novelist and journalist, was born on 21 March, 1934 in Lahor, British India. He belongs to a Punjabi Hindu family. His mother, Shanti Mehta was house wife and his father, Amolak Ram Mehata was doctor in public health service in Punjab. He lost his

eyesight at the age of three and half due to the cerebrospinal meningitis, a kind of serious infection that can damage the optic nerve responsible for sight, resulting in partial or total blindness. After that, his parents sent him to the Dadar School for the Blind in Bombay where he learned certain skills of independence.

As his father recognized that there was no future for blind in India, he sent him to America for education. The author was very much impressed by America where he could live normal and independent life. Along with excellent education, he enjoyed the freedom of movement and a complete sense of self-reliance that he couldn't enjoy in India. He also went to England for his further achievements. While living in America and England, he was influenced by the writings of various well-known writers like T. S. Eliot, James Joyce, Johann Goethe etc. In the meantime, his writing career also flourished and he became prolific writer later on. Now Mehta is successful author of twenty-seven books including fiction and non-fiction.

His first book is *Face to face*, an autobiography which was published in 1957. His other literary works are- *Walking the Indian Streets* (1960), *Fly and the Fly-Bottle: Encounters with British Intellectuals* (1962), *The New Theologian* (1966), *Delinquent Chacha* (1966), *Portrait of India* (1970), *John Is Easy to Please: Encounters with the Written and Spoken Word* (1971), *Daddyji* (1972), *Mahatma Gandhi and His Apostle* (1977), *The New India* (1978), *A Family Affair: India Under Tree Prime Ministers* (1982), *A Ved Mehta Reader: The Craft of the Essay* (1998), and *All for Love* (2002).

2. Lakshmi Subramani

Lakshmi Subramani is currently working as a senior sub-editor in Bangalore. He has written his autobiography entitled *Lights Out* which

was published in 2014. This book describes his fighting for living normal life in spite of having progressive blindness. At the age of eighteen, he completely lost his eyesight due to the Retinitis Pigmentosa, a genetic disorder which affects the retina. Since then, he started experiencing gradual and incurable condition leading to complete blindness. Although, he became visually impaired later on in his life, he had been suffering from retinal disorder since his childhood.

Because of his serious condition of progressive blindness, he was often experiencing unexpected blurriness. His eyes were suddenly getting blur while walking or cycling. With the experience of sudden and recurrent haziness, he started losing his self-confidence frequently. He wanted to live free from sudden and recurrent haziness, but it would never happen due to the problem of deteriorating condition of his eyes.

3. Preeti Monga

Preeti Monga was born in Amritsar in 1959 in middle class Sikh family. She is one of the India's disability rights activists. She is the founder of Silver Linings, a non-profitable organization that works for inclusion and empowerment of blind children and women. She lost her eyesight due to the reaction of Smallpox vaccine given few days after her birth, which made an allergic infection in her eyes. Thereafter, she developed Retinitis Pigmentosa that caused to the deterioration of her functional eyesight. When she was in 8th class, she was expelled from regular school because of the frequent complaints of her teachers about school performance. Therefore, her parents decided to admit her in a blind school of Delhi. But as they found that school was not in good condition, they didn't leave her alone there. Despite having poor education, she made her career in many other arenas by taking huge hard

efforts. Instead of giving up in her bad times, she proved herself by achieving grand success in life.

Being visually impaired, she has devoted herself to work for well-being of other visually impaired or disabled. She worked at various levels that may not be possible for able bodied person either. She is a well-known corporate trainer, a fitness consultant, a successful business woman, a trauma counselor, a trained coach and a PR profession. Along with this, she is one of the most inspiring motivational speakers. She motivates saying: “It is only one life we all have, I want all of us to live it to its best!” She is the author of two books that are *The Other Senses* and *Flight Without Sight*. *The Other Senses* is the first part of her autobiography, published in 2012 and *Flight Without Sight* is the second part published in 2017. These two books are true witness of her hard struggle in life.

For her achievement, she has won some prestigious awards including- The State Award for the Exceptional Achievement in Entrepreneurship in 2015, The National Award for the Empowerment of Persons with Disabilities in 2013, The National Women Excellence Award in 2010, The Red and White Bravery Silver Award in 1999, The Vocational Service Award in 1996, The Manav Sewa Award in 1995 and many more.

4. Shivani Gupta

Shivani Gupta is the founder of Non-governmental Organization called ‘AccessAbility’ and one of the India’s best-known access consultants. She has spent most of her professional life in working towards improving accessibility of public spaces for persons with disabilities. Her famous motto is “Access=Ability”. She has completed

her hotel management, architecture and inclusive management degrees from well-known institutes in India and foreign countries.

She has written her autobiography entitled '*No Looking Back*' which is published in 2014. In this book, she has described true story of her life in which she unfortunately faces overwhelming odds. She meets with an accident twice in her life. In these two accidents, she loses everything including hopes desires and aspirations in her life. Despite of having too much troubles in life, she tries to keep herself stable in every situation.

After becoming disabled, she devoted her life in helping to make environment accessible for persons with disabilities in India. For her achievement, she has been endowed with following honors and awards- the Helen Keller Award (2008), the CavinKare Ability Mystery Award (2008), the Neerja Bhanot Award (2004), the National Role Model Award (2004), the Red and White Social Bravery Award (1999) and the Sulabh International Women of the Year Award (1996).

5. Malini Chib

Malini Chib is one of the India's disability rights activist and writer. She suffers from severe disabling condition called Cerebral Palsy which is congenital disorder affected person's muscle movement and coordination. This physical condition makes her to use wheelchair lifetime. She learns how to type with her one little finger by sitting in a wheelchair. Despite of having such severe condition, she has successfully done her two International master degrees in Gender Studies and Library Science and Information Management in London.

She is the founder and co-chairperson of Able Disabled All People Together (ADAPT), through which she is actively working for the well-

being of other disabled people like her. For her contribution in the disability sector, she has been honored with National Award for the empowerment of persons with disabilities from the Indian Ministry of Social Justice and Empowerment in 2011. Likewise, on the occasion of World Cerebral Palsy Day, she was honored with the first global Cerebral Palsy Day Award in 2017 for ensuring the rights of disabled people.

She unfolds her life experiences in autobiography entitled *One Little Finger* (2010). The Indian film named *Margarita with a Straw* (2014) is somewhat based on her life. It is in Hindi language film directed by Malini's cousin, Sonali Bose. The main role is played by Kalki Koechlin, French actress and writer who appears as teenager with cerebral palsy.

6. Madan Vasishta

Madan Vasishta was born in a village called Gagret, in Northern India, in 1941. After the two weeks of high typhoid fever and the mumps, Madan became deaf at the age of eleven. It was very hard for him and his parents to accept the truth of his sudden transformation from normal into abnormal hearing world. Due to his deafness, he stopped going to school from the middle of sixth standard and started working in the field as farmer. At the same time, he started studying at home with the help of his cousins.

After his matriculation, he moved to Delhi and joined All India Federation of Deaf where he came in contact with other deaf people who had used to speak in sign language. Once he had got chance to go to Gallaudet University, in Washington DC, where he did his B.A. in History and Psychology, M. A. in Deaf Education and Ph. D. in Special Education Administration. Later on, he worked as a teacher, researcher,

principal, program evaluator and retired as superintendent from New Mexico School for the Deaf in 2000.

He has written his autobiography which is divided into two parts that are *Deaf in Delhi* and *Deaf in DC*. His *Deaf in Delhi* was published in 2006, in which he has shared his own experiences of disability in India. Afterwards, he wrote the second part of his autobiography entitled *Deaf in DC* which was published in 2010. In this book, he explores his personal experiences of disability in Washington DC.

Review of Relevant Literature:

The researchers and scientists have always been interested in the study of disability, but they have viewed disability through the lens of doctors or service providers. Disability is considered a personal medical condition, rather than a social issue. However, the social model of disability challenges this orientation. According to the eminent disability scholars such as Vic Finkelstein, Mike Oliver and Colin Barnes, the source of a person's impairment is in her or his medical condition, but the source of disability is in society.

Jane Campbell and Mike Oliver in *Disability Politics* have traced emergence and survival of the disability movement in Britain. Scot Danforth and Susan L. Gabel have edited a volume on *Vital Questions Facing Disability Studies in Education*. David T. Mitchell and Sharon L. Snyder have edited a volume on *Disability Theory*. Alice Hall in *Disability and Modern Fiction* has examined the depiction of disability in modern fiction.

Rajesh Verma and Pragya Verma in *Disability Perspective in Rehabilitation* have examined National and International Scenario in

rehabilitation. G. N. Karna in *Disability Studies in India Retrospect's And Prospects* has significantly traced the academic development of Disability Studies in India.

In his essay, 'The Autobiographical Artist', Jai Arjun Singh provides glimpses of Ved Mehta's literary insights containing the touch of autobiographical elements. If one reads his essay thoroughly, the due focus could be found on *Face to Face* which is his first book published in 1957. It tries to describe his whole life story in very short and precise language. Maya Jaggi's article "Sight Unseen" (2001) describes that Ved Mehta's *Face to Face* is a record of his life, which contains his experiences in both India and western countries. Margalit Fox's article in The New York Times focuses on Ved Mehta's autobiography, *Face to Face* along with his other fictional and non-fictional works. In the article, "Ved Mehta: Painter of Words", Ziya Us Salam gave reference of his autobiography, '*Face to Face*' while discussing the facts of his life.

The Penguin India has written an article on 12th April, 2014 entitled "Inspirational Stories from Real Life Heroes" on four books of inspirational stories which include *No Looking Back* by Shivani Gupta and *Face to face* by Ved Mehta. It shows Shivani Gupta's *No Looking Back* is a heart touching story of Shivani's life which is full of challenges and indignities. This article again talks about Ved Mehta's *Face to Face*, an autobiography which tells a story of a man who became blind at the age of four. Other two books mentioned in this articles are *Courage Beyond Compare* by Sanjay Sharma and Medini Sharma and *This Star Won't Go Out* by Esther Grace Earl. In fact, this article brings an overview of these four books. It tries to introduce such invisible faces to the readers who may be unknown to these well-known figures.

“Lights Out- A true story of a man’s descent into blindness by L Subramani” is a book review written by Privy Trifles where she expresses her views about L. Subramani’s *Lights Out* (2014). In this article, she admires the man who fought against his disability to strive for normalcy and transform his weaknesses into greatest strengths. In her article “I am prone to mistakes too”, Sangeetha Devi Dundoo has also done critical assessment of L. Subramani’s book *Lights Out*. She has denied the notion that disabled are too weak.

Ambica Gulati glimpses on Preeti Monga’s struggle in her article “Through Your Eyes Only”. She appreciates Preeti’s hard journey of life which is described by Preeti in her two books *The Other Senses* and *Flight Without Sight*. “A Sight To Behold” is blog written by Shelvin Sebastian on Preeti Monga’s life, in which he unfolds the secret of her success that is her faith in her own abilities and hard work. S. Gokul’s article entitled “Understanding the Relations of Religion and Disability: A Study of Preeti Monga’s *The Other Senses* and Nalseema Hurzuk’s *The Incredible Story*” studies the relations of disability and religion with the help of two Indian disabled women’s life narratives such as *The Other Senses* and *The Incredible Story*. This article examines how the life narratives challenge against the stereotypical notions of the society.

In the article, “Ability Unlimited” Budhaditya Bhattacharya critically writes about Shivani Gupta’s autobiography *No Looking Back* (2014). He explains how social and material environment hinders the persons with mobility disabilities like Shivani Gupta. Binjal Shah’s “Two accidents, a wheelchair and a National award from APJ Abdul Kalam: Shivani Gupta’s heroic tale” highlights various stages and calamities in Shivani Gupta’s life.

In his research paper “One Little Finger: An Outcry for Inclusive Society” Vishal Singh brings critical analysis of Malini Chib’s autobiography *One Little Finger* (2010). Singh tries to shed light on Chib’s heroic battle against stereotypical and stigmatised notions of Indian society. Along with this, he briefly compares Indian and western attitude towards disability, which is significantly reflected in Chib’s autobiography. Ramya Kannan has appreciated Malini Chib’s arduous journey of life in her article “An Arduous Journey” (2011). She points out that it is very hard to survive in an indifference society for the people like Chib, who always struggle to live meaningful and independent life.

“Deconstructing the Medical Model of Disability: A Review of Malini Chib’s Autobiography *One Little Finger*” is a research paper written by Sharada Devi who attempts to analyse Malini Chib’s *One Little Finger* in relation to the concept of disability and its various approaches. “Activist and author Malini Chib: Yes She Can!” is an article written by DNA, which is about her life. It slightly talks her book, *One Little Finger* which has inspired to all who have read it. The Times of India has published article on Malini Chib entitled “Activist-author honoured with global cerebral palsy award”, which mainly discusses about her global Cerebral Palsy Day Award. But it has also given reference of her autobiography and its film adaptation in Hindi language. “With 2 masters & book, she’s defeated disability” is Shreya Chowdhury’s article discusses Malini Chib’s successful journey of life despite of having severe disabling condition with reference to her autobiographical book ‘*One Little Finger*’. Renu Addlakha wrote book review on Malini Chib’s *One Little Finger* in which she briefly gives some ideas about the journey of her challenging life.

Trudy Suggs' in her article "Deaf in Delhi offers Rare Perspective of Being Deaf in India" discusses the first part of Madan Vasishta's autobiography named as *Deaf in Delhi* which is a story of man who became deaf at the age of eleven. It rightly points out that due to the poverty, there is very little hope of future for the deaf people in India.

This short review of relevant literature demonstrates that the autobiographies of persons with disabilities in India have not yet been studied in the light of disability perspective.

Significance of the Present Study:

Literary theories and modes of interpretation are generally appreciative of class, race, and gender, but disability is largely ignored as category of analysis. Disability is generally considered as an abnormality or deviation, rather than a human variation, like race, sex and religion.

The autobiographies of persons with disabilities are generally read as a source of inspiration. The experiences of authors are regarded as personal and the readers sympathise with the authors and draw inspiration. However, the social, political and legal issues raised in these autobiographies are overlooked. The present study aims to analyse and interpret the authors' experience of disability from social, economic, political and psychological perspectives.

Further, understanding of disability is dominated by European and American experience and this is applied as a universal norm. However, the experience of disability in India is complicated by poverty, gender, caste and community.

The present study will take into consideration all these factors which make the experience of disability in India unique and perhaps worse.

Hypothesis of the Study:

The experience of disability in India is complicated by poverty, gender, caste and community. This experience may be unique to India. The autobiographies of the persons with disabilities narrate this unique experience. This narration is also a form of protest against the social attitude towards disability.

Aims and Objectives of the Study:

In the light of above hypothesis the aims and objectives of the present study are as follows:

- To draw theoretical framework of Disability Studies.
- To analyze the select autobiographies in the light of Indian Experience of Disability.
- To highlight inaccessibility and other social issues like discrimination and injustice against disable persons.
- To create awareness among people to remove negative attitude towards disability and persons with disabilities.

Scope and Limitations of the Study:

The present research work focuses on six autobiographies of Indian persons with disabilities to find out Indian experience of disability. It tries to discuss the various problems of persons with disabilities within Indian

context. With the help of these autobiographies, the researcher seeks to explore the social issues regarding disability.

Research Methodology:

The researcher has selected six Indian autobiographies of persons with disabilities. The theory of Indian Experience of Disability will be studied thoroughly. The historic and contemporary attitude of Indian society to disability will be studied. The available interviews of the authors will be analyzed to supplement the information available in their autobiographies. The analytical, interpretative and evaluative methods will be used for the present research work.

Chapter Scheme:

The chapter scheme of the study is as follows:

❖ Chapter I : Introduction

- Introduction
- Autobiography as a genre
- Importance of Autobiography to Understand the Experience of Disability
- Biographical Sketches of the Authors
- Review of the Relevant Literature
- Significance of the Study
- Hypothesis of the Study
- Aims and Objectives of the Study
- Scope and limitation of the Study

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- ❖ **Chapter II:** Disability Studies: A Theoretical Framework
 - ❖ **Chapter III:** Autobiographies of Visually Impaired
 - ❖ **Chapter IV:** Autobiographies of Wheelchair Users
 - ❖ **Chapter V:** Autobiography of Hearing Impaired
 - ❖ **Chapter VI:** Conclusion.

Chapter II

A Theoretical Framework

Introduction:

In the present chapter, a modest attempt is made to prepare a theoretical framework of Disability Studies which critically examines the concept of disability thoroughly. The theory of disability studies helps to understand past and present representation of disability. After formulating the theory of disability studies, this chapter focuses on Indian experience of disability which is different from western experience of disability. The main point i.e. Indian experience of disability contains other sub-points with proper explanations. It includes- disability rights movement in India, disability studies in India, the present scenario of disability in India, disability status in urban and rural India, specified categories of disability in India, rights of disabled people in India, problems of disabled people in India and experience of women with disabilities in India. The researcher has chosen six Indian autobiographies of persons with disabilities for analysis in order to study the Indian experience of disability.

Disability Rights Movement:

Disability Rights Movement was significantly influenced by the civil rights and women's rights movements which began in the United States during the 1960s and 1970s. It came into reality when the people suffering from disabilities noticed their disability in the same socio-political sense as blacks and women viewed their race and gender respectively. However, they decided to come together and fight for their own rights. Consequently, after the great contribution of various groups and their organizations in America, the Disability Rights Movement came

into existence in the 1980s. This movement always seeks to fight for equal rights and opportunities for persons with disabilities. The most popular slogan of this movement is ‘Nothing about us without us’ which is used at international level.

Disability Studies:

The evolution of disability studies as separate academic discipline began with the disability rights movement which started during the 1980s and 1990s. Just like racial studies and women studies which emerged through the civil rights movement and women rights movement respectively, disability studies also came out of the disability rights movement. After the 1970s, the world-wide growing social and political movements of disabled people have tremendously influenced the study of disability. Later on, the concept of disability was introduced in various western universities or academic institutions for teaching and doing research. Many academicians and social activists of diverse profession are attracted towards this newly emerging area of knowledge. Like gender studies and cultural studies, disability studies has also developed as a separate academic discipline in various parts of the world.

Definition of Disability Studies:

Disability studies has significantly emerged as distinct academic discipline which critically examines meaning and nature of disability. It also examines various definitions of disability proposed by various experts and scholars from different parts of the world. Along with diverse approaches to disability, it studies various types, causes and consequences of disability. G. N. Karna defines disability studies:

“as a discipline which reformulates the study of disability by perceiving the problem of disability as a social phenomenon, social

construct, metaphor and culture, thereby suggesting minority group approach to its study” (250).

According to Simi Linton:

“Disability studies takes for its subject matter not simply the variations that exist in human behavior, appearance, functioning, sensory acuity, and cognitive processing but, more crucially, the meaning we make of those variations. The field explores the critical divisions our society makes in creating the normal versus the pathological, the insider versus the outsider, or the competent citizen versus the ward of the state. It is an interdisciplinary field based on a sociopolitical analysis of disability and informed both by the knowledge base and methodologies used in the traditional liberal arts, and by conceptualizations and approaches developed in areas of the new scholarship. Disability studies has emerged as a logical base for examination of the construction and the initiatives undertaken by the disability rights movement have resulted in new paradigms used to understand disability as a social, political, and cultural phenomenon” (02).

The above definitions show that disability studies explains the changing dimensions of social attitude towards disability through the different historical periods. It primarily offers an in-depth explanation of treatment which is given by the society to disabled people from past and present years. In other words, its main task is to observe historical as well as contemporary scenario of disability. It widely focuses on a social, political, cultural and historical representation of disability. Most

importantly, it also focuses on intersectional or interdisciplinary study of disability.

Disability has historically been conceptualized as biological or individual problem, but after recasting the disability as civil rights issue, disability studies, a new academic discipline, has reframed the concept of disability in a social relationship or context. According to Rosemarie Garland-Thomson, “Disability studies views the condition of having a disability as a social relationship characterized by discrimination and oppression rather than as a personal misfortune or individual inadequacy” (01). The social approach to disability is central to the field of disability studies. It states that the main source of disability is rooted in society, but not in medical condition of particular individual. It means, the problem of disability does not reside in individual’s medical condition, but it resides in social disabling environment that restricts individuals with impairments from full integration in society. Disability studies thinks that individual’s impairment is universal human condition that may not be avoided all the time. Hence, it should be accepted as a part of human variation.

Feminist Disability Studies:

The ethnicity, race, class and caste have extensively been studied, but the concept of disability is omitted in the realm of feminism. Hence, feminist disability studies significantly concentrates on the relationship between feminism and disability. It arises through the notion of disabled women’s exclusion in the women’s movement. Needless to say that feminism always talks about the objectification of female body and conventional roles of women, but women with disabilities have been excluded from the feminist agenda. Renu Addlakha explicates, “While

the invisibility of women with disabilities in the male dominated disability movement is, to some extent, understandable, their absence from the women's movement cannot be so easily overlooked" (223). It shows that omission of disability from the theory of feminism is not acceptable. Hence, the feminist disability studies tries to focus on this issue. According to Rosemarie Garland-Thomas, "Feminist Disability Studies also seeks to correct traditional feminism, which sometimes ignores, misrepresents, or conflict with disabilities" (05).

It is well-known fact that in the patriarchal society, women with disabilities are more oppressed than normal women. They face double discrimination of being women and disabled. Generally, women in such society perform conventional roles like managing household chores and taking care of children and family. But women with disabilities are considered as incapable of performing these roles. Furthermore, such women are considered as physically unattractive and sexually undesirable. This is because their physical appearance may not fit in the cultural idea of beautiful body. Hence such women are often rejected in the marriage proposals on the basis of their disabilities. Due to such traditional expectations, they remain isolated for lifetime. Rosemarie Garland-Thomason rightly points out that "Feminist Disability Studies emphasizes changing public policy and cultural institutions rather than viewing the problems of disabled women as residing in their own supposedly inferior bodies" (05). Just as social approach states that disability resides in social structure, but not in person's biological condition, the feminist disability studies steps forward with the same impression that the issues regarding disabled women reside in cultural institutions instead of inferior bodies of disabled women. The feminists usually talk against the female foeticide, but the use of genetic screening

technology for aborting foetuses with abnormalities is not discussed in their female foetuses debate.

The Concept of Disability:

Disability is an indispensable part of human experience because it is quite natural phenomenon. Like diverse colors, genders and heights of people, it is also one of the parts of human diversity which cannot be separated from human beings. In fact, diversity is found everywhere in nature. For instance: one can find it within trees, flowers, fruits, birds and animals, although it may or may not be noticed. However, it can rightly be said that like other living beings, “heterogeneity among the human beings in various sphere is also normal” (Malkar & Sarker, 88). But the people may never think about that with this perspective. So they always hesitate to accept such heterogeneity or diversity among human beings.

The divergence is also found within disability because it includes various categories. One can find that some disabilities are visible and some of them are invisible. Its causes and effects are also different because some disabilities are congenital and many of them are acquired later in life. Likewise, “some disabilities are static while others are progressive” (Karna, 33) in nature. Diversity is also seen among the persons with disabilities because each person with disability may suffer from different disability. Such persons with different disabilities are found all over the world. Most importantly, divergence among persons with disabilities is also dependent upon the severity of each impairment. One can find that the degree or severity of each impairment varies from person to person, although some persons suffer from the same disability. Thereby “some people with impairment of mobility can commute in certain situations, whereas others cannot” (Karna, 33). In short,

divergence within disability and persons with disabilities depends upon the category and severity of individual's impairment.

Disability is an unpredictable thing because it can affect anybody, at any time or any stage of his/her life. In fact, it is present everywhere in the world. So it is true to say that this is not just problem of one country but of the whole world. In this context, Peter Coleridge says, "Disability is an issue that touches us all. It is not only, or even mainly, associated with poverty: disability can affect anybody of any background, in any country at any time" (06). It shows that having any kind of disability is a fact of human existence. It was present in past, is seen in present and will remain in future. Even though some disabilities are preventable by taking precautions and proper care, it is impossible to eliminate it completely from the social milieu. According to Karna, "human life has ever been marred by the ravages of natural disasters, hereditary as well as birth defects and accidents—causing disability of one sort or the other to many people" (Karna, 68). It means that there are various factors related with human life. So it is difficult to avoid the influence of disability every time.

It is said that unlike other categories involving gender, religion, race, caste, creed and color, disability is a fluid concept because it involves many multifaceted aspects. For instance, some disabilities are inherent and some of them are accidental or acquired later on with aging. In fact, some disabilities appear sporadically, others are constant in nature and some of them are life-long. In addition to that some disabilities are visible whereas others are hidden or invisible. Here Alice Hall rightly clears that "a person can become disabled suddenly, temporarily, and at any time in their lives. Disabilities can be invisible and most disabilities are acquired over the course of a lifetime rather than from birth" (06).

Most importantly, some disabilities can be controlled or cured by proper medical treatment, but many of them remain lifetime.

Definitions of Disability:

Disability is a complex term because it has multifaceted aspects. Although it is difficult to define, many scholars seek to define it in their own ways. Mamata Rao defines:

“Disability is the disadvantage or restriction of activity caused by a society which takes little or no account of people who have impairments and thus excludes them from mainstream activities” (173).

According to Merriam Webster Dictionary, disability is

“a physical, mental, cognitive, or developmental condition that impairs, interferes with, or limits a person’s ability to engage in certain tasks or actions or participate in typical daily activities and interactions” (<https://www.merriam-webster.com>>).

Disability Discrimination Act (DDA) 1995 defines person with disability as

“a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities” (01).

The above definitions show that disability is physical, mental, intellectual or developmental condition that makes more difficult for person to perform certain activities. In other words, it is a condition in

which person cannot cope up with other non-disabled person while doing something due to his /her physical or mental limitations.

Sometimes the terms ‘impairment’ and ‘handicap’ are interchangeably used for ‘disability’, but these terms have different meanings. An international classification of impairment, disability and handicap has been made by the World Health Organization (WHO) in 1980 to differentiate the meanings of these three terms.

Impairment: It means “any loss or abnormality of psychological, physiological or anatomical structure or function” (47).

Disability: It is “any restriction or lack (restricting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being” (143).

Handicap: It is a “disadvantage for a given individual, resulting from an impairment or disability, which limits or prevents the fulfilment of the role that is normal (depending on age, sex and social and cultural factors), for that individual” (183).

The above definitions show that impairment is defective biological structure. Disability is an interaction between impaired person and disabling social environment. And handicap is the result of both person’s impairment and disability. For instance: If a person has walking impairment, it directly affects person’s mobility power. Due to the disabling social environment, he/she cannot participate in mainstream society. As a result, he/she cannot avail the same things like others.

Approaches to Disability:

Many international scholars and bodies have tried to define the concept of disability, but there is no single definition which carries the

whole sense of disability. The reason behind that it has undergone considerable changes and modifications due to its heterogeneous nature. Subsequently, many approaches to disability have also been developed with new frameworks of how society views disability.

1. Religious Approach to Disability:

Religious approach is the oldest approach to disability. According to this approach, there are many religious causes significantly related to disability. Indeed, each religion has perceived the fact of disability in different way. One can find that no single religious text has sought to define it with scientific and broad manners. The Hindu doctrine of Karma Phala also reveals the Indian ideology of disability which mainly states that “disability is sought to be linked with the retribution for the sins committed by individuals in the past” (Karna, 71). It means, having any kind of disability is considered as God’s punishment for sin or crime that may have committed by either individuals or their parents or ancestors in the present or previous birth. Along with this, another prevalent cause of disability especially in Indian society is that having a lack of faith in God. The contemporary scholars and experts have rejected this approach to disability considering disability is not curse or punishment from God.

2. Medical Approach to Disability:

After the mid-18th century, the religious approach to disability was gradually replaced by the medical approach to disability. The medical approach to disability primarily refused the theological ideas of religious approach. Since the drastic change in the field of medical science, disability has been considered as nothing else but medical issue. Hence, this approach mainly thinks that disability as a defect within the individual. It means that the person himself/herself is responsible for

his/her inability to participate in society because of his/her biological condition or health problem which can be cured or eliminated completely by proper medical treatment or surgery. Therefore, it is prime responsibility of medical science to diagnose the defect within individual and give proper treatment accordingly. Briefly stated, the main objective of this approach is to make the disabled persons able or normal as soon as possible by providing them required medical treatment. However, the limitation of this approach is that it fails to support the persons who have severe or permanent impairments which may not be cured by any treatment. However, it is right to say that the persons with severe or permanent impairments get failure in this system. Additionally, this approach does not take into account the social attitude towards disability which is the main cause of exclusion of persons with disabilities from all spheres of life.

Most important thing is to be noted that this approach asserts disability as a ‘personal problem or tragedy’ rather than social responsibility. So it is also referred as the ‘personal tragedy’ approach of disability. It is considered as personal tragedy because this approach thinks disability “as a deficit residing in the individual; they refused to see disability as a pathology or to treat it as a problem that is necessarily in need of cure, rehabilitation or concealment” (Hall, 21). In this view, the role of persons with disabilities remains passive recipients of medical care rather than active participants of society. This approach implies charity approach to disability considering disabled people as needy and requiring welfare measures. Briefly stated, this model does not adequately capture the phenomenon of disability.

3. Social Approach to Disability:

The phrase ‘social approach to disability’ is coined by Michael Oliver, a British disability rights activist in 1983. This social approach to disability shows its reaction against medical approach to disability which tries to explain the problem of disability through the lens of medical science. After the emergence of this approach, the issue of disability has been seen as social problem rather than medical or individual problem. According to this model, disability comes after impaired person’s interaction with disabling environment. In this context, Insa Klasing explicates “disabling environments prevent the participation of disabled people in all walks of life due to badly designed buildings or inaccessible transport” (32). It shows that disabled people are physically disabled, but the society makes them more disabled by not providing them proper resources.

Along with this, negative attitude of the society also tends to exclude them from various mainstream activities. Klasing further elaborates that “Life is made difficult not so much by the individual’s medical condition, but mainly by a hostile physical and social environment which excludes disabled people from all spheres of village life” (30). It means that persons with disabilities suffer more from social disabling condition than their medical condition. Indeed, it is not possible to avoid the influence of disability every time, but the society can remove attitudinal and environmental barriers that exclude disabled people from all spheres of life. The limitation of this approach is that it excludes the issues of cognitive impairments like Autism or learning disabilities. In short, this approach only correlates social environments with individual’s physical impairments without considering cognitive disabilities.

4. Human Rights Based Approach to Disability:

In the last few decades, there has been a rapid expansion in legal conceptions. Since then, the facts of human life are significantly scrutinized through the legal aspects. Hence, the phenomena of disability is also seen with the lens of legal perspective. As a consequence, human rights-based approach of disability came into reality. This approach predominantly deals with the human rights of disabled people. The persons with disabilities are entitled to the same rights enjoyed by non-disabled citizens. The Americans with Disabilities Act has first time put forward this approach to disability in 1990. This approach is an improvement over the social model of disability, which sees disability as human rights issue. Like non-disabled people, disabled people have also right to enjoy civil and political as well as economic, social, and cultural rights in order to live life with dignified manner. David Johnstone describes:

“It has only been in recent years that the discourse around disability has turned to a consideration of human rights. Human rights, in their turn, have been influence by the growing strength of the disability movement and the emerging self-confidence of disabled people. A rights-based discourse spreads the dimensions of disablement to include civil, political, economic, social, cultural and environmental obligations” (23).

This approach focuses on the empowerment of disabled people rather than providing charity or welfare measures to them. In short, this approach views disabled people as subjects, not as objects.

Thus, these four predominant approaches have been adopted to describe the phenomenon of disability. They bring some changes within the perceptions of disability framework. Briefly stated, they represent some different observations and try to describe disability within a specific system, time and culture.

Nature of Disability:

As discussed earlier, disability is physical, mental, intellectual and sensory impairment. It may be permanent or temporary in nature. Likewise, there are diverse categories of disability in which some disabilities are curable and some of them are incurable in nature. Likewise, permanent disabilities cannot be cured by medicines, therapies or surgeries. For instance: some disabilities like blindness, deafness or dumbness may not be cured by any treatment. Whereas temporary disabilities like broken limbs can be cured by proper medical treatments like medicine therapies and surgeries.

Types of Disability:

Visible disability and invisible disability are the two types of disability.

1. Visible Disabilities:

Visible disabilities cannot be hidden because they are obvious to others. Hence, one can easily identify a person whether he/she is disabled or not by his/her physical appearance. For instance: the person who has walking impairment can be easily identify by others at first sight.

2. Invisible Disabilities:

Invisible disabilities are not immediately obvious to others. Hence, they have also been called as hidden disabilities. For instance: disabilities like deafness and dumbness are considered as invisible disabilities because it is very difficult to recognize a person who suffer from such disabilities by his/her appearance at first glance.

Some disabilities like mental disabilities are invisible to others but its symptoms are visible which are usually reflected through the behavior of person who suffer from such type of disabilities.

Causes of Disabilities:

There are two main causes of disability: natural causes of disability and man-made causes.

1. Natural Causes of Disability:

The old age is considered as one of the natural causes of disability. It is a natural process which may come in every human beings life if s/he lives long life. Such old age people have their own problems. They go through the various old age ailments including diabetes, deafness, cataract, rheumatics, asthma, weakness, dental problem, walking problem and unstable mental state. Such type of ailments badly affect their power of mobility which is required to work independently. Along with old age, various diseases are also the causes of disability. Some diseases come for short time but their impacts may remain for long time or permanent. For instance: leprosy cured person generally suffers from extreme physical deformities. Hence, its impact remain permanent, although it seems to be cured.

Consanguinity is also one of the main causes of disability, which reduces genetic variations in a group which may significantly protect

against the expression of recessive genes that can lead to congenital or genetic disorders. Some disabilities like Down Syndrome come naturally because they are inherited. The natural disasters including earthquake, fire, tsunami, famine, storm and landslide are also natural causes of disability. Such natural calamities often occur in various parts of the world by which many people are killed, but most of them are severely injured and become disabled permanently.

2. Man Made Causes of Disability:

Poverty and disability go hand in hand because both are cause and consequence of each other. Due to poverty, it is very difficult for people to get proper nutrition and physical care which may give rise to many disabilities. The most important thing is that most of disabilities are preventable if the poverty is reduced. Malnutrition is closely associated with poverty, which causes certain disabling conditions. Illiteracy about the proper knowledge of physical care also causes many disabilities. Another man-made reason of disability is road accidents.

People can be severely injured and become disabled in wars and civil conflicts. There are many chances of bomb attacking in wars. Along with wars, many people become disabled due to the civil conflicts. Especially, in India people from different communities, castes, creeds, and religions live together. There can be some disputes among them on various issues that may lead to civil conflicts.

Now a day's technology is an inseparable part of human life that makes the things easy. But, excessive use of technology may be harmful for health. For instance: constant use of mobile creates a lot of vision problems among people. DJ is a device that produces a lot of noise which can weaken the hearing capacity. Industrialization is also important cause

of disability because it increases pollution which may lead to the numerous health issues.

The Experience of Disability:

Disability is an inescapable part of human diversity which is found in every corner of the world. Although it is a global reality, the experience of disability varies from person to person, society to society, place to place, country to country and culture to culture. The reason behind that every individual with disability has different family background which may lead to different experience. For instance: some disabled people belong to rich families, but many of them have poor family background. The family members of all disabled individuals may be supportive. But many of them receive little or no assistance from their family.

The experience of disability varies from society to society as well. It depends upon what type of treatment society gives to its disabled people. It also varies from country to country because each country has different social and cultural background. In addition to that the experience of disabled people who live in developed countries is also different from those who live in developing countries in terms of getting resources. For instance: along with all the other problems, the problem of accessibility is severely faced by the people living with disabilities in developing countries. Even this experience can be different in country itself. For instance: the experience of disabled people who live in rural areas is different from their urban counterparts. In fact, “the experience of disability today in any country is likely to be very different from the experience of disability in that country a hundred years ago” (Klasing,

38). During the last few decades, each country has been trying to ameliorate the condition of their disabled population.

Another important thing is that every individual with distinct disability has to face different challenges and problems in their lives. For instance: in the case of education, the problems faced by visually impaired persons are different from wheelchair users. Their experience pertaining to education is completely different. Just as, inaccessible reading materials create obstacle in the way of persons with visual impairments whereas inaccessible school buildings are big hindrances in the way of all wheelchair users. Even if, their experience of disability is different from each other, they have to undergo the same sufferings of exclusion from the regular schools. Indeed, each person with different disability has to acquire different kind of skills and techniques to tackle the various situations of their life.

Western Experiences of Disability:

The ideas of bodily perfection in ancient times are reflected through the mythical stories of that period. The well-known story in Greek mythology tells that:

“The only physically flawed God in the Greek pantheon was Hephaestus who was born lame to Zeus and Hera. Hera practiced a form of infanticide by ‘casting him out of heaven’ whereupon he was rescued by Aphrodite, the Goddess of Love” (Karna, 69).

The above description reminds that body should be in perfect form. If one can lose bodily perfection, he/she has to face the harsh reality of life like Hephaestus.

Christian ideology is generally considered as cornerstone of western civilization. In spite of that, it speaks out against disability and disabled persons. It separates body and spirit from each other assuming that “The body is, however, meant to house the spirit, so that we are supposed to be consider our bodies as a temple that must be sanctified” (Karna, 69). As per the Christian belief system, the occurrences of diseases are not treated as natural but as moral failure or imperfection.

Even in the holy Bible, there are numerous allusions to the images of disability which represent disability as an evil. The Old Testament reveals that “blindness, leprosy and other disabling diseases are punishment for blasphemous behavior” (Karna, 71). The New Testament also links disability with sin which can be forgiven by God. Hence, many churches in the modern society are opened to get rid of that sin. In the middle ages, the grotesque ideas about disability were significant. During that age, disabled people were associated with the court jesters as well as the Christian fools which were used for the purpose of entertainment.

After that, freak shows were prevalent in European and American cultures. Disabled people were the professional performers of freak show in which exotic or deformed humans as well as animals were exhibited for public amusement. Due to the problem of their education and employment, their families also sent them to participate in that show to earn money. Although, freak show was a commercial and profitable business for their employers, its main purpose was to amuse or entertain the audiences. The people used to attend such shows to see the varieties of freaks with curiosity. In short, it was a big business of “presenting human oddities for amusement and profit” (Bogdon, 510). In reality, the freaks were misused under the name of profit and amusement because the presentation of such shows was always exaggerated with extraordinary

physical abnormalities in order to attract huge audiences. But that led to create negative impact of freaks identity which was misrepresented in front of world. Therefore, the people also saw them as an object of amusement but nothing more than that.

Even though, freak show was very popular in European and American culture for many centuries, it was ended in the early 20th century after the medicalization of human abnormalities. Gradually, the people in western countries like USA, UK and Canada also began to accept human abnormalities as a part of human diversity. So, the present experience of disability in western countries is better than India because most of things are accessible for persons with disabilities.

Indian Experience of Disability:

One can find that the present understanding of disability in India is dominated by European and American experience of disability. This experience is applied as a universal norm. The present research work seeks to understand the unique experience of disability in India because Indian experience of disability is complicated by poverty, gender, caste and community. Another fact is that India is one of the developing countries where people with disabilities get limited resources, facilities and opportunities. So, it is obvious that the experience of disability in India is different as compare to developed countries like USA, UK and European countries where they get adequate resources and facilities to lead normal life. Even though "...no country in the world has solved the problem of integrating all its disabled citizens into active social and economic life" (Sugaritha and Madeswaran, 2), the condition of persons with disabilities in developed country may be much better than developing countries.

Disability Rights Movement in India:

After the establishment of disability rights movement in America in the 1980s, the whole world became aware about the rights of persons with disabilities. The evolution of this movement in India can be traced back in the early part of 1990s. It emerged after the people suffering from disabilities started demanding their rights. There were various groups and the organizations from different parts of country supporting them. As a result, three legislations that are- Rehabilitation Council of India Act of 1992, Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act of 1995 and National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability Act of 1999 were subsequently enacted by the government of India for persons with disabilities. After that, Indian government adopted the United Nations Convention on the Rights of Persons with Disabilities in 2007. Then the government came up with the new act i.e. the Rights of Persons with Disabilities in 2016.

Disability Studies in India:

After the success of disability rights movement, several universities and academic institutions in various countries have given scope for the researchers to work on this newly emerging field. For the last five decades, many researchers from diverse professions have been studying the multiple aspects of disability all over the world. But the fact is that the field of disability studies is unfortunately ignored in the curriculum of universities and academic institutions in India. So far, very few Indian researchers from humanities, social sciences and other disciplines have been attracted to this topic. As far as literature is concerned, there is very

little research which has been done on disability as compare to other branches of humanities and social sciences.

Historical Representation of Disability in India:

Even though, the experience of disability varies from country to country, the history of disability in India somewhat resembles western history. Bhat states “during a ‘pre-historic’ time, many tribes killed off people who were deemed physically unfit to survive in the world” (Anand, 43). In traditional societies, there was a religious meaning attached to the occurrence of disability. It is said that occurrence of any kind of impairment was considered god’s punishment for one’s sin in the previous or present life.

According to Karma theory “Disability was considered the result of ‘wrong actions’ in one’s past life or the present one’ (Anand, 44). Such type of views regarding disability are still prevalent in Indian society. In reality, the Karma theory deprives disabled people from their inherent rights to lead independent life. During the medieval period, disability had been linked with supernatural factors. In the modern era, many supernatural and superstitious beliefs were gradually replaced by rational and secular thinking of people due to progress in medical science and later on the social approach has been linked to disability. Likewise, in the postmodern era, the issue of disability relates to the human rights approach.

The historical representation of disability in India is significantly reflected through the fictional characters with disabilities depicted by the authors in their literary work of arts. The disabled characters are represented in negative manners by some authors. They mostly appeared as evil, weak, ugly, fool, exotic and abnormal by nature. In this context,

Anita Ghai argues: “in the epics Mahabharata and Ramayana, many characters with disabilities are presented in a negative light” (Anand, 44-45). For instance: Dhritrashtra, the blind king of Kuru Kingdom in Mahabharata, who had been deprived of his throne on the account of his blindness. Even though he was eldest son, his younger brother Pandu was made the king. The characters Shakuni, an orthopedically disabled, in Mahabharata and Manthara, a dwarf woman in Ramayana are also represented negatively.

The Present Scenario in India:

Although the situation of persons with disabilities has finally begun to change, the history witnesses that having a disability meant something much worse and socially outcaste. Due to the global concern of disability, the United Nations has formulated many schemes and policies for the betterment of persons with disabilities. As a part of signatory of United Nations, Indian government also has come forward with the range of policies to ameliorate their condition. Even if they are still facing the enormous problems in their path, the significant progress has been continuously occurring in their lives due to some anti-discriminatory laws that can increase their participation in society.

The change in the situation of disabled people is gradually reflecting through the recent terminologies used for disabled people as ‘disabled’, ‘persons with disabilities’, ‘differently abled’ and ‘persons with special needs’ instead of ‘crippled’, ‘handicap’ or ‘defective’. Thus, many abusive and objectionable words from colloquial language are replaced by sophisticated verbal expressions. In the present scenario, persons with disabilities are viewed as persons with a wide range of abilities. Despite their abnormalities, they are also human beings with all

social, economic, emotional, physical, political, intellectual and cultural needs with other non-disabled people.

Disability Status in Urban and Rural India:

To understand the Indian experience of disability, it is necessary to focus on rural areas “Because disabled people in rural India are a silent and invisible group in spite of their significant numbers” (Klasing, 26). It is estimated that about 80 percent of total Indian disabled population lives in rural area, whereas remaining 20 percent live in urban area. Actually, there is huge gulf between the population of disabled who live in rural and urban areas. Needless to say that the condition of disabled people in urban areas is better than disabled people in rural areas. Even today the basic facilities are beyond the reach for those disabled people who live in urban India. Hence, they are often deprived of their basic rights.

In particular, each person wants to be independent in life. The people with disabilities have also the most common desire to do everything independently as other non-disabled people. But it never happens in the case of persons with disabilities due to their functional limitations. In reality, they feel humiliated by the sense of dependency even doing the simplest daily activities like walking, bathing or eating. Their dependency can be mitigated significantly by providing them proper education, employment, assistive devices and medical assistance. But, it is beyond the reach for those people with disabilities who live in rural India.

There is need to provide them various benefits such as education facilities, medical facilities, accommodation facilities, rehabilitation facilities, self-employment policy, pension schemes, reservation in education and employment for their welfare. Now-a-days the

Government, NGO's and other private institutes try to provide them these facilities but the rate of beneficiaries is very low because disabled people in rural area may not be aware about these schemes.

Specified Categories of Disability in India:

The entire magnitude of disability in India can be enormous. India has largest population of disabled people possibly after China. The National Sample Survey (NSS) of India conducted 76th round survey program on disability during July to December, 2018. It is estimated that 2.2 per cent which means around 30 million people of total population are disabled in India. It has been considered all the specified categories of disability stated in the Rights of Persons with Disabilities Act of 2016.

There are various categories of disability by which the persons with disabilities come under the protection of concern laws. The Persons with Disabilities Act of 1995 has listed seven categories of disability including "Blindness, Low-vision, Leprosy (cured), Hearing impairment, Locomotors disability, Mental retardation and Mental illness" (Singh and Mehmi, 12). Meanwhile, there was growing public awareness of some more disabilities. The Rights of Persons with Disabilities Act of 2016 classifies twenty-one disabilities including above seven. These twenty-one disabilities comprise in five main categories. They are as follows:

1. Physical disability:

Physical disabilities limit the person's functioning, mobility, dexterity and stamina while doing something. It includes four major categories of disability: locomotor disability, visual impairment, hearing impairment and speech and language disability.

A. Locomotor disability:

In this type of disabilities, it is very difficult for person to move from one place to another due to the afflictions of musculoskeletal or nervous system. It includes ‘Leprosy cured person’, ‘Cerebral palsy’, ‘Dwarfism’, ‘Muscular Dystrophy’ and ‘Acid attack victims’.

B. Visual impairment:

It includes person who cannot see at all or has blurred vision even with the help of spectacles. But person who has proper vision in one eye will not be treated as ‘visually impaired’.

C. Hearing impairment:

As a person of this category cannot hear anything or can hear only loud sound, he/she will be considered as hearing impaired. In other words, person of this category suffers from ‘deafness’ or ‘hard of hearing’. Along with visual impairment, hearing impairment is also included in the category of sensory disabilities.

D. Speech and Language Disability:

“Speech and language” disability comes due to the organic or neurological condition. A dumb person is included in this category. Similarly, a person will be considered as having speech disability, if his/her speech is not understood by the listeners of normal comprehensive and hearing condition.

2. Intellectual disability:

It is a condition in which persons of below average intelligence or mental ability are included. It includes both ‘specific learning disabilities’ and ‘autism spectrum disorder’. The conditions of dyslexia, dysgraphia,

dyscalculia, dyspraxia and developmental aphasia are included in learning disabilities.

3. Mental disabilities:

Mental disabilities are also known as ‘mental illnesses’ or ‘mental disorders’ in which a person has abnormal thoughts, emotions, behaviors, perceptions and relationships with others. If someone lacks comprehension appropriate to his/her age, he/she will be called as ‘mentally disabled’ or ‘mentally retarded’. Depression, bipolar disorder, schizophrenia, dementia are the causes of mental disabilities.

4. Other disabilities:

It includes two types of conditions such as chronic neurological conditions and blood disorder.

A. Chronic Neurological Condition:

It includes ‘multiple sclerosis’ and ‘parkinson's disease’. These two categories are associated with nervous system of person. In multiple sclerosis, person’s nerve cells in the brain and spinal cord are seriously damaged. Parkinson’s disability is a progressive disease that affects the central nervous system of person. It creates cardinal symptoms like muscular rigidity, tremor, slowness of movement and postural instability.

B. Blood Disorder:

It comprises three categories of disability such as ‘Haemophilia’, ‘Thalassemia’, and ‘Sickle cell disease’. ‘Haemophilia’ means the loss of normal ability of blood clotting which may cause fatal bleeding. ‘Thalassemia’ results an excessive destruction of red blood cells and hemoglobin in which transport of oxygen from the lungs to other parts of

the body is hampered. 'Sickle cell disease' is a hemolytic disorder caused by the destruction of red blood cells.

5. Multiple Disabilities:

In the category of multiple disabilities, the person suffers from more than one of the above stated disabilities. For instance: If the person has hearing impairment, he cannot develop his speaking ability. It affects his overall communicative and developmental activities.

Human rights of persons with disabilities in India:

The human history shows that from the man's first existence in this universe till the 20th century, there was no provision for persons with disabilities. But first time in the human history various provisions are made for them at international and national levels after the second half of the 20th century. Actually, these provisions have originated from the needs of people who became severely disabled in World War II.

Although Indian constitution has not made specific provisions for persons with disabilities, Article 14 mainly talks about that each person is equal before the law. However, the principle 'everyone is equal before the law' applies to the persons with disabilities like others because they are also human beings. Therefore, it is completely barred to discriminate or exclude someone on the ground of disability. They have the same rights that other people enjoy. Despite that they need some special rights for their overall developments. However, like other nations, Indian government has subsequently made some separate provisions to remove the barriers in their ways.

1. The Mental Health Act of 1987:

The aim of this act is to protect the rights of persons who suffer from mental illness. It directs Central and State Authorities to provide mental health facilities and services for them. To regulate their mental illness, they have to be admitted at Psychiatric hospitals or nursing homes. The presence of these persons may be dangerous for the society. However, it is necessary to protect society from the presence of such persons. Another most important thing is that it is illegal and unconstitutional to send non-criminal mentally ill persons to jail.

2. The Rehabilitation Council Act of India (RCI) of 1992:

Its main focus is to provide rehabilitation facilities for persons with disabilities. It includes training for their encouragement and motivation. It also promotes the research in rehabilitation field.

3. The Persons with Disability Act of 1995:

The Persons with Disabilities (Equal Opportunities Protection of Rights and Full Participation) Act, 1995 was passed by Parliament in December, 1995 and came into force on February 7, 1996. The prime objective of this legislation is to provide barrier free environment which helps to stop any kind of discrimination against the persons with disabilities and integrate them into mainstream society. It enacts the rights of disabled in relation to their education, employment, non-discrimination, and social security.

4. National Trust Act of 1999:

National Trust Act is also known as National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act of 1999. This act endeavors to take care of the persons

with the categories of Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities. This act mandates to arrange the welfare programs for them.

5. National Policy for Persons with Disabilities (2006):

It was formulated when it was realized that persons with disabilities are also valuable human resources of country like other citizens. This is mainly focused on rehabilitation of persons with disabilities. Along with this, it also focuses on barrier free environment, social security, and research.

6. Rights of Persons with Disabilities Act of 2016:

The RPWD act has identified twenty-one different types of disability including earlier seven that are mentioned in Persons with disabilities Act of 1995. Its main focus is on the provision of accessibility for persons with disabilities.

Even after so many provisions by the Indian government, disabled people especially in rural India are facing enormous problems. This is because such provisions are only seen on the papers, but the proper implementation is not done by the government.

Various Problems Faced by Persons with Disabilities in India:

In India, the persons with disabilities are most disadvantaged or socially marginalized group of people who do not have access to the basic social services and resources. Hence, they have to face enormous problems regarding education, employment, transportation system, rehabilitation and many more to survive in this condition. All their problems regarding their disability are interlinked with each other. For instance: due to the inaccessible school buildings and materials, persons

with disabilities are deprived of education and without acquiring proper education they cannot get employment. However, to understand the experiences of persons with disabilities in India, it is necessary to study their problems. Those problems are given below:

1. Education:

As far as education is concerned, the ratio of students with disabilities in India is very low as compare to non-disabled students. If the students with disabilities want to take education, a lot of obstacles come in their ways. Mostly, their parents think that giving education to disabled child is a waste of time, money and energy because there is no “point of investing in education for a child who is “not normal” (Klasing, 31). Sometimes, they cannot afford to send their child in school because they have other expenditures of that child including frequent and expensive medical treatments like surgeries and therapies. Furthermore, such children require special aids and appliances to perform their daily tasks and the cost of these instruments are very high. Another thing is that each disabled child may not belong to the rich family. In some cases, those who are disabled but rich may not have a big problem in accessing education, whereas those who are disabled but poor may suffer a lot even to get basic education. Likewise, it is not possible for each disabled child to get education in special schools. If they are admitted in the mainstream schools, they face a lot of problems because such schools are very poor in case of accessibility.

Generally, the ramps or elevators are absent in regular schools. Furthermore, toilets are also not accessible for them. The entrances of doors are mostly narrow. Hence, it is very problematic for those children who have physical disability. Most unfortunate thing is that these schools do not show any kind of interest to modify the infrastructure. In the case

of others students who have hearing, seeing or learning impairments, there are no special teachers and teaching aids to facilitate the problems of their learning. Klasing also says that "...children who were mentally slow, or speech and hearing impaired, or blind, felt isolated and marginalized in the course of teaching" (12). It is true to say that the mainstream schools never fulfil the needs of disabled students as per their requirements. Hence, such students always feel isolated in such schools. Briefly stated, in the absence of supportive equipment, trained teachers and educational settings make children with disabilities lag behind other normal children. As a result, they do not realize their full potential.

Thus, the students with disabilities need accessible school environment. Along with this, they need accessible school materials and facilities including teaching curriculum, textbooks and computers. They need special teachers and appliances for learning too. But the mainstream schools are unable to provide these things to them. However, they need to take the help of special schools where they can get individual support, barrier free environment, trained teachers and necessary equipment. But, such special schools are mostly located in urban areas and majority of disabled population live in urban areas in India. The people in rural area are unaware about such special schools. But the special schools sometimes refuse to admit the students with extensive physical disabilities.

2. Employment:

Unemployment is a big obstacle in the way of persons with disabilities because there are limited job opportunities available for them. Indian Government's the Persons with Disability Act of 1995 guarantees three percent of job opportunities for them in public and private sectors. Only having such kind of reservation in job opportunities is not enough.

But they need barrier free environment at their workplace, which enables them to work equally with non-disabled people. Even today, very few buildings and premises are accessible for them in India. For instance: most of buildings have number of floors without lifts and ramps that they can use. But they have to take help of others to carry them up from one floor to another. The entrances of such buildings and toilets are very small in which wheelchair users cannot enter. Besides that toilets have no bars that are essential to hold on them for stability. Mostly, the people with mobility disabilities face the problems of moving in such type of inaccessible buildings and premises.

The first and foremost reason of their exclusion in the placement is that employers have some prejudices and misperceptions against them. However, the employers may think that such persons are incapable or have no potential to manage work. Hence, they are always reluctant to employ them at the workplace. The fact is that the employers have no right to discriminate against persons with disabilities on the basis of physical abnormalities during the process of their placement. In fact, physical restrictions can be mitigated by making suitable modification in environment at workplace.

3. Transportation:

The poor accessibility in transportation system stops people with mobility impairment to go out of their homes. One can find that various platforms, roads, buses, trains, airports and places are still inaccessible in India, so that it is very difficult for them to travel or reach at their workplace. Sugirtha and Madeswaran also illustrate that “The transportation problem is one of the major issues facing the disabled.

Without a customized transportation system, many disabled who will otherwise be able to join workforce will be confined to their homes” (05).

Especially, persons with mobility disabilities always suffer on the account of inaccessible transportation system. For instance: public service vehicles do not have wide entrances for the wheelchair users. They are built with staircases at the entrance, so that wheelchair users cannot enter or exit without help of others. The public service operators probably think that waiting for wheelchair user while entering and getting off the bus is also wasting of their time. Persons with mobility impairment are often abused and mistreated by both operators and public as well. In some cases, the priorities are not given to the persons with disabilities, even though many seats are reserved for them. In a rush, they can be shoved aside by able-bodied people who may sometimes ignore the presence of disabled person. The reality is that all wheelchair users’ economic condition may not be good, so that it is not affordable for all of them to travel in private vehicles all the times.

Now a day’s both public and private transportation is completely inaccessible for visually impaired person. Pedestrian paths are not available everywhere for them. Even crossing the roads is very difficult thing because there is no arrangement of sound system while indicating the signal through lights. In such situation, it is impossible to understand when they have to stop and cross the roads. It short, mainstream facilities are not designed on the basis of inclusion but exclusion of disabled people.

4. Accessibility:

The word ‘accessibility’ means approachability of anything that person wants to achieve without encountering barriers. The Cambridge

Dictionary defines accessibility as “the fact of being able to be reached or obtained easily”. It shows that accessibility brings necessary benefits to all its users. Although the general meaning of this word refers to the access of services or other things that can be used by everyone, it is often used to describe facilities or services that assist persons with disabilities because most of the things or places are inaccessible to them while they are accessible to persons without disabilities. The fact is that their needs are not taken into consideration while building or developing things for others. As a result, they cannot participate fully or equally in the mainstream society with other people.

India is very poor in the case of providing accessibility to its disabled population. Hence, disabled people in India are always confronted with various problems due to the lack of physical accessibility. It prevents them from participating fully in social activities like non-disabled people. The public and private buildings are mostly inaccessible. For instance: the ramps and elevators are not seen anywhere in these buildings. The toilets are also not accessible. Even the parking services of such buildings are inaccessible for them.

Most of the time, the students with disabilities are not enrolled in regular schools due to the lack of accessible buildings and study material. Furthermore, having required qualification, knowledge and talent at disabled people, the employers never give them opportunities to work because they do not want to restore the structure of their buildings. As noted earlier, inaccessible platforms, roads, buses, trains, airports, buildings, places, toilets and parking services deprive disabled people to work independently. Actually, it is responsibility of society to make the things accessible.

5. Accessibility of Information:

It is true that today's world is based on information technology. That information must be accessible for everyone including persons with disabilities because

“Accessibility allows individuals with disabilities to have use of information and services that is equal or equivalent to the use enjoyed by everyone else. Accessibility to information and communication technologies (ICTs) encompasses issues of both physical and intellectual disabilities” (Jaeger and Bowman, 70).

Nowadays, the devices like computers and mobiles are the main sources of getting any information. Hence, such devices must be accessible for persons with disabilities. Even though such devices are accessible, many websites are not accessible for them. Therefore, they cannot reach at proper information which may be valuable for them. Even online transactions are not yet possible for visually impaired people because of inaccessibility in e-banking services. In addition to that ATM are also not accessible for them. Overall, it seems that the needs of these people are not taken into consideration while developing new technologies.

6. Aids and Appliances:

Aids and appliances play a crucial role in compensating the loss of particular body part or function. So, some aids and appliances are specially created for the persons with disabilities, which assist them to improve the qualities of their life. There is availability of various appliances such as crutches, calipers, prostheses, tricycles and wheelchairs for physical movements, Braille writing machines,

dictaphones, CD players, tape recorders and special mobility aids like cane for visually impaired, low vision aids for low vision and hearing aids for hearing impairment. Such aids or appliances help to mitigate the severity of their physical impairments. But many surveys in India revealed that most of the aids and appliances are of poor quality. Furthermore, due to the lack of training, many people with disabilities fail to use or handle them. More often, these aids are not suited to local conditions and the repairing centers are also not available.

7. Health/Medical Services:

Disabled people frequently need specific medical treatment and care. But, it is sometimes very difficult for them to manage the cost of their treatments and medicines because all disabled people's economic condition may not be good. The Indian government spends some amount on the health of disabled people, but that expenditure is insufficient compared to the actual costs of their treatment. Most often, the medical services provided by the government to disabled population are beyond the reach for those who live in villages. Furthermore, other professional therapists, physicians and surgeons in India are few in number and most of them are settled in big cities. It is impossible for disabled villagers to get the required treatment at the initial stage.

Government healthcare services are very poor in quality. Especially, the Primary Health Centers are the cornerstone of the rural healthcare system, but they are not wholly accessible for people with disabilities even today. Along with environmental barriers, they find that these centers have shortage of staff including special doctors, trained workers and supplies. Likewise, these health centers never distribute aids and appliances which are really essential for them. Additionally, they never offer physiotherapy or counseling to them either. Even the district-

level hospitals do not take into account the special needs and requirements of persons with disabilities. The lack of awareness on the part of disabled people keeps them away from seeking medical help at several levels. For instance: most of the disabled people especially in rural India are unaware about the dates of medical camps which are sometimes near to them.

8. Rehabilitation:

According to The Persons with Disabilities Act of 1995, “Rehabilitation” refers to a process aimed at enabling persons with disabilities to reach and maintain their optimal physical, sensory, intellectual, psychiatric or social functional levels” (03). The above description shows rehabilitation plays important role in the life of persons with disabilities. It teaches them how to survive in this world. It is the process of integrating disabled people into mainstream society. It covers diverse areas including social, educational, occupational, physical or psychological rehabilitations. Many rehabilitation centers are available in India. But rehabilitative services are concentrated only in urban areas and not in rural areas. Most of disabled population is unaware about these centers due to lack of knowledge.

9. Reasonable Accommodation:

The provision of reasonable accommodation for persons with disabilities is crucial to perform essential functions efficiently and productively. Indeed, not all the individual with disabilities required accommodation. It depends upon the nature of that individual’s disability. In fact, each person with disability does not require the same accommodation. It varies person to person because each disabled person may have different disability. Although some people suffer from same

disabilities, they may require different accommodation because the severity of each individual's impairment can be different.

10. Social Security:

The state has to arrange social security programs for the welfare of its citizens to improve their standard of living. Although it is responsibility of each state to protect their basic human rights, Indian states have failed to protect its disabled population from many adversaries like poverty, illiteracy and unemployment. This is because many provisions are made for the full social security of disabled people, but they are not implemented properly. So they always feel insecure about their lives.

11. Integration:

Generally, disabled are separated from the society because of the negative attitude of the people who may think that disabled people cannot contribute anything due to the lack of their ability. But, integration is always required for the welfare of society because division of the society into various minorities groups is not good for any society. In addition to that such division of society never help to achieve the main goal of that concerned society. It is said that the fingers of hand are not equal, but the roles of each finger are important while doing any kind of work successfully. In that way, the role of disabled people is also important in the process of national development. Hence, it is prime responsibility of policy makers who design and implement development programs to encourage the process of inclusion of disabled people in the mainstream society like others.

12. Negative Attitude of Society:

In Indian society, the persons with disabilities are still facing attitudinal barriers including prejudices, misconceptions and stereotypes. These negative attitudes and beliefs can result in stigma by which persons with disabilities are excluded and segregated from the society. Actually, people have lack of knowledge and awareness about the occurrence of disability and its implications in future. This ignorance also leads to stigma. Rohwerder explains that “the lack of understanding and awareness regarding the causes of disabilities and their resulting characteristics is a key factor in the stigma experienced by persons with disabilities” (2). It clears that inadequate knowledge and awareness regarding disability and disabled people create negative attitude among people.

13. Social Exclusion:

Social exclusion means not giving equal opportunities or resources to any individual by the majority of people in the society while participating in common activities. The society excludes many people from social, economic, cultural and political activities. According to Levitas et al.:

Social Exclusion involves the lack or denial of resources, rights, goods and the inability to participate in the normal relationships and activities, available to the majority of people in a society, whether in economic, social, cultural or political arenas (9).

The concept of social exclusion was first used by Renee Lenoir, the then French State Secretary of Social Action in 1774. He used this term to describe a wide range of excluded people which include aged, poor,

suicidal, physical or mental disabled and other socially marginalized groups of people.

Persons with disabilities are largely dispossessed social group of people than other marginalized groups of people in India. They are always hidden behind the walls at home by their families due to some stereotypical opinions and misconceptions about disability. As a consequence, they lead their life in isolation, loneliness and silence. They remain invisible, unnoticed and voiceless, in spite of their significant number. They are rarely seen in schools, workplaces, streets, markets, theaters, factories, temples, churches, buses, weddings or playgrounds.

They have not been given chance in political decision-making. “Unlike other minority and caste groups, disabled people have not yet established themselves as special interest group in state or national politics” (Klasing, 24). They are absent from both state and national level political agendas. “The lack of political representation may translate into a lack of policies and programmes targeted towards the excluded” (Klasing, 34). In some cases, political exclusion may impact their access to social services like health and education.

After studying these problems, it is cleared that persons with disabilities in India lead very challenging life. They often get limited resources and opportunities to participate in mainstream society. Along with disabling environment, they face attitudinal barriers in their ways.

The Experience of Disabled Women in India:

Despite all the above discussed problems, disabled women face some additional problems on the basis of gender inequality. Hence, in order to understand Indian experience of disability, it is necessary to

understand the problems of disabled women in India. The problems of disabled women are as follows:

1. Societal Role:

The role of disabled women in social life depends upon the tradition and culture of concerned society. In Indian society, many superstitions are still prevalent in the mind of people about disabled girls or women, so that they have limited opportunities to participate in community life. For instance: disabled women's presence is usually considered as inauspicious on the occasion of community celebrations and gatherings. "Even their presence in a family can hamper the marriage prospects of their siblings significantly" (S. Datta, 36). As a consequence, they confine themselves in their parental homes. This leads them to live under the feelings of isolation, loneliness and low self-esteem.

The idea of education for women is usually considered as unnecessary waste of time, energy and money in male dominant society like India. In such condition, the prejudice against educating disabled girls or women is even stronger. Many surveys revealed that disabled women in rural areas face even harsher discrimination while taking education compared to their urban counterparts. According to Klasing, "No school had ramps or special toilet facilities for its disabled students, making education a daily struggle especially for physically disabled girls" (12). Having limited and unequal access of participation in education, disabled women have little chances of participating in employment. Statistical data reveals that disabled women are often denied the access to employment due to the negative attitude of the employers. Even if disabled women find job opportunities, they earn lowest wages compared to disabled men and non-disabled women.

2. Double Discrimination:

Double discrimination means discrimination against person on the basis of more than one ground. Generally, the social status of women varies from culture to culture or tradition to tradition of country in which they live. It is well-known fact that women have low status especially in Indian patriarchal society. Since women face discrimination due to gender bias, women with disabilities face two fold discrimination of being both women and disabled. “Women with disabilities are marginalized within an already marginalized group” (Morgan, 23). Likewise, due to the poverty, some disabled women face triple disadvantages. “Being a women, origin in a poor family and suffering from a disability constitute triple disadvantages in maintaining existence” (Datta and Datta, 15). In addition to that if such women belong to any lower caste, then they will have to face multiple segregations in society. Briefly stated, due to their gender, impairment, poverty and caste, disabled women face multiple forms of oppression in India.

3. Marriage Problem:

In Indian society where the marriages are mostly arranged by elders rather than individual choices. Disabled women are completely ignored in marriage negotiations between two families. Hence, they have less chances of getting suitable marriage partners due to their impairments. As a result, they are mostly married off by their families with wrong persons who are already married or too much older than them. Klasings also describes the situation of rural women with disabilities that “Most were forced to marry in highly unequal situations, as second wives to older men, widowers or divorced men” (15).

The most unfortunate thing is that women's physical endowments are primary important factors in Indian societies while determining their social value or status. Their chances of getting married and having sexual partnership also depend on their physical appearances which disabled women don't have. In short, strong emphasis on the physical appearance of women creates negative image of disabled women. It is widely accepted that disabled men can marry non-disabled women but disabled women cannot marry non-disabled men because disabled women are perceived as those who are unable to perform their traditional roles of wife, mother and home maker due to their impairments. But, there are numerous disabled women who have proved that they can handle extra challenges in their marital life while managing official duties.

4. Misconceptions:

Women are generally expected to perform traditional role of looking after household duties. Unlike non-disabled women, disabled women are usually considered as incapable of fulfilling sexual, reproductive and maternal roles. Hence, disabled women do not have the same life options that are being performed by non-disabled women in the form of marriage, motherhood, and care taker of their families. Because, it is common belief that if disabled women cannot take care of themselves, then how they can take care of their family and children which requires physical strength and mobility. This belief is strong in the case of women with mental disabilities.

Another misconception is that mother's impairment can be inherited by her children. People have fear that disabled women will produce defective children. But, the fact is that majority of impairments are not hereditary or congenital. This fear in the mind of people makes severe discrimination against disabled women especially those who have

mental disabilities. So, disabled women who are born with disabilities remain unmarried for lifetime. If they become disabled after their marriage, they are abandoned or divorced by their husbands. There are very few cases in which disabled women remarry.

5. Sexual Abuse:

All over the world, girls or women with disabilities are frequently affected by the violence like sexual abuse. The most horrible thing is heard that "...in Africa, there is a myth that having sex with virgin can cure a person of HIV/AIDS. Women and girls with disabilities are targeted for rape, because they are presumed to be asexual and thus they are virgins" (Sowmya, 264). Such type of abuses have happened not only in Africa but also in various parts of the world. It is reported that girls or women with disabilities in rural India are mainly treated "...as unpaid domestic labour and sexual objects, and suffered high levels of physical and psychological domestic abuse, sometimes even desertion" (Klasing, 15). Especially girls or women who have mental or intellectual disabilities frequently go through sexual abuses. It is also reported that the number of sexual abuse is highest in women or girls with hearing and speech impairments because the culprits take advantage of the fact that such victims are unable to communicate the crime to others. But the judicial system is unable to protect them from such cruelties.

6. Forced Sterilization:

"Forced sterilization is the process of permanently ending someone's ability to reproduce without his or her consent" (Kumar, 228). Especially, girls with mental retardation are forcefully sterilized by the doctors as per the demands of their parents. Klasing also points out that "Girls with disabilities, particularly those who are mentally challenged,

were found to suffer from routine sexual abuse and unwanted pregnancies” (15). Instead of forced sterilization to avoid future complications like unwanted pregnancies, it is necessary to eradicate the problem of sexual abuse from the society.

After studying the condition of disabled people in India, it shows that there is still lack of awareness found among people about nature, causes and consequences of disability. The preceding theoretical framework of disability studies will be applied to the analysis of autobiographies of persons with disabilities to understand the experience of disability in India.

Chapter III

Autobiographies of Visually Impaired

1. *Face to Face* by Ved Mehta

Ved Mehta was a prolific writer and journalist. He started his career as writer by writing his autobiography entitled *Face to Face* which was published in 1957. Later on, he wrote twenty-seven fictional and non-fictional books. Most importantly, he worked for the magazine called *The New Yorker* as a staff writer for many years. Through his writing, he tried to introduce many things about India to the American readers. Margalit Fox says that Mr. Mehta was widely considered the 20th-century writer most responsible for introducing American readers to India” (www.nytimes.com). While describing about the simplicity of his writing, Ian Jack said that “His essays were clear and informal, and always rooted in the concrete and the particular” (<https://www.theguardian.com>).

The book '*Face to face*' is about the life of author who became blind at the age of three and half due to the problem of Meningitis which is a kind of serious infection that can damage the optic nerve responsible for sight, resulting in partial or total blindness. In this book, he mainly focuses on his childhood memories in India and early education at a School for the Blind in Arkansas. It is divided into three parts that contain twenty-seven chapters with different names. The name of first part is 'India and Home' which comprises first ten chapters. The second part entitled 'Pakistan and Transition' contains next eight chapters and the part third 'America and Education' includes last nine chapters. The whole story of this book moves around author's struggle for education which is the basic right of every individual including disabled people. He faced a

lot of problems like inaccessibility and negative attitude of people because India had little provisions for blind at his time.

He was born on 21st March, 1934 in British India and died on 9th January 2021 in New York City at the age of 86. His father was a doctor in the Public Health service and mother was house wife. At the age of three and a half, Mehta started suffering from the prolonged sickness i.e. Meningitis. During this sickness, he lost his eye sight and became visually impaired for lifetime. As he lost his sense of eyesight, he started living with his other four senses. He describes:

I started living in a universe where it was not the flood of sunshine streaming through the nursery window or the colors of the rainbow, a sunset or a full moon that mattered, but the feel of the sun against the skin, the slow drizzling sound of the spattering rain, the fell of the air just before the coming of the quiet night, the smell of the stubble grass on a warm morning (Mehta, 03).

It shows that the problem of his eyesight transformed him to live in the world of four senses. It is difficult for anyone to live in the absence of one of the senses, but Mehta had to accept the new situation of his life and developed different techniques to observe things with other four senses.

His father was a trained doctor but he could not save his son's eye sight. His wide medical experience had made him to accept the truth that his son would be blind for the rest of his life. Once his father declared that "But now, by fate or by the will of God, blindness had struck not only a child of the well-to-do, but that of an excellently trained doctor, who found his training in this instance useless" (04). It is true that

disability can affect anyone at any time. It never sees the background of any person. Initially, it was hard for Mehta's family especially for his parents, his three sisters and brother to accept the truth of his blindness. But they could not deny the reality.

Author's father was a rational man and he had always scientific explanation about everything. Whereas his mother had faith in conventional beliefs and practices. This was because of their coming from different background. His father was a trained doctor who travelled abroad extensively. He was influenced by the western ideas and cultures. But his mother belonged to a large middle-class religious family. She was brought up in the strict discipline of a very conventional Indian home. She could not go to school after passing her eighth class which was considered good education at that time. From that time until her marriage, she devoted herself to cooking, sewing and caring of her younger sisters and brothers. Mehta thinks "While these skills trained her to be an excellent mother, they did not prepare her to cope rationally with an unfamiliar tragedy such as blindness" (07). So, her irrational thinking made her to believe in some superstitious causes behind her son's blindness.

It was difficult for his mother to accept that her son's sight would never return. She wanted him to be cured at any cost. She firmly believed his blindness as tragedy which came due to the past misdeeds. Once she called the family pandit at her home for consultation. The pandit started examining the lines of author's palm but he could not explain their problem. He suggested her to consult other pandits. Thereafter, she took consultation of some other pandits. According to the author, "Although their analyses and remedies differed considerably, they all agreed that by doing penance for her sins, my mother could improve my chance of

regaining sight” (05). It means that most of these pandits were talking about sin that was committed by his mother in the previous birth and now she had to do penance to restore the sight of her son. So, they prescribed various methods including prayers and necessary rituals to get rid of that. Most interestingly, even if his father would scorn such methods, his mother performed them secretly.

Along with these methods, religious counsel was taken in the form of series of visits to Bakims, physicians who followed the Greek or Unani medicine. Author says that “These quacks prescribed all types of concocted drops to put in his eyes” (05). His mother followed such non-scientific methods in the hope that his blindness could be cured. Once his father returned home unexpectedly and saw the author was crying loudly because his mother was administering the drops into his eyes. He became furious as he saw the repulsive act of his mother. He strictly forbade her to make the visits of hakims and the purchase of surmas. After that, his mother stopped visiting the hakims but she continued to apply the surmas to his eyes until he was eleven.

His father completed his education in public health in the University of London in England. After that, he took a job in newly created Public Health Department as Municipal Health Officer. Because of having such strong base of education and job status, he perfectly knew the importance of education. Most importantly, his strong determination to give high education to all of his children was quite natural. But he soon realized that it was difficult in the case of author because there are very few schools for blind in India at that time. Therefore, he decided to send him abroad for education. In reality, after author’s blindness, his father determined that at any cost he would give him better education like his other children. Once the author accidentally came upon his father’s diary in

which he had written that “I will sell my soul to give him the highest education possible” (62). Until then, his father never hesitated to take hard efforts to provide him better education.

Meanwhile, his father tried to read all available literature on blindness. He found that “almost all India’s blind people had turned to begging for their livelihood, or had become owners of *Pan* and *Biri* shops and spent their days rolling nuts and condiments in a betel leaf or tobacco in a cigarette paper” (10-11). It shows that there was no scope for personal growth for blind people in India at that time. Consequently, such people turned towards begging or spent their lives in small shops. But the author’s father didn’t want such future for his son.

His father started corresponding with many prominent educational authorities to ask their advice. But concerned authorities gave him negative response by saying “For the blind, educational facilities and personnel were limited, and often the schools became semi-asylums with all ages grouped together in classes without any gradation system” (11). Briefly stated, getting education was difficult thing for blind in India. The reason behind that, the regular schools could not consider their special needs and on the other hand the special schools also provided them limited opportunities to take education.

At the age of five, his parents sent him to Dadar School for the Blind in Bombay where Dr. R. M. Halder was principal who promised them to take special care of their son. In the first class, he spent his time looking over stuffed animals and birds to get their images in mind. He also learned how to count with the help of abacus. Thereafter, he made rapid progress in arithmetic class and correctly associating the names and shapes of birds and animals. Along with academic progress, he learnt

personal adjustment and discipline. Most importantly, he learnt to do everything independently. In his second year at school, he had begun to learn multiplication and division on an arithmetic slate. He had also started reading and writing Braille in English. Likewise, he spent his spare time to take care of his own little plot of land where he planted vegetables as everyone else. He describes “I continued my studies at the school for another year and a half and within two and a half years I had absorbed all the school had to offer” (25). Indeed, Dadar School and Bombay gave him scope for overall improvement in very early days of his life. He liked Dadar School so much but the climate didn’t suit him. So, he was sick a good part of time.

Mr. Halder, the principal of Dadar School, encouraged the author as he expressed his wish to go to America for education. He tried to contact Dr. Ferrell who was the director of Perkins Institute on his behalf. But the reply of Mr. Ferrell ruined the dreams of his immediate visit to America. He strongly recommended that he should not leave his home environment in such early age. According to him, “...his experience with those coming from the East at an early age to study in the Western world indicated that there was a grave risk of becoming total misfits in Eastern as well as in Western cultures” (25). Thereafter, Mr. Halder suggested his father that no immediate provision could be made for author to go abroad for education because in his opinion he should spend early days of his life with family instead of staying in boarding school.

Thereafter, his father learnt about Emerson Institute at Lahor. Like Dadar School, Emerson Institute also gave vocational training which might help to rehabilitate the students who got admission there. In fact, there was no gradation system with regular classes like other schools. The author says “Their education followed no system of gradation by classes,

and even if it had, the education would have ceased by the fifth grade because of the lack of funds to engage qualified teachers, who are so scarce everywhere” (78). It shows that very few institutes were trying to work for blind people at that time. But due to the lack of funds, such institutes were suffering from inadequate resources. So, they could not work properly and effectively.

The fact is that India is one of the developing countries where most of the people still live in poverty. In such condition, very little attention is given to special needs of disabled people. The author’s father knew “The blind in India have no future, for in a country ridden with starvation and poverty, little attention can be paid to those with special problems” (78). It shows that the society is not aware about the special needs of disabled people.

As his father had observed that in India the most of blind people were musician, he hired a tutor, Pandit Hukum Chand to teach music to his son. Panditji came three times in a week in the afternoon to give him lessons in music. But he had to discontinue his classes as his family left Lahor and shifted to Bombay as refugees after the partition of India. His parents had not been able to bring anything with them from Lahor except their summer clothes. They left everything there.

Meanwhile, his family again shifted from Bombay to Delhi and then to Simla for their safety. Sometimes he felt frustrated as he saw his parents and siblings were busy in their works and he alone would not do anything. In Lahore, at least he was engaged by his music teacher. But here in Shimla he could not do anything. His musical instruments were left behind in Lahore. He tells “All my musical instruments, *table*, *tambura*, *sitar* and harmonium had left behind, and no teacher here could

add to my progress” (149). Along with these musical instruments, he left his few Braille books in Lahore. Furthermore, his electric transformers and carpentry tools were gone. So, he had to pass few months in the state of inaction.

Once his father heard about Sir Clutha Mackenzie, a totally blind Englishman who was directing St. Dunstan’s Hostel for the war-blinded in Dehradun. Sir Mackenzie was first blind person that his father had ever met and was impressed by his learning and abilities. St. Dunstan’s Centre was only for war-blinded people. So, the author had little chance to get admission there. But, after requesting the concerned authority, his father was able to admit the author at St. Dunstan’s Centre which was considered as best training center for the blind in India.

The author found that St. Dunstan’s Centre was a beautiful place. He says “The classroom atmosphere was as wholesome as that of the huge compound with its scores of lichee trees” (151). He tried to learn all the things whole heartedly. His teacher, Mr. Cameron spent ample time to teach him language and typing. Likewise, Mr. Advani, another teacher, taught him grade-two Braille, the more complex Braille which includes contractions and abbreviations. He expresses that “My stay in Dehra Dun was not only fruitful but happy” (151). The reason behind that he was allowed to take out Braille books and magazines to read from their small library. Most importantly, he learnt the value of doing things independently. But the St. Dunstan’s had given him only eight months’ opportunity to stay there and sent him back home considering he had learnt all St. Dunstan’s had to offer him.

Once he had an interview with Mr. Baldwin, a representative of a large American corporation. Unfortunately, he performed very poorly in

that interview. Mr. Baldwin found that he had poor language skill and educational foundation. So, the author again lost his hope of going to America. He wrote a long letter to Pandit Neharu about their losses in Pakistan, his search for education and his growing frustration. Pandit Nehru expressed “Why do you want to leave home and go to places where no one will take care of you? You can get all the education you need here, by going to schools for the seeing children” (157). But the author felt too discouraged to tell him that he had tried to approach in seven schools where the teachers showed their incapability to handle blind students and they seemed fearful that the students like him would disrupt the routine of their classes.

The author had strong desire to go abroad for education but couldn't find the right way. He himself had lost few opportunities to go there for one or other reason. So, he felt frustrated. But his father often tried to give him hope by saying

“I will stand behind you, and you will go to England or America even if you have no financial assistance, or as far as that goes, no admission. Don't forget, child that I myself went to England without promise of admission. Once you are there, they won't send you back” (156).

His father encouraged him by telling his own example of going to England and making excellent career, although he had no assurance of admission at the initial stage. These encouraging words of his father again created new hope of going abroad.

The author kept trying, once he wrote a letter to Arkansas School for the Blind and expressed his wish for getting admission in their school. It was unexpected for him but he received letter of acceptance from them.

Finally, his dream of going to America for education came true. He was very much impressed by America where he could live normal and independent life like others. Along with excellent education, he enjoyed the freedom of movement and a complete sense of self-reliance that he couldn't enjoy in India. He writes "All these things my own country had not been able to do, because I was blind" (303). It is clear that his hopes and aspirations were not fulfilled while living in his own country because of his blindness. He thinks "In India I will not only have to surrender my freedom of movement, but may have to join the thousands of students with liberal-arts degrees who sit day after day in a park because there is no job to be had" (303). So, he thought that he took right decision to leave India and went to America where he got the chance to prove himself despite his blindness.

He found that most of the things like roads, transportation services were accessible for visually impaired in America. But In India, inaccessible public places especially roads restrict visually impaired people from moving independently. Indeed, the visually impaired people need audio signals, guiding blocks and warning blocks on the required places to navigate or cross the roads safely. But these things are not found on Indian roads. Most importantly, pedestrian are not given first priority while walking on or crossing the roads. So, it is very dangerous especially for visually impaired in terms of safety. The author describes "...in India there were no red and green lights, no regulated traffic laws comparable to America, and the erratic tonga men, bicyclers or ox carts could not be expected to look after the interests of a pedestrian, especially a blind one" (256). It shows that traffic rules are strictly followed by the public in America. So the blind people can go anywhere independently.

In the epilogue, he has cleared that he was going to Oxford University after completing his graduation for his further achievements. His teachers in Arkansas school encouraged him to go there. While living in America and England, he was influenced by the writings of various well-known writers like Plato, T. S. Eliot, James Joyce, Johann Goethe etc. In the meantime, his writing career also flourished and he became prolific writer.

He decided to spend two years in Oxford before making his way to India. But he was doubtful about this decision. He thought "...whether I was dreading returning to India because I had become too Americanized, whether this postponement of two years might not ultimately result in my returning to America to live" (306). He had strong love for India but he would like to live in America where he was already fascinated by so many things including education, accessibility and positive attitude of people towards disabled. So, he had hope to enjoy American life again.

Overall, Ved Mehta's impression about India in terms of education, accessibility, people's attitude was not so good as compared to America. However, he considered that America was his own home. He says "...for now America is as much my home as any place is in this foot-loose world" (309). Briefly stated, he felt much more comfortable to live in America than in India in every aspects of life.

2. *Lights Out* by L. Subramani

Lakshmi Subramani was born in 1973, in Tamil Brahmin family, in Madras. Presently, he is working as senior sub-editor with Deccan Herald in Bangalore. His autobiography entitled '*Lights Out: A True Story of a Man's Descent into Blindness*' is a real story of his life. Since the early age of his life, he had been suffering from Retinitis Pigmentosa, a genetic disorder which affects the retina. Being a patient of Retinitis Pigmentosa, he was experiencing the debilitating process of going blind which often demoralized him. In the book review, Privy Trifles writes "Lights out shows with painful clarity the debilitating process of going blind and the agonizingly bewildering effect it had on him" (www.privitriflies.co.in). Indeed, it is a physical, mental and psychological journey of author who was mainly experiencing the progressive blindness and the way it affects him and his family.

This book comprises twelve chapters with different names. It starts with the chapter named 'A Trip to the Doctor' in which he describes his frequent visits to the Dr. Rakesh's clinic for his eye treatment. In reality, he had been suffering from the eyes problem since his childhood. At the age of five, he had to fix the thick black spectacles frame over his nose permanently. However, he was used to visit Dr. Rakesh's clinic to check up his eyes or change the glasses accordingly.

Once he went to his clinic for routine checkup. He noticed the great anxiety on the face of Dr. Rakesh while examining his eyes with ophthalmoscope. He had perhaps found something wrong in his eyes than usual. After doing few more tests on his eyes, it was clear that he had detected the problem of retinal disorder. In fact, he was blind at the age of

eighteen but he had been suffering from retinal disorder since his childhood.

It is true that the whole family gets disturbed when one of its members suffers from some kind of disability. The author's family which included his parents and three siblings, became restless after hearing the news of his approaching blindness. His father was running a family business and his mother was a house wife. He had three siblings named Lakshmi, Arjun and Eshwar. Lakshmi was nine-years-older than him. Likewise, Arjun was three years and Eshwar was four years younger than him. Every one of his family supported him in the critical journey of life.

If a child acquires a disability, it's very hard for his/her parents to make themselves stable. At the initial stage, the parents who have disabled child, need mental support especially from relatives and friends. The same thing happened with the author's parents who felt devastated as they heard the news of their son who was going blind over the period of time. His father called his siblings for getting comfort and support. Along with the parents, his whole extended family were disturbed by getting this news. Uncle Raman, his father's brother who was doctor by profession, came to console author's parents. After seeing the reports which were given by Dr. Rakesh, he didn't believe his nephew's progressive deterioration of vision. He thought that the reports perhaps showed wrong results. However, he decided to take the advice of other doctors to confirm whether the diagnosis was right or wrong.

Meanwhile, the author observed how it was difficult for him to mix up in non-disabled students in the school. He was losing his confidence as other non-disabled students were calling him by the nickname 'four eyes'

in the school on the account of his wearing of spectacle. Indeed, nobody likes nicknames that indicate their physical deformities.

He found that the non-disabled students showed their unwillingness to include disabled students in their group while playing or doing other school activities because they thought that disabled students were not fit for those activities. He felt isolated in his school. He always wanted to be a part of the group of playing boys, but never dared to go on the ground. Because he was embarrassed by his first experience when he was not chosen in the team by other boys. He narrates “I was the only one left standing, alone, not chosen, with absolutely no one wanting me in their team” (Subramani, 06). It was really humiliating for him. Even Mr. Simi, their physical education teacher, suggested all of them to take him in, but no one wanted him in their team because he wore spectacles.

He was excluded from most of the activities on the account of his wearing of spectacles. But at the same time he was aware that the wearing of glasses was more valuable for him than the urge of running around with other boys. Even the elders in his family always restricted him from doing most of the activities saying ‘Don’t run around and break your glasses!’.... ‘Don’t walk alone at night!’; ‘Don’t chase after your brother!’ (07). As a result, he hated the spectacle even if he had no other option. But he sometimes thought that the glasses made him look intellectual and attractive rather than the object of weakness or impairment.

Each disabled person has to go through the physical suffering on the account of their impairments. The author thought that no one can understand his sufferings except the person who went through the same sufferings. He described his pains in the words of that “The pain is

continuous, unrelenting, and it almost pushes me to the threshold of tolerance” (10). Even in the clinic, he found other patients whose tears were rolling down from their cheeks due to the liquid poured into their eyes. He also describes that “I knew what it feels like when the liquid is poured into the eyes—the burning sensation—as if acid has touched its sensitive surface” (08). He understood their sufferings because he was also going through the same sufferings like them.

After hearing the news of his progressive blindness, the relatives came to console his family and some of the pious among them suggested to his mother that “...prostrating before god, begging for his mercy with tearful eyes, would help us find a way out” (31). Even his family believed that the answers of such problems could be found after praying the God for the act of purification that removed sins. His mother didn’t want to lose any chance of trying to find his cure. Hence, along with the medical treatment, she started using non-scientific methods in the hope of his cure. She met a number of miracle workers, astrologers, healers who all claimed to have knowledge of the past sins and remedies to get rid of their effects.

Once his uncle told his mother about a tantrik whom he knew personally. He had got his appointment at evening with great difficulty. The author saw the images of Goddess ‘Durga’ in his home. After looking at him, that tantrik declared “This boy is the victim of curse” (39-40). He further continued “He dragged with him the effects of a very bad curse from his previous birth. He’s very impure! We have to cleanse him and make him worthy of the Goddess’s blessings” (40). Thus, he was trying to relate his present condition with the effect of curse from his last birth. However, he suggested them to conduct three ‘homas’ for him, so that he would come out of that curse. Afterwards, he gave a long sheet of

paper on which he had written the names of all the ingredients to perform these homas. But the expenditure of these Homas was not affordable for his family because of their low income.

Few days later, they went to visit an alternative healer who also possessed divine spirit. The author saw that healer was worshiping Devi Upasaka in his house. After looking at the author, he suddenly fell down on the floor and started doing the movements like snake. His wife explained what he was trying to show with his gestures. She declared by confirming with him that this boy had 'Naga Dosha'. It means that he was carrying impurity within him because he had hurt a snake in some way. So, he suggested them that "You must take him on a pilgrimage to Nattarasankotai, a shrine located near Madurai. Also offer a pair of silver eyes to the Goddess. This will cleanse him of his Naga Dosha" (42). After all, he observed one thing common among those godmen to whom he visited so far that they all were seen him as the product of impurity which led him to born with imperfection. Nobody was talking about his defective gene which was the real cause of his trouble. In reality, they were cheating people under the name of different Gods and Goddesses. But still his family did not stop visiting the parlours of godmen and astrologers because they desperately wanted him cure.

His mother took him to the pilgrimage of Nattarasankottai, Samayapuram, Chidambaram and a few other shrines where he had to perform various rituals. It was a plan of one month in which they had to cover different temples. In reality, the transport, medical expenses and fees of different godmen impacted their family savings. His family business had many partners, so it was difficult for them to manage it. But his mother juggled with whatever money she had.

Afterwards, his mother took him to meet another therapist who assured them saying “I can work on this. This should be curable” (44). In fact, he had never given direct treatment before to Retinal Pigmentosa in his practice, but he was familiar with the symptoms. In this therapy, the author had to consume a bagful of obnoxious medicines. He wrote “Every day, I force myself to swallow them, if not for my own comfort, at least for mother’s sake” (45). Thus, there were number of tonics and powders that he forced himself to swallow only for his mother’s sake.

They went to Chidambaram to meet an astrologer whose predictions were absolutely correct. That astrologer asked his birth details in order to see his horoscope. As he closely studied the squares representing the planetary positions, he declared “There’s something wrong with this boy’s eyes” (53). Even he reeled out the details of his past that he had been using spectacles since childhood. His mother and Uncle were surprised by his amazing accuracy about his past. They were told that his serious eye problem would disappear soon and he would lead a normal life. They were happy with the prophecy of that astrologer. The author asked his mother to stop dragging him to such places because he knew the reality of his condition which was explained by Dr. Rakesh.

Raman Uncle again suggested to take second opinion of other ophthalmologist about his eyes. He helped them to get an appointment at one of the city’s best eyes hospitals. A young female doctor of that hospital diagnosed that the author had all the symptoms of night blindness which was one of the symptoms of RP. The opinion of this doctor proved whatever Dr. Rakesh had diagnosed earlier was right. It was really a setback for his mother and others in the family. They did everything including allopathic, spiritual, cosmic or alternative medicines, but it did not help. Their trips to godmen, astrologers and

others took too much time. So, the author had to miss the school for a long time. Consequently, it affected his overall performance in the school.

He wanted to live normal life but he suffered a lot due to the momentary lapse of his eyesight. However, the fear that he was going blind soon haunted his mind wherever he went. Once he was riding a bicycle for going to theatre to watch a movie with his friends. Suddenly, he felt discomfort due to the reflection of bright afternoon light. As his regular exercise, he blinked the eyes many times to clear up the vision but still he continued to see nothing. He describes his fear:

“My pulse quickens, heart pounds, and sweat streams down my forehead. I want to shut out that one thought which seems to flicker like a danger signal: Have I gone blind?... Have I?... Have I!” (60).

The first time he realized what blindness is. He wanted to share this incident especially with his mother to get rid of fear but he stooped himself because he didn't want to see his mother's meaningless efforts to treat the condition.

Another incident made him to realize how the eyes are important to live normal life. Once he fell down in empty corridor in the school while descending the flight of stairs. His books and notebooks were scattered across the stairway. His spectacle flew off and crashed into the railing. He didn't understand what he had done to deserve this all. It made him to remember that it was really the result of some unknown sin as many people and godmen seemed to suggest. He thought that the eyes are most important than any other part of body. He says “... I would have probably bartered an arm or a leg to retain my eyes because I do realize their

importance” (68). Indeed, he became helpless due to his momentary lapse of eyesight.

After that incident, his mother took him to Dr. Rakesh who was the only person who could fully comprehend the complexity of his eyes condition. Dr. Rakesh scientifically explained them the present condition of his retina which had a dark blue spots scattered across the retina’s red region. Such dark blue spots decayed the light sensing cells that were most necessary while functioning of eyes. This is all because of “The defective gene prevents blood and oxygen from reaching these light-detecting cells and triggers a slow process of blindness” (71). The first time he realized that the real cause of his retinal disorder was not related to the sin of his previous birth but the defective gene.

Dr. Rakesh disclosed a strong possibility of having this condition was consanguinity which is also one of the important causes of disability. He explained consanguinity in scientific language that “It’s a kind of genetic similarity usually found between a closely related male and a female. An identical weaker gene in them could possibly express itself as a disability in the offspring” (72). The author thought that although his parents felt guilt for contributing such weaker gene now, they would not be confused hereafter with the sin that astrologers talking about all the times. In reality, at the time of his parent’s wedding, no one had thought that the marriage within genetic proximity would prove to be something problematic. Even today, it is a common practice in many regions of India to fix marriages within blood relations for familial bonding. In fact, the people are not yet aware about the fact that such marriages are one of the causes of genetic defects. Hence, due to the consanguinity, many people in India are probably affected by the genetic defects like Retinal Pigmentosa. His mother now became aware about the results of intra-

family marriages. However, she wouldn't even think of settling her children's marriages within the relatives.

Many incidents described by the author in this book show the attitude of Indian people toward disability and disabled people. When the news of his progressive blindness spread everywhere, he had to face more and more undue attention from the people while walking on the road. Some people stared at him differently. Some of them had pretended to show sympathy toward him but that was only for curiosity or contempt. He remembered incident in the vegetable market where he went to bring tomatoes for his mother. As he saw most of the tomatoes were raw and he asked about that, the shopkeeper reacted rudely "They are not raw. Look properly—or are you really going blind" (76). Even at the barbershop, he had been asked if he was really going blind. Actually, he was annoyed by constant questions from the strangers. Such unexpected questions from the people revealed their attitude towards disability.

He thought that once he had a brilliant future ahead of him. But now his status was being a worthless boy due to his impending blindness. He didn't understand why people thought that a person who was going blind must be useless. Instead of supporting the person with disability and his/her family, they showed such insensitivity towards them. Even in the family gatherings, there was only discussion about his condition. He felt "my place in the family's list of promising children to occupy an altogether new status-the most unfortunate one" (79). Not all of his relatives but few of them were genuinely concerned about his condition. They visited them with holy ashes and kumkums from temples. They also came with some therapy techniques. Some of them had suggested recipes with vegetables that could have a healing effect. His mother started including healing foods in daily cooking especially green vegetables to

improve eyesight. He was fed up with swallowing mixture of milk and drumstick flowers or crape jasmine regularly. After drinking these herbal concoctions, the taste unbearably lingered on his tongue for long time.

The fear of going blind in future remained in his mind. Once in the corridor of school, he saw the boy whose eyes were completely white. Actually, he was blind. His face was attractive but his blind eyes made him so unattractive, strange and unusual. The whole picture of that boy threatened him. He thought that “The boy is both a peek into my future and embodiment of my present fear” (83-84). His heart was started sinking by the fear of becoming like that boy in the future. He tried a lot but couldn't overcome his deeply rooted fear.

He did various temple visits and appointments with therapists. He remembered his last visit to Tirupati where he had to wash his body in the intolerably cold waters of the temple tank at 3 am to perform some rituals. Then, along with other fifty devotees, he sprawled on the cold granite of the temple corridor and started to roll on the floor. Even he bartered his hair in return for God's blessings. In this context, he points out “I've stuck to my side of the bargain, and now can only hope that God sticks to his” (96). In reality, he was annoyed by countless temple visits and performing various rituals. Now he realized that such visits were nothing but waste of time and money. Even such visits affected the result of his exam. He failed in the exam. He knew that marks cannot decide his future but he was regretting losing one year of his life. In the meantime, the family friend Mr. JRK made him stable in this situation. He encouraged saying “You've just failed in the exam, not in life. Try taking this as a stepping stone towards success” (98-99). He also added “Failure can sometimes be helpful,’ ‘It makes you take a step back and get a fresh perspective on life” (99). These words gave him courage to

move forward. The author found that there were very few people like Mr. JRK supported him in his critical condition except his family.

His mind was suppressed by the fear of haziness. Sometimes his fear reflected in the dreams at night. Once he saw the dreadful dream which was about a boy who wore a large pair of dark glasses and was holding a white stick in his hand while walking on the busy street. He was scared terribly. But after waking up, he realized that the boy whom he had seen in his dream was he himself. He said “I am not sure if the enemy is blindness or my fear of this uncertainty” (112). Because the fear of going blind was more dominant in his mind than the actual condition of his blindness.

Along with family, it is responsibility of teachers to understand the problems of disabled students. But it never happens especially in regular schools. The author shares one of his school experiences that his vision started to blur after writing few lines from the top of the board because of the sunlight ricocheting from the entrance of the door. He wanted to do the exercise which was taught by one of his therapists to relax the eyeballs. So, he slumped on his desk and covered his eyes with the palms. But his exercise was interrupted by the teacher who thought that he was sleeping. He was hurt by the words of teacher who said “If I’m not wrong, aren’t you a detainee from last year? For how long do you want to warm these benches?” (118). As punishment from the teacher, he remained standing for the rest of the class and copied from the board. It was really difficult for him to explain his haziness which often came at the most unexpected movements.

His mind was filled with fear whenever his eyes started getting blur while walking. In such situation, he had to discontinue his walking and

blink many times for clearing his eyes. The obscurity of his eyesight was sudden. He describes it “my condition is such that to me a mirage looks like a stream and a stream seems as faint as a mirage” (120). However, most of the time he didn’t understand how to handle the situation. One day his eyes were getting blur while boarding the bus which suddenly started to move. So, the growing distance between him and the bus made it difficult to step on the footboard. At that time, he was close to colliding with a cyclist riding in the wrong direction.

The author was persistently disturbed on the account of haziness of his eyes. His vision started diminishing day by day, even after taking proper care. Once his uncle gave him a bicycle to go to post office to post few of his letters. While riding the bicycle, his eyes suddenly became blur for long time. His grip on the bicycle’s handlebar slicked and he reeled on his left side. He felt incapable of handling the traffic. So, he parked the bicycle in a corner and tried to settle down his nerves. After this incident, his uncle decided to take him to a pilgrimage. Actually, he didn’t understand which thing either his blindness or recent bicycle incident had prompted his uncle to join the forthcoming Sabarimala trip with him. But he was not interested to attend such trips anymore.

He didn’t like his mother’s thinking that miracle would save his eyes. Once she was praying for the positive results of his test while Dr. Rakesh checking his eyes. Her expectations became true when Dr. Rakesh told the news that he didn’t see a lot of dark spots spreading across his retinas. The author didn’t understand whether stability of his retina was really the result of bitter pills and liquids or the various rituals performed on the cold granite floors of the temple. Whatever it was, but the fact was that the immediate threat of his blindness had dissipated. Everyone in his family became happy with this news. He described the

ambience of his home after hearing the good news “Incessant smiles have now replaced the usual, anxious frowns. Now, every day the radio is turned on for music. Ma’s evening coffee is tasty again and I see her praying fervently before God, thanking the supreme force in the only way she knows” (131). It shows that everyone in his family seemed to be happy as they heard about the stable condition of his eyesight. Everyone in his home started praying to thank God.

Considering this happened by god’s grace, his uncle suggested that this was the proper time to take him to Sabarimala pilgrimage. Actually, the author wanted to prepare for his first year’s final exam because he had a good chance to reach among the top rankers. But his mother firmly declared that he had to go on that pilgrimage to honor her prayers. This trip would have ended in three or four days, but his uncle had scheduled a longer trip covering many temples across the southern states. So, it took about forty days. The experience of that trip was unforgettable because his tress, fear and anguish simply faded away in the company of beautiful nature. He expressed his gratitude partly for the magical sight and partly for the mystery that life had become. But the fear of blindness again came in his mind. And he asked himself “Would I be seeing more of these mesmerizing images or was this some kind of a finale before the lights went out forever?” (136). It seems that wherever he went through, the fear followed him like a shadow.

In the last chapter named ‘The Descent Begins’, he describes his memories of September 1990. He was not blind yet but still fighting with the obscurity more acute than earlier. As walking with the chaos, he had to rely on the familiarity which was a kind of mental picture of his surroundings to navigate instead of eyes. He thought that while passing the road, he was not worried about injuries but the repeated question of

riders who asked “don’t you have eyes?” (140). It made him upset every time. Everyone in the family was happy after the good news from Dr. Rakesh earlier but “the obscurity returned with a vengeance, freezing me in the middle of the chaos and dreadfully closer to moving vehicles” (141). Different therapies were turning out well but the blur was occurring with alarming frequency which reinforced the fear that he was not quite out of it.

The fear always lingered in his mind because he thought that sudden and prolonged lapse of vision might cause a nasty collision with vehicle. Once his vision started blurring in the middle of the street. So, he didn’t understand where to move exactly. When he moved backward to avoid a direct collision with auto rickshaw, there were two bicycles turning around the corner behind the auto. He describes “I freeze when I feel the rear-view mirror of the auto rickshaw brush against my shoulder and the front tyre of one of the cycles roll over my left foot” (144). His eyes were closed and the tears were rolling down from the cheeks. After opening the eyes, he found a crowd gathered around him. The thought of an accident scared him terribly. But he soon realized that he hadn’t fallen down or met with accident. The cyclist had applied brakes and took him to the corner of the road. This incident shows that it was all nothing but the fear of his mind.

At the initial stage, he had problem of seeing in daylight and he could see at night. But his heart started sinking when he experienced the disturbances of seeing at night for the first time. So, he thought that his vision was probably going downhill. He again asked the causes of his sudden lapses of vision to Dr. Rakesh who explained him “The photo receptor cells which sense light begin to decay for a person with RP, resulting in disturbances in vision” (146). Now it had become challenge

for him to walk through the congested lanes around his home also. He no longer felt confident and enthusiastic to walk.

Due to the problem of his eyesight, he had to face many horrible incidents in the life. Once his mother sent him alone to one of the godmen's house where he found Maari Amman's images displayed in different postures. While returning to his home, he stood alone at the deserted bus stop and waited for the bus. After waiting for some time, he eagerly got in the bus without checking its final destination. Asking the way to the station from a fellow passenger, he entered at a desolate street hoping that he was going towards the right place. In the meantime, he heard the voice of man who came near to him and asked him for help. As that man started speaking, the unpleasant smell of local liquor started lingering around him. He strongly felt that he could be in danger. It was difficult for him to escape from that heavily drunken man. He wanted to go to the suburban station but he came to the wrong way because the road suggested by the drunkard was nothing but a narrow, muddy trail that runs parallel to the railway tracks where he heard the electrical train's whistle that pierced the silence. He climbed up some steps thinking that must be a station. But he again turned into panic when an odour similar to that drunken man who assailed him at down the street. Before he could do anything, someone grabbed his wrist and pulled him into a crowded place. After blinking his eyes to adjust in the bright light to see better, he saw a liquor shop. He was rescued from the next unpredictable crisis and managed somehow to return home.

His vision was deteriorating more rapidly than earlier. The objects around him were getting blur with every passing day. He thought that to live with decaying vision is more dangerous than complete blindness. While facing such horrible reality of life that his vision was obscured by

the smoky blur or the flashes every time, he often lived under the fear and shame. He felt humiliated before his peers and classmates. He describes “I feel I don’t have a choice because I have an eyes condition that is unlikely to give me a blissful death, or, at least, swifter blindness” (153). It shows that he was living life without choice. He didn’t want to live life that he was living presently. Instead he would like to die or go blind completely.

Thus, this book seeks to describe his long and torturous battle with approaching blindness. The end of this book is a very pessimistic one. As his vision started deteriorating day by day, his confidence level also declined. He himself said “I am seventeen and still have the best part of life ahead, but I feel old and defeated with each ‘incident’ chipping away my confidence” (156). This was because the battle with failing vision was now getting more and more difficult for him than anything else. He didn’t think that his blindness was likely to be a blessing for him. Instead he thought that everything was better than blindness.

3 The Other Senses by Preeti Monga

Preeti Monga was born on 22nd April, 1959 in Simla, in Sikh family. She is the founder of Silver Linings, a non-profit organization that works for inclusion and empowerment of blind children and women. Being a visually impaired since her childhood, she has devoted herself to work for the well-being of other visually impaired or disabled people. Most importantly, she has very dynamic personality. Despite of blindness, she has led various roles as social worker, disability activist, aerobics instructor, entrepreneur, consultant, counsellor, author and many more throughout her life. She won many prestigious awards such as National Award for Empowerment of Persons with Disabilities from the President of India, Red and White Bravery Award and Rajiv Gandhi Manav Seva Award for her other valuable contribution to society.

The Other Senses is her autobiographical book published in 2012. It contains sixty-seven sections without names but each section shows its number in Braille script. The story of this book is about the life of Preeti Monga who lost her vision in childhood. S. Gokul describes “This book is about how being a woman she managed her childhood with a disability, her adolescent days as a young woman and how she molds herself with the disability as a successful person today” (32). Being a woman and visually impaired, she had to suffer social rejection and discrimination, but she never gave up. Even in so much troubles, she found different ways to become successful.

She was the first-born child of her parents. So she was brought up with a great care and adoration. Her mother’s name was Mohini who did her graduation in bachelor degree and she took up the role of house wife. Her father’s name was Charanjit who had completed his bachelor degree

in science. When Preeti Monga was seven or eight years old, her parents came to know about her approaching blindness. It was very depressing thing for them.

Thereafter, her parents took her to the several eyes specialists to see what was wrong with her eyes. She had to undergo different tests in the hospital. Ignoring her loud protest, the countless drops of atropine were forcefully dropped into her eyes at the time of test. She describes “No matter how much I cried or pleaded, nothing seemed to release me from painful injections and petrifying examinations” (Monga, 24). As a child, she didn’t really understand what is blindness and its serious impacts in future. So whenever she was taken to eyes specialist, her only concern was that she should not be recommended spectacles. However, only to avoid spectacles, she was trying to misguide the doctors when they were repeatedly asking her about the clarity of glasses.

Innumerable trips to doctors for in-depth consultation with the most competent doctor revealed that both the optic nerves of her eyes were partially paralyzed for unknown reasons and no treatment was still available anywhere in the world. After becoming disabled, everything had changed for her. She started experiencing the changing attitude of people around her as they heard about her disability. They looked at her with pity and compassion. She describes “Friends, teachers, and neighbours, all looked at me with pity; I seemed to have been transformed into a strange pitiful object to be handled with extra consideration or simply left alone!” (28). She was completely taken aback by this type of attitude of people. She also found that her friends didn’t come to call her to join them at playtime. They sent her back home by giving some excuses if she dared to go out herself to join them. She writes “I was completely bewildered and felt guilty for some unknown

crime I had committed” (27). She didn’t want to live such dull and sad life. All people had changed except her parents and her brother. In her interview with Ria Das, she says “Outside my home, however, and in school, I faced social rejection, shame, sadness and fear” (<https://www.shethepeople>). So she was really happy for that one blessing.

Along with her eyesight, she had lost her right to be like everyone else. As she realized that her life was never going to be the same again, she decided to do something in her life because she didn’t want to go on like this. She expresses that “Never mind what they all make me feel, I just can’t just sit around sulking and depressed, waiting for life to get back to normal, when nothing at all is wrong with me” (Monga, 28). She decided to live life by ignoring the attitude that surrounded her.

She shared her one more experience that shows negative attitude of the people who were much closed to her earlier. Once she was suffering from fever along with angry red rashes after the inoculation of smallpox vaccine which was given by visiting doctor to all the students in her school. Due to her problem of skin disorder, no one wanted to have her around. Some of her friends had broken their friendship with her because they didn’t wish to come in the contact of such skin disease at all. Her mother repeatedly attempted to convince her friends regarding the non-infectious nature of her skin disorder but it prove unsuccessful. During that period, she was left alone because she herself was most uncomfortable with her condition and felt more comfortable indoors. She felt “So tragically imprisoned and deeply saddened, I spent most of my time alone, feeling like a bird that had lost its wings and yet could not abandon a longing to fly” (30). She was utterly crushed under the feelings of discomfort and loneliness. In fact, this skin disease stayed for the next

forty years with her. Sometimes she was bedridden for as long as six months as a consequences of severely infected and painful sores. For such long period, she had to depend on others while eating food and using the washroom too.

Her family was shifted from Agartala to Delhi where she had got the place in Loreto Convent, Delhi. At the time of admission, her parents told Sister Clare, the Principal of the school, about her vision impairment and they might need to make few adjustments in the school for their daughter's sake. Thereafter, Preeti Monga got complete cooperation in her school. All the teachers were helpful and cooperative in nature. She elaborates "At school, the teachers were not only great teachers but also wonderful human beings..." (43). Along with teachers, the classmates were always ready to help her whenever she needed something. But the change came in her life after the transfer of Sister Clare from that school. She was expelled from the school by the new Principal. After the exclusion from the formal education "Everything seemed to have come to a full stop: no school, no studies, no play, no friends, and nothing to look forward to" (45). So she was left alone once again.

She realized that the regular schools were not willing to admit her due to her visual impairment. Therefore, the school for blind was the only option to complete her education. A couple of days later, she accompanied her parents to only school for blind girls in Delhi. But, her wish of going to school remained unfulfilled forever because her parents disagreed with the condition of staying her compulsory in the hostel of that school which was in poor condition.

She decided to make her career in music. So she enrolled as a distance-learning student for the Visharad, a six years diploma course in Indian classical music, in the Gandharva Maha Vidhyalaya which is one of the India's finest music institutes. After the enrolment, she started taking music lessons from Mr. P. D. Saptarashi, a well-known violinist. In the final year of her diploma, her Guruji could no longer come to teach her due to his illness. Therefore, she was placed under the guidance of Mr. Narendra Nath Ghosh who was also a well-known radio artist. Her present Guruji expected a perfect performance from her while practicing but she failed to do that. He made her realize that she didn't possess a natural ear for music. So her dream of learning music was shattered. She saw many cases of blind persons who were bestowed with the ear for music but she was not. She blames "When God takes away a person's eyesight, he makes an unfailing gift of an ear for music. ...if He had decided not to gift me an ear for music, why did He plant such dream in my mind" (52). She didn't understand what she had done to deserve so much failure in life.

She thought that she was constant source of worry and concern to her parents. So, she decided at least to avoid creating a situation of greater pain and grief for them. She diverted her mind on the other major but unnoticed activities at home. Thereafter, she started spending most of her time to help mother in the house hold chores like cooking, dusting, ironing, cleaning and watering the plants. She had also mastered the skill of making their beds, setting and keeping their room tidy, especially on the days when their housemaid went on leave. Her parents kept a distance learning option before her to resume schooling. But she was not interested in studying subjects that would not be helpful her in practical

usage. In fact, she would prefer to get married and raise a family instead of doing that.

Fortunately, with the help of magnifying glasses, she could read some printed material in controlled environment. Now she was enjoying the reading of different books independently. Her mother gave her a book of Denise Robbins' *The Leopard in The Snow*, a romantic story. After reading that story, she became pleasantly conscious of her youthful womanhood and began paying attention to her appearance.

At the time of morning walk, she suppressed her sorrow after seeing a large number of enthusiastic students from renowned universities like JNU. It evoked a desire to be a student herself in her mind. She thought that the prospect of a university education was entirely out of question for her because of her blindness. So, she desperately felt being incomplete.

Her nature was very fantastic and enthusiastic. She always endeavored to learn something new despite her blindness. She had found way of communicating independently in a legible script with the help of portable typewriter which her Daddy had brought from the US. Soon she became a master in the skill of typing. As she went to Calcutta at her Aunt Frauke's home, she learnt swimming at the Calcutta Swimming Club under the guidance of Mr. Kerna.

At the time of living in Calcutta, she heard about dating first time. She had been associated with doctors from patient's standpoint and so much enamored with doctors. So she didn't miss the chance to make friendship with a medical student whose name was Govind. She wanted to continue dating with him but their relationship was ended very soon. She found that he hardly uttered more than a few words throughout the

one and a half hour of their meeting. She didn't want such monotonous man as a life partner.

As she described earlier, her friends left her alone when they heard about her disability. But she didn't see such attitude in the nature of her dearest childhood friend, Madhumita from Agartala, who now coincidentally moved into her neighborhood in Delhi. Madhumita was pursuing her graduation from Delhi University. She would often take her along to the college festivals and other social events. She proudly introduced her to the college mates without feeling ashamed of bringing along a blind girl as her friend. The normal people were generally hesitant to proclaim any association with persons with disabilities, but Preeti never felt this with Madhumita.

Her only ambition was to marry and settle down in life. According to her, that was the best option left in her hand. But she suffered a lot in that process on the account of her disability. It was a trend in Indian society to marry off the daughter of family as soon as possible, she wondered why her turn had not come. Therefore, she promptly decided to look one herself rather than waiting for someone to find a husband. She felt that she herself could choose correct life partner as she had an exact picture of her life partner in the mind. She seriously started looking for her prospective life partner everywhere in her neighborhoods, relatives and friends by putting aside her predetermined conditions regarding partner's appearance and profession. Meanwhile, she discovered the 'Pen Pal' column in Sun magazine that helped to seek a friend. She found a friend named Narendra who was from Madras and started writing letters to him. Narendra gave her positive response even after hearing about the problem of her disability.

Meanwhile, her family shifted from Delhi to Goa as her father had accepted an offer to serve as chief engineer with the state electricity department. Preeti was pleased as she got the letter from Narendra who was coming to Goa to meet her. Few days after their first meeting, she asked him about the future of their relationship. But she got the negative response from him just as “Well, I am not sure...whenever my father brings up the matter of my marriage, I will definitely suggest your name, and if he approves of you, I will definitely marry you!” (83). She was hurt by his audacity to dare such expression towards the girl that he claimed to love so much.

Once a proposal of marriage arrived for her from a relative in Chandigarh. The prospective bridegroom was a Sikh air force officer who was looking for a second wife. In fact, he was ready to accept her with disability. Preeti was also happy with this relation because the man who didn't see her but willing to marry her as he was fully aware of her disability. Their wedding would be scheduled within few months. But her sweet dream of new life crashed when the matter of their marriage took an unexpected turn. The dejection and despair both engulfed her when she heard the prospective bridegroom was going to marry another woman at the same time in Patiala. She didn't understand why he had deceived her as she never asked him to marry her but he himself intended to marry her.

In Goa, a general manager of a five star hotel offered her to work in the hotel. She spent two days of her job very happily. But on the second evening general manager of the hotel requested her parents not to send her to the hotel anymore because the employees of the hotel had gone on a strike due to her ad-hoc appointment. This was the most shocking thing for her. In fact, she was being denied the basic right to live

in this world on the account of her blindness. She felt “I was not snatching anything from anyone, I meant no harm, and only wished to live with dignity” (89). Her simple urge was that to live with dignity as everyone else. In reality, she possessed different skills including cooking, knitting, housekeeping, swimming, reading and writing. She also had an excellent conversation skill that she could hold with anyone without hesitation. But still she felt that no one wanted to share this world with her because she is blind.

Her family moved to Delhi from Goa. She heard about the National Open School, a special distance learning institution for school dropouts. Her parents also succeeded in convincing her to acquire some formal education. Although, this idea didn't attract her, she decided to give class 10th examination. She also went to the Blind Relief Association (BRA), a school for blind boys to confirm whether she could learn a vocation. The principal who himself was blind, advised her to learn braille to read and write independently.

Once her grandfather had advertised in the matrimonial section of the Sunday newspaper for her. Actually, he didn't mention her disability intending to inform them at the time of their coming to see her. But the prospective groom and his relatives sprinted out of her home as they heard about her blindness. Even none of them had shown any courtesy to see her. She tells “Thankfully, I never had to go on display, but it was certainly a nerve shattering experience to watch prospective grooms and their relatives sprint out our home when they learnt of my impaired vision” (93). It shows that disabled women are not usually preferred for marriage in Indian society.

Meanwhile Keith, who was regular visitor of her home, fell in love with Preeti despite her disability. Preeti was also attracted toward Keith's attractive and handsome personality. She was very happy with this relationship. She thought "The Lord had not allowed any other man to claim my hand...because he had intended this very special man for me" (95). They decided to marry soon but his parents didn't give positive response to their marriage because she was not a Catholic and she was blind too. Keith left his parents' home for their relationship and shifted in one room rented apartment. Considering Preeti would not manage to live with him in one room, Keith himself requested her parents to permit them to live with them after marriage. Preeti's parents also agreed with that decision but she was not happy with this arrangement because she didn't want to put burden upon her parents.

After all, she married the man of her choice. So she was very happy but her happiness didn't last long. On the first night of their wedding, she realized that she married a strange, alcoholic and abusive man. She never ever heard that type of abusive language and strange behavior in her twenty-two years. She says "I could not figure out what had suddenly hit me; everything had been completely enchanting and joyful till a couple of minutes ago; what had so suddenly triggered off such violence in this wonderful individual?" (99). She observed that he went out of control because of drinking too much liquor.

Thereafter, she also found that Keith was doing nothing but spent the rest of the day in front of the television. On the top of that, he drank liquor and tortured her regularly. She realized "With my wedding having changed the course of my life so drastically, my self-esteem and confidence crushed and diminished, I went about life as if in a nightmare!" (101). She was frustrated after marriage. So she felt that she

was better off without husband. After few months of their marriage, she was pleased by the news of her pregnancy. But even in pregnancy, Keith continued to torture her. Fed up with his regular torturing, she attempted to end her life by swallowing half a bottle of rum. Fortunately, it didn't affect her and her infant.

She was not only bearing his physical but also mental torture. He often asked her to bring money from her father for one or other reason. But he never returned them again. Actually, she didn't want to put extra financial burden on her father but still she had no option. She was going with a lot of mental pressure and wanted to share her sorrow with someone. There was no one with whom she could share her pains and troubles. However, most often she would suffer in solitude and silence.

Keith was very careless. He didn't want to take any responsibility. He spent his time with playing carom or going to movie with friends every day. Whereas Preeti spent each day under the tension and guilt of being so helplessly and hopelessly dependent upon her loving family. Many times, she was possessed with the thought of dying in childbirth. But she knew that putting an end to her life would bring unbearable pain to her family, so it was better to remain alive and hope for the best.

She often lived under the fear of his unpredictable outburst and sarcasm. She considered herself fortunate because Keith had accepted her despite of having disability. But after their marriage, Keith often made fun of her blindness. Once he made fun of giving her an empty plate with spoon on it and then asked her to eat that. As she put her hand on the plate searching for the food, he had a hearty laugh. On the top of that, he often call her 'blind bat'. He told her that "You should thank your stars I

married you... don't you all ever forget it" (105). He thought that he had done a great job by marrying disabled woman like her. Till the time of their marriage, she never felt that she was blind because he cared for her a lot and never behaved like that.

Meanwhile, she was bestowed with a baby girl whom she named Fiona and second time a baby boy whom she named Mark. She thought that Keith might be changed after becoming father, but it did never happen. He never took the responsibility of her and children. The major part of his salary went on his own entertainments. She was annoyed by the thought of how she would look after her two children or how much burden she had given to her parents.

He would never allow them to live in peace. While his own wife and children craved for a few movements of love, care and affection, he spent a large part of his time running errand for friends or neighbors and solving the problems of sad and lonely women. If he felt in mood, he would play with his children, if not, he would beat them cruelly. Everything depended upon his mood that could change any time. If he ever did something good for them, it was only for winning the appreciation of outsiders. People were impressed by his goodness. They often appreciated him saying "What a wonderful act of kindness to have married a blind girl" (113). It reflects the tendency of Indian people who are never surprise if the non-disabled woman accept disabled man, but they are surprise if the non-disabled man accept disabled woman as their life partners. The people also thought that Keith was very caring and wonderful man who left his parents' home just in order to look after her entire family. But the reality was that Keith himself decided to live in her parents' home after their marriage. And now he established himself as

ruler of her parents' home but none of them dared to raise any objection just to maintain peace at home.

She realized that Keith was not good as husband or father. He didn't have any love or care for them. He was neither in happiness nor in sorrow with them. She was already depressed by the thought of living a life with total dependency. In addition to that her two children's responsibility also came on her family. So she decided to do something through which she could earn money. She was aware that no one would give her job with just a class ten certificate. She couldn't take music classes. She could take on some typing work but it was too poorly paid even after taking hard efforts. She thought of opening a day care facility for children of working mothers but it was also difficult enough to look after the two of her own.

She knew that if she wanted to live dignified life, she had to become financial contributor first. So the idea of running aerobic classes struck her. She was motivated by Veena Merchant's 'Keep Fit Show'. At first, Veena showed her negative response on the account of her blindness but Preeti convinced her successfully by showing her ability to take up the profession of an aerobics instructor in spite of her blindness. After getting the permission from Veena, she joined the instructor training program. Charlie, the instructor, was teaching both via visual and verbal instructions. If she was unable to follow anything, Veena corrected her physically by pulling and pushing her arm and legs. Thus, she successfully completed her classes. After completing her classes, she started teaching Veena's classes. Soon she had launched her own aerobic classes.

Within three months of launching her own aerobic classes that was called 'Preeti's Keep Fit', she had got both fame and money. Along with that she was transformed into a confident and self-assured woman. Her new found financial freedom and professional success only triggered further negative feeling into her relation with Keith. As years passed her fear and humiliation suddenly transformed into anger. So she retaliated Keith through the open verbal battles. Now she was becoming an aggressive retaliator rather than being impatient all the time.

The entire responsibility of running the home, classes, and the children devolved on her when her Mummy and Daddy went to Ireland and Germany to visit her Uncles for three months. She would take the help of Sandy but he fell seriously ill after the day following of her parent's departure. Meanwhile she could somehow manage the household duties but it was difficult for her to manage the responsibilities outside the home due to her disability. During that period, she took the help of her friends and students instead of her husband. In the toughest journey of life, her friends not only gave her hand but also emotional strength.

At this juncture, she came in contact with other blind people who had greatly inspired her by their talents and achievements. Even she got other opportunities to work. She met Vimal Mohite, director of education at the National Association for the Blind (NAB), who requested her to teach aerobics to the blind children in school. Thereafter, she began teaching aerobics to hundreds of students at the school, which gave her a new and vibrant energy. Now she got the meaning and purpose of her existence. Thereafter, she was drawn into the other activities at the institution like teaching English to the students, counselling parents and other administrative activities under Vimal's expert instruction.

Meanwhile Keith's words and action still continued to hurt and upset her. She wanted to separate from Keith forever in order to get rid of him. Her inner voice told her that it was the proper time to reach at the correct solution to the most painful problem of her life. She described "It was the most wonderful feeling that once I could have Keith out of our lives, we could all live free of dread" (122). She was annoyed with his merciless physical and mental torture. So she wanted to live with peace by letting him out of her life.

Her mother convinced her to give him one opportunity. So she came up with the idea of asking him to take her and the children to his own home because he might be bothered while living with all of them. Even the idea of her own home appealed to Preeti. She herself was not looking her lonely life forever. In fact, she didn't wish to deprive her children of their father's love. So, she agreed to give him another chance. They shifted in their new rented two-room apartment in East Delhi. But within few days, he was back to his way. He again started drinking. He completely ignored the responsibilities of his family. On the top of that once he beat the children mercilessly. She found that her children also felt unhappy and insecure in their home. So she sent them back to her parents' home. As she thought it is unbearable and unsafe to live with him, she also came back and stated living with her parents.

Now she promised herself that she would live the life on their own terms with self-respect and dignity. She suffered an excruciating pain in Keith's company but she took it positively thinking "My marriage to Keith had given me two beautiful children, my own home, and the opportunity to manage life independently" (136). Thereafter, she built up such confidence and capabilities that helped her to move forward. She met innumerable people and grew her knowledge. In the meantime, she

went to Germany to her favorite Aunt Frauke. In Germany, she realized that why she hadn't tried to look beyond the spectrum of growing up, marrying and bringing up the children and waiting for death. The trip to Germany transformed her from battered or frightened into a smart, confident, self-assured and sparkling individual.

Once Mr. Vikram Dutt visited her with an invitation to go to Calcutta for the Disabled People' International Conference as a resource person as expert on aerobics. At first, she was scared by the thought. But her fear vanished when she was greeted by the cheerful voice of other participants. As a resource person, she had the privilege of staying in the luxurious rooms at the Taj Hotel. The overwhelming experience of meeting three hundred persons with various disabilities and their limitless admiration restored her lost confidence and self-esteem. She returned home with scores of friends and she got many offers of employment as well. Mr. Vikram Dutt and Anuradha motivated her to join National Association for the Blind, Delhi to teach aerobic and typing to the blind children at the school. Thus, she joined her very first job with fifteen hundred rupees. At the very first few weeks of working in NAB, she had made loads of new friends. She was for first time aware about a huge world out and so much more could be done. She expresses "I felt like a little bird that that had been let out of her cage and was flitting from branch to branch, and then from tree to tree" (154). After a long time, she felt herself free.

Once she telephoned her old friend Sunil with whom she learnt about her new business about marketing and sales of pickles. Seeing an opportunity of making extra money and keeping in close touch with the man she loved, she showed interest to sale few boxes of pickles. She sold

the boxes to her friends, colleagues, neighbors and people in her locality. Sunil offered her the job of marketing manager in her company.

Their product which had been rejected by the market many times earlier, was prominently displayed without any charge by the relevant outlets because of her innovative ideas and natural selling skills. They decided to market other products like popcorn and papadom under the brand name of 'Preeti'. However, along with pickle, they launched popcorn with her signature as a new product. As their workload increased, they needed more people to help. Therefore, Sunil highly recommended Ashwani, one of his former employees as marketing concern. Ashwani was twenty-six, a young boy with smart and good looking personality. She liked his dedication and meticulous work habit.

Although she was visually impaired, she successfully managed to do all the activities. Her day began at five in the morning with teaching of aerobics before to help kids to get ready for school and readying herself to work. She worked almost twelve to fourteen hours in day. Sunil told her about the special benefits offered by Delhi Financial Corporation for persons with disabilities if she took a loan for business. As she did so, she received the exhilarating partnership in Sunil's business. Meanwhile, she thought that it was proper time to file for a divorce. To find a lawyer and to afford the fees was beyond her reach. So, she took the help of non-profitable organization 'Shakti' or 'Shaktishalini' in this matter.

In the meantime, the bank refused to proceed the loan on her name because she was blind. So, she took this matter to Human Rights Commission who thereafter ordered to issue the loan to her. This was her major victory because henceforth no bank in India could refused a blind client the right to open and operate a current account. Thus, as their

business extended, they launched their products in the neighboring states. Working in streets and markets in the burning heat of summer and freezing cold nights had strengthen her determination. Even though she was working hard, she was still unable to earn enough money to fulfill her and children' needs without her family's help. So, she buried her desire to assist other disables temporarily and to find only partial rendering services like counselling and encouraging disabled people.

It was totally unexpected for her that Sunil was getting married second time with another woman. She wanted to give up the life but she couldn't because she didn't want to see her family again in pain. She thought that she hadn't any right to fulfill the relationship because she was blind. She shared her grief with Ashwani who was also defeated in the game of love at the same time because his girlfriend left him for someone else. Sharing the similar experience with each other made a close bonding between them. Once she declared her true feelings of love towards him. He also accepted her proposal. They decided to marry.

Meanwhile, she was regularly attending court for her divorce which was finally granted. She soon married Ashwani. She finally won the man of her dream to live with love and care. They both were working hard to take Sunil's business forward. But Sunil didn't want to continue her in his business partnership now onwards. He terminated Ashwani's services and instructed him never to enter in his office. She asked Sunil to return her money that the company had borrowed against her name to enable her to leave too. Now they both were jobless.

She went to participate in a fashion show organized by the Ability Foundation. She always dreamt of walking the ramp, so in the form of this fashion show, her dream came true once more. It was fashion

show where the persons with disabilities were to model alongside professional models like Aishwarya Roy. It gave her chance of modeling in another fashion show where the famous Bollywood actor, Rahul Dev was to be her co-model.

The positive changes in her life began to come. Ashwani's parents had reconciled with them. Likewise, she got the excellent news of the allotment of a DDA flat. Their dream of taking flat in the locality of Mayur Vihar came true. Most importantly, both of them had got good job. Her children also completed their education, got jobs and settled in their married life.

She joined her new job in Katha, an NGO working in the field of education and publishing as a public relations and revenue manager. In the office, her co-workers felt inferiority complex due to her efficient performance while working there. She had major disability and low qualification but she performed better than them though they were much qualified and able-bodied. Their resentment was expressed in various forms such as some of them showed unsolicited sympathy to her or few of them tried to find her faults. Likewise, others intentionally ignored her or placed needless obstacles in her way. But she always ignored their ridiculous actions and utilized her working time to best of her ability.

Apart from working at Katha, she continued to work freelance with the disability sector. She had been offered a position with one of north India's most prestigious eye hospitals where she got the opportunity to head the public relations department of Dr. Shroff's Charity Eye Hospital. She was drawn into fund raising, marketing, training trauma counseling and patient relations activities for the hospital.

She also launched her own organization called Silver Linings. She was practicing art of writing and spent the rest of the time expanding the knowledge. Once she conducted a motivational seminar for the corporate employees. After that, she worked as corporate trainer. Now her mission was to inspire, guide and motivate people all over the world. She was first appointed as the Indian coordinator and then nominated as a board member for the Combat Blindness Foundation India, a US based organization, working in the area of avoidable blindness in the developing world.

With the encouragement from her family and friends, she began the journey of this book. Furthermore, she wrote the content of her web site and worked on a story for the Chicken Soup' series in addition to authoring a 'Hot Shot' recipe book in collaboration with Susan Vishwanathan, a scholar and her dear friend. Then, she gave up the job at SCEH and launched a new business venture called Silver Linings HR Solutions Pvt. Ltd., an executive search company.

Thus, her overall journey shows that life was not easy for her. Being a woman and disabled, she herself faced double marginalization in Indian patriarchal society. So she has been working for the empowerment of visually impaired women or girls for many years. In her Interview with Ria Das, she has given the valuable message for all women or girls to become successful that "Women need to understand that we are equal citizens on this globe. We have equal responsibilities and equal rights" (<https://www.shethepeople>). She faced many difficulties in life but she never gave up. By taking hard efforts, she achieved magnificent success in her life.

Chapter IV

Autobiographies of Wheelchair Users

1. *No Looking Back* by Shivani Gupta

No Looking Back is Shivani Gupta's autobiography which was published in 2014. It is divided into five sections with significant titles, including prologue and epilogue. In this book, Shivani Gupta unfolds a true story of her life that inspires thousands of people all over the world. It is unbelievable but twice in her life she met with car accidents by which her dreams and aspirations were shattered completely. In fact, she lost everything that was familiar to her, but still she made herself stable in these situations and resumed her life again.

In the prologue of this book, she has provided some essential information about the background of her life journey. In the background, it is clear that she is going to attend alumni meet of her batch mates of 1991 at the Institute of Hotel Management (IHM), New Delhi. Her caregiver, Ritu is also accompanying her for assistance. She needs assistant because she is a wheelchair user. The venue of their meeting is The Kingdom of Dreams in Gurgaon. As she reaches in her car at the venue, her classmates come and gather around her. She met some of them at her wedding ceremony one and half years ago. But she is meeting many of them after a long time of twenty years.

In the first section entitled 'Rebirth', she has described how she met with first accident at the age of twenty-two while riding in a car on the road with her friends after attending the party at night. In that accident, she survived somehow, but her spinal cord was injured severely,

resulting in permanent disability. As she found that she could no longer walk, she started using wheelchair.

The main story of this book begins with her hospitalization after the first accident. At first, she was admitted to one of the hospitals where she had been diagnosed with a spinal injury. So, she was shifted to the All India Institute of Medical Science (AIIMS) for further treatment. This hospital was considered as one of the best government hospitals in India, but she received very poor treatment in that hospital. It was unbelievable but she had to spend so many hours even to get admitted, although she was in very serious condition. Along with her, many other people like her were waiting to get medical assistance or a hospital bed. She describes “I lay on a stretcher for hours in a dirty and overcrowded corridor, along with so many others, in line to get admitted” (Gupta, 14). In such condition, Shivani felt just like being in hell. Due to the shortage of resources in such government hospitals, patients have to wait for hours in order to get proper treatment.

On the top of that, the hospital was very poor in terms of cleanliness and sanitization. She explains “Flies buzzed around the place and the obnoxiously strong odour of disinfectant overpowered my nose” (14). Likewise, lying on the back, she sometimes found lizards crawling around the roof of dirty room of that hospital. Indeed, it is very disgusting thing that the patients and their relatives have to stay in such unhygienic condition all the time. Briefly stated, health care facilities provided by the government hospitals to people in India are not up to the mark.

Even after staying for many days in the hospital, there was no improvement in her physical condition. In fact, it was getting worse day by day. She developed ‘Tetraplegia’ which is one of the most severe

forms of paralysis that may again lead to the further complications. She soon started suffering from lung infection that was sure to aggravate into a lung failure. The doctors were unable to control her deteriorating condition. According to her, “it was as if they were waiting for my condition to deteriorate, having decided that I was not going to improve even if I survived” (35-36). It means that the doctors were waiting for her condition to deteriorate because they were completely negative about her condition.

Fortunately, she was rescued by Dr. Chahal who was a senior doctor specialized in spinal surgery and a director of impending spinal cord injury center in Delhi. After going through her files, Dr. Chahal realized that she should have been operated as soon as possible after the accident for maximum recovery. But the fact was that due to the lack of attention of doctors in AIIMS, her condition had become more complicated. It took time but her condition improved to some extent by proper treatment and surgery of Dr. Chahal. After spending Two months under the supervision of Dr. Chahal, she was able to sit on a wheelchair. She accepted the wheelchair willingly because it was better than lying on the bed all the time.

She started understanding her condition with the help of Dr. Chahal who created hope of living in her mind. Indeed, Dr. Chahal played a crucial role in her life because he always tried to encourage her by telling the stories of other people who had done very well in life in spite of being tetraplegics. It is true that human being can naturally accept and adjust with each new situation. She tells “It is uncanny how, over time, a human being can adjust to and accept his or her changing circumstances” (40). She also started accepting her condition without any hesitation.

There was nothing that she could visualize in future. Even there was no ambition or aspiration to think about. At this time, she had to relearn simply how to live. Delhi was a capital city of India but no single rehabilitation center was available there. Therefore, she had to go to Pune where the only rehabilitation center available, that was a part of military hospital. At the center, she realized the permanence of her situation after meeting with the people who had been living in a wheelchair for long years. She didn't understand how to react to this realization that she was not going to walk again.

Before the accident, she was living a carefree and relaxed life. As other girls, she had also dreamt of marriage with Sunil, her boyfriend from college, having children and settling down in life. She elaborates "All I really seemed to want, I had realized, was a family— a husband and children, and a life with them" (08). But everything had changed after the accident. She realized that the things were not going to be the same in future. Now she could not even dream of that.

She was confident and independent person earlier. She always liked to handle all of her affairs on her own. She could do whatever she liked without bothering anyone. But after meeting with accident, everything had changed suddenly. Now she had to completely depend on people around her. In reality, her surviving in this accident is like a rebirth which gives her new identity as a disabled. She had no other option but to accept this new identity. Before her accident, she had never even thought about disability. In fact, she never heard anyone in her contact who was disabled. But now she understood what was disability and its implications.

As mentioned earlier, her independent existence had vanished after her accident. She could not walk and work on her own. So, she had to depend on others even for doing simple activities like grooming, toileting, sitting, eating or turning. She got personal caregiver named Putul, a young girl from West Bengal to do these things for her. She first time realized how it was challenging to accept and adjust with personal caregiver. It was difficult to maintain physical and emotional privacy by having a constant company of caregiver every time. But the problem for the disabled people is to spend most of the time in the company of caregiver. According to her, “Having a caregiver also meant goodbye to the privacy that is usually important to maintain one’s sanity. Life with caregiver wasn’t just a compromise on physical privacy but also emotional privacy” (52). It means that there was little space for individual to think about something in a constant forced of someone’s company. But being a disabled there was no other option left. So she accepted this fact by thinking that because of caregiver, at least she was going to stop being dependent on her relatives. At this movement, she missed her mother who would have taken her responsibility, but she passed away some years ago.

As time passed, she accepted and adjusted with the new reality of her life. Most importantly, she understood that her spirit was stronger than her body. Although her body looked so weak outwardly, she felt very strong internally. She realized that despite her impairment, there were a lot of things that she could focus on. In fact, she knew that it was difficult for her to fit in the society where disabled people have low status. Although everything was casual for her earlier, now “Each day was a challenge, with several ups and downs. Each day was like a lifetime of learning and experiencing” (54). It means, as she became

disabled, she started facing new issues and challenges through which she learnt a lot.

A couple of years after her accident, Sunil, her boyfriend, occasionally came to meet her. But as time passed, he stopped visiting altogether. She already knew that there was no place for her in his life any longer because everything had changed after the accident. So, when she received the news of his marriage, five years after her accident, she was not surprised. The reality is that disabled women are not culturally accepted for marriage. In most of the cases, they are abandoned by their partners after becoming disabled. This is all because of the society that expects woman to perform different traditional roles like to take care of her children or family and manage all house hold duties. And the people believe that such house hold duties cannot be managed by disabled women. The same thing happened with Shivani whose boyfriend, Sunil abandoned her after she became disabled.

After the realization that her spirit was stronger than body, she decided to do something that could help to prove her identity. She knew that her acceptance back into society after her disability was not possible. She tried to get a job in a back office of the hotel where she used to work before meeting with an accident, but she was rejected on the account of her disability. Even getting a job anywhere else on the basis of her hotel management degree was not going to be easy for her. So, she decided to restart her life once again with retaining another skill. Meanwhile, one of her friends reminded her skill of painting. Although she could not hold the brush in her hand, she learnt alternative way of holding her brush to get better control over it. Thereafter, she started practicing her painting which provided exercise to her hands. After some days of practice and discarding numerous sheets of paper, she found improvement in her

painting skill. Then, she produced a number of cards with beautiful paintings. Once she had got the chance of displaying and selling her painting cards in a fair of one of the colleges in Delhi. Thereafter, she got chance of displaying and selling them even in various fairs of the charitable organizations.

As she started facing the outside world, she confronted various issues and challenges. Most importantly, transportation became serious problem of her life. While going to display her painting cards in a fair, she first time became aware of inaccessibility of public transportation in India. On that particular day, her friend managed to drop her at college in her father's car. But she noticed that it is difficult task to transfer herself into vehicle. She needed at least two-three people to get in and out of that. Every time she had to take the help of other to do so. So she realized that if the public transportation provided the access, she would have managed to travel on her own without giving trouble to others.

As she got chance of attending other fairs of charitable organizations to display and sell her painting cards, she somehow managed to travel by auto rickshaw to attend these fairs. She comments:

“Travelling in an auto for a tetraplegic with a wheelchair and a personal caregiver was reckless and next to impossible—yet, I did so because that was the cheapest mode of transportation available to me” (70).

It shows that it was very difficult for her to adjust in auto rickshaw while travelling, but she had no other option. She knew that travelling by bus was not feasible for her because there was no way that she could board the bus in her wheelchair. Although it was easy to transfer her into auto rickshaw than the bus, each time going by the private vehicles was

not affordable for her. In fact, almost half of her money that she earned in these fairs was spent on her travelling. She tells “my money went towards my transport and buying more materials for painting” (70). In short, due to the inaccessible public transportation system in India, she had to meet a wide range of challenges as she wanted to go out.

Along with the problem of accessibility, she had to face attitudinal barriers in her life. This is because the attitude of society towards disabled people is not good in India. Once Shivani went to Haridwar for blessings with her family. As she was waiting in the queue to enter the temple at Haridwar, a poor middle-aged woman came to her and handed her a twenty-five-paisa coin assuming that she was a beggar. She didn't understand how to react in this situation. It was really a humiliating experience for her. Generally, the people in India view that disabled people are needy and they live with the charity. She felt bad because people started judging her only on outward appearance instead of her internal qualities. According to her, “Providing me with charity was probably much easier than to try and really understand what I needed” (64). She hated such charitable act of people towards disabled people. She found that the same charity being distributed for persons with disabilities in so many ways in the society. According to her, it is always better to provide them barrier free environment instead of offering any kind of charity.

She observed a kind of condescending behavior of society towards disabled people. She started finding her own opportunities and creating a path for herself by avoiding negative attitude of society. She writes “I could learn to handle and overcome all the problems my disability brought with it, but there was no way I could change society's attitude towards me” (64). It is really difficult task to change the attitude of the

society because society has already stereotypical opinions and misconceptions about disability and disabled people.

Her father returned to India from Nigeria to take care of her after two years of accident. Although he took her responsibility, there were other challenges that awaited her attention. She didn't want to depend on her family any longer. In this situation, painting somehow seemed to be her new profession which gave her confidence and encouragement to face the world. In fact, her painting skill gave her new identity and again brought meaning in her life. Additionally, it also provided her a way to become a self-reliant and gave her strength to push herself beyond her limits. Some charitable organizations gave her opportunities to display and sell her painting cards in their monthly fair through which she started earning small amount of money. Sometime she felt that she was selling her hand-painted cards as her college friends were holding good positions and had promising futures. But still she was happy for doing something productive and remunerative. In reality, it was easy for her to be dependent on her father for the rest of the life, but she didn't want to do that.

Once she got the opportunity to have a solo exhibition for her paintings. During this exhibition, she was appreciated for her work and ability by the people. All the media people took the notice of her creativity. She was interviewed for TV channel. There were articles printed in the newspapers showing "The Flower Girl' who could not hold a brush properly in her hand created delicate watercolour paintings" (70). But she didn't like media's act of highlighting her stories more than art to inspire readers. They were making her paintings to be some kind of superhuman act that required a lot of courage. In reality, she was getting too much attention because she was disabled.

In India, people believe that disabled people can be cured with the divine power. So, she had been told the names of miracle healers available in some village especially by the auto drivers or some other person on the road. But she writes “I could not blame people for sharing these recommendations because a disabled person is generally viewed as someone needing treatment to become ‘normal’” (70). The people didn’t understand that she was not ill but she used wheelchair as mobility aid to overcome her walking difficulty. She took these incidents as amusing.

She was in search of stable profession. Luckily, she got a job in the rehabilitation centre at the India Spinal Injuries Centre in Delhi. Before joining rehabilitation centre, she attended two-months training in Salisbury in UK, which was required to be a peer counsellor. She was very much impressed by the accessibility for persons with disabilities in UK. She had been to other countries in Europe before having disability, but this experience of visiting such developed nation was different in many ways. Earlier she had just noticed the beauty, infrastructure or cleanliness of the places but now she observed how disabled people interact with their environments and society responded to their needs.

In Salisbury, she found that a number of wheelchair users were leading their life with the most regular manner that she had never seen in India where disabled people are confined to their homes or other charitable institution. As she went outside in India, the bystanders were always curious about what had happened to her. She often heard their comments like “Chhi chhi! See, such a young and pretty girl in a wheelchair—who will marry her now?” (76). Such type of remarks made her unhappy but she deliberately tried to avoid them.

As she visited other offices for some work, her physical presence seemed like a burden to people who expected from her to send a representative instead of troubling herself to visit personally. Actually, she wanted to be self-reliant but people made her feel that she was different from others. During her training, she saw the disabled people in Salisbury were doing their chores themselves. Through her training in Salisbury, she understood the true meaning of rehabilitation which taught disabled people how to overcome the obstacles.

For her, one of the most memorable events during that training was a cocktail party which was organized for all the current and ex-patients of the rehab centre in Salisbury. In this party, she was surprised to see the unique relationship of Andrew and Nina. Andrew was one of the patients and Nina was the physiotherapist in the centre. They had met in the hospital and fallen in love during his rehabilitation. It was beyond her imagination that a non-disabled person can fall in love with a disabled person. She never ever saw such kind of relationship in her life. She saw “They seemed so much in love that it was like something out of a fairy tale” (79). It shows that their relationship was so unique. Such type of unique relationship are rarely found in India.

After returning from her training in UK, she joined rehabilitation center where she had got an opportunity to help people struggling with spinal cord injuries. She offered proper information and support to spinal injury survivors about their spinal injury. This was exactly what she was not given at the time of her accident. While doing this job, she met various people with spinal injury from different backgrounds. The rehabilitation center was located in Vasant Kunj and it was not possible to travel up-and-down distance of almost sixty kilometer every day. The

management kindly offered her a room on campus, which was not in good condition but it was better than travelling daily.

Shivani found that along with the transportation services, the places of entertainment are also not accessible for persons with disabilities in India. Once Shivani went to the first multiplex cinema theatre at Delhi to watch Titanic, with her friend Annie and her another colleague at rehabilitation center. It was her first time to go to such newly built multiplex theatre. So she had no idea about its accessibility. As she reached there, she was informed that a wheelchair user can get access only to two out of the four halls. She became furious because she had to sit in one corner of the hall separately accompanied by unknown people while her friends sat somewhere else. The whole plan of watching movie together with her friends remained unsuccessful due to the lack of accessibility in that multiplex.

Before leaving the place, she started screaming at the manager of the multiplex for giving such poor and discriminatory treatment. She wrote a long note in complaint register for receiving such poor service in their multiplex, even after knowing it was completely a waste of time. Most of the time, she had experienced that “Living in India, I was used to having all my complaints ignored” (93). It shows that ignoring the complaints is common practice in India. But this time, she got a call from the senior manager of that multiplex and he expressed his wish to meet her. After their call, the senior manager came at the center to meet her with an apology note on behalf of the owner of that multiplex. At the end of their meeting, he assured her that the authority would certainly look after the issues of improving accessibility in their multiplex for disabled people.

She describes her another horrible experience of visiting the temple of Kanyakumari a couple of years ago with her colleagues from the center. As she reached there, she was not allowed to enter in the temple with her wheelchair considering it was impure. Then, after a great deal of hesitation, she made one of her colleagues to carry her in his arm to get a darshan of Goddess Kanyakumari. She was allowed to take a darshan in this way instead of using wheelchair. She also agreed to do so because she didn't know much about her rights and non-handicapping environment at that time. But it was really injustice to her. Under the name of impurity, she was prohibited from using her wheelchair which is her basic need. As she analyzes such type of past experiences in the present times, she understands that people have no problem with her disability, but they have problem with her wheelchair. The reason behind that they are unable to provide accessibility for the wheelchair users like her. Due to the lack of accessibility and negative attitude of people, many times she was either excluded from the things or she had to take the help of others to do that. She considers that this is one of the most humiliating and embarrassing experiences in her life.

Along with theatres, temples and other places, she had bad experience of the hotels or restaurants in India. As she went to Nainital trip, with her friends from the centre, she found that the hotel which was booked by them was not accessible. They got the rooms on the first floor of the hotel. So she had to be carried all the time. It was difficult to spend two nights in such uncomfortable and inaccessible hotel but she made her mind that it was better than living in the horrible hospital accommodation which was offered her by the authority of spinal centre.

She and her father suffered a lot till the final allotment of a DDA flat that she got on the basis of her disability. They went to concerned

government office in the case of approval, but they were neglected. Thereafter, they met various officers including Lieutenant governor of Delhi regarding the case, but it didn't help. One of the officers openly asked her father to pay him one lakh rupees as bribe to get the work done. But her father refused to do it. As a result, her case was further delayed. As they went to meet the minister of urban affairs, he approved the case and demanded immediate allotment. But their immediate action also took two years for the final implementation. So, when she did get her flat, the cost was double as much as they had made the application. She thought thought "If only we had paid the bribe, we could have saved ourselves a large amount of money by getting an allotment earlier, when the costs were lower!" (127). Just like her, many disabled people do not meet their needs due to such corrupt people in government offices.

While working at Rehabilitation centre, she met Vikas who was an occupational therapist at the spinal centre. At first, they were just casual friends but the trip to Nainital brought them closer. During the trip, she noticed that Vikas was different from her other friends. He was the only person who had not left her alone while others were enjoying trekking or visiting other places that were inaccessible to her wheelchair. She assumed that she would find some excellent friends in this trip but much later she got to know that none of them had really wanted to take her along because she was disabled and was going to be accompanied with her carer. Through this incident, she learnt the hypocrisy of people to whom she thought her real friends. She thought that it was better for her to remain in her own space where the people would not bother her while making a special arrangement for her.

After this incident, she developed a habit of inviting people to her place instead of going out with them. She explains:

“As a disabled person, if my friends exclude me from taking me along for a rock show, a movie or a pub, then I am supposed to understand their difficulty and let go rather than expect them as friends to assist and ensure my inclusion” (101).

It shows that she usually adjusted with the things that excluded her from mainstream society and stopped expecting from the people especially friends to assist for her inclusion.

Over time, intimate relationship developed between Vikas and her. Once she got an invitation to participate in a fifteen days training organized by the United Nations Economic and Social Commission for Asia and Pacific (UN-ESCAP) in Bangkok, Thailand. Vikas also joined her for this training. They attended this training very seriously. It made them realize the importance of non-handicapping environment in the lives of persons with disabilities. They understood that providing accessible environment for disabled people was the most basic right for them to live with same ease and dignity as a non-disabled person. In short, this training created interest in their mind to work on accessibility for persons with disabilities in India.

Vikas decided to do job as occupational therapist in UK, but he had to give the exam to work there. On the occasion of his exam, they again travelled to UK together. After going to UK, they heard about access survey for London Access Guide. In the form of this survey, they got an opportunity to travel Europe for a week with the group of eighteen people. Their stay and food was taken care by the group. It was a novel experience for both of them. Having an access guide in all tourist areas is useful concept. In India, many travel guides are available in the market

but they have lack of information on accessibility for the benefit of disabled travelers like her. They were impressed by this project. They started dreaming to bring the new concept of access guide in India. And after eight years, they had successfully developed their own travel portal called 'Free to Wheel' with access information for places in Delhi.

The last phase of their trip was a journey to Paris and Brussels. Vikas pushed her wheelchair throughout the trip. They found that most of the places in foreign countries were accessible, but she shared her horrible experience when they were going to visit Eiffel Tower. As they got off at the station for Eiffel Tower, they saw a flight of fourteen steps while coming out of the station. They might be not knowing other accessible road and they could not ask anybody due to the problem of communication. So there was no option but to pull her wheelchair up all these steps. At this movement, she started cursing herself for coming to this trip but it was not her fault but this was because of the poor designing of spaces. As Vikas slipped out of his shoes while pulling her up with wheelchair, she was petrified by the thought that:

“My wheelchair could have easily slipped out of his hands at any movement, or he could have lost his balance and both of us would have gone lolling down and hurt ourselves severely, in this country where we couldn't even communicate” (137).

Vikas somehow managed to pull her up alone. But no one around them came to help them and they also did not tried to call anyone for help. She thought that “At least, even if facilities are not accessible in India, people would have come forward to help without even being asked” (137). It is true that not only family members, but strangers also

come forward to help disabled people in India if they need some kind of help. Except this incident, her overall experience of this trip was fascinating.

While working at the rehabilitation centre, she came to realize that there was nothing new to learn there. On the top of that, there was no prospects for any sort of promotion. After the UN-ESCAP training, she identified her area of interest which was to work on accessibility for persons with disabilities. So, she decided to quit the job at the centre. She started looking for another option seriously. Once she went to a job fair organized by a private university which was affiliated to Edexcel, a British company. She decided to do a full-time two years diploma course in architecture technology.

After taking admission, she shifted to a rented house closer to university with her father and Ritu, her new caregiver. Her faculty at the university was most accommodating but no single place in the whole university was accessible for wheelchair except the studio and computer room. There was no other place where she could go, not even the restroom that she needed a lot. So, while attending classes, she had to face the biggest challenge that was to manage her incontinence. But managing incontinence was not easy task for her. She sometimes failed to manage that. She described her plight in the words that:

“As always, my biggest challenge was managing my incontinence. Her bladder training and practice of remaining thirsty and not drinking any liquids for hours together helped me attend my classes. Despite this, there were accidents; on those bad days, I had to leave for home early and miss my classes. These accidents never failed to pull me down. I

would often return home and cry helplessly for not being able to manage” (152).

She suffered a lot due to inaccessible premise of her university but she had no other option but to complete the course anyhow.

Vikas had started his new life with new job in the UK and she was also busy with her new course. Living apart from each other had not affected their relationship. They had started recognizing each other’s importance in their life in greater depth. Even they probably loved each other more than before. They were physically separated but still they were emotionally connected. She says “Without communication with one another, the day seemed incomplete” (152). They both knew the fact that they had no future together because Vikas’s parents would not accept her as their daughter-in-law at any cost. His parents always advised him to stay away from her. Although there was no future of their relation, they loved each other selflessly.

After completing her course in architecture technology, she was looking for higher studies. Meanwhile, she received the Neerja Bhanot Award which was given to a woman who shows exemplary courage and works for the benefit of others in spite of her own trying circumstances. In the same year, she received the National Role Model Award from the Ministry of Social Justice and Empowerment. Having the same dream of working for inclusive environment for persons with disabilities, Vikas and she took admission for a postgraduate programme at the University of Reading in the UK. During this programme, they lived together without any social pressure, which was not possible for them in India. She writes “Both of us made our home with each other, away from the society that forced us to hide our feeling for each other from everyone”

(162). She considered it to be most beautiful time in their lives. This course gave them direction in terms of fulfilling the dream of accessibility. The foundation of their organization called AccessAbility, was an outcome of this.

After completing her postgraduate programme in inclusive environment in UK, she joined a corporate company in Delhi as a Programme Manager in the department of social responsibility. Here, she had to set up the programmes for the company to work towards improving accessibility for people with disabilities in India. So, she was now happy with her perfect job profile in this company. But from the first day of her working, she started facing the issue of accessibility at her workplace. The building where her office was located, had an inaccessible main entrance with ten or twelve steps. There was another entrance which was accessible for wheelchair but that was only for V.I.Ps. Even after requesting the concerned authority, she was not allowed to use that accessible V.I.P entrance. It was really shameful because she was supposed to be a proponent of accessibility but she herself faced the problem of inaccessibility at her workplace.

The similar discrimination on the account of inaccessibility was continuously going on with her in the office. So, she didn't want to continue her work with the organization which had no proper attitude towards its one and only disabled employee. In her interview with Ananya Sarkar, she states that "Unfortunately, disabled people are always looked at as a separate group rather than part of the whole. This leads to odd attitudes of people towards us, inaccessibility, lack of opportunities and ultimately results in discrimination" (<https://www.indianruminations.com>). So she had no other source of income but still she quit her job after ten months. She didn't want to

continue working with the organization where her abilities would not be appreciated. Thereafter, along with their old friends, she and Vikas had formed AccessAbility, their own organization through which they worked for the promotion of inclusive environments in India. For the recognition of their work, she received the Ability Award and the NCEPDP Shell-Helen Keller Award.

It was unbelievable but Vikas's parents suddenly accepted their relationship. They had been aware of her existence and importance in his life. Now the constant fear of losing him was replaced by immeasurable happiness. She thought that it would be a privilege to be a part of his family. Finally, they married on 13th April, 2009. They were happy in their married life. But their happy married life was devastated after four months of their marriage. As they were going to the first family trip with his parents, they suddenly met with major car accident on their way to Manali. The oil tanker hit them hard and they were all injured very seriously.

Soon after the accident, they were taken to a nearby hospital which had lack of resources and facilities. She describes "This was, by far, the most ill-equipped hospital I had ever seen and looked more like a hostel than a hospital" (Gupta, 214). On the top of that, the staff of the hospital took them in reluctantly. In reality, the same situation is found in most of the hospitals in India.

After checking Vikas's father, the doctor declared him dead. She was terribly shocked by this news. She could do nothing but to lie down and wait for what happened next. She articulates:

"Life seemed completely out of control. Our education, our social status, our material possessions had no meaning at that

moment. The situation had taken a charge, and my family and I lay there helplessly” (215).

Afterwards, they were shifted to Sundernagar hospital where their wounds were stapled and again they were recommended to shift at PGI hospital in Chandigarh. Only Papaji’s body was being retained in Sundernagar. The PGI hospital is considered as the pride of Chandigarh, but Shivani was surprised after seeing such disgraceful place with dreadful services and inadequate resources. She saw that the staff of the hospital took them in reluctantly. The emergency ward of that hospital was full of patients and their families. At time of her first accident, she had seen the same scene in the corridor of AIIMS hospital where all the patients were waiting to get in. The worst thing was that the basic care of patients was not taken care. Everything seemed to be unhygienic. She explains “This hospital, however, was worse—the stretcher I was transferred to from the ambulance was soaking wet from the rain” (217). The doctors detected that Vikas had an internal bleeding in his stomach and Mammyji was diagnosed with a head injury and a fractured arm. Shivani had a broken femur, a fractured left hand and a deep gash across her neck.

After doing initial examinations in the PGI hospital, the doctors suggested both Shivani and Mammyji could shift to Delhi but Vikas was not recommended to shift because of the bleeding in his stomach. So, Vikas had to stay back for further treatment in that horrible hospital. They were brought straight to a super specialty hospital in Delhi where they were treated by Dr. Bajaj very carefully.

Shivani was restless in Delhi with the thoughts of Vikas who was still in that dreadful hospital. Mamaji, Vikas’s uncle was taking care of

him. She remembers that the day they got admitted to the hospital was 14th August and the next day was Independence Day, a national holiday. The doctors told Mamaji that Vikas's internal bleeding could be managed by oral medicine. As Mamaji called and passed this news everyone to Delhi, all were happy. But at that time, none of them was aware that this was the worst news they could get. The only reason of putting him on oral medication was that the doctors were not in mood to operate him on their holiday. He was operated on the next day but he was completely out of hand. PGI was famous government hospital in that region. But just like AIIMS, the nursing care in this hospital was very dismal. Even if his condition deteriorated, Vikas was not kept in the ICU before and after his operation. He just laid there on the bed fighting hard to recover. Later on, he developed septicemia that resulted in multiple organ failure. He finally gave up. She describes "Once again, it was the negligence of doctors that took everything away from me" (220). The thing which happened with her some years before, happened with him. The doctors kept assuring them that he would be fine without disclosing the seriousness of the situation until the case was completely gone out of hand.

At the initial stage of injury, the patients should receive proper and quick treatment for their better recovery. But due to the lack of resources and facilities, the patients remain untreatable for long time. Most of the time is wasted in shifting them from one hospital to another because of the scarcity of equipment. At the time of her first accident, Shivani herself suffered due to the poor treatment and negligence of the doctors. And she and her in-laws family went through the same experience at the time of their second accident as well.

Thus, Shivani Gupta tries to portray her life in this book. Her meeting with the serious accidents twice in life shocks the readers. These

two accidents snatched everything that was familiar to her. In the first accident, she lost her independent living due to the spinal cord injury. Over time, she somehow accepted and managed to live with change in her life. But again unexpected turn came in her life. She met with the second accident in which she lost Vikas who was her soul-mate and strong pillar of strength.

She survived both the times, but she was deeply disturbed by the loss of most valuable things in her life. She tried to take everything positively considering there should be a purpose behind her survival in this world. In this context, Binjal Shah states “After all, she wouldn’t have survived two such colossal calamities if she didn’t have a purpose to fulfil in the world” (<https://yourstory.com>). After seeing her great contribution in field of disability sector, one can understand why she had survived even after facing such colossal calamities in her life.

Indeed, the life of Shivani Gupta represents the situation of other disabled people in India. Her first-hand experiences reveal that even today people with disabilities have to face various issues and challenges. Accessibility is the major issue in their life. In reality, India is one of the developing countries and has failed to provide them barrier-free-environment. In her conversation with Aqueel Qureshi, Shivani tells that “Surely the present environment is a witness to the fact that planner and architects are not aware of the issue in India” (<https://www.dnis.org>). It means that the designers or architects are not aware about the needs of persons with disabilities in India.

Along with accessibility, they face issues regarding education, employment, health facilities and many more because the society has not fully accepted them. During her interview with Ananya Sarkar, she tells

that “I think society’s acceptance of persons with disabilities as a part of the human diversity is the main thing that is missing” (<https://www.indianruminations.com>). It is true that the situation has begun to change, but still they are facing many issues.

2. One Little Finger by Malini Chib

Malini Chib is one of the India's disability rights activist and writer. Since her birth, she has been suffering from severe disabling condition called Cerebral Palsy which is congenital disorder affecting muscle movement and co-ordination. Her medical condition forced her to use wheelchair all the time. She has learnt how to type with one little finger which can only work properly except her other body parts. She cannot speak properly due to her lack of speech ability. In such condition, she has completed two International Master Degrees in Women Studies and Library Science and Information Management in London. At the time of her interview with Priyanka Dasgupta, she tells "I educated myself, learnt to type with my one little finger and speak through the Lightwriter" (<https://m.timesofindia.com>). Shreya Chowdhury writes "In late 1998, at the University of London, she was one of the first international students with disability" (<https://m.timesofindia.com>).

She unfolds her life experiences in autobiography entitled *One Little Finger* which was published in 2011. The Indian film named *Margarita with a Straw* (2014) is based on her life. *One Little Finger* is divided into four sections with different names. The first section is entitled 'Roots', in which she covers earlier journey of her life. She discusses the points that are—the real cause of her disability, her parents' decision to go to England, her school days at Cheney in England, coming back to India, breaking down of her parents' relationship and her boarding life at Delarue. 'Growing up' is the second section which consists of four sub-chapters. It focuses on the later journey of her life. She describes her experience in the non-disabled world where she often

faced the problems of inaccessibility and negative attitude of people. The third section is ‘A slice of Freedom’ which seeks to emphasize her journey towards empowerment. She describes how she had successfully completed her two Master’s Degrees and got a job in Bombay. She also illustrates how she had actively started working for the disabled people in India. Fourth section is ‘Reflections’ which mainly focuses on the overall reflection of her life. She elaborates how she had got the chance of revisiting her life while writing this book.

At the very outset, she describes her traumatic birth process. She tells “During the process, the umbilical cord got stuck around my neck, resulting in a lack of oxygen to my brain...” (Chib, 03). In the medical language, this process is called ‘*Anoxia*’, a result of *Hypoxia*. Due to the lack of oxygen to her brain at time of birth, Malini was affected by a severe disabling condition called Cerebral Palsy for lifetime.

The Pediatrician was doubtful whether she would survive. He kept repeating to himself that “*it was a mistake I should have carried out a caesarean...lets see if she survives...I am not sure if she will survive...at the most 72 hours*” (03). But the luck would have it, she survived and entered into the world. She was a beautiful baby and had a fair complexion with a large eyes. Therefore, her Australian nurse called her by the name of ‘Rosebud’ and ‘Princess’.

As time passed, her family noticed that she was not doing much activities like other normal child of her age. She describes “The little effort necessary for sucking the bottle was enough to tire me and I slept all day” (03-04). Her overall activities didn’t seem to be normal. Even after few months, there was no improvement found in her condition. So she was shown to the renowned experts and doctors. Thereafter, various

examinations were carried out by the doctors to find out correct diagnosis. And it was diagnosed that she was affected by Cerebral Palsy. The motor cells of her brain were completely damaged by the lack of Oxygen. Initially, it was difficult for her family, especially for her mother, to accept the fact that her child was not normal.

Indian doctors were pessimistic about her condition. They thought that the damage to her brain was irreversible. Even the further assumption of doctors that Malini was not only physically but also mentally handicapped made her parents more depressed. But later on it was cleared that even though her body was severely disabled, her mental condition was quite normal. The witness of this fact that she was excellent in solving memory games and master mind.

Being physically disabled, she could not enjoyed the same things that other kids could do. She wondered why she could not run, play or explore the surroundings like others. Other children also not understood why she didn't play the usual games with them. They usually left her alone while playing the games.

She was upset because of people's discriminating attitude towards her. In one birthday party, she was depressed as the hostess gave all the kids their going away presents of balloons, hats and whistles but left her alone. The hostess apologized for that but she thought that Malini was unable to play with them because of her present condition. So Malini was left alone during the party as other children went to enjoy. In reality, to remain lonely is a common experience of disabled people. Such type of incidents make them to feel that they are different from others and have no right to enjoy.

Malini was very fortunate to belong to a privileged and well educated family. Her uncle, Samiran, who was a physician at the Royal Post-Graduates Medical School at Hammersmith Hospital, London, told her parents that the Indian doctors didn't know much and were extremely negative about her condition. So he suggested them to go to England for better treatment. Her parents also knew that in the area of medicine and education, England was far superior to India. Therefore, they decided to move there for her treatment. It was not simple decision for them because they had to give up many things including job, home and friends and start all the things again.

In London, Malini was admitted in a special school called Roger Ascham School in Cambridge. Later on, she moved to a school at Cheyne Walk, Chelsea in London. Her parents found that the people in England had more positive attitude towards disabled people than India. They became happy after seeing the result of her IQ test by a well-known psychologist, Agatha Bowley. In this test, she had been given many tasks to complete. The report of her IQ test showed that she was not only normal, but also above average in intelligence. A graphic description commonly used to describe the children like her in England is “an intelligent mind with a disobedient body” (09). It means that one has deformed body but intellectual mind.

Fortunately, she had received very good exposure in both home and school. Her family spent most of the time to teach her normal activities. Her father taught her swimming. She was taught how to read at the age of two by her mother and aunt through a flash card method. Everybody in her family treated her normally and spent their quality time with her. These early years shaped her personality in a proper manner.

At her school Cheney, she received the best treatment from the team of different professionals who came there to deal with the students like her. Cheney was a Teaching Hospital which offered a variety of activities that included physiotherapy, Speech and Occupational therapy, along with education. With love and support from her family and school, she grew stronger.

Malini's mother successfully completed her post-graduate diploma course at the institute of Education, University of London. Later, she became a professional special education teacher and also began to work with mentally handicapped adults at the institute in Balham. It gave her a lot of knowledge about Malini's condition. The decision of her parents to move to England was very fruitful.

Malini's parents wanted to have a second child but they were worried that something would go wrong. Then, under the consultation of Professor Brown, they decided to have second child. After her brother's birth, her parents decided to go to India. So, it was difficult for Malini to leave London because it was the place where she blossomed and she got the stability in excellent management. The most important thing was that in London, she never felt that she was different from others. She experienced that "People here loved and accepted me for what I was" (15). But she knew that there was different situation in India. That's why she didn't want to go to India. She described that "My parents and I did not realize then that a dark period in our lives was approaching, and there were momentous challenges that awaited us in India" (15). It shows that they were going to meet such new challenges in India that they never ever thought.

After returning to India, they often faced the negative attitude of people. She shared her experience in the Children's hospital in India where she went for treatment. The staff members of that hospital would not treat her as a human being. She said "They poked and examined me as if I did not feel any pain" (16). She missed the staff at Cheney, who were so kind and sensitive towards her. In fact, they treated her as a child first, not a handicap child. She writes "I well remember that the Cheyne staff had been so nurturing, friendly, warm, sensitive and egalitarian" (17). She never saw such sensitive staff in India.

It is fact that along with disabled people, their families also suffered from negative social attitude. The same thing happened with Malini and her family. Especially her mother didn't like people's different attitude towards Malini. Malini tells:

"My distress and the trauma of being with people so completely different affected my mother terribly. She had no one to talk to about her grief and became quite distraught. The social attitude towards me affected her badly, and she became isolated with her grief and suffering" (17).

She found that there was no schooling for children with disabilities in India. So, the idea of schooling for the children with multiple disabilities came in her mind. She started a school called 'The center for Special Education' in Bombay. Later on, she subsequently launched Spastic Societies in Calcutta, Delhi, Bangalore and Madras, with the help of her close family members and good friends.

Malini found that education in the Centre for Special Education was a little unsystematic and it seriously hampered her intellectual growth. She had a major problem of communication because of dysarthria, a slow

monosyllabic speech that takes longer time for people like her to communicate. Therefore, she was always imprisoned in her thoughts due to the lack of opportunity to communicate. She thought that if she was in a normal school, it would have been possible for her to interact with normal peers. So, she didn't like the idea of sheltering disabled children in special school where they had no exposure to the outside world. So, she strongly felt that normal environment was necessary for all human being to develop their intelligence and social networking skills.

After returning to India, her parents took divorce. The separation of parents was really a traumatic experience for her. She considered that this was the darkest period of her life. Along with her mother and brother, she had to leave her father's home. So she missed the good time that she had spent with her father. She had many friends of her age in building, but she had to leave them after her parent's separation. She thought that "Perhaps, if we had stayed on there, my life would have been very different. I would have grown-up with normal friends of my own age" (27). She felt bad if she went to school regularly, she would have friends of her age. But the concept of inclusive education was not yet introduced in India. In short, she remained lonely with no school, no friends and no interaction with children of her own age. Meanwhile, her father remarried a wonderful person named Margot Raymond. Her mother also remarried Sathi Alur, a Chartered Accountant, who first came to the Spastic Society to look after its accounts.

Once she got an opportunity to go back to England for education. She also agreed to go back because she realized that the things were too stagnant in Bombay. Furthermore, the negative attitude of people made her and her mother unhappy at every movement. Malini wanted to go away from such monotonous life in Bombay. She explains "I was bored

by the monotony of life in Bombay. The education offered was not challenging enough and the negative attitude of people towards me made me and mother very despondent” (40). She needed a change and wanted to try out something different.

In England, she was admitted in Thomas Delarue, a secondary special school run by the UK Spastics Society for bright A-level students. She found that the school was spread over five acres of land and the premises of that school were fully accessible and wheelchair friendly. Everything was structured and systematic there. The school functioned like a normal secondary school, where all the subjects were taught. The academics of school at Deralue were very hard for her because she had not received much of a formal education before, but she managed everything.

She got an electric wheelchair which helped her to increase the mobility. Now she could move anywhere without others assistance. At first, her life at Deralue, a boarding school was very hard but it helped her to organize the time and build up the confidence. While living in boarding school at Deralue, she remembered the sentence which was written by Abraham Lincoln to his son who was living in boarding school that “The best steel goes through fire” (45). These inspiring words gave her strength all the time. After two years of living in boarding school, she got the General Certificate for Secondary Education which made her eligible to get admission in any college. Her dream of studying with normal students of her age came true when she was admitted in St. Xavier’s Junior College which is one of the prestigious colleges in India. After getting admission in that college, she had worried about whether she would academically cope up with other normal students.

The campus of the college was wheelchair unfriendly, so she faced extreme problems of accessibility. The main building of college comprised of the four floors with two lifts. The first lift was small. It was really hard to adjust her electric wheelchair in it. Therefore, she always had to depend on others while pulling and pushing her wheelchair. Likewise, the second lift was big in size but it was at the far end. In fact, both of these lifts didn't stop at the middle floor of building where the library was situated. So, she couldn't go to the library, although she had strong desire to go there.

On the top of that, there were ledges at the end of each classrooms. She always had to depend on others to overcome these barriers. She thinks "Why do all normal people think that everyone in the world must keep to the norm of the walking pattern, and if one does walk like everyone else, one will be left out of life?" (53). In short, the needs of physically disabled people are generally ignored by architects while constructing the buildings. Hence, they have to depend on others even for doing simple task.

Being a disabled, she had to meet with many embarrassing incidents at the very first day of her college. For instance: as she entered the classroom, the whole class remained silent and paid attention towards her until she was settled on her place. In fact, it was terribly painful for her when all the class started whispering and staring at her as if she entered in the wrong classroom. Another incident was that due to her speech problem, nobody understood her name even after she repeated it many times. The same scene was repeated in every class.

To cope up with the normal students, she had to use different methods and techniques. For answering the questions in the class, she

used cannon communicator, a device for those who have speech impairment. But it took long time. Along with the speech, she had a problem of hand functioning by which she couldn't hold the pen in her hand and write down the notes in classroom. However, her mother came up with new idea that she gave her classmates a pad with a sheet of carbon paper, so that the notes of whole lecture could be covered in that and Malini would get other copy from them. To do so, she had always to depend on her classmates for notes.

Her speech was slow and arduous. Therefore, it was difficult for her to participate in any conversation in the school. Although she had a lot of things to share, it was not possible for her to contribute them quickly at the time of conversation. When she was in the special school, the professionals and others were trained to listen them sympathetically and they would prefer to give extra time for listening to the students like her. But in this regular school, she had a little space to converse with others. So, she was isolated and frustrated by not being able to participate in conversation like other normal peers.

She realized that her feelings were not understood by the normal world. Once the group of her classmates went to see the movie leaving her alone. They might have thought that she would be a trouble for them. She was hurt whenever people treated her as if she had no feelings. People didn't understand that although she had abnormal body, her mind was quite normal like others. She explained that "I knew that I was different and trapped in a dysfunctional body, but did others realize I had a spirit and a mind separate from this body?" (55). She didn't understand how she could tell them that she had the same feelings or desires that every human being has.

In the journey of her self-introspection, a lot of questions touched her heart, “what is normal? Who is normal? Why am I abnormal? Who decides? I cannot speak, I cannot walk; does that make me abnormal?” (56). It was obvious that she was physically disabled but what about her mind that was quite normal. Being a physically disabled, she was fully aware that she was never going to be easily accepted by the so-called normal society. Therefore, she decided to prove herself intellectually.

As she failed in the first unit test of the college, she thought that she had lost the first chance to prove that she was intelligent. But the main reason of her failure was the rote kind of learning in India. The examiners wanted broad and essay type answers. A great deal of efforts was needed to write such long answers. In this style of writing, it was hard for her to remember the exact words given in the textbook. It was difficult task to master over such kind of writing because of her poor speech and poor hand. Another thing was that her writer had to take the strenuous efforts to comprehend her expressionless speech. Therefore, she didn't like education system in India. She said that “...the education system in India teaches students to be like sausage machines rather than thinkers of future” (61). In England, she was trained to conceptualize what she learnt.

In college, she had many friends but no boyfriend. She felt bad because of her disability no one even thought of her. She knew that the boys wanted normal girlfriends rather than disabled girlfriends. She wrote “For the typical boys, it was not acceptable to be seen with a disabled girl-friend. They wanted a ‘normal girlfriend’ on their arm” (59). Many times, she thought that if she had not been disabled, she would have boyfriends like her other normal girl-friends.

Indeed, she liked a normalcy of life. So she never left any chance to feel normal. It's very funny but she secretly felt normal as she saw her name in the blacklist on the account of low attendance, along with her other normal peers in the college. She says "Secretly, I felt normal; I too had been blacklisted like anyone else" (60).

She gave the HSC exam and passed it with good marks. Then she took admission for BA course in the same college. Unlike the HSC classes, her BA classes were held on the third floor where lift could not reach. She requested the management of the college to shift the classes on the floor which was accessible by the lift. But the management shirked its responsibility by saying that the lecturers wanted their classes in certain rooms and the lecturers placed the responsibility with the management. She realized that no one cared about her inconvenience. So, her problem remained unsolved. She points out that "Xavier's was following a good policy in agreeing to admit disabled student, but facilities for accessibility were appalling" (70). It shows, even in education system, many policies are made for the well-being of disabled students but they remain only on paper without implementation.

She wanted to enjoy mainstream activities as others but she was hurt many times due to the negative attitude of the people. She narrates two social events that made her to go into depression. Once she went to Prom Night with the group of her girlfriends only for enjoyment. As the loud music began in the background, she started dancing with her crutches in group. But after a while, one of the organizers didn't allow her to dance with the crutches. She remembered her words "why don't you sit down, you are bound to fall. You can't dance with crutches" (65). So she had to stop dancing unwillingly. Thereafter, she found that her group of friends went to dance with their male friends. But she was left

alone. She felt unhappy because she was no longer a part of them. She always dreamt of man who could see beyond her body. She expresses her feelings:

“I wondered if there would ever be a man in my life. Would a man see beyond my body? Would anyone put their arms around me and dance with me? Would anyone kiss me passionately? Would I ever be needed by a man emotionally or would I always be regarded as a burden for someone to take care of?” (65).

It shows that she wanted a man who could care or love her and accept her as she was. She didn't want to live her life alone.

There was another incident by which she was terribly hurt. She remembered that she visited Nargis' house on the occasion of her birthday. She had been left alone at the table for having a lunch in that birthday party because her friends went to join the crowd. On the top of that she didn't expect from Nargis who openly refused to sit with her and went to join her other friends. In reality, she would like to join them but it was not possible for her to hold the plate and eat with them. She felt very bad as other's enjoyed the lunch in each other's company and she sat and ate in solitude. Thus, these two occasions remained in her mind forever. She tells “It taught me to be a bit distant from my friends, as I seemed to collapse emotionally if they did something which upset me” (67). So she decided to avoid the social gatherings which made her upset.

After her request, Zubin Petit, one of the English lecturers in Xavier's, came to her home to explain T. S. Eliot's *The Wasteland*. In the meantime, they got to know each other and came close through the poem. They found that there were a lot of things similar between them. As a

result, they started enjoying each other's company. Thereafter, Zubin became a part of her family. Even her mother gave him a part time job at the society. She realized that Zubin was the only person from the opposite gender who could handle her extremely well. He was one of those who could understand her speech. She found him to be warm, compassionate and caring.

Meanwhile, she went through the BA exam which was really torturous for her. It was held in the month of May. So, her throat was getting dry dictating long essay type answers. She narrates that:

“The worst thing was that the exam took place in the heat of May, when temperatures soared. My throat got so dry calling out long essay type of answers that I could not speak without sips of water” (74).

This time her each paper was six hours long. The whole process was arduous for both the writer and her. After overcoming such kind of difficulties, she finally completed her BA degree.

She went for Goa trip with her brother Nick and his American friend, Alison. It was the first time Nick had gone with her without family. In fact, that was one of the rare occasions for her to spend time with her own generation. So, she was very excited about the trip. In Goa, they stayed in Erica's boutique at Baga. Erica and her sister Joanne had come to India from South Africa 20 years ago. They were friends of Ranjit, her father.

In her Goa trip, she had to face the problem of toilet accessibility. She was usually comfortable with English toilets instead of Indian style toilet which required good balance. But English toilets were not available there. She explains:

“One has to balance in a squatting position to spend a penny, which is all very well for the rest of humanity who possess good balance, but not an easy task for someone like me, who suffers from ataxia and has limited balance” (78).

It shows that while constructing the buildings, attention is only given to the needs of average people, but the needs of disabled people are not taken in to consideration. It was surprising to discover that in the whole Baga, there was only one public western-style loo which was in the small café on the beach, known as Anthony’s. Due to the small space of that loo, they had to keep wheelchair outside, so that Nick and she could get enough space to fit within it. In short, Goa was not a very friendly place for her wheelchair, but it was possible to enjoy the whole trip because of Nick who handled the wheelchair beautifully.

After her degree, she went to USA for a short visit which was a great learning experience for her. She visited the University town of Berkeley, where she saw amazing accessibility for the wheelchair users. She found that “Every place was accessible, be it a library, museum, restaurant, shop, school, public toilet or theatre, and this facilitated independence” (83). Such wheelchair friendly environment made someone to forget that he/she could not walk. But there was an opposite picture in India where the most of places and buildings were totally inaccessible to the wheelchair users. She was often upset while trying to enter in five star hotels, theatres, art galleries or any other place in India.

In Berkley, she also found that there were several organizations working for the welfare of disabled people. She visited one of the organizations called Centre for Independent Living which trained disabled people on how to manage their life even if they had severe

disabilities. Likewise, there were many disabled people who had charge of heading disability organizations. Another thing she liked most that they themselves hired or fired their personal helpers. In fact, they would prefer to hire outsiders rather than their own family members or friends to assist them. Along with these things, she liked the ideology of disabled people in Berkley. Malini describes:

“They argue that nobody is completely independent. For instance, a normal person would need a carpenter, a plumber or an electrician, perhaps. The disabled, too, are dependent on getting help to enable independent living, so that they can function more efficiently and able to take up employment” (84).

It means no one in this world is completely independent. Even normal people depend on others to meet their daily needs. Just like normal people, disabled people also take the help of other human beings to lead an independent life.

The personal assistants of disabled people come in the form of other human beings to fulfill the needs of walking or doing something. This concept of independence appealed her. She knew that most of the people in society considered them as dependent or helpless because they see their deformities rather than their personal attribution. She rightly points out that “The person within the disabled person is always unnoticed because their physical demands are so immense and often glaring” (85). It means that the society is used to see their disabilities but they never see their abilities. After her trip to Berkley, she decided to get an attendant because she no longer wanted to depend on her family.

After graduation, she decided to do MA. She applied for the course of Publishing in Oxford Polytechnic. Meanwhile, Zubin also went to Oxford for studying Chaucer. After some days, Malini got the acceptance letter from the Oxford Polytechnic for that course. So she was excited to go to London where she was more comfortable than India in all aspect of life. Now her dear friend, Zubin was also there. As she arrived in Oxford, she met Zubin who greeted her with special warmth and affection. She always felt comfortable in his company. Zubin was one of those who understood her speech completely and he managed her and her wheelchair entirely on his own. In fact, she secretly hoped for this relationship where he and she were more than just a friends.

In Oxford, she got disabled friendly room in a student's residence called Pollock House which was located in Pullens Lane in Headington. It was very close to Oxford Polytechnic. In her room, she started living with Maya, her attendant. Maya was fluent in English. Due to her knowledge of English, she soon became a star of Pollock house. Malini observed that it was a good thing for her that Maya was proficient in English which helped her a lot for having an impaired speech, but the people easily ignored her and turned to speak with Maya. She tells "The problem with having a carer who is fluent, as Maya was, is that it was easier for people to ignore me and address the carer instead" (93). Whereas, she felt doubly disabled in the company of her new attendant named Vimla who was not good communicator due to the lack of language skill. She said "With my speech impairment, and Vimla's lack of language skill, it doubly disabled me" (176).

Like the problems of accessibility in the Xavier's, she faced the same problems of accessibility in the Publishing department too. The Publishing Department was up on the flight of stairs, so she had to take

great efforts of walking with Maya if she wanted to visit the department. She had two tutors named Kevlin Smith and Bob Woodlings who had strange attitude towards her. They were a bit confused about how she would finish her course. They could not understand her speech, so Zubin and Navina, her another friend assisted her during tutorials to interpret her speech. There were twenty other students in her class, who were not so helpful. She had to repeatedly ask them for notes. She could not go to the library which was not accessible. In the situation, she missed her classmates at Xavier's, who were helpful in nature and would always lend their notes to her.

As a part of course, she had to go through the mock interview for a job along with other students. Thereafter, she got the job in the publishing house. It was really a good news for her. But there was another news that hurt her terribly. In their routine walk, Zubin told her that he was gay and had partner from Belgium whose name was Bart. She didn't show her emotions right away but she was deeply hurt by this news. She wanted a boyfriend or partner just like her other girlfriends but it would never happen in her case. She expresses "I yearned for all that was normal despite my disabled body" (99). She silently desired for romantic relationship but the problem was that she was disabled girl and no one tried to develop that type of relationship with her. Later on, she heard from a common friend, Helen that "Zubin was also upset and had admitted that had he not been gay, he would have been with me" (99).

After doing Master's Programme, she returned to Bombay where she began working with the recreational club that Zubin and she had started. She had got a job in Bombay Times. But she started facing a lot of issues because the workplace was not wheelchair friendly. The attitude of the people at her workplace was good towards her but they didn't think

in term of her accessibility. She tells that “The attitude of the editor and my colleagues was great, but they did not think about accessibility concerns, which was unfortunate” (104). She found that the canteen was far away from her office, so she could not join her colleagues for tea or lunch. She felt isolated during lunch time. Even toilets in her workplace were not accessible for her. Once she fell from the steps of that toilet and was badly hurt. She also faced the problem of inaccessible transportation service in India. Likewise, the pavements were not wheelchair friendly. The streets had too many potholes. She tells that “The basic problem of working in India was the lack of accessibility” (104). She had to leave the job because of this disabled unfriendly environment.

Meanwhile her mother had got an opportunity to work with the ‘London School of Economics’. Along with her mother, Malini again went back to her favorite place called London. Meanwhile, her mother registered for Ph. D in the Institute of Education, University of London which was situated in Bloomsbury under the guidance of Jenifer Evans. During Ph. D, both her mother and Malini were influenced by the social model of disability which claimed disability was socially constructed.

Malini had a lot of things and experience to share but her poor speech stopped her. Once her mother and she were invited by Professor, Klaus Wedell in a workshop where she found that disabled people who were more disabled than her could communicate independently. But her speech was incoherent and difficult to understand. She felt that it was important to be able to communicate without help of third party. So, she went to Roehampton Hospital in Putney for an assessment of her communication difficulty. She was recommended a smaller and new compact version of communicator that she could carry easily in her handbag. Now it was possible for her to communicate with others.

Instead of manual wheelchair, she started using electric wheelchair which gave her a wonderful feeling of movement and freedom also. Now she was confident to manage the busiest road of London on her own. She explains “With this, I did not feel as if I could not walk. I did not feel helpless. I could slip into shops, chemists, bookshops, restaurants etcetera. Whatever the so called normal person does, I could do” (111). She could go everywhere. In fact, she could change the several buses to meet her friends. She didn’t feel that she could not walk. She could enjoy the feelings of walking in London but that was not possible in India due to the lack of accessibility on the roads or pavements for wheelchair users. She wrote “Moving around outdoors is not an easy task in India” (112). Even though she had an electric wheelchair which was far better than her earlier manual wheelchair, she could not go out in India because of inaccessible roads and buses.

One day Maya left her job as attendant and went to Calcutta where her family lived. It made Malini upset, but she soon made her mind that attendants like Maya should not be a permanent fixture of her life. It made her to realize that she was thirty, but could not achieve much in terms of independence. Her lack of independence became a cause of trouble when her mother was busy in her Ph. D. Her mother was spending most of her time in reading and writing. Therefore, Malini herself began doing every possible thing independently. First time, she took the charge of managing her whole day. After Maya’s departure, Malini felt herself freed instead of being constantly forced to be with someone and having to instruct someone what to do. According to her, “Every human being needs space and time on their, own to develop and think. If a disabled person is constantly with a person and taken care of, she or he is not going to develop into their own person” (115). It is clear that every

human being needs his/her own space in life to think or act. But it is not possible in the case of disabled people who have to live mostly in the company of person who takes care of them.

Malini's parents took a great efforts to teach her most essential and new things intending that she should not be dependent on someone in future. She remembered that her father trained her how to climb stairs with the help of banisters. Even her mother taught her how to access email that revolutionized her life because it was possible for her to communicate with others.

The attitude of the people towards her was good in London. She narrates a good experience in the supermarket while shopping "It was unbelievable how helpful people were. Nobody stared. Nobody asked me rude questions. If she could not reach for things, other shoppers would pass me an items" (121). But her experience was different in India where she had to bear stares of people or answer their unnecessary questions.

Once she made a plan of Paris trip to spend a summer holiday along with her friend, Fiona. All over her journey, she found out that most of the places like airports, hotels, roads, museums or churches were wheelchair friendly. Even the attitude of people toward her was better than in India. In fact, during her trip, she would not feel that she was disabled. So, it remained unique holiday for her.

She got an admission in the Institute of Education for doing the Master's Programme. Although she had got admission, the institute didn't allow her to stay in student's accommodation. The institute was not ready to take her responsibility because she was disabled. In reality, the institute had no specific provisions in term of accommodation or personal

assistance for students with disabilities. She herself found that there were some disabled friendly rooms, but the authority directly suggested her to live in Care Home. She applied for the same flat where her mother stayed in while doing her Ph. D, but the administration was unwilling to give it to her as she had earlier lived there for five years with her mother. Her American friend, Gregg who was the President of Students Union, kept up the lobby on her behalf and brought up the topic of disabled student's accommodation. The lobby helped her and the institute granted her to stay in the same room where she lived during the time of her mother's Ph. D. Although she was granted permission to live there, the institute didn't take the responsibility of her safety. Another problem was that her Master's Programme was one year course which needed a lot of hard work. Therefore, she asked the University authorities to allow her to do it in four years. The authority also supported her by granting her permission.

Her Master's classes began in the evening regularly. She enjoyed these academic days because her tutors and other students of the class had very good attitude toward her. Being influenced with the ideas of inclusive education, her tutors always encouraged her to participate actively in the classroom. Most of the time, they made their classes busy with the interaction on intellectual level that helped her to develop her intellectual sense. She felt that her voice was heard first time throughout her academic journey.

In the initial stage, she faced many issues regarding accessibility in the present institute as well, but the necessary modifications were done by the authority for her in the four years. The most admirable thing was that the authority had made the changes in their infrastructure only for one student who was disabled. She had not found such type of positive

attitude of the authority in the St. Xavier and Oxford Polytechnic where most of the places including classrooms, toilets, library and canteen were not accessible to her. But these places were accessible in the present institute. Now she could go wherever she wanted without any help. She wrote “I spent hours in the library trying to absorb the texts” (140). So her wish to go and spend time in the library was fulfilled because the library of that institute was wheelchair friendly.

The society mainly talks about independence of persons with disabilities, but some people are surprise if they see disabled people do some activities independently. Malini described her two experiences that show the typical attitude of people towards disabled people. The first incident happened in the lift of institute, where a lady surprisingly asked her that “*Are you alone? Where’s your helper?*” (140). But she didn’t give any reply to that lady and went away. Another incident happened in the canteen where she went to have breakfast. As she stood in a long queue, a young man in his thirties came forward and offered his help to her. After a while, a lady companion of that man came there and she was surprised as she saw Malini who was alone. She started talking in very rude language. She repeatedly saying “Someone must be with her. She can’t be on her own. I have worked with these mental people. It can be very dangerous” (142). She went to call the management regarding that. The security guard came with that lady. He was also stating that no one has reported her missing yet. It was really traumatic episode for her. Thus, these two incidents show that the normal people cannot imagine disabled people without helper.

Her present tutors always motivated her to read more on women and disability. After reading she realize that she was also a part of that

society where disabled women faced double discrimination of being both disabled and woman. She confirms:

“Other feminists also suggest that being both disabled and a woman, is a ‘double discrimination’ which means women with disability have to struggle with the oppression of being a woman in a male-dominated society, as well as the oppression of being disabled in a society which is dominated by able-bodied people” (145).

She understood that the disabled women suffer double discrimination because of the cultural expectations of society from women, in which the disabled women could not be fitted at all.

According to her, only to talk about inclusion of disabled women in society is not enough but it is also necessary to think about their physical or emotional needs. She noticed that it was easier for disabled men to get an able-bodied partner, but it is almost impossible for disabled women to get able-bodied partner for marriage. This was because women were culturally expected to do most of the housework alone. The society thought that the tradition roles of women could not be fulfilled by disabled women. She learnt another most important thing that:

“Traditionally, women are only considered to look beautiful and that is it. Most men desire their women to be attractive and beautiful. As far as a disabled woman is concerned, she always gets unnoticed because her body is different” (146).

It shows that disabled women never fixed in the criteria of beautiful body. So they have low demand in the marriage proposals. At first, Malini had a strong desire to have a male partner in her life but she realized that no one could see her as life partner because of her severe

disabling condition. In her interview with Dasgupta, She expresses “I have had a hard time accepting that I’m trapped in a rejected body that is not sexually attractive. But most men look at me as asexual” (<https://m.timesofindia.com>). It was certainly painful for her, but she accepted the reality. As she grew older, her desire to have a partner in life was automatically minimized.

It is considered that disabled are always dependent on family or society. But she thought that “everyone is inter-dependent” (Chib, 149). It is quite natural that all human beings are socially, emotionally, physically, and intellectually dependent on one another. She gave her own family example while her mother was doing Ph. D, they shared the household chores between them. She says “While I did all the outside chores, like the shopping, the laundry, posting letters, she did all the cooking and cleaning of the house” (149). They were inter-dependent. The four years of her Master’s Programme broaden her knowledge and perspective that enriched her life. She felt confident and empowered. She describes “I was, for the first time, able to accept my own identity as a disabled woman, and was proud of being one” (150). She felt proud of being a disabled because it gave her chance to understand the life very closely.

In London, everything was so accessible and the people around her were eager to help her. She was able to master over her the daily chores. She made herself as independent as she could live without her parents. Once she refused her parents to come to India with them even after they were insisting her to come. In fact, she successfully managed to live that weekend in the absence of her parents. Once again she lived alone as her parents went to India for six weeks. Her parents didn’t want to leave her alone this time also, but she thought that it was pointless for to go and

come back. Thereafter, she was completely fine with staying back while her parents travelled. As time progressed, she was glad that her parents could leave her alone at home without worrying about her. She realized how significant her new found independence was.

She always expressed her gratitude towards technology because it played important role in her life. Her electrical wheelchair helped her to increase her mobility power. If it had not existed, she would be confined at home all the time. Even the computer technology made her easy to communicate with others. She said that “Thank goodness for technology for people like me who needed wheelchairs for mobility and computers for communication!” (165). It shows that technology helps to reduce the severity of her disability. It made her capable to handle a wide range of activities independently.

After completing her Master’s programme, working at the Institute’s Library was really ideal for her. She found that all the information was computerized. Anyone could communicate or interact through the internet. She buried herself one year in the library to complete four assignments for her Master’s Programme. She had to do a lot of hard work to complete that because “Each assignment needed an argument which was crucial, a reference to all the current writings on the subjects and a detailed bibliography stating all sources of information” (165). She had to write all these things carefully. Because of the lack of her functioning hand, she had to do all this with one finger. Whatever the people did in an hour, she did it an entire day. Therefore, every day she had to spend a great deal of hours in front of computer.

After the suggestion of her Librarian friend named Gwyneth, she decided to become a Librarian. After searching various institutes and universities, she decided to do her second Master’s course in Library

science at the London Metropolitan, University of North London. The course of Library Science at London Met was a professional one, which concentrated more on management style of functioning within library. She was allotted two rooms flat in the residency known as The Arcade on Holloway Road in Holloway, which was fully accessible. But the only problem was transport because she had to change two buses to get to college.

While travelling by bus, she frequently went through different experiences. Once one of the passengers in the bus started admiring her friend, Varsha as she saw her helping to get into the bus. She said her that 'You are a wonderful person'.... 'God bless you' (170). It shows attitude of people towards disabled people, who believe that if one can help disabled people, he/she would be blessed by the God.

Her both Master's degrees gave her enough confidence. She thought that she would get job but it was not easy for her. She applied for two jobs at the Institute, one was for the post of a Disability Officer and one was for a Cataloguer in the Institute's library. Now she had a good qualification but no experience. Even her speech and limited hand function were the biggest barriers in finding job because most of the jobs needed it. According to her "The actual fact is that employers could see only my disability, not my capability" (174). Even after getting two MA degrees, she didn't get job. So, she felt demotivated.

Then, she started lecturing at the Institute of Education. Her new friend Felicity Armstrong, a prolific writer and academic on Inclusion Education, invited her to deliver lecture for the students of her Institute. She delivered her entire lecture with the help of power point presentation. This experience gave her huge confidence. Thereafter, she started lecturing in India too. Once she had got an opportunity to deliver a lecture

at the Sorbonne University in Paris. Even though she had poor speech, she used power point presentation while delivering the lecture. She liked to deliver lecture, so she would not let the chance of giving lecture anywhere in the world. She observed that the attitude of people towards disabled people gradually began to change. She wrote "...the lecture confirmed that the world was beginning to accept us—they did not look at us as if we had come from Mars!" (180). It is true that the voices of the disabled people have started to be heard in the normal world of people. In fact, the attitude that they are something different or strange, also began to change.

In spite of her two Master's, she didn't get job in London. She realized that most of the jobs needed speech but she lacked that. Fortunately, she had got job as a Senior Event Manager at the Oxford Bookstore in Mumbai. After coming to India for job, she started actively working for the welfare of disabled people in India. She believed that both able and disabled people should come together to build inclusive society where all people were included. So, she started working with the organization called Able Disabled All People Together (ADAPT), that she had earlier formed. Being influenced with foreign accessibility, she thought that such type of accessibility must be there in India for disabled people.

Now she is actively working for the well-being of other disabled people like her. For her contribution in the disability sector, she has been honored with National Award for the empowerment of persons with disabilities from the Indian Ministry of Social Justice and Empowerment in 2011. Furthermore, on the occasion of World Cerebral Palsy Day, she was honored with the first global Cerebral Palsy Day Award in 2017 for ensuring the rights of disabled people.

Chapter V

Autobiography of Hearing Impaired

1. *Deaf in Delhi* Madan Vasishta

Deaf in Delhi is Madan Vashistha's autobiography which was published in 2006. It is the life story of author who became deaf at the age of seven from a bout of mumps and typhoid. After becoming deaf, his life had changed and he had started facing different challenges that he never even imagined. He was excellent in school and wanted to become a doctor, but he had to stop schooling in the middle of sixth standard. His dream of becoming a doctor was shattered. But he was still positive about his life. Within limited exposure for deaf person in mainstream society, he never lost any chance to prove himself. So he later on achieved a huge success in his life. His book, *Deaf in Delhi* helps to know his overall journey of his life through in detail. According to Islam & Jana, "Madan Vasishta's *Deaf in Delhi: A Memoir* (2006) is a remarkable work of literary disability scholarship, informed by the author's sense of pain, struggle, and triumphant march in life" (203). This book is divided into thirty-nine sections with significant titles in which he describes his real experience of deafness while living in India especially in Delhi.

Madan Vasishta was born in 1941, in a village named Gagret in Northern India. He became deaf at the age of eleven. Due to the suffering from two weeks of typhoid and the mumps, he woke up one night with strange feeling of discomfort. He elaborates "My head was full of very loud noises, as if I were standing in a major railroad station. I heard blaring whistles, people yelling, and trains thudding along the tracks" (Vasishta, 01). As he cried loudly, all the members in his joint family

gathered to see him. He realized that he could see their lip movements but no longer heard their voice. So he was taken to their family doctor, who was considered as expert in Ayurveda. But his Ayurvedic medicine could not cure his hearing problem. Afterwards, he was treated by various renowned doctors from different cities, but his deafness could not be cured. Along with scientific treatments, various non-scientific methods were adopted by his family to cure his deafness.

Since long, as many other societies from different countries, there have been some religious superstitions linked to disability and disabled people in Indian society too, where having disability is considered as God's punishment for sins that may have been committed by either individuals or their parents or ancestors in the present or previous birth. Another prevalent misconception about disability is that disabled have no faith in God. Madan Vasishta belonged to a middle class family in Gagret, a farming village. His whole family always tried to defend such type of religious ideas. Bhua Parvati, his father's younger sister, was a very religious woman. The author says "Everything in the world, according to her, happened according to the pre-written will of Rama or Krishna or Vishnu or Shiv—the four major Hindu gods" (15). She strongly believed that his deafness was caused by his lack of respect for God.

The author was influenced by Ramayana and Mahabharata that he read at the age of ten. So he was convinced that neither Rama nor Krishna were faithful gods. Whenever he tried to argue his theory about the gods, Bhua Parvati refused to listen him by covering her ears with palms. She scolded him saying "That is sinful, young boy" She added "Lord Rama will hear you. Do not talk that or He might punish you" (16). According to her belief, his deafness was the result of his mocking of the gods. She

believed that he would regain his hearing as he asked for forgiveness. But the author would refuse to pray and ask for forgiveness for a sin or crime that he had not committed.

Considering his deafness the result of some celestial punishment, he was taken to number of sadhus, miracle healers, temple priests and many more who claimed to have a direct link to gods. At first, he was taken to Gurkha Baba who lived in a cave. Gurkha Baba dressed only in a langoti which resembles thong bikini underwear and his whole body was covered with white ash just like many other holy men in India. Bhua Parvati brought him to their home. The author describes:

“He sat there in front of my bed, erect on a chair with his left foot crossed over his right knee, holding the *trishul* in his right hand. His eyes were very serious, and he did look very graceful—almost holy” (17).

The author had to touch his feet for blessings. Before leaving the place, that Baba gave him white ash in his palm and applied some of it to his forehead. He had to lick that so-called holy ash from his palm and swallow it. As he left, the author got mad at Bhua Parvati. He tried to convince her that Gurkha Baba was nothing but a thug and was leading a nice life by fooling people. According to him, “God does not need a Gurkha as a middle man to help me” he added “If God wants to make me hearing, he would do it without that faker” (18). Here, the author wanted to suggest that if the God existed in the world, he didn’t want such faker as mediator between them.

The second sadhu to whom he was taken was called Mahatma from Andora, a small village two miles from Gagret. He was in the Andora Temple located on the bank of Swan River. He was well-known sadhu

throughout the district. Bhua Parvati took the author to receive the blessings of Mahatma, so that he would be able to hear soon. They touched his feet to receive his blessing. While leaving that place, he told Bhua Parvati that he didn't know when but he would receive his hearing soon. According to the author "it was an open ended and broad answer-anytime between now and whenever" (19). He wanted to comment on his ambiguous prophecy but he had to keep quite because Bhua Parvati had a firm belief that his deafness was caused by his mocking everything religious.

Bhua Parvati took him to other faith healers who professed to have connections with ghosts, goblins and lost souls. The sadhus and Mahatmas to whom he had visited earlier at least practiced from temples and had some kind of legitimacy. But these healers used old tombs, broken down temples or their own houses to run their business. He had visited such places several times, but he has described only one experience that he once decided to visit a Siddh who was plying his trade in Bheekuwal, a village not far from Hoshiarpur. In reality, he never made such plan on his own but this time his interest in movie led him to plan this trip to Bheekuwal which was near cinema house in Hoshiarpur. Before going to cinema house, he reached at the place of that Siddh with his cousin, Ramesh, where they saw a huge crowd of people who came for the blessing. It was apparent that this Siddh didn't provide individual service but bless people in masses. He describes "Since we had walked twenty-three miles in the hot sun for this, we needed to get some ash" (21). So they managed to get some ash in a piece of paper. Then, they went to see movie and returned to their home.

The treatment for his deafness didn't stop with the holy men or miracle workers, but there were other home remedies that were

administered by his family. His elder sister, Brahma applied milk steam to cure his deafness. She learned this technique from an old lady. During this experiment, many people gathered around to see the miracle, but nothing happen. He tells “The warm steam felt good on my cold ears at first, but soon it became uncomfortable” (24). The trial of this experiment went on for whole month on a daily basis but ended abruptly when his sister returned to her in-laws. This home remedy of his sister was really painful and torturous to him.

Baba Hardev Ram, his grand uncle came up with new idea for his cure. Once he told him to follow him to the well. After reaching there, his uncle leaned on the wooden derrick and said something to the well. Then, he told the author to yell something to the well. The author obliged and yelled a few times. His uncle repeatedly asked him if he could hear himself. But he could not hear anything. The author clears “Perhaps my uncle thought that hearing my echo might cure my deafness” (25). After few tries, his uncle gave up and left the place.

He had to go through another non-scientific experiment that was arranged by his other grand uncle, Baba Khushi Ram. He frequently invited the guy named Sain in his inn. Sain cleaned people’s ears for half a rupee. When he saw the author, He expressed his wish to cure his deafness. Almost thirty people gathered to see how Sain was going to cure his deafness. The author describes “I was nervous as he had laid out a small red doll in front of me. I wondered what was in it, and visions of sharps knives and hot oil were making me uneasy” (27). Then, he slowly and dramatically waxed both of his ears with the tools of his trade. After waxing his ears, he asked one of the young men in attendance to yell into his ear and asked the author if he could hear. But still he could not hear anything.

Once he himself decided to test God. Bua Parvati's ongoing accusation that his deafness was the result of his refusal to believe in God strengthened his resolution. He prayed to God to make him hearing. He conversed privately "If you make me hearing, I will worship you all my life and live like a holy man" (81). He gave him three months to prove his existence. For a three months, he prayed daily after taking his bath. The deadline passed but he didn't regain his hearing. So, he stopped worshipping God from the next day.

Thus, every non-scientific method failed to cure his deafness. The author didn't like these methods but he complied only for the wish of his family. The superstitions regarding the causes of disability are responsible for such unscientific treatments of disabilities. Madan Vasishtha's experiences show that Indian people still believe in superstitious causes of disability and expose the disabled to bizarre treatments. Such treatments cause pain to persons with disabilities and delay the process of their rehabilitation.

Before becoming deaf, he was one of the clever students in his class. He wanted to become doctor but he could not fulfill his dream after becoming deaf. Because his hearing problem stopped him to attend the school. In reality, the regular schools in India have no place for such type of disabled students. As he requested the headmaster of his school, he was given permission to give final examination of his sixth grade. On the very first day of his examination, he realized that everything had changed after his deafness because he could not communicate with people as before. Everyone was talking to each other but no one had patience to communicate with him. He observes that the students walked at a distance from him. Some students never lost opportunity to tease him. He describes "They would stand behind me and make all kind of noise" (30).

In fact, his inability to hear was a part of their amusement. Likewise, his teachers were more sympathetic towards him.

The condition of disabled people in rural India is worse than urban area. In rural areas, they get limited resources and facilities that are usually available in urban areas. Madan Vasishta was living in a small village in northern India. He and his family were not aware of special schools for deaf people. In reality, the special schools of disabled people are usually located in urban areas and most of the people in rural areas are unaware about the availability of special schools.

As he stopped attending school, a lot of time remained in his hands. So, as per his father's wish, he started herding cattle and rest of the time he spent working in farm along with other family servants. His full time farming didn't stop or create obstacle in his education. Even after spending most of his time in working in the farm, he passed the high school examination in first division by doing study on his own at home.

He was dreaming to become a doctor earlier, but now he thought that it would not be possible due to his hearing problem. In fact, he was working in farm after becoming deaf but he didn't want to do farming lifetime. He wanted a glamorous job instead of working in farm all the time. He writes "I wanted a glamorous job. A job for which I wore fancy clothes and shiny shoes, slicked back my hair, and whistled while I worked" (71). He knew that it was not possible for him while living in the rural area like Gagret, where he saw limited opportunities. But still he kept thinking about other jobs. Once the idea of working as truck driver's assistant called 'cleaner' came in his mind. But he stopped thinking as his friend, Tilku who was a driver on his own truck made him aware about this hard and dirty work.

He wanted to do something but he could not get proper direction. In fact, he had only high school education which was not enough for looking any kind of job. Even higher education was not possible for him because none of the colleges was going to admit a deaf person like him. He describes:

“My high school education had not prepared me for any jobs, and I thought you have to be able to hear to work for other people. Higher education was out of the question since I knew none of the colleges in Hoshiarpur were going to admit a deaf person” (81).

It shows that regular schools in India are not given chance of education for disabled students. Such education system closes all the doors of employment opportunities for them in future. In the case of author, he didn't understand what to do with his little education. Once the idea of becoming a sadhu came in his mind. He might have thought that it was easy to become sadhu because it does not require any educational qualification or background. He knew:

“India is a country of sadhus, or holy men. These sadhus come in all shapes and sizes with all kinds of beliefs and degrees. Educationally, they range from being totally illiterate to being scholars” (82).

But he didn't share the idea of becoming sadhu with anyone. Instead he kept it in his mind and waited for right opportunity. Once a mahatma or a great soul passed through his village and stayed a few weeks in their house. The author didn't want to lose this opportunity. So, he expressed his wish of becoming a sadhu and go to Rishikesh with this

sage before his father. But he became more upset as this plan was not accepted by his father.

The government of India provides various schemes and facilities for persons with disabilities for their betterment. Due to poor implementation of laws, persons with disabilities are deprived of various government benefits. Once the author heard from his eldest brother, Narain about a photography school for the deaf in Delhi which was going to provide training in photography and a government law offering scholarships to the physically handicapped. Along with his brother, he went to inquire about that at the office of the vocational rehabilitation department. After going there, they realized that no one in the office knew about this new scheme of scholarships and training programs for the physically handicapped. The head clerk of that office sent them to the director's office for more information. The author observed that the clerks in the director's office were spending their office hours in relaxed manner. These clerks had no concern for people who came there with new hopes and aspirations. According to the author, "None of these clerks knew about this new law that would change the lives of millions of handicapped children in India" (92). In reality, implementing such type of government laws is a part of their job but such employees in government offices often overlook to that. As a result, most of the disabled people remain away from their rights that can bring a huge change in their life.

The drastic change came in the life of author when he was admitted as student in the All India Photography Training Institute for the Deaf (PID) which was located behind All India Federation of the Deaf (AIFD) office at Cannought Place in New Delhi. There he was registered as an AIFD student. Mr. B. G. Nigam was the general secretary of the AIFD. At first, there were only two students in the classroom named Khurana

and Goel. Few students were admitted later. V. R. Goyle was the only one teacher who spent most of the time in his Photo Studio and less time in the classroom.

After joining PID, he began to learn photography but more than that he began to learn about new world which was different from normal world. Initially, he got confused as he saw people were used to communicate with their hands and fingers with each other. He describes that “The idea that people could communicate with their hands and, worse still, that people could understand this wild flailing of hands and fingers, was just inconceivable to me” (98). Later on, he understood that it was a sign language used by deaf people while communicating with each other.

He became deaf later in his life. At that time, he was seven years old. So he could speak and write in Hindi or English language. He first time came to realize that there were other people who didn't know how to speak or write in any language because they were born with deafness. Therefore, they used sign language as medium of their communication. His lack of signing skills created barrier while communicating with them. So, he decided to learn sign language as soon as possible. Thereafter, he kept practicing this new method of communication which seemed to be very interesting to him. He writes “I was thrilled about the possibility of communicating with this new mode” (100). He became fascinated with this language and within a couple of weeks he was able to fully communicate with his new deaf friends.

One of the reasons he moved to Delhi was the availability of government scholarships for persons with disabilities. He applied for one of the fellowships after getting admission at the PID and was waiting for

approval. After doing inquiry at the office that granted scholarships, it was cleared that he had not received the scholarship as they had never received his application. The author writes “This, in bureaucratic language, means they had either lost it or it was still sitting in some tall pile of files in front of one of those sleeping clerks” (116). It shows that the clerks in government’s offices never do their job carefully, so that many people like him do not meet their needs.

Because of the carelessness of the clerks, he didn’t receive scholarship. He didn’t want to become economic burden on his brother, Narain with whom he lived in Delhi. So, he had no other option but to work somewhere. As he told his predicament to Mr. Nigam, he offered him two part time jobs. First, he was going to work in Mr. Goyle’s studio after school and second, he was going to teach an adult literacy class at night. Mr. Goyle was going to pay him 25 rupees a month and his night class would pay him another 25 rupees. So, he was going to earn 50 rupees per month. He tells “The idea that I was making some money satisfied me, and the opportunities to do professional photography at the studio and be a teacher were much more valuable than any amount of money” (117). He was very happy with this job opportunities that gave him a lot of practical knowledge. Working at the Goyle’s Studio gave him a lot of experience. At first,

“Instead of being behind the counter and dealing with fancy people, I found myself working in the darkroom, washing and drying prints, trimming and retouching them, and then putting them in envelopes with marked order numbers” (121).

In spite of that, he had sometimes got opportunity to work at the counter. Likewise, he had also got the opportunity to take photographs at

weddings, new events and various ceremonies. So, within a few months, he had also developed skills of processing and printing films at the required speed and professional quality. He describes “I could produce professional quality photographs, shoot portraits and action photographs, and deal comfortably with clients” (123). All these new skills gave him a lot of courage and self-confidence.

After joining PID, he heard about deaf clubs where the deaf people met once in a week. But after visiting twice these clubs, he stopped going there. The reason behind that a distinct class system which was related with money bothered him and never encouraged him to visit these places. He found that most of the members came there from wealthy families. He unfolds “My clothes clearly indicated that I was not wealthy, therefore, I did not belong to their group” (124). Actually, he belonged to the rural background and it was clearly reflected in his dressing style and overall personality. So, other members looked him down. He also tells “Despite my wearing pants and coats, I looked like a country bumpkin” (124). As he tried to associate with the poorer members, they didn’t show their interest even to talk with him. Since he was not comfortable with the members of deaf clubs, he stopped attending their meetings.

But the attitude of these people changed little bit as he began to teach the night class. Some of his students introduced him as their teacher to people. In addition, the news that he could read, write and speak in English like hearing people helped to move up in the circle of people. Most importantly, his reputation was strengthened as he became a member and joint secretary of the Deaf and Dumb Association (DDA), which was established by Mr. Nigam and his friends. Now he was invited to join the group of richer members who associated with Mr. Nigam. He writes “The deaf people who used to avoid me were now hovering around

me” (134). So he enjoyed this role as an important member of the deaf community.

Every day he had to spend his time from 7:00 am to 11:00 pm in the classroom, Goyle’s Studio and then, in the night class. There was only Sunday to spend with his family. After becoming joint secretary of DDA, his life became busier than earlier. Now he had to spend his Sunday for DDA. After joining the DDA, he gradually began to learn that the main goal of AIFD was to raise enough money to run the office and pay for Nigam’s annual trip abroad. He illustrates “Each year, Nigam went to another country for the World Federation of the Deaf’s annual conference or some other meeting, and the AIFD paid all the expenses” (134). Everyone in the organization knew how Mr. Nigam used the federation money for his lavish lifestyle and expensive trips, but no one dared to speak against him. One of the income sources of AIFD was the annual Flag Week. During National Flag Week, the deaf people wondered all over the city in groups of three or four to collect donation by selling miniature India flags. The author didn’t like this work but there was no choice. He clears “It bothered me that we all had to go out and beg for paisas so Nigam could make his trip” (136). It means, some organizations in India misuse the money that they collect under the name of welfare. The author didn’t want to let this happen anymore. So, he discussed this issue with his friends but they suggested him to stay quite.

The deaf people always face considerable challenges due to the problem of communication. The main thing is that deafness is an invisible disability which is not easily apparent to all. So in some cases, such people have to prove that they are deaf. Another thing is that there are many deaf people who can talk like hearing people because they became deaf later in their life. So people do not believe in them in certain time.

Once the same thing was happened in the case of the author and his friend, Kesh, as they went to visit Rashtrapati Bhavan's (President's House) garden which was generally open for the public in each March. They saw the president, Dr. Rajendra Prasad who had been sick for a few weeks and being wheeled around in the secure part of the garden. While moving to get closer view of the president, their way were blocked by several policemen assuming that they were trying to assassinate him. They told them that they were deaf and requested him to write on the piece of paper what was their problem. But they didn't believe that they were deaf. Even the author and his friend didn't understand what they expected from them exactly. One of the guys from the crowd transcribed what he was saying "They do not believe you are deaf, and they think you were trying to kill the president" (148). The fact of author's talking like hearing people made them more doubtful about their deafness.

His teacher, Mr. Goyle who was his role model died in road accident. His sudden death affected his school and work. After waiting for few months, Mr. Nigam appointed Mr. Yadhav as teacher but he became more important to Mr. Nigam as a writer because his writing was so good. Soon Mr. Nigam appointed Mr. Lal, another teacher who had never met deaf people before, but he treated all the students as regular people not as deaf one. The author writes "Despite the fact that he had never met a deaf person before, he adapted to us as if he had known us all his life" (150). It shows that there are very few teachers like Mr. Lal in India who treat their disabled students with genuine care and love. Otherwise, there are some other teachers who never show their interest in disabled students.

Author's fluency in signing increased but he felt shy signing in the public. The main reason was that signing was not a common sight in

India at that time. He frequently observed that as he and his friends started signing in the public, the people gave them different and curious look all the time. He expresses “Every time my friends and I signed in public, we drew a crowd of curious onlookers who behaved in a variety of ways” (156). However, to avoid strange look and staring of onlookers, he generally avoided to communicate in sign language.

After finishing his two years at the Photography Institute for the Deaf (PID), he started working full time in the Goyle’s Studio. But Mr. Nigam offered him job as teacher at the PID. He was also settled in his new routine as teacher at PID. A huge change came in his career after getting permanent job as assistant photographer at the National Physical Laboratory in Delhi. For this job, he had to face practical examination in photography and an interview. At first, he thought that he would be kicked out before the interview because he was the only deaf out of all seventy-plus hearing people who came for the same. But he got that job after competing such large number of hearing people who came for that position. He describes:

“That position did much more for me. Slowly I began to realize that deafness was not going to stop me from succeeding in life. All I had to do was to venture out, and I might get a better job than the one I had just gotten” (165).

This position made him to realize that his deafness would not stop him to become successful in life. In short, this gave him confidence.

He became deaf later in his life so he never went to the deaf school before coming to PID. But he learnt horrible deaf stories about deaf schools from his friends who had attended them. His friends told him that the teachers didn’t care about them and didn’t know how to sign. His

dealings with Mr. Nigam had also shown him that deaf people needed to be united against tyranny and manipulation. He specified that “We needed better schools, better organization, and, perhaps, a college for the deaf” (166). He wanted to bring change in the lives of deaf people in India. He also added “I was going to fight the government to get rights and for the deaf” (167). He wanted to take initiative with full force.

Until now, he was just thinking about his career. In fact, the idea of getting married was never in his list. But he soon realized the importance of partner in life and he decided to marry. Thereafter, his marriage was fixed by the family with Nirmala Devi who had been called by her nickname called Nikki. After his engagement, he again resumed his busy life in Delhi.

Now he started working as an assistant photographer for the Indian National Scientific Documentation Centre (INSDOC) a new department of the National Physical Laboratory (NPL). This agency made copies of scientific journals and books for scientists all over India. This was his first experience to work with hearing people. Initially, his coworkers gave him furtive looks and left him alone. Over time, they accepted him as a part of their group. Although communication was always an issue, they adjusted him. One thing was sure that after getting government job, his status had risen in the deaf people.

Although he had got that government job, he was still working for DDA. Once Suraj, a general secretary of DDA assigned him a task of escorting the deaf American woman whose name Hester Bennet, around Delhi. So, the author and his friend, Kesh went to escort that American lady. The reason of his selection was knowledge of English. This task gave him opportunity to learn something about deaf people in America.

The author describes “Hester learned a few Indian signs, and Kesh and I picked up some American sign” (180). She was impressed by author’s English. So, she suggested him to go to Gallaudet.

After getting job at the National Physical Laboratory (NPL), he thought that he was settled for his life. Other deaf people looked at him enviously for having such a well-paid and secure job. None of his friends who had received training at the PID had a job like him. He should have been happy and proud of his job. But he felt restlessness within a couple of years at the NPL. He wanted another job with more responsibility and better salary. He heard that several friends of Bhai Narain worked in private companies and banks where they got high salary.

He learnt about a college for a deaf in America. He had an address of Gallaudet College, which was given by Hester Bennet. He sent applications twice but he could not get any reply. As per the advice of Mr. Nigam, he again wrote application to Dr. Leonard Elstad, the president of Gallaudet College and expressed his desire to take further education in their college. One month later, he received a letter and an application form from the registrar of Gallaudet College. He was told that admission test would be arranged for him through the U.S embassy in New Delhi. Later on, he learnt that Gallaudet did not admit Indian students as their experience with other students from India had not been very good. But Hester Bennet helped him in this instance. After giving admission test, he was waiting for result. Meanwhile, he married Nikki. Being a deaf, thousands of questions crossed his mind just as “Would she be a good wife? Would she be able to learn signs and communicate with me, or would she just write on her palm like the other members of my family?” (198). He thought that his deafness might bother her but it was not like that.

After few months, he received letter of his acceptance from Gallaudet. He could not believe it, but his goal of higher education was going to be fulfilled soon. He got admission but money was a big issue. But he managed it somehow after visiting different government officials. During the process of visa, he had not 'P' Form which was an assurance that he would have full financial support in the currency of the host country. The U. S. embassy could not issue him a visa unless he produced that form issued by Reserve Bank of India. He and his brother, Narain went office to office for that form but no one had paid attention to them. The clerks in those offices wanted a few hundred rupees in a bribe to issue the form. The author explains "For wealthy people, shelling out a few hundred rupees was nothing, and those clerks were used to getting that baksheesh, or tip, as they called it. But for us, that money was difficult to get" (206). He felt glad because his brother's ferociousness made the clerks to forget their bribe.

Unfortunately, his 'P Form' was denied under the criteria of the \$250 donation from Mr. Burnes for books was from a private party. The Indian government considered only government or major university grants not private donations. Regarding this matter, they visited many high positioned people in concerned government offices, but they were neglected. The author describes "Bhai Narain and I visited each of these "high position" people. Some of them refused to see us; others simply expressed their sympathy by telling us that this was not under their jurisdiction" (206). It shows, the people in government offices do not have genuine concern for the needs of common people. They never try to solve their problems. In the meantime, the author's friend, Kesh finally came to rescue him, introducing him to a friend's friend- a judge called Mr. Erady's, the director of the department that issued 'P' Forms. A short

phone call from the judge, his form was accepted. Finally, he got his visa and he went to America for further education.

In the epilogue, he has shared some of his experiences in America. Being a deaf, he observed that in India hearing people had always written to him and he had always responded them with his voice. So he never had to write to express himself. But hearing people in America didn't prefer to write for him. On the top of that they didn't understand his speech. He says "My heavy Gragret accent made my speech unintelligible to the America" (212). Actually, he had never heard English spoken by American people. So he had no idea about their sounds.

As he entered the Gallaudet College, he saw about thirty students who were signing rapidly with each other. He could not understand even single word because he had no idea about American Sign Language. The students in Gallaudet ignored him totally. He felt bad because this never happened in case of him in India. He illustrates "In India, the arrival of a stranger is a big event. A student from another country would have been surrounded by people and questioned about where he was from and what he was doing" (213). His first few attempts to get someone's attention were totally failure. Then, he did succeed in getting attention of one of the male students called Godsay from Florida, who helped him further. He writes about him that "My friend from Florida was very patient guy and fingerspelled words slowly for me wrote on paper to explain things" (214). As time went on, he learnt more American English.

Apart from education, he learnt many more things while living in America. He was first time exploring new culture which was totally different from his own country. In short, his experience of living in America was quite new and different from India in all aspect of life. He

considered himself as lucky to become deaf because he thinks “Deafness did open new doors for me, and I used them to arrive where I am now” (220). Along with many issues and challenges, deafness brought him many opportunities and he took advantage of those opportunities.

After completing his graduation and post-graduation from the Gallaudet University, in America, he did his Ph. D from the same University. Thereafter, he worked as teacher, principal, superintendent in the schools for the deaf in Texas, Illinois and North Carolina. After the retirement, he also started working on Indian Sign Language (ISL), interpreting, and educational research projects in in India. Most importantly, he published the first Indian Sign Language (ISL) Dictionary in 1981.

He thought that the provision of Indian Sign Language must be there in mainstream educational system for the inclusion of deaf students. In his conversation with Parvinder Singh, he strongly expresses this ideas. He says “The ideal should be to achieve true inclusion, for instance basic sign language should be made a mandatory part of all teachers training programmes” (<https://www.dnis.org>). It shows that true inclusion of deaf students is possible when it becomes mandatory part of all teacher training programs.

Chapter VI

Conclusion

The present research work aims to understand Indian experience of disability with reference to select autobiographies of persons with disabilities. It comprises six chapters. The first chapter of this study is introduction that consists following points- autobiography as a genre, importance of autobiography to understand the experience of disability, biographical sketches of authors, review of relevant literature, the significance of the study, hypothesis of the study, aims and objectives of the study, scope and limitations of the study, research methodology and chapter scheme. The second chapter is theoretical framework which focuses on the theory of disability Studies. After examining the theory of disability studies, the researcher tries to find out how Indian experience of disability is different from western experience of disability. Third, fourth and fifth chapters are analytical parts of the study. In these chapters, selected autobiographies of persons with disabilities are analyzed to understand Indian experience of disability. After examining and analyzing the select autobiographies of persons with disabilities, certain conclusions are drawn in the sixth chapter that is concluding part of the present research work.

Disability is a global phenomenon because it is present everywhere. Although disability is found in every part of the world, treatment which is received by disabled people can be different from one part to another due to its traditional or cultural variations. So, it is true to say the experience of disability is different from country to country. One can even find that the experience of disability in each country is likely to be very different from the experience of hundred years ago of that

country. In fact, the complete integration of disabled people into society has not yet been achieved in any country in the world, but each country is trying to remove the present barriers in their ways.

Since long, the persons with disabilities have been facing the problems of social negligence, environmental barriers and other major hindrances in their ways. But, after the establishment of disability rights movement at a global level during 1970s, some improvement is found in their condition. In order to improve their status in the society, this movement had undertaken various programs and activities all over the world. Most importantly, disability studies emerged out of the disability rights movement in the late twentieth century. It studies the concept of disability thoroughly. Just like race and gender studies, disability studies is also introduced by many institutes, colleges and universities in their curriculum for doing study or research.

The present understanding of disability is dominated by the experience of America and European countries. And it is used as universal standard. The experience of disability in India is also unique and it is complicated by poverty, caste, gender and community. The reason being that India has different socio-political and cultural background. Furthermore, it is considered one of the developing countries where the experience of disability is different from developed countries like USA and UK in terms of resources and facilities.

The researcher has selected six autobiographies of persons with disabilities to understand Indian experience of disabilities. In the third chapter, the researcher has analyzed three autobiographies of visually impaired persons- *Face to face* by Ved Mehta, *Lights Out* by L. Subramani and *The Other Senses* by Preeti Monga. The fourth chapter

contains the analysis of two autobiographies of wheelchair users- *No Looking Back* by Shivani Gupta and *One Little Finger* by Malini Chib. The fifth chapter seeks to understand experience of deafness with the help of *Deaf in Delhi* by Madan Vasishta. These autobiographies of persons with disabilities significantly help to understand Indian experience of disability through their first-hand experiences.

After analyzing selected autobiographies of persons with disabilities, some findings are detailed in the sixth chapter. These autobiographies reveal that although the persons with disabilities suffer from different impairments like visually, walking or hearing impairments, they commonly recognize with the same identity called 'abnormal'. In fact, the persons with diverse disabilities have to confront with different issues and challenges in their day-to-day life, but they face one common problem i. e. exclusion in the mainstream society. They cannot live their life as other normal beings. Just like other marginalized groups of people, their life experiences are also distinct from other average people

The experiences of these authors remind that every individual with distinct disability has to face different challenges and problems in their lives. For instance: in the case of education, the problems faced by visually impaired persons are different from wheelchair users or hearing impaired persons and vice versa. Just as, inaccessible reading materials create problem for visually impaired persons, inaccessible school buildings and the problem of communication have created big hindrances in the ways of wheelchair users and hearing impaired persons respectively. It means that their experiences pertaining to education are completely different, but they have to undergo the same sufferings of exclusion in the regular schools. Although they have same suffering of exclusion in all spheres of life, each person with diverse disability has to

acquire different kind of skills and techniques to tackle the various situations of their life.

The experiences of these authors also show that disability can affect anyone at any time. It never sees the background of the people. For instance: it is well-known fact that poverty brings disability. But the case of all these authors was different. They belonged to well-to-do family, still they are affected by disability. Some people are born with disabilities and some become disabled later in life, although the causes of their disabilities are different. For instance, Except Malini Chib who was born with Cerebral Palsy, all these authors became disabled later in their life. Ved Mehta, L. Subramani and Preeti Monga became blind at the age of three and half, eighteen and six respectively. Shivani Gupta became physically disabled at the age of twenty-two and Madan Vasishta became deaf at the age of eleven. One can mitigate the influence of disability to some extent by taking proper care and precautions, but it is not possible for anyone to avoid it completely.

It is cleared that some people are born with disabilities and some of them become disabled later in their life. The question of identity is easy for those who are born with disabilities, but it is very difficult for those who acquire disability later in their life. The reason behind that they have to adjust with their new identity and at the same time their families also have to accept new situation. Hence, disabled persons and their families need a vital support and counselling at the initial stages, so that they can easily adjust with the reality of their lives.

These autobiographies reveal that accessibility plays a crucial role in the lives of persons with disabilities to lead normal lives. But persons with disabilities in India face major problems of accessibility. Most of the

places or things like transportation services, parking facilities, roads, platforms, buses, trains and various public or private buildings in India are not accessible for them. For instance: being wheelchair users, Shivani Gupta and Malini Chib face various issues on the account of inaccessibility. In their autobiographies, they have described such awful experiences that reveals how India is poor in terms of providing accessibility in required places for disabled people. The lack of accessibility in various places restricts them from working independently. Every time they have to rely on others help while going out for any work. Accessibility is a basic need of persons with disabilities because it helps them to work or perform independently.

Due to the lack of accessibility in various places, persons with disabilities have to face discrimination every time in society. Shivani Gupta describes her experience in the theatre where she went to see movie with her friends. But she had to sit in one corner separately accompanied by other unknown people while her friends sat somewhere else. At that time, she became furious that the whole plan of watching movie together with her friends remained unsuccessful due to the lack of accessibility in that multiplex. This incident shows that the places of entertainment are also not accessible for persons with disabilities in India. In short, various experiences of all these authors regarding accessibility show that the needs of persons with disabilities are not taken into consideration by the architects or planners while constructing or developing new things.

These autobiographies also reveal that persons with disabilities usually face discriminatory attitude of people in their workplace. Although they have good education, it is very difficult for them to find a job because of the negative attitude of employers who may think that

disabled people cannot work efficiently. Malini Chib had completed her two master's degrees in Publishing Course and Library Science in London, but she faced difficulties in finding job. Once she got a job in Bombay Times but she found that there were a lot of issues of accessibility. Along with inaccessibility on the workplace, wheelchair unfriendly transportation service also forced her to quit job. Shivani Gupta also had to quit her job as Programme Manager in a big corporate company in Delhi on the account of inaccessibility. The main entrance of her office building was inaccessible to her wheelchair. There was another accessible entrance which was only for V.I.Ps. But she was not allowed to use that accessible V.I.P entrance.

The experiences of these authors regarding education show that persons with disabilities in India have to face many problems in education. Most of the time, regular schools are reluctant to admit disabled students. Consequently, poor education affects their employment opportunities. Preeti Monga was expelled from the regular school Loreto Convent, Delhi. So she had to stop her formal education in ninth standard. Later on, she faced various problems while finding a job with this little education. Madan Vasistha also stopped attending school after becoming deaf at the age of eleven because he was facing the major problem of communication. But his passion for education motivated him to study at home and appear for exam in school. He somehow completed his matriculation by studying individually at home. Thereafter, he wanted to take higher education but none of the colleges was going to admit a deaf person like him. He was actually deprived from the basic right of his education on the basis of disability. Being a wheelchair users, Shivani Gupta and Malini Chib faced the problem of physical accessibility in their colleges where they took admission. The premises of the colleges

including library, canteen, washroom, lifts and other many things were inaccessible for their wheelchairs. In this regard, they tried to meet concerned authorities of the college but nothing happened. The fact is that the concerned authorities of such institutes do not want to modify the structure of their buildings for few students who need it. Needless to say that such schools or colleges have no provisions for the students with various disabilities who have special needs in the form of trained teachers, assistive devices, accessible study materials and accessible school buildings. But regular schools in India are unable to fulfill their needs.

Health care is most indispensable part of human life because it is prime need of every human being. But the health care system in India seems to be worse than other countries. Due to the lack of public expenditure, both public and private health care centers in India always struggle with inadequate infrastructural facilities and poor maintenance. There is always shortage of manpower including doctors, trained nurses and paramedical staff to handle overcrowded patients in India. In reality, one can either become permanently disabled or lose the life due to such poor quality of health care facilities. Gupta's autobiography reveals the abysmal condition of health care in India. After her two accidents, she observed that the hospitals, especially government hospitals, in India were poor in terms of maintaining hygiene or cleanliness. Likewise, the patients were not taken care properly by the staff of these hospitals.

Many doctors in these hospitals have negative attitude towards their disabled patients. Being a patient of Cerebral Palsy, Malini Chib's experience of Indian doctors was not so good. The doctors were negative about her condition. They assumed that she was not only physically but also mentally handicapped. This assumption of Indian doctors made her

parents more depress. As they moved to London, they took the proper consultation of doctors about her condition. After doing several tests there, it was cleared that she was not only normal, but also above average in intelligence.

Even today the attitude of Indian people towards disability and disabled people is negative. Disability is generally perceived as a tragedy or loss of individual as well as his/her family. So, along with impairment, disabled people and their family always confront social stigma, prejudice, exclusion, discrimination and negative attitude of people. The society does not understand that disability is nothing but natural phenomenon. It should be accepted as a part of human variation but due to the lack of awareness and knowledge among people about the causes of disability, it is seen as something different or strange.

Since time immemorial, many false assumptions about disability and disabled people are held by society. There are some religious superstitions linked to disability and disabled people in Indian society. Sometimes disability is considered as God's punishment for sins that may have been committed by either individuals or their parents or ancestors in the present or previous birth. Another prevalent misconception about disability is that disabled have no faith in God. Madan Vashista's autobiography reveals some of these superstitions about disability prevalent in Indian society. After becoming deaf, he had to follow some superstitious beliefs and practices that were carried out by his family to cure his deafness. Considering his deafness as the result of some celestial punishment, he was taken to number of sadhus, miracle healers, temple priests who claimed to have a direct link to gods. The treatment for his deafness didn't stop with the holy men or miracle workers but there were

other non-scientific home remedies that were administered by his family. But every non-scientific method failed to cure his deafness.

The same non-scientific methods and practices were carried out by Ved Mehta's mother after his blindness. Her irrational thinking made her to believe in some superstitious causes behind her son's blindness. She took consultation from various Pandits and Hakims. Even if his father scorn such methods, his mother performed them secretly.

L. Subramani's family also believed that his blindness was a result of his sinful act in previous birth and it can be cured by praying to God. Thereafter, his mother started doing various non-scientific treatments in the hope of his cure. She met a number of miracle workers, astrologers, healers who all claimed to have knowledge of the past sins and remedies to get rid of their effects. In reality, superstitions regarding the causes of disability are responsible for such unscientific treatments of disabilities. Such treatments cause pain to persons with disabilities and delay the process of their rehabilitation.

Since long, persons with disabilities have been leading their lives with the charity given by society. Even today non-disabled people think that disabled people are needy and they give charity to disabled people. Shivani Gupta describes one of her most humiliating experiences that she never even imagined. As she was waiting in the queue to enter the temple at Haridwar, a poor middle-aged woman came to her and handed her a twenty-five-paisa coin assuming that she was a beggar. She was surprised by the act of that woman and didn't understand how to react. But she later on understood that disabled people are generally considered as needy and they live on charity which is given by the society through different ways.

This incident reminds that disabled people are still seen as passive recipients rather than active participants or contributors of society.

A significant proportion of disabled population in India resides in rural regions. The condition of disabled people in rural India is worse than urban area. In rural area, they get limited resources and facilities that are usually available in urban areas. Madan Vasishtha was living in a small village in northern India where he had limited exposure. After becoming deaf, he had to stop school in the middle of sixth standard. Thereafter, he spent next ten years of his life working in his family farm as a farmer. He and his family were not aware of special schools for deaf people. There are very few special schools for disabled available in India and most of them are located in urban areas. So most of the people in rural areas are unaware about the availability of special schools.

Some of these authors have bad experience about some people who worked in the government offices. Madan Vasishtha found that the clerks in government offices never do their job sincerely. Once he applied for a fellowships after getting admission in the All India Photography Training Institute for the Deaf in Delhi. He waited long time for approval but he received nothing. After making inquiry at the office that granted scholarships, he was shocked by their response that he had not received the scholarship as they had never received his application. The author expressed the possibilities that either they lost his application or kept it in a big pile of files in front of them. He also experienced that while doing his visa process the clerks in the concerned department wanted a few hundred rupees as bribe to issue 'P' Form which was an assurance that he would have full financial support in the currency of the host country. Actually, the government employees have not genuine concern about the

suffering of common people. They do not show their interest in work until they do not get money as a bribe from the people.

Shivani Gupta and her father also went through the same experience. They suffered a lot till the final allotment of a DDA flat which was given her on the basis of her disability. They went to concerned authority for approval, but they were neglected. Thereafter, they met various officers including Lieutenant governor of Delhi regarding the case but nothing happened. One of the officers openly asked her father to pay him one lakh rupees to get the work done. But her father refused to do it. As a result of it her case was further delayed. As they went to meet the minister of urban affairs, he approved the case and demanded immediate allotment. But still their immediate action also took two years for the final implementation. So when she did get her flat, the cost was double as much as they had made the application. She thought that if they had paid the bribe, they could have saved a large amount of money by getting an allotment earlier when the cost was lower. Thus the experience of Madan Vasishta and Shivani Gupta shows that many disabled people like them may not meet their rights due to such corrupt people in government offices in India.

Some organizations in India misuse the money that they collect in the name of welfare of disabled. For example: while working with the All India federation of the Deaf (AIFD), Madan Vasishta experienced that the members of this federation wandered all over the city in groups of three or four to collect donation by selling miniature India flags. And the general secretary of that organization used the federation money for his lavish lifestyle and expensive trips to foreign countries. Due to such malpractices, disabled people do not meet their genuine needs, although some organizations are established for the wellbeing of disabled people.

Many cultural and traditional beliefs make disabled women's experiences different from non-disabled women. Indeed, disabled women have double disadvantages in Indian patriarchal society. Being a woman and disabled, they usually suffer with two fold discrimination. Because women are expected to perform traditional roles like cooking or taking care of family. So it is assumed that disabled women are unable to perform such household duties. Hence, Indian families never accept disabled woman for marriage. As a result of it, disabled women remain unmarried for lifetime. On the top of that, if they become disabled after their marriage, they are abandoned or divorced by their husbands. Especially in Indian society, there are very few cases in which disabled women remarry.

In her autobiography, Malini Chib expresses her dire need of life partner who could love her beyond her disability. Most of her friends had partners in their college life but no one showed his interest in her. She was serious about her relationship with Zubin, her friend, but she got frustration as he told the fact that he was a gay. Unfortunately, she remained unmarried for lifetime. In the case of Preeti Monga, many times she got rejection in marriage proposal because of her blindness. Finally, she married Keith but she had to leave him to get rid of his daily tortures and remarried Ashwani, who met her at office where she worked. The case of Shivani Gupta is different. She was abandoned by her boyfriend as she became disabled. Although she had tetraplegic condition, Vikas married her. At first, Vikas's parents were not happy with their relationship. But, as they realized her importance in his life, they gave permission for their marriage. So they married after completing ten years of their relationship. Most importantly, they were happy in their married life. But their happy married life was devastated after four months of their

marriage while going to Manali for family trip. In that accident, her husband, Vikas and her father-in-law died. Thereafter, she remained alone without partner.

Almost all of these authors have travelled in western countries like USA, UK and European countries for academic or other reason. Their western experience of disability is better than India. They found that there is better understanding and awareness found among western people about disability and its causes. Most importantly, western people have accepted disability as a part of human variation. So their attitude towards disability and disabled people is not negative. In fact, they usually give priority to special needs of disabled people. These countries provide them better accessibility that helps them to lead normal land independent life like non-disabled people. Both Shivani Gupta and Malini Chib were very much influenced by the wheelchair friendly environment in western countries in which they had lived.

The fact is that disabled children in those countries go to school as their non-disabled peers. Likewise, disabled people earn their own income by doing jobs everywhere like their non-disabled colleagues. In their country, they get required aids and appliances which assist them to work without help of others. They also get proper correctional surgeries and therapies in their countries. In short, disabled people in foreign countries enjoy the same rights enjoyed by non-disabled people. Ved Mehta was very much impressed by America where he could live normal or independent life like other normal beings. He found that most of the places or things like roads, transportation services were accessible for visually impaired in America. But In India, inaccessible public places especially roads restrict visually impaired people like him to move independently. Most importantly, pedestrian are given first priority while

walking on or crossing the roads in America. So, it is better especially for visually impaired in terms of safety. But he never observed these things in India. Indeed, the visually impaired people need audio signals, guiding blocks and warning blocks on the required places to navigate or cross the roads safely. But these things are not found on Indian roads.

Along with excellent education, Ved Mehta enjoyed the freedom of movement and a complete sense of self-reliance that he couldn't enjoy in India. In short, he felt more comfortable to live in America than in India. Malini Chib also felt more comfortable to live in London where she enjoyed wheelchair friendly environment and educated attitude of people everywhere.

Most important thing is that persons with disabilities in India get strong support from their family. Even today some people live in a joint family. Therefore, persons with disability are not only supported by their parents but also other family members or relatives. After becoming disabled, these authors have also got physical or mental support from their family. They all belong to well to do family. Even they get support from other people apart from their family members. Some people voluntarily come to help disabled people without any ulterior motive. But it does not happen in foreign countries. For instance: in their trip to Eiffel Tower, Shivani Gupta and Vikas badly needed the help as they saw fourteen steps while coming out of the metro station. No one around them came to help. Even they had not tried to call anyone for their help because they were in strange country where most of the people speak in French, so they could not communicate with them.

Overall, it is right to say that the life of persons with disabilities in India is more challenging than western countries. Many laws exist for

disabled person but due to the poor implementation of those laws, there is no expected change found in their situation even today. There is need to create awareness among the people about disability and disabled people In India. It will help to change the negative attitude, misconceptions and stereotypical opinions about disability. One of the effective ways to create mass awareness is to introduce concept of disability in schools, colleges and universities. In order to understand the various facets of disability, it should be studied as a separate academic discipline like gender and women's studies. In reality, Indian universities and academic institutions have not yet incorporated disability studies in the curriculum.

Another way to create awareness is to increase the number of trained volunteers in the disability sector so that they can help to change the negative attitude of the society. Social media can also be effectively used to sensitize the people because it can reach a large number of people. Along with this, various seminars, workshops and conferences can also help to create awareness.

One thing is to be noted that the society shows sympathy or pity towards persons with disabilities, but they don't need sympathy and charity. Instead they want such support that they can fully participate in mainstream activities like others. If the family and the society come forward to fulfil their special needs, thousands of disabled persons can be like Stephen Hawkins who has contributed enormously in Physics in spite of having severe locomotor disability.

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**UNDERSTANDING INDIAN EXPERIENCE OF DISABILITY WITH
REFERENCE TO SELECT AUTOBIOGRAPHIES OF PERSONS WITH
DISABILITIES**

A THESIS SUBMITTED TO

SHIVAJI UNIVERSITY, KOLHAPUR

FOR THE DEGREE OF

DOCTOR OF PHILOSOPHY

IN

ENGLISH

UNDER THE FACULTY OF

HUMANITIES

BY

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JULY- 2022

80-Recommendation

Persons with disabilities is one of the marginalized groups of people. For long, their basic needs have been overlooked. Although some awareness programs regarding disability related-issues have been carried out at global level for the last five decades, still the expected change is not found in their situation especially in developing countries. The majority of world's disabled population lives in developing countries like India where they live in miserable condition due to the lack of access of essential services like education, employment, transportation, information, rehabilitation, accommodation and medical services. The fact is that developing countries are economically backward, so they are unable to provide even the basic facilities to their citizens including persons with disabilities. Hence, the persons with disabilities are often confronted with various difficulties while surviving in such condition. It is obvious that disability related experiences of such people in developing countries are very different from developed countries like USA, UK and European countries.

Persons with disabilities have taken initiative to write their autobiographies to expose the blemishes of the society in which they lived. The autobiographies of Dalit have been extensively studied, but autobiographies of persons with disabilities have not attracted attention of research scholars. They are not only marginalized from the social economic, cultural and political activities but also from the research agendas. Therefore, to fill the research gap, the present researcher is attempting to scrutinize select autobiographies of Indian persons with disabilities. The researcher has selected following autobiographies- *Face to Face* (1957) by Ved Mehta, *Deaf in Delhi* (2006) by Madan Vasishta, *Lights Out* (2014) by L. Subramani, *One Little Finger* (2010) by Malini Chib, *The Other Senses*

(2012) by Preeti Monga, *No Looking Back* (2014) by Shivani Gupta for the present research work. The main purpose of choosing the genre, 'autobiography' to understand the experience of disability is that autobiography provides authentic and reliable information about person's life and social conditions.

Conclusion

These autobiographies reveal that the persons with disabilities in India face the major problem of accessibility because most of the places or things are not accessible for them in India. Along with accessibility, they face the problems regarding education, employment, rehabilitation, medical care, reasonable accommodation and many more. Due to the lack of knowledge and understanding of people regarding the causes of disability, they face the negative attitude of society. Many laws exist for them, but due to the poor implementation of those laws, there is no expected change found in their situation even today. Indeed, there is need to create awareness among the people about disability and disabled people. It will help to remove the negative attitude, misconceptions and stereotypical opinions about disability. One of the effective ways to create mass awareness is to introduce concept of disability in schools, colleges and universities. In order to understand the various facets of disability, it should be studied as a separate academic discipline like gender and women's studies. Another way to create awareness is to increase the number of trained volunteers in the disability sector so that they can help to change the negative attitude of the society. Social media can also be effectively used to sensitize the people because it can reach a large number of people. Along with this, various seminars, workshops and conferences can also help to create awareness.

Summary

Chapter I: Introduction

In this chapter, the researcher attempts to introduce the topic of present research work in brief. It also focuses on the biographical sketches of selected authors. The researcher has chosen autobiographies of persons with disabilities to understand Indian experience of disability. Hence, this chapter tries to study 'autobiography' as genre.

Chapter II: A Theoretical Framework: Disability Studies

In this chapter, the researcher has drawn the theory of disability studies which critically examines the concept of disability thoroughly. This theory also helps to understand the experience of disability. The understanding of disability is dominated by American and European experience of disability. It is considered as universal norm. But Indian experience of disability is also unique and it is complicated by poverty, gender, caste and community. Hence, this chapter also focuses on the Indian experience of disability. To understand the Indian experience of disability, the historical representation of disability, rural and urban experience of disability, specified categories of disability, human rights of persons with disabilities, various problems of persons with disabilities are studied in Indian context.

Chapter III: Autobiographies of Visually Impaired

In this chapter, three autobiographies of visually impaired persons are analyzed. It includes Ved Mehta's *Face to Face*, L. Subramani's *Lights Out* and Preeti Monga's *The Other Senses*. These autobiographies show that the biggest challenge for persons with visually impaired is to navigate around the places without help of others. Besides that they often face the problem of

accessible reading material. Very few books or textbooks are available in Braille script.

Chapter IV: Autobiographies of Wheelchair Users

Two autobiographies of wheelchair users are analyzed in this chapter. Shivani Gupta's *No Looking Back* and Malini Chib's *One Little Finger* shows that the wheelchair users face the major issue of physical accessibility in India because most of the places are inaccessible for them.

Chapter V: Autobiography of Hearing Impaired

In this chapter, the autobiography of hearing impaired person is analyzed. It focuses on Madan Vasishta's *Deaf in Delhi*. After analyzing this autobiography, it is cleared that the persons with hearing impairments face the major problem of communication.

Chapter VII: Conclusion

After analyzing the selected autobiographies of persons with disabilities, certain conclusions are drawn in this chapter.

FUTURE FINDINGS:

The present research work attempts to understand Indian experience of disability with reference to select Indian autobiographies of persons with disabilities. The autobiographies of visually impaired, wheelchair users and hearing impaired person are analyzed to understand Indian experience of disability. In the next research, western experience of disability can be studied through the western autobiographies of persons with disabilities. The experience of disability varies from country to country because each country has different socio-political

and cultural background. Furthermore, the experience of disability in developing countries is different from developed countries in terms of getting resources and facilities. Hence, a comparative study of Indian experience of disability and western experience of disability can also be done. The experience of disability in rural areas is different from urban areas. So the future research can be concentrated on the rural and urban experience of disability separately or it can be compared. Most importantly, various authors have thrown negative light on disabled characters in their fictional writings. Even in films, such disabled characters are portrayed as strange, exotic or pitiable objects. Such fictional works and films can also be studied through the different perspectives.

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Chapter I: Introduction

In this chapter, the researcher attempts to introduce the topic of present research work in brief. It also focuses on the biographical sketches of selected authors. The researcher has chosen autobiographies of persons with disabilities to understand Indian experience of disability. Hence, this chapter tries to study ‘autobiography’ as genre.

Chapter II: A Theoretical Framework: Disability Studies

In this chapter, the researcher has drawn the theory of disability studies which critically examines the concept of disability thoroughly. This theory also helps to understand the experience of disability. The understanding of disability is dominated by American and European experience of disability. It is considered as universal norm. But Indian experience of disability is also unique and it is complicated by poverty, gender, caste and community. Hence, this chapter also focuses on the Indian experience of disability. To understand the Indian experience of disability, the historical representation of disability, rural and urban experience of disability, specified categories of disability, human rights of persons with disabilities, various problems of persons with disabilities are studied in Indian context.

Chapter III: Autobiographies of Visually Impaired

In this chapter, three autobiographies of visually impaired persons are analyzed. It includes Ved Mehta’s *Face to Face*, L. Subramani’s

Lights Out and Preeti Monga's *The Other Senses*. These autobiographies show that the biggest challenge for persons with visually impaired is to navigate around the places without help of others. Besides that they often face the problem of accessible reading material. Very few books or textbooks are available in Braille script.

Chapter IV: Autobiographies of Wheelchair Users

Two autobiographies of wheelchair users are analyzed in this chapter. Shivani Gupta's *No Looking Back* and Malini Chib's *One Little Finger* shows that the wheelchair users face the major issue of physical accessibility in India because most of the places are inaccessible for them.

Chapter V: Autobiography of Hearing Impaired

In this chapter, the autobiography of hearing impaired person is analyzed. It focuses on Madan Vasishta's *Deaf in Delhi*. After analyzing this autobiography, it is cleared that the persons with hearing impairments face the major problem of communication.

Chapter VII: Conclusion

After analyzing the selected autobiographies of persons with disabilities, certain conclusions are drawn in this chapter.

FUTURE FINDINGS:

The present research work attempts to understand Indian experience of disability with reference to select Indian autobiographies of persons with disabilities. The autobiographies of visually impaired, wheelchair users and hearing impaired person are analyzed to understand Indian experience of disability. In the next research, western experience of disability can be studied through the western autobiographies of

persons with disabilities. The experience of disability varies from country to country because each country has different socio-political and cultural background. Furthermore, the experience of disability in developing countries is different from developed countries in terms of getting resources and facilities. Hence, a comparative study of Indian experience of disability and western experience of disability can also be done. The experience of disability in rural areas is different from urban areas. So the future research can be concentrated on the rural and urban experience of disability separately or it can be compared. Most importantly, various authors have thrown negative light on disabled characters in their fictional writings. Even in films, such disabled characters are portrayed as strange, exotic or pitiable objects. Such fictional works and films can also be studied through the different perspectives.

