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Autobiographical Memoir as a Counter-dialogue to Misrepresentation of Disabled Body

A Thesis Submitted to the Central Department of English
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By
Shrijana Pathak

Central Department of English
Kirtipur, Kathmandu
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Tribhuvan University

Central Department of English

Letter of Recommendation

It is certified that Mrs. Shrijana Pathak has prepared this thesis entitled **"Autobiographical Memoir as a Counter-dialogue to Misrepresentation of Disabled Body"** under my guidance and supervision. I recommend this thesis for approval to the Research Committee.

……………………

Mr. Shankar Subedi

Central Department of English

Tribhuvan University

Kirtipur, Kathmandu

December 2008

Tribhuvan University

Faculty of Humanities and Social Science

Letter of Approval

The Thesis entitled **"Autobiographical Memoir as a Counter-dialogue to Misrepresentation of Disabled Body"** by Shrijana Pathak submitted to the Central Department of English, Tribhuvan University has been approved by the undersigned members of the Research Committee.

Members of Research Committee

Internal Examiner

External Examiner

Head
Central Department of English
Date

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Abstract

This research entitled “Autobiographical Memoir as a Counter-dialogue to Misrepresentation of Disabled Body” was carried out from July to December 2008. It became possible by review of different writers’ books, journals and articles. For this study, four essays were selected namely “Carnal Acts”, “Living with an Unstable Body”, “Bells and The Unification of Stephen Hawking” written by Nancy Mairs, Barbara Rosenblum, Ved Mehta and Mark O’Brien respectively. The hypothesis set for this study was “Autobiographical memoir written by writers with disability helps the writer to privilege their self and to acquire an agency. Such a move makes the autobiographical memoir a counter-dialogue to misrepresentation of disability experience.” Disability theory is used for the review of these essays using the tools like Constructing normalcy, Stigma, Ideology and Discourse.

All four writers in memoir come to the experience of writing with a desire to make them heard and use the ‘written’ voice to formulate the expressions of identity that will complicate and disrupt stereotype about disabled self. The expressive and assertive voice developed throughout the memoir writing claims a certain kind of authenticity, agency and subjectivity at the hearty of which is the privileging of the point of view of the disabled narrator. It helps them to face the marked body and to provide an account that is truthful and trustworthy. It exceeds the way people with disability are (mis)represented by “normal” people because it tells what it means to be with disability for really disabled people.

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Chapter I

Introduction

Autobiography, like poetry, drama and fiction is considered to be a separate form. But it is not easy to define it as a genre like them. However, it has its own long tradition as well as history as a form of literature. The word memoir comes from the Latin word 'Memoria' which means memory. A memoir is an evolution of the autobiography. A memoir, in the style which the publishing market are flooded with at the moment tends to deal with a more specific period or theme in our life. Significance of memoir lies in the depiction of actual condition of the people. They write to represent their selves so as to struggle against the discourse of normalcy, ideology, stigma etc.

Autobiographical memoir is the record of one's own life. It is the exploration of self. It is a sequence of events from birth to death, during which he/she has many names and relations, jobs and experiences, joys and sorrows, meetings and separations, and commitments, success and failure etc., which are the part and parcel of his/her life. These are the different aspects of life that he/she generally has to come across and autobiography is the medium of expressing those personal things. It reveals the person as he/she is to himself or herself. So, autobiography is a self written document.

Autobiographical writing also allows disabled artists to explore spaces and feelings that do not have a place in traditional discourses on disability. Despite what common reading trends lead us to believe a memoir does not need to be a blockbuster written for the whole world to read. A memoir is written for own reasons and for whatever result you want (Norton-Smith, 2008). A memoir is a piece of autobiographical writing, usually shorter in nature than a comprehensive autobiography. The memoir often tries to capture certain highlights or meaningful moments in one's past, often including a contemplation of the meaning of that event at the time of the writing of the memoir. The memoir may be more emotional and concerned with capturing particular scenes, or a series of events, rather than documenting every fact of a person's life. A memoir usually has a particular focus of attention, focusing on the selected events from a perspective that may not include other facts and details from the person's life.

Autobiographical memoir is the self memory of the writers in which they express their feelings, experiences, anxieties, pains and sufferings of their own. Now a days, autobiographical memoir is used as a medium to counter the misrepresentation of disabled people by able bodied persons. It provides the medium for counter discourse that challenges stereotype and misconception. Autobiographical memoir written by writers with disability helps the writer to privilege their self and to acquire an agency. Such a move makes the autobiographical memoir a counter-dialogue to misrepresentation of disability experience. Besides it, writing autobiographical memoir helps writer to escape “the anxiety of speaking aloud” in physical society and about “the waves of shame”, and to lay stress on “a body replaced with the disturbing stranger, sick or dead, who so often is a bad influence”.

Disability is functioning judged to be significantly impaired relative to personal or group standard or spectrum. Disability may involve physical impairment, sensory impairment, cognitive or intellectual impairment, mental disorder (also known as psychiatric disability), or various types of chronic diseases. Disability may occur during a person's lifetime or may be present from birth. Disabled is the most generally accepted term to refer to people with a permanent illness or injury that makes it difficult for them to use part of their body completely or easily. It describes somebody with a condition that makes it difficult to perform some or all of the basic tasks of daily life.

It is generally agreed that people with disabilities have been misrepresented in most literary and mass media. Among literary genres, autobiography, which William Dean Howells (1909) referred to as the "most democratic province of the republic of letters," may be an exception. Autobiography seems to require less in the way of literary expertise and experience than other, more exalted, genres; it seems to require only that one have a life—or at least, one considered worth narrating—and sufficient narrative skill to tell ones own story. (Collaborative autobiography is even more accessible, since it does not require even literacy.) In any case, I think that most literary scholars would agree that autobiography has served historically as a sort of threshold genre for other marginalized groups; it might do so for disabled people as well (Couser, 305).

It is not just the apparent accessibility of autobiography a kind of negative qualification that recommends it but also something more positive: the notion that autobiography by definition involves self-representation; as such, autobiography offers an alternative to patronizing and marginalizing (mis)representation by others; it thus provides a medium for counter-discourse that challenges stereotypes and misconceptions. An important aspect of its counter-discursive potential is that in autobiography disability is likely to be represented as a fact not a trope, a "living condition" not a metaphor for some undesirable moral status, which is too often the case in fiction, drama, and film. It may even be seen as a condition that is not only culturally constructed but constructive of distinctive culture (Couser, 306).

Recent theories of autobiography have stressed the fictiveness of discourse that purports to describe (the history of) a self. A broadly constructivist view underwrites such theories: autobiographies are not bare chronicles of fact, but the artful manipulation of details and events that acquire the status of facts during the construction of a particular person as a self. Yet a constructivist interpretation of autobiographical discourse does not of itself commit us to reading autobiographies as we would read fictions (Herman, 351).

Disabled people are stigmatized by cultural and social values of society and they are always treated as second class citizens in their respective societies. Disabled scholars are writing their autobiographical memoir to create their identity as a normal human being in society. These writings try to play the role of agents by countering the misrepresentation done by society and writing the counter-dialogue to the society.

Nancy Mairs, though born by accident of war in Long Beach, California, grew up north of Boston. She did editorial work at the Smithsonian Astrophysical Observatory and the Harvard Law School before moving to Tucson, Arizona, where she earned the M.F.A. in creative writing (poetry) in 1975 and the Ph.D. in English literature in 1984 from the University of Arizona. She has taught writing and literature at Salpointe Catholic High School, the University of Arizona, and the University of California at Los Angeles.

A poet and an essayist, she was awarded the 1984 Western States Book Award in poetry for "*In All the Rooms of the Yellow House*" (Confluence Press, 1984) and a National Endowment for the Arts Fellowship in 1991. Her first work of non-fiction, a collection of essays entitled *Plaintext: Deciphering a Woman's Life,* was published by the University of Arizona Press in 1986. Since then, she has written a memoir, *Remembering the Bone House*, a spiritual autobiography, *Ordinary Time: Cycles in Marriage, Faith, and Renewal*, and many essays like "Carnal Acts". (nancymair.com). Carnal Acts focus on what it means to "cope" with multiple sclerosis, the most conspicuous and consuming aspect of Mairs' life. She reveals her inner life as writer, wife, mother and then looking outward to discuss the nature of female discourse. She is living with full gratitude and excitement despite the struggles and hardships that are part of all day-to-day experience.

Ved (Parkash) Mehta (Born 1934) is a distinguished Indian writer who was born in Lahore, British India (now a Pakistani city) to a Hindu family. He lost his sight at the age of three as the result of a long bout of cerebrospinal meningitis. His father, a doctor, tried to give him an education, like his other children, so that the boy could become a self-supporting citizen of the world.

Mehta has lived in the Western world since 1949; he became an American citizen in 1975. He was educated at Pomona College, at Balliol College, Oxford where he read Modern History, and at Harvard University. His first book was published in 1957. Since then he has written 24 books, as well as hundreds of articles and short stories, for British, Indian and American publications, including the New Yorker, where Mehta worked as a staff writer for 33 years.

He is the recipient of several awards including the Guggenheim Fellowship and the MacArthur Prize. He has been a visiting Fellow at Balliol College, Oxford, held the Rosenkranz Chair in writing at Yale University and taught Literature and History at a number of colleges and universities.

At the age of sixteen, Mehta went to a school for the blind in Arkansas, where he completed his elementary and high school education in three years. From there he went on to Pomona, Oxford and Harvard.

Ved Mehta was partly educated in the USA and Britain, and as a young man worked for The New Yorker, where many of his essays have first appeared. Although he has written a short satirical novel, *Delinquent Chacha* (1967), he is best known as a shrewd and observant commentator on Indian society. His most distinguished work is highly autobiographical. *Face to Face* (1957) describes his childhood and his early struggle with blindness. *Walking the Indian Streets* (1963) deals with a journey round India after his years abroad. A more ambitious journey resulted in *Portrait of India* (1970), an epic travelogue in which public figures such as Indira Gandhi alongside ordinary people. Mehta explores the intellectual life not only of India but also of Europe and USA in *Fly and the Fly Bottle* (1963) and *John is Easy to Please: Encounters with the Written and Spoken Word* (1971). *Daddyji* (1972) and *Mamaji* (1979), touching studies of his parents, have been followed by more volumes of autobiography, now collectively titled *Continents of Exile: The Ledge between the Streams* (1977), *Vedi* (1983), *Sound Shadows of the New World* (1986) and *The Stolen Light* (1989). He has also published a *Study of Gandhi* (1977) (vedmehta.com).

“Bells” is one of the marvellous essays in the book named ‘*Vedi*’. This essay is about Mehta’s incidents like introduction to Braille script, wanted to be like his siblings, writing with a pen and a paper. The importance of fingers in a blind person’s life has been well described in this chapter.

Mark O'Brien, poet, journalist and inspirational voice in the movement of disabled people to lead independent lives. Born in Boston and raised in Sacramento, Calif., O'Brien was six years old when he contracted polio which left him paralyzed from the neck down. At the time of his death, he was one of some 100 polio survivors in the United States who still used an iron lung to breathe.

In 1978 O'Brien moved from Fairmont State Hospital to Berkeley, after being accepted as a freshman at the University of California. He became a familiar figure on the streets of Berkeley, navigating his motorized gurney between the campus and his tiny apartment which housed his iron lung.

O'Brien received his BA in English literature in 1982 with the support of note takers, home health-care attendants and the then-fledgling Centre for Independent Living. After repeated efforts, O'Brien gained admission to UC's Graduate School of Journalism, helping to set a precedent for severely disabled applicants to state universities. Although a serious health setback prevented him from pursuing his graduate degree, O'Brien began his career as a journalist with the publication of an essay on what leading an independent life means.

Initially, he composed his pieces by dictation, and then he learned how to type with a mouth stick, first on an electric typewriter, later on a word processor. His first collection of poems, "*Breathing*", was published by Little Dog Press in 1990. O'Brien considered it one of his proudest accomplishments. He completed two later volumes of poetry -- "*The Man in the Iron Lung*" (1997) and "*Love and Baseball*" (1998), both published by Lemonade Factory, an independent small press he co-founded in Berkeley with Susan Fernbach.

At the time of his death, O'Brien was completing an autobiography. A long-time editor of Pacific News Service, O'Brien published essays, book reviews, and news stories for the San Francisco Chronicle, the Examiner, and the National Catholic Reporter. He wrote about sports, religion (he was an ardent opponent of euthanasia), his life-changing two hour session with a sex therapist, his experience with Stephen Hawking, and the culture and politics of being disabled. (In one piece he writes about coping with the fleas from an alley cat that shared his one-room apartment for many years.)

His twin passions, according to film-maker Jessica Yu, were baseball (specifically the San Francisco Giants), which gave him entry to the sports culture of his peers, and

Shakespeare. O'Brien delivered the 1998 commencement address to graduates of Berkeley's English Department.

As an advocate of the "independent living" movement, O'Brien emphasized the universal need for human beings to have a measure of control over their own lives. "I want people to think of disability as a social problem . . . Everyone becomes disabled unless they die first." O'Brien spoke candidly on film of his struggle to overcome loneliness. "You can't make someone love you . . . you have to be lovable yourself," he said, adding that he wasn't convinced he knew how to do that.

Barbara Rosenblum is a physically disabled writer and she is famous with her works in autobiographical memoir. Barbara founded Strategic HealthCare Programs in conjunction with its Board in 1996. As author and winner of the 1997 National Managed HealthCare Organization's HITS Award, she is recognized as a healthcare leader through her ability to use technology for the improvement of patient care. Her major areas of focus have been outcomes and disease management programs with an emphasis in cardiopulmonary diseases, oncology, HIV and the use of pharmaceuticals. Barbara is a visionary as well as an experienced manager. She is well known for her ability to build a cohesive, hard-working team. She is well networked and respected in her field. She writes and speaks at trade industry conferences on a regular basis where she is known as a pioneer of change and reform in healthcare practices. Barbara holds a Master of Arts in Organizational Management as well as a Bachelor of Science in Nursing Administration. She is a member of the Healthcare Information Management Society (HIMSS), The Data Warehouse Institute, the MIT Technology Forum and the Southern California Software Council.

In *Cancer in Two Voices,* Barbara Rosenblum "went inside [herself] and wrote about [her] life and feelings", instead of using traditional "sociological data" to build an interpretation. Despite repeated visits to at least three different physicians in the Kaiser (HMO) system after she discovered a lump in her breast, and even though she noticed the lump growing, her breast swelling, and finally the skin around her nipple puckering, cancer was not diagnosed for almost a year. She attributed these errors to "mass medicine" and her working class background: "I never learned to recognize a good doctor. Public medicine was all I had ever experienced. Rosenblum believed that had she known how to recognize bad medical care, and gone to a private physician in a private hospital, mistakes would not have happened (Bell, 300).

For Barbara Rosenblum, life became her work. As she put it, "I want to do work now that is moving and stirring, not merely smart and academically well reasoned. I want to touch on life's cruel ironies, on the bigger questions of courage, humanity, the meaning of time, the experience of bodily disintegrate, and the struggle to become whole to oneself". She believed she was merely the first of many of her friends who would have breast cancer, and so she offered her experiences to them, that they might learn from her (Bell, 302).

All the four essays “Carnal Acts”, “Bells”, “The Unification of Stephen Hawking” and “Living in an Unstable Body” by Nancy Mairs, Ved Mehta, Mark O’Brien and Barbara Rosenblum respectively talk about the lived experience of themselves.

“Bells” is an autobiographical memoir of Ved Mehta which explains about the disability experience of its characters. The different functions of characters in this essay are regulated by bell ring. In this essay, all the characters are disabled. Vedi, one of the major characters of this memoir, always imagine or expect to learn as an able body people though he deserves the disable body. Through out this text, writer explains about the problems faced by disabled people in their daily lives. This autobiographical essay frequently questioning on the discrimination based on sights.

The next essay entitled “The Unification of Stephen Hawking” by Mark O’Brien is really an interesting autobiographical memoir of disabled writer. The main character of this essay, Stephen Hawking, is a reputed and renowned physician all over the world. Writer explains all the difficulties faced by him being a disabled reporter throughout the essay. In this essay, writer makes continuous attempts to meet Stephen Hawking for an interview. After several attempts, he becomes successful to meet Dr. Hawking and take interview which was the dream for the writer. After interview with Dr. Hawking, he concluded that sufferings of disabled people can be healed by remarkable works in their lives.

Other two essays namely “Carnal Acts” and “Living with an Unstable Body” by Nancy Mairs and Barbara Rosenblum respectively are meditation on their disabled bodies. These autobiographical memoirs are attempts to construct a self through the narrative of past events and compete for the recognition with visible differences and disability and cultural meanings assigned to the marked bodies. Both the writers run the risk of being misidentified on daily basis and their cultural meanings and value of difference. Both writers are unhesitant to meditate on the disability and they politically position the disabled self in the memory that claims agency of the people with disability privileging their view points.

Nancy’s memoir begins like an analysis of her life as an attempt to “cope with” disability and authorship. In course of her meditation, she criticizes western tradition of distinguishing the body from the mind and or soul. Barbara Rosenblum, a lesbian suffers from an internal cause because she acquires an unstable marked body because of breast cancer. She draws the attention of readers to the fears of the female with marked bodies. All the women she is in contact with have lost their breasts because of cancer and it becomes a nightmare to all of them.

In “Living in Unstable body” Rosenblum writes, "When the body, like my body, is no longer consistent over time, when it gives different signals every month, when something that meant one thing in April may have different meaning in May, then it's hard to rely on the stability . . . and therefore the truth . . . of the body. And because of that, it's hard to interpret and hard to predict" This threw her into a crisis of meaning, forcing her to learn a new language and vocabulary. Rosenblum courageously explored even the meaning of sexuality that is how the language of her body became a "language of symptoms, not sexuality".

Any restriction or lack, resulting from impairment, of ability to perform any activity in the manner or within the range considered normal for a human being is called disability (WHO, 1980). Until 1975 disability was studied within the academy largely within medicine and its allied disciplines but in that year the Open University introduced an undergraduate course entitled “The Handicapped Person in the Community”. It continued in various guises for more than 15 years and the first postgraduate programme emerged in 1979 at the University of Kent. Various other initiatives were established in the 1980s but it was not until the 1990s that disability studies began to emerge with an academic identity of its own. This emergence has largely been ignored by medicine and its allied disciplines but has caused some major concerns within that sub-branch of sociology called the sociology of health and illness. There is not the time here to review all of these tensions save to point out that, as with all contested knowledge, there are issues of territoriality, representation, legitimacy, validity and politics at stake (Oliver and Barton, 3).

Representations of disabled people have too often been carried out by non-disabled people in different areas (literature, media, newspaper etc) with varying degrees of discursive knowledge of what is disability. The results are frequently misrepresentations that reduce the disabled people to the specificities of their apparent physical differences. It leads to the “othering” of the people with disability because the marked body is not “composed from the ideal parts of living models” as discover in “human body…in art and imagination” and in the socio-political space dominated by non-disabled people (Davis 10).

Defining or creating the category of people with disability is fraught with social and political tensions because any idea related to marked body in our society and culture is always done through the discourses that are produced by the society wherein the non-disabled people do have access to all sorts of discursive interpretation of the body. In the context Lennard J. Davis says “the marked body in our society is always defined in terms of norms of social discourses. The society (mis)represents the marked body as ‘deviant or extremes’ because ‘when we think of bodies is society, where the concept the norm is operative, then people with disabilities will be thought of as deviants” (13).

The prevailing concept on disabled people in the society is still stigmatized. According to Goffman, “the disability in our society is stigmatized that results in dehumanizes the person”. This process of stigmatization, a kind of misrepresentation, is basically because of the discrepancy between what he says “virtual social identity” and “actual social identity” (204).

The intrinsic conception imagines a tight connection between disability and handicap; the circumstantial conception loosens and relativists that connection. The circumstantial conception reminds us that we all depend on various tools and structures—in particular, on cultural artefact—to enable us to do what we want to do. In many cases it is the design of these tools and structures that prevents a disabled person from accomplishing what they want, rather than anything intrinsically connected to the disability (Perry et. al. 1).

It is no secret that disability has been grossly misrepresented in popular culture, as it has often been used metaphorically to symbolize criminality, tragedy, pity, fear, charity and ridicule. Thus, we are faced with the challenge of countering these negative constructions and redefining disability as a valued human condition. It is here that the political and cultural significance of Disability Arts and Culture emerges, as disabled artists and performers are empowered to challenge cultural misrepresentation and reshape the disability narrative. As such, Disability Arts and Culture marks the growing political power of disabled people over their narratives, as disabled artists use it to counter cultural misrepresentation, establish disability as a valued human condition, shift control to disabled people so they may shape their narratives and bring this disability controlled narrative to wider audiences (Abbas et. al. 1).

Body image in people with physical disability is an important area of investigation, which has received little attention in the research literature. Disability scholars argue that disability is too frequently used in art as a metaphor for negative situations of tragedy or evil, rather than as a recognizable and accurate human element itself. By examining these critiques of cultural misrepresentation, we begin to appreciate how “the representation of disabled people in the media and other art forms, such as literature, film and photography, is then regarded as confirming what it means to be a disabled person in this society" (Barnes et. al. 190).

The worldwide disability movement has entered a new phase. This new dimension of disability activism shifts from an exclusive focus upon the attainment of legal and citizenship rights towards the creation, exploration and advancement of a Disability Culture. This phenomenon began to be recognized as one of the great 'undiscovered' territories of the late twentieth century (Abbas et. al. 4).

In literature disability functions largely as a metaphor of social collapse, while in autobiography disability represents the coordinates of a singular subjectivity. The distinction is important because most literary critics in disability studies have argued that autobiography offers up a necessary antidote to the objectifying symbolism of artistic representation. For instance, in this forum Tom Couser argues for the importance of disability life writing as a form of auto-ethnography; Brenda Brueggemann and Georgina Kleege use first-person experiences to reflect upon their experiences as disabled teachers and writers; Leonard Cassuto argues that Oliver Sacks's identification with his "patients" inverts the traditional objectifications of the scientific case study; Rosemarie Garland Thomson theorizes the re-appropriation of the stare through the first-person artistic performances of disabled women; and Michael Bérubé poses an intimate portrait of his disabled son while contemplating his precarious position as a parent-turned lobbyist (Mitchell, 311).

In this research, the essays are textually analyzed and attempt to be made to explore the underlying issues as the focus of the text. By using disability theory, writers are trying to get their agency in society.

Chapter II

Disability Studies: A Methodology

Disability study is a new field of study that claims its space in contested area traces its existence and justifies its assertion in the form of discipline. It is very inclusive term that hugs to all the largest minority group of global scenario. It centres neither to the western field nor eastern or non-western. Therefore it is a new discourse.

Disability is socially constructed from the biological reality because our cultures idealizes the body and demands that we must have control upon it. Able bodies thus dictate upon the disabled body and the knowledge is always silenced and invalidated. Moreover, the nature of disability has often very little to do with the individuals capabilities and true characteristics. The stigma and stereotypes are the cause of discrimination more than the disability itself. Hence, it could be argued that the disability is not the cause at all, that the social reaction to disability is the cause.

Disability is again a cultural and historical construction fabricated by the socio-cultural factors. It is therefore a broad term that clusters around ideological categories as sick, deformed, ugly, old, afflicted, abnormal etc. which disadvantages people by devaluating bodies that do not confirm to certain cultural standards. Disability therefore refuses to be normalized, neutralized or harmonized. In this sense, disability functions to preserve and validate such privileged destinations as beautiful, healthy, normal, fit, competent, intelligent etc. and all of which can claim such status and reside within these social identities. It is, then, the various interactions between bodies and world that create disability from the human variation and instability. In this regard, disability is shaped by history, defined by particularly, and negates the stable physical state of being. In short, the concept of disability writes a heterogeneous group of people whose commonality is being considered as abnormal. It is a social than a biological reality.

The very bitter reality is that people with disabilities have been isolated, observed and marginalized from mainstream society. This study searches the space of such people relating it with the issues of the basic formation of disability, the concept, outcomes and reality in details. The very first and essential aspect of disability study is the study of “normalcy and its construction”. Disability study questions the social formation of normalcy and the way of taking somebody or something as disabled. It says that is the ‘normal’ or ‘able’ person is already full up to speed on any subject? Is it who that determines the normal and abnormal? What is the basic demarcation of “able” and “disabled”? The critics of disability study go very far from “pity” or “empathy” and seek the social, political, individual and intellectual space of so called abnormal people in the society. Disability studies, for the most part stops unequal power transactions in the favour of advocacy, investigation, inquiry, archaeology, genealogy, dialectic and deconstruction. So, the construction of normalcy and the issue of stigma are the most striking aspects under the field of disability studies.

A person with a disability may try to blend in as much as possible, trying to downplay the significance of the disability. This is a process of accommodating oneself to one’s environment, while asking and expecting little or no effort of the environment to accommodate the disability (Pothier and Delvin, 16).

In general, people with disabilities have been traditionally separated and isolated from society. A stigmatizing label of" disabled" may make it difficult for people with disabilities to integrate into mainstream social settings. On the other hand, people with disabilities are often excused by the public for behaviors that deviate from social norms because of their disability (Li, 99). The corollaries are presumptions that the structures for societal organization based on able-bodied norms are inevitable, and that productivity is essential to personhood. The goal of critical disability theory is to challenge these assumptions and presumptions so that persons with disabilities can more fully participate in contemporary society (Pothier and Delvin, 2).

Social norms and values regarding the ideal body are likely to have an important influence on the body images of people with disabilities. Murphy (143) argued, ‘‘the disabled, individually and as a group contravene all the values of youth, virility, activity, and physical beauty that Americans cherish’’. Murphy drew on his personal experience living with quadriplegia to reflect on the position of physical disability in American society. He believed that disabled people are resented by the able-bodied and are seen by them as ugly and repulsive; they are perceived to subvert the social values and ideals. According to Murphy, these values and ideals include strength, independence, virility and health and they are promoted and affirmed constantly in the media, while the disabled body is hidden or presented as something to be avoided, corrected and pitied.

2.1 Constructing Normalcy

Modern society judges all human experiences by putting them through the parameters of ‘normalcy’, which is seen as a matter of social and historical construction rather than the condition of human nature. The boundaries and strictures of normalcy, which we think of as “natural” given now, seem to have constructed just one and half century ago. Before that, the concept of normalcy was not pervasively prevalent. Lennard J. Davis, in his essay “Constructing Normalcy” in *The Disability Studies Readers,* says:

> The word ‘normal’ as ‘constituting, conforming to, not deviating or different from the common type of standard, regular, usual’ only enters the

> English language around 1840. (Previously the word had meant 'perpendicular', the carpenter's square, called a 'norm' provided the root meaning). Likewise, the word 'norm' in the modern sense, has only been in use since around 1855, and 'normality' and 'normalcy' appeared in 1849 and 1857 respectively (10).

All of us are living in the world of norms. Norms are such aspects that categorize us in different ranks. Everywhere norms are functioning as the vital aspect to determine one's position. Whether it is society or education, politics, power everywhere norms are becoming crucial part to give the position of us. The matter of 'able' and 'disable' also moves around the concept of construction of the normalcy. "The problem is not the person with disabilities but the problem is the way that normalcy is constructed to create the 'problem' of the disabled person (9). So what are the actual social norms and who and how they are constructed is very discursive aspects.

To understand the disabled body, one must return to the concept of the norm, the abnormal body. So much of writing about disability has focused on the disabled person as the object of study, just as the study of race has focused on the person of colour (9). According to Davis the 'problem' is not the person with disabilities; the problem is the way that normalcy is constructed to create the 'problem' of the disabled person.

> A common assumption would be that some concept of the norm must have always existed. After all, people seem to have an inherent desire to compare themselves to other. But the idea of norm is less a condition of human nature than it is a feature of certain kind of society. Recent works on the ancient Greeks, on pre-industrial Europe and on tribal people, for

> example, shows that disability was once regarded very differently from the way it is now (9).

Thus, some concept of norms must have existed in any society. By taking the demarcation line with the privileged norms of any specific society people are categorized in the group of ‘able’ and disable’. People try to compare with other and form an idea about it. The responsibility is possessed by the society rather than an individual in formation of norms. Another concept which is inter-related with the construction of normalcy under the disability study is the concept of ‘Stigma’. Stigmatization and constructing normalcy exist associatively between each other. But these terminologies are different in their position. The former is a kind of mark of disgrace where as the later is medium of the base through which something or somebody is stigmatized in any society.

2.2 Stigma

Stigma is a mark of disgrace associated with a particular circumstance, quality, or a person. It is social, cultural and psychological construct which is understood as a kind of negative values and attributes of the society. Stigma is any condition, attribute, or behaviour that symbolically marked off the bearer as culturally unacceptable or inferior with the consequent feelings of shame, guilt and disgrace. In other words, it is a social process or related to personal experience characterized by exclusion, rejection, blame or devaluation that results from experience of anticipation of an adverse social judgement about a person or a group. In any society, stigma has a negative connotation and its discrediting effects are very adverse:

> . . . sometimes it is also called a failing, a shortcoming, a handicap. It constitutes a special discrepancy between vital and actual social identity. For example, the kind that causes us to reclassify an individual from one

> socially anticipated category to a different but equally well-anticipated one, and the kind that causes us to alter our estimation of the individual upward. Note, too, that not all undesirable attributes are at issue, but only those which are incongruous with our stereotype of what a given type of individual should be (Goffman, 204).

It is thus a social categorization that legitimates the negative attributes because differences are highlighted than similarities.

Stigma often results in a special kind of downward mobility. Part of the power of stigmatization lies in the realization that people, who are stigmatized or acquire a stigma, lose their place in the social hierarchy. Stigma is also a term that connotes a relationship. It seems that this relationship is vital to understanding the stigmatizing process. Stigma allows some individual to feel superior to others (Coleman, 218).

Goffman (12) provided one of the earliest and most notable psychosocial perspectives on physical disability. Goffman built his theoretical discussion around the concept of stigma that he defined as ‘‘an attribute that is deeply discrediting’’. He distinguished between three different types of stigma. The first type he described as abominations of the body, and within this category were the physical disabilities or disfigurements. The second type was blemishes of individual character, such as mental disorder. He labelled a final category as the tribal stigma that included racial, cultural and religious minorities. In explaining the process of stigmatization, Goffman wrote:

> While the stranger is present before us, evidence can arise of his possessing an attribute that makes him different from us ... of a less desirable kind ... He is thus reduced in our minds from a whole and usual person to a tainted, discounted one (12).

Thus, according to stigma theory, when a person with a physical disability meets a stranger, the stranger immediately becomes aware of the person’s ‘discrediting attribute’, i.e. the physical impairment. The impairment results in ‘stigma’, and the stranger makes many other attributions about the person based on this one attribute. These attributions may include that the person with the physical disability is unattractive, impotent, asexual, receiving welfare payments or of lower intelligence. The person may be immediately discounted as a possible lover or friend. Hence, the disability becomes an all-permeating, overwhelming classification that obscures all other personal characteristics, skills and abilities (Teleporos and McCabe, 972).

Social stigma is a severe social disapproval of personal characteristics or believes that are against cultural norms. Social stigma often leads to marginalization. Examples of historical social stigmas can be physical or mental disabilities, disorders or illness, as well as illegitimacy, skin tone or affiliation with specific nationality, religion or being deemed to be or proclaiming oneself to be of certain ethnicity, in any of a myriad of geopolitical and corresponding socio-political contexts in various parts of the world.

Different types of people exist in the society. The dissimilarity in shape, size, skin colour, gender, cultural background etc can be stigmatized at any time. That’s why Eriving Goffman says, “Stigma is equivalent to understand differentness” (cited in Coleman 217). First, any human difference serves as the pre-requisite to be stigmatized. Secondary, to be stigmatized is an inescapable fate as this process depends upon cultural and historical background. “No one really ever knows if he or she will acquire a stigma or when societal norms might change to stigmatize a trait he or she already possess” (Coleman, 226). In this sense stigma is the social factor and it becomes necessity of non-stigmatized groups. Those possessing power of dominant group in the society determine the concept of stigmas, which human differences are desired and which are not. So, the stigmatized people are always marginalized from the mainstream of the community simply because they do not relate to the norm of specific culture and thus possess an undesired difference from what the norm anticipates.

Thus, it has become necessary to understand the concept of the norm in the prevalent society because anyone can be stigmatized at any time. The concept of normalcy is again a social; it is not fixed and shaped by cultural, historical and social forces. “Normalcy becomes the supreme goal for many stigmatized individuals until they realize that there is no precise definition of normalcy except what they would be without their stigma” (Goffman 225). A man is stigmatized because he fails to represent the majority of the population. That’s why, Lernard J. Davis says “The concept of the norm, unlike that of an ideal, implies the majority of the population must or should somehow be part of the norm”. Ultimately, average then becomes paradoxically a kind of ideal, devoutly to be wished. In this way, the various extremes of human traits as tallness, shortness, intelligence, ambitiousness, strength etc would have been seen as errors. Such differences are therefore stigmatized in the long-run. In a way, the construction of normalcy divides the total population into standard sub-population as well as conceiving norm and non-norm.

Stigma is human construction, which legitimatize the negative attributes to the human differences. The process of stigmatization occurs only when the social control component is imposed or the undesired differentness leads to some restriction in physical and social mobility. Besides, it also restricts access to the opportunities that allow an individual to develop his/her potential. In addition, stigmatized people are segregated, ignored, neglected, and isolated from social participation. Negative attributes related to stigmatized people are thus cast down from the social periphery. For instance, the dwarf people in every society are marginalized simply because they do not fulfil the pre-requisite for being normal. Though they are used in movies, they are not portrayed as the main protagonist; they simply partake in the role of idiots and foolish. In this way, they are used as the objects of the entertainment rather than the subjects, and their contribution is seen as inferior. Not only this, they are given less priority in the other jobs too. People do not suspect on their capability to work but they suspect on their differences, which they do not represent with the majority of the population with such attributes they are deprived and marginalized in every sectors.

> Stigma often results in a special kind of downward mobility. Part of the power of stigmatization lies in the realization, that people who are stigmatized or acquire to stigma lose their place in the social hierarchy. Consequently, most people want to ensure that they are counted in the non stigmatized "Majority". This of course, leads to more stigmatization (Coleman, 218).

Different ideologies are constructed by the society to prove that the stigmatized people are fundamentally inferior to the so called normal beings. Nevertheless, they were even regarded as less than humans – the "others". Thus stigmatized groups are not treated on equal grounds.

> We construct a stigma theory, an ideology to explain his inferiority and account for the danger he represents, sometimes rationalizing an animosity based on the differences, such as those of social class. We use specific stigma terms such as cripple, bastard, moron in our daily discourse as a

> source of metaphor and imagery, typically without giving thought to the original meaning (Goffman, 205).

Thus stigmatization appears to be uncontrollable because any human difference serves as the basis of stigma. Moreover it also manifests the underlying fear of being stigmatized as anyone can be stigmatized at any time. Stigma is therefore non stigmatized people's necessity in order to feel good about themselves. They posses false superiority thereby enslaving the concept that stigmatized people is fundamentally inferior. Likewise, non stigmatized people convey a sense of inferiority to stigmatized people as invisible, non existent, or dead through social avoidance and social rejection.

Therefore, stigmatized people accept themselves as "Other" in the society. They accept their derogatory, self hate and devalued status as the puppet of the social system. This is a kind of social and psychological death to them. Stigmatized people thus become dependent, passive, helpless and childlike because that what is expected from them. In fact, they internalize what theoretical norm desires them to be and "…to agree that he does indeed fall short of what he really thought to be…" (Goffman, 206) social rejection and avoidance affect not only the stigmatized individuals but also everyone who is socially involved with them as family, friends and relatives. Hence, paradoxical social norms establish a subordinate and dependent position for stigmatized people. Stigma is in fact, the need of non stigmatized people to maintain a sense of supremacy. It is thus seen as social taboo.

2.3 Discourse

Discourse is the way of presenting something. In straight sense, it is talking and communicating using signs to designate things. It also shows the implication for speech and relationship between signifiers and what they signify. But, in broad sense, it can help us to interpret many slices of our social and political system that we have never been considered before. It also helps to illuminate part of the ordinary world that is controlled by the expert of the society. Thus, discourse is major point in the society that effects how we speak, act and interpret the things. As Michel Foucault views:

> Each society has it's regime of truth, its "general politics" of truth: that is, the types of discourse which it accepts and makes function as true, the mechanisms and instances with which enable one to distinguish true and false statement, the means by which each is sanctioned; the techniques and procedures accorded value in the acquisition of truth; the status of those who changed with saying what counts as true (73).

Discourse is not merely a sign but it is a set of practices that constitutes the object in which it is speaking of. Most importantly it is a system of constraint or exclusion which sets boundaries for what can and cannot be said or done in our everyday lives. The experts define the situation and then divide the line between reason and unreason for society. And it determines for us what is proper and improper through the eyes of the experts. In most societies, it has never been a matter of what you do. The only thing that really matters is what is thought about it according to what can and cannot be said. The system of discourse in regard to everything constantly changes within years, decades, and centuries according to who has the power. And power holders use the discourse according to their benefits. The discourse is formative and action-oriented. It is constructed to achieve particular social goals rather than representing facts. And it helps power holder to control people. The people have to believe on presented truth because when one does not have what one wants; one has to believe on what one has. Our social lives are dominated by the written words of discourse. Any form of discourse is considered to be a source of power, because it tells us to speak and act in certain ways. Almost every slice of social life is taken over the rules and rituals of discourse and the expert that it out within society. This form of modern sociological theory has shown us a shift toward a different type organization of power in the ordinary world. So, discourse is more of an invisible type of power that we take for granted, and do not even thinks to question in our everyday lives.

Power and discourse are very much interrelated. To get hold of discourse it is necessary to be in power and to make that power more powerful and durable it is necessary to take the help of discourse. There are two ways of exercising power; one is to control and rule and another is to liberate and serve the people. In every society, power is exercised through these two ways. But, most of the time power is exercise to control and rule rather than to serve. The present world is highly intellectualized by which the way of exercising the power is not with blood-shed, but with the change of concept and beliefs of the individual in the change in belief is possible only through the various types of discourse.

Discourse is the way of presenting something. It includes media, language (television, radio, newspaper, advertisement) and every written and spoken word which narrows the range of thinking and publishes what is profitable to the ruler, what the rulers think irrational is censored.

Discourse means either “written or spoken communication or debate” or “a formal discussion or debate”. The term is often used in semantics and discourse analysis. In semantics, discourses are linguistic units composed of several sentences; in other words conversation, arguments, or speeches. In discourse analysis, which came to prominence in the late 1960s, the word “discourse” is shorthand for “discursive formation", which is what Michel Foucault called communication that involves specialized knowledge of various kinds. It is in this sense that the word is most often used in academic studies.

A sampling of Disability Arts and Culture through various media including photography, theatre, performance, dance, autobiography and life writing, poetry, humour, music, and visual arts, illustrates the cultural, educational, and political significance of this movement. These works and the artists who produce them highlight issues of oppression, social constructions of the body, and the quest to build a disability identity grounded in pride by using their work to challenge traditional discourses of disability. This building of culture uniquely contributes to a broader rights movement by packaging issues in innovative and accessible ways, and giving audiences who may not otherwise engage with these issues the opportunity to explore a radical discourse on disability (Abbas et.al, 1).

The material emanating from disability communities tends to be descriptive and celebratory while academic writing has been preoccupied with discourse analysis – multiple examinations of the ways in which particular representations of disabled people and images of disability infuse art, architecture, literature and multi-media (Abbas et.al, 32). The discourse of difference makes life unbearable for many people in our societies. This leads to 'different' people keeping silent about issues that are very pertinent to their survival.

Discourses are created by the people who are in power in the society. To make the power more powerful and durable it needs the help of discourse. Able bodied people create discourse in terms of norms, policy, programs of the disabled people. Disabled people are portrayed as less than whole and as a population requiring particular forms of regulation, discipline, and control by state programs and policies. Discourses see disability as a social burden which is a private, not public, responsibility. The impairment is the focus of concern, and biological intervention and care are seen as the appropriate responses. The problem of immobility is seen as personal and specific to the impairment; that it is this that needs to be eradicated, rather than transformations in socio-cultural attitudes and practices, if mobility is to be restored (Imrie, 1643). Disabled people's mobility is also challenged and constrained by the prejudices, assumptions, and practices of service providers who, arguably, do little to understand the specific or personal needs of disabled people. Disabled people are increasingly seeking to assert their self-defined needs in relation to their claim that they have the right to equality of opportunity in moving from one place to another. This, though, is far from an unproblematic position and process.

2.4 Ideology

The term ‘ideology’ refers to away of looking at things. It is a set of ideas or beliefs with the help of which we make sense of our world and also of ourselves. Ideologies are neither true nor false because they are just constructed realities. Some early definitions of it are related with the interest of the dominant social or political class or power as distorted and illusionary body of ideas. In this regard, it is defined as a body of ideal characteristics of a particular social group or class; ideas or false ideas, which help to legitimate a dominant political power; as forms of thought motivated by socially interest; as socially necessary illusion.

The term ideology was initially coined by Antonio Destutt de Tracy during the French revolution, who defined ideology as ‘a science of ideas’ according to Michael Freeden, Tracy “intended to create proper branch of study concerned with ideas” (4). His intention was to “reflect the need that current scholar perceive for professional and dedicated approach to the study of ideology” (5). In other words, Tracy wanted to study human ideas objectively and scientifically because he believed that ideas are independent from external conditions. Actually, he saw the possibility of constructing “politics, economics and ethics from ground up, moving from simplest process of sensation to the loftiest regime of spirit” (Eagleton, 66).

Though, it is very difficult to chat the development of ideology as a concept in single and unambiguous way certainly, the significant amount of credit foes to the Marxist line of thinkers. Actually, the term was much used and popularized through the writings of Karl Marx and Friedrich Engels. But these thinkers took ideology in negative way, hence, the term wants carried pejorative connotation in its meaning.

In the German Ideology, both Marx and Engels criticised the German culture and philosophy that was highly influenced by the thought and ideas of Friedrich Engels that ignored the ground reality of society and strongly believed in its superstructure, so, criticizing the German ideology, they wrote, “German philosophy which descends from heaven to earth, here, we ascend from earth to heaven” (qtd. in Adams 625). By turning the Hegelian philosophy upside – down, they wanted to show that ideology is nothing but a form of false consciousness. Pointing out that ideology is never farce and independent rather ‘it is always shaped by material conditions, they write’.

> Morality, religion, metaphysics, all the rest of ideology and their corresponding forms of consciousness, thus no longer retain the resemblance of independence. They have no history, no development, but men, developing their material production and their material intercourse,

> alter, along with this their real existence, their thinking and the products of their thinking (625).

In this regard, Marx and Engels viewed all art, law, religion, morality, politics, metaphysics as a form of ideology that didn’t develop autonomously and independently but through the development of material production and material intercourse. They thought ideologies have no history because they are more fantasies and illusions.

An ideology is an organized collection of ideas. An ideology can be thought of as a comprehensive vision, as a way of looking at things, as in common sense, and several philosophical tendencies, or a set of ideas proposed by the dominant class of society to all members of this society. The main purpose behind an ideology is to offer change in society through a normative thought process. Ideologies are systems of abstract thought applied to public matters and thus make this concept central to politics. Implicitly, every political tendency entails an ideology whether or not it is pronounced as an explicit system of thought.

Chapter III

Countering the Discourse of disability through memoir: A Textual Analysis

It is no secret that disability has been grossly misrepresented in popular culture, as it has often been used metaphorically to symbolize criminality, tragedy, pity, fear, charity and ridicule. Thus, we are faced with the challenge of countering these negative constructions and redefining disability as a valued human condition (Abbas et. al. 1). It includes concepts such as ‘stigma’ and ‘otherness’ as well as integrating the problem of exclusionary social ideals and social norms. The social model of disability ‘‘challenges the traditional view of disability as a medical tragedy, and replaces it with a view of disability as a social oppression . . . arguing that disability is socially constructed not biologically determined’’ (Shakespeare et. al. 3).

Representations of disabled people have too often been carried out by non-disabled people in different field such as literature, media, newspaper etc. with varying degrees of discursive knowledge of what is disability. The results are frequently misrepresented that reduce the disabled people to the specificities of their apparent physical differences. It leads to the “othering” of the people with disability because the marked body is not “composed from the ideal parts of living models” as discovered in “human body . . . in art and imagination” and in the socio-political space dominated by non-disabled people (Davis, 10). Furthermore, there is a tendency of erasing or rendering invisible the disabled self denying its sociability: “. . . the disabled body . . . (is) excluded from culture, society, the norm” (11). The vicious effect is a frequent denial of agency, integrity and complexity of the subjectivity of the disabled body.

In recent years, despite the above mentioned practice by the non-disabled people, writers with disability have started meditating on their own disabled bodies privileging their own view points. For example Nancy Mairs in “Carnal Act”, Barbara Rosenblum in “Living with an Unstable Body” Ved Mehta in “Bells” and Mark O’Brien in “The Unification of Stephen Hawking” frankly recount their experiences of what it means for them to be disabled. Setting their memoirs against the background of (mis)representation produced by the non-disabled people, these texts seek to argue that how these writers with disability privileging the view point of their respective disabled narrators and claiming and often denied agency in actual socio-cultural encounters, disrupt the pervasive misrepresentation and liberate the self of the disabled body.

Creating the category of people with disability is filled with social and political tensions because any idea related to marked body in our society and culture is always done through the discourses that are produced by the society wherein the non-disabled people do have access to all sorts of discursive interpretation of the body. Lennard J Davis notices that the marked body in our society is always defined in terms of norms of social discourses. The society (mis)represents the marked body as “deviant or extremes” because “when we think of bodies, in a society where the concept of the norm is operative, then people with disabilities will be thought of as deviants” (13). Davis at the same time observes a thought of criminalization of the body in which “differentness” (Goffman 203) because of “irrepressible identifiable physical qualities” (Davis 15) that are visible and contradictory to “the usualness” of non-disabled person (Goffman 204).

Based on Goffman’s perception, the disability in our society is stigmatized that results in the dehumanization of the person. This process of stigmatization, a kind of misrepresentation, is basically because of the inconsistency between what he says “virtual social identity” and “actual social identity” (204). Further this misrepresentation supported by generating discourses in order to give permanence and to actualize the stereotype:

> By definition, of course we believe the person with stigma is not quite human. On this assumption, we exercise varieties of discrimination, through which we effectively, if often unthinkingly, reduce his life chances. We construct the stigma theory, an ideology to explain his inferiority and account for the danger he represents, sometimes rationalizing an animosity based on other differences such as cripple, bastard, moron, etc (Goffman 205).

Goffman's interpretation is not only toward the stripping off of the human self of the stigmatized (often with disabled bodies) people but toward how representations (stigmatization in this case), discourse and ideology form a coalition to describe the marked bodies who are not "full-fledged human being(s)" and thus "(insulate them) with alienation" (206). Therefore, in everyday socio-political encounter, people with disability are always reduced to stigmas and represented as non-desired and it risks the erasure of the disabled self. The important thing in both Davis and Goffman is that both of them view disability as social construct in which the disabled body accrues social and cultural meanings and imagined as 'other'.

All the essays "Carnal Acts", "Living with an Unstable Body", "Bells", "The Unification of Stephen Hawking" are reflections of their disabled bodies. These autobiographical memoirs are attempts to construct a self through the narrative of past events and compete for the recognition with visible differences and disability and cultural meanings assigned to the marked bodies. All these essays are the result of own experiences, feelings, and the problems faced during daily life having the marked body.

All the writers run the risk of being misidentified on daily basis and their cultural meaning and value of differences.

“Carnal Acts”, one of the autobiographical memoirs written by disabled writer, Nancy Mairs, express her pains and sufferings and struggling herself to create an authority.

> Inviting me to speak at her small liberal-arts college during Women’s Week, a young woman set me a task: “We would be pleased” she wrote, “if you could talk on how you cope with your M. S. disability and also how you discovered your voice as a writer”. Oh Lord I thought in dismay, how am I going to pull this one off (Mairs 51)?

The task set for her was diverged in nature and she had to yoke both of disability and writer. It was difficult to present such disparate subjects into a coherent presentation. To yoke such two disparate subjects into a logical presentation she is moving around her sufferings and experiences. Nancy Mairs’ memoir begins like an analysis of her life as an attempt to “cope with” her disability and authorship. Her disability can be defined as “abomination of the body” (because she has sclerosis) and “blemishes of the individual character” (because she attempt at suicide). In course of her meditation, she criticizes “western tradition of distinguishing the body from the mind and or soul” (53). This distinction between body and soul becomes more problematic if the body is marked. On the one hand, there is a long tradition of taking the body as subordinate to the soul and on the other hand social discourses too often relegate the marked differences to social insults thereby one can not claim “I have a body” (53).

The problem becomes more complex if the body is of a woman because even without disability “woman’s body” is stigmatized as “hidden, dark and secret” (Mairs

54). Mairs sees the situation as “doubly other(ed).” This body is not only stereotype in the patriarchal discourses but it marks it suffers from desexualisation “by the standards of physical desirability erected for everybody in our world” (54). Asch and Fine with reference to W. J. Hanna and B. Rogovsky depict this situation: . . . the disabled woman may be more negatively viewed by both women and men than the similarly disabled man . ... When asked how women and men using wheelchairs become disabled, the non-disabled college students attributed male disability to external situations such as war, work injury, or accident. They attributed female disability to internal causes such as diseases (243).

Mairs “goes on telling what it’s like to be a crippled woman” and by the use of collective pronoun “we” seems ambiguity which makes her powerful. She says, she tells this story “trusting that, we’re fellow creatures who have been living together for some thousands of years now, much of my experience will resonate with theirs” (54). The ambiguity inherent in it is that being a writer, she is not unaware of the fact of having attention even in the world of non-disabled and at times she seems to be talking only to the people with disability. Does this imply that even the so-called people are with some kind of disability” (Davis 10). This drag all the claimed non-disabled into the construct of disability theory disrupts the act of misperceiving a disabled body that is displaced by an ‘idea’ about disability.

“The brace makes my M. S. concrete and force me to wear it on the outside. As soon as I strapped the brace on, I climbed into trousers and stayed there . . . the idea of going around with my brace hanging out seemed almost as indecent as exposing my breast” (56). The idea about disability arises from a misrepresentation that persists because of the very social disconnect between disabled people and non-disabled people.

This social disconnection allows stereotypical images of the disabled people to go largely unchallenged. It puts a psychological pressure on the disable to repress any marked difference in the body

> All the experiences have passed by . . . I've born two children. Milk tricking out of my breast. . . . You don't want to hear about it . . . . Sometimes, I am too scared to leave my house. . . . No one could possibly desire a body like this. It's not your fault. It's mine. I didn't mean to start crying. I am sorry . . . sorry . . . sorry (60).

The apologetic voice of the writer on the surface level seems to acquitting of the society for the suffering that she undergoes due to restrictions put on her as a disable, but this narration of her lived experience, especially her experience of child bearing like other non-disabled women, bridges the gap between the experience of the disabled and non-disabled. Such a narration claims a certain kind of authenticity on her part.

Besides it, writing autobiographical memoir helps the writer to escape "the anxiety of speaking aloud" in physical society and about "the waves of shame," and to lay stress on "a body replaced with a disturbing stranger, sick or dead, who so often is a bad influence" (60). The writers speaking aloud stare at the cultural othering of the disabled body that consists of a process that takes place at the cost of subjectivity of the disabled people. Mairs asserts her agency and subjectivity and seeks to give them voice: ". . . (In) the weeks I've had the themes 'disability' and 'voice' sitting around in my head, they seem to have coverage on their own . . ." (52). Memoir allows her to 'subvert' the 'power' of misrepresentations that "cracks and stifles (her) voice" and to discover her self: "I have found, by acknowledging who I am, shame and all, and, in doing so, raising what was hidden, dark and secret about my life into the plain light of shared human experience" (58). Through the power that depends upon "how language work(s)," she raises the "voice that had shucked off its own body" (58). To be silent is to comply with the standard of feminine grace. But my crippled body already violates all notions of feminine grace. What more have I got to lose? I've gone beyond shame. I'm shameless, you might say. You know, as in "shameless hussy"? A women with her bare brace and her tongue hanging out (60).

Therefore writing memoir enables the writer to encounter "the rules of the polite discourse" that expects them to keep their "shame, and the neatly lethal sense of isolation and alienation it brought, to (them)". Ultimately they "redeem both 'cripple' and 'woman' from the shameful silences" (61).

The second essay, "Living with an Unstable Body" is also autobiographical memoir which attempts to construct a self through the narrative of past events and compete for the recognition with visible differences and disability and cultural meanings assigned to the marked body.

Rosenblum makes it clearer by revealing how the society and its norms operate on the body and create truth, identity and desirability about someone:

> In our culture, it is very common to rely on the body as the ultimate arbiter of truth. We consult our bodies like an oracle. While every emotion may not be consciously available to be experienced, the body knows the truth. We can not conceal the truth from the body. . . .turn to the body to decipher its coded language, to apprehend its grammar and syntax (101).

In our culture, if the coded language, when deciphered, does not come to the terms of the grammar and syntax of the social discourses, the body can easily be stereotyped as deviant. This is done on the basis of assumptions of "uninterrupted stability and continuity of the body" which Goffman includes in 'virtual social identity' (101). Though such an assumption is a product of imagination, thus virtual category but it does exert greater effect upon the disabled self.

Barbara Rosenblum, a lesbian, suffers from is indeed an internal cause because she acquires an unstable marked body because of breast cancer. But the problem is of a hasty generalization. Rosenblum draws the attention of readers to the fears of the female with marked bodies. All the women she is in contact with have lost their breasts because of cancer and it comes as a nightmare to all of them because the discursive interpretation of the female body puts breast at the centre as an important "aesthetic criteria" to evaluate the beauty of the body. Besides it, breasts are supposed to be important parts in the sexual intercourse and husband "(can't) bear the sight of his wife (without breast)" (94). Such viewed woman self gathers a strength in memoirs of Rosenblum who frankly foregrounds the internality of her experiences like sexual experience after chemotherapy.

The idea of disability arises from a misrepresentation that persists because of the very social disconnect between disabled people and non-disabled people. This social disconnection allows stereotypical images of the disabled people to go largely unchallenged which puts psychological pressure to the disabled people. This type of pressure is registered by Rosenblum who tells what she felt after losing her hair – one of the side effects of chemotherapy:

> I am still aware that people look at me. A vital aspect of my social identity has been taken away. In the last six months, I have lost my hair twice. And before that, three times. Practice does not make it easier. Losing my hair has been much harder than losing my breast. No one can see underneath

> my clothes. But everyone can see my hair. I never thought my hair was beautiful. . . . It was mine (94).

To acquire baldness, no matter whatsoever the reason might be, is to acquire a visible "differentness" which opens up a person to the stigmatization. This brings the gap between the ideal image of woman with long hair and woman with the bald head. But writing autobiographical memoir, she claims an authority over the agency and the self in performance in the essay as in drama bridges the gap between the disabled person and society.

The disabled narrator in this essay though the self in performance achieve two important effects out of it: first, the specificity of the body in performance creates a representation of living person, which works against the displacement and second, the voice and the presence of the real person speaking from disabled point of view presents a radical alternative to stereotypical images of the disabled: "Now it is clear that I will never have a full head of hair again . . .. I will always look like a Buddhist monk until the day I die" (Rosenblum 95). Rosenblum's comparison of her after losing the hair with a Buddhist monk is in fact her attempt to do away with the stereotypes and stigmas. To render her in terms of religion is a vital alternative that she achieves privileging her viewpoint. Such effects which the writers exert through the self in performance empower their self to release it in all of its complexity and to talk back to the social discourses that so often silence the people with disability.

> Together we have developed a new form that can accommodate our individual and unique voices into a dialogue. We write about things that are important to us. We make love at the typewriter, not in the bedroom . ... Losing a breast did alter my body image, as well as my body, but I

> never felt a diminishment of my femininity. My breasts were never the centre of my womanness (97).

Above mentioned lines clearly states that the writer has courage to live as a normal human being though she has the problem of cancer. She always tries to defend her marked body with constructive works. Her marked body ‘breast’ is not the centre of womanness which is generally supposed for woman in our society.

In this essay Barbara demonstrates the power of disabled like normal human being. She not only criticizes the women who are “concerned about reconstructive surgery” in order to please their husbands but also comes up with a frank celebration of her being a lesbian – an identity which is already stigmatized in heterosexual discourses which are dominant in our culture.

Rosenblum becomes vociferous and claims humanness inherent in her disabled body even when she is not quite sure “what miraculous shape (it) will prefer next time” (104). “Sometimes I can hardly use human language to tell how I feel . . . But I am not an animal. I am a human being, an articulate one at that, who is challenged to find words to apply to sensations I’ve never had before, . . . ” (103). The failure of human language to describe her feelings is related to the complexity of her being which is often denied in the representations of the disabled people. At the same time, it hints to the impossibility of the representation of the disabled body by an outsider.

In this essay, Rosenblum is unhesitant to meditate on the disability and she strongly positions her disabled self in the memory that claims agency of the people with disability privileging her viewpoints.

The third essay ‘Bells’ is also an autobiographical memoir written by distinguished writer, Ved (Parkash) Mehta. He lost his sight at the age of three as the result of a long bout of cerebrospinal meningitis. ‘Bell,’ which regulates the overall classes of school, is lying in the core of the essay. Writer in his autobiographical memoir tries to violate the strict rules and regulations set for the blinds and attempt to behave as a common human being time and again.

This essay consists of the most monumental incident – Vedi’s introduction to Braille script. Vedi wanted to be like his siblings, writing with a pen and a paper, however, he was made to realize that Braille was most suited for him. Interesting to note is Miss Mary, teaching in Vedi’s school, who was a young girl (Age- 14 years, partially sighted, and had passed out from the same school). The importance of fingers in a blind person’s life (reading Braille) has been well described in this essay. Miss Mary as his teacher, she was most sympathetic to Vedi as she herself was partially blind. Matron had an important role in Vedi’s life at school, as she introduced him to the Braille script. Vedi learning Braille for the first time, and though he was frustrated with it in the beginning, he got the grasp of it in no time. The matron, Miss Mary and Ras Mohun were together a support system for young Vedi to learn and enhance his skills at school education and upbringing, in my opinion, helped Vedi stand his ground amongst all his fully sighted siblings and this is therefore, an important lesson to learn from this essay.

Characters in this essay are facing the problems of language because able bodied language is guided by norms. To learn the language, they should know the norms regulated by able bodied people. Norm is an affecting factor for them:

> Once I remember, Miss Marry handed me something fluffy and bulgy and made out of clothes. “What is it, Vedi?” she asked. “A stuffed bird,” I said absently. . . . I picked up the soft, round thing and felt it all over. It had a

> beak, claws and a tail. “It’s a Myna.” Everybody laughed. . . . Abdul said, it is a talking bird.

In any case, power works through discourses and discursive formations. In its policing of ‘abnormal’ behaviour, the power of the human sciences derives from what they claimed to be knowledge; it derives from the claims to expertise. Such a cluster of claims to knowledge is what Foucault calls a ‘discourse’ (Bertens, 154). In every society, able body people create discourse and able body people determine what is norm.

> This is a toy elephant. You can always tell an elephant by its trunk in the front. “I want to see a real elephant,” I said “Blind people can never see a real elephant,” Miss Marry said. “But if sighted people say to you, ‘there goes an elephant,’ you should know what they mean.” “I wanted to argue the matter with her, but just then we heard the lunch bell” (Mehta, 65).

Above mentioned statement clearly states that the norms are set by able body people as discourse and disabled people are forced to follow the set norms. Writer, in his essay, tries to defend against norms which are regulated by able body people with the help of bell stops him from arguing. Mehta, in his essay, wants to violate the norms set by able body people for disabled one and tries to compare himself with normal human being. Being blind, he does not want to hide his desire but cried out to be like his siblings. “. . . I cried out. I want pencil and paper! I want to write like sister Umi” (68). He is very much hunted by able body people and their set norms and suffers a lot.

The concept of agency has commonly been associated with notions of freedom, free will, action, creativity, originality and the very possibility of change through the actions of free agents. All the characters of this essay are expressing themselves, performing themselves, playing the role of agents to change the normal view of able body people towards disables.

> "I am determined to become a good Braille reader, even faster than Deoji, so that I can become a doctor like Daddyji." "I said to Abdul one day." "I would rather be a carpenter than doctor; Abdul said referring to a story in the book". In the story, Jesus said that being a carpenter was just as good as being a doctor (69).

To understand the disabled body, one must return to the concept of norm, the normal body. Norms are human constructions so they can not be universally applicable. On the basis of norms, stigma is created. Since, norms are production of the majority or power; they exert harsh impact on minority.

> All of us liked the game very much because at the end we all fell on each other in a heap in the mud. "We begged to play some more but the Sighted Master said, "This is Tug of War." Mr. Ras Mohun says you can hurt yourself, so it must be played only once in a while under my supervision". It was many weeks before we a got chance to have a tug of war again (73).

In this essay, sighted master himself represents as a norm. All the characters are in pressure of sighted master and stigmatized time and again being disabled.

This essay taught about how easy it is to consider a blind person disabled and think of him as a burden. But proper education and some courage from Vedi's part enabled him to be his own in front of his siblings. To conclude it was an enriching experience to read this essay and understand life from the minds eye. This truth telling gives the essay an ancient but classic quality and makes us wonder where the blind child gets the courage to endure a life which has so much unexpected terror in it.

In this essay, Vedi himself tries to counter attack the stereotype of society that is set for the disabled people. His attempt to go to school for study is itself a counter-dialogue for the norms set by the society.

The fourth essay, “The Unification of Stephen Hawking” is an autobiographical memoir of one of the disabled reporters, Mark O’Brien, who is suffered polio. In this essay, writer tries to elaborate the hurdles to practice the craft for disabled reporter where every thing is normalized and made for the able body people. It is often difficult to find suitable jobs to the disabled writers and they are facing tremendous challenges and sufferings and are treated with discrimination.

> “When *The Fessenden Review* asked this disabled journalist to leave him Berkeley apartment and trek to southern California to interview Elizabeth Bouvia, a disabled women who demanded medical assistance to help her starve herself to death. I had to say no. I very much wanted to talk with her, but I would have had to rent a van with the wheelchair lift, find accommodations for myself, an attendant or two . . . dependence on the iron lung greatly reduces my mobility . . . I had to refuse the assignment” (O’Brien, 74).

Although he was given the opportunity of job in *The Fessenden Review*, because of his disability, he was compelled to refuse though he had a great interest on that job. In writer’s feeling, normalcy is hindering for disabled people to get anticipated progress in his/her life. Every circumstances and facilities are made considering the able body people that might not be fit for the disabled one. Though, the writer deserves the capacity to accomplish the assigned job in Fessenden Review, due to the lack of physical facilities and extra supports he became unable to hold the opportunity and starts his career as a small time poet, freelance book reviewer and author of an unfinished novel.

Stephen Hawking, who is the central character of this essay, is disabled by Amyotrophic Lateral Sclerosis (ALS). Hawking is a renowned physicist and mathematician and successful person from whom writer is very much encouraged indifference of his disability. "I felt no such reticence or shame emanating from Hawking. While not wishing to hide his disability neither did Hawking seem to regard it as the only important thing in his life"(75). Though Hawking is a disable character, he never been stigmatized himself but always tries to behave and work more than an able body people. He has power, voice and agency. He fought successfully with stigma and disability. Writer wondered how Hawking deal with becoming severely disabled. How did he get to be so tough? What was it like for him to have a wife and children? What has he done with the feelings of depression which disability usually brings? These questions strike him and made a plan to meet him. When a person is physically disabled, he is regarded as second class citizen in the society.

> "Near the end of the lounge, folding chairs had been set up in an open, glass world area, presumably as a special accommodation to the able bodied journalists. On a long table in front of us all were press handouts and a vase of flower in a Cal colour, yellow and blue. No one asked me to produce anything to prove that I was a reporter. I concluded that if you look sufficiently disabled, people will judge you to be harmless (77)."

In above mentioned lines, writer feels dominancy of normalcy which is hindering for the disabled people to get advantage from it. Our society does not care about the special arrangement and facilities especially to the disabled people. General conception or ideology about disability is that the disable people can not do anything and they are indifference to the society. O’Brien tries to put questions to Dr. Hawking but other journalist obstruct him time and again but he become able to put the question as

> Looking steadily into his halcyon eyes, I pretended to have the courage to ask him my question. “Dr. Hawking, what can you say all the disabled people who are struck in nursing homes living with their parents or in some other untenable situation and who feel that their life is over, that they have no future” (79)?

In his important question Dr. Hawking replies that whatever the situation prevail everyone should do their best. Hawking was regarded as a very important scholar and respectful in the contemporary society. He was very much successful to counter dialogue the misrepresentation about disability with his works.

By his success, O’Brien was impressed and wanted to get in touch and make some interview. To get in touch with Dr. Hawking, writer tried impatiently though there were many frustrations and hurdles in his way. After several attempts, he became successful to meet Dr. Hawking and put some queries of disability which were striking around him for a long period. In his short interview, he doesn’t get any problems and bottlenecks faced by Dr. Hawking due to his disability. His answers are the counter-dialogue of disability regarded by the contemporary world where disabled people are severely stigmatized. Writer attempts to get rid of disability by interacting with Dr. Hawking. After having an interview with Dr. Hawking, he learned that Hawking’s works succeed in distracting him from becoming obsessed with his disability.

> Through the other channel, I heard the red haired man talk with the Briton about the bizarre nature of the universe as described by Dr. Hawking at

> one of his lecture. It struck me that any one's description of the universe must sound bizarre upon a first hearing, but that Hawking's description seemed especially bizarre, what with black holes seeming . . . and big bang not necessarily signifying any sort of Beginning.

Those lines counter the discourses made by the mainstream society. In our society, disabled people are unknown about important place and events but O'Brien is trying to put Hawking as a royal model to counter the misrepresentation of contemporary world. He assumes, even the disabled people, have the sound knowledge about the universe.

At last the writer concluded this essay, if the unification of the forces that cause Stephen Hawking is ever achieved, "it will teach us the necessity of works not only for those of us who are trapped in unworkable bodies but for everyone who is trapped in the stark, unyielding prison of time space" (86).

Beyond artistic development, autobiographical memoir became avenues whereby individuals could reclaim, and to some extent rewrite, the stories of their lives. Martha Watson described autobiography as "an interplay, a collusion, between past and present" and observed that its significance lies not only in its uncovering of the past, but also in its *revelation of the present* (18). Each of these autobiographical memoirs affirm the significance of autobiography to encompass the many aspects of personhood—the self as artist, who responds personally and subjectively to the past.

All four writers covered in this study are disabled and trying to search their identities and role where they are severely stigmatized and misrepresented from the mainstream society. By the help of memoirs, they are able to counter the beliefs of the society towards the disabled.

Chapter IV

Conclusion

Disability is a socially constructed from the biological reality because our culture idealizes the body and demands that we must have control upon it. All the essays reviewed here are written by disabled writers about their feelings and realities. All these essays are the result of own experiences, feelings, and the problems faced during daily life having the marked body. Disabled scholars are writing their autobiographical memoir to create their identity as a normal human being in society. These writings try to play the role of agents by countering the misrepresentation done by society and writing the counter-dialogue to the society.

All the four essays “Carnal Acts”, “Bells”, “The Unification of Stephen Hawking” and “Living in an Unstable Body” by Nancy Mairs, Ved Mehta, Mark O’Brien and Barbara Rosenblum respectively talk about the lived experience of themselves. These autobiographical memoirs are attempts to construct an identity through the narrative of past events and compete for the recognition with visible differences and disability and cultural meanings assigned to the marked bodies. Writers in their memoirs run the risk of being misidentified on daily basis and their cultural meaning and value of differences.

Representations of disabled people have too often been carried out by non-disabled people in different areas (literature, media, newspaper etc) with varying degrees of discursive knowledge of what is disability. The results are frequently misrepresentations that reduce the disabled people to the specificities of their apparent physical differences.

All four writers covered in this study are disabled and trying to search their identities and role where they are severely stigmatized and misrepresented from the mainstream society. By the help of memoirs, they are able to counter the beliefs of the society towards the disabled.

Nancy Mairs, in course of her meditation, criticizes western tradition of distinguishing the body from the mind and or soul. Barbara Rosenblum, a lesbian suffers from an internal cause because she acquires an unstable marked body because of breast cancer. She draws the attention of readers to the fears of the female with marked bodies. All the women she is in contact with have lost their breasts because of cancer and it becomes a nightmare to all of them.

In “Bells”, writer explains about the disability experience of its characters. The different functions of characters in this essay are regulated by bell ring. Vedi, one of the major characters of this memoir, always imagine or expect to learn as an able body people though he deserves the disable body. Through out the text, writer explains about the problems faced by disabled people in their daily lives. Mark O’Brien, in “The Unification of Stephen Hawking”, tries to counter the discourses made by the mainstream society. In every society, disabled people are unknown about important place and events but O’Brien is trying to put Hawking as a royal model to counter the misrepresentation of contemporary world. He assumes, even the disabled people, have the sound knowledge about the universe.

To conclude, it is an enriching experience to read those essays and understand life from the minds eye. All the writers are putting efforts to show the misrepresentation of society for disabled people and constructed normalcy, ideology and discourse by able bodied people. Their efforts to counter-dialogue the misrepresentation of disabled people are appreciable.

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