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# The Independence Paradox: A Study of Shivani Gupta's Autobiography, *No Looking Back*♣

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*Abstract*

*People with disabilities are often perceived as dependent individuals. Disability studies scholars propose various models of disability that conceptualize different viewpoints that are prevalent in society. Each model takes a different stance on disability and dependency. The most practiced is the medical model that views disability as an individual responsibility where the disabled are dependent on the medical professionals for support and care. Whereas the social model proposes that dependency prevails partly because of the environmental and attitudinal barriers created by the society. The Independent Living Model, taken for this research, solely focuses on the aspects of dependence and independence and how systematic dependence can be implemented to the benefit of the disabled. This paper has taken the autobiography, No Looking Back by Shivani Gupta to analyze her experiences, which are reflective of the disability scenario in India. This study scrutinizes the facets of the Independent Living framework and attempts to find the gaps that hinder the autonomy of the disabled through her autobiography. It also examines how being dependent on certain services can help the disabled to lead an independent life.*
**Keywords:** disability, dependence, Independent Living model, autobiography, interdependence

## Introduction: Disability Studies and Its Backdrop

The term 'disability,' for many, is synonymous with the state of 'dependence.' Historically, people with disabilities were dependent either on their families or community for their livelihood. There existed no categorization such as 'disabled' in ancient Greece, and the disabled were not segregated and banned from participating in social events. Disability was not 'medicalized' but "there were attempts to cure or "fix" people with disabilities in ancient Greece, and there was some classification of incurable illness and defects present in the Hippocratic corpus" (Penrose, 504). Some scholars argue that maintenance payment was given to the severely disabled to prevent them from begging. Though the impaired were cared by the community and the state to a certain extent, the ancient Greco-Roman society, obsessed with the concept of 'ideal body', did not regard them as equals to the able-bodied individuals. They were exempted from politics, military, and religious roles. The Spartans known for their rigid values and valor, totally chastised who could not fight and appreciated who tried despite their disability. 'Overcoming' disability, a common trope identified by the contemporary disability studies scholars including Simi Linton and Jay Dolmage,

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was found in Plutarch's *Life of Agesilaus* revealing the immutable perception of disability since antiquity.

History of the disabled in other parts of the world discloses a similar kind of perception and treatment. In America, given its colonial tradition and fast developing industrial culture, the disabled were considered 'invalids.' Historian Steven E. Brown traces the historical perceptions of people with disabilities in the United States. He observes five shifts of perceptions from colonial period to late twentieth century. The colonial period witnessed a paternalistic approach towards people with disability. The change from agrarian to industrial revolution rendered many disabled unemployed. Families shared responsibility and in the absence of family, community came to rescue. This was the "dominant form of social support" (Brown, 486), and was known as 'outdoor relief'. In the early nineteenth century, many number of residential schools were built for the disabled to train them to become a part of the mainstream society but this resulted in medicalizing and segregating the disabled population. Only after the civil rights movement, homes, and financial support for the disabled war veterans were established. The welfare programs originally initiated for the disabled soldiers were also benefitted by the disabled American population. Rehabilitation services began for the world war veterans funded by the government. Brown observes that "the rehabilitation service programs and services were built upon an individualized medical construct of disability with an emphasize on professional guidance and individual change, but most importantly rehabilitation often missed a key component: people with disabilities guiding their own destinies" (492). This gave rise to disability advocacy and organizations ensuing the ascent of Disability Studies in academia.

Tobin Siebers pronounces that the central purpose of Disability Studies is "to reverse the negative connotations of disability, but this pursuit tends to involve disability as an identity formation rather than as a physical or mental characteristic (4). Emerged in 1980's, disability studies initiated scholarly debates on policy making, marginalization and representation of the disabled. "Nothing about us without us" became the slogan of the scholar-activists, who demanded inclusion in the practices like policy-making, legislature, and inclusive design programs by the government, underscoring their experiential value and expertise in disability sector. The scholars also identified different models of disability that influenced in shaping people's attitude throughout the years. In the moral model, disability is viewed as punishment for one's flaw in character hence the disabled are held responsible for their condition. It is believed to indicate a sinful past of the family bringing shame, hence disabled were ostracized from their own family. In the medical model, disability is considered a bodily impairment. Paternalization, medical intervention, rehabilitation and dominance of the medical expert are prevalent, leaving little space for the disabled to be in control of their own destiny. The social model was considered a paradigmatic shift that brought out the difference between impairment (limitation in bodily function) and disability (limitation in opportunities due to social barriers). Similar to the social model is the Independent Living model, the framework taken for this study.

**Disability in India: A Contour**

In India, the disability rights movement gained visibility only in the 1980's. Not supported by media, shunned by politicians and with lack of leadership, the movement was only a battle between few individuals and policy makers. Indian disability scholars argue many events such as Rehabilitation Act of 1973 and the launch of Asian and Pacific Decade of Disabled Persons in 1993 as the crucial points for beginning the movement. Demonstrations, rallies, hunger strikes, petitions and protest letters were used as advocacy tools by the activists leading to the Persons

with Disabilities Act, that was passed by the parliament on December 12, 1995. This act resulted in more visibility to disability issues and a change in social perception. Like West, the academic leanings of disability in India were the result of disability rights movement. The Indian scholar-activists adapted the western models to theorize disability. These scholars emphasized the need for change by addressing the stigma, stereotypes, and negative social attitudes towards people with disabilities. The historical attitude of Indians towards disability is found similar to the moral/*karma* model. The notion that disability is a "retribution for the past sin" (Ghai, 29) was ingrained in people's mind. Though a complete shift was not possible in a multifaceted and culturally rooted country like India, education, employment, and government policies have contributed a significant change in perception towards disability. Today, in India, different models of disability co-exist that includes moral, medical, charity, social and identity-based models.

**Shivani Gupta: Embodying Independence**

The disabled activists while advocating for their rights of social inclusion and participation, taken the opportunity of sharing their life through the autobiographical mode of writing. By presenting their personal life, they throw light on the reality of disabled people, thus bringing an experiential value to disability studies. Thomas Couser in his essay, "Disability and Autobiography: Enabling Discourse", iterates that "autobiography is the literary expression of the self-determined life, the genre that may be said to embody personal autonomy, it seems an ideal medium for contesting the association of disability with dependence and invalidity" (292). In India, disability autobiography is an emerging genre that boasts authors like Ved Mehta, Madan Vasishta, Preethi Monga, and Malini Chib who fought the long-established prejudices of the society. One such activist is Shivani Gupta. She is one of the pioneers in advocating inclusive architecture and worked with various firms as an accessibility consultant. She is passionate about independent living for persons with disabilities in rural settings. Her AccessAbility is a Universal Design and Disability Employment Specialist that offers consultancy services to various governmental and non-governmental agencies. Her autobiography recorded the most turbulent years of her life and her journey in overcoming those hardships. The work also showcases the plight of the disabled in India, the stereotypes and stigmas attached to disability and how a glimpse of non-handicapping environment changed her life for good. Her *No Looking Back* is an autobiography of pain, grief, acceptance, and reconstruction of identity. This paper tends to analyze her journey from a 'patient' as identified in the medical model to an 'individual' in her quest of living an independent life.

**Independent Living Model: The Framework**

Ed Roberts, the pioneer of Independent Living Movement was a student in University of California at Berkeley, when he with his fellow disabled students, together known as 'Rolling Quads' raised voice about their loss of autonomy and inaccessibility. Soon this group moved beyond the university campus, extending their demands for an accessible city. This slowly gained momentum and the Rolling Quads increased in number. In 1972, the Berkeley Centre for Independent Living (CIL) was established, staffed by disabled members. Hayman states that "the core values of the Berkeley CIL, dignity, peer support, consumer control, civil rights, integration, equal access and advocacy, remain at the heart of the independent living" (Briget Hayman). Soon multiple CIL centers were started all over the country. A fruition of several individuals hard work, Disability Rights Movement gained prominence in 1960's. This movement voiced for the social, political, and legal rights of the disabled and demanded equal opportunities in education and employment.

Paradigm "provides a framework for identifying and solving problems" (DeJong, 21) Independent Living paradigm is the academic counterpart of the Independent Living Movement. Developed by Gerben DeJong in 1970's, this model, though posits a lot of similarities with social model, focuses mainly on the independence and decision-making power of the disabled. The key aspects of the IL model include autonomy for the individuals to make decisions and be in control of their life choices, removing physical, social, and attitudinal barriers to enable an accessible society, creating peer support to help each other through lived experience and campaigning inclusive policies. DeJong compares the rehabilitation or medical paradigm with IL paradigm. While the medical model completely focuses on the individual, treating his physical impairment as the problem that could be treated/cured only by professional intervention, IL model poses a stark contrast where architectural and economic barriers are the real problems and the disabled are not patients but consumers of health care services. Solution to disability problems lies in "peer counseling; advocacy; self-help; consumer control; removal of barriers and disincentives" (DeJong, 23). The dominant medical paradigm was, if not replaced, pushed to the side with the social and IL model by the disability activists. But this was not the case with Shivani Gupta's life, where multiple models co-existed.

**Contextualizing *No Looking Back* in IL Framework**

Having acquired disability at the age of twenty-two, Shivani begins the narrative with the aftermath of the fatal accident she had the previous night. She came to know that she had been diagnosed with spinal injury and she had no awareness about it. The lack of information about her condition made her cower in fear throughout her diagnosis. Even when she was taken to the operation theatre, she writes that "the doctors had not thought it important to brief me" (14), leaving her feeling helpless and terrified. Later she came to know that it was a simple procedure but she observes how, "No one had thought of preparing me for the 'simple procedure' that, in my ignorance had made me suffer such horror" (16). Shivani's process of coping with an acquired disability underwent the 'four stages of adjusting to a new form of disability' as proposed by Thomas C. Weiss – Shock, denial, anger/depression, and adjustment/acceptance. The first stage, that shows 'emotional and physical numbness' was evident in Shivani's case. Even when poked with a needle, she could not feel anything and she still had not grasped the reality of her condition. She was in shock by catheter insertions and the heavy tongs that supported her head. She traversed the second stage of 'denial' by accepting the wheelchair for mobility (which she thought was only temporary). she reflects thus: "Some time ago, the mere mention of a wheelchair had seemed like a step backwards – today, it represented hope of mobility" (Gupta, 40). The third stage of anger/depression was experienced by the author only at the rehabilitation center when she witnessed others in conditions similar to her. She comments, "the injury had not touched my soul so far; but now inevitably, depression crept in" (44). After a year of becoming a tetraplegic, Shivani finally came in terms with her disability. she started ignoring people's stares and questions as "adjustment and acceptance were my (her) mantra" (53). She started to gain a sense of achievement with her small every day accomplishments.

**Attendant Care: A Prosthesis**

Shivani had been fiercely independent since her adolescence. Losing her mother at seventeen and her father working abroad, she had soon learnt to live on her own. For Shivani, 'disability' more than anything meant 'dependence on others.' Her life had been a journey of finding ways to be autonomous that allows her freedom of choice, self-respect and dignity. In her pursuit of independence, Shivani's life encapsulates the Independent Living model. The IL model suggests

some key independent living services as solution to the dependent lives of the disabled. One such service is attendant care. "Attendant care services are those tasks performed by an attendant when assisting a severely disabled person in bathing, dressing, grooming, toilet care and other activities of daily living" (DeJong and Wenker, 157). Shivani got her attendant, Putul, a young girl from West Bengal. She was not a qualified nurse but was trained by Shivani's relative to take care of her needs. The author describes how difficult it was to accept and adjust to a carer. While she was extremely obligated for her carer's services, it came at the cost of her physical and emotional privacy. Shivani quips: "my carer was the person because of whom I was going to stop being dependent on my relatives and gain enough independence to do whatever little I could" (52). This statement of Shivani runs parallel with Kittay's notion that needing assistance is not a weakness but a "sort of prosthesis that permits one to be independent" (50). Shivani also shares few incidents where carer breached her privacy and behaved nastily. At some point her relationship with carer was smooth and sometimes it was like a forced marriage. Shivani's narrative candidly exposes the reality of having a personal carer.

**Peer Counseling: A Catalyst of Transition**

Another important service that the IL model propose is Peer Counseling – facilitating necessary information and counseling through a fellow disabled person. It is the primary constituent for Independent Living and a key component in rehabilitation process. Shivani, when she became a tetraplegic, struggled for necessary information that made her transition harder. Thus, when she was offered the position of peer counsellor for women with disabilities in a rehabilitation center, she was in for the job. "Intervention by a disabled peer can significantly accelerate the transition to independent living" (Saxton, 184). Shivani observes the willingness in the patients to learn information from her rather than the medical expert. She explains the four ways she tried to explain the injury – the medical aspects of disability, habits to inculcate for a healthier life, examples of successful people with spinal injury and the inevitable change in the relationship with their family. She counselled women from various backgrounds and records their struggle to negotiate the identity of care-receiver opposed to the traditional role of "care-provider" (87). She was happy for all who tried to accept their new reality and continued to fight. She explains how conversely,

> In the fears of these women, I seemed to relive my own fears over and over again. The only thing I had wanted out of life before my accident was to find a caring husband and children – this simple dream was shattered the day I looked at myself in the mirror at the rehabilitation centre in Pune. If I myself could not accept my changed physical form, how could I expect anyone else to? (Gupta, 88).

**Accessibility: Enabling Movement**

An important service of IL model is accessible transportation. The barriers one finds in the immediate environment reveal the reason why many disabled could not commute. Lack of accessible transportation prevent many disabled from working thereby leading financially dependent lives. Shivani iterates how inaccessible environment and rigid rules often prevent the disabled from venture out of their homes. An eye-opener for Shivani was the fifteen-day training programme on 'Non-Handicapping Environments for the Disabled and Elderly' in Bangkok, Thailand. The author who felt humiliated in the face of discrimination before, realized the true reason to blame – the inaccessible environment. Shivani quips, "With the knowledge of non-handicapping environments and better understanding of my rights came anger with the system: why could it not provide a simple thing such as an accessible environment to me so that, as a disabled person, my life could be easier?" (Gupta,120). Shivani shares an incident from her trip to

Paris. On her way to Eiffel Tower, she encountered the nightmare of the disabled - a flight of fourteen steps. She criticizes the ableist spaces thus:

> We were always angered by inaccessibility and poor design of spaces that so easily excluded people. It is not easy being a disabled traveller. One can never travel impromptu; one needs to have done a lot of homework on the accessibility of a place even before reaching it. Architects, designers and planners have often a distorted understanding of accessibility, because of which even spaces that are signposted as being accessible are often unusable by disabled people (137).

Shiavani points out that the accessible options like hiring taxi or staying in a five-star hotel is hardly affordable for majority of the disabled. She further shares an incident, where, as an employee in a big corporate company, she was denied the accessible entrance as it was only for VIPs. Shivani was frustrated by the company's way of treating its only disabled employee. The irony here is she was appointed in the firm to improve accessibility of the disabled people in India. Her experiences are evidences for the kind of treatment disabled receive in India. Though highly qualified and experienced, the disabled face discrimination and oppression on a daily basis. Tobin Siebers in his seminal work, *Disability Theory,* discusses how oppression manifests itself in handicapped environment. He insists that one becomes disabled not by his/her body but by the environment. He states that, "it makes no sense to link oppression to physical and mental characteristics of the body, visible or not, because the cause of oppression usually exists in the social or built environment and not in the body. Every inaccessible building is a closet representing the oppression of people with disabilities by able-bodied society" (100). This realization made Shivani to initiate AccessAbility, an organization that provide professional guidance in creating an inclusive environment in companies.

Independent Living requires certain skills that enable individuals to fulfill their basic needs. The Independent Living centres in America provide such training either on a one-to-one basis or in groups. Mary Ann Lachat, in her article, "The Independent Living Service Model", explains that "Skill development cuts across all of the content areas associated with independent living including personal care, self-care and daily living skills, communication, financial management, and personal growth" (35). She lists out a variety of skills to be acquired to live independently that includes recruiting and interviewing personal attendant, developing mobility skills within and outside home and coping with attitude towards disability. Shivani, though without the help of any IL center, learned most of the skills through her experiences. She recalls the first time she went out in her wheelchair to buy a bathing soap. She was afraid of meeting people who would pity her. But a little shopping act had given her great confidence. She writes thus:

> At the end of the day, however, there was an immense sense of accomplishment and satisfaction I felt in having been outside and faced the world. I couldn't compare it with any other achievement in my past. It wasn't so difficult after all, I thought. Of course, the stares of strangers made me squirm; but if I was able to ignore that, it wasn't so bad…adjustment and acceptance were my mantra. In my own eyes, I was a winner and my award was the soap bar I had purchased (53).

To study and work in a handicapped environment, Shivani had rigid schedules. She even scheduled her bowel movements to avoid accidents. She gradually figured out that an autorickshaw would be the cheapest and best mode of transportation for a person with wheelchair. She learned to manage her finance and made her house accessible with the help of her father. She recollects how her "Daddy, very patiently and with a lot of care, had the raw structure renovated and made accessible so that I could live there comfortably, with as much independence as possible" (127). While a training session about these skills would have made her struggles lesser, Shivani had to self-learn everything.

**Conclusion**

While independent living demands skills and adaption of services by the disabled individual, it largely depends on the government and society to provide accessible environment, medical guidance, job opportunities and skill training that enable each disabled individual to lead an autonomous life. Shivani's autobiography is a record of numerous challenges she confronted to emerge as an independent individual and this work is a representation of thousands of disabled women who share the same kind of experience. An Independent Living Center in every locality that offers guidance and services would make their lives much easier. It is important that every disabled individual becomes independent but disability scholars rightly point out that it is impossible for any person to become totally independent. Dan Goodley in his seminal work, *Disability Studies* argues that "an interdependent view of the individual suggests that health and illness are aspects of larger systems and are not located entirely within the single person" (82). This understanding of independence and interdependence would facilitate the non-disabled to empathize with the disabled population. This understanding would have prevented doctors from pronouncing Shivani as a 'vegetable' that metaphorically stands for 'total dependence.' Shivani sarcastically asks, "Who could have imagined that I was the same person for whom doctors had given up hope ten years ago, saying I would live the life of 'vegetable'?" (138). She asserts thus: "I wanted to live on my own terms, take risks and carve out my identity" (82). By being dependent highly on attendant care, peer counselling, accessible environment, and such services, paradoxically, she fulfills her quest for independence.

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