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Disability and Poverty: Impacts on Families in Nepal

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Abstract

People with disabilities are rarely seen as relaxed. Barriers, illnesses, shortage, neglect, stigma, stress, marginalization, oppression, exclusion, and similar adversities are very common conditions, which these people do typically encounter. Furthermore, families must also respond to disability through either adaptation or resistance. Families adapting to disability must strive to maintain equilibrium despite potential challenges and stigma they may encounter, while rejecting the notion of disability denies its existence as a socially constructed disadvantaged reality. In many respects, families in Nepal assume the entire social and financial burden associated with disability, indicating that they have been compelled to adapt to the challenges of disability while enduring significant hardships due to the limited responsibilities assumed by the state. Thus, the role of disability in influencing family dynamics emerges as a crucial area of research, which this paper seeks to elucidate. This paper analyzes the ways in which disability impacts households and the extent to which these households adjust to the presence of disability. Drawing on some qualitative data gathered through comprehensive interviews, this study contends that persons with disabilities have endured a distressing life and their families have gradually become entwined with poverty. Therefore, disability should be viewed as a macro social concern, rather than solely an individual issue, when considering its impact on the family.

Key words: caregiving, disabling barriers, disability studies, household poverty, risk

Introduction

People with disability (PWD) are recognized as survivors of harsh living conditions. They endure physical, mental, intellectual, or sensory impairments, which, when coupled with social barriers, hinder their participation in social functioning (Subedi, 2024). They are predominantly exposed to barriers, affliction, illness, neglect, suffering, deficiency, stigma, and exclusion, which compel them to lead impoverished and vulnerable life. Therefore, disability is taken mostly as antithesis of advantage, beauty, capability, joy, dignity, pride, and worth. Given that the success or failure of individuals hinges on the degree to which they experience advantages or disadvantages, the normal existence of PWD

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within such disparaged circumstances can scarcely be envisioned. Moreover, considering disability as opposed to non-disability generally implies that the former has no relation to the latter. This paper argues, however, that disability, as a specific human condition, significantly impacts non-disability as well. In other words, disability influences others while also being affected by various other factors or situations. Thus, this paper endeavors to investigate the influence of disability on the given family. It primarily addresses the social and economic challenges encountered by households with a disabled member.

Disability refers to the condition in which certain impairments in physical, mental, and sensory organs of individuals, along with the stigma associated with these impairments, hinder them from leading a dignified life. The WHO and WB (2011) have, therefore, confirmed impairment, activity limitation, and participation restriction as key indicators of disability. Disability as defined by the Government of Nepal (GON) is a state wherein individuals experience difficulty in performing routine daily activities or fails to engage fully in social life due to impairments in physical body, as well as the obstacles imposed by physical, social, and cultural environments. Impairment and participation restriction are acknowledged as corresponding contributors to disability (UN, 2006). Disability encompasses various forms, including physical, visual, auditory, speech, deaf-blind, mental, and multiple disabilities. It can also be categorized based on severity. The GON has classified complete disability, severe disability, moderate disability, and simple disability as the principal types of disability (MOWCSW, 2006). However, the affirmation of an individual's disability status is profoundly shaped by the physical, cultural, and legal contexts of a specific country.

Disability has consistently been a significant contributor of adverse living conditions. The WHO and WB (2011) have recognized extensive evidence of disabling barriers, encompassing a lack of fundamental services at home to societal stigma, insufficient governmental policies, challenges in service delivery, inadequate financial support, lack of consultation during planning and decision-making processes, and underreporting of disability cases. Concerning the consequences of these disabling barriers, the entire family and society experience detrimental effects. The broader ramifications of these disabling barriers include social stigma and isolation, financial hardships, and a decline in social status, among others. Despite the substantial social and financial burdens that disability induces, this paper highlights the disability path of household poverty, a subject that has yet to be addressed or studied in Nepal.

Review of Literature on Disability and Poverty

Disability exacerbates poverty, even though both factors mutually reinforce each other. The author firmly asserts that the trajectory from disability to poverty is less costly than the trajectory from poverty to disability. Here are some instances by which poverty smoothly enters into the households having disabled members.

High healthcare expenses

While poverty imposes greater physical hardships on individuals, potentially leading to life-threatening risks and disabilities, disability simultaneously exacerbates poverty through various mechanisms and processes. Meyers, Lukemeyer, and Smeeding (1998) identified that the increase in costs is linked to different medical services including the rehabilitative and restorative such as hospitalization, outpatient care, home health care, medications, rehabilitative services and devices, and

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the loss of earnings due to the high intensity of caregiving responsibilities, for which the financial burden is primarily shouldered by the households themselves. A study on the treatment of brain disabilities in Korea indicated that brain disorders impose a significant economic burden due to treatment costs and the lost productivity of patients and caregivers, including ongoing care provided by family members (Kim, et al., 2020). Likewise, the impact of chronic diseases indicates high financial burden among individuals. The prevailing emphasis in health systems on curative models over preventative measures has led to increased out-of-pocket health expenditure (Brinda, et. al., 2015). Literature clearly indicates that the healthcare costs associated with each type of disability are excessively high.

Hidden cost of disability

Poverty is easily permeated by households having disabled members through various mechanisms. Elwan (1999) states that, in addition to income-related factors, additional expenses associated with disability, along with marginalization or exclusion from services and community activities, can exacerbate the challenges faced by individuals with disabilities and their families. Other costs are related to the payment of medical expenditure, buying specialized tools and services, as well as expenses incurred by caregivers. In the absence of income opportunities, many people with disabilities in underdeveloped countries often rely on their families; without financial support from external world, which make the circumstances of disabled people more precarious. Disability had a stronger association not only with individual's health-related quality of life and costs, but also the way in which an individual's pain influences his or her daily activities (Mutubuki, et. al., 2020). Similarly, Subedi (2018) argued poverty as equal to living with disability as he showed that the cost of living with a disability is significantly high due to factors such as disabled people's limited access to education, reduced access to healthcare facilities, social isolation from employment and other public opportunities, unfair relationships with household members, and a lack of property ownership.

Limited options and long-term loss

Disability results into household poverty through several measures and mechanisms. When any household member fails to earn or reduces the normal working hours, and indirectly when the household is unable to maintain its routine due to caregiving pressure, poverty automatically comes to the household. Furthermore, researchers identify the diminished literacy rates among people with disabilities, limited access to employment and income opportunities, discouragement and harassment, as well as the scarcity of technical, vocational, and other forms of training, as significant contributors to financial crisis in their families. The majority of school drop-out cases pertain to children with disabilities. Additionally, the absence of adequate education exerts a long-term detrimental effect on all members of a family (Braithwaite and Mont 2008).

Indirect costs of disability are high

The negative role played indirectly by disability in igniting household poverty is shown by many researchers. Altman, Cooper and Cunningham (1999) say that the varying degrees of involvement in caregiving and the ramifications of role alterations induced by the disability can amplify the stress experienced by all family members, not solely the key caregiver and parents. This stress can be associated with the necessity for some or all family members to seek increased healthcare, thereby elevating medical expenses and financial strain for the entire family. Likewise, Stabile and Allin (2012) argue that the direct economic damage encompasses expenditures on healthcare, therapeutic,

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behavioral, or educational services; transportation; caregivers; and other specialized services for needs. Indirect costs predominantly involve reductions in parents' capacity to maintain paid employment. This decline in productivity may be linked to the extra time necessitated to care for a child with a disability, coupled with the high costs or lack of suitable childcare.

Raising a child with disability is more costly

When a household raises a child with a disability, it must confront multiple crises that impact various dimensions of the household (Fortier and Wanlass 1984). The family necessitates ongoing attention and requires to offer the essential assistance for the child, occasionally needing to urgently transport the child to the hospital due to the diagnosis of the illness. Caring for a disabled child poses significant challenges as well. Raising children with disabilities presents multiple challenges, as the child is a minor who may struggle to communicate effectively, and the children have a disability means they require various diagnoses and treatments, thereby incurring higher costs.

Women with disability face more financial crisis

Many societies overlook women in practice, despite making provisions to invest in them and recognize their inherent dignity as human beings. Nepal is one of the countries with very low payment to the employees. Additionally, it is a nation that offers minimal social security allowance to disadvantaged populations, including the poor, unemployed, and disabled. In a society where women are not fully recognized as socially sovereign, women with disabilities experience more disadvantages. Within the disability category, women with severe disabilities experience greater economic hardship than those with mild or less complex disabilities. "For women with disabilities who fall under the last two categories, the probability of increasing their income through diversification of income generating activities seems possible but for women with severe forms of disability, their only chance of improving their livelihood is the increase in social security benefits" (Niraula, 2022:61). In a country where disability receives minimal governmental attention, where individuals with severe disabilities receive significantly low social security allowances, and where women with disabilities are marginalized from social practices and the employment sector, the likelihood of these individuals and their families experiencing prolonged poverty is considerably elevated.

After examining various scholarly works on disability and poverty, disability can be defined as the strong contributor of poverty. Principal contentions encompass the association of disability with illness, necessitating increased expenditure for treatment, ancillary costs such as the mental strain on families resulting from disability, diminished earning potential for caregivers due to caregiving responsibilities, insufficient educational and health services contributing to unemployment and future chronic health issues, and challenges in raising children with disabilities. It appears that disability not only induces poverty within households but also acts to intensify poverty across all strata.

Research Methodology

This paper is predicated on qualitative data amassed through firsthand research conducted in Kathmandu valley. Initially, I engaged in a conversation with a colleague from my university, who possesses a visual disability, regarding potential respondents for this study. He supplied the names of 12 individuals with different types of disabilities along with methods for contacting them. From this pool of 12 potential respondents, I was able to reach only 7 individuals with severe disabilities, which, according to the disability policy of the Nepalese Government, fall into Category B and are denoted by

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the blue color. The rationale for selecting only 7 respondents as a sample was to create a homogeneous cohort to mitigate sampling error in this qualitative research and facilitate the generalization of research findings. To gather information from them, a checklist was developed, outlining 10 discussion areas that would yield insights into the financial challenges they and their families had encountered. Each respondent was allotted a full hour to convey their experiences. Among the 7 respondents, 3 were men and 4 were women. Within the men side, 1 had visual disability and 2 had physical disability, while in the women's side, 1 had physical disability and the remaining 3 were the caregiving mothers of their respective children. Out of those 3 children, one boy and one girl had intellectual disability, and the remaining one boy had autism. This paper does not assert that disability is difficulty or disadvantage in itself; rather, its emphasis lies solely on how disability engenders and exacerbates economic hardships within households. While this paper could have also examined pathways to prosperity associated with disability that was not its purpose. Therefore, a major limitation of this research is its exclusive focus on the disability pathways to poverty.

Discussion and Analysis

The details gathered during the interview are described below and subsequently examined under various sub-headings.

Absorption of extra human resources

Individuals with severe disabilities require increased support. However, it is not possible to guarantee that individuals are receiving the requisite level of support, as there is currently no legal obligation for anyone to provide comprehensive care for those with severe disabilities. Support for individuals with disabilities is largely contingent upon the personal preferences of the individual. Let us analyze how respondents express their perspectives regarding their need for support and the availability of such support.

One wheelchair user (respondent 1, hereafter referred to as R1) stated:

"My legs below the knee are non-functional. The utilization of this wheelchair does not imply the existence of wheelchair-accessible roads and buildings in all locations. I primarily need a caregiver to assist me while using this wheelchair. I am capable of independently managing my food intake; however, I require assistance with washing up and sanitation-related activities. Children require assistance for a number of years; however, individuals like myself need caregivers throughout our lives. The state has not recognized the extent of support that we people and our caregivers require."

Condition of R1 indicates that wheelchair users typically require assistance from a helper, who must possess adequate physical fitness to support an individual in a wheelchair. It suggests that approximately two individuals' lives are dedicated to caring for one person with a disability. Furthermore, the necessity for a physically fit caregiver implies that a primary income earner in the family is partially or fully engaged in unpaid caregiving responsibilities required by a disabled family member. If the state offers financial support to these families recognizing this reality, the families of individuals with disabilities will not need to endure too much financial hardships. In a country like Nepal, where financial assistance for individuals with disabilities and their families is scarce, these families are likely to experience a vicious cycle of poverty.

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Disability permeates poverty than prosperity

All individuals possess unique strengths and capabilities. They face disparities in accessing both the material goods and spiritual issues such as peace and happiness, because these can be achieved either from people's inherent strengths or from social provisions. Thus, disability often serves as an obstacle to a prosperous life. The second respondent (hereafter referred to as R2), who had a visual disability and is employed as a government worker, stated:

"I possess a permanent job; however, my potential for increased earnings and wealth accumulation would be significantly enhanced if I had access to the same opportunities as others. My blindness has resulted in significant financial losses, see how difficult is this society for us to live. I do not attribute blame to anyone for bringing this situation; however, it is a noted reality that individuals living with disabilities, especially those who are blind, are more likely to experience poverty than wealth."

Expressions of R2 indicate that practicing equality in society is not as simple as it is imagined. The probability of individuals with disabilities achieving wealth is low in contrast to their significantly higher likelihood of experiencing poverty. It further suggests that a reduced range of choices results in increased compromises and hardships throughout life.

Some disabilities are riskier to handle

Some individuals with disabilities experience more challenging situations that can be difficult to manage. If disabled people are overweight, maintaining their cleanliness and health can pose significant challenges for any sole caregiver. In a society like Nepal, where the most of the built environment is significantly unaccommodating to individuals with disabilities, the associated risks and burdens are borne by the families of those individuals. Below is the account provided by an individual with a physical disability (respondent 3, henceforth referred to as R3), who lost his left foot during the Maoist-led war in Nepal:

"See my physique (his physique appeared to be overweight). I appear to be quite well when seated. However, I am unable to walk. My wife is unable to handle my body effectively. She sustained multiple injuries while carrying me while I walk and while take shower. Two years ago, she sustained an injury in the bathroom while assisting me with bathing; she fractured her right ankle."

Certain individuals with disabilities require a greater degree of physical care and support. The experience of R3 indicates that caregivers are consistently at risk when they try to provide physical support to people with lower limb disabilities and obesity. For such individuals, one caregiver may be insufficient when accompanying them, taking them outdoors. Furthermore, if the caregiver becomes ill as a result of the demanding nature of caregiving, there is no support available. Consequently, families with such disabled members experience greater financial hardship.

Intellectual disability is costly for the family

The concept of diversity is applicable to the realm of disability. Different types of disabilities result in varying outcomes for families. In comparison to physical, visual, and hearing disabilities, intellectual disability presents greater challenges. Caring for children with any form of intellectual disability incurs greater expenses. Consider the experience of a woman (respondent 4, hereafter referred to as R4) who was caring for her teenage son with an intellectual disability:

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"Doctors recommend that a combination of nutrient-dense foods should be provided regularly to my son to support his brain development. Foods rich in Omega-3, such as salmon, walnuts, and seeds, which also contain calcium and iron, are expensive. Thinking his intellectual development along with his growth, I am making significant compromises in pursuit of his well-being."

Mothers are the primary caregivers who are willing to sacrifice their own lives and happiness for the well-being of their children. The poignant narrative presented by a caregiving mother illustrates various mechanisms through which disability contributes to familial poverty. Firstly, caring for a child with a disability can be inherently stressful, potentially leading to chronic anxiety in the mother. Secondly, there is no assurance that the children will develop intellectually to their full potential. Furthermore, it cannot be guaranteed that an individual with an intellectual disability will perform effectively, regardless of the provision of emotional and financial support. Currently, there are no institutions or organizations in Nepal that can assume responsibility for the employment of individuals with intellectual disabilities. Leaving teenagers with intellectual disabilities alone at home poses significant risks, potentially leading to unforeseen consequences. The high cost of rearing is likely to drive an average Nepali family into long-term poverty. The narrative suggests that the presence of a highly vigilant caregiver is essential for the care of children with intellectual disabilities, imposing significant financial burdens on families.

Regular routine is ruined

People with severe disabilities often require a significant amount of care, impeding caregivers from effectively performing personal or household responsibilities. This may be attributed to the fact that caregivers are not comparable to financial resources or commodities that can be borrowed from others or exchanged for alternative goods. Not all caregiving activities disrupt the household routine; however, in certain instances, caregivers are required to reside full-time with their disabled family members by postponing some household activities. The following narrative is provided by another participant (Respondent 5, hereafter R5), which illustrates how household activities were disrupted by her involvement in caregiving responsibilities.

"When guests visit my home and do not arrange their shoes or slippers in an orderly manner, my child, who is 11 years old, tends to throw or damage them. He not only becomes cool after doing that, but also keeps on shouting or prolonged weeping. He becomes excessively distressed when we make minor changes within the home and its surroundings. Many times, I had to concentrate solely on him for long hours."

Individuals of working age are obligated to adhere to their professional responsibilities to sustain their personal lives and contribute to the family economy. However, there are certain circumstances that are so burdensome that individuals cannot conceive of being interrupted at any moment. This is typically the case for parents of children with autism, who exhibit markedly unusual reactions when they observe minor mistakes made by others. During that period, parents, family members, and caregivers become the primary victims. In many instances, people may experience significant losses due to damage to their personal belongings as well as to the belongings of others. The experience shared by R5 highlights that families with children diagnosed with autism endure significant direct and indirect financial losses as these children need to have a quality time with their parents.

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Similar type of stress and significant disruption in household tasks was experienced by a mother (Respondent 6, hereafter referred to as R6) of a 14-year-old girl with an intellectual disability. R6 stated:

"Leaving my teenage daughter at home presents significant risks. She lacks basic ideas of nutrition, clothing, health, sanitation, adolescence, sexuality, the perceptions of others towards her, and the potential risks she may encounter during her teenage years, which could arise not only from her own actions but also from being exploited by others. My husband is employed as a construction worker, earning a low wage, and I am unable to work to my full capacity without jeopardizing the safety of my young daughter."

Parents often are anxious of their teenage children; however, the challenges encountered by parents of a teenage daughter with an intellectual disability are particularly pronounced in mental, social, and financial dimensions. Furthermore, a mother can feel the real risks that a teenage girl may encounter. Upon evaluating the circumstances surrounding R6, it occurred to me that families with limited financial resources who have daughters with intellectual disabilities face both immediate and long-term financial crisis.

Disability breeds poverty

People with disabilities encounter challenges across various domains, including social, cultural, political, economic, and legal-administrative sectors, encompassing both emotional and rational dimensions. A multitude of challenges presents a substantial threat not only to the survival of the individuals with disabilities but also to their families and kinship circle. The contemporary world operates within a capitalist framework, wherein the most pronounced effect of disability is its contribution to the perpetuation of poverty, as disability is often not readily embraced by the profit-maximizing capitalist system. An unmarried young lady in her early twenties with a physical disability (Respondent 7, hereafter referred to as R7) expressed her current financial difficulties and her perceptions of her poverty situation in the future as follows:

"I am currently a wheelchair user. This wheelchair is also provided by someone. I will be able to walk if I get a prosthesis. However, the purchase of prosthetic devices poses a significant financial burden for my family. I cannot envision my marriage and family life. I understand that I must marry someone who has a disability. Living a single life with a disability presents significant challenges; thus, how can one anticipate a fulfilling life when both partners are disabled?"

The current realities experienced by an unmarried lady with a physical disability, combined with her aspirations for the future, demonstrate that disability significantly contributes to the birth of poverty and its perpetuation. Isolating individuals with disabilities under the pretext of social stigma or highlighting their perceived weaknesses establishes a significant barrier to their inclusion and participation in society. Society's inability to recognize disability as a form of diversity has significantly contributed to the emergence and perpetuation of poverty.

Major Findings

Based on the review of literature and the discussion of data made in this paper, this paper draws some findings. Firstly, People with severe disabilities require more support, but there is no law to ensure they receive enough care. The responsibility to care for disabled individuals often falls solely on individuals, leading to inconsistent support. For example, the situation of R1 demands a physically fit

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helper, which absorbs one of the family's breadwinners, putting the entire family in financial strain. In Nepal, where government support for disabled individuals is limited, families can fall into a cycle of poverty.

Disability can lead to increased poverty. All people possess different strengths, but those with disabilities may struggle more due to less access to opportunities. Since people with full visual disability are filled with compromises and hardships, the experience of R2 shows that it is very hard for them to achieve wealth.

Some disabilities present greater challenges. Caregiver may face risks when handling individuals with disabilities and obesity. This difficult caregiving can lead to other unwanted financial troubles for families if the caregiver becomes ill.

Intellectual disabilities can be more costly for families. Caregiving for such children is demanding and can lead to stress and anxiety. There are no guarantees of improvement, and support systems for employment are lacking in Nepal. Thus, rearing a child with intellectual disability can push families into poverty due to high costs and lack of institutional support.

Caregivers often have their routines disrupted. Many people with severe disabilities need extensive care, which prevents caregivers from performing personal or household tasks. Disruptions can lead to financial losses and stress due to the unpredictable behavior of children with autism. Intellectual disability gives additional stress to family, which may result in big financial loss.

Overall, disability perpetuates poverty. People with disabilities encounter difficulties across various aspects of life; not only they but also their families face significant challenges. In today's capitalist society, the impact of disability is evident in how it contributes to poverty, as it is often not accepted or accommodated. The societal stigma and the failure to recognize disability as a part of human diversity contribute to the barriers faced by disabled individuals, ultimately leading to vicious circle of poverty.

Conclusion

This paper explored the relationship between disability and poverty within households, revealing that the presence of disabled members not only triggers immediate financial hardships but also exacerbates long-term economic problems. It highlighted that the caregivers, often vital but unpaid laborers, experienced significant restrictions on their ability to engage in productive activities due to their caregiving obligations. As a result, those households faced a double burden of increased medical expenses and diminished income opportunities. The financial strain was compounded by the necessity of frequent medical care, specialized dietary needs, and the management of caregivers. To conclude, without effective intervention, families having disabled members are likely to remain ensnared in a cycle of poverty, with implications extending to future generations.

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