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Exploring the Challenges of Disability : A Study of Sindhuli District in Nepal

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Abstract

This study examined socio-economic challenges faced by people with disabilities in Sindhuli district, Nepal, using both qualitative and descriptive research methods. Demographic characteristics, care dynamics, and social cohesion were examined through purposive sampling and household surveys. Findings reveal the prevalence of congenital disabilities, with most respondents practicing self-care, while differing views on family support were evident. Despite challenges, the family appears as an important source of support recommending their inclusion. Addressing socio-economic inequalities and promoting a supportive environment are of utmost importance to enhance the well-being and social inclusion of people with disabilities in Nepal.

Keywords

Disability, Socio-economic Challenges, Nepal, Familial support, Social integration.

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1. Introduction

Disability is characterized by a restriction or lack of ability to perform activities within the normal human range, resulting from impairments. It can be temporary or permanent, and may affect physical, mental, or social functioning (WHO, 1980). New ERA (2011) defines disability as the inability to perform daily activities appropriate for one's age and sex due to impairments.

Statistics on disability are crucial for policy analysis and action, but estimates vary widely. The National Federation of Disabled Nepal claims about 2.04 million disabled individuals, but the 2021 National Census reports only 2.2% of the population as disabled. UNDP (2004) suggests at least 12% of Nepal's citizens may have disabilities.

Communication disabilities include visual, hearing, and speech impairments, while locomotion disabilities involve limb deformities hindering daily activities (New ERA, 2011). This encompasses mobility and manipulation disabilities in the lower and upper limbs, respectively.

Disabled individuals often face severe social exclusion due to policy, environmental, and attitudinal barriers, making them one of the most discriminated minority groups worldwide (Sapporo Declaration, 2002). Approximately 600 million disabled people, constituting about 10% of the global population, face this discrimination, with 82% residing in developing countries (UN, 1995). Globalization encompasses various dimensions (Ojha, 2023a; 2023b), and it provides a framework through which we can analyze and address diverse issues, including disability.

Disability is a public health concern, often resulting from factors like malnutrition, lack of immunization, socioeconomic status, and geographical location (UN, 1995). Discrimination against disabled individuals, fueled by ignorance, superstition, and fear, hampers their development and social participation (Sapporo Declaration, 2002).

The prevailing concept of disability in society, influenced by illiteracy, negligence, and superstition, needs to be addressed to promote inclusion and empowerment. Rehabilitation aims to enhance functioning despite impairments, enabling individuals to perform activities through modified methods or specialized equipment (Duwal, 2004).

Disability is a severely overlooked issue in Nepal, often attributed to superstition and ignorance. Many view disabilities as a punishment from the gods or a familial stigma, leading to social ostracization and shame. Families often hide disabled members from society due to societal disdain.

This study addresses the gap in previous research on disability by focusing on the socio-economic challenges and coping mechanisms of disabled individuals in Sindhuli District of Nepal. It aims to understand the lived experiences of disabled people within this specific community and how they navigate societal barriers. By delving into these aspects, the study aims to provide valuable insights that can inform efforts to improve the well-being and inclusion of disabled individuals in this locality.

2. Literature Review

Disability refers to physical or mental impairments hindering usual activities (Bhatta Tamang, 2003). Developmental disability necessitates special care for children unable to live independently due to physical, mental, or sensory disorders (Bhatta Tamang, 2003). According to WHO (1980), impairment denotes loss or abnormality in structure or function, while disability refers to restrictions in normal human activities. Handicap results from impairments or disability, limiting or preventing normal functions (WHO, 1980). It's crucial to distinguish between disability and handicap, with handicap originating from horse racing terminology and being potentially misleading (Allen, 1990).

Efforts to improve the situation of disabled people in developing countries face obstacles including poverty, ignorance, misconceptions, and faulty priorities (Shirley, 1983). Walner (1999) notes inadequate options for contraceptives among disabled women, citing physical access barriers, socio-economic factors, and educational gaps. Disability significantly impacts quality of life, particularly in marriage, education, employment, and emotional

well-being, with women and girls facing discrimination (Hosain et al., 2002; Voluntary Health Association of India, 1994).

According to UNDP (2004), estimates of the disabled population in Nepal vary widely, with the latest census reporting 1.63% (0.37 million) of the population as disabled. However, this figure likely under-represents the actual number of disabled individuals, as obtaining accurate information about disabilities is challenging. The discrimination against people with disabilities is pervasive, especially in rural and remote communities. The 2021 national census identified the disabled individuals in Nepal, comprising 2.2% of the total population, with most being physically disabled, followed by those with deafness (UNDP, 2004). New ERA's (2011) study on disability in Nepal found a prevalence rate of 1.63% in the total population, with disabilities more common among males than females. Additionally, the study revealed that many disabled individuals have multiple disabilities, making up 31% of the total population. Moreover, disabled individuals often face exclusion from community activities and facilities, such as schools and water taps, highlighting their deprivation of social justice and vulnerability (New ERA, 2011).

A variety of studies underscore the multifaceted challenges faced by disabled individuals, particularly in developing countries. The Universal Declaration of Human Rights emphasizes equal dignity and rights for all (UN, 1995), while efforts to prevent disabilities stress promoting peace, ensuring basic needs like food and clean water (UN, 1996), and addressing maternal malnutrition to prevent birth-related disabilities.

Despite global recognition, disabled individuals are often marginalized, with devastating impacts on their quality of life (Hosain et al., 2002). Disability is also a significant predictor of mortality and can exacerbate economic disparities (Mulhorn, 2011; Bound et al., 1996). Women with disabilities face double discrimination and are at increased risk of poverty and isolation (Habib, 1995). Health disparities among different racial and ethnic groups, as well as socioeconomic status, further compound the challenges faced by disabled individuals (Santiago, 1994; Natale et al., 1992; Angels, 1984). These findings underscore the urgent need for comprehensive strategies to address the complex interplay of health, socioeconomic, and cultural factors affecting disabled individuals worldwide.

3. Methodology

This study used both exploratory and descriptive research designs to investigate the socio-economic challenges faced by disabled individuals in Sindhuli District. Purposive sampling method was employed to select 52 households with disabled members for primary data collection. Household surveys were conducted to gather information on socio-economic and demographic characteristics, utilizing structured interviews. Observational techniques were also employed to understand daily life, social interactions, and household activities among disabled individuals in the sampled area.

4. Data Presentation and Analysis

4.1 Age and Sex Composition of the Respondents

The respondents were distributed in five years age group. It is because there was no restriction in the age and respondent of all age groups are attempted to include in the study. Age and sex composition of the study population is shown in the following table :

Table-1 : Composition of Respondents by Age and Sex

Age group	Sex		Total	Percentage
	Male	Female		
5-9 years	4	3	7	13.4
10-14 years	1	3	4	7.6
15-19 years	6	4	10	19.2
20-24 years	4	—	4	7.6
25-29 years	4	2	6	11.5
30-34 years	1	2	3	5.7
35-39 years	2	3	5	9.6
40-44 years	1	1	2	3.8
45-49 years	2	3	5	9.6
50-54 years	1	1	2	3.8
55-59 years	2	1	3	5.7
60+ years	1	—	1	1.9
Total	29	23	52	100.00

Source : Field Survey, 2024.

The table-1 shows that age group 15-19 contains highest number (19.2%) of respondents. About 20 percent respondents were below 15 years of age and 1.9 percent were 60 years and above. Of the total study population 55.7 percent were male and 44.2 percent were female.

4.2 Period of becoming Disabled

The period for receiving disability benefits varies based on the country's social welfare system. Eligibility criteria typically include proving a significant impairment hindering work or daily activities. Once approved, benefits are usually provided regularly, often monthly. The duration varies, from temporary assistance for short-term disabilities to long-term or permanent benefits for chronic impairments. Some programs offer vocational training and rehabilitation. Overall, the period depends on medical condition, severity of impairment, and ongoing assessments of work ability.

Table-2 : Distribution of Respondents by Period of becoming Disabled

Types of disability	Period of becoming Disabled			Total
	By birth	Childhood	Adulthood	
Physical	13	5	3	21
Blind	1	2	—	3
Deaf	14	10	—	24
Mentally retarded	2	—	—	2
Multiple	2	—	—	2
Total	32	17	3	52
Percent in whole	61.5	32.6	5.7	100.00

Source : Field survey, 2024.

The above table shows that more than 60 percent respondents became disabled by birth and 32.6 percent respondents became disabled during his/her childhood. Rest of the respondents (5.7%) received their disability during adulthood.

4.3 Causes of Disability

Causes of disability include accidents, injuries, congenital conditions, illnesses, genetic disorders, and aging. These factors can result in physical, sensory, cognitive, or mental impairments, leading to varying degrees of disability. Environmental factors, such as

inadequate access to healthcare, sanitation, and safety measures, can also contribute to disabilities. Additionally, socio-economic disparities and cultural practices may impact the prevalence and severity of disabilities within populations. The causes of disability are shown in the following table.

Table-3 : Cause of Disability of Respondents (in percent)

Causes of Disability	Types of Disability					Total (N=52)
	Physical (N=21)	Blind (N=3)	Deaf (N=24)	Mentally retarded (N=2)	Multiple (N=2)	
By birth	61.9	33.3	58.3	100	100	61.5
Accident	23.8	—	12.5	—	—	15.3
Diseases	14.2	66.66	29.1	—	—	23.07
Total	100.00	100.00	100.00	100.00	100.00	100.00

Source : Field survey, 2024.

The above table reveals that respondents were asked what the cause of their disability was. Majority of respondent (61.5%) were disabled by birth. About 15 percent were become disabled in accident. Disease is found to be major cause for disability after birth. About 23 percent of disabled received their disability from disease. It is clear from the 20 that about 61 percent of physical, 33 percent of blind, 58 percent of deaf and all mentally retarded and multiple disabled by birth. It can also be noted that accident caused disability in 23.8 percent of physically disabled respondents. It makes clear that there is high risk getting physically disabled through accident. 66.6 percent of blind, 29.1 percent of deaf and 14.2 percent of physically disabled received their disability through disease.

4.4 Care-taker in the Family

Care-givers in the family provide essential support and assistance to family members with disabilities or chronic illnesses. They fulfill various roles, including providing physical care, emotional support, and managing medical needs. Care-givers often navigate complex healthcare systems, coordinate appointments, and administer medications. Additionally, they may handle household tasks, such as cooking, cleaning, and transportation, to ensure the well-being of their loved ones. The role of care-givers is vital in maintaining the overall health and quality of life of individuals with disabilities or health conditions.

Table-4 : Distribution of Respondents according to the Care-taker in the Family

Care-taker	Types of Disability					Total (N=52)
	Physical (N=21)	Blind (N=3)	Deaf (N=24)	Mentally retarded (N=2)	Multiple (N=2)	
Self	85.7	33.3	91.6	—	—	78.8
Parents	14.2	—	—	100	100.00	13.4
Brother/Sister	—	66.6	—	—	—	3.8
Son/ Daughter	—	—	8.3	—	—	3.8
Total	100.00	100.00	100.00	100.00	100.00	100.00

Source : Field survey, 2024.

The above table shows that although disabled people need special care and support to perform usual activities. It was found that more than 78 percent of total respondents take care themselves. About 13 percent respondents are cared by their parents. In very few cases, brother, sister, and son/daughter serve as caretaker.

4.5 Family Members' Treatment towards Disabled

Family members play a critical role in caring for and supporting individuals with disabilities. They provide physical assistance, emotional encouragement, and advocacy for their disabled relatives. Family members adapt living spaces and routines to accommodate needs and act as intermediaries with external institutions. Overall, family support is essential for the well-being and independence of individuals with disabilities.

Table-5 : Distribution of Respondents as treated by their Family Members

Family members' treatment	Types of Disability					Total (N=52)
	Physical (N=21)	Blind (N=3)	Deaf (N=24)	Mentally retarded (N=2)	Multiple (N=2)	
Good	80.9	66.6	62.5	50	100	71.15
Discriminate	9.5	33.3	8.3	—	—	9.6
Tease and hate	4.7	—	16.6	—	—	11.5
Scold	4.7	—	8.3	50	—	3.8
Beat	—	—	8.3	—	—	3.8
Total	100.00	100.00	100.00	100.00	100.00	100.00

Source : Field survey, 2024.

Table-5 on the preceding page reveals that about 71 percent of total respondents said that they had been treated nicely in the family. About 9 percent respondents react that they had been discriminated by family members. Altogether about 29 percent of respondents were ill-treated in the family.

4.6 Perception of Family Members towards Disabled

Family members' perceptions of disabilities vary widely, influenced by cultural and personal factors. Positive perceptions lead to support and inclusion, while negative perceptions may result in neglect or marginalization. Understanding and acceptance within families are crucial for the well-being of individuals with disabilities.

Table-6 : Family Members' Feelings about Disabled Person in Household

Family members' feelings	Types of Disability					Total (N=52)
	Physical (N=21)	Blind (N=3)	Deaf (N=24)	Mentally retarded (N=2)	Multiple (N=2)	
Huge burden	9.5	33.3	41.16	50	50	11.5
Not much burden	19.04	33.3	45.8	50	—	32.6
Not at all	61.9	33.3	29.16	—	50	40.3
Do not know	9.5	—	20.8	—	—	15.3
Total	100.00	100.00	100.00	100.00	100.00	100.00

Source : Field survey, 2024.

During the interview respondents were asked whether their family members feel economic burden having disabled member in the household. The above table-6 shows that about 11 percent of respondents said that they were felt huge burden by the family members while 32.6 percent of respondents replied not much burden. About 40 percent of respondents were not felt economically burden in the household whereas 15.3 percent respondents were unknown about their family members feelings towards them.

4.7 Disabled Members' Expectation from the Family

Disabled individuals expect understanding, support, and inclusion from their families. They rely on empathy and advocacy to navigate challenges and access necessary resources. While seeking independence, they value a supportive environment that fosters their well-being and sense of belonging within the family unit.

Table-7 : Expectation of Respondents from Family Members (in percent)

Disabled peoples' expectation	Types of Disability					Total (N=52)
	Physical (N=21)	Blind (N=3)	Deaf (N=24)	Mentally retarded (N=2)	Multiple (N=2)	
Love	19.04	33.3	37.5	—	—	26.9
Support	28.5	—	12.5	—	50	19.2
Love & support	42.8	66.6	33.3	50	-	40.3
Help	9.5	—	—	50	50	5.7
Nothing	—	—	16.6	—	—	7.6
Total	100.00	100.00	100.00	100.00	100.00	100.00

Source : Field survey, 2024.

The above table shows that most of the respondents' centered on love and support from the family. 26.9 percent respondents hope love, 19.2 percent hope support and 40.3 percent respondent hope both love and support from the family.

4.8 Problems in Participating in Social Activities

Disabled individuals often encounter various challenges when participating in social activities. These may include physical barriers such as inaccessible venues or transportation, societal stigma and discrimination leading to exclusion, lack of accommodations for their specific needs, and limited awareness and understanding from others regarding their abilities. These barriers can hinder their full participation in social events and activities, resulting in feelings of isolation, frustration, and inequality. Overcoming these obstacles requires addressing systemic barriers, promoting inclusivity, and fostering greater awareness and acceptance of disability within society.

Table-8 : Distribution of respondent according to difficulties

Problems	No. of Respondent	Percentage
Because of disability	9	21.9
Fear of being mocked	4	9.7
Feel uncomfortable	5	12.19
No problem	23	56.09
Total	41	100.00

Source : Field survey, 2024

Table-8 on the preceding page shows that respondents of 15 years and above were asked about their involvement in social activities and difficulties for participating social activities. 56.09 percent of total respondents answered that they had faced no problem in participation. 21.9 percent responded had not participated in social activities because of their impairments while 9.7 percent fear of being mocked and 12.9 percent of respondent feel uncomfortable to participate in social activities.

5. Findings of the Study

The major findings of this study may be summarized as under:

- ▶ Age group 15-19 comprises the highest number of respondents, accounting for 19.2%.
- ▶ Over 60% of respondents acquired their disability from birth, with 32.6% experiencing it during childhood.
- ▶ The majority of disabilities (61.5%) were present from birth, with accidents contributing to 15% and disease to 23%.
- ▶ More than 78% of respondents primarily take care of themselves, with around 13% receiving care from their parents.
- ▶ Approximately 71% of respondents reported being treated nicely by family members, while about 29% experienced ill-treatment.
- ▶ Around 11% of respondents felt a significant economic burden on their family due to their disability.
- ▶ Love and support are the primary expectations of disabled individuals from their families, with 26.9% hoping for love, 19.2% for support, and 40.3% for both.
- ▶ While 56.09% of respondents faced no problems participating in social activities, 21.9% cited impairments as a barrier, 9.7% feared mockery, and 12.9% felt uncomfortable participating.

6. Conclusion

The findings from the study shed light on various aspects of the lives of disabled individuals in the community. It is evident that a significant proportion of disabilities are acquired from birth, highlighting the need for early intervention and support. Despite facing challenges, such as impairments and social stigma, a majority

of respondents demonstrate resilience by taking care of themselves and participating in social activities.

Moreover, the positive treatment received from family members underscores the importance of familial support in the lives of disabled individuals. However, there are areas of concern, including economic burdens felt by some respondents and instances of ill-treatment within families. Overall, the study emphasizes the importance of addressing the socio-economic needs of disabled individuals and fostering an inclusive environment that provides love, support, and opportunities for their well-being and participation in society.

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