

To Assess The Livelihood Options Among The People With Disability (Pwds) in the Selected Areas of Uttarakhand

KEYWORDS

Hospital

People with Disability, diversifying, accumulating, non-productive assets

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ABSTRACT

The World Health Organization defines disability as "an umbrella term, covering impairments, activity limitations, and participation restrictions. Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. The World Bank considers that leaving people with disabilities outside the economy translates into a foregone GDP of about 5-7 percent. Studies prove that the costs of economic exclusion outweigh the costs of full economic citizenship of PwDs. 'Disability limits access to education and employment, and leads to economic and social exclusion. The sample size was selected based on the base line conducted by Institute in the 2012 in the same locations. For conducting this study 25 % cases were selected among the total 929 people with disability (18 -50 years). Inside the community the cases were selected randomly however ratio of male and female as well as all participation of all groups of society were ensured at all levels. Majority of respondents interested in off farming (47.5%), tailoring (13.5%), computer (26.6%), farming (11%), professional courses (2%) and others (3%). Out 234 respondents 16% were agree to bear their training expenditure, 86% respondents needed financial support and 40% require financial as well as second person support during training. On a positive note however it is important to highlight that disability did not prevent the respondents from striving to be independent and contributing towards improving their families. The majority of respondents stated that they gained economic benefits from income generating activities in various ways. These included strengthening small businesses, diversifying sources of income, accumulating productive and non-productive assets, raising money for regular meals and medical expenses, and reinvesting.

Introduction

The World Health Organization defines disability as "an umbrella term, covering impairments, activity limitations, and participation restrictions. Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations (28). Thus disability is a complex phenomenon reflecting an interaction between features of a person's body and features of the society in which he or she lives" (29). United Nations Convention on the Rights of Persons with Disability defines Persons with Disabilities as those who have long term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others (27).

There are an estimated 650 million people with disabilities in the world (10- 12 percent of the global population) and 80 percent of these (520 million) are concentrated in developing countries. Furthermore, 80-90 percent of the persons with disabilities of working age are unemployed compared to 50-70 percent in industrialized countries (22). The World Bank considers that leaving people with disabilities outside the economy translates into a foregone GDP of about 5-7 percent (27). Studies prove that the costs of economic exclusion outweigh the costs of full economic citizenship of PwDs. 'Disability limits access to education and employment, and leads to economic and social exclusion (19). Poor people with disabilities are caught in a vicious cycle of poverty and disability, each being a cause and a consequence of the other (17). The Indian National Sample Survey conducted two country-wide surveys in 2001 and 2011 to assess the number of people with disabilities. From these it was estimated that the population with a disability in India is approximately 90 million (1). Within this figure it is estimated that 12 million are blind, 28.5 million have limited vision, 12 million have speech and hearing impairments, 6 million are orthopedically handicapped, 24 million have a cognitive disability, 7.5 million are mentally ill, and 1.1 million are disabled as a result of leprosy (8). Estimates vary greatly according to definitions and methods, but negative attitudes towards disability in most communities mean that these are probably underestimates (10).

'Women with disabilities' suffer a double discrimination, both on the grounds of gender and of impairment (6). The consequences of deficiencies and disablement are particularly serious for women. Women are subjected to social, cultural and economic disadvantages, which impede their access to, for example, health care, education, vocational training and employment. If, in addition, they are physically or mentally disabled, their chances of overcoming their disablement are diminished, which makes it all the more difficult for them to take part in community life (4). All women and men with disabilities can and want to be productive members of society. In both rural and urban, promoting more inclusive societies and employment opportunities for people with disabilities requires improved access to basic education, vocational training relevant to labor market needs and jobs suited to their skills, interests and abilities, with adaptations as needed. Many societies are also recognizing the need to dismantle other barriers, making the physical environment more accessible, and providing information in a variety of formats, and challenging attitudes and mistaken assumptions about Persons with

Disabilities (10).

Chambers and Conway have defined the sustainable livelihoods approach (SLA) as 'the capabilities, assets and activities required for a means of living (6). They argue that it provides the basis for engaging with the complex and diverse portfolio of activities and assets people use to support themselves. The Department for International Development (8)conceptualize the sustainable livelihoods approach as a framework showing how access to assets are affected by the 'vulnerability context' (trends, shocks and seasonality), mediated by 'transforming structures and processes' (i.e. the policies, institutions and processes) and resulting in a number of 'livelihoods strategies' being adopted to achieve 'livelihood outcomes (7).

Livelihood is a means by which life is sustained. Sufficient and sustainable livelihood for all people with disabilities is the one of challenging tasks for everyone (5). Sufficient means adequate income to enable PWDs to meet their basic needs, including nutrition, housing, clothing etc. and participation in the community with dignity. Sustainability is the capacity of natural and social systems to survive and thrive together over long term. Effects to provide sufficient livelihood must be sustainable economically (6). Status of employment i.e. paid jobs is depressing in general all over the world. Many People with disability (PWDs) in rural area have excellent thoughts to contribute towards development of their communities and indeed their nation, through their services towards society but generally they are not allowed the opportunity to do so due to their disability and inaccessibility and lesser-friendly approaches. They will contribute as significant roles for their society development. But it's ridiculous that there are limited opportunities i.e. Rights on paper, Certificate registration, pension, assistive devices and skills training for some extend. Even though many people in the interior hills are not able to receive these services due to un reach ability from district office. If some attention given to caters for their special needs, it encourages to them to come forward from their situation of social exclusion, increases dishonor and social rejection (11).

Empirical evidence shows that Persons with Disabilities are the vulnerable communities that get marginalized in the competition for access to assets and markets, having a huge negative impact on their social, emotional and economic well-being (4). In this competitive race, PwDs are the majority group on the peripheries with no access to human, social and financial capital and having limited or negligible control and access to physical and political capital. The negative fallout of the same hampers their enjoyment and opportunity of economic livelihood. Globally, it has been observed that the vulnerability index is increased manifold due to disability (26). It is directly impacted by the ecosystem in which the vulnerable live. People's livelihoods and the wider availability of assets are fundamentally affected by critical trends as well as by shocks and seasonality over which they have limited or no control. Shocks can be the result of human health, natural events, economic uncertainty, and conflict and crop/ livestock health. The vulnerability context in turn affects a household's assets

It is widely recognized that employment and income generation are key factors for empowering and promoting the inclusion of people with disabilities into society (9). Some studies have indicated that many people with disabilities have proven their capability in various sectors. Across

the world, people with disabilities are entrepreneurs and self-employed workers, farmers and factory workers, doctors and teachers, shop assistants and bus drivers, artists, and computer technicians (7). Thus if effective support and protection in employment and income generation are achieved for disabled people, many extremely poor disabled people will be allowed to not only live more healthy and happy lives, but will also make a significant contribution to economic and social progress across society (21).

According to Census 2011 of Uttarakhand, the total population of Uttarakhand is 10.3 million and out of them 2% (185272) persons are living with disability. There is no specific study has been done yet in the state to understand the various aspects of among people with disability in relation to their employment status and small income generation interventions. Uttarakhand is one of the mountain states which has scattered population, difficult terrain, small land holding farming and most of lands are not irrigated.70% household across the state is dependent on farming but it covers only 46% of their expenditures annual. In the context of people with disability agricultural is not the best option for their livelihood option because of difficult terrain and traditional patterns of agriculture. Most of the time people with disability are not involve in the farming however in few places they work as subordinate and their works are not counted in main outcomes. Understanding the ability of people with disability, the study is planned to understand the present education, income, employment and skills of people with disability. It also investigates the scope for engagement of people with disability in agriculture, horticulture, floriculture and producing fertilizers for organic farming. Finally study was assess and recommended the livelihood options among the people with disability base on the types of disability. The findings of the study and its recommendations will also support the local and state governments in their programs towards social inclusion and poverty reduction.

Methodology

The key objective of study was to understand the current status of people with disability (18- 50 years) and future possibilities for livelihood and skill development. The cross sectional study was conducted from the direct interview with selected people with disability (18-50 years). The structural questionnaire was prepared with the help of professionals and it was pre tested with the selected cases. The feedbacks and observations were discussed with larger group of professionals and incorporated according to their suggestions. For quantitative analysis direct interviews with define age group were conducted however for qualitative findings, focus group discussions were conducted with people with disable, community members and providers.

2.1 Selection of area and sampling method

The study was conducted in one district (Dehradun) from Uttarakhand and one district (Bijnor) from Uttar Pradesh. The selection of district is purposely decided because institute has already implementing Community Base Rehabilitation intervention n these areas since 2011. In Dehradun district, the study was conducted in two blocks (Doiwala and Chakrata) however in Bijnor district only one block (Nazibabad) was selected. Doiwala is basically migrated urban community and Bijnor is totally urban area however Chakrata mountain rural area. The sample size was selected based on the base line conducted by Institute in the 2012 in the same locations. For conducting this study 25 % cases were selected among the total 929 people with disability (18 -50 years). Inside the community the cases

were selected randomly however ratio of male and female as well as all participation of all groups of society were ensured at all levels.

2.3 Data collection processes and analysis

Field investigators collected data using the standardized tools by visiting the households. Out of the total reported cases of people with disability (18-50 years), the cases were selected for this study randomly ensuring representation of all groups and villages. At village level, younger age group was selected in priority for the study. For the qualitative data, the interviews and community meetings were conducted through based a pre designed and pre tested semi -structured questionnaires. Three focus group discussions were organized among people with disable, their family and community members and providers, one in each of the identified block.

SPSS-PC Version 19 was used for data entry, analysis and Interpretation. Responses of the respondent's interview schedule were done carefully to remove the possible errors and inconsistency for the raw data. The frequencies of respondents were tabled and test statistically for reliability. After editing the raw data necessary data and information was presented in the form text, table. Percentage, chart, graph and figure finally the data were interpreted according to the need of the research.

Findings

The finding revealed that the mean age of the respondents was 27 years. Majority of the respondents (85.5%) were between the age 18-40 years and rest were of the more than 41 years. Largest numbers of respondents were from marginalize section of society (Backward, schedule caste & tribe) having 63% followed by general category with 37%. Maximum numbers of respondents were illiterate (25.4 %). Highest number of respondent's education level was primary and junior (41%) and the least with graduated and above 8.7%. out of 234 respondents least number (4.6%) of respondents were engaged in agriculture almost half (46.7%) of them were working off farming activities. The major source of income for more than half of the respondents was pension (56.6%) and rest of respondents was totally dependent in their family members.

The study illustrated that out 234 respondent's majority were physical (63%), Mental retardation (8.4%) visual (4.2%) deafness (5.3%) speech (1.3%) and multiple disability (18.1%). The study indicated that 45.5% of respondents suffering from disability since their birth, 33% between 1 to 8 years, 5.5% between 9 and 19 years and 14% were affected after the age of 20 years in their life. Only 37% respondents was married and majority were unmarried (63%) above the age of 30 years. The minimum age of marriage was 19 years and maximum age was 47 years however the mean age marriage was 23.4 years. Out of 88 married people with disability only 40% have children.

Out of 234 respondents only 25.1% have their own income source however within them only 15% respondents are living financially independent. The study also revealed that almost two third respondents were completely financially dependent on their family members. Although 86% of respondents who have disability certificate receiving at least one benefit from the State Social Department in which maximum number were receiving pension scheme. The survey indicated that only 24.8% respondents were received assertive device and only 11.2% were using it currently. However, 81.2% respondents were expressed their

needs for assertive devices during the survey. Out of all respondents only 27% were taken any types of vocational training in which only 18% taken one week or more than one week course. The study also pointed out that only 13% were satisfied with their last vocational training and mentioned that these skills are helping them in their current job.

The study revealed that 66% of respondents were agreeing to join vocational training in future. Most of the people with people with disable would like to join residential vocational training less than one week at block level however 5.3% are agree to join more than one week course anywhere in the state. Majority of respondents interested in off farming (47.5%), tailoring (13.5%), computer (26.6%), farming (11%), professional courses (2%) and others (3%). Out 234 respondents 16% were agree to bear their training expenditure, 86% respondents needed financial support and 40% require financial as well as second person support during training.

Discussions

The World Health Organization (WHO) defines disability as "an umbrella term, covering impairments, activity limitations, and participation restrictions. Impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus disability is a complex phenomenon reflecting an interaction between features of a person's body and features of the society in which he or she lives" (WHO and The World Bank, 2011).

The working paper -2 published by Extreme Poverty Research Group (2013) indicated that the disability screening survey in Bangladesh identified the various types of disabilities. The majority (33%) were suffering from a physical impairment, 13% of reported a visual impairment and 9.5 percent experienced hearing and speech difficulties. A significant proportion (33%) of people with disability reported experiencing multiple impairments. However, current study indicated that physical (63%), Mental retardation (8.4%) visual (4.2%) deafness (5.3%) speech (1.3%) and multiple disabilities (18.1%). Both studies have significant difference in the percentage of physical and multiple disabilities.

Bangladesh Bureau of Statistics (2010) claimed that the causes of disability showed that 45% had suffered from their impairments since birth, 29% reported impairments due an illness, 17% due to accidents, 3% caused by malnutrition and 5 percent due to other external shocks or stressful social situations. However current study found that 45.5% of respondents suffering from disability since their birth, 33% between 1 to 8 years, 5.5% between 9 and 19 years and 14% were affected after the age of 20 years in their life but the current study did not explore the other causes of disability.

The survey indicated that only 24.8% respondents were received assertive device and only 11.2% were using it currently. However, 81.2% respondents were expressed their needs for assertive devices during the survey. However, Seeley, J., 2001 found in her study that the one third of the people with disability used assistive devices to move, to do day-to-day tasks and for social and economic activities. She also pointed out that over two third of respondents were not using any assistive device. Similarly the

qualitative sample also revealed that many extreme poor people would have their disabilities reduced if they could have proper treatment or could afford assistive devices.

Beckett, A.E (2006), indicated that safety-net programmes are an important component of the government's social protection strategy. The study indicated that coverage is very low among the disabled extreme poor, which is surprising given their usual levels of vulnerability. The present study findings indicate that 31% of disabled were receiving government safety nets that had the disability certificate. It means significant percent of people with disability are excluded from of government safety nets. Although current study revealed that 86% of respondents who have disability certificate receiving at least one benefit from the State Social Welfare Department in which maximum number were receiving pension scheme. The survey indicated that only 24.8% respondents were received assistive device and only 11.2% were using it currently. However, 81.2% respondents were expressed their needs for assistive devices during the survey. Out of all respondents only 27% were taken any types of vocational training in which only 18% taken one week or more than one week course. The study also pointed out that only 13% were satisfied with their last vocational training and mentioned that these skills are helping them in their current job.

Out of 234 respondents only 25.1% have their own income source however within them only 15% respondents are living financially independent. The study also revealed that almost two third respondents were totally dependent financially on their family members. Although 86% of respondents who have disability certificate receiving at least one benefit from the State Social Department in which maximum number were receiving pension scheme. The study conducted by Appunni, SS & Deshpande, AP,(2009) shows that out of 457 respondents, 30% were not engaged with any income generating activities. Another 20% solely relied on social schemes providing by State Government. However, 50% of respondents were working as wage laborers' and support supplementary farm based activities.

A number of respondents from the individual interviews and focus group discussions shared their experiences of wage discrimination within the workplace. Most of them were only able to do manual work as they had no formal education. Most of the respondents from the life history interviews mentioned that when they went to the government hospital but did not get proper care.

Gender inequality is deeply embedded in the overall social structure in the selected areas. In this patriarchal setting women are deprived in most spheres of their lives. Social customs and traditions, high illiteracy rates and poor employment opportunities have hampered the integration of women into mainstream of development activities. In this study we observed that poverty affected men and women project beneficiaries in different ways, since their social roles were different. Disabled women tended to be the most disadvantaged group among the extreme poor. Several other studies have also showed that women with disabilities suffer a double discrimination, both on the grounds of their gender and their impairment (DFID, 2000).

Findings from the individual interviews demonstrate that a significant number of households gained economic benefit from income generating activities in various ways. These include strengthening their small businesses, diversifying sources of income, accumulation of productive and non-

productive assets and accumulating money for regular meals, medical expenses, and reinvestment. We found that very small businesses were viable livelihoods options for people with disabilities. These required minimal physical effort and mobility and allowed disabled people to earn a regular income. Most of the respondents were able to run shops, cloth or firewood businesses from their home.

Those with visual impairments did better with handicrafts such as mat weaving. These activities benefit from technical and vocational training on different items to increase skills. People with psychological disorders, behavioral problems and learning difficulties were more likely to be involved with unskilled. At the same time these people had to face a range of exclusionary attitude in their daily life. These individuals need more protection and support that will enhance their ability to cope and to give them a sense of self-worth and belonging. Families and communities also need awareness rising on psychosocial care and support to reduce discrimination and stigmatization and improve positive caring. Most of FGD participant agreed that after being involved with the self-help group they become confident enough to claim their rights and entitlements. They also shared their experiences and observations which gave them a sense of group solidarity

The study revealed that 66% of respondents were agreeing to join vocational training in future. Most of the people with people with disable would like to join residential vocational training less than one week at block level however 5.3% are agree to join more than one week course anywhere in the state. Majority of respondents interested in off farming (47.5%), tailoring (13.5%), computer (26.6%), farming (11%), professional courses (2%) and others (3%). Out 234 respondents 16% were agree to bear their training expenditure, 86% respondents needed financial support and 40% require financial as well as second person support during training. The study findings were same as Chambers, R., and G. Conway. (1992) regarding the most of people with disability prefer off farming activities. However, in her study 100% of people with disability require financial support although in the current study 16% of people with disability were agreed to pay their financial cost for their vocational training.

5. Conclusion

It is clear that disabled people are the most vulnerable and disadvantaged group in across the community. Disabled people face significant challenges in maintaining their livelihood activities. The most common limitation is an inability do physical work over long periods due to physical impairments, which results in prospective employers not wanting to recruit or hire them. A number of respondents who had physical and mental disabilities experienced wage discrimination within the workplace. They are therefore deprived of employment opportunities and deprived of a fair wage. It was found that in particular those who have visual, speech and hearing difficulties are deprived of special education and other opportunities. As disabled people are not getting access to proper education, they are unable to get skilled jobs, driving them further into poverty.

Findings also revealed that the ill health associated with their impairments often further erodes their income and assets, as they lose working days and have to spend money on treatment. Sometimes they are even forced to sell assets to pay for treatment costs. Disabled people are subjected to various types of discrimination and negative attitudes in their daily lives. Respondents reported exclusion-

ary and discriminatory attitudes displayed in verbal attacks, jokes or bullying. They reported exclusion from land inheritance. Children are also affected by the negative attitudes and behavior of family members and wider society, often through bullying, which leads to self-low esteem. Thus discrimination, social exclusion and isolation are a frequent part of life, for both the disabled person and their family. They are often neglected by their families, neighbors and community.

On a positive note however it is important to highlight that disability did not prevent the respondents from striving to be independent and contributing towards improving their families. The majority of respondents stated that they gained economic benefits from income generating activities in various ways. These included strengthening small businesses, diversifying sources of income, accumulating productive and non-productive assets, raising money for regular meals and medical expenses, and reinvesting.

Inclusion into income generating activities and skill development are two important ways of supporting extremely poor disabled people and reducing their vulnerabilities. The involvement with income generating activities or the productive use of an asset provided disabled people the opportunity to improve their incomes and social dignity, and allowed them to strengthen their ability to cope with crises or shocks in a sustainable way.

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