

Social Security for Persons with Disabilities in India: A Study of Sikkim

A Dissertation Submitted

To

Sikkim University



In Partial Fulfillment of the Requirement for the
Degree of Master of Philosophy

By

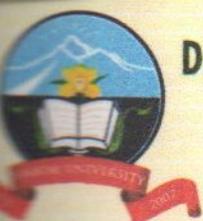
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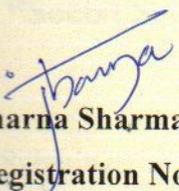
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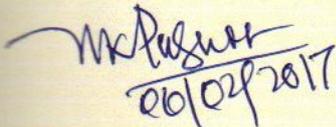
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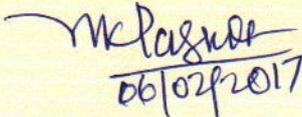
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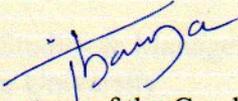
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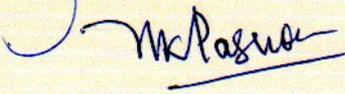
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“Social Security for Persons with Disabilities in India: A Study of Sikkim”

Submitted by Jharna Sharma under the supervision of Dr. Nawal K. Paswan of the Department of Peace and Conflict Studies and Management, School of Social Sciences, Sikkim University, Gangtok 737102, INDIA


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CERTIFICATE

This is to certify that the dissertation entitled “**Social Security for Persons with Disabilities in India: A Study of Sikkim**” submitted to **Sikkim University** for the award of the degree of **Master of Philosophy** in Peace and Conflict Studies and Management, embodies the result of bona fide research work carried out by Jharna Sharma under my guidance and supervision. No part of the dissertation is submitted for any other degrees, diploma, associate-ship and fellowship. All the assistance and help received during the course of investigation have been deeply acknowledged by her.

Dr. Nawal K. Paswan
06/02/2017

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I would like to express deepest appreciation for Dr. Nawal Kishore Paswan, my supervisor, who helped and guided me all through my dissertation. He has given me his time on each occasion to discuss my problem during the study and every meeting with him has turned out to be fruitful for the study, as well as, for my future. Without his guidance and persistent help, this would not have been possible.

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Last but not the least, I would like to thank the Almighty for his constant blessings.

Jharna Sharma

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ABBREVIATIONS

ADIP	ASSISTANCE TO DISABLED PERSONS FOR PURCHASE/FITTING OF AIDS AND APPLIANCES
CRPD	CONVENTION ON THE RIGHTS OF PERSONS WITH DISABILITIES
DDRC	DISTRICT DISABILITY REHABILITATION CENTRE
GOI	GOVERNMENT OF INDIA
GOS	GOVERNMENT OF SIKKIM
IED	INCLUSIVE EDUCATION FOR THE DISABLED
IGDP	INDIRA GANDHI DISABILITY PENSION
ILO	INTERNATIONAL LABOUR ORGANISATION
MDG	MILLENIUM DEVELOPMENT GOALS
MHRD	MINISTRY OF HUMAN RESOURCE DEVELOPMENT
MSJE	MINISTRY OF SOCIAL JUSTICE AND EMPOWERMENT
NGO	NON GOVERNMENTAL ORGANISATIONS
NHFDC	NATIONAL HANDICAPPED AND FINANCIAL DEVELOPMENT CORPORATION
NIOS	NATIONAL INSTITUTE of OPEN SCHOOLING
NT Act	NATIONAL TRUST FOR WELFARE OF PERSONS WITH AUTISM, CELEBRAL PALSY, MENTAL RETARDATION AND MULTIPLE DISABILITY ACT 1999
PWD	PERSONS WITH DISABILITIES
PWD Act	EQUAL OPPORTUNITIES, PROTECTION OF RIGHTS AND FULL PARTICIPATION ACT
RCI	REHABILITATION COUNCIL OF INDIA

RMSA	RASHTRIYA MADHYAMIK SIKSHA ABHIYAN
RTE	RIGHT TO EDUCATION
SDG	SUSTAINABLE DEVELOPMENT GOALS
SSA	SARVA SIKSHA ABHIYAN
UN	UNITED NATIONS
UNESCO	UNITED NATIONS EDUCATIONAL, SCIENTIFIC AND CULTURAL ORGANISATION
UNICEF	UNITED NATIONS CHILDREN'S FUND
UT	UNION TERRITORIES
WHO	WORLD HEALTH ORGANISATION
UNHQ	UNITED NATION HEAD QUATER

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CHAPTER– 1

INTRODUCTION

1.1 BACKGROUND

International Labour Organisation (ILO) defines social security as “the protection which society provides for its members through a series of public measures against the economic and social distress that otherwise would be caused by the stoppage or substantial reduction of earnings resulting from sickness, maternity, employment injury, invalidity and death; the provision of medical care; and the provision of subsidies for families with children” (ILO, 1984).

Social security protection is clearly defined in ILO conventions and United Nations (UN) instruments as a basic human right (ILO’s Declaration of Philadelphia 1944). It further emphasises that individuals and families must be given confidence so that their level of living and quality of life does not deteriorate by social or economic eventuality. They must be provided with medical care and income security against the consequences of defined occurrences, facilitate the victims physical and vocational rehabilitation, prevent or reduce ill health and accidents in the occupations, protect against unemployment. It acts as a facilitator – it helps people plan their own future through insurance and assistance.

The family is the primary source of welfare even before the welfare state, on the lines of modern welfare approach. Following that comes community, membership institutions, markets, and finally state-provided welfare facilities. The enormity of sufferings for persons with disabilities is vast, and its impact on the individual, family and community is severe. The most vulnerable groups among the persons with disabilities include very young children, women and the aged. Their existence and livelihood requirements need to be taken care of by some agency in the society—that agency could be the state, in the absence of benevolent markets and communities, especially when the families of the persons with disabilities cannot do so. Disabled persons, their families and caregivers incur substantial additional expenditure in their

day-to-day lives with expenses like medical care, transportation, assistive devices, etc. Therefore, there is a need to provide them with social security by various means.

Central Government has been providing tax relief to persons with disabilities and their guardians. The State Governments/ U.T. Administrations have been providing unemployment allowance or disability pension. The State Governments are encouraged to develop a comprehensive social security policy for persons with disabilities. Parents of persons with disabled autism, cerebral palsy, mental retardation and multiple disabilities feel a sense of insecurity regarding the welfare of their wards after their death. National Trust for persons with autism, cerebral palsy, mental retardation and multiple disabilities has been providing legal guardians through Local Level Committee. They are also implementing the Supported Guardianship Scheme to provide financial security to persons with the above-mentioned severe disabilities, who are destitute and abandoned by supporting the cost of guardianship.

Since Independence, the Government of India has developed various policies to address their position - both as a matter of human right and in recognition of the close links between disability and poverty. From the mid-1990s, these efforts have taken a more fervent turn, with revised schemes and policies. The Government of India has enacted three legislations for persons with disabilities (PWDs) viz. (i) Persons with Disability (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 (PWD Act 1995), which provides for education, employment, creation of barrier-free environment, social security, etc; (ii) Rehabilitation Council of India Act, 1992 deals with the development of manpower, for providing rehabilitation services; and (iii) National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability Act, 1999 as provisions for legal guardianship of the four categories and creation of enabling environment, for as much Independent living as possible. India has one of the more progressive disability policy frameworks in the developing world. As a part of United Nation Signatory, India has adopted all of its acts and policies for the disabled from The Convention on the Rights of Persons with Disabilities (CRPD). However, there remain huge challenges in the operationalisation of the policies.

Currently reservations in services, concessions in employment, disability pension under the Employees' Provident Funds and Miscellaneous Provisions Act 1952, medical and maternity benefits under Employees' State Insurance Act 1948, benefits under the Workmen's Compensation Act 1923, special schools for the disabled children, inclusive education for the disabled, National health mission, disability specific assistance programmes are available in the country, through the coverage is not comprehensive. Ironically, three major Social Security Acts listed above are the employer liability and employment related benefit schemes. They are operative only in the case of disability during the course of employment.

There are no programmes for old age and survivor benefits in the case of the disabled, who cannot be employed or for the disabled person still unemployed even after having crossed the employable age. There is no any programme for the disabled, dependent and aged widows, except a few measly assistance given by some State Governments, such as an old age minimum pension of Rs. 50 or at the maximum Rs 150 per month, which varies from state to state. To add to this problem, there are a huge number of agencies mushrooming by the day, as well as fraudulence and foul play in terms of benefits is a common phenomenon in India's various social security programmes.

Currently, the existing and available schemes or programmes do not comprehensively address the problems of the disabled persons. The major Social Security Acts available in India only cater to employment-related disability. However, in truth, there is a greater number of disabled persons either unemployed, in an informal economic activity or dependent on parents, children and/or spouses. Disabled persons in India are the most vulnerable group. Unfortunately, disabled persons, irrespective of their economic status, are subjected to social exclusion in the society. In the same line, Sikkim being one of the smallest states in India accounts for having a population of more than 18,187 disabled persons, against the total population of 6,07,688 (Census, 2011), that is recorded. It is also believed that many of them go unrecorded in the census because of inaccurate identification, by the surveyor, unable to place the disabled person in a clear category.

Against this background, an attempt has been made in this study to examine the status of social security of persons with disabilities in India in general and Sikkim in particular. It also aims to look into the issues related to the schemes and the beneficiaries, to gain an insight from the life of a disabled person in rural and urban setting, and examine various programmes and schemes that are functional in India in general, focused particularly at Sikkim. This study would facilitate Government organisations, NGOs, persons with disabilities, civil societies and to those who are concerned with the related field of study and will provide a better understanding of the role of social security in the lives of Persons with Disabilities.

1.2 REVIEW OF LITERATURE

Review of literature has been divided into three sections. Section one focuses on concept, definition and origin of social security. The second part looks into the attitude and infrastructure development for persons with disabilities and the third section sees how social security has been perceived and regulated in India and Sikkim.

a. Social Security: Conceptual Understanding

Germany was the first country to introduce Social Security scheme during 1883. Each member of a particular trade (blacksmiths, painters, weavers, cobbler etc) would be required to contribute money at regular intervals and this fund would then be used for food, lodging, hospital and funeral expenses of aged and disabled members (Justino , 2007).

It was only in the late 19th century that systems of socio-economic security were introduced in Europe. These were slowly implemented in most countries, during the early 20th century and consolidated after the Second World War. These programmes were established as a means of improving the well-being of the poor, aimed to reduce inequality within the society and settle different social demands, thus avoiding social and political conflicts, which necessarily arose as capitalist forms of production evolved in industrialised countries (Justino . 2007).

Two of the most influential examples were the United States' 1935 Social Security Act and the Social Security programme implemented in the UK, summarised in the 1942 Beveridge Report. These programmes established the basis for modern forms of social security, defined by the International Labour Organisation (ILO). The framework of human security was pioneered by the United Nations Development Programme in 1994 where they have outlined seven areas of human security i.e. economic security, food security, health security, environment security, personal security, community security and political security. It is estimated that nearly fifteen percent of the global population has a disability (World Health Organisation: 2011). Persons with disabilities account for nearly one-fifth of the global poor, and are often among the poorest of the poor (Elwan: 1999).

The Report of the Expert Group Meeting (WHO 2009) on 'Mainstreaming Disability in MDG Policies, Processes and Mechanisms: Development for All' recognises that there have been limited efforts at mainstreaming disability within the Millennium Development Goals, which are commonly recognised as the unifying objectives of the development community, globally. However, the limited progress has only emerged with the efforts of organisations of persons with disabilities.

Historically, people with disabilities have largely been provided for through solutions that segregate them, such as residential institutions and special schools (Parmenter, 2008). Responses to disability have changed since the 1970s, prompted largely by the self-organisation of people with disabilities (Campbell & Oliver, 1996), and by the growing tendency to see disability as a human rights issue (Quinn, 2002).

Policies have now shifted towards community and educational inclusion, and solutions are today medically-focused, paving a way to more interactive approaches, that recognise people are disabled by environmental factors as well as, by their bodies. National and international initiatives – such as the United Nations Standard Rules on the Equalization of Opportunities of Persons with Disabilities (United Nations, 2003) have incorporated the human rights of people with disabilities, culminating in 2006 with the adoption of the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

The transition from the medical perspective of an individual to a structural, social perspective has been described as the shift from a “medical model” to a “social model” in which people are viewed as being disabled by society, rather than by their bodies (Oliver, 1990). The Ministerial Declaration of July 2010 recognises disability as a cross-cutting issue, essential for the attainment of the MDGs, emphasising the need to ensure that women and girls with disabilities are not subject to multiple or aggravated forms of discrimination, or excluded from participation in the implementation of the MDGs (UN, 2010).

The United Nations General Assembly has highlighted the invisibility of persons with disabilities in official statistics. The General Assembly concluded its High Level Meeting on the MDGs in September 2010 by adopting the resolution “Keeping the promise: united to achieve the Millennium Development Goals,” which recognises that “policies and actions must also focus on persons with disabilities, so that they benefit from progress towards achieving the MDGs”.

b. Attitude and Infrastructure for Persons with Disabilities

A person’s environment has a huge impact on the experience and extent of disability. Inaccessible environments create disability that hinder participation and inclusion. Environmental factors include a wider set of issues than just physical and information access. Policies and service delivery systems, including the rules underlying service provision, can also be obstacles (Miller et al., 2004)

Knowledge and attitudes are important environmental factors, affecting all areas of service provision and social life. Raising awareness and challenging negative attitudes are often the first steps towards creating more accessible environments for persons with disabilities. Negative imagery and language, stereotypes, and stigma – with deep historic roots – persist for people with disabilities around the world (Yazbeck et al., 2004). Negative attitudes and behaviours have an adverse effect on children and adults with disabilities, leading to negative consequences such as low self-esteem and reduced participation. People who feel harassed because of their disability sometimes avoid going

to places, changing their routines, or even moving from their homes (Disability Rights Commission, 2004).

Lack of access can exclude people with disabilities, or make them dependent on others (Meyers, et al., 2002). Transportation provides independent access to employment, education, and health care facilities, and to social and recreational activities. Without accessible transportation, people with disabilities are more likely to be excluded from services and social contact (Roberts & Babinard 2005). A survey conducted in the United States of America showed that lack of transportation was the second most frequent reason why a person with disability was discouraged from seeking work (Loprest&Maag 2001). The lack of public transportation is itself a major barrier to access, even in some highly developed countries (Gonzales, 2006).

A United Nations survey of 114 countries, in the year 2005, found that many had policies on accessibility, but none had made much progress. Of those countries, 54% reported no accessibility standards for outdoor environments and streets, 43% had none for public buildings, and 44% had none for schools, health facilities, and other public service buildings. Moreover, 65% had not started any educational programmes, and 58% had not allocated any financial resources to accessibility. Although 44% of the countries had a government body responsible for monitoring accessibility for people with disabilities, the number of countries with ombudsmen, arbitration councils, or committees of independent experts was very low (UN Special Rapporteur on Disabilities, 2006).

Reports from countries with laws on accessibility, even those dating from 20 to 40 years ago, confirm a low level of compliance (Disability right monitor 2005, 2007). There is an urgent need to identify the most effective ways of enforcing laws and regulations on accessibility – and to disseminate this information globally. Relief workers, for instance, have reported accessibility standards to be inappropriate, for the problems in refugee camps and reconstruction projects that follow natural disasters (Whybrow, 2009). In general, children with disabilities are less likely to join school and the ones who do, either do not stay or get promoted. (Filmer, 2008).

The importance of schooling cannot be underestimated. Attending a formal school, in many cultures, is part of becoming a well-rounded person. It alleviates the status of people with disabilities in society and affirms their rights, and transforms their social relations (Nott, 1998), however this form of status and dignity is a far cry when infrastructure acts as a barrier. In 1994, the World Conference on Special Needs Education in Salamanca, Spain produced a statement and framework for action The Salamanca Declaration encouraged governments to design education systems that respond to diverse needs so that all students can have access to regular schools that accommodate them in child-centered pedagogy.

The number of children with disabilities who receive education in either mainstream or segregated settings, is widely different around the world and no country has a fully inclusive system. Educational needs must be assessed from the perspective of what is best for each individual (Farrell et al., 2007) and the availability of financial and human resources must be examined, within the country's context. Good health is a prerequisite for participation in a wide range of activities, including education and employment. Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) reinforces the right of persons with disabilities to attain the highest standard of health care, without discrimination (UNCRPD 2006).

Disability is associated with a diverse range of primary health conditions: some may result in poor health and high health care needs; others do not keep people with disabilities from achieving good health. Access to primary health care is particularly important for those who experience a thinner or narrower margin of health to achieve their highest attainable standard of health and functioning (Drum.,et al ,2005). A primary health condition is the possible starting point for impairment, an activity limitation, or participation restriction: a primary health condition can lead to a wide range of impairments, including immobility and sensory, mental, and communication impairments (Jette& Field, 2007). A secondary condition is an additional condition that presupposes the existence of a primary condition. It is distinguished from other health conditions by the lapse in time from the acquisition of the primary condition to the occurrence of the secondary condition (Jette& Field, 2005).

Evidence show that health promotion interventions such as physical activities are beneficial for people with disabilities (Mead, 2009). But health promotion activities seldom target people with disabilities, and many experience multiple barriers from participation. For example, limited access to health promotion has been documented for people with multiple sclerosis (Becker & Stuijbergen, 2004), stroke, poliomyelitis (Wang et al., 2008), intellectual impairment, and mental health problems (Disability Rights Commission, 2006). People with disabilities may be reluctant to seek health care because of stigmatisation and discrimination (Maulik & Darmstadt, 2007).

A study on people with epilepsy in rural Ghana, for example, found that spiritual beliefs surrounding epilepsy influenced health and seeking of treatment (Coleman et al., 2002). People with intellectual impairment in minority ethnic communities have also been found to be less likely to use health care services (Hammond et al., 2006). People with disabilities encounter a range of barriers when they attempt to access health care services (Drainon, 2006). Physical, social, and attitudinal environment can either disable people with impairments or foster their participation and inclusion. The CRPD – the most recent and extensive recognition of the human rights of persons with disabilities – outlines the civil, cultural, political, social, and economic rights of persons with disabilities. Its purpose is to “promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by people with disabilities and to promote respect for their inherent dignity”.

The CRPD applies human rights to disability, thus making general human rights specific to persons with disabilities (Megret, 2008), and clarifying existing international law regarding disability. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) stipulates the importance of interventions to improve access to different domains of the environment, including buildings and roads, transportation, information, and communication. These domains are interconnected – people with disabilities will not be able to benefit fully from improvements in one domain, if the others remain inaccessible.

The basic features of access in new construction should include: provision of curb cuts (ramps), safe crossings across the street, accessible entries, an accessible path of travel to all spaces, access to public amenities, such as toilets. Universal design guidelines do deal with matters such as better support for finding the way and for reducing stress which can be considered in accessibility standards (Castell, 2008). Appropriate standards are needed for rural construction in developing countries. A study on accessibility in rural villages in Gujarat, India, found that current practices in affluent urban areas in India were not appropriate in these villages (Raheja, 2008). Laws with mandatory access standards are the most effective way to achieve accessibility.

c. Social Security for Persons with Disabilities in India and Sikkim

Despite differing estimates, empirical evidence as of 2007 suggests that between 4 to 8 percent of the population in India is comprised of people with disabilities (World Bank 2007). This translates into 40-90 million people, a substantial number. People with disabilities in India are subject to multiple deprivations and limited opportunities in several dimensions of their lives.

Disability statistics were collected in the Census of India from as early as the late nineteenth century and the country had special schools that catered to the needs of people with disabilities from around the same time period. However, integration of people with disabilities and policy commitment to their participation as equals in society occurred only twenty-five years ago with the passage of four important laws. These included the Mental Health Act of 1987, the Rehabilitation Council of India Act of 1992, the People with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act of 1995 (PWD Act), and the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act of 1999 (World Bank 2007).

Poverty is one of the biggest causes and consequences of disability in India. People with disabilities in India are among the poorest, often are disabled at birth or before school age, are mostly uneducated and widely unemployed (Thomas, 2005). A reason for the inter-linkage between disability and poverty is that people with disabilities

have significantly lower employment rates on an average even though the large majority of this population is capable of working (Mitra & Sambamoorthi, 2008).

The number of people with disabilities in India is substantial and likely to grow. Disability does not go away as countries get richer. People with disabilities in India are subject to deprivation in many dimensions of their lives - deprivation, social attitudes and stigma play an important role in limiting the opportunities of disabled people for full participation in social and economic life, often even within their own families (Philip, 2007). Infrastructure barrier, transport and communication contributes widely towards the exclusion of Persons with Disabilities.

The National Policy recognises that Persons with Disabilities are valuable human resource for the country and seeks to create an environment that provides them equal opportunities, protection of their rights and full participation in the society. National Handicapped and Finance Development Corporation (NHFDC) has been providing loans on concessional terms for undertaking self-employment ventures by the persons with disabilities through State Channelizing Agencies (Ministry of Social Justice and Empowerment, 2006).

Barrier-free environment enables people with disabilities to move about safely and freely, and use the facilities within the built environment. The goal of barrier free design is to provide an environment that supports the independent functioning of individuals so that they can participate without assistance, in everyday activities. Therefore, to the maximum extent possible, buildings/ places/transportation systems for public use will be made barrier free. (Ministry of Social Justice and Empowerment, 2006)

National Policy for Persons with Disabilities 2006 speaks about social security for disabled persons, their families and caregivers incur substantial additional expenditure for facilitating activities of daily living, medical care, transportation, assistive devices, etc. Therefore, there is a need to provide them social security by various means. Central Government has been providing tax relief to persons with disabilities and their guardians. The State Governments/ U.T. Administrations have been providing unemployment allowance or disability pension.

Currently available schemes or programmes do not comprehensively address the problems of the disabled persons. The major Social Security Acts available in India aim only at employment-related disability. In fact a large number of disabled persons are outside employment or in informal economic activities or simply dependent on their parents, children and/or spouses. In some of the Rural Development and other programmes, there are some disabled beneficiaries. However, keeping in view the statutory provision of 3% reservation for persons with disabilities, all poverty alleviation schemes, the coverage is negligible. This provision needs to be effectively implemented (Rao, 2015)

Among countries with comparable levels of income, India has one of the more progressive disability policy frameworks. However, people with disabilities in India are still subject to multiple disadvantages (Menon, 2013). Sikkim being one of the smallest states in India with a total population of 6, 07,688 (census, 2011) accounts for having a disabled population of 18,187 with no detailed data with the state government.

Sikkim in itself does not have any provision for disabled population, except for a mere disabled pension of Rs 150/- per month. Though it has all the government of India policies in place, its extent of functionality is yet to be researched. There have not been any investigations carried out and there are no finding in this matter yet. All the Government of India Acts and other related schemes designed to provide security and benefits for persons with disability in India, function in Sikkim through some Government Departments and Non Government Originations. However, there remain huge challenges in operationalising the policy, due to lack of awareness, trained manpower and many other factors.

1.3 RATIONALE AND SCOPE OF STUDY

Many factors lead to the exclusion of disabled person from their basic rights: education, primary health care and employment opportunities, to name a few. This leads to a direct question on the status of their social security. To be eligible for the benefits, one has to become disabled after getting into employment. The current Social Security programmes are employment-related and do not appear to be tailored around the disabled

persons. Economic, psychological and social confidence-building is therefore immediately necessary. Social Security programmes for the disabled, to some extent free disabled persons from the clutches of dependency. Comprehensive administrative arrangement, pooling up funds from various sources and delivering the benefits under professional supervision and control are the other immediate requirements. Lack of information and awareness make persons with disabilities often unaware of what benefits and schemes are available. Besides, ensuring that the existing benefits reach them, more resources from Local, State, National and International Agencies, Government and Non-Government Organizations need to be mobilised.

Apart from the background, the study tries to make a connection between the security issues in regards to disabilities, and its relevance in the contemporary society. The study analyses various security perspectives to examine their effectiveness. The drawbacks of the States and the government in their policies and their flawed implementation, when it comes to social security of the persons with disabilities are examined. Lot of policies and Acts have been passed for more than two decades, especially from the mid-1990s: these efforts have taken a more fervent turn. With revised schemes and policies, The Government of India has enacted legislations to bring disabled persons into the mainstream and in the process build communities and societies that are inclusive and void of environmental barriers (infrastructural & attitudinal) However, while the states have been directed to enforce these policies for the sake of an inclusive society, the reality at the receiving end is still grim.

In practice, only a few places like the Airport, a few buildings and the university, in urban areas are made barrier-free. Its usability is however to the minimum, mostly because there is a higher number of disabled persons in the rural areas, who need benefits at their doorstep. This highlights that policies though enacted are weak - almost null - at the level of implementation. The reasons are unknown. Hence it is this gap in literature that this study proposes to address, for the sake of perhaps a small, yet significant contribution to the society and for the purpose of bringing awareness of the challenges faced by people living with disabilities.

1.4 OBJECTIVE OF THE STUDY

- To understand social security of persons with disability from a theoretical perspective.
- To examine the policies, programmes and schemes for the disabled in India and the barriers or constraints that is preventing its implementation.
- To understand how health, education, employment of persons with disabilities have been addressed in the national social security discourse.
- To understand the role of social security scheme in the lives of disabled persons.
- To analyse the role of Government, NGOs and civil society in facilitating lives of persons with disability.

1.5 RESEARCH QUESTIONS

- What are the schemes, funds, programmes available in India that provides social security for persons with disabilities?
- What are the problems faced by disabled persons in the society?
- How will social security bring transformation in the lives of disabled persons?

1.6 HYPOTHESES

- Social security can play a great role in providing security and dignity to disabled persons.
- Lack of awareness and ignorance regarding the rights of Persons with Disabilities complicate the social security of the disabled.
- Programmes and schemes designed for Persons with Disabilities have not yet been implemented properly in India.

1.7 RESEARCH METHODOLOGY

In 2011 Census, the total population of disabled persons in Sikkim was 18187 scattered in the four district of the state, out of which 100 has been taken as the universe and 25 each, has been bifurcated to each district. The study is based on field work where both qualitative as well as quantitative methods are employed to collect both primary and secondary data. The primary data collection is through questionnaire and interviews while the sample size is 100, from the age group 18 and above.

Disability are of many categories and fall into different degrees: this research however is only on the category of disability, interviewed and mentioned in Persons with Disability (equal opportunity, protection of right and full participation) Act, 1995, and National Trust Act, 1999 namely (i)Blindness (ii)Low vision (iii)Leprosy-cured (iv)Hearing impairment (v)Loco motor disability (vi)Mental retardation (vii)Mental illness (viii)Cerebral palsy (ix)Autism (x)Multiple disability. In some categories of disability, take for example, a mental retardation where the Respondents is not able to interpret due to his/her disabling condition, the guardian has been interviewed instead.

1.8 ORGANISATION OF THE STUDY

Chapter one provides with the introduction section of the dissertation, it gives the overview of social security and the theoretical framework, the research questions, the objectives, hypotheses, scope of the study and the methodology to be adopted. This in an introductory part of the research. Chapter two elaborates and discuss the origin of social security, concept and definition by different organizations. It basically deals with the theoretical perspective. Chapter three discusses factors which decisively affect social security for persons with disabilities in India. It focuses on determinants that's calls for social security and also examines and sees the area which has already been covered in the present legislations and those that needs to be covered so that it brings transformation in the lives of disabled persons. Chapter four deals with field survey, data collected from the field and are recorded; the collected data has been analyzed and interpreted using various forms of figures and tables. Chapter five summarises the previous chapters in brief.

Suggestions and recommendations have been made and the scope of further studies and research in the field has been narrated.

1.9 LIMITATION OF THE STUDY

This study provides an in-depth insight in the lives of people living with disability in Sikkim. During the research, especially during the field visits, many problems were faced such as not everyone was willing to participate in the interviews, some hesitated to face outsider for interview due to their physical appearance, while some Respondents took longer time to express their views due to their disability. Research material like literature, books and reports especially about PWDs of Sikkim is not available and few that are available are not reliable. Therefore, various studies in this field are of utmost importance.

CHAPTER- 2

UNDERSTANDING SOCIAL SECURITY AND ITS EVOLUTION

2.1 CONCEPTUALIZING SOCIAL SECURITY

Security studies is understood as an area inquiry-focused around a set of basic but fundamental questions whose answers continually change over a period of time. As any study of the world's etymology will show, security has meant different things to people depending on their time and place in Human history (Rothchild, 1995). Traditionally the state has been the thing to be secured and it has sought security through military might. With the cold war over security, studies has reemerged and core assumptions about what is to be secured, and how, have come to occupy our thoughts.

War and peace, threat and strategy, as well as welfare and epidemics: issues like these have been on the agenda of thinkers and writers for centuries. However, anything resembling security studies, as we know it did not become a distinct field of study until around the end of the Second World War. As always, when a field is established, it is easy to see predecessors and preparatory work done in previous phases, and thus security studies can be projected back into the interwar period, with reference to work done on the causes and prevention of wars (Baldwin, 1995). There are philosophies to security, two such philosophy of security can be identified as follows:-

The first philosophy sees security as being virtually synonymous with the accumulation of power. From this perspective, security is understood as a commodity i.e. to be secure, actor must possess certain things such as property, money, weapon, armies and so on. In particular, power is thought to be the route to security, the more military power one accumulates, the more secure he will be.

The second philosophy challenges the idea that security flows from power. Instead, it sees security as being based on emancipation i.e. a concern with justice and the provision of human rights. From this perspective, security is understood as a relationship between different actors rather than a commodity. This view argues that it is not

commodities in particular, like nuclear weapons that are crucial factor in understanding security-insecurity equation, but rather the relationship between the actors concerned.

The second philosophy emphasises that true or stable security does not come from the ability to exercise power over others. Rather, it comes from cooperating to achieve security without depriving others of it. Such approach was evident in Olfa Palme's call for 'common security'. Palme argues that international security must rest on a commitment to joint survival rather than on the threat of mutual destruction (Palme, 1982). In practical terms, it means promoting emancipator politics that take serious issues about justice and human right.

The later philosophy could be seen taking shape towards the end of cold war as traditional understanding of security diminished and the decreasing threat of nuclear weapons let other non-military conceptions of security emerge. The same was supported by Jessica Tuchman Methew (1989) when she suggested that international security be rethought to include resource, environment and demographic issues. Booth 1991 and Ullman 1983 agree with this and they were also known as 'widener' - those wishing to broaden the concept of security out of its military-centric confines. One such widener was Barry Buzan .

However a key development within the academic mainstream of security studies occurred in 1983 with the publication of Barry Buzan's book 'People, State and Fear' (Ullman, 1983). This book fundamentally undermines at least two of the four Ss (states, strategy, science and status quo) of traditional security studies. Buzan argued persuasively that security was not just about state but related to all human collectivities, nor could it be confined as an 'inherently inadequate' focus on military force. Instead, Buzan developed a framework in which he argued that the security of human collectivities was affected by factors in five major sectors, each of which had its own focal point and way of ordering priorities. The five sectors highlighted by Buzan are Military, Political, Economic, Societal and Environmental.

Security in the contemporary world has a major role in varied fields as mentioned by many researchers, may it be international relation, environmental security, health

security, economic security, societal security, military security, areas are growing by the passing year .The spectrum of security studies is broadening and with it, national and international agencies are working together in framing policies and programmes to provide security for all human being so that they live in the world without fear. One such area in security studies is social security which is considered important in today's contemporary world.

Social Security plays a critical role in realising the human right to social security for all, reducing poverty and inequality, and supporting inclusive growth.

2.2 ORIGIN OF SOCIAL SECURITY

The concept of social security is as old as the history of human being. Stories from ancient scripts like The Bible tells us how, during the years of famine, Joseph tried to tide over the situation by making use of surplus stocks of food produced, which he had stocked during the earlier years when it was in plenty. The oldest and largest institution of social security is family – this includes the extended family. Industrial revolution in Europe had seen an increased growth of urban and industrial centres that affected the rural joint families, thereby disturbing the institution of social security in the joint family system. Modernisation and urbanisation have resulted in radical socio-economic changes that gave rise to new conflicts and tensions, consequent upon the erosion of age-old family and fraternal security (Rao, 2004). The transition from agricultural economy to an industrial economy accompanied problems that called for social security. When an individual was unable to take care of his own needs, the society realised the importance of protecting the individual and his family.

Germany was the first country to introduce Social security scheme in 1883, each member of a particular trade (blacksmiths, painters, weavers, cobbler etc) was required to contribute at regular intervals, money to this fund which was used for food, lodging, hospital and funeral expenses of the aged and disabled members.

It was only in the late 19th century that the systems of socio-economic security were introduced in Europe. These were slowly implemented in most countries during the early 20th century and consolidated after the Second World War (Justino, 2006). These

programmes were established as a means of improving the well-being of the poor, reduce inequality within society and settle different social demands, thus avoiding social and political conflicts, which necessarily arose as capitalist forms of production evolved in the industrialised countries. Two of the most influential examples were the United States' 1935 Social Security Act and the Social Security programme implemented in the UK, summarised in the 1942 Beveridge Report (Justino, 2006). These programmes established the basis for modern forms of social security, defined by the International Labour Organisation (ILO) as "the protection which society provides for its members through a series of public measures against the economic and social distress that otherwise would be caused by the stoppage or substantial reduction of earnings resulting from sickness, maternity, employment injury, invalidity and death; the provision of medical care; and the provision of subsidies for families with children" (ILO, 1984).

Social security ensures that all people have security of knowing that in the event of loss of their job or prolonged illness, and also when they grow old, their needs are secured. Our modern society can afford to provide universal social protection everywhere.

2.3 SOCIAL SECURITY IN THE CONTEMPORARY WORLD

As per International Labour Organisation "Social security is the protection that a society provides to individuals and households to ensure access to health care and to guarantee income security, particularly in cases of old age, unemployment, sickness, invalidity, work injury, maternity or loss of a breadwinner".

Social security was established as a basic human right in the ILO's Declaration of Philadelphia (1944) and its Income Security Recommendation, 1944 (No. 67). This right is upheld in the Universal Declaration of Human Rights, 1948, and the International Covenant on Economic, Social and Cultural Rights, 1966.

Social security measures are essential elements of a policy response that can address challenges that society faces. They not only support the realisation of the universal human right to social security, but are both a social and an economic necessity. Well-designed social security systems support incomes and domestic consumption, build

human capital and increase productivity. The bold efforts in extending social protection in many developing countries, from Brazil to China, from Ecuador to Mozambique, have underlined its key role in reducing poverty and vulnerability, redressing inequality and boosting inclusive growth (World Social Protection Report,2015). Social security policies also accelerate progress towards the Millennium Development Goals (UN, 2010a; UNICEF, 2010). Sustainable and equitable growth cannot be achieved in the absence of strong social protection policies which guarantee at least a basic level of social protection to all in need and progressively extend the scope and level of social security coverage.

While the need for social protection is widely recognised, the fundamental human right to social security remains unfulfilled for the large majority of the world's population (ILO, 2010a). Despite the impressive extension of social protection coverage over the past century, especially over the past decade, only a minority of the world's population is effectively protected. According to ILO estimates, in 2012 only 27 percent of the working-age population and their families across the globe had access to comprehensive social security systems. In other words, almost three-quarters, or 73 per cent, of the world's population, about 5.2 billion people, do not enjoy access to comprehensive social protection. Many of those not sufficiently protected live in poverty, which is the case for half the population of middle- and low income countries (World Bank, 2014). Many of them, about 800 million people, are working poor (ILO, 2014a), and many work in an informal economy. In view of this, many countries, have brought out a number of programmes in recent years that provide some degree of protection but lack a legal foundation. These cannot be considered as offering the same quantity and extent of protection as programmes provided by law, as they do not establish legal entitlements or enforceable rights. Still, they play an important role in improving the situation of those benefiting from them.

In view of such issues, International Labour Organisation came up with the adoption of the ILO's Social Protection Floors Recommendation, 2012 (Recommendation No. 202 is the first international instrument to offer guidance to countries to close social security gaps and progressively achieve universal protection through the establishment and maintenance of comprehensive social security systems) .

Thereafter the world has taken a significant step forward in realisation of the human right to social security. This Recommendation is the first international legal instrument that explicitly recognises the triple role of social security as a universal human right and an economic and social necessity. It recognises the importance of national social protection floors, which provide basic social security, guarantees to all with the aim of ensuring effective access to at least essential health care and a basic level of income security as a matter of priority, as the indispensable foundation for more comprehensive national social security systems (ILO, 2012a).

2.3.1 COMPONENT OF SOCIAL SECURITY

A society that provides security for its citizens protects them not only from war and disease, but also from the insecurities related to making a living through work. Social security systems provide for basic income in cases of unemployment, illness and injury, old age and retirement, disabled, family responsibilities such as pregnancy and childcare, and loss of the family's breadwinner. Such benefits are important not only for individual workers and their families but also for their community as a whole. By providing health care, income security and social services, social security enhances productivity and contributes to the dignity and full realisation of the individual. Social security systems also promote gender equality through the adoption of measures to ensure that women who have children enjoy equal opportunities in the labour market. For employers and enterprises, social security helps maintain a stable workforce adaptable to change. Finally, by providing a safety net in case of economic crisis, social security serves as a fundamental element of social cohesion, thereby helping to ensure social peace and a positive engagement with globalization and economic development.

While designing social security policy of any Nation, many things need to be identified for example areas, vulnerability, needs, which mostly is country specific. The area that needs to be secured in low Income Countries may not be of concern in High Income countries, likewise it differs with middle income countries. But few of the areas are of concern to all the countries of the world - under developed, developing or developed countries. The areas that need to be secure in almost all the countries are identified by ILO and have laid down the minimum standard for the level of social

security benefits and the conditions under which they are granted. It covers the nine principal segments of social security, namely medical care, sickness, unemployment, old age, employment injury, family, maternity, invalidity and survivors' benefits.

To ensure that it could be applied in all states circumstances, the convention offers member states the possibility of ratification by accepting at least three of its nine segments and of subsequently accepting obligations under other segments, thereby allowing them to progressively attain all the objectives set out in the convention. The level of minimum benefits can be determined with reference to the level of wages in the country concerned. Temporary exceptions may also be envisaged for countries whose economy and medical facilities are insufficiently developed, thereby enabling them to restrict the scope of the convention and the coverage of the benefits granted.

Table: 2.1 The 9 Principal Components At A Glance.

Sl No	Component	Description
1.	Sickness Benefits	Sickness programmes cover short-term illnesses that result in incapacity to work (usually up to one year, afterwards the case is considered under disability programs). Cash benefits are paid out to compensate, for the loss of earnings (part or all).
2.	Maternity Protection	Maternity programmes are designed to maintain earnings for working mothers before and after giving birth. Maternity programmes can be related to sickness or family allowances.
3.	Old Age Pension	Old-age benefits represent usually the largest share of social security expenditures. It is probably also the area with the most varied provisions. It is designed to provide resources to former workers who stop their activities or to any person reaching retirement age.
4.	Disability Benefits	Disability programmes provide resources to persons who have disability.
5.	Survivors' Benefits	Survivors' programmes are usually part of the old-age pension programmes. Survivors' benefits are paid when a member of the family dies, as rights to the survivors. The branches old-age, disability and survivors' usually provide annuities, except when the programme is a provident fund, in which case a lump sum is paid (sometimes there is a possibility to convert the lump sum into an annuity).

6.	Work Injuries	This branch provides compensation for work-connected injuries and occupational illnesses. It is probably the most widely covered social security risk in the world.
7.	Unemployment Protection	Unemployment benefits are usually paid only to involuntarily unemployed workers, who are capable and available for work. Unemployment programmes are usually provided to compensate after a lay off. But some unemployment programmes may not be related to a previous activity such as unemployment assistance programmes
8.	Family and Children Allowances	Family allowances can include very different provisions, from school grants, birth grants, maternal and child health services, supplements for adult dependents.
9.	Health Protection	Health insurance, Investing in health protection, including paid sick leave, yields returns.

Source: [https://www.ILO Compilation, World Social Protection Report 2015/](https://www.ILO.org/Compilations/WorldSocialProtectionReport2015) Accessed 9/9/2016

To achieve fully, the mission goals of ILO’s contributing to peace, prosperity and progress by advancing the creation of decent work opportunities and providing social security to all women and men.

One among the nine principle branches of ILO’s social security is Disability, which is also considered to be one of the most neglected groups, among the rest. These study focuses on the specific group i.e. Disabled population, therefore, it is important to effectively and systematically see the stand of international organisations on social security issues of women and men with disabilities. There are over one billion people with disabilities in the world, out of which between 110-190 million experience very significant difficulties (World Report on Disability, 2011). The prevalence of disability is growing due to an ageing population and the global increase in chronic health conditions. Patterns of disability in a particular country are influenced by trends in health conditions and trends in environmental and other factors – such as road traffic accidents, natural disasters, conflict, death, mental conditions, substance abuse etc, therefore there is a great need of social security for this group of population.

The ILO has a longstanding commitment to promote social justice for people with disabilities, dating back to the 1920s. Highlights in the ILO covenant promotes equal

opportunities for persons with disabilities in the work place, through all its means of action like the Vocational Rehabilitation and Employment (Disabled Persons) Convention, 1983 (No. 159) and the Code of Practice on Managing Disability in the Workplace of 2001.

With the major international policy shift to a human rights-based approach to disability, there is a far greater emphasis on promoting disability inclusion and tackling discrimination, faced by people with disabilities. This shift was marked by the adoption of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) in 2006, which, among other provision, promotes fundamental principles and rights at work and social protection.

The emphasis has shifted to non-discrimination as a cross-cutting theme in the ILO's Declaration on Social Justice. Fair Globalisation of 2008 reinforces this new perspective on disability. These developments lead to a greater focus than in the past, on people with disabilities, accessing the general labour market and employment-related programmes and services. This is also reflected in the increasing demand for the ILO's expertise on disabled inclusion in a wide range of areas, including skills development.

On December 13, 2006, the United Nations formally agreed on the Convention on the Rights of Persons with Disabilities(CRPD).This is the first human rights treaty of the 21st century, to protect and enhance the rights and opportunities of the world's estimated 650 million disabled people (French, Phillip, 2008). One hundred forty seven countries participated and agreed on the convention (CRPD) ratification in their countries. As of April 2011, 99 of the 147 signatories ratified the Convention. Countries that sign the convention are required to adopt national laws and remove old ones, so that persons with disabilities will, for example, have equal rights to education, employment, and cultural life; the right to own and inherit property; not to be discriminated against in marriage, etc.; and not to be subjected to medical experiments.

UN officials, including the High Commissioner for Human Rights, have characterised the bill as representing a paradigm shift in attitudes toward a more right-

based view of disability in line with the social model (Kayess, Rosemary; French, Phillip 2008).

2.4 DEFINITION OF DISABILITY

Different terms have been used for people with disabilities in different times and places.

Article 1 of UN convention on Right of Persons with Disabilities says:-

“People with disability are 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”.

In 1980, the World Health Organisation (WHO) introduced a framework for working with disability, publishing the "International Classification of Impairments, Disabilities and Handicaps". The framework they proposed approached disability using the terms Impairment, Handicap and Disability. (WHO, International Classification of Impairment, Disabilities and Handicaps, 1980).

- Impairment = a loss or abnormality of physical bodily structure or function, of logic-psycho origin, or physiological or anatomical origin
- Disability = any limitation or function loss deriving from impairment that prevents the performance of an activity in the time-lapse considered normal for a human being
- Handicap = the disadvantaged condition deriving from impairment or disability limiting a person performing a role considered normal in respect of their age, sex and social and cultural factors

The International Classification of Functioning, Disability and Health (ICF), published in 2001 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's 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. (World Health Organization, 2012).

Disability is the consequence of an Impairment that may be physical, cognitive, intellectual, mental, sensory, developmental, or a combination of these that result in restrictions on an individual's ability to participate in what is considered "normal" in the day-to-day society. A disability may be present from birth or occur during a person's lifetime. Disability is a contested concept, with different meanings for different communities. (Linton, Simi 1998).

Medical model of Disability refer to physical or mental attributes that some institutions, particularly medicine, view as needing to be fixed. As per the Social model, it may refer to limitations on participation in social life imposed by the abled person, or the term may serve to name a social identity claimed by people with disabilities in order to mark their shared goals and politics. (Shakespeare, Tom, 2006).

The contest over disability's definition arose out of disability activism in the U.S. and U.K. in the 1970s, which challenged how medical conceptions of human variation dominated popular discourse about disabilities and how these were reflected in common terminology (e.g., "handicapped," "cripple"). Debates on a proper terminology as well as over appropriate models and their implied politics continue in disability communities and the academic field of disability studies. In many countries the law requires that disabilities be clearly categorised and defined in order to assess which citizens qualify for disability benefits. (Davis, Lennard, 1995).

The prevalence of disability is growing due to an ageing population and the global increase in chronic health conditions. People with disabilities face widespread barriers in accessing services like health care, education, employment, transport as well as information - these include inadequate policies and standards, negative attitudes, lack of service provision, inadequate funding, lack of accessibility, inadequate information and communication and lack of participation in decisions that directly affect their lives. People with disability have worse health and socioeconomic outcomes. Across the world,

people with disability have poorer health, lower education achievements, less economic participation and higher rates of poverty than people without disabilities.

As per world report on disability: More than 1 billion persons in the world have some forms of disability. This corresponds to about 15% of the world's population. Around 110-190 million people have very significant difficulties in functioning.

People with disabilities often do not receive the needed health care. Half of the disabled population cannot afford healthcare, compared to a third of non-disabled people. People with disabilities are more than twice as likely to find healthcare providers' skills inadequate; nearly three times more likely to be denied healthcare; and four times more likely to report being treated badly than non-disabled people.

Children with disabilities are less likely to attend school than non-disabled children. Education completion gaps are found across all age groups and in all settings, with the pattern more pronounced in poorer countries. Even in countries where most non-disabled children go to school, many children with disabilities do not go to school.

People with disabilities experience increased dependency and restricted participation in their societies. Even in high-income countries, many of the barriers that people with disability face are avoidable and the disadvantage associated with disability can be overcome. 20-40% of people with disabilities lack the help they require to engage in everyday activities. However, there are majority of the disabled persons who are not employed but require social protection.

2.4.1 DISABILITY AND SOCIAL SECURITY

Society and communities in every country is still infected by the ancient beliefs and assumption that people with disabilities are less than full humans and therefore, are not fully eligible for the opportunities which are available to other people as a matter of right. Throughout history, people with disabilities have been treated differently from those who conform to or fit societal norms.

The following list outlines some of the unfair treatments that were practiced by different societies in given time periods.

- Killed or abandoned in the woods in ancient Greece.
- Kept as jesters (clown) for nobility in the Roman Empire courts.
- Experienced acts of infanticide during the Renaissance.
- Drowned and burned during the Spanish Inquisition.
- Dehumanization in orphanages and asylums in nineteenth-century Europe.
- Primary care given by the family at home in the early history of the United States instead of children being allowed out in public, e.g., homeschooled and excluded from community activities.
- “Institution for Idiots” founded in Massachusetts in 1848.
- Shackled to their beds in U.S. institutions because there was an insufficient number of staff members to care for residents.
- Involuntary sterilization of people with developmental disabilities in the United States, beginning in 1907, to prevent the passing on of inferior traits.
- Considered by eugenicists as defective and an interference with the process of “natural selection”.
- Gassed, drugged, blood let, and euthanized in Nazi Germany.
- Institutionalized regardless of needs, e.g., person with cerebral palsy was considered mentally retarded
- Housed in separate institutions throughout the world
- Not allowed to attend neighborhood schools
- Aversion techniques used
- Seclusion policies applied
- Restraint applied

- Abuse prevalent (physical, mental, sexual, and financial)
- Victimized with inhumane treatments
- Lives devalued
- Stigmatized as criminals
- Viewed as sickly
- Inaccurately tested
- Inappropriately labeled and incorrect services rendered

History shows how pathetically disability was perceived and treated and how the attitude towards the disabled has secluded them from getting to the right place in society and highlights the importance of social security for them.

Evidence shows how persons with disability were perceived and treated in the past and how the attitude towards disabled have being changing over time, rules and rights of people with disability have been enacted. In the olden days there was the Joint Family system which took care of the social security needs of disabled member. However with rise of migration, urbanization, and the advent of nuclear families and demographic changes, Joint family system declined, as a result, the desired care of the disabled member got neglected. Hence, this called for the need of a formal system of social security.

Amartya Sen (1999) propounded the idea of —“protection” as a means of social security. Protection means protection against a fall in living standards and living conditions through ill health, accidents etc. Jean Dreze (1999) another distinguished economist focused on “promotion” as a means of social security. Promotion includes enhanced living conditions, helping everyone overcome persistent capabilities deprivation etc.

Numerous efforts, both substantive and promotional, were taken nationally and internationally to improve the situation of persons with disabilities aimed at increasing

integration in society and improvements in physical and psychological adjustment of disabled persons within their community. Many Programmes were launched focusing on rehabilitation and prevention of disability by the different stakeholders and society. The most significant role was however played by United Nations. Few of the land mark steps introduced in the concerned area are as follows:-

- **1982** - The General Assembly adopted the World Programme of Action concerning Disabled Persons. Disability policy was now structured in three main areas: prevention, rehabilitation, and equalisation of opportunities.
- **1982** - On 3 December the General Assembly made recommendations on the implementation of the World Programme, incorporating the recommendations of the Advisory Committee for the International Year. In the same resolution it also proclaimed 1983-1992 the United Nations Decade of Disabled Persons.
- **1990s** - Five United Nations world conferences were held during the 1990s which emphasized on the need for a "society for all", advocating the participation of all citizens, including persons with disabilities, in every sphere of society
- **1996** - The Preparatory Committee for the United Nations Conference on Human Settlements, held in Istanbul, Turkey, in June 1996, issued a draft statement of principles and commitments and a global plan of action, which paid particular attention to persons with disabilities who might benefit from affirmative governmental action.

The first Millennium decade - The negotiation and adoption of the Convention on the Rights of Persons with Disabilities

2008: The Convention on the Rights of Persons with Disabilities and its Optional Protocol entered into force on 3 May 2008, one month after the required 20th country ratified the treaty. The first Conference of States Parties to the Convention is held at UNHQ in New York from 31 October to 3 November.

Sufferings of the persons with disabilities are varied and vast, plus its impact on the individual, family and community is severe. The most vulnerable groups among the

persons with disabilities include very young children, women, and the aged with disabilities. Their existence and livelihood requirements have to be taken care of by some agency in the society-that agency could be the state in the absence of compassionate family and communities and more so when the families of the persons with disabilities cannot afford to do so. Disabled persons, their families and caregivers incur substantial additional expenditure for facilitating activities of daily living, medical care, transportation, education, assistive devices, etc. Therefore, there is a need to provide them with social security by various means.

CHAPTER - 3

DETERMINANTS OF SOCIAL SECURITY FOR PERSONS WITH DISABILITY IN INDIA

3.1 GENERAL STATUS OF DISABILITY

The survey of the population having disability conditions in India is done periodically and the data of disabled population showing the nature of disabilities etc is compiled by Government of India every ten years. The data not only shows the nature of disability but also the socio-economic conditions, gender wise segregation, health status etc. The data shows the actual positions of the person's living with disability. As per 2011 census 2.21% of the population suffers from one kind of disability or the other and the figure is on the rise if we look at the decadal growth. It is therefore, imperative to provide social security for this segment of the population - to safeguard them from their disability - which acts as a facilitator to plan their own future.

When we discuss social security of disabled persons, we need to take into consideration all the requisites of their day-to-day lives - educational needs, health care facilities, rehabilitation services, skill development, employment opportunities, emotional and psychological requirements to suit their temperaments and their absorbing capacities – and take them as the main determinants while framing the social security guidelines, programmes for the disabled.

The environment people live around should also be secure. It should be accessible for both able and disabled people so that they don't have to depend on anybody to be mobile and reach where they want: for that we need to identify factors that act as a hindrance and find out the determinants of social security which will define the area that needs priority. Only then can we say that social security is fully achieved. In the following chapter different determinants are discussed.

3.2 BARRIER FREE ENVIRONMENT

Every single person at some point of life has been physically disabled. An elderly person, a child, a person with a broken leg, a parent with a baby buggy, etc. are all

disabled in one way or another. Those who are able-bodied and stay healthy all their lives, are few. As far as a settled environment is concerned, it is important that it should be barrier-free and adapted to fulfill the needs of all people falling into every category equally. As a matter of fact, the needs of the disabled co-occur with the needs of the absolute most, and all people are at ease with them. As such, planning for the majority implies planning for people with varying abilities and disabilities. A person's environment has a huge impact on the experience and extent of disability. Inaccessible environments create disability by creating barriers to participation and inclusion.

Examples of the possible negative impact of the environment include:

- a hearing impaired individual without a sign language translator
- a wheelchair user in a building without an accessible or approachable bathroom or lift
- a visually challenged person using a computer without screen-reading software

"A barrier-free environment is a world that accommodates the daily needs of the people may it be elderly, sick person or the disabled." Environments – physical, social, and attitudinal – can either disable people with impairments or foster their involvement and inclusion. The United Nations Convention on the Rights of Persons with Disabilities (CRPD) stipulates the importance of interventions to improve access to different domains of the environment including buildings and roads, transportation, information, and communication. These fields are interconnected – people with disabilities will not be able to benefit fully from improvements in one area if the others remain inaccessible.

To succeed, accessibility initiatives need to take into account outer constraints including affordability, competing priorities, availability of technology and knowledge, and cultural dissimilar. Even after physical barriers have been removed, negative attitudes can produce barriers in all domains. To overcome the ignorance and preconceptions surrounding disability, education and awareness-raising is required. Such education should be a regular feature of professional training in construction, design, architecture, information science, and marketing. Policy-makers and those working on

behalf of people with disabilities need to be educated about the importance of accessibility.

3.2.1 INFRASTRUCTURAL AND ACCESSIBILITY

When we talk about Infrastructure in public accommodations, it includes buildings publicly owned or functional for the public, such as courts, hospitals, schools and police stations etc or privately owned such as shops, eateries, and sports stadiums as well as public roads. Transportation – vehicles, stations, public transportation systems, infrastructure, and pedestrian environments. Communication – “includes languages, text displays, Braille, tactile communication, large print, and accessible multimedia as well as written, audio, plain-language, human-reader and augmentative and alternative modes, means, and formats of communication, including accessible information and communication technology” (UN, 2006). These formats, modes, and means of communication may be physical, but are increasingly electronic.

Access to public accommodations like roads and buildings is beneficial for participation in civic life and is necessary for health care, education and labour market participation. Lack of access can keep out people with disabilities, or make them dependent on others (Meyers AR et al., 2002). As an example, if public toilets are inaccessible, people with disabilities will find it difficult to participate in everyday life.

Transportation provides independent access to employment, education, and health care facilities, and to social and recreational activities. Without approachable transportation, people with disabilities are more likely to be excluded from services and social contact (Roberts P, Babinard J., 2005). In a study in Europe, transport was an often cited obstacle to the participation of people with disabilities (Leonardi M et al., 2009). The lack of public transportation is itself a leading hindrance to access, even in some highly developed countries (Gonzales L et al., 2006).

Inaccessible information and communication affects the lives of many people with disability (Olusanya BO et al., 2006). Individuals with communication difficulties, such as hearing or speech impairment, are at a significant social disadvantage, in both developing and developed countries. This disadvantage is particularly experienced in

sectors where effective communication is important such as those of health care, justice, education and local government. For instance.

- People who are hard of hearing may need speech-reading, assistive listening devices, and good environmental acoustics in indoor settings.
- People with intellectual impairments need information presented in a clear and simple language.
- People who are blind or have low vision require instruction in Braille, equipment to produce Braille materials, and access to library services that provide Braille, audio and large-print materials, screen readers, and magnification equipment.
- Non-speaking individuals need access to “augmentative and alternative communication” systems and acceptance of these forms of communication where they live, go to school and work. These include communication displays, sign language and speech-generating devices.

A United Nations survey in 2005 of 114 countries found that many had policies on accessibility, but they had not made much progress (UN, 2006). Of those countries, 54% reported no accessibility standards for outdoor environments and streets, 43% had none for public buildings, and 44% had none for schools, health facilities, and other public service buildings. Moreover, 65% had not started any educational programmes, and 58% had not allocated any financial resources to accessibility. Although 44% of the countries had a government body responsible for monitoring accessibility for people with disabilities, the number of countries with ombudsmen, arbitration councils, or committees of independent experts was very low. The gap between creating an institutional and policy framework and enforcing it has been ascribing to various components, including:

- lack of planning and design capacity
- lack of user involvement
- lack of enforcement mechanisms
- lack of a disability-awareness component in the training curriculum of planners, architects and construction engineers
- lack of financial resources

- limited research and information
- lack of cooperation between institutions
- geographic and climatic constraints

Reports from countries with laws on accessibility, even those dating from 20 to 40 years ago, confirm a low level of conformity. There are reports from countries as diverse as Australia, Brazil, Denmark, India, and the United States of similar examples of non-compliance (Mazumdar S, Geis G.2003). There is an urgent need to identify the most effective ways of enforcing laws and regulations on accessibility and to propagate this information.

Experience shows that voluntary efforts on accessibility are not enough to remove barriers. Instead, mandatory minimum standards are required. In new construction, full abidance with all the requirements of accessibility standards is generally viable at 1% of the total cost (Schroeder S, Steinfeld E, 1979). Making older buildings accessible requires flexibility, because of technical difficulties, issues of historic preservation and variance in the resources of the owners.

Modern standards have been developed through a largely accordant process. The participation of people with disabilities in developing standards is important for providing perceptivity about the needs of users. But a systematic, evidence-based approach to standards is also a requisite. Evaluations of the technical accessibility provisions in high-income settings have found that wheelchair clearance and space requirements are often too low (Steinfeld E, Feathers D, Maisel J, 2009). These shortcomings stem from the changing characteristics of assistive technology such as bigger wheelchairs, from the advances in knowledge about how to facilitate access, and from the time lag for incorporating new knowledge into standards. The basic features of access in new construction should include:

- provision of curb cuts (ramps)
- safe crossings across the street
- convenient and approachable entries
- an accessible path of travel to all spaces

- access to public amenities, such as toilets.

Most of the handiness or accessibility measure that are practicable or are framed, focus on the needs of people with mobility impairments. The precise standards, for instance, contain many criteria to ensure enough space and guide clearances for wheelchair and walking aid users. It is also important to meet the needs of people with other disability and needs like sensory impairments, primarily avoiding hazards and finding the right way. The State Administrative Training Institute for government officials in Ahmedabad, the state capital, has become a model of accessible building. Programmes of modifications require regular follow-up to support the implementation of recommendations for standard specifications. The maintenance of access features was best achieved when both users and managers of a space were aware of the importance of these features. The project has shown architects and builders how to comply with the access provisions in the Persons with Disabilities Act 1995 and local access by-laws. A design institute in Ahmedabad now offers an elective course on universal design. People with disabilities have seen benefits in greater dignity, comfort, safety, and independence. All the same, non-compliance has resulted in new barriers. Accessibility for people with visual impairments remains a problem, with signage standards not commonly followed due to limited information in accessible user-friendly formats. Source (Unnati and Handicap International, 2008).

Appropriate standards are also needed for rural construction as the maximum number of the disabled population reside in rural areas. A study on accessibility in rural villages in Gujarat, India, found that current practices in wealthy urban areas in India were not appropriate in these villages (Raheja G, 2008). India has a lot of policies on barrier free access and PWD act 1995 specifically spells out the accessibility criteria but the compliance of the same is very low and whatever little that has been achieved can be only seen in big cities and places like airport, universities, five star hotels and corporate buildings, located in metropolis. This however, serves very little purpose because majority of the disabled population dwell in the village and the one's in the cities hardly have such accessibilities because of the attitudinal barrier they faces in their day to day lives. Therefore, planning should take into consideration both the urban and rural setting.

Laws with mandatory access standards are the most effective way to achieve accessibility. Standards and compliance should be regulated and mandated by law.

3.2.2 SUPPORTING ATTITUDE

While discrimination is not deliberate, yet the system indirectly leaves out persons with disabilities, by not taking their needs into account. Knowledge and attitudes are important environmental factors, affecting all areas of service provision and social life. Raising awareness and challenging negative attitudes are often the first step towards creating more accessible environments for persons with disabilities. Negative imagery and language, stereotypes, and stigma with deep historic roots persist for people with disabilities around the world (World Bank, 2009). Disability is generally linked with incapacity. A study in 10 countries found that the general public lacks an understanding of the abilities of people with intellectual impairments (Siperstein GN et al, .2003). Negative attitudes towards disability can result in negative treatment of people with disabilities, for example:

- children bullying other children with disabilities in schools
- bus drivers failing to support access needs of passengers with disabilities
- employers discriminating against people with disabilities
- strangers mocking people with disabilities etc.

Unsupportive attitudes and behaviours have an unfavorable effect on children and adults with disabilities, leading to negative outcomes such as low self-esteem and reduced participation (Thornicroft G, Rose D, Kassam A, 2007). People who feel harassed because of their disability sometimes avoid going to places, changing their routine, or even moving from their homes (Disability Rights Commission, 2004). Stigma and discrimination can be combated if the right kind of awareness is provided for general public.

Negative attitudes are a key environmental factor which needs to be addressed across all domains. If all the domains of infrastructure is achieved and made accessible, yet if this negative attitude continues then the whole purpose of creating a barrier free environment remains defeated. Therefore, negative attitude towards the disabled should

be changed through awareness programmes, involving disabled organisations and activists in all the activities, organising community-based rehabilitation programmes addressing their needs and by felicitating them for good work.

3.3 HEALTH SERVICES

Health can be defined as “a state of physical, mental, and social well-being and not merely the absence of disease or infirmity” (WHO). Good health is a basic requirement for participation in a wide range of daily living activities, also in the field of education and employment. Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) reinforces the right of persons with disabilities to attain the highest standard of health care, without discrimination (UN, 2006). People with disabilities require health services for general health care needs like the rest of the population. General health needs include health promotion, preventive care measures like immunisation, general health screening, treatment of acute and chronic illnesses, and appropriate referral for more specialised needs where required. These needs should all be met through primary health care in addition to secondary and tertiary as applicable. Access to primary health care is particularly important for those who experience a thinner or narrower margin of health to achieve their highest attainable standard of health and functioning (Drum CE et al., 2005). Some people with disabilities may have a greater need for specialist health care than the general population. Specialist health care needs may be associated with primary or secondary health conditions. Some people with disabilities may have multiple health conditions, and some health conditions may involve multiple body functions and structures. Assessment and treatment in these cases can be quite complex and therefore, may call for the knowledge and skills of specialists (Dejong G et al., 2002).

Disability is associated with a diverse range of primary health conditions: some may result in poor health and high healthcare needs, some do not keep people with disabilities from achieving good health (Emerson E et al., 2009). For example:-

- A child born mentally challenged may not specifically require ongoing healthcare for a primary health condition and associated impairment.

- An adolescent with a traumatic spinal cord injury may have considerable healthcare needs during the acute phase of the primary condition but thereafter may require only services to maintain health – for example, to prevent secondary conditions.
- Adults with chronic conditions such as multiple sclerosis, cystic fibrosis, severe arthritis, or schizophrenia may have complex and continuing health care needs related to their primary health condition or associated impairments (Iezzoni LI, 2006).

People with disabilities develop the same health problems that affect the general population, such as influenza and pneumonia. Some may be more susceptible to developing chronic conditions because of the influence of behavioural risk factors, such as increased physical inactivity (Rimmer JH, Rowland JL.2008). They also may experience the earlier onset of these conditions. The prevalence of diabetes in people with schizophrenia is around 15%, compared with the general population rate of 2–3% (Prince M et al, 2007). The ageing process for some groups of people with disabilities begins earlier than usual. Some people with developmental disabilities show signs of premature ageing in their 40s and 50s (Institute of Health and Welfare, 2000) and they may experience age-related health conditions more frequently. For example, people with Down Syndrome have a higher incidence of Alzheimer disease than the general population, while people with intellectual impairments (unrelated to Down syndrome) have higher rates of dementia (Institute of Health and Welfare, 2000). The health behaviours practiced by some adults with disabilities can differ in degree from those from the general population (Drum CE et al., 2009a).

People with disabilities are at greater risk of violence than those without disabilities. Violence is linked to health outcomes both immediate and long term, including injuries, physical and mental health problems, substance abuse, and death (WHO, 2002a). The prevalence of sexual abuse against people with disabilities has shown to be higher, especially for institutionalised men and women with intellectual disabilities, intimate partners and adolescents..Disabled population are also at higher risk of unintentional injury: one study found that children with developmental disabilities –

including autism, attention deficit disorder, and attention deficit hyperactivity disorder – were two to three times more at risk of an injury than those without (Lee LC et al., 2008). Other studies conclude that children with disabilities have a significantly higher risk of falls (Petridou E et al., 2003), burn-related injuries (Chen G et al., 2007), and injuries from crashes involving motor vehicles or bicycles (Xiang H et al., 2006).

Need and unmet needs exist across the spectrum of health services – promotion, prevention, and treatment. Misconceptions about the health of people with disabilities have led to assumptions that people with disabilities do not require access to health promotion and disease prevention. Evidence shows that health promotion interventions such as physical activities are beneficial for people with disabilities. But health promotion activities seldom target people with disabilities, and many experience multiple barriers to participation.

People with disabilities encounter a range of barriers when they attempt to access health care services. Analysis of the World Health Survey data showed a significant difference between men and women with disabilities and people without disabilities in terms of the attitudinal, physical, and system level barriers faced in accessing care. Research in Uttar Pradesh and Tamil Nadu states of India found that cost (70.5%), lack of services in the area (52.3%), and transportation (20.5%) were the top three barriers to using health facilities (World Bank, 2009).

All groups in society should have access to comprehensive, inclusive health care (Gwatkin DR, Bhuiya A, Victora CG, 2004). Providers may have to cater to the range of needs stemming from hearing, vision, speech, mobility, and cognitive impairments to include people with disabilities in primary health care services. Primary care teams require support from specialised services, organisations, and institutions (WHO, 2008) to provide comprehensive health care to people with disabilities. Common barriers include health-service providers' attitudes, knowledge and skills, and ensuring that health practices do not conflict with the rights of persons with disabilities. People with disabilities may be reluctant to seek health care because of stigmatisation and discrimination (Maulik PK, Darmstadt GL, 2007). People with disabilities may have

experienced institutionalization or other involuntary treatment, abuse, neglect and persistent devaluation.

Negative experiences in the health system, including instances of insensitivity or disrespect, may result in distrust of health providers, failure to seek care, and reliance upon self diagnosis and treatment (Loon J, Knibbe J, Van Hove G, 2005). Therefore, respectful, knowledgeable and supportive responses to people with disabilities from health-care providers are vital. However, attitudes and misconceptions among health-care providers remain barriers to health care for people with disabilities (Hewitt-Taylor J, 2009). Some health-care providers may feel uncomfortable about treating people with disabilities (Aulagnier M et al., 2005), and clinical decision-making may be influenced by negative attitudes and assumptions.

3.4 ACCESS TO EDUCATION

Education contributes to human capital formation and is thus a key determinant of personal well-being and welfare. Excluding children with disabilities from educational and employment opportunities has high social and economic costs. For example, adults with disabilities tend to be poorer than those without disabilities, but education weakens this association (Filmer D, 2008). Countries cannot achieve Education for All or the Millennium Development Goal of universal completion of primary education without ensuring access to education for children with disabilities (UNESCO, 2009). For children with disabilities, as for all children, education is not only vital in itself but also instrumental for fostering participation in employment and other areas of social activity. Many children and adults with disabilities have historically been excluded from mainstream education opportunities.

Respondents with disability in the World Health Survey experience significantly lower rates of primary school completion and fewer mean years of education than Respondents without disability; evidence shows young people with disabilities are less likely to be in school than their peers without disabilities (Filmer D, 2008). This pattern is more pronounced in poorer countries (UNESCO, 2009). Primary school attendance rates between disabled and non-disabled children in India are 10% (WHO, 2002). Enrolment

rates also differ according to impairment type, with children with physical impairment generally faring better than those with intellectual or sensory impairments. In India, a survey estimated the share of disabled children not enrolled in school at more than five times the national rate, even in the more prosperous states. In Karnataka, the best performing major state, almost one quarter of children with disabilities were out of school, and in poorer states as Madhya Pradesh and Assam, more than half (World Bank, 2009). While the best-performing districts in India had high enrolment rates for children without disabilities – close to or above 90%, school attendance rates of children with disabilities never exceeded 74% in urban areas or 66% in rural. Most special education facilities are in urban areas (Porter GL, 2001), so the participation of children with disabilities in rural areas could be much worse than the aggregated data imply (Singal N, 2006).

Despite improvements in recent decades, children and youth with disabilities are less likely to start school or attend school, than other children. They also have lower transition rates to higher levels of education. A lack of education at an early age has a significant impact on poverty in adulthood.

Definitions and methods for measuring disability vary across countries based on assumptions about human difference and disability and the importance given to the different aspects of disability – impairments, activity limitations and participation restriction, related health condition, and environmental factors.

There are no universally agreed definitions for such concepts as special needs education and inclusive education, which hampers comparison of data. The category covered by the terms ‘special’ needs education, special educational needs, and special education is broader than education of children with disabilities, because it includes children with other needs – for example, through disadvantages resulting from gender, ethnicity, poverty, war trauma, or orphan hood (Naidhu A. 2008).

A stricter sense of inclusion is that all children with disabilities should be educated in regular classrooms with age-appropriate peers. This approach stresses the need for the whole school system to change. Inclusive education entails identifying and

removing barriers and providing reasonable accommodation, enabling every learner to participate and achieve within mainstream settings. There are different approaches around the world to providing education for people with disabilities. The model adopted include special schools and institutions, integrated schools, and inclusive schools. Inclusive education seeks to enable schools to serve all children in their communities (Dupoux E, Wolman C, Estrada E., 2005).

The inclusion of children with disabilities in regular schools – inclusive schools – is widely regarded as desirable for equality and human rights. The United Nations Educational, Scientific and Cultural Organization have put forward the following reasons for developing a more inclusive education system (UNESCO, 2001).

1. Educational. The requirement for inclusive schools to educate all children together means that the schools have to develop ways of teaching that respond to individual differences, to the benefit of all children.
2. Social. Inclusive schools can change attitudes towards those who are in some way “different” by educating all children together. This will help in creating a just society without discrimination.
3. Economic. Establishing and maintaining schools that educate all children together is likely to be less costly than setting up a complex system of different types of schools specialising in different groups of children.

Educational needs must be assessed from the perspective of what is best for the individual (Farrell P et al., 2007) and the available financial and human resources within the country’s context. Many barriers may hinder children with disabilities from attending school. In some countries, education for some or all children with disabilities falls under separate ministries such as Health, Social Welfare, or Social Protection (El Salvador, Pakistan, and Bangladesh) or distinct Ministries of Special Education. In other countries (Ethiopia and Rwanda) responsibilities for the education of disabled children are shared between ministries (Lewis I, 2009). In India children with disabilities in special schools fall under the responsibility of the Ministry of Social Justice and Empowerment, while children in mainstream schools come under the Department of Education in the Ministry of Human Resource Development (Naidhu A, 2008). This division reflects the cultural

perception that children with disabilities are in need of welfare rather than equality of opportunity (World Bank, 2009). This particular model tends to further segregate children with disabilities, and shifts the focus from education and achieving social and economic inclusion to treatment and social isolation.

While there are many examples of initiatives to include children with disabilities in education, a lack of legislation, policy, targets and plans tends to be a major obstacle in efforts to provide Education for All (Forlin C, Lian MGJ, eds. 2008). Issues such as data collection, teacher training, access to school buildings, and the provision of additional learning materials and support are some of the hindrance for educating children with special needs, limited or inappropriate resources are regarded as a significant barrier to ensuring inclusive education for children with disabilities (Stubbs S,2008).

Some of the problems faced by school that hinders the education of students with disabilities are as follows.

- **Physical barriers**

Physical access to school buildings is an essential prerequisite for educating children with disabilities (Stubbs S., 2008). Those with physical disabilities are likely to face difficulties in travelling to school if, for example, the roads and bridges are unsuitable for wheelchair use and the distances are too great (UNESCO, 2010). Even if it is possible to reach the school, there may be problems of stairs, narrow doorways, inappropriate seating, or inaccessible toilet facilities.

- **Curriculum and pedagogy**

Curricula and teaching methods are rigid and there is a lack of appropriate teaching materials – for example, where information is not delivered in the most appropriate mode such as sign language and teaching materials are not available in alternative formats such as Braille – children with disabilities are at increased risk of exclusion (UNESCO, 2009). Assessment and evaluation systems are often focused on academic performance rather than individual progress and therefore can also be restrictive for children with special education needs (UNESCO,

2009). Flexible approaches in regards to pedagogy and curriculum are needed to respond to the diverse abilities and needs of all learners.

- **Violence, bullying, and abuse**

Violence against students with disabilities – by teachers, other staff, and fellow students – is common in educational settings (United Nations Children’s Fund, 2005). Students with disabilities often become the targets of violent acts including physical threats and abuse, verbal abuse, and social isolation. The fear of bullying can be as great an issue for children with disabilities as actual bullying (Watson N et al., 1998). Children with disabilities may prefer to attend special schools, because of the fear of stigma or bullying in mainstream schools.

- **Labelling Children**

Students with disability are reluctant about revealing their disability due to negative attitudes, thus missing out on needed support services (Kwon H., 2005). Disabilities are often categorised according to their health condition to determine their eligibility for special education and other types of support services . For example, a diagnosis of dyslexia, blindness, or deafness can facilitate access to technological and communication support and specialised teaching (Macdonald SJ, 2009). But assigning labels to children in education systems can have negative effects including stigmatization, peer rejection, lower self-esteem, lower expectations, and limited opportunities (Florian L et al., 2006)

- **Inadequate training and support for teachers**

Teachers may not have the time or resources to support the disabled learners (Wright SL, Sigafos J., 1997). In a resource poor set classroom, there is frequent overcrowding and severe shortage of well trained teachers capable of routinely handling the individual needs of children with disabilities. The majority of teachers lack sign-language skills creating barriers for Deaf pupils (Haualand H, Allen C, 2009). Other supports such as classroom assistants are also lacking. For example, in India, the pre-service training of regular teachers includes no familiarisation with the education of children with special needs (Bines H, Lei P, eds. 2007).

- **Attitudinal barriers**

Negative attitudes are a major obstacle to the education of disabled children (Price P, 2003). In some cultures, people with disabilities are seen as a form of divine punishment or as carriers of bad fortune. As a result, children with disabilities who could be in school are sometimes not permitted to attend. A community based study in Rwanda found that perceptions of impairments affected whether a child with a disability attended school. Negative community attitudes were also reflected in the language used to refer to people with disabilities (Karangwa E, Ghesquière P, Devlieger P, 2007). The attitudes of teachers, school administrators, other children, and even family members affect the inclusion of children with disabilities in mainstream schools. Some school teachers, including head teachers, believe they are not obliged to teach children with disabilities (Kvam MH, Braathen SH, 2006).

For creating universe for all and educating all children in the same environment, barriers as mentioned above need to be addressed to ensure the inclusion of children with disabilities in education, requires both systemic and school level change (McGregor G, Vogelsberg RT, 1998).

Changes can be brought in at different levels like at system level barrier needs to be addressed in

- Legislation
- Policy
- National plan
- Funding etc

At school level addressing barrier like

- Recognizing and addressing individual differences
- Providing additional supports
- Building teacher capacity
- Removing physical barriers
- Overcoming negative attitudes etc

The role of communities, families, disabled people, and children with disabilities are equally vital for addressing the barriers.

Children with disabilities should have equal access to quality education, because this is the key to human capital formation and their participation in social and economic life. While children with disabilities have historically been educated in separate special schools, inclusive mainstream schools in both urban and rural areas provide a cost-effective way forward. Inclusive education is better able to reach the majority and avoids isolating children with disabilities from their families and communities.

3.5 PARTICIPATION IN LABOUR MARKET

Article 27 the United Nations Convention on the Rights of Persons with Disabilities (CRPD) “recognises the right of persons with disabilities to work, on an equal basis with others; this includes the opportunity to gain a living by working freely, chosen or accepted in a labour market and work environment that is open, inclusive and accessible to persons with disabilities” (UN, 2006). Furthermore, the CRPD prohibits all forms of employment discrimination, promotes access to vocational training, promotes opportunities for self-employment, and calls for a reasonable accommodation in the workplace, among other provisions.

Almost all jobs can be performed by someone with a disability, and if given the right environment, most people with disabilities can be productive. But as documented by several studies - both in developed and developing countries - working age persons with disabilities experience significantly lower employment rates and much higher unemployment rates than persons without disabilities (Mitra S, Sambamoorthi U, 2006). Poverty among the disabled population is mostly due to lack of participation in the labour market .

If people with disabilities and their households are to overcome exclusion, they must have access to work or livelihoods, breaking some of the circular links between disability and poverty (Yeo R, Moore K, 2003). Some employers continue to fear that people with disabilities are unqualified and not productive (Roberts S et al., 2004). But people with disabilities often have appropriate skills, strong loyalty and low rates of

absenteeism making a growing numbers of companies choose the disabled person for work, because of efficiency and profitability (Unger D, 2002). People with disabilities are disadvantaged in the labour market. For example, their lack of access to education and training or financial resources may be responsible for their exclusion from the labour market – but it could also be the nature of the workplace or employers’ perceptions of disability and disabled people. Social protection systems may create incentives for people with disabilities to exit employment onto disability benefits (OECD, 2010).

Misconceptions about the ability of people with disabilities to perform jobs are an important reason both for their continued unemployment and – if employed – for their exclusion from opportunities for promotion in their careers (Shier M, Graham J, Jones, 2009). Such attitudes may stem from prejudice or from the belief that people with disabilities are less productive than their non-disabled counterparts (Gartrell A., 2010). In particular, there may be ignorance or prejudice about mental health difficulties and about adjustments to work arrangements, that can facilitate employment (Jones MK, Latreille PL, Sloane PJ., 2006). Misconceptions are often prevalent not only among non-disabled employers but also among family members and disabled people themselves (World Bank, 2009). Some people with disabilities have low self expectations about their own abilities creating their own mental barriers from being employed or seeking employment.

The social isolation of people with disabilities restrict their access to social networks - especially of friends and family members - that could help in finding employment (ILO, 2006). Different impairments elicit different degrees of prejudice, with the strongest prejudice exhibited towards people with mental health conditions (Baldwin ML, Marcus SC., 2006). Education and training are central to good and productive work for a reasonable income (ILO, 2006). But young people with disabilities often lack access to formal education or to skill-development-opportunities – particularly in the increasingly important field of Information Technology (Burchardt T., 2004). The gap in educational attainment between those with a disability and those without, is thus an ever-increasing obstacle (World Bank, 2009). People with disabilities experience environmental obstacles that make physical access to employment difficult. Some may not be able to afford the daily travel costs, to and from work (Roberts P, Babinard J.,

2004). There may also be physical barriers to job interviews, to the actual work setting, and to attending social events with fellow employees (ILO, 2006).

Access to information can be a further barrier for people with visual impairments (Butler SE et al., 2002). In many countries, labour markets are largely informal, with many self-employed workers. In India, 87% of working people with disabilities, are in the informal sector (Mitra S, Sambamoorthi U, 2006). People with disabilities may need flexibility in their scheduling and other aspects of their work – to give them proper time to prepare for work, to travel to and from work, and to deal with health concerns. Contingent and part-time work arrangements, which often provide flexibility, may therefore be attractive to them. But such jobs may provide lower pay and fewer benefits.

Laws and regulations affecting employment for people with disabilities, found in many places (Degener T, 2005) include anti-discrimination laws and affirmative action. General employment laws also often regulate retention and other employment-related issues of those who become disabled, while working. But the implementation and effectiveness of disability protection provisions varies considerably. Often they are poorly enforced and not well-known (Mitra S, Sambamoorthi U, 2006). Many countries stipulate quotas for the employment of people with disabilities in the public and private sectors. The implicit assumption is that, without quotas employers would turn away disabled workers because of discrimination, doubt of lower productivity, or the potential increase in the cost of labour, for example the cost of accommodations (ILO,2004).

Almost all jobs can be performed productively by someone with a disability given the right environment. But working age persons with disabilities experience significantly lower employment rates and much higher rates of unemployment than persons without disabilities. This is due to many factors, including lack of access to education and vocational rehabilitation and training, lack of access to financial resources, disincentives created by disability benefits, the inaccessibility of the workplace, and employers' perceptions of disability and disabled people. In improving labour market opportunities for people with disabilities, many stakeholders have a role, including government, employers, disabled people's organisations, and trade unions.

3.6 SCHEMES, POLICIES AND PROGRAMMES FOR PWD IN INDIA

According to the Census 2001, there are 2.19 crore persons with disabilities in India who constitute 2.13 percent of the total population. This includes persons with visual impairment, hearing impairment, speech impairment, Locomotor impairment and mental disabilities, cerebral palsy etc. Seventy five percent of persons with disabilities live in rural areas, 51 percent of disabled population is illiterate and only 34 percent are employed (census, 2001).

The earlier emphasis on medical rehabilitation has now been replaced by an emphasis on social rehabilitation with the right based approach. There has been an increasing recognition of abilities of persons with disabilities and emphasis on mainstreaming them in the society based on their capabilities.

Currently reservations in services, concessions in employment, disability pension under the Employees' provident Funds and Miscellaneous Provisions Act 1952, medical and maternity benefits under Employees' State Insurance Act 1948, benefits under the Workmen's Compensation Act 1923, special schools for the disabled children, disability specific assistance programmes are available in the country, though the coverage is not comprehensive.

Despite differing estimates, empirical evidence as of 2007 suggests that between 4 to 8 percent of the population in India is comprised of people with disabilities (World Bank 2007). This translates into 40-90 million people, a substantial number. People with disabilities in India are subject to multiple deprivations and limited opportunities in several dimensions of their lives. Households with people with disabilities are 25 percent less likely to report having 3 meals per day year around, more likely to have members who are illiterate and children who are not enrolled in school, have much lower employment rates and have limited awareness of entitlements and services available by law for people with disabilities (World Bank 2007). Not surprisingly, these households are over-represented among the poor and socially marginalised.

The experiences of people with disabilities are in stark contrast to the fact that certain government departments in India such as the education sector have been viewed

as progressive in their delivery of options to children with distinctive needs (World Bank 2007). Disability statistics were collected in the Census of India from as early as the late nineteenth century and the country had special schools that catered to the needs of people with disabilities from around the same time period. However, integration of people with disabilities and policy commitment to their participation as equals in society occurred only twenty-five years ago with the passage of four important laws. These included the Mental Health Act of 1987, the Rehabilitation Council of India Act of 1992, the People with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act of 1995 (PWD Act), and the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act of 1999 (World Bank 2007). India also ratified the UN Convention on the Rights of Persons with Disabilities in 2007.

The PWD Act of 1995 was the key central legislation that provided certain entitlements in the areas of education, employment and affirmative action, and other privileges in prevention and early detection of disabilities. In the same line there are a number of schemes that provide Disability certificates and identity cards, Education programmes for children with special needs Children's education allowance and scholarships. Assistance to disabled persons for purchase/fitting of aids & appliances (ADIP Scheme). Preference in allotment of STD/PCO to handicapped person, Custom concession, National awards for people with disabilities and many more are running in the country for the benefit of the disabled population.

3.6.1 DISABILITY LAWS /RIGHTS AND POLICY

Indian Constitution

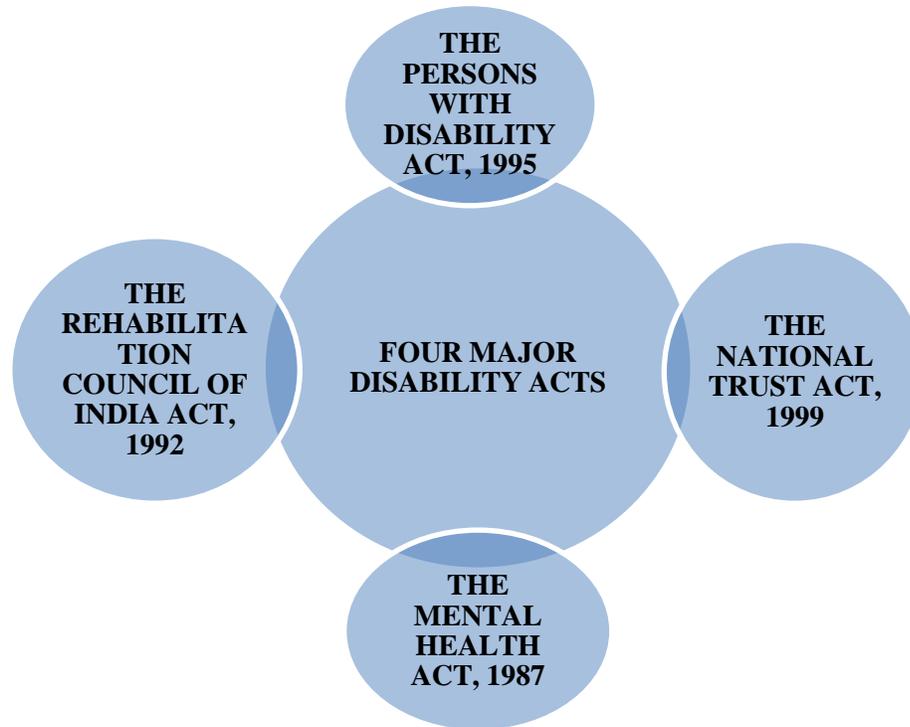
The constitution of India applies uniformly to every legal citizen of India, whether they are healthy or disabled. Under the constitution, the disabled have been guaranteed the following fundamental rights:-

1. The constitution secures to the citizens including the disabled, right of justice, liberty of thoughts, expression, belief, faith and worship, equality of status and of opportunity and for the promotion of fraternity.

2. Article 15(1) enjoins on the government not to discriminate against any citizen of India (including disabled) on the ground of religion, race, caste, sex or place of birth.
3. Article 15(2) states that no citizen (including the disabled) shall be subjected to any disability, liability, restriction or condition on any of the above grounds in the matter of their access to shops, public restaurants, hotels and places of public entertainment etc.
4. No person including the disabled irrespective of his belonging can be treated as an untouchable. It would be an offence punishable in accordance with law as provided by article 17 of the constitution.
5. Every person including the disabled has his life and liberty guaranteed under Article 21 of the constitution.
6. Every disabled person can move the Supreme Court of India to enforce his fundamental right and the right to move the Supreme Court is itself guaranteed by Article 32.
7. Every disabled person (like the non-disabled) on attainment of 18 years of age becomes eligible for inclusion of his name in the general electoral roll for the territorial constituency to which he belongs.

All the benefits that are mentioned in the constitution of India for its people is applicable to everyone including the disabled. Besides these articles, there are 4 specific laws which promote and propagate rights of persons with disabilities (see figure 3.1).

Figure No 3.1
Disability Acts



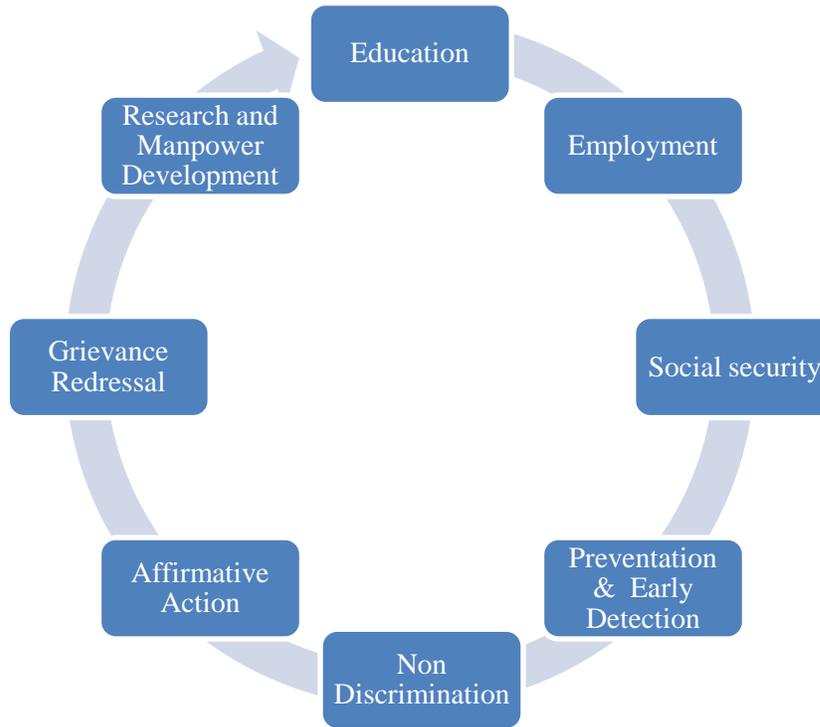
Source: Self Compiled

1. The Persons with Disability (Equal Opportunity, Protection of Rights and Full Participation) Act, 1995

The persons with disability (Equal opportunity, protection of rights and full participation) Act, 1995 came into enforcement on February 7, 1996. It was a significant step which ensured equal opportunity for the people with disability and their full participation in day-to-day life. The act provides for both preventive and promotional aspects of rehabilitation like prevention, early intervention, education, employment and vocational training, reservation, research and manpower development, creation of a barrier free environment, unemployment allowances, and special insurance scheme for the disabled employees and establishment of homes for persons with disability etc. The PWD Act, 1995 has 8 main provisions (see figure 3.2).

Figure No 3.2

Provision under PWD Act 1995



Source: Self Compiled

- I. Prevention and early detection of disability: the Acts considers it a very important area of concern and includes aspects such as :-
 - Survey, investigation and research shall be conducted to ascertain the cause of occurrence of disabilities.
 - Various measures shall be taken to prevent disabilities and staff at primary health center shall be trained to assist in the work.
 - All the children shall be screened once in a year for identifying ‘at- risk’ cases.
 - Awareness campaigns shall be launched and sponsored to disseminate information.

- Measures shall be taken for pre natal, perinatal and post natal care of the mother and child.
- II. Education: elementary education is a fundamental right under the constitution. The PWD Act also enumerates various provisions to ensure right education with right format at right time for children with disabilities. It ensures the right of every child till the age of 18, towards a free education. They also have the right to free books, scholarship, uniform and other learning materials. Schools should be able to provide them with the enhancing environment by creating barrier free access, appropriate transportation and restructuring or modification in the examination system to ensure optimum benefit to CWSN. Teacher training institute shall be established to develop requisite manpower etc.
- III. Employment: one of the many aims of education is to prepare an individual for future employment. This Acts ensures many things including:
- 3% of vacancies in government employment shall be reserved for people with disabilities; 1% each for the persons suffering from
 - i. Blindness or Low Vision
 - ii. Hearing impairment
 - iii. Locomotor disabilities and Cerebral Palsy
 - Suitable scheme shall be formulated for the training and welfare of PWDs, relaxation of upper age limit, regulating employment, ensuring health and safety and creating a non handicapping environment in place where PWDs are employed.
 - No employee can be sacked or demoted if they become disabled during service, although they can be moved to another post with the same pay and condition and promotion cannot be denied on the basis of impairment.
- IV. Non-Discrimination: Act enumerates that all public buildings, rail compartments and aircraft will be designed to provide easy access to the disabled people, all the places of public utility and waiting room shall be made barrier-free by providing ramps with hand rails, the toilets shall be wheel chair accessible. Braille and sound symbols are also to be provided in all elevators.

- V. Affirmative Action: PWD Act also provides other measures including: - Aids and Appliances shall be made available to people with Disabilities. Allotment of land shall be made at concessional rates to the people with disability for
- i. House
 - ii. Business
 - iii. Special recreational centers
 - iv. Special schools
 - v. Research schools
 - vi. Factories by entrepreneurs with disability.
- VI. Research and Manpower Development: Act acknowledges the importance of research and manpower development in the area of rehabilitation and says the following:
- i. Research in the areas such as prevention of disability, rehabilitation including community based rehabilitation and development of assistive devices shall be sponsored.
 - ii. On site modification of office and factories
 - iii. Job identification
 - iv. Financial assistance shall be made available to the universities, other institution of higher learning, professional bodies and non- government research institutions, for undertaking research on special education, rehabilitation and manpower development.
- VII. Social Security: under this section Act speaks on financial assistance to non government organizations for the rehabilitation of PWDs, insurance coverage for the benefit of the government employees with disability and unemployment allowance to the PWDs who are registered with the special employment exchange for more than a year and could not find any gainful occupation.
- VIII. Grievance redressal: the Act provides a mechanism to address grievance of PWDs. In case of violation of the right, as prescribed in the act, PWDs can move an application to the: i) Chief Commissioner for Persons with Disabilities in the Center or ii) Commissioner for Persons with Disabilities in the State.

2. The Mental Health Act, 1987

According to the WHO estimate, it is believed that over 130 million people suffer from one or another mental disorder in India. The disorder ranges from Depression, to

Anxiety, to psychosomatic disorders and Schizophrenia with others. Under the Mental Health Act, mentally ill persons are entitled for many rights few are mentioned below:

- A right to be admitted, treated and cared in psychiatric hospitals or psychiatric nursing homes or convalescent homes established or maintained by the Government or any other person for the treatment and care of mentally ill persons (other than the general hospitals or nursing homes of the Government).
- Minors under the age of 16 years, persons addicted to alcohol or other drugs which lead to behavioral changes, and those convicted of any offence are entitled to admission, treatment and care in separate psychiatric hospitals or nursing homes, established or maintained by the Government.
- The police have an obligation to take into protective custody, a wandering or neglected mentally ill person, and inform his relative, and also have to produce such a person before the local magistrate for issue of reception orders.
- The costs of maintenance of mentally ill persons detained as in-patient in any government psychiatric hospital or nursing home shall be borne by the state government concerned, unless such costs have been agreed to be borne by the relative or other person on behalf of the mentally ill person and no provision for such maintenance has been made by order of the District Court. Such costs can also be borne out of the estate of the mentally ill person.
- Mentally ill persons undergoing treatment shall not be subjected to any indignity (whether physical or mental) or cruelty. Mentally ill persons cannot be used without their own valid consent for purposes of research, though they could receive their diagnosis and treatment.

- Mentally ill persons who are entitled to any pay pension, gratuity or any other form of allowance from the government (such as government servants who become mentally ill during their tenure) cannot be denied of such payments. The person who is in-charge of such mentally person or his dependents will receive such payments after the magistrate has certified the same.

3. The Rehabilitation Council of India Act, 1992

Persons with disability in India have been receiving rehabilitation services for more than 100 years. However before establishment of RCI, there was hardly any planned effort made in the field for developing trained manpower. Lack of appropriate trained manpower has been one of the major constrains in the expansion of rehabilitation service in the country. It was therefore, in 1986 decided by government of India to set up Rehabilitation Council of India to be responsible for the following activities:-

- To standardise the training course for professional dealing with PWDs.
- Development and regulation of training polices and programmes
- To grant recognition to the institutions running these training courses
- To maintain a Central Rehabilitation Register of rehabilitation professionals and
- To promote research in rehabilitation and special education.

In order to give the statutory powers to the council for carrying out its duties effectively the Rehabilitation Council of India Act ,1992 was passed by the Parliament which came into force with effect from 22nd June 1993.This act provides guarantees so as to ensure the good quality of service rendered by various rehabilitation personnel. RCI is the only institute which takes care of manpower development of different categories of professionals for comprehensive rehabilitation of PWDS to meet the need of their entire life cycle i.e. physical and medical rehabilitation, education, vocational and social rehabilitation.

4. The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act,1999

The objective of the act is to provide and constitute a national body for the welfare of persons with autism, cerebral palsy, mental retardation and multiple disabilities. Such a national body will be a trust whose objectives areas under:

- The enabling and empowering of PWDs to live as independently and as fully as possible within and as close to the community to which they belong.
- Strengthening facilities to provide support to PWDs to live within their own families.
- Extending support to registered organisations to provide a need-based service during the period of crisis in the family of persons with disability.
- Dealing with problems of persons with disability who do not have family support.
- Promoting measures for care and protection of persons with disability in the event of death of their parents or guardians.
- Evolving procedures for appointment of guardians and trustees for persons with disability requiring such protection.
- Facilitating the realisation of equal opportunity , protection of right and full participation of PWDs

The Act received the assent of the President on 30th December, 1999 and extended to the whole of India, also announcing various schemes for the welfare of groups enumerated in the ACT.

In addition to the above legislation, there are many provisions under different headings of the constitution of India which ensure opportunities to protect the right of PWDs. But the 4 laws as mentioned above are the most important legislations specially enacted for the welfare of this group and covers all the areas that needs attention.

3.6.2 PROGRAMMES AND SCHEMES FOR PERSONS WITH DISABILITIES

There are many schemes and programmes running in the country for the welfare of PWDs but to avail any facility, concession and benefits, one should have the basic documents i.e. disability card or identity card and the degree of disability should be at

least 40% in order to be eligible for any concession or benefits. However, this is not required for gaining admission in a school for formal education. The classification of various concessions being recommended is applicable to the person with permanent disabilities only. Facilities and concessions are available for the disabled under the following programmes.

I. Disability Certificate and Identity Card

Disability certificate is issued to PWDs mentioned in the PWD Act 1995, the certificate is valid for a period of five years. When there are no chances of variations in the degree of disability, a permanent disability certificate is given. The respective medical boards constituted at state or district level are the certifying authority to issue disability certificate. The Government of India has issued guidelines (August 2000) to states/UTs for issuing of identity card (IC) to the persons with disabilities so as to enable them to easily avail any applicable benefits/concessions. The IC will contain information like identity card number, disability code, district code, state code etc. A passbook will also be issued along with the IC. This passbook is meant to contain the details of various benefits and concessions provided to that person.

II. Education Programme for Children with Special Needs

There are different provisions for education of children with disabilities. After the assessment of their disabilities by a team of multidisciplinary team, the child will be placed in an appropriate education setting. Children with mild and moderate disabilities of any kind may be integrated in regular school after a thorough assessment, dropouts who have problem in availing benefits in regular schools can join open schools. Children with severe disability can attend special schools. Open and special schools also offer vocational courses for children with special needs.

a) Inclusive Education for Disabled (IED) under Sarva Shiksha Abhiyan (SSA):

The main focus of MHRD and SSA is on increase access, enrolment and retention of all children as well as improving the quality of education. The general guidelines issued by the ministry as follows:

- Every child should get free and compulsory education up till the age of 14 years
- A zero rejection policy

- Education to CWSN should be provided in an environment most suited to their learning needs
- Flexibility in planning- to make it need based
- Provision of 1200 per child for integration of CWSN per year
- Encourage involvement of resource institute

b) Inclusive education for the disabled at secondary stage:

This is centrally sponsored scheme under which the central will assist the State/UT and autonomous bodies of stature in the field of education. The schemes aims and objectives are as follows:

- Enable all students with disabilities completing eight years of elementary schooling an opportunity to complete four years of secondary schooling (class IX to XII) in an inclusive and enabling environment.
- Provide education opportunities and facilities to students with disabilities in general education system at the secondary level.
- Support the training of general school teacher to meet the need of children with disabilities.
- Provision for aids and appliances as per the need.
- Appointment of Special Educators and establishment of resource room in every block etc.

The scheme covers all children of age 14+ years who've finished elementary schooling and are studying in the secondary stage in Government, local body and Government aided schools, having one or more disabilities as defined under the PWD Act 1995 and the National Trust Act 1999 in the age group 14 to 18 years (class ix to xii). The scheme includes assistance for two component (i) student oriented component, everything that ensures the CWSNs retention in the class and avoids all hindrances is covered under the component. It also provides an amount of Rs 3000 per disabled child per annum to provide all sorts of assistance that will create an enhancing learning environment. (ii) Other component includes all those relating infrastructure, teacher training, awareness generation, etc.

c) Special schools:

This is a programme of the ministry of Social Justice and Empowerment. Children with severe multiple disabilities who have difficulty in coping with regular school are referred to special schools. Most of these special schools are located in urban areas and are run by voluntary organization.

d) National open School (NOS):

The NOS was established as an Autonomous Registered Society in 1989 with the mission to provide education through an open learning system at the school stage as an alternative to formal education system. It is specially suited to the need of certain categories including the disabled.

III. Children's Education Allowances and Scholarship

To ensure that the students with disabilities have fair access to higher and technical education: 3% seats in education intuitions are reserved for them. Besides, the ministry of Social Justice & Empowerment supports 500 scholarship for students for persuing their studies at the post school level. The objective of the scheme is to provide financial assistance to disabled students for higher and technical education. They will also be supported for acquiring special aids and appliances for studies.

IV. Assistance to Disabled Person for Purchase/ Fittings of Aids and Appliances (ADIP Scheme)

The main objective of the scheme is to assist the needy disabled to procure durable sophisticated and scientifically manufactured, modern, slandered aids and appliances that can promote their physical, social and psychological rehabilitation by reducing the effect of disabilities and enhancing their economic potential. The scheme is implemented through different government and non government agencies. A Person with Disabilities fulfilling conditions laid by ministry would be eligible for assistance under ADIP Scheme. Aids and appliances like prosthetic and orthotic devices, tricycle, wheelchairs, crutches/walking sticks, all type of surgical footwear, all type of devices for ADL (Activity of Daily Living), talking thermometer, Braille writing equipment, communication equipments, low vision aids, adaptable walkers, various types of hearing aids etc are provided under the scheme.

V. Preference In Allotment Of STD/PCO To Handicapped Persons

Educated unemployed persons are eligible for allotment of STD/PCO. The education qualification for the applicant is:

- a. 8th or middle school pass for rural areas.
- b. Matriculation or High school pass for urban areas.

VI. Employment of The Disabled

Assistance to the disabled persons in getting gainful employment is available either through the special cells in normal employment exchanges or through special employment exchanges for the physically handicapped. Up to 100% financial assistance is provided in case of special cell and 80% in case of special employment exchange of state government and union territory administration.

VII. National Award for Persons with Disabilities

The Ministry of Social Justice & Empowerment has been giving National Awards since 1969, on the occasions of the World Disability Day, every year (3rd December). Institutions of award has created awareness amongst the disabled persons both in public and private sector and brought them into the mainstream. The awards are given in different categories, namely - best employee, the best employer of disabled, best individual, best institute, barrier free environment, best placement officer, creative disabled persons and National Technology Awards' for people involving in the rehabilitation and welfare of persons with disabilities . The awards are handed by the President of India.

VIII. Incentives to Private Sector Employers for Providing Employment to Persons with Disabilities

The scheme giving incentives to employers for providing employment to persons with disabilities in the private sector as approved by Government would be as under:

- Total outlay: Rs 1800 crore for the 11th five year plan
- Sector covered: private sector
- Job to be created: 1 lakh per annum

- Salary limit: employees with the disabilities earning a monthly wage up to Rs 25000 per month working in a private sector would be covered.
- Incentives: payment by Government of the Employers contribution to the employee's provident fund and employee's state insurance for the first three years.

The scheme will be applicable to the employees with disabilities covered under the PWD Act, 1995 and the National Trust Act, 1999.

IX. Reservation of Jobs And other Facilities for Disabled Persons

As per the order of government of India, reservation of 3% in jobs has been made in Grade 'C' and 'D' posts for the disabled persons. The categories benefiting from this are -blind 1%, Deaf 1%, orthopedic handicap 1%. For effective implementation of the reservation, it has been advised to maintain a roster of vacancies arising in Grade 'C' and 'D' posts on the yearly basis. As per the decision of Government of India, disabled persons recruited for regional Grade 'C' and 'D' posts may be given their posting near their native place in that region subject to the administrative constraints. As per the government order it has been decided to extend the age concession upward by 10 years in favor of disabled person. This applies to posts filled through SSC and through Employment Exchange.

X. Economic Assistance

- i. Public sector banks: under the 'scheme of public sector banks for orphanages, Women's home and physically handicapped persons' the benefits of the deferential rate of interest are available to physically handicapped persons. Physically handicapped persons are eligible to take loans under this scheme, if they satisfy the conditions that have been outlined to avail this facility.
- ii. Subsidy to Disabled under Swarnjayanti Gram SwarozgarYojana (SGSY): this scheme was launched in 1999 with an aim to lift poor families above poverty line, by providing them income-generating assets through a mix of bank credit and government subsidy. This scheme covers all aspects of self employment, which includes organisation of rural poor in to Self Help Group (SHG), training, planning of activity clusters, infrastructure build up, technology and marketing

support. In case of disabled person, a SHG may consist of a minimum of 5 persons belonging to the family below poverty line. This scheme is being implemented by the district rural development agencies (DRDAs) along with the involvement of Panchayati Raj institutions, the banks, and the Non Government Organisations.

- iii. National Handicapped Finance and Development Corporation (NHFDC): The Scheme has been incorporated by the Ministry of Social Justice & Employment, Government of India on the 24th January 1997, under section 35 of the Companies Act 1956 as a company not for profit. It runs several schemes to financially assist the disabled persons who are eligible for this purpose. Some schemes are setting up small business in service/trading sector, setting up small industrial unit, for higher studies/professional training to cover tuition fee books, stationery etc, for agricultural activities, for manufacturing /production of assistive devices for disabled persons, for self employment etc.

XI. Grant-In-Aid Scheme of The Ministry of Social Justice and Empowerment

There are many schemes running under this head. Few are as follows:

- Assistance to Voluntary Organisations for the Disabled
- Assistance to voluntary originations for the Rehabilitation of Leprosy-Cured persons
- Assistance to organisations for persons with Cerebral Palsy and Mental Retardation
- Establishment and Development of special School

XII. Other Concession and Schemes

The Government of India has recently announced the following additional concessions for individual or Hindu Undivided families which have physical disabled or mentally retarded relatives.

- Standard Deduction in the medical treatment including nursing - this is applicable only if the annual income of the Hindu Undivided family is less than Rs 100,000.

- Tax deduction from the total income of handicapped person under section 80U of the income tax has been raised from Rs 20000 to Rs 40000.
- Professional tax exemption - disabled persons are exempted from payment of professional tax.

XIII. Indira Awas Yojana

This is a centrally sponsored housing scheme for providing dwelling units free of cost to the rural poor living below the poverty line at a unit cost of Rs 20,000 in plain areas and Rs 22,000 in the hilly/difficult areas. Three percent of its fund are reserved for the benefit of disabled persons living below the poverty line in the rural areas.

XIV. Jawahar Rojgar Yojna (JRY)

With the coming into effect of the persons with Disabilities (Equal opportunity, Protection of Rights and full participation) Act it has been decided to earmark 3% of the JRY fund for the benefits of the persons with disabilities.

XV. Rural Sanitation Program

As per the approval from the Ministry for the Rural Area and Employment it has been decided that in the rural sanitation programme, there should be 3% reservation for PWDs in works relating to sanitation latrines for Individuals below the poverty line. In the context of work related to such group, it should be ensured that the environment is barrier free for the disabled.

XVI. Science and Technology Development Projects In Mission Mode

The project in Mission Mode was launched in 1988 concentrating on new scientific inputs, generation of new technologies and guiding these to large-scale use. The objectives of such projects are to coordinate, fund and direct application of technology for development and utilization of:

- Suitable and cost effect aids and appliances.
- Emphasis on education and skill development leading to enhancement of opportunities for employment.
- Easier living and integration in society.

XVII. Other Concessions for the Disabled

- **Concessions on Railways:** Railways allow disabled persons to travel at concession fares up to 75% in the first and second classes. Escorts accompanying blind, orthopedically and mentally handicapped persons are also eligible to 75% concession in the basic fare. A deaf person is allowed 50% concession in railway fare, both in the first and second class, The escort, however, will have to pay, (see annexure I for details).
- **Air Travel Concessions** Indian Airlines allow 50% concession fares to blind persons.
- **Postage** Payment of postage, both inland and foreign, for transmission by post of 'Blind Literature' packets is exempted, if sent by surface route.
- **Customs/Excise** Braille paper has been exempted from excise and customs duty, provided the paper is supplied direct to a school for the blind or to a Braille press against an indent placed by the National Institute for the Visually Handicapped, Dehradun. All audiocassettes recorded with material from books, newspapers or magazines for the blind are exempt from custom duty. Several other items have also been exempted from customs duty if imported for the use of a disabled person.
- **Conveyance Allowance** All central government employees who are blind or orthopedically handicapped are granted conveyance at 5 percent of basic pay subject to a maximum of Rs. 100 per month.
- **Award of Dealership by Oil Companies:** The Ministry of Petroleum and Natural Gas has reserved 7.5 percent on all types of dealership agencies of the public sector companies for the orthopedically handicapped and blind persons. However, persons with visual handicap are not eligible for LPG distribution. Similarly, the Ministry has also reserved 7.5 percent of such dealership/agencies for defense personnel, and those severely disabled either in war or while on duty in peacetime.

CHAPTER - 4

SOCIAL SECURITY FOR PERSONS WITH DISABILITIES IN SIKKIM

INTRODUCTION

This chapter gives a brief overview of the situation of people living with disabilities in Sikkim, and also attempts to explore the day-to-day plight of Persons with Disabilities (PWDs). The chapter also takes a detailed look at disability rights and assesses its awareness among people, from various perspectives. It brings about a present-day-perspective and understanding of the entire scenario, through discussions with respondents. This chapter attempts to include all the major variables such as age, educational qualification, occupation, public policies and societal issues. This study is a humble attempt to bring forward the issues related with PWDs in Sikkim. For this study to manifest, a sample population was taken from all the four district of Sikkim.

4.1 DISABILITY AND SIKKIM: AN OVERVIEW

Sikkim is a small Himalayan State situated in the North-Eastern region of India. It became part of the Indian Republic on 16 May 1975. Area-wise, Sikkim is the second smallest state in India. It is divided into 4 districts – East Sikkim(Gangtok), North Sikkim(Mangan), South Sikkim(Namchi) and West Sikkim(Geyzing). It shares international borders with Nepal in the west, Bhutan in the east and China in the north. In the south, it shares border with India's West Bengal. According to the 2011 national census, Sikkim had a total population of 6, 10,577 – the least populated among all the other Indian states. 47 percent of the total population are female while 53 percent are male.

in the last category i.e. 2.5 and above, which signifies that the ratio of disabled population and total population is soaring high, and in fact is equivalent to states enormous in size and population, like Maharashtra, Orissa, Jammu & Kashmir and Andhra Pradesh. To have such a high number of disabled population for such a small state of 6 lakh people only, is in fact quite an alarming situation.

State report on the implementation of the Disability Act of 1995 gives out a very positive and proactive image where many measures that have promoted rights and equal opportunities for persons with disabilities have been cited. However the picture is completely different at the receiving end. The state of Sikkim has only one DDRC and it is based in the STNM Hospital complex in Gangtok, East district. It has very few NGOs working in this field and children and adults with disabilities in the state are only identified during Assessment Camps organised annually at block level by SJEW, in collaboration with Ministry of Health, NGOs, health professionals and Department of Human Resource Development (SJEW Sikkim, 2015), but not many PWDs benefit from them.

Persons with disabilities in Sikkim get benefits from two different pension schemes, namely: The Indira Gandhi Disability Pension (IGDP) scheme which provides Rs 700 per month to persons in the age group of 18 to 79 years, and Rs 1000 per month to persons above 80 years. To get this pension, the disabled person must be from Below Poverty Line, with at least 80% disability. For this pension, Rs 200 per person comes from the Central Government while the remaining is provided by the State Government. A state subsistence allowance provides Rs 600 per month to persons with at least 40% disability, who are not covered under the IGDP, however, the truth remains that many do not receive any pension, inspite of being qualified for it.

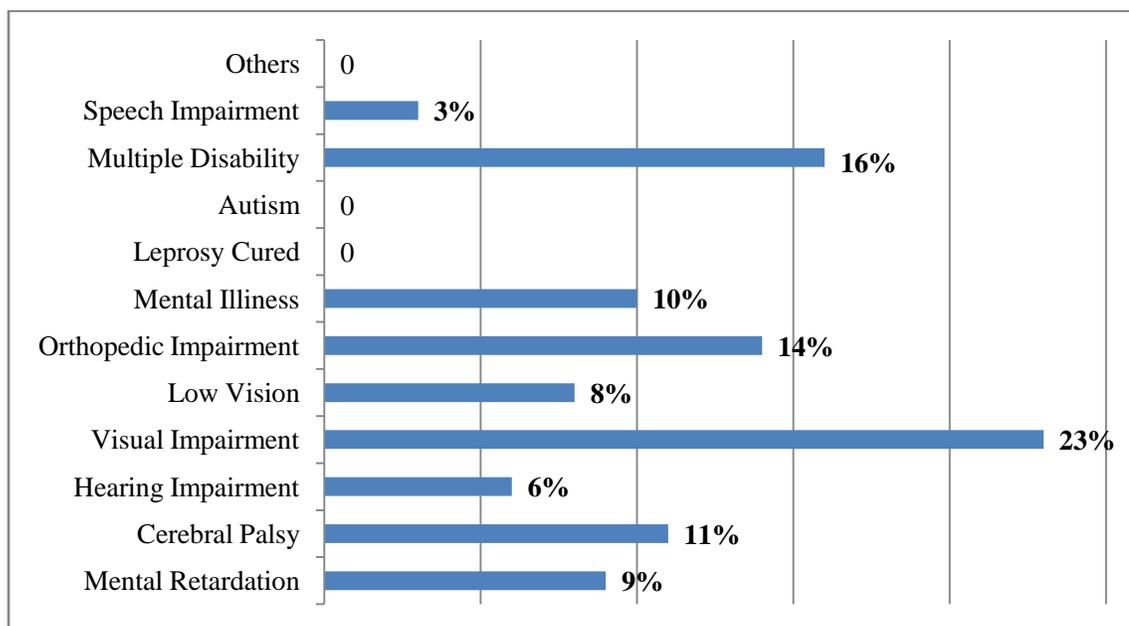
The state of Sikkim lacks far behind when it comes to disability rights: very few facilities are provided to PWDs, and whatever provided is actually dependent solely on the GOI schemes. The state in itself does not have any substantive programme for PWDs. Based upon fieldwork, this chapter attempts to bring out the various problems and also the prospects for PWDs in Sikkim. The chapter consists of different themes, each where awareness, accessibility, availability, infrastructure barrier and underutilization of

available programmes are thoroughly examined. It also brings out the different priorities, requirements and the areas that need proper focus and work, for improvement of lives of PWDs.

4.2 SOCIO ECONOMIC STATUS OF PERSONS WITH DISABILITIES

Around 9 percent of the Respondents were Mentally Retarded, 11 percent had Cerebral palsy, 6 percent were Hearing Impaired, 23 percent – the highest number of respondents - were Visually impaired, 8 percent were low visioned, 14 percent were orthopedically impaired, 10 percent were mentally ill, 3 percent were speech impaired and 16 percent had multiple disabilities(see figure 4.2.)

Figure: 4.2 Composition of Category of Disability among the Respondents



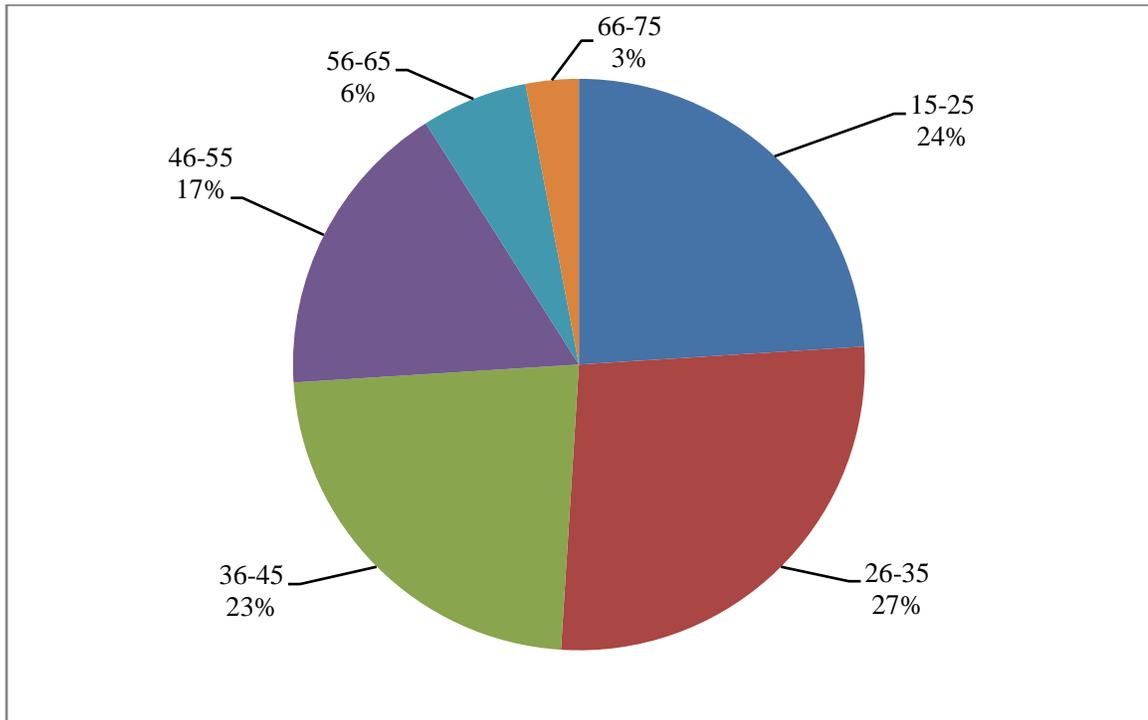
Source: Field Work, 5th October, 2016 to 15th November 2016, Sikkim

4.2.1 RESPONDENTS AGE WISE

All the Respondents in the sample are persons with disability belonging to different age groups. The figure below shows the composition of the age group of the Respondents. The age of Respondents are classified into four categories: (a) 15-25 years, (b) 26-35 years, (c) 36-45 years, (d) 46-55 years, (e) 56-65 years and (f) 66-75 years. As

seen in figure 4.3 the Respondents the maximum number of Respondents are of age group 26-35 years, followed by 15-25 years, 36-45years, 46-55 years, 56-65 years and 66-75 years respectively.

Figure 4.3 Composition of the Age Group of the Respondents

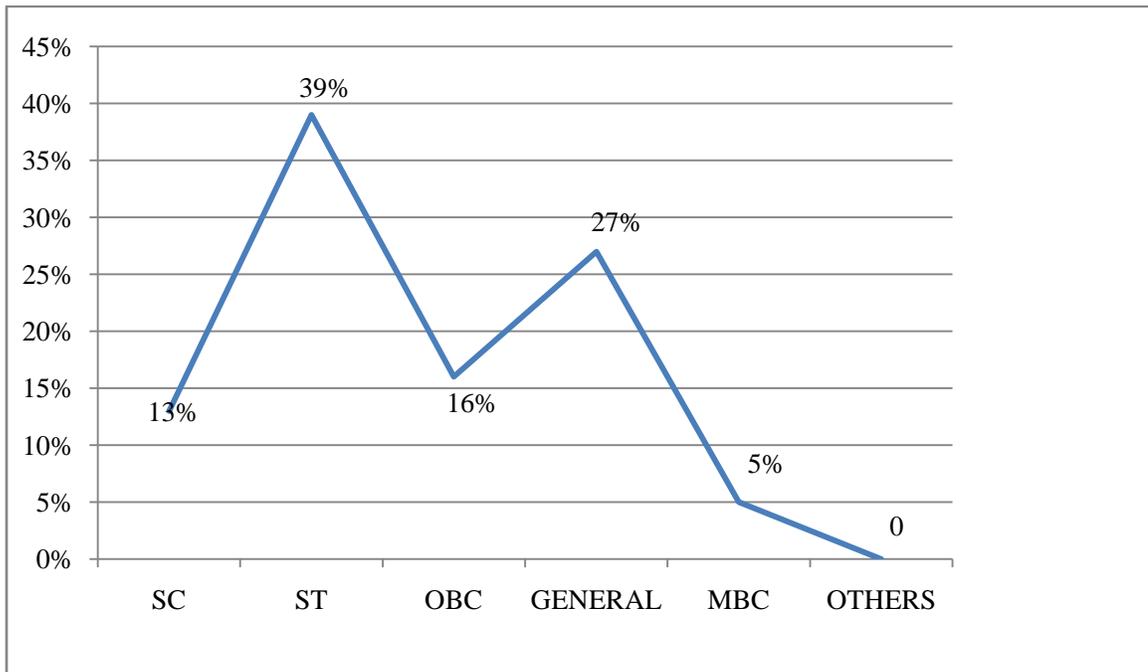


Source: Field Work, 5th October, 2016 to 15th November 2016, Sikkim

4.2.2 COMPOSITION OF THE RESPONDENTS CASTE AND GENDER WISE

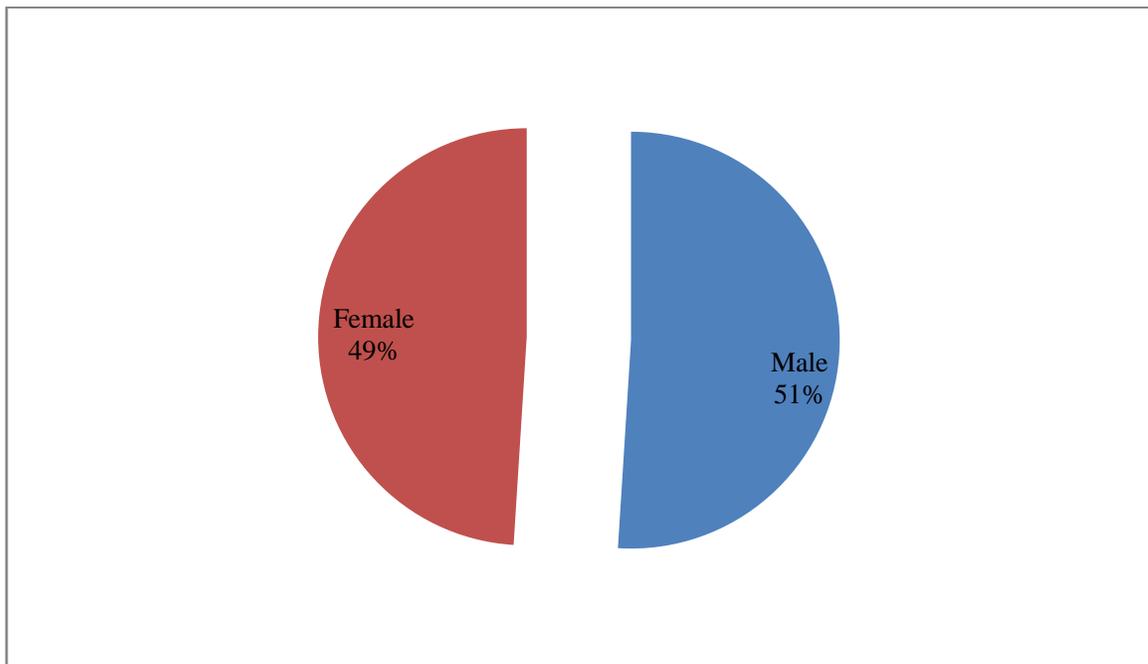
The sample group belong to the varied castes and communities of Sikkim – 39percent of the sample of study belong to the Tribal communities like the Bhutias, Lepchas, Sherpas and others. 27 percent the second highest number of PWDs are from the General category like Sharma, Chettri, Pradhan etc. That is followed by other backward castes consisting of around 16 percent like Rai, Thapa, Thami, Gurung, Sunuwar etc. Around 13 per cent of the Respondents belong to scheduled castes like Barailey, Sunam, Balmiki, Sewa, Pariyar etc. A total of 5 percent fall under Most backward class like Tamang, Subba etc (see figure 4.4). Figure 4.5 shows that among the sample size of 100 heads, 51 percent were male Respondents and 49 percent were female Respondents.

Figure: 4.4 Compositions of the Respondents Caste Wise



Source: Field Work, 5th October, 2016 to 15th November 2016, Sikkim

Figure 4.5 Composition of the Respondents Gender wise



Source: Field Work, 5th October, 2016 to 15th November 2016, Sikkim

4.2.3 COMPOSITION OF EDUCATION QUALIFICATION OF THE RESPONDENTS

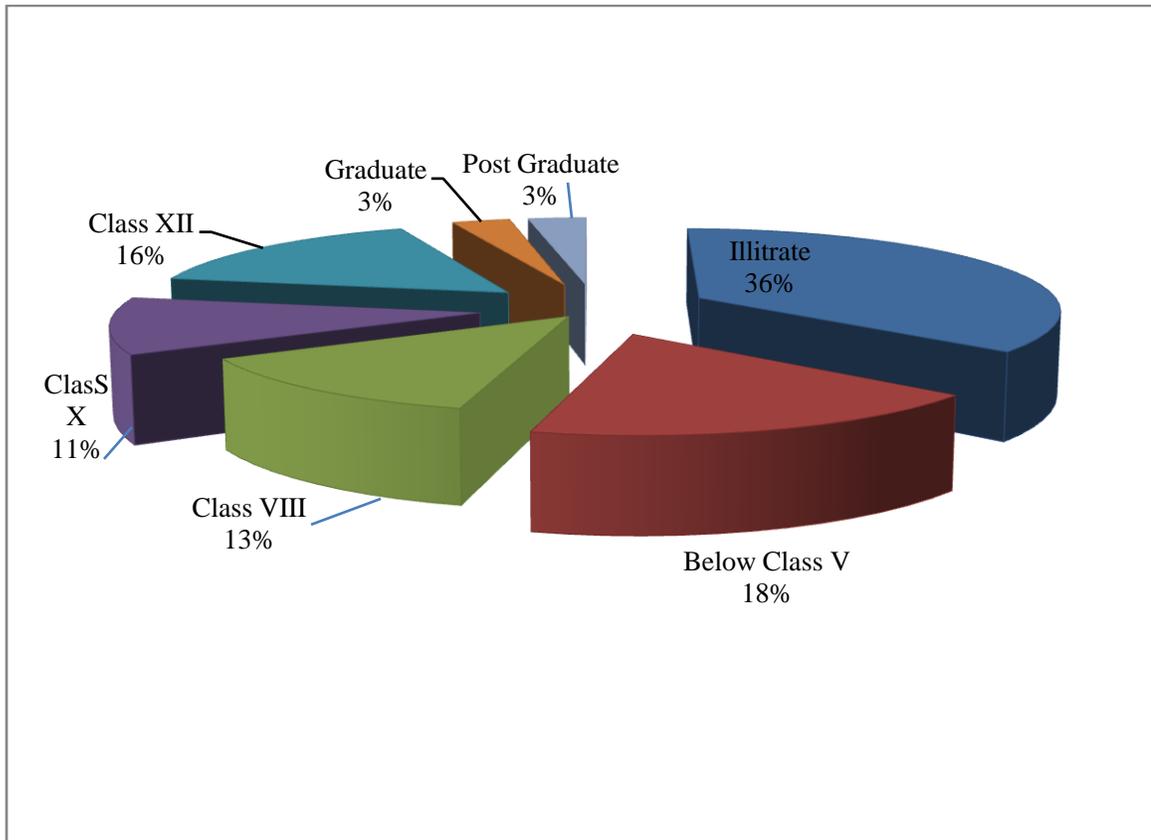
As per the Census 2011, Sikkim has a total population of 610,577. In 2001, total population was 540,851. Literacy rate in Sikkim has seen an upward trend and is 81.42 percent as per the 2011 population census. In 2001, literacy rate in Sikkim stood at 68.81 percent. In actual numbers, total literates in Sikkim stands at 444,952. The education qualification criteria among the Respondents were divided into seven sections namely Illiterate, below Class V, Class VIII, Class X, Class XII, Graduate & Postgraduate. Out of the 100 population size of PWDs, 36 percent of the interviewed PWDs were illiterate and never got a chance to attend school, 18 percent got to attend school but dropped out before completing class V, 13 percent of them attended school till class VIII, 11 percent attended till class X, 16 percent attended till class XII, 6 percent of the PWDs were educated till graduation, 3% till post graduation each (see figure 4.6.)

Education has always been considered to be a very important dimension of any agenda, for development programmes in a society. With the socio-economic and political evolution of mankind and its growth in consciousness, education has been gradually recognised as a “human right”. Education always plays a vital role in every sector. So here too, education is taken as one of the main variables and the education qualifications of the Respondents are analysed. As highlighted above, when it comes to Literacy rate, Sikkim has seen upward trend as per census 2011, but when take a look at literacy rate, amongst the disabled population, it shows a complete different picture - 36 percent being illiterate, not able to read and write and only 6 percent of the PWDs were able to complete degree courses.

As per Filmer D, 2008 children and youth with disabilities are less likely to start school or attend school than other children without disabilities. They also have lower transition rates to higher levels of education. There are various reasons that contribute to such results, for example, - a) a regular school may not accept a CWSN b) parents may be unwilling to send a CWSN to school c) there are not enough special schools d) there is the harbouring of negative attitude e) awareness rate is low f) there are infrastructure

barrier and untrained teachers - are a few reasons as spelled out by the Respondents, for being dropped out or not being able to attend school

Figure: 4.6 Composition of Education qualifications of the Respondents:



Source: Field Work, 5th October, 2016 to 15th November 2016, Sikkim

4.2.4 COMPOSITION OF OCCUPATION AMONG THE RESPONDENTS

In a contemporary society, occupation is a necessity for a stable source of income. Since a good and stable source of income is a major factor which helps in determining social security of an individual. In this study, occupation of the sample population was divided into seven sections, namely, Government. Servant, Pvt. Jobholder, Farmer, Student, Self Employed, Others, Unemployed.

The survey revealed that 21 percent of the population were in government sector jobs, 8 percent were engaged with private sector, 9 percent were farmers, 20 percent were

students, 3 percent were self employed, 2 percent were engaged on ad hoc basis and 37 percent of them, were unemployed.

36 percent of the sample population were Illiterates as seen in figure: 4.6 so naturally, they were not in any kind of employment and were dependent on some other person for financial security, but 29 percent of the population were engaged in government and private jobs, which was possible due to three percent job reservation for PWDs as per PWD Act 1995. 20 percent of those who were still students were aware of the reservation and expressed their willingness to join the government sector after completing their education. Those who were in some kind of employment expressed that they are not satisfied with their job as they are not given the job of their interest, but were taken in due to reservation and asked to work either in special schools or given clerical work. They feel they are capable of doing much more than what they are served with, but they lack opportunities. Misconceptions about the capabilities of people with disabilities to perform jobs are important reasons, both for their continued unemployment and – if employed – for their exclusion from opportunities for promotion in their careers (Shier M, Graham J, Jones, 2009).

Table: 4.1 Composition of Occupation among the Respondents

OCCUPATION	NUMBER OF RESPONDENTS	PERCENTAGE
Government Servant	21	21%
Private Jobs	8	8%
Farmer	9	9%
Student	20	20%
Self Employed	3	3%
Unemployed	37	37%
Others	2	2 %
Total	100	100%

Source: Field Work, 5th October, 2016 to 15th November 2016, Sikkim

4.2.5 COMPOSITIONS OF EARNERS IN RESPONDENTS FAMILY

The number of earners in a household is also a great indicator of social security for persons with disabilities. More the earners in the family, more facilities can be availed

by PWDs like therapeutics, medical, education, transportation needs etc. Most of the Respondents - about 38 percent - did not have any earning member in the family, 32 percent had one earning member, 25 percent had two earning members, 4 percent had three earning members and only 1 percent had more than five earning members in the family. This signifies that the maximum number of PWDs are not secure and do not enjoy the fulfillment of their basic needs and requirements, due to financial instability in the family. Also, facilities of financial assistance to such people by GOI do not reach them, as they don't have proper identification cards either. Most of them are not aware of such facilities and huge number of them don't know where to seek facilities from.

Table: 4.2 Compositions of Earners in Respondents Family

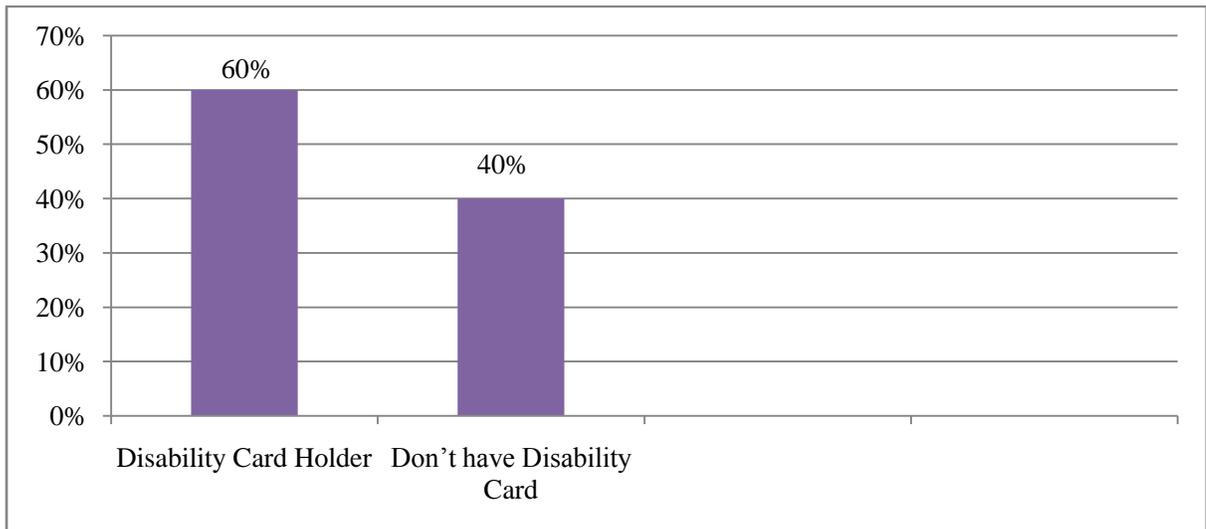
Numbers of Earning Member in the Family	NONE	ONE	TWO	THREE	FOUR	FIVE & ABOVE
	38%	32%	25%	4%	0%	1%

Source: Field Work, 5th October, 2016 to 15th November 2016, Sikkim

4.3 COMPOSITION OF RESPONDENTS HAVING DISABILITY CARD

Disability identification card is one of the main documents for PWDs. Only those that possess Disability card can seek for Government facilities. It works as identification for them to be considered for concession and their rights. The figure below shows that about 60 percent of the Respondents have disability card and 40 percent do not have any kind of disability identification card.

Figure: 4.7 Compositions of Respondents having Disability Card

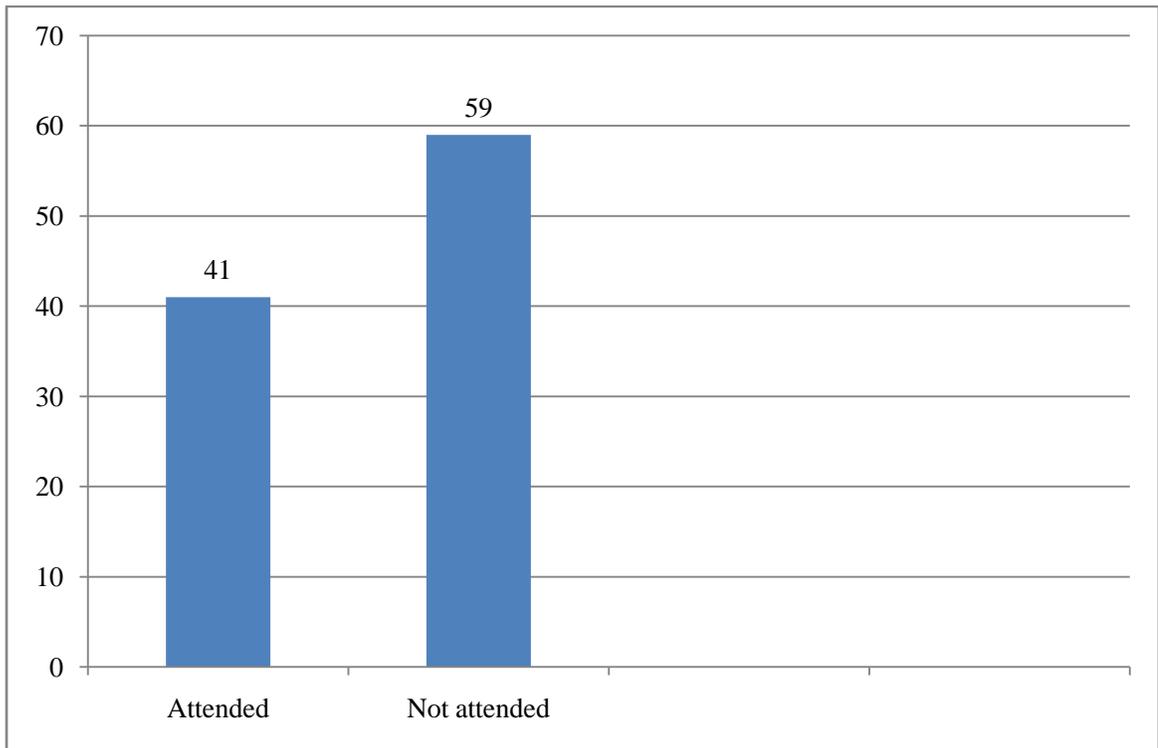


Source: Field Work, 5th October, 2016 to 15th November 2016, Sikkim

4.3.1 COMPOSITION OF RESPONDENTS WHO HAS ATTENDED DISABILITY CAMPS

Around 41 percent of the Respondents have attended disability camps, organised by different Government departments in the district head quarters. 59 percent never got any chance to attend such camps. (i) Not aware of such camps (ii) location too far to attend camps (iii) did not have anybody to escort them to the venue, were some of the reasons why the Respondents answered that they could not attend the camps. The 41 percent who had attended disability camps were the ones residing in urban areas - they said (i) it was easy for them to get the conveyance to reach the camp venue, (ii) they were taken to the camp by the Village Panchayats, school heads and parents (iii) they knew about the camp from the local newspaper and (iv) lived in the organised camps' vicinity (see figure 4.8.).

Figure: 4.8 Compositions of Respondents who has Attended Disability Camps

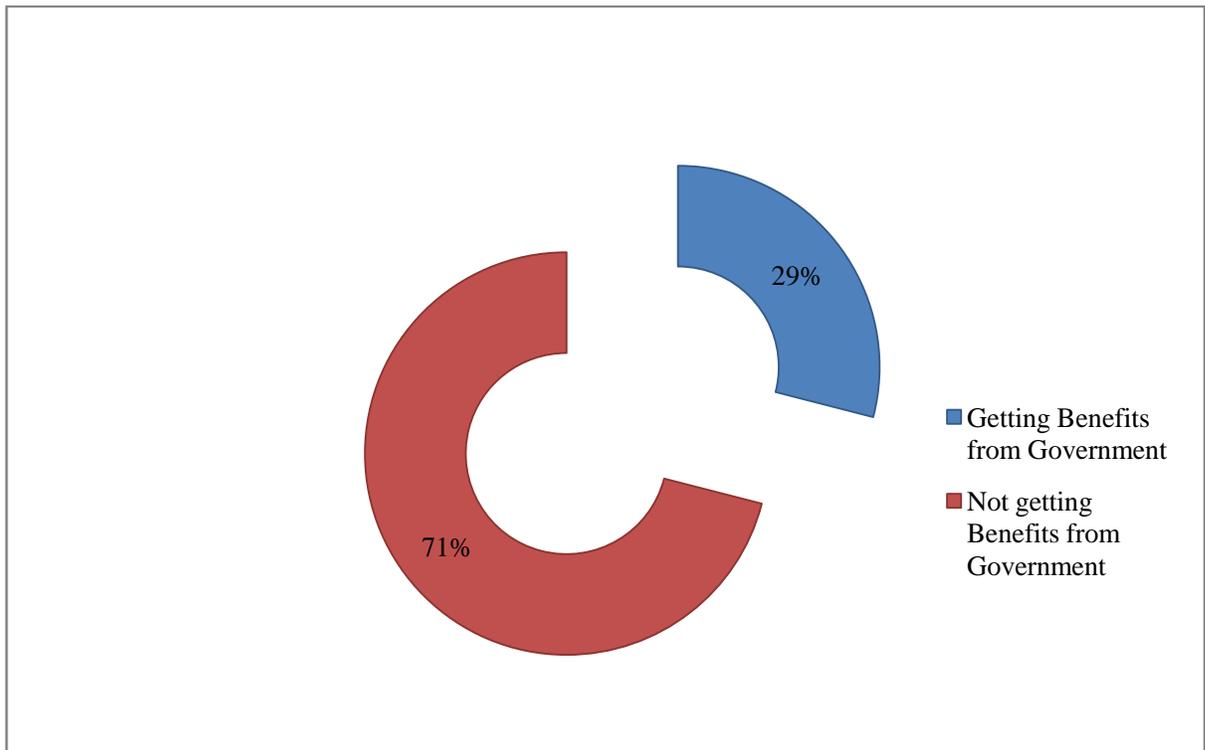


Source: Field Work, 5th October, 2016 to 15th November 2016, Sikkim

4.3.2 RESPONDENTS GETTING BENEFITS FROM THE GOVERNMENT

Figure 4.9 shows that only 29 percent out of 71 percent of the Respondents, receive Government benefits. As seen in figure 4.7, around 60 percent of the Respondents possess disability cards which makes them eligible for getting disability pension and other benefits but only 29 percent out of 60 percent receive Government benefits, especially designed for PWDs. The various reasons contributes to such result like low awareness about ones right being the most prominent one, negligence from government part , state does not have a center or cell where PWDs can enquire about their benefits and rights. Disabled persons, their families and care givers incur substantial additional expenditure for facilitating activities of daily living, medical care, transportation, assistive devices, etc. Therefore, there is a need to provide those benefits and facilities at their doorstep by various means

Figure: 4.9 Respondents getting and not getting benefits from the Government

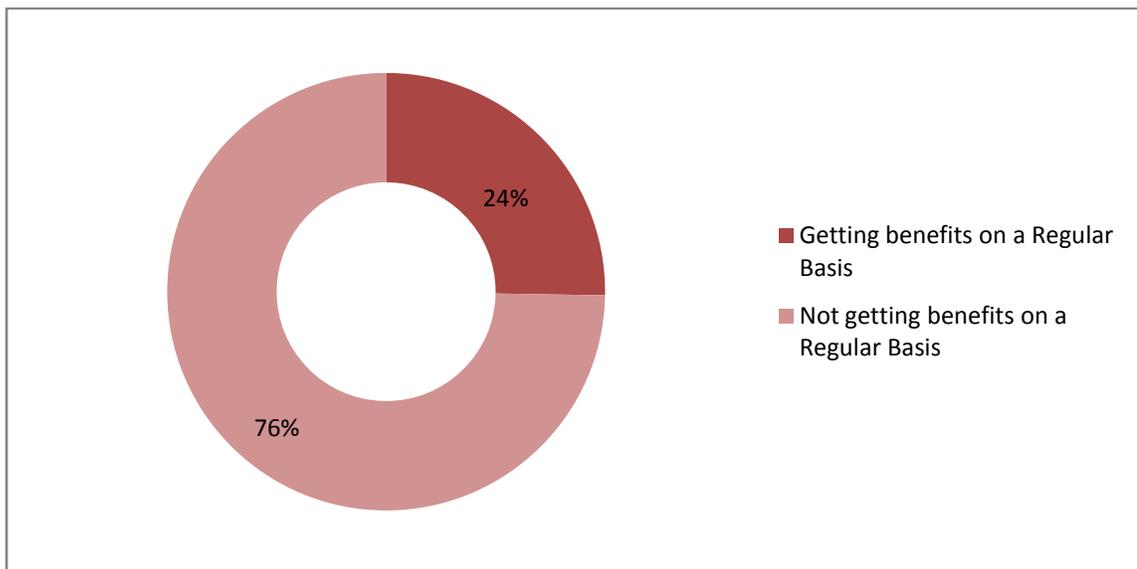


Source: Field Work, 5th October, 2016 to 15th November 2016, Sikkim

4.3.3 RESPONDENTS GETTING BENEFITS FROM GOVERNMENT ON REGULAR BASIS OR IRREGULAR

Figure 4.10 shows that only 24 percent gets benefits on a regular basis and 76 percent do not get any benefits and those who do receive benefits comprise of around 5 percent of the 76 percent do not get them on a regular basis.

Figure: 4.10 Respondents Getting Benefits on a Regular Basis



Source: Field Work, 5th October, 2016 to 15th November 2016, Sikkim

4.4 AWARENESS ON GOVERNMENT SCHEMES AND OBSTRUCTUAL FOR DISABLED PERSONS

Knowledge and awareness is a basic requisite to avail any kind of facilities, made for PWDs. Lack of information and awareness make persons with disabilities often unaware of the available benefits and schemes, primary health care and employment opportunities, which directly question their social security.

4.4.1 RESPONDENTS AS AWARENESS ABOUT GOI SCHEMES FOR THE DISABLED

Table 4.3 highlights awareness of Respondents on GOI schemes that are designed for PWDs. The scheme is designed to ensure a better life for the disabled, with assistance. Respondents when asked about such schemes answered in a manner that came as a surprise. 38 percent were not at all aware of any of the schemes and these lot of people were the ones who never got a chance to attend school, and those who were mentally ill. 39 percent of the Respondents knew about the entire scheme designed for PWDs and these Respondents were those who were already engaged in some kind of employment and those who were studying in higher classes. 9 percent were aware of educational

scheme while 6 percent were aware of employment and travel concession 3 percent each, while 8 percent were aware of ADIP scheme and these were the ones who had availed facility from the schemes in the past.

As per the field survey, it was found that maximum number of Respondents and their families are not at all aware of any schemes and facilities. It was observed that those who are aware of such schemes and programmes only had a rough idea about it and lacked in-depth knowledge. Further they don't even know where to seek facilities from. This is of great concern to the family members as they feel nothing has been done by the government, to bring awareness of such schemes. There were many such cases reported where the local level government functionaries had promised the Families of PWDs about providing them with disability cards and benefits, but it never materialised even after submitting the required documents and papers, a multiple numbers of times. Scenarios like these have led to a situation where families do not have faith in Government Functionaries and GOI and State schemes.

Table : 4.3 Respondents as Awareness about GOI schemes for the Disabled

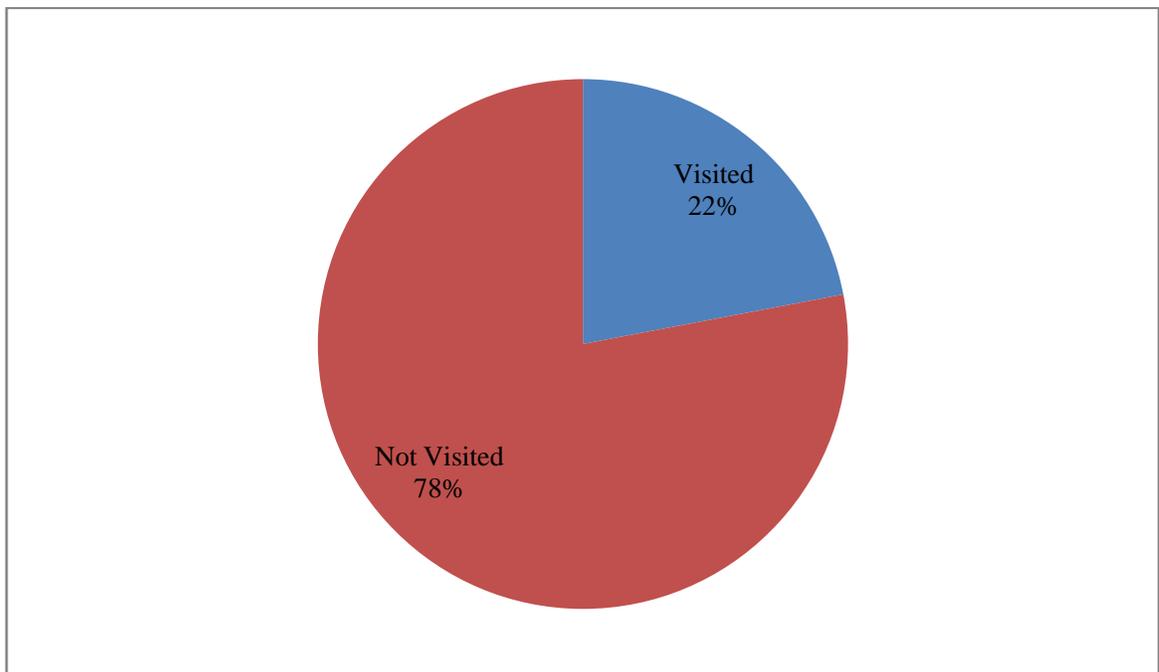
Government of India Schemes	Number of Respondent	Percentage of Respondents
Education Scheme	9	9 %
Employment Scheme	3	3%
ADIP Scheme	8	8%
Economic Assistance	0	0%
Travel Concession	3	3%
All Of The Above	39	39%
Not Aware	38	38%
Total	100	100%

Source: Field Work, 5th October, 2016 to 15th November 2016, Sikkim

4.4.2 COMPOSITION OF RESPONDENTS VISITED OR NOT VISITED DDRC

District Disability Rehabilitation Centres (DDRCs) started as outreach activity of the Ministry of Social Justice and Empowerment of Government of India, for (a) providing comprehensive services to persons with disabilities at the grassroot level (b) facilitating the creation of infrastructure and capacity building at the district level and (c) awareness generation, rehabilitation and training of rehabilitation professionals. Sikkim has one DDRC located at Gangtok. When asked about DDRC, only 22 percent of the Respondents had visited DDRC, and they are the ones who live in Gangtok, the capital town of Sikkim where the DDRC office is situated. 78 percent of the population never got a chance to visit DDRC. These were the Respondents who did not have any idea about what DDRC is and how it functions, some of them knew about it but could not visit as they were located too far away, and some even said that the office was located around many infrastructure barriers, restricting their visit.

Figure: 4.11 Composition of Respondents visited or not visited DDRC

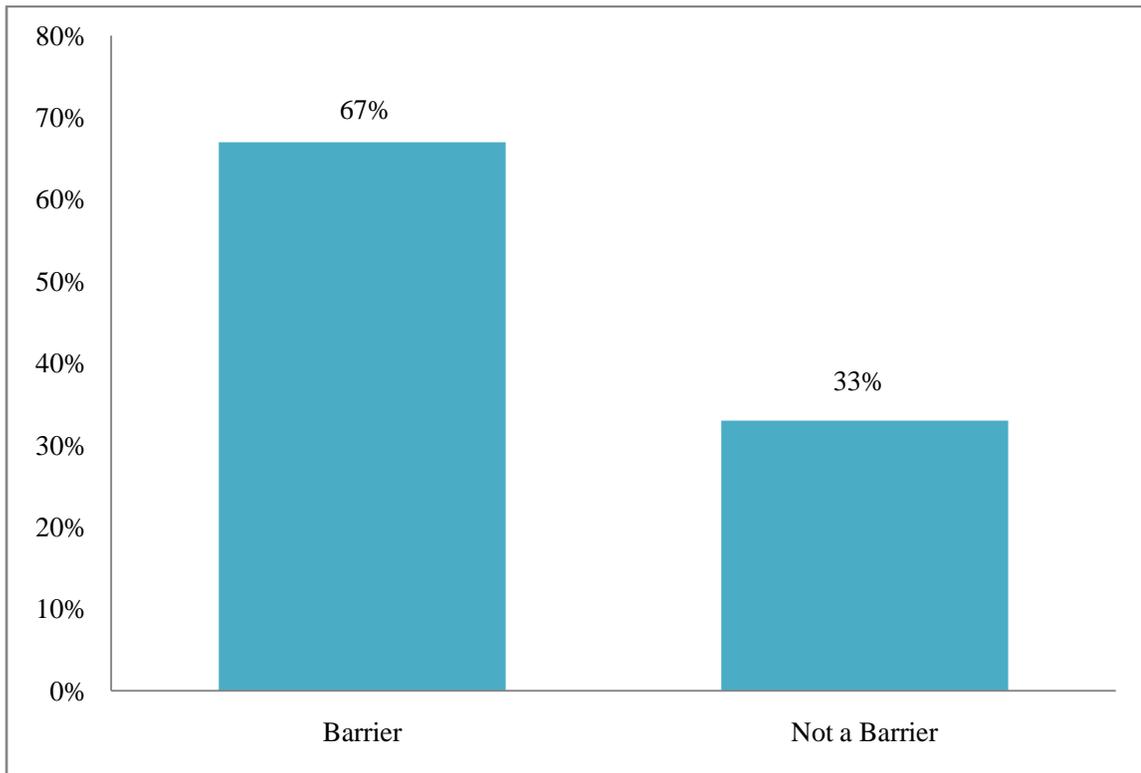


Source: Field Work, 5th October, 2016 to 15th November 2016, Sikkim

4.4.3 RESPONDENTS FEEL INFRASTRUCTURE IS A BARRIER

A person's environment has a huge impact on the experience and extent of disability. About 67 percent of the Respondents feel that the infrastructure around them are the major hurdle that adds to their disability, making them more handicapped than the actual condition, leading them to depend on others for minutest of things. They feel that they could achieve many things on their own if the barrier was not there or if it was made accessible for PWDs. 33 percent don't feel any barrier in the infrastructure, these are the Respondents who have less degree of disability and Respondents - hearing & speech impairment, mental illness, mental retardation - and not any physical disability and easier mobility. People with orthopedic impairment, cerebral palsy, multiple disability and visual impairments were the Respondents who felt infrastructure is a major barrier in their lives. As per Meyers AR et al., 2002, inaccessible environments create disability by creating barriers to participation and inclusion. As per the field survey, the same thing has come into light, majority of the Respondents feels their participation and inclusion is hampered by inaccessible environment. Further, they feel transportation provides independent access to employment, education, and health care facilities, and to social and recreational activities in which they are lagging because of the barrier in the environment. Without approachable transportation, people with disabilities are more likely to be excluded from services and social contact (Roberts P, Babinard J., 2005). Therefore, immobility and dependency, as per the view of Respondents are the reasons for not availing facilities made for them. Some PWDs have never stepped out of the house since their birth, have never visited even their own locality and yearn to travel by motor vehicles and see towns and touristy places, like Gangtok, Namchi, Chardham (tourist destination) etc.

Figure: 4.12 Respondents View on Infrastructure

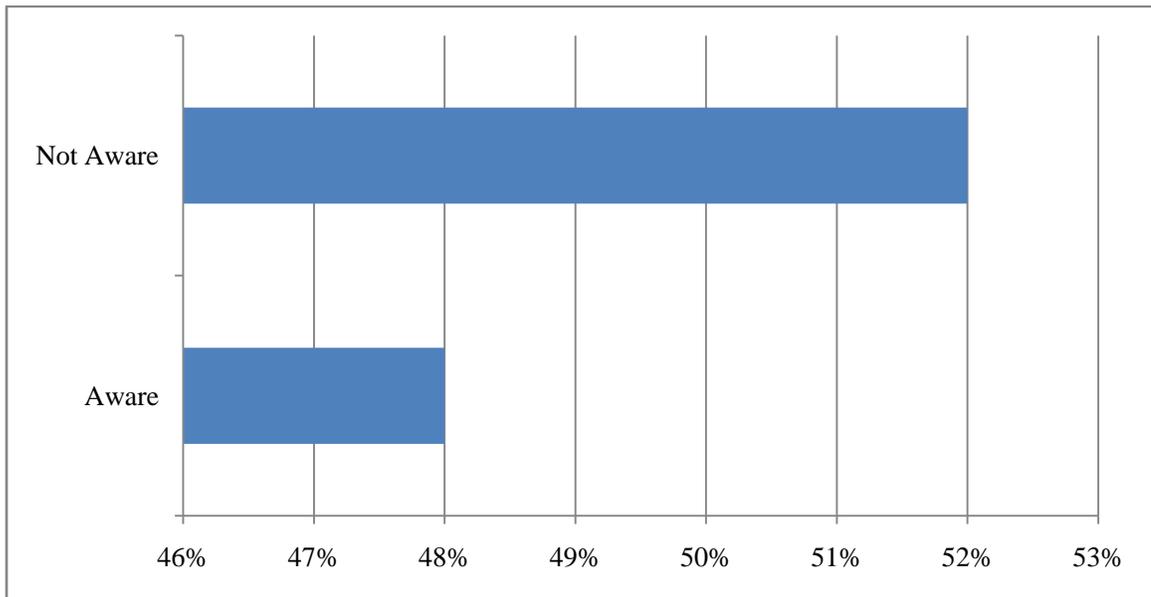


Source: Field Work, 5th October, 2016 to 15th November 2016, Sikkim

4.4.4 COMPOSITION OF RESPONDENTS AWARENESS ON 3% JOB RESERVATION FOR PWD'S

Three percent reservation has been granted to persons with disabilities as per the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995. Table 4.13 shows how aware Respondents are about this important right. As per the table, 52 percent of the Respondents are not aware of such reservation and have never heard of it, while 48 percent of the Respondents are aware and maximum from this group are already in a job through the same reservation. 52 percent of the Respondents who are not aware of the reservation are the ones who are illiterate, don't have a disability card and are not in any kind of job.

Figure: 4.13 Respondent's Awareness On 3% Job Reservation for PWD in Sikkim



Source: Field Work, 5th October, 2016 to 15th November 2016, Sikkim

4.4.5 RESPONDENTS AWARENESS ON FACILITIES & CONCESSIONS FOR PWD'S

Awareness and knowledge is a basic requirement to avail any kind of facilities, made for PWDs. As per the field survey, it was found that maximum number of Respondents and their families are not at all aware of any schemes and facilities. About 39 percent and 30 percent are aware of the entire scheme, possess disability card and are getting facilities from the programmes. 6 percent were aware of job reservations, 7 percent were aware of schemes that provide aids and appliance, 8 percent knew about travel concessions and are already availing it on train journeys, out of Sikkim. 10 percent knew about disability card and disability pension. Lack of awareness was one of the major reasons for not being able to get facilities and concession made for PWDs.

Table: 4.4 Respondents Awareness on Facilities and Concessions for PWDs

FACILITY & CONCESSION	NUMBER OF RESPONDENTS	RESPONDENTS IN PERCENTAGE
Disability Pension	5	5%
Disability Card	5	5%
Travel Concession	8	8%
Aids & Appliances	7	7%
Education Scholarship	0	0%
Reservation In Jobs	6	6%
Not Aware	39	39%
All Of The Above	30	30%
Total	100	100%

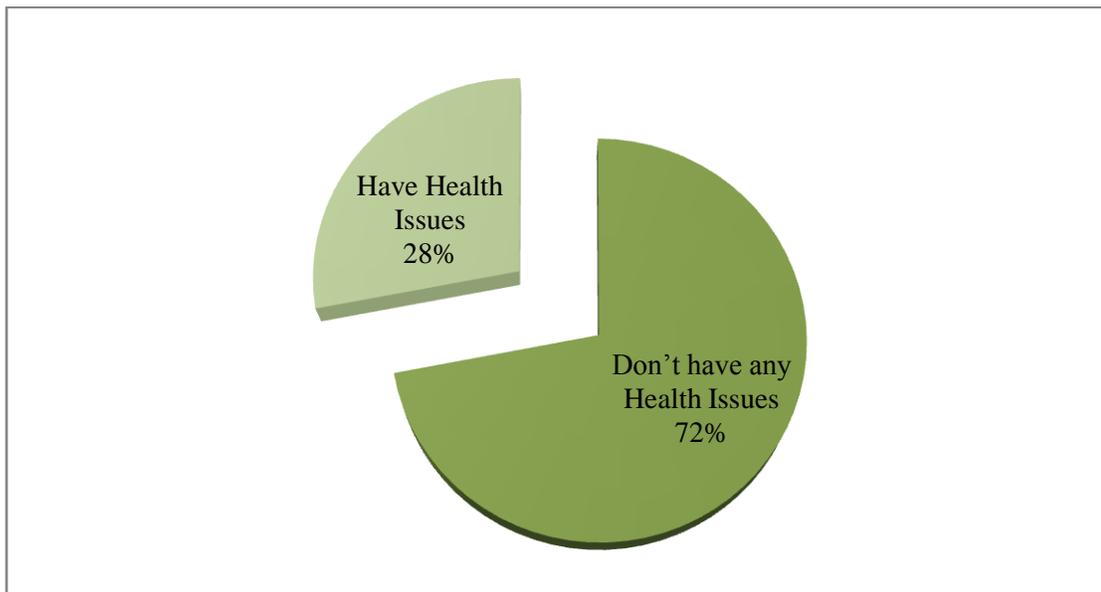
Source: Field Work, 5th October, 2016 to 15th November 2016, Sikkim

4.5 HEALTH ISSUES OF PERSONS WITH DISABILITIES

As seen in figure 4.14, around 28 percent of the Respondents had an accompanying health condition with the disability like high blood pressure, obesity, diabetes, heart problem etc and were from the well-informed families, aware of the disabling conditions, living in the district headquarters, with easy access to health care service: few of them even had doctor as a family members. It explained why they got an opportunity to do their routine check-ups and find out of other health issues as well. Around 72 percent of the Respondents reported not having any health issues. This is because they were never taken to the hospital or never visited a doctor to consult about the condition or never had a routine check-up done. The Respondents believed they would never have any health conditions. Being born with disability, the Respondents believed, was the biggest of all health problems, and nothing could surpass this. That's why, other health issues – like influenza - are considered minor, not worthy of a check-up or examination.

An interesting and astounding piece of information that revealed itself during the field work was that families of persons with disabilities sought the help of the Dhamis & Jhakris (shamans) and medicinal plants, instead of Doctors for recovery from the condition. They believe that disability is caused by one's Karma (Religious Belief) of past life and can be cured only with the help of Dhamis & Jhakris. This system is prevalent even today in some parts of the district.

Figure: 4.14 Compositions of Respondents Having Health Issues Along with Disability



Source: Field Work, 5th October, 2016 to 15th November 2016, Sikkim

Some people with disabilities may have a greater need for specialist health care, than the general population. Specialist health care needs may be associated with primary or secondary health conditions. Some people with disabilities may have multiple health conditions, and some health conditions may involve multiple body functions and structures. Misconceptions about the health of people with disabilities have led to assumptions that people with disabilities do not require access to health promotion and disease prevention.

4.6 SOCIETAL PROBLEMS

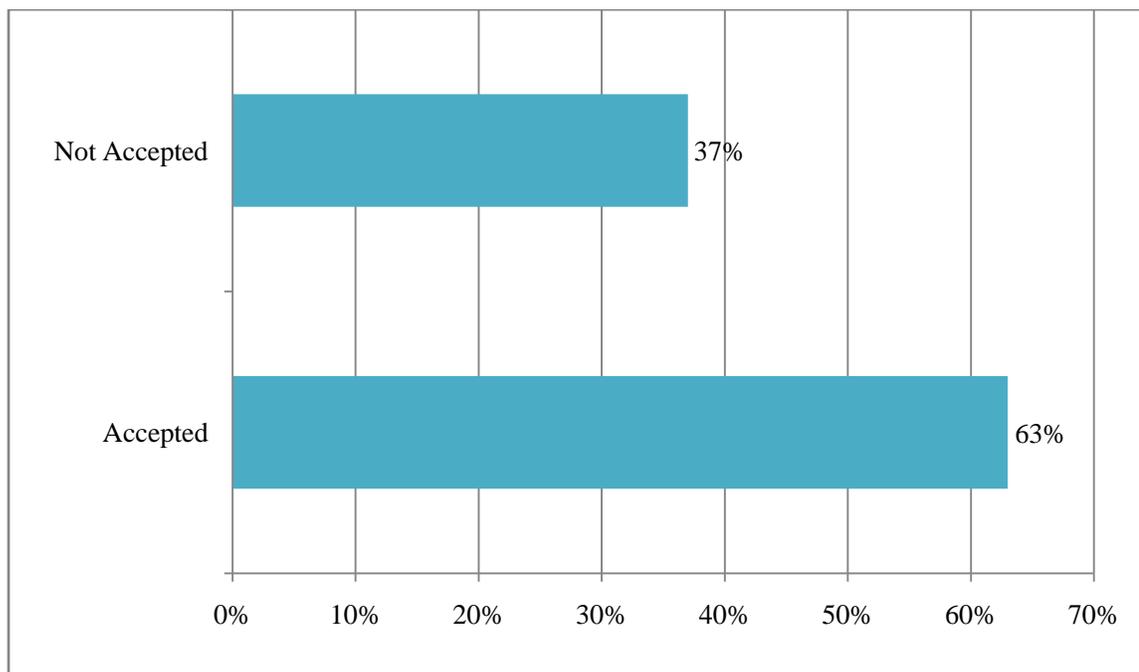
Attitude is an important environmental factor, affecting all areas of service provision and social life. Raising awareness and challenging negative attitudes is often

the first step towards creating more accessible environments for persons with disabilities. Negative imagery and language, stereotypes, and stigma – with deep historic roots – persist for people with disabilities around the world (Yazbeck et al., 2004). Most of the Respondents shared how they are treated in the society, and what they believe, can bring a positive change.

4.6.1 SOCIATAL ACCEPTANCES ABOUT RESPONDENTS DISABILITY

In the present scenario, Sikkim, for the Disabled is fairly accepting (see table 4.15.) It shows that 63 percent of the Respondents feels they are well-accepted in the family and society and that they don't face any discrimination based on their condition, while 37 percent of the population feel they are not accepted as equals or as other regular person: they feel they are discriminated against and not given equal opportunities owing to their disabling conditions.

Figure: 4.15 Societal Acceptances about Respondents Disability



Source: Field Work, 5th October, 2016 to 15th November 2016, Sikkim

4.6.2 COMPOSITIONS OF RESPONDENTS WHO FEEL PEOPLE MAKE FUN OF THEIR DISABILITY

Table 4.16 shows that around 79 percent of the Respondents felt people make fun of their disability and 21 percent felt they are not made fun of. This is in stark contrast to figure 4.15, where 63 percent of the Respondents feel accepted, like any other person in the family and society. This reveals that even when the PWDs are accepted, there are times when people make fun of the PWDs and their disabling conditions. Imitating how PWDs look, talk, walk, eat: name calling, use of slangs and degrading them are few of the degrading instances that PWDs face in the society. Negative attitudes towards disability can result in negative treatment of people with disabilities.

Figure: 4.16 Compositions of Respondents who feel people make Fun of their Disability



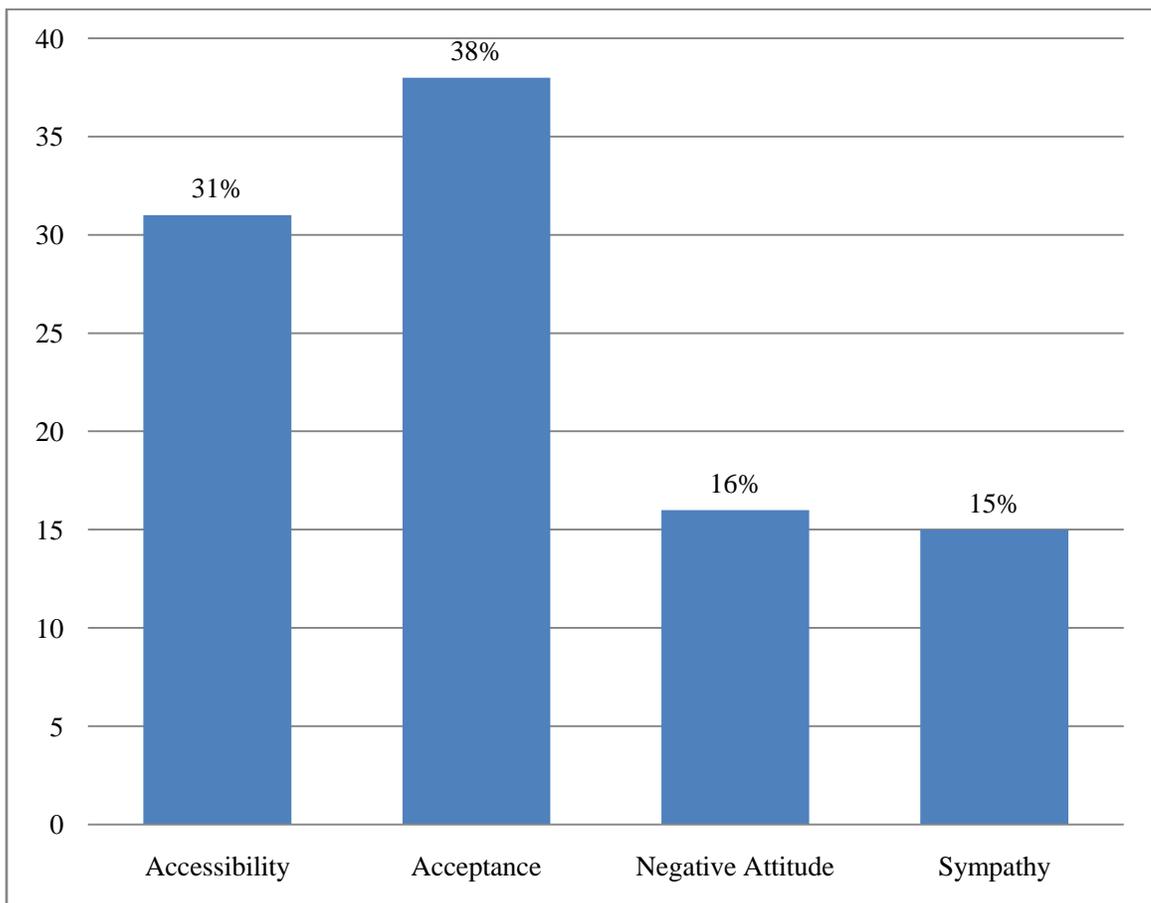
Source: Field Work, 5th October, 2016 to 15th November 2016, Sikkim

4.6.3 MAJOR PROBLEM FACED BY PWDs IN SOCIETY

Environments – physical, social, and attitudinal – can either disable people with impairments or encourage their involvement and inclusion. Table 4.14 highlights the issues faced by PWDs in the environment that they live in. 31 percent feel accessibility is the problem that contributes to the disabling condition, 38 percent feel they are not

accepted like any other regular person and that is the major problem which leads them to self-pity and brings about a feeling of uselessness, 16 percent feel that the society's negative attitude is the problem and 15 percent feel people's sympathy brings in a feeling of inferiority. Rather empathizing with PWDs and giving them equally opportunity to participate in day-to-day activities, would restore their dignity. While discrimination is not deliberate, yet the system indirectly leaves out persons with disabilities, by not taking their needs into account. Unsupportive attitudes and behaviours have an unfavorable effect on people with disabilities, leading to negative outcome such as low self-esteem and reduced participation (Thornicroft G, Rose D, Kassam A, 2007).

Figure: 4.17 Problems Faced by the Respondents in the Society

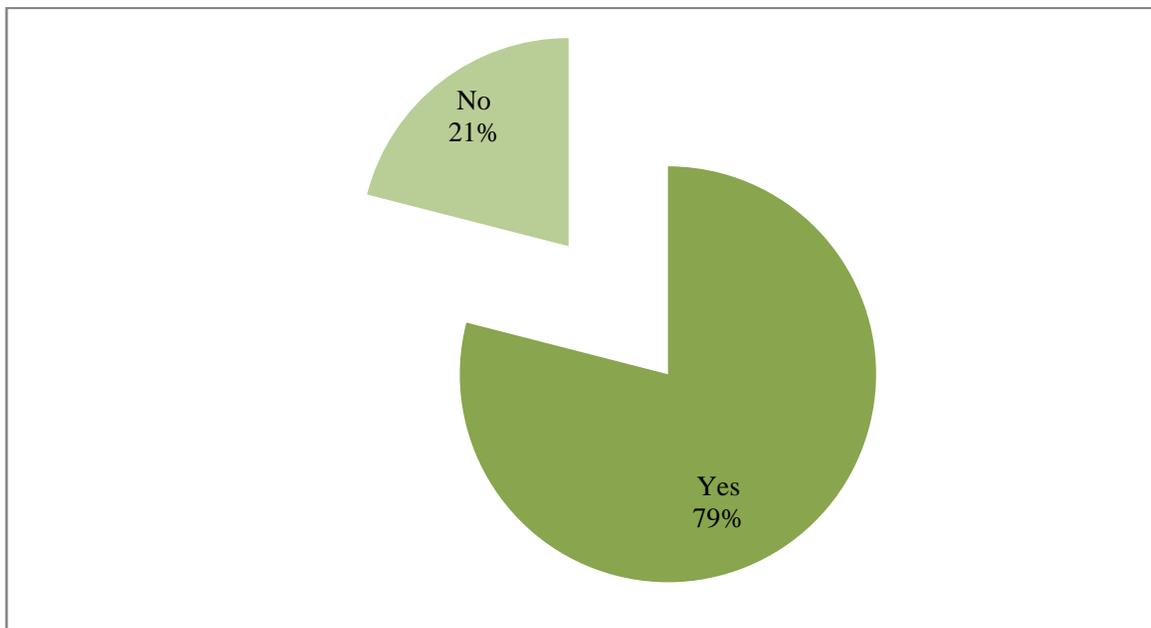


Source: Field Work, 5th October, 2016 to 15th November 2016, Sikkim

4.6.4 COMPOSITIONS OF RESPONDENTS WHO FEEL THEY ARE A BURDEN TO SOCIETY

Around 79 percent of the Respondents felt that they are a burden to their families , to society and to the country and 21 percent felt they are not burdensome as highlighted in figure 4.18. The Respondents who don't feel like burden were people who were engaged in some kind of employment and expressed that they were financially secure and could afford paid caretakers. In fact, some of them already have fixed deposits kept to take care of themselves, when the situation arise, which is why they felt they are independent and equal with other regular person. The maximum lot of people who felt that they are a burden to their family, society and country were the ones who are unemployed and from families without any earning member. Visually impaired person, mentally ill persons, persons with severe disabilities were the maximum number of Respondents who felt they are a burden to the family, society and country.

Figure: 4.18 Respondents Perception on being Burden

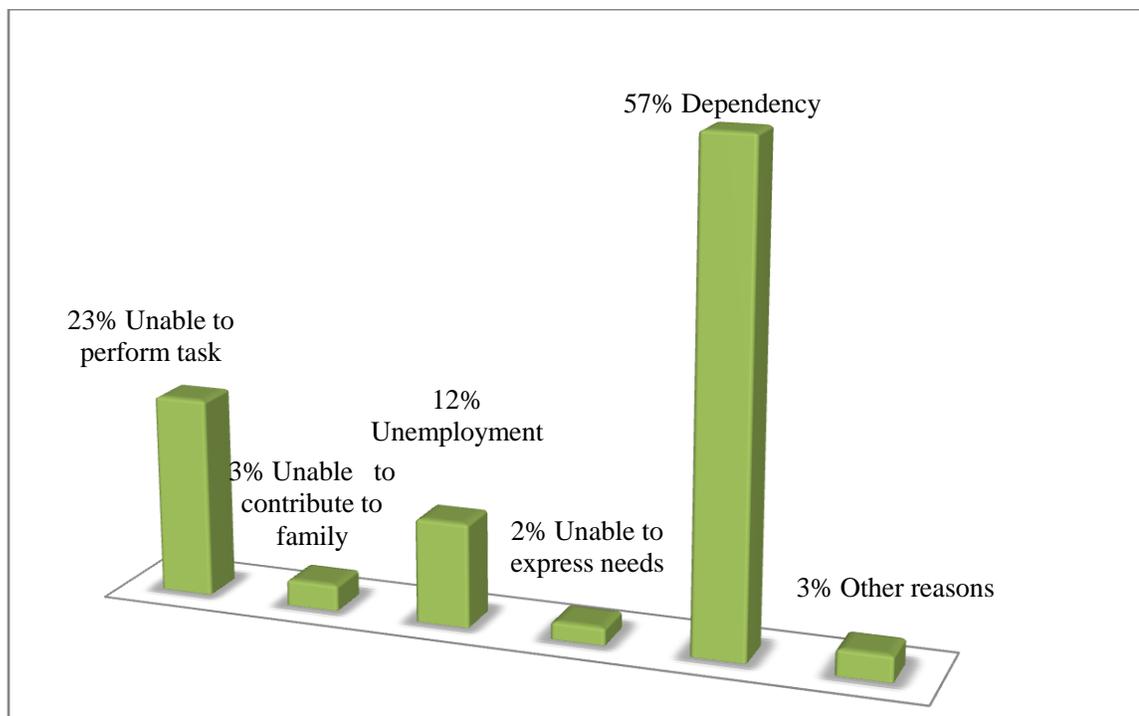


Source: Field Work, 5th October, 2016 to 15th November 2016, Sikkim

4.6.5 RESPONDENTS REASONS FOR FEELING BURDEN

Out of the total population of the sample, 23 percent felt that not being able to perform any task is the reason for feeling burdensome, 3% felt it was because of their inability to contribute to family in any way, 12 percent thought of unemployment as the main factor, 2 percent reason that that it is their inability to express their needs and feelings while the majority of the Respondents opine it is their constant dependency on another, that brings about this feeling. In fact, even those financially secure feel a sense of dependency, which in turn makes them feel burdensome. Maximum number of Visually impaired Respondents felt this way. 3 percent felt there are other various reasons for feeling burdensome. Table 4.19 highlights the details.

Figure: 4.19 Respondents Resons for feeling Burden



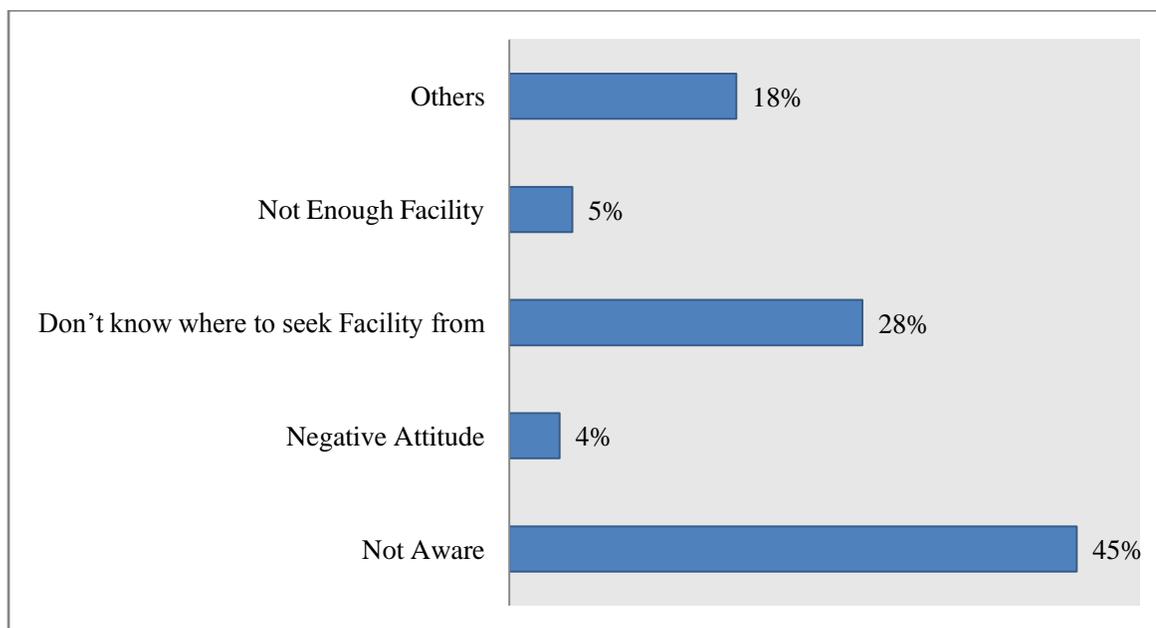
Source: Field Work, 5th October, 2016 to 15th November 2016, Sikkim

4.6.6 RESPONDENTS'S REASONS FOR NOT AVAILING FACILITIES

Around 28 percent think they are aware of the facilities designed for them, but don't know where to seek them from, 5 percent felt that there is not enough facilities to

suffice their needs, 4 percent felt that the negative attitude of people is a contributing factor that discourages them from seeking facilities, 18 percent felt there are various other reasons for not availing the facilities and a large number of Respondents - 45 percent - were not aware of the existence of the facilities.

Figure: 4.20 Respondents Reasons for Not Availing Facilities



Source: Field Work, 5th October, 2016 to 15th November 2016, Sikkim

In order to raise the quality of the lives of the disabled and improve their living standards and provide social security, the government has set up a number of programmes, reservations and departments. The main aim of designing programmes, schemes and policies for PWDs is to manage and provide some sort of security and create an environment, that is inclusive and welcoming: to build infrastructure and other facilities for the people, so that proper utilisation of the facilities granted by the government is benefited by the people. The work of the concerned department or system to ensure their utilisation through public awareness of the facilities available, as well as, of their benefits, concessions and other programme made for PWDs. However, the field survey reveals that in majority, the schemes, funds, programmes available in India to provide social security for persons with disabilities are not utilised by the disabled people.. Most of the government facilities are underutilised and people are unaware of

their facilities. Also, there have not been any efforts taken by the Government, civil society or NGOs to make this group of people aware of their rights and facilities.

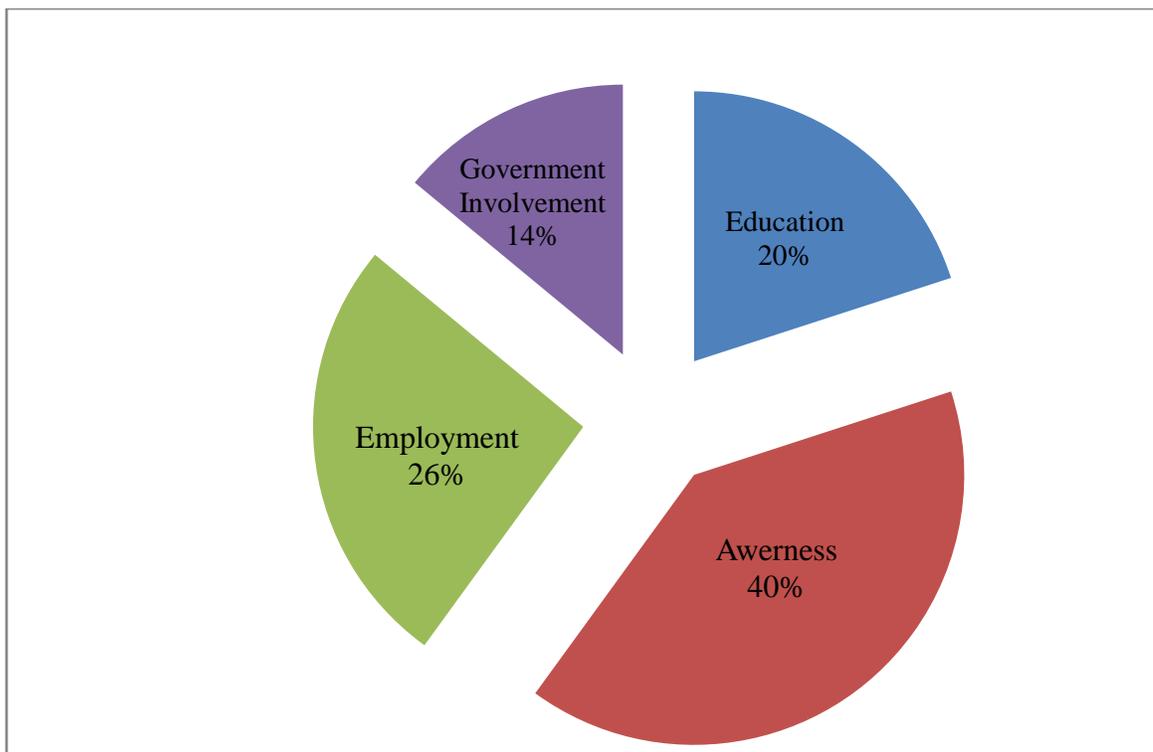
4.7 VIEW OF RESPONDENTS ON FACTORS THAT CAN ACT AS CHANGE AGENT

There are multiple factors – lack of education, unemployment, reduced or no participation in societal activities or nation building - that lead to exclusion of disabled person. Lack of information and awareness makes Persons With Disabilities often unaware of the benefits and schemes available - primary health care and employment opportunities which directly questions their social security. Hence, this study takes the point of view of the Respondents themselves on what can be the agent or factor for change,. Simply put, what in their opinions will bring positive change among people towards accepting disabled population as fully human?

Response can be seen in figure 4.21. Around 26 percent felt that employment can bring change in the perspective of people as they will be able to participate in labour market and stand on their own feet like others, bringing financial security to themselves, as well turn them into equal catalysts for nation building enhancing productivity and becoming part of the mainstream society. 20 percent felt that education can bring change in the society: education is a basic factor for information and updates and only the educated can fight for their rights and bring desirable change, as per the Respondents. 14 percent of the total Respondents believe that the issue of PWDs can be tackled by Government involvement only; they believe change is desirable and also feasible, but only when government is willing to do so. Strong political will and firm determination could manifest this dream, according to the Respondents. 40 percent of the total Respondents realise the fact that positive change is feasible only through awareness programmes - they feel that every individual in every society, whether disabled or not, should be made aware of their existence. Every village and block should organise awareness camps wherein Government representatives and experts speak about facilities, educate the society of certain behavior norms – how to treat a PWD – and inform about their rights like disability card, pensions and other facilities. Hence, they believe that the idea of bringing change into the society should come holistically from the Government,

civil societies, NGOs and every individual. Adding to this, Respondents believe that if everybody unites and comes forward to bring change, than definitely it could be achieved.

Figure: 4.21 View of Respondents on Change Agent



Source: Field Work, 5th October, 2016 to 15th November 2016, Sikkim

4.8 SUGGESTIONS GIVEN BY THE RESPONDENTS TO ADDRESS THE PROBLEMS

The Respondents of the study are PWDs from all walks of life. They comprise of students, employed, farmer, unemployed, self-employed, literate, illiterate etc. Hence, the responses are varied as well as their suggestions come from their own challenges, perspectives and coping mechanisms.

Some of the suggestions given by the Respondents to address the Disability issues are;

- **Employment opportunity:** If people with disabilities and their households are to overcome exclusion, they must have access to work or livelihoods, breaking some

of the circular links between disability and poverty. Productive engagement of persons with disabilities increases individual well-being and contributes to the national output. Disabled people feel maximum of the employment opportunity created requires higher level of education, and maximum of them fail to have such qualification, which is why, they are left behind from the labour market participation. Therefore, they wish to have more number of jobs to be created that don't require education qualification as a criteria to enter into. They express some jobs should only be created for PWDs. Some feel 3% reservation is too less and wants it to be increased at least to 5-7 %

- **Education:** For children with disabilities, as for all children, education is vital in itself but also instrumental for participation in employment and other areas of social activity. Ensuring that children with disabilities receive good quality education in an inclusive environment should be a priority of all. Student Respondents of the study suggested that they be provided with more special teachers, visually impaired students require materials in Braille, which they say never get in time and hampers their studies. They want trained teacher on the needs of special children. They want exam pattern to be changed as per the needs. They also want a residential school for CWSN.
- **Awareness:** Since most of the people of the area of study are not aware of programmes, schemes and infrastructure facilities provided by the government, there should be occasional awareness camps or even a body of people to make known to them about the available facilities. This will also enable them to be aware of their condition and look for the means tackle them.
- **Barrier free environment:** Maximum of the Respondents felt that barriers in the environment - attitudinal or infrastructural - handicap them not because of the existing conditions, but due to barriers. Therefore, accessible environment should be created wherever possible, and general people must be made aware of such condition.

- **Health services:** Proper health facilities, especially focusing on the PWDs should be designed. There should be some provisions to get free medicines .The government and private hospitals do not have sufficient infrastructure that can meet the demands of the people. Therefore they want the government to provide adequate and necessary infrastructure to the hospitals and health centres.
- **Government involvement:** At present, there is only one section in one department that caters to the needs of the PWDs of the State, which is not sufficient. Therefore, they feel government should be involved in every activity that can bring positive change to the lives of disabled. They want Government to implement programmes that are made for them and also to monitor its progress and evaluate its success.
- **Special Residential Home:** At present, there is only one NGO that gives shelter and looks after the needs of mentally ill person. The NGO runs on a donation basis and the continuity is not guaranteed .Therefore they want the Government to provide a full-fledged government undertaking Asylum equipped with all the necessities and professionals that will look after people who are disabled and don't have anyone to take care of them .

CHAPTER -5

CONCLUSION

This chapter summarizes the entire discussion on Persons with Disabilities, with special reference to Sikkim state of India. The study is based on both primary and secondary data collection. In addition, the study focuses on measures to improve accessibility and equality of opportunity; promoting participation and inclusion; and increasing respect for the autonomy and dignity of persons with disabilities. It analyzes the validity of the hypothesis, brings forward the limitations and recommends a few suggestions for future course of research.

5.1 SUMMARY OF THE STUDY

Survival has been the core of every State since ages and in order to secure its nation and its people, war was the only outcome for it. Military might was the weapon for the security of the nation. But as time passed on and this security agenda was challenged by other forms of issues like environment, health, economic, societal etc, where people became the centre of protection. The definition of security thus moved from the state to human. This present study shows how traditional concept of security has been broadened to include nontraditional threats where the role of the national and international system is very important and plays a very crucial role providing societal security to the world. The condition worsens many folds if it is Persons with Disabilities. This study attempted to understand the issues related to disabled population and the status of their social security from international, national and regional perspective by examining the experiences of PWDs in Sikkim.

Conceptualisation of Social security and its origin and the concept of social security in conventional and contemporary world is discussed in the second chapter of this study. Further, it highlights the components that are considered important around the world, that need special attention especially if it is for the disabled population. A detailed discussion on the concept and definition of Disability, impairment and handicap. A growing body of empirical evidence from across the world indicates that people with disabilities and their families are more likely to experience economic and social

disadvantage than those without disability. The vulnerability of the PWDs to socio-economic shocks can be reduced by policies that protect their livelihoods, increase their human capital and assist them in times of crises. Finally the link as to why disabled population around the world is in need of social security has been scrutinized.

Many people with disabilities do not have equal access to health care, education, and employment opportunities, do not receive the disability-related services that they require, and experience exclusion from everyday life activities. Disability is also an important development issue with an increasing body of evidence showing that persons with disabilities experience worse socioeconomic outcomes and poverty than persons without disabilities. Despite the magnitude of the issue, both awareness of and scientific information on disability issues are lacking. There is no agreement on definitions and little internationally comparable information on the incidence, distribution and trends of disability. There are a few documents providing a compilation and analysis of the ways countries have developed policies and responses to address the needs of people with disabilities. Therefore, the third chapter discusses the determinants of disability and draws attention to ensure available benefits reach the beneficiaries, more resources from local state, national and international agencies, Government and Non-Government Organisations need to be mobilized

Disabled persons in India are the most vulnerable group and the tiny state of Sikkim is no different when it comes to providing social security to PWDs. Unfortunately, disabled persons irrespective of their economic status are subjected to social exclusion in the society. Economic, psychological and social confidence building is therefore immediately necessary. Social Security programmes for the disabled, to some extent will relieve the pain of being dependent. Comprehensive administrative arrangement, pooling up funds from various sources and delivering the benefit under professional supervision and control are the other immediate requirements. Lack of information and dissemination and absence of a single window approach make persons with disabilities often unaware of the benefits and schemes that are designed for them.

5.2 FINDINGS OF THE STUDY

Sikkim is no different than other state when it comes to implementation of policies and programmes. In fact, unlike the other many states of India, Sikkim has a higher prevalence of disability now and also has higher tendency of having it in the future, if proper causes of the disability and right facilities are not provided in time. The study draws an understanding that most of the programme and facilities made for PWDs are underutilized where illiteracy, negligence from Government and lack of knowledge and awareness among the Disabled population makes the situation even worse. The lack of knowledge about rights and reservations create an extra burden on the PWDs and their families. Few of the findings of the study are pointed below.

- The number of people with disabilities is increasing.
- Disability disproportionately affects vulnerable populations. There is a higher disability prevalence in lower-income countries than in higher-income countries
- The disability experience resulting from the interaction of health conditions, personal factors, and environmental factors varies greatly.
- Lack of awareness is one of the major factors that keeps PWDs away from availing their rights. Further, illiteracy, inadequate facilities and lack of infrastructure worsens the situation.
- Lack of accessibility including public accommodations, transport systems and information are often inaccessible. Lack of access to transportation is a frequent cited reason that discourages a PWD from seeking work or from accessing health care service, financial support, education etc.
- Often people with disabilities are excluded from decision-making in matters directly affecting their lives
- Negative attitude constitute barriers where teachers do not see the value in teaching children with disabilities, employers discriminate people with disabilities, and family members have low expectations of their relatives with disabilities, neighbors make fun of disabilities.

- People with disabilities are particularly vulnerable to deficiencies in services such as education, health care, rehabilitation, or in getting support and assistance.
- Issues such as poor coordination among government and PWDs, inadequate staffing in concerned department, are adversely affecting the quality and adequacy of services that are made for persons with disabilities.
- Households having persons with a disability have higher rates of poverty than households without disabled members. As a group and across settings, people with disabilities have worse living conditions and fewer assets.
- Illiteracy among the PWDs is one of the major factors in terms of underutilisation of facilities in Sikkim
- Most of the people in the study area live in insecurity because because they lack awareness about their condition, rights and legalities.
- Dependency is one concerning factor that leaves PWDs insecure.
- Lack of community living, inaccessible transport and other public facilities, and negative attitudes leave people with disabilities dependent on others and isolated from mainstream social, cultural, and political opportunities.

5.3 FEW RECOMMENDATIONS

Many of the barriers people with disabilities face are avoidable and the disadvantages associated with disability can be overcome. People with disabilities have ordinary needs – for health and well-being, for economic and social security, to learn and develop skills, and to live with dignity in their communities. These needs can and should be met through mainstream programmes and services. Mainstreaming not only fulfils the human rights of persons with disabilities, it is also more effective.

- Government should review mainstream and disability-specific policies, systems, and services to identify gaps and barriers and to plan actions to overcome them. Effective planning, adequate human resources, and sufficient financial investment should be accompanied by targeted programmes and services to ensure that the diverse needs of people with disabilities are adequately met.

- There is a need for more services, there is also a need for better, more accessible, flexible, integrated, and well-coordinated multidisciplinary services. Broad range of stakeholders including relevant government departments, non governmental organisations, professional groups, disabled people and their representative organisations, the general public, and the private sector should come together to bring awareness on disability , the condition, the type and how people can help PWDs achieve optimum benefits from programmes and schemes, that are made for them . As seen in the field survey, lack of awareness is one single major factor that is keeping PWDs away from availing facilities, made for them.
- Adequate and sustainable funding services are needed to ensure that they reach all targeted beneficiaries and that good quality services are provided. Consideration should be given to expanding health and social insurance coverage, ensuring that people with disabilities have equal access to public social services, education authorities should ensure that schools are inclusive and have an ethos of valuing diversity. Employers should be encouraged to accept their responsibilities towards staff with disabilities and provide those responsibilities that they are appointed for, and providing them with equipments that will foster their efficiency in workplace.
- Implement communication and interaction campaigns to increase public knowledge and understanding of disability.
- Develop a range of quality support services for persons with disabilities and their families at different stages of the life cycle. Special residential home needs to be set up that will look after PWDs who do not have anybody to look after them.
- Counseling and skill development programmes should be developed for PWDs who are not educated and are of age group 30 and above.
- Community environments should be made accessible for people with disabilities, including schools, recreational areas and cultural facilities. Promote the rights of persons with disabilities within their local communities.
- Lastly research is essential for increasing public understanding about disability issues, informing disability policy and programmes, and efficiently allocating

resources. Not much in regards to research has been done in Sikkim. Therefore, many studies should be initiated to better understand PWDs and to come out with solutions to problems.

BIBLIOGRAPHY

Primary sources

Civil society engagement for mainstreaming disability in development process report of an action research project initiated in Gujarat with multi-stakeholder partnership (2008). Gujarat: UNNATI and Handicap International.

Constitution of the World Health Organization (1948). Geneva: World Health Organization.

Convention on the Rights of Persons with Disabilities (2006). New York: United Nations.

Country report: Bolivia. La Paz, Confederación Boliviana de la Persona con Discapacidad (2009). Retrieved from <http://www.yorku.ca/drpi/files> on 23rd August 2016.

Disabilities (2016). *World Health Organization*. Retrieved on 23rd August 2016.

Disability and ageing: Australian population patterns and implications (2000). Canberra: Australian Institute of Health and Welfare.

Disability Rights Commission (2004, 2006). United Nations.

Disability World Report (2011). *World Health Organization*.

Disability, poverty, and schooling in developing countries: results from 14 household surveys (2008). *The World Bank Economic Review*, 22, 141-163.

Education for All Global Monitoring Report (2009). Paris: United Nations Educational, Scientific and Cultural Organization.

Filmer D. (2005). Disability, poverty and schooling in developing countries: results from 11 household surveys. Washington DC: World Bank.

Government of India (2006). Ministry of Social Justice and Empowerment National Policy for Persons with Disabilities.

Hate crime against disabled people in Scotland: a survey report (2004). Edinburgh, Capability Scotland and Disability Rights Commission.

Inclusion International. Better education for all: when we're included too (2009). Salamanca, Instituto Universitario de Integración en la Comunidad.

International Year for Disabled Persons (1981). *Public Health Reports*, 95(5), 498–499.

Office of the UN Special Rapporteur on Disabilities (2006). South-North Centre for Dialogue and Development. Global survey on government action on the implementation of the standard rules on the equalization of opportunities for persons with disabilities. Amman.

O Jean Dreze and Amartyasen, Social Security in Developing Countries, 1999 retrieved from

http://shodhganga.inflibnet.ac.in/bitstream/10603/71638/9/09_chapter%20%20social%20security.pdf. On 14/11/2016

People with disabilities in India: from commitments to outcomes (2009). Washington DC, World Bank.

People with disabilities in India: from commitments to outcomes (2009). Washington DC: Human Development Unit, South Asia Region, World Bank.

Policy Guidelines on Inclusion in Education (2009). Paris: United Nations Educational, Scientific and Cultural Organization.

Policy recommendations (2008). Measuring Health and Disability in Europe.

Proposal for a national plan for special needs education and related services in Rwanda (2005). Kigali: Government of the Republic of Rwanda.

Rao, P. (2004). Social Security for Persons with Disabilities in India. Retrieved from http://www.eldis.org/fulltext/Rao_PM020804.pdf Accessed on 12/12/16.

Reaching the marginalized EFA Global Monitoring Report 2010 (2010). Paris: United Nations Educational, Scientific and Cultural Organization.

Regional report of Asia 2005. Chicago: International Disability Rights Monitor.

Regional report of Europe 2007. Chicago: International Disability Rights Monitor.

Report to Comic Relief on Oriang Cheshire inclusive education project (2006). London: Leonard Cheshire Disability.

Researching our experience: a collection of writings by Zambian teachers (2003). Mpika and Manchester, Enabling Education Network.

Roberts P, Babinard J, (2005). Transport strategy to improve accessibility in developing countries. Washington DC: World Bank.

Students with disabilities, learning difficulties and disadvantages: policies, statistics and indicators (2007). Paris: Organisation for Economic Co-operation and Development.

Summary report. Violence against children. UN Secretary-General's report on violence against children. Thematic group on violence against children. Findings and recommendations (2005). New York: United Nations Children's Fund.

Understanding and responding to children's needs in inclusive classrooms (2001). Paris: United Nations Educational, Scientific and Cultural Organization.

United Nations (2003). *Standard rules on the equalization of opportunities of persons with disabilities*. New York: United Nations.

United Nations (2006). *Convention on the Rights of Persons with Disabilities*. New York.

United Nations Educational, Scientific and Cultural Organization (1994). *Education for All. Salamanca framework for action*. Washington: United Nations Educational, Scientific and Cultural Organization.

United Nations, General Assembly (2010). *Realizing the MDGs for persons with disabilities*. New York: United Nations.

World Bank (2007). *People with Disabilities in India: From Commitments to Outcomes*.

World Health Organisation (2011). United Nation.

Secondary Sources

Allen J *et al.* (2004). Strength training can be enjoyable and beneficial for adults with cerebral palsy. *Disability and Rehabilitation*, 26, 1121-1127.

Aulagnier M *et al.* (2005). General practitioners' attitudes towards patients with disabilities: the need for training and support. *Disability and Rehabilitation*, 27, 1343-1352.

- Ahmad E et al.(1991). *Social Security in Developing Countries*. Clarendon Press, Oxford.
- Bagshaw M. (2006). *Ignoring disability: a wasted opportunity*. Wellington, National Equal Opportunities Network.
- Baldwin ML, Johnson WG (1994).Labor market discrimination against men with disabilities.*The Journal of Human Resources*,29, 1-19.
- Baldwin ML, Marcus SC. (2006). Perceived and measured stigma among workers with serious mental illness. *Psychiatric Services (Washington, D.C.)*, 57, 388-392.
- Barrett KA *et al.* (2009).Intimate partner violence, health status, and health care access among women with disabilities.*Women's Health Issues: official publication of the Jacobs Institute of Women's Health*, 19, 94-100.
- Barton L, Armstrong F (2007). *Policy, experience and change: cross-cultural reflections on inclusive education*.
- Becker H. Stuifbergen A. (2004). What makes it so hard? Barriers to health promotion experienced by people with multiple sclerosis and polio.*Family & Community Health*, 27, 75-85.
- Bines H, Lei P. (Eds.) (2007).*Education's missing millions: including disabled children in education through EFA FTI processes and national sector plans*. Milton Keynes, World Vision UK.
- Bogdan, Robert (1998). Freak Show: Presenting Human Oddities for Amusement and Profit.*
- Bowers B *et al.* (2003). Improving primary care for persons with disabilities: the nature of expertise.*Disability & Society*, 18, 443-455.
- Braddock, David, and Susan Parrish (2001).An Institutional History of Disability. In (Ed.) Gary Albrecht, Katherine Seelman, and Michael Bury *Handbook of Disability Studies*. Thousand Oaks, Calif.: Sage.
- Burchardt T. (2004). *The education and employment of disabled young people*. York, Joseph Rowntree Foundation.

- Butler SE *et al.* (2002). Employment barriers: access to assistive technology and research needs. *Journal of Visual Impairment & Blindness*, 96, 664-667.
- Castell L, (2008). Building access for the intellectually disabled. *Facilities*, 26, 117-130.
- Chen G *et al.* (2007). Incidence and pattern of burn injuries among children with disabilities. *The Journal of Trauma*, 62, 682-686.
- Chimedza R, Peters S. (2001). *Disability and special educational needs in an African context*. Harare, College Press.
- Coleman R, Lopy L, Walraven G (2002). The treatment gap and primary health care for people with epilepsy in rural Gambia. *Bulletin of the World Health Organization*, 80, 378-383.
- Degener T. (2005). Disability discrimination law: a global comparative approach. In Lawson A Gooding C (Eds.) *Disability rights in Europe: from theory to practice*. Portland, Hart Publishing.
- Dejong G *et al.* (2002). The organization and financing of health services for persons with disabilities. *The Milbank Quarterly*, 80, 261-301.
- Drainoni M-L *et al.* (2006). Cross-disability experiences of barriers to health-care access: consumer perspectives. *Journal of Disability Policy Studies*, 17, 101-115.
- Drainoni M-L *et al.* (2006). Cross-disability experiences of barriers to health-care access: consumer perspectives. *Journal of Disability Policy Studies*, 17, 101-115.
- Drum CE *et al.* (2005). Recognizing and responding to the health disparities of people with disabilities. *Californian Journal of Health Promotion*, 3, 29-42.
- Drum CE *et al.* (2005). Recognizing and responding to the health disparities of people with disabilities. *Californian Journal of Health Promotion*, 3, 29-42.
- Drum CE *et al.* (2009a). Health of people with disabilities: determinants and disparities. In Drum C, Krahn G, Bersani H (Eds.), *Disability and Public Health (125–144)*. Washington, American Public Health Association.

- Dupoux E, Wolman C, Estrada E. (2005). Teachers' attitudes toward integration of students with disabilities in Haiti and the United States. *International Journal of Disability Development and Education*, 52, 43-58.
- Durstine JL *et al.* (2000). Physical activity for the chronically ill and disabled. [Erratum appears in *Sports Medicine* 2001, 31:627] *Sports Medicine (Auckland, N.Z.)*, 30, 207-219.
- Eide AH, *et al.* (2003). *Living conditions among people with activity limitations in Zimbabwe: a national representative study*. Oslo, SINTEF.
- Elwan, A. (1999). *Poverty and disability: A survey of the literature*. Washington, DC: Social Protection Advisory Service.
- Emerson E *et al.* (2009). *Intellectual and physical disability, social mobility, social inclusion and health*. Lancaster, Centre for Disability Research, Lancaster University.
- Farrell P *et al.* (2007). SEN inclusion and pupil achievement in English schools. *Journal of Research in Special Educational Needs*, 7, 172-178.
- Farrell P *et al.* (2007). SEN inclusion and pupil achievement in English schools. *Journal of Research in Special Educational Needs*, 7, 172-178.
- Field MJ, Jette AM (Eds.) (2007). *The future of disability in America*. Washington: The National Academies Press.
- Field MJ, Jette AM, Martin, L (Eds.) (2005). *Workshop on disability in America: a new look*. Board of Health Sciences Policy Washington.
- Filmer D, (2008). Disability, poverty, and schooling in developing countries: results from 14 household surveys. *The World Bank Economic Review*, 22, 141-163.
- Florian L *et al.* (2006). Cross-cultural perspectives on the classification of children with disabilities: Part 1 issues in the classification of children with disabilities. *The Journal of Special Education*, 40, 36-45.
- Forlin C, Lian MGJ, (Eds.) (2008). *Reform, inclusion and teacher education: toward a new era of special education in the Asia Pacific Region*. London: Routledge.
- Foucault, Michel (1980). *The History of Sexuality, (1)*. New York: Vintage.

- Fragala-Pinkham MA, Haley SM, Goodgold S. (2006). Evaluation of a community-based group fitness program for children with disabilities. *Pediatric Physical Therapy: the official publication of the Section on Pediatrics of the American Physical Therapy Association*, 18, 159-167.
- Fujiura GT, Yamaki K, Czechowicz S. (1998). Disability among ethnic and racial minorities in the United States. *Journal of Disability Policy Studies*, 9, 111-130.
- Gartrell A. (2010). 'A frog in a well': the exclusion of disabled people from work in Cambodia. *Disability & Society*, 25, 289-301.
- Gonzales L *et al.* (2006). Accessible rural transportation: an evaluation of the Traveler's Cheque Voucher Program. Community Development: *Journal of the Community Development Society*, 37, 106-115.
- Gwatkin DR, Bhuiya A, Victora CG (2004). Making health systems more equitable. *Lancet*, 364, 1273-1280.
- Harriss-White B. (1999). On to a loser: disability in India. In Harriss-White B, Subramanian S, (Eds.) *Essays on India's social sector in honour of S. Guhan (135–163)*. New Delhi: Sage Publications.
- Hualand H, Allen C. (2009). *Deaf people and human rights*. Helsinki, World Federation of the Deaf and Swedish National Association of the Deaf.
- Hewitt-Taylor J. (2009). Children with complex, continuing health needs and access to facilities. *Nursing Standard (Royal College of Nursing (Great Britain): 1987)*, 23, 35-41.
- Houtenville AJ, *et al.* (Eds.) (2009). *Counting working-age people with disabilities. What current data tell us and options for improvement*. Kalamazoo, W.E. Upjohn Institute for Employment Research.
- Iezzoni LI. (2006a). Quality of care for Medicare beneficiaries with disabilities under the age of 65 years. *Expert Review of Pharmacoeconomics & Outcomes Research*, 6, 261-273.
- Ingstad B, Whyte SR, (Eds.) (1995). *Disability and culture*. Berkley: University of California Press.

- Ingstad B, Whyte SR, (Eds.) (2005). *Disability and culture*. Berkley: University of California Press.
- Jones MK, Latreille PL, Sloane PJ. (2006). Disability, gender and the British labourmarket. *Oxford Economic Papers*, 58, 407-449.
- Justino, P. (2007). Social security in developing countries: Myth or necessity? Evidence from India. *Journal of International Development*, 19(3), 367-382.
- Karangwa E, Ghesquière P, Devlieger P. (2007). The grassroots community in the vanguard of inclusion: the Rwandan perspective. *International Journal of Inclusive Education*, 11, 607-626.
- Karangwa E. (2006). Grassroots community-based inclusive education: exploring educational prospects for young people with disabilities in the post-conflict Rwandan communities. *Louvain, Centre for Disability, Special Needs Education and Child Care*.
- Kayess, Rosemary; French, Phillip (2008). Out of darkness into light? Introducing the Convention on the Rights of Persons with Disabilities. *Human rights law review*.
- Krahn GL, Hammond L, Turner A, (2006). A cascade of disparities: health and health care access for people with intellectual disabilities. *Mental Retardation and Developmental Disabilities Research Reviews*, 12, 70-82.
- Kvam MH, Braathen SH. (2006). *Violence and abuse against women with disabilities in Malawi*. Oslo, SINTEF.
- Kwon H. (2005). Inclusion in South Korea: the current situation and future directions. *International Journal of Disability Development and Education*, 52, 59-68.
- Lee LC et al. (2008). Increased risk of injury in children with developmental disabilities. *Research in Developmental Disabilities*, 29, 247-255.
- Leonardi M et al. (2009). *MHADIE background document on disability prevalence across different diseases and EU countries*. Milan, Measuring Health and Disability in Europe.
- Lewis I. (2009). *Education for disabled people in Ethiopia and Rwanda*. Manchester, Enabling Education Network.

- Linton, Simi (1998). *Claiming Disability: Knowledge and Identity*. New York: New York University Press.
- Loon J, Knibbe J, Van Hove G. (2005). From institutional to community support: consequences for medical care. *Journal of Applied Research in Intellectual Disabilities*, 18, 175-180.
- Loprest P, Maag E, (2001). *Barriers to and supports for work among adults with disabilities: results from the NHIS-D*. Washington, the Urban Institute.
- Macdonald SJ. (2009). *Toward a sociology of dyslexia: exploring links between dyslexia, disability and social class*. Saarbrücken, VDM Publishing House.
- MacLachlan M. O'Sullivan C, (2009). Childhood disability in Burkina Faso and Sierra Leone: an exploratory analysis. In M.Machlan, L.Swartz (Eds.), *Disability and international development: towards inclusive global health*. Dordrecht, Springer.
- Maulik PK, Darmstadt GL, (2007). *Childhood disability in low- and middle-income countries: overview of screening, prevention, services, legislation, and epidemiology*. *Pediatrics*, 120: Suppl 1S1-S55.
- Mazumdar S, Geis G. (2003). Architects, the law and accessibility: architects' approaches to the ADA in arenas. *Journal of Architectural and Planning Research*, 20, 199-220.
- McCarthy M. (1999). *Sexuality and women with learning disabilities*. London: Jessica Kingsley Publishers.
- McCull MA *et al.* (2008). Physician experiences providing primary care to people with disabilities. *Healthcare Policy = Politiques de Sante*, 4, e129-e147.
- McGregor G, Vogelsberg RT. (1998). *Inclusive schooling practices: pedagogical and research foundations. A synthesis of the literature that informs best practices about inclusive schooling*. Baltimore, Paul H Brookes.
- Mead GE *et al.* (2009) *Exercise for depression*. Cochrane Database of Systematic Reviews.
- Mead GE *et al.* (2009). *Exercise for depression*. Cochrane Database of Systematic Reviews.

- Megret F, (2008). The disabilities convention: human rights of persons with disabilities or disability rights? *Human Rights Quarterly*, 30, 494-516.
- Mete C, (Ed.) (2008). *Economic implications of chronic illness and disability in Eastern Europe and the Former Soviet Union*. Washington: World Bank.
- Meyers AR *et al.* (2002). Barriers, facilitators, and access for wheelchair users: substantive and methodologic lessons from a pilot study of environmental effects. *Social Science & Medicine* (1982), 55, 1435-1446.
- Miller P, Parker S, Gillinson (2004). *How to tackle the last prejudice*. London: Demos.
- Mitra S, Sambamoorthi U. (2006a). Employment of persons with disabilities: evidence from the National Sample Survey. *Economic and Political Weekly*, 41, 199-203.
- Mitra S, Sambamoorthi U. (2006b). Government programmes to promote employment among persons with disabilities in India. *Indian Journal of Social Development*, 6, 195-213.
- Mitra S. (2008). The recent decline in the employment of persons with disabilities in South Africa, 1998–2006. *South African Journal of Economics*, 76, 480-492.
- Mitra, Sophie, and UshaSambamoorthi (2008). Disability and the Rural Labor Market in India: Evidence for Males in Tamil Nadu. *World Development*, 36(5), 934-952.
- Naidhu A.(2008). Collaboration in the era of inclusion. In Forlin C, Lian M-GJ (Eds.), *Reform, inclusion and teacher education: toward a new era of special education in the Asia Pacific Region*. London: Routledge.
- Nott J, (1998). *Impaired identities? Disability and personhood in Uganda and implications for an international policy on disability*.Oslo, Department of Social Anthropology, University of Oslo.
- Ogot O, McKenzie J, Dube S. (2008). Inclusive Education (IE) and community-based rehabilitation. In Hartley S, Okune J, (Eds.), *CBR: inclusive policy development and implementation*. Norwich: University of East Anglia.
- Oliver M. (1990). *The politics of disablement*.Basingstoke, Macmillan and St Martin's Press.

- Olusanya BO, Ruben RJ, Parving A. (2006). Reducing the burden of communication disorders in the developing world: an opportunity for the millennium development project. *JAMA: Journal of the American Medical Association*, 296, 441-444.
- Oliver M.(1996). Disability politics: understanding our past, changing our future. London, Routledge
- Paley, John (1 October 2002). The Cartesian melodrama in nursing. Nursing Philosophy, 3(3), 189–192.*
- Parmenter TR. (2008). *The present, past and future of the study of intellectual disability: challenges in developing countries*. SaludPublica de Mexico.
- Peckham NG. (2007).The vulnerability and sexual abuse of people with learning disabilities. *British Journal of Learning Disabilities*, 35, 131-137.
- Petridou E *et al.* (2003). Injuries among disabled children: a study from Greece. *Injury Prevention. Journal of the International Society for Child and Adolescent Injury Prevention*, 9, 226-230.
- Philip O Keefe (2007). People with Disabilities in India: From Commitments to Outcomes Lead Social Protection Specialist World Bank.
- Porter GL. Disability and inclusive education (2001). Paper prepared for the InterAmerican Development Bank seminar, Inclusion and Disability, Santiago.
- Price P. (2003). Education for All (EFA): an elusive goal for children with disabilities in developing countries in the Asian Pacific Region. *Asia Pacific Disability Rehabilitation Journal*, 14, 3-9.
- Prince M *et al.* (2007). No health without mental health. *Lancet*, 370, 859-877.
- Quinn G, Degener T. (2002). *A survey of international, comparative and regional disability law reform*.
- Raheja G, (2008). *Enabling environments for the mobility impaired in the rural areas*. Department of Architecture and Planning, Indian Institute of Technology Roorkee, India.

- Ratzka A. (1994). *A brief survey of studies on costs and benefits of non-handicapping environments*. Stockholm, Independent Living Institute.
- Reichard AA *et al.* (2007). Violence, abuse, and neglect among people with traumatic brain injuries. *The Journal of Head Trauma Rehabilitation*, 22, 390-402.
- Rimmer JH *et al.* (2004). Improvements in physical fitness in adults with Down syndrome. *American Journal of Mental Retardation: AJMR*, 109, 165-174.
- Rimmer JH, Rowland JL. (2008). Health promotion for people with disabilities: implications for empowering the person and promoting disability-friendly environments. *Journal of Lifestyle Medicine*, 2, 409-420.
- Rimmer JH, Wang E, Smith D, (2008). Barriers associated with exercise and community access for individuals with stroke. *Journal of Rehabilitation Research and Development*, 45, 315-322.
- Roberts P, Babinard J. (2005). *Transport strategy to improve accessibility in developing countries*. Washington: World Bank.
- Roberts S *et al.* (2004). *Disability in the workplace: employers' and service providers' responses to the Disability Discrimination Act in 2003 and preparation for 2004 changes*. London, Department of Work and Pensions Research Summary.
- Russell C. (1999). *Education, employment and training policies and programmes for youth with disabilities in four European countries*. Geneva: International Labour Organization.
- Schroeder S, Steinfeld E. (1979). *The estimated cost of accessibility*. Washington, United States Department of Housing and Urban Development.
- Shakespeare, Tom (2006). The Social Model of Disability. In Lennard Davis (Ed.), *The Disability Studies Reader (197-204)*. New York: Routledge.
- Shier M, Graham J, Jones M. (2009). Barriers to employment as experienced by disabled people: a qualitative analysis in Calgary and Regina, Canada. *Disability & Society*, 24, 63-75.

Sickness, disability and work: breaking the barriers (2010). *A synthesis of findings across OECD countries*. Paris, Organisation for Economic Co-operation and Development.

Singal N. (2006). Inclusive education in India: international concept, national interpretation. *International Journal of Disability Development and Education*, 53, 351-369.

Siperstein GN, Norins J, Corbin S, Shriver T. (2003). *Multinational study of attitudes towards individuals with intellectual disabilities*. Washington, Special Olympics Inc.

Skills development through community-based rehabilitation (2008). Geneva: International Labour Organization.

South-North Centre for Dialogue and Development (2006). *Global survey on government action on the implementation of the standard rules on the equalization of opportunities for persons with disabilities*. Amman, Office of the UN Special Rapporteur on Disabilities.

State of disabled people's rights in Kenya (2007). Nairobi, African Union of the Blind, 2007. Retrieved from <http://www.yorku.ca/drpi/> on 25 September 2016.

Steinfeld E, Feathers D, Maisel J. (2009). *Space requirements for wheeled mobility*. Buffalo, IDEA Center.

Stiker, Henri (2000). *A History of Disability*. Ann Arbor, Michigan: University of Michigan Press.

Strategies for skills acquisition and work for people with disabilities: a report submitted to the International Labour Organization (2006). Geneva, International Labour Organization.

Swadhikaar Center for Disabilities Information, Research and Resource Development. Monitoring the human rights of people with disabilities. Country report: Andhra Pradesh, India. Toronto, Disability Rights Promotion International, 2009 (<http://www.yorku.ca/drpi/India.html>, accessed 29 september 2016).

Thomas, Phillipa. (2005). *Mainstreaming Disability in Development: India Country Report*. Disability Knowledge and Research Report.

- Thornicroft G, Rose D, Kassam A. (2007). Discrimination in health care against people with mental illness. *International Review of Psychiatry (Abingdon, England)*, 19, 113-122.
- Unger D. (2002). *Employers' attitudes toward persons with disabilities in the workforce: myths or realities?* Focus on Autism and Other Developmental Disabilities.
- United Nations global audit of web accessibility (2006). New York: United Nations.
- Van der Voordt TJM. (1999). Space requirements for accessibility. In Steinfeld E, Danford GS, (Eds.) *Measuring enabling environments (59–88)*. New York, Kluwer Academic Publishers.
- Venter C *et al.* (2004). *Towards the development of comprehensive guidelines for practitioners in developing countries*. In Proceedings of the 10th International Conference on Mobility and Transport for Elderly and Disabled Persons (TRANSED 2004), Hamamatsu, 23–26 May 2004.
- Vocational rehabilitation and employment of people with disabilities [Report of a European conference, Warsaw–KonstancinJeziorna, Poland, 23–25 October 2003] (2004). Geneva: International Labour Organization.
- Watson N *et al.* (1998). *Life as a disabled child: research report*. Edinburgh, University of Edinburgh.
- WHO (1980). *International Classification of Impairments, Disabilities and Handicaps*.
- WHO, World Bank (2011). *World Report on Disability*.
- Whybrow S *et al.* (2009). Legislation, anthropometry, and education: the Southeast Asian experience. In Maisel J, (Ed.), *The state of the science in universal design: emerging research and development*. Dubai, Bentham Science Publishers.
- World Health Survey (2002–2004). Geneva, World Health Organization.
- World report on violence and health (2002a). Geneva, World Health Organization.
- Wright SL, Sigafos J. (1997). Teachers and students without disabilities comment on the placement of students with special needs in regular classrooms at an Australian primary school. *Australasian Journal of Special Education*, 21, 67-80.

Xiang H *et al.* (2006b). Risk of vehicle-pedestrian and vehicle-bicyclist collisions among children with disabilities. *Accident; Analysis and Prevention*, 38, 1064-1070.

Yazbeck M, McVilly K, Parmenter TR. (2004). Attitudes towards people with intellectual disabilities: an Australian perspective. *Journal of Disability Policy Studies*, 15, 97-111.

Yeo R, Moore K. (2003). Including disabled people in poverty reduction work: “nothing about us, without us”. *World Development*, 31, 571-590.

Yoshida KK *et al.* (2009). Women living with disabilities and their experiences and issues related to the context and complexities of leaving abusive situations. *Disability and Rehabilitation*, 31, 1843-1852.

Yousafzai AK *et al.* (2005). HIV/AIDS information and services: the situation experienced by adolescents with disabilities in Rwanda and Uganda. *Disability and Rehabilitation*, 27, 1357-1363.

ANNEXURE-I

FACILITIES AND BENEFITS AVAILABLE FOR PERSONS WITH ISABILITIES

Several ministries/departments of the Government of India provide various concessions and facilities that include:

Concessions on Railways: Railways allow disabled persons to travel at concession fares up to 75% in the first and second classes. Escorts accompanying blind, orthopedic ally and mentally handicapped persons are also eligible to 75% concession in the basic fare.

Air Travel Concessions Indian Airlines allow 50% concession fares to blind persons on single journeys.

Postage Payment of postage, both inland and foreign, for transmission by post of 'Blind Literature' packets is exempted if sent by surface route.

Customs/Excise Braille paper has been exempted from excise and customs duty provided the paper is supplied direct to a school for the blind or to a Braille press against an indent placed by the National Institute for the Visually Handicapped, Dehradun. All audiocassettes recorded with material from books, newspapers or magazines for the blind are exempt from custom duty. Several other items have also been exempted from customs duty if imported for the use of a disabled person.

Conveyance Allowance All central government employees who are blind or orthopedic ally handicapped are granted conveyance at 5 per cent of basic pay subject to a maximum of Rs. 100 per month.

Educational Allowance Reimbursement of tuition fee of physically and mentally handicapped children of the Central government employees has been enhanced to Rs. 50/-.

Income Tax Concession: The amount of deduction from total income of a person with blindness, mental retardation or permanent physical disability has been increased to Rs. 40,000/-.

Award of Dealership by Oil Companies: The Ministry of Petroleum and Natural Gas has reserved 7.5 per cent of all types of dealership agencies of the public sector companies for the orthopedically handicapped and blind persons. However, persons with visual handicap are not eligible for LPG distribution. Similarly, the Ministry has also reserved 7.5 per cent of such dealership/agencies for defence personnel, and those severely disabled either in war or while on duty in peacetime.

Posting: Candidates with Physical handicaps, appointed on a regional basis be given as far as possible, appointments as close to their native place.

Economic Assistance by Public Sector Banks : All orphanages, homes for women and persons with physical handicaps as well as institutions working for the welfare of the handicapped, are given loans and advances at very low rates of interest (4% under DRI) and a subsidy of 50% up to a maximum of Rs. 5,000/- is also admissible. State Governments/Union Territories also give concessions/facilities such as reservation in jobs, scholarships, old age pension, free travel in buses, etc.

Funding scheme for special schools: A grant-in-aid scheme for voluntary organisations to develop institutes that serve to provide educational and social oppurtunities for persons with disability.To know more about scheme and to download the application form

ANNEXURE-II
QUESTIONNAIRE SCHEDULE

SECTION I (SOCIO ECONOMIC STATUS of PERSONS WITH DISABILITIES)

1.NAME: _____

2. AGE:

3. RELIGION:

HINDU-1, CHRISTIAN-2, BUDDISHT-3, MUSLIM 4, OTHERS

4. CASTE:

SC-1, ST-2, OBC-3, GEN -4, MBC-5, OTHERS -6

5. GENDER:

MALE-1, FEMALE-2,

6. PLACE OF RESIDENCE/DISTRICT:

NORTH-1, SOUTH-2, WEST-3, EAST-4

7. MARITAL STATUS:

MARRIED-1, UNMARRIED-2, DIVORCEE-3, WIDOWER-4

8. OCCUPATION:

GOVT. SERVANT-1,PVT JOB-2, FARMER-3, STUDENT-4,
SELF EMPLOYED-5 ,OTHERS-6, UNEMPLOYED- 7.

9. EDUCATION:

ILLITERATE-1, BELOV CLASS V -2 CLASS VIII-3, CLASS X-4,
CLASS XII – 5, GRADUATE-6, POSTGRADUATE-7

10. NO. OF FAMILY MEMBERS:

11. NO. OF EARNERS IN THE FAMILY:

12. CATEGORY OF DISABILITY:

Mental retardation-1, Cerebral palsy-2, Hearing impaired-3
Visual impaired-4, Low vision-5, Orthopedic impaired-6,
Mental illness-7, Leprosycured-8, Autism-9, Multiple disability-10,
Speech impairment-11,Others-12

SECTION II (PUBLIC POLICIES)

1. Do you have a Disability Card?

ANSWER CODE: YES-1, NO-2

2. Did you ever get a chance to attend a disability camp?

3. Did you ever receive any kind of aids and appliance or benefits from Government?

4. Are you getting the benefits on a regular basis?

5. Are you aware of the Government of India schemes for persons with disabilities, if yes?

EDUCATION SCHEMES -1, EMPLOYMENT SCHEMES- 2, ADIP SCHEME- 3, ECONOMIC ASSISTANCES- 4, TRAVEL CONCESSION -5, OTHERS- 6, ALL OF THE ABOVE- 7, NONE- 8

6. Have you or your family member ever visited a District Disability Rehabilitation Center?

7. Have you ever gone to seek help/consultancy in regards to your disability condition _____

8. Do you face problem in mobility because of infrastructure barrier?

9. Are you aware of the 3% reservation for persons with disabilities on Government Jobs?

10. Have you ever consulted a doctor with regards to your disability?

11. Do you have any other health issues along with your disability?

12. Are you aware of your facilities and concessions?

DISABILITY PENSION -1, DISABILITY CARD- 2, TRAVEL CONCESSION -3, AIDS AND APPLIANCES -4, EDUCATION SCHOLARSHIP- 5, RESERVATION IN JOBS- 6 ,OTHERS -7, NOT AWARE-8, ALL OF THE ABOVE-9

SECTION III (SOCIETAL)

1. Are you accepted in your community/society like any other person?

2. Do people call you names or make fun of your disability?

3. What kind of problem do you face in the society?

ACCESSABILITY-1, ACCEPTANCE-2, NEGATIVE ATTITUDE-3, SYMPATHY-4

4. Do you feel that you are a burden towards your family/society/country?

5. Why do you feel you are a burden?

UNABLE TO PERFORM TASK-1, UNABLE TO CONTRIBUTE TO FAMILY-2, UNABLE TO GAIN EMPLOYMENT-3, UNABLE TO EXPRESS NEEDS-4, DEPENDENCY -5 , OTHERS -6

6. What can be the reason behind not availing the facilities that are made for persons with disabilities?

NOT AWARE OF THE FACILITIES -1, DUE TO INFRASTRUCTURE BARRIER-2, NEGATIVE ATTITUDE-3, DON'T KNOW WHERE TO SEEK THE FACILITY FROM-4, NOT ENOUGH FACILITIES TO SUFFICE FOR OUR NEEDS -5. OTHERS-6

7. What do you think can bring positive change among people towards accepting disabled population as fully human?

EDUCATION-1, AWARENESS-2, EMPLOYMENT-3, GOVERNMENT INVOLVEMENT-4, OTHERS-5

8. Do you have any suggestion and recommendation to improve the impact of disability in Sikkim? _____