



INDIAN  
INSTITUTE OF  
PUBLIC HEALTH  
HYDERABAD



SOUTH ASIA CENTRE FOR DISABILITY  
INCLUSIVE DEVELOPMENT & RESEARCH



# **Sex differences in the uptake of health care services in persons with disabilities:**

## **A REPORT**



# **SEX DIFFERENCES IN THE UPTAKE OF HEALTH CARE SERVICES IN PERSONS WITH DISABILITIES**

**IDENTIFYING BARRIERS TO  
HEALTH CARE ACCESS**

**REPORT- 2014**



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**South Asia Centre for Disability  
Inclusive Development & Research**

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## Acknowledgements

This report is an outcome of a study undertaken to understand the health needs and access to health services, education and employment of people with disability. The project was conducted in one district each of Andhra Pradesh (Medak) and Karnataka (Bidar).

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The team expects that this report will provide evidence on the health status and barriers that people with disability face in accessing health services, employment and education opportunities.

### **From the Study Team**

Acknowledgements



## Executive Summary

### Background

Evidence suggests that disability is more common among vulnerable populations which include women, elderly and children. And people with disabilities face widespread barriers in accessing services in relation to health, education, employment and transport. This study looks at the barriers women with disability face in accessing health care services. The present study was undertaken in two states of India - Andhra Pradesh (Medak district) and Karnataka (Bidar).

This is a descriptive study with a nested case control for comparison of access to health, education and employment status among those with and without disability

The study was funded by CBM South Asia Regional Office (SARO) and was technically supported by CBM SARO

### Aim

The main aim of the study was to look into whether women with disability have equitable access to health care in India and if there are disparities in access, the underlying causes and reasons for the same.

### Rationale of study

Access to quality and timely health care is critical for all populations. For people with disabilities who may have complex health conditions it is even more important. Understanding the health needs of people with disabilities, and barriers to accessing health services is a public health priority. It is important to document whether disabled women have equitable access to health care in India, and if there are any differentials in access, the underlying causes and reasons for the same.

### Sample size estimation

Cluster random sampling was used for sample estimation. Two separate sampling frames were constructed for both the study areas (Sangareddy mandal and Bidar Taluk), which only included rural areas. For each case, an age-sex matched control was chosen from the neighborhood to compare experience of quality of life and access to health care.

### Methodology

Two mandals/ taluks from Medak district in AP (Sangareddy mandal) and Bidar district in Karnataka (Bidar Taluk) were the study sites. The key informant method was used in identification of cases. All key informants in this study were persons with disability. The key informants were initially trained using a flip book on identification of persons with disability, based on visible impairments/abnormalities and a brief history. Each key informant covered a population of between 2000-3000 over a period of 4 to 6 weeks with assistance from trained field investigators.

The key informants would list persons with disability and a neighborhood control without disability. The field investigators then filled the questionnaire which consisted of Washington group disability criteria, demographic details, general health, and activity limitations in daily living, social participation, employment, rehabilitation details, maternal health care access, immunization and barriers to health care access. The questionnaires were translated in Telugu and Kannada and were pilot tested. A written informed consent was obtained from all the participants.

Lastly, a verification of disability status was done by a specialist medical team.

### Results

The key informants listed 978 persons with disability and 1317 persons as matched neighborhood controls. After administering the Washington group questionnaire, participants who stated they experienced disability in the control group were clubbed with those with impairments. Therefore, the comparison group finally included 1039 persons with disability and 1256 controls. Approximately 1 to 2 KIs were trained per selected village.

#### a) Profile of key informants

A total of 57 key informants were identified and trained. All key informants had some form of disability. Approximately three fourths of the KIs have at least primary education qualification. The KIs covered 13 villages in Sangareddy and 16 villages in Bidar.



## **b) Socio-demographic characteristics of persons identified by KIs**

Among persons identified with disability; 64% were male and 36% were females. Approximately 60% were in the age group of 21 to 50 years.

## **c) Estimated prevalence of disability using KI and WG criteria**

We calculated the prevalence of disability in both the districts; using the denominator as population covered by key informants in both the districts. All cases identified as persons with disability were validated by the medical team. By this method, it was observed that none of the controls had impairment and that all the cases identified have some impairment.

However on administering the WG questionnaire, there were some persons with disability who had no complain in any of the six domains. And some of controls reported significant degree of impairment in one of six domains.

From our study, the prevalence of disability over all the age groups is 10.5 cases per 1000 population in Sanga Reddy (AP) and 18.1 cases per 1000 persons in Bidar (Karnataka)

## **d) Educational status of persons with disability**

None of the persons with disability from both the study sites had educational achievements of beyond class 10th in comparison to 10% of controls having achieved qualifications beyond 10th class (some upto post graduate). In terms of educational status, there was a significant lower educational attainment in persons with disability compared to their controls in both the study areas ( $p < 0.05$ )

Male with disability have a significant lower rate of accessing education than male with no disability ( $p = 0.033$ ). However this difference was not noted in women with disability.

## **e) Health care access among persons with disability**

Persons with disability reported visiting a health care facility (18.8%) more than persons without

disability (7.4%) ( $p < 0.001$ ). Also persons with disability had a significantly higher risk of reporting chronic illness. Approximately 19% of men with disability and 15% of women with disability reported a chronic illness.

In the past year, both males and females with disability had a significantly lower rate of access to a hospital as compared to the controls ( $p < 0.05$ ). A significant proportion of both male (25%) and females (18%) with disability perceived that they could not access health services whenever they were in need of it. And the biggest barrier in achieving this was lack of a person to escort them to the health facility.

Also persons with disability (both male and females) had a significantly higher use of current medication ( $p < 0.001$ ). The conditions for which majority of persons with disability were on medication was diabetes, convulsions, and depression. These conditions were significantly higher than their controls.

## **f) Reproductive health**

Women with disability (49%) have a lower pregnancy rates when compared to women with no disability (66%). Also women with disability were prone to more complications during pregnancy (35%) like diabetes, depression and fits. Women with disability have a significantly more delivery related complications.

Women without disability had significantly more frequent antenatal examinations. The major barriers that they face include lack of someone to accompany them to health care center, negative attitude of the hospital staff, and lack of awareness of need for regular checkups. However there was no difference noted in the type and place of delivery between the two groups.

## **g) History of immunization**

For adults with disability, it was noted that 30% of the disabled men and women had no vaccination for prevention of polio, DPT and tuberculosis in the past.

However, for children with disability aged  $< 5$  years, there was no difference in immunization status when compared with controls. However there were significant differences in the health



problems reported by children with disability and those without disability ( $p < 0.05$ ).

### **h) Employment among adults**

Employment was observed to be 1.6 times higher among persons without disability compared to persons with disability. Approximately 60% of men with disability were employed, which was significantly lower than the controls (90% employed). Women with disability were at seven times higher risk of unemployment than men without a disability. The two main barriers reported for employment reported were need for assistance and lack of job that can suit them.

### **i) Social participation in children**

School attendance was significantly lower in children with disability. The disability status was cited as the commonest reason for not attending

school. Children with disability commonly encountered bullying and abuse, which was significantly higher among them compared to controls.

### **j) Social participation in adults**

Persons with disability report a three times higher rate of difficulty in participation in terms of meeting people, making friends, dealing with strangers, getting along with peer groups and attending social activities. Also more severe the disability, the greater was the limitation of activities.

### **k) Rehabilitation support for persons with disability**

Only 7% of the persons with disability recruited in this study had access to rehabilitation. The most common barrier for this was ignorance on where such support was available.





## Introduction

There are more than 1000 million people with disabilities in the world, of whom between 110 million and 190 million experience significant difficulties. This corresponds to about 15% of the world's population and is higher than World Health Organization's (WHO) previous estimates in 1970 which was around 10% [1]. People who have disability have profound difficulties in functioning and participating in their daily activities. The number of people having different disabilities is growing because of ageing populations and the increasing chronic health conditions. In addition, medical advances that preserve and prolong life create overwhelming demands for health and rehabilitation services [2]. The growing prevalence will result in prolongation of poor quality of life if there are no interventions to benefit the disabled. Evidence from different countries showed that patterns of disability are influenced by trends in health conditions and environmental and other factors – such as road traffic crashes, natural disasters, conflict, diet and substance abuse [3]. Disability abnormally affects vulnerable populations like older people and people that are poor. It is estimated that low-income countries have a higher prevalence of disability than high-income countries (WHO Disability Report, 2011) [3]. People with disabilities experience various barriers in accessing services, such as those for health care (including rehabilitation), education, transport and employment. The different kinds of barriers documented by Convention for Rights of Persons with Disabilities (UNCRPD) and International Classification of Functioning (ICF) include inadequate policies and standards, negative attitudes, lack of service provision, inadequate funding, lack of accessibility, inappropriate technologies and formats for information and communication, and lack of participation in decisions that directly affect their lives [4-6].

Disability has been defined differently in different contexts, which makes it difficult for data collection, comparison and dissemination of disability-related data and information. There are lacunae of evidence in the field of promotion to update the knowledge level of disabled about their health conditions, or in building the capacity level of policy-makers and service providers, scaling up services, and most importantly protecting the rights and dignity of persons with disabilities.

The prevalence of underlying impairments causing disability in India poses a public health challenge. The evidence in the country from different studies shows differences in the rates of disability mainly due to difference in methodology adopted in various studies. Disability in a social context has to be understood in a better way and research has to give priority to explore evidence in the socio-economic and cultural context. Estimates of the prevalence of underlying impairments that cause disability are available from very few sources at the national level though some studies have provided evidence in selected pockets of the country. In South-east Asia, the prevalence of disability ranges from 1.5 – 21.3% of the total population [7]. The difference in prevalence in different countries is due to the difference in defining disability and its severity levels. Patterns of disability are influenced by multiple factors, by trends in health conditions and trends in environmental and other factors. Disability is more common in vulnerable populations and amongst women, older people and households that are poor. Lower income countries have a higher prevalence of disability than higher income countries. People with disabilities face widespread barriers in accessing services (health, education, employment, transport as well as information). Every area of human life is affected by disability. It affects the rights in terms of equality in health care access, employment, education, political participation, denied dignity in terms of violence, abuse, prejudice and disrespect or being part of society. Development is another important area which is affected due to disability in terms of its effects on better education, performance, and costs involved in health care. Though there is an increasing prevalence of disability worldwide, adequate attention has not been given in terms of evaluation, management and prevention of disability [3].

### Current scenario

The Census of India (2001) showed that the prevalence of disability in India was 2.2% translating into 21.9 million affected individuals in the country [8]. The data also showed that 14.9% of the disabled were children aged  $\leq 10$  years of age. The National Sample Survey (NSSO) round of 2002 also revealed a high magnitude of disability in India and revealed that 8.4% of rural households had at-least one disabled person at home and that 10.6% suffered multiple



impairments. The NSSO considered persons as disabled if they had any of the five types of disabilities – mental, visual, hearing, speech and locomotor [9]. Evidence generated from sources like census and NSSO will underestimate the true magnitude of disability as only the more severe manifestations are reported and the early and moderate levels of disability will be missed. Similarly co-morbidities will also be underestimated. Data is also available from a few surveys in the country. A recent survey in 4 villages of Karnataka observed that the prevalence of disability (all ages) was 6.3% and 80% had multiple disabilities [10]. Evidence from Karnataka again showed that prevalence of mental disability is 2.3% which is more prevalent among females (3.1%) than males (1.5%) and significantly higher among elderly people and illiterates [11]. A study in rural area of Chandigarh showed a prevalence rate of 4.8% and the rate was significantly more in those aged 55 years or more (31%) compared to those aged 25-54 years (5.4%) and <25 years (0.1%) ( $p < 0.001$ ). Also rates were higher in females compared to males ( $p < 0.001$ ) [12]. A study from Kerala showed disability prevalence rate to be 2.7%. Disability due to underlying visual impairment was the commonest, followed by disability due to underlying movement disorders. Literacy rate was 67% among the disabled people against the state literacy rate of 90.9%. The male-female gap in literacy rate in the general population is 6.5% which widens to 15.8% among the disabled population [13]. Evidence from Karnataka also showed that prevalence of disability was 2.02%, higher in 45-59 years age groups and higher in females (2.14%) compared to males (1.89%). This study observed that locomotor disability had the highest prevalence [14].

The Indian Council for Medical Research (ICMR) coordinated a survey of disability among children at three centers in India in 2005 and it was observed that among children aged 0-6 years, the prevalence of disability was 8.8/1000 at Delhi, 6.5/1000 at Jaipur and 12.6/1000 at Lucknow [15]. There was a wide variation in the prevalence at the three locations, which are geographically very close. This perhaps is due to the differences in access to services at the 3 centers.

Data from the National Family Health Survey, India assessed the sex disparities in functional health among persons 55 years and older and compared the situation in the northern and southern parts of the country. Logistic regression analyzed the relation between marital status, living arrangements and functional status of older adults

in the states of Uttar Pradesh and Haryana in the north and Kerala and Tamil Nadu in the south. The results showed a female disadvantage in physical impairments in the northern states, although these differences were not significant in the south [16].

A study done in Vellore compared house-to-house survey and rapid rural appraisal as methods used to identify people with disabilities in a sample rural population in South India. The research showed that by using these methods, two distinctly different populations were identified. The factors that influenced the identification processes were: local perceptions and definitions of disability; social dynamics, particularly those of gender and age; relationships within the rapid rural appraisal groups and between the health auxiliary and the respondents in the house-to-house survey; and the type of disability and the associated social implications and stigma of that disability. While a few more people were identified through the house-to-house survey, the rapid rural appraisal was a better approach for identifying disability in the community because of the greater community participation. They suggested that a judicious combination of methods which takes into account local perceptions and priorities, includes more specific screening techniques, and facilitates informed voluntary referrals, would be the most effective approach [17].

Disability is neither purely a biological nor a social construct but the result of interactions between health conditions and environmental and personal factors [18]. People with disabilities include those who are traditionally classified as disabled (for example wheelchair users, people who are blind or deaf or people with intellectual impairments), and people who experience difficulties in functioning due to a wide range of health conditions such as chronic diseases, severe mental disorders, multiple sclerosis and old age. The traditional disease approach to disability has recently been replaced by a more vibrant and positive strategy to tackle disability using the 'social model' wherein the individual's functioning is given more importance than the impairment. The WHO has recommended the use of the International Classification of Functioning, Disability and Health (ICF) as the framework for measuring health and disability both at the individual and community level.

Prevalence of Disability:

The Census data 2001 on Disability did not cover the social aspects of disability. It helped to estimate overall prevalence



of physical impairment and helped to plan further services in the country, but it was an underestimate of the real burden of disability. Estimates of prevalence of disability on a national level available in India are through Census of India and National Sample Survey Organization survey results. As mentioned earlier, the Census 2001, estimated that there were 21 million people with disabilities in India (Out of which 12 million were males and 9 million were females) which equated to 2.13% of the total population in India. The National Sample Survey Organization estimated that the number of persons with disabilities in India was 18.5 million people which represented 1.8% of the Indian population. The difference in distribution in each category of disability according to the two surveys could be explained by the methodological differences adopted in these surveys.

### **Washington Group - Short Set of Questions on Disability:**

The United Nations Washington Group on Disability measurement greatly uses ICF concepts to define disability. The questions address the issue of whether persons with disability participate to the same extent as persons without disabilities in activities such as education, employment or family/civic life [19].

Washington group of short set questions was used in the current study due to its importance of the issue of social participation and equal rights angle which was illustrated in the UN Convention on the Rights of Persons with Disabilities and because this will generate evidence for national comparisons [20].

Through Millennium Development Goals women equality and health have been given prime importance by WHO. Also in recent years, women's health has emerged as a prominent public health priority in many countries. Many researchers have demonstrated evidence showing differential health of women and it's imperative to explore why certain diseases affect women more or differently compared to men.

Though evidence shows that there is concern and a growing interest in women's health, research addressing the health care access related issues of women with disabilities is new to most of the countries including India. Over the past decade research addressing health of women with disabilities and addressing topics such as access to care, health care utilization, and the prevention of secondary conditions has been on the rise [21-23].

### **Rationale for the current study:**

Access to quality and timely health care is critical for all populations. For people with disabilities who may have complex health conditions it is even more important. Understanding the health needs of people with disabilities, and barriers to accessing health services is a public health priority. It is also important to document whether disabled women have equitable access to health care in India, and if there are any differentials in access, the underlying causes and reasons for the same. The study was conducted in 2 blocks/mandals of Medak in AP and Bidar in Karnataka state.



## Methodology

### Study sites

Two mandals/ taluks from Medak district in AP (Sangareddy mandal) and Bidar district in Karnataka state (Bidar Taluk) were chosen. The study focused on care issues for self and family with relevance to health matters like antenatal care, immunization, care for chronic conditions like TB and acute care. Barriers to employment in productive age groups, education opportunities for children and socio-cultural events and participation in the elderly groups were also assessed. Both the districts have medical teaching institutions and this helped in referral and facilitating service delivery.

Medak is located towards the north of Hyderabad city some 60 kms away. Medak is a small district with the boundaries shared by the adjacent districts of Warangal, Nalgonda, Hyderabad and Nizamabad. It has an estimated population of about 3 million and comprises about 45 mandals (revenue divisions/blocks). The health and nutritional indicators of Medak, show that it is one of the poorer districts in the state of Andhra Pradesh.

Bidar district is located in the extreme northern part of Karnataka and lies south west of Hyderabad. It has a population of 1.7 million and comprises 5 talukas (revenue divisions/blocks). Bidar is also rated as a needy district with respect to its health and development indicators.

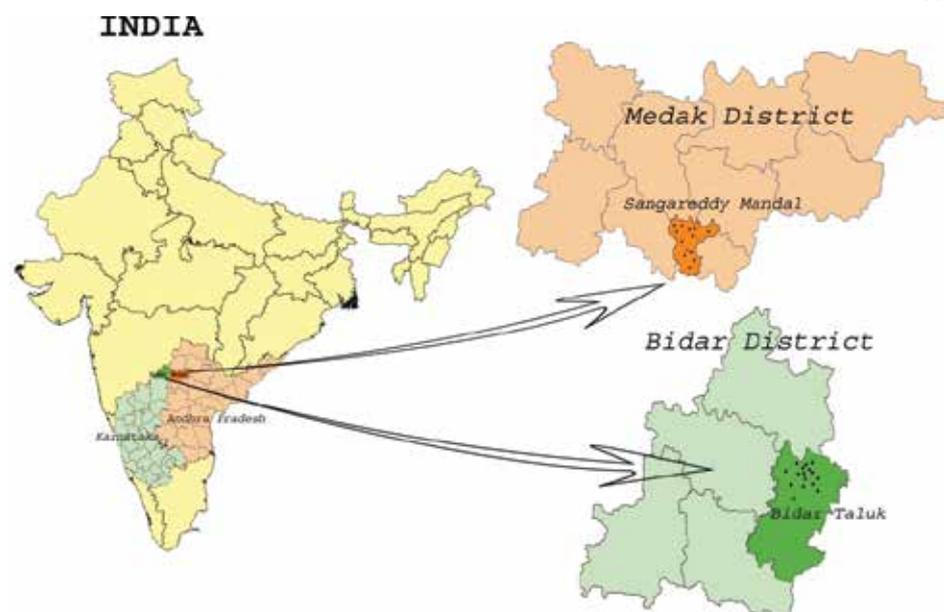


Figure 1: Areas Covered in the Study

Requisite communication, permissions and co-operation of the local self governments in the respective areas and the district administration were secured for undertaking the study after provision of the necessary information for the same.

### Study Methodology

The study used a mixed methods approach. The following steps were undertaken:

1. Preparation of Key Informant training modules
2. Identification of field investigators
3. Training of field investigators to support key informants (KI)
4. Identification of key informants
5. Training of key informants to identify persons with disability based on visible impairments/ abnormalities and a brief history.
6. Listing of persons with disability by key informants and neighborhood controls without disability.
7. Interviews of KI listed individuals by field investigators using a questionnaire schedule, including Washington Group criteria (Short set), activity limitation and participation.
8. Verification of disability status and Washington Group criteria by a specialist medical team (general physician and therapist).

Thus the study used a descriptive study design with an embedded case-control design for comparison of access to health, education and employment status among those with and without disability as determined by Washington Group criteria.



## Key Informant Methodology

The Key Informant Methodology has previously been validated by as an effective way to identify children with disability, severe visual Impairment (SVI) or blindness in Bangladesh [24,25]. KIM has since been utilized to identify childhood blindness in Iran and Malawi and was earlier used for childhood epilepsy in India [26-27]. The method was also used to identify persons with epilepsy in West Bengal, India [28]. The method relies on the training of community-level volunteers (Key Informants, or KIs) for identification of disabled children with targeted impairments or health conditions. The same methodology was adopted for the current study as well to identify persons with disability in the community. The study used flip books to train the KIs which contained details for identifying the impairments by observation with the external eye. Lists prepared by KI were assessed by field investigators using the Washington short set of disability questions. Once the identification process finished, the KIs made a list of disabled people with their identification particulars. The clinical team confirmed the diagnosis in cases identified by KIM. The individuals identified with a disability were either referred to tertiary hospitals, or provided appropriate advice as needed. Persons with disability were compared with persons without a disability (control group) on aspects of quality of life, social participation and daily living, general health, employment, rehabilitation services, maternal health care services, and general barriers to health care access.

## Sample size and sampling procedure

Cluster random sampling was used for the study. A sampling frame was first constructed for both the study areas, separately, covering only the rural areas (Sagareddy mandal and Bidar Taluk). It was estimated that the 2 blocks would comprise of about 2,000 persons with disabilities (2.2% disabled out of total population in rural area from Census of India, 2001) and this number will give sufficient number of disabled to answer the research questions posed. A similar number of age-sex matched controls were chosen from the neighborhood to compare the experience of quality of life and access to health care.

Specially designed data collection formats were translated and back translated into Telugu and Kannada. These were then piloted. The questionnaire schedule included Washington Group short set of questions on disability, questions on general health and other components like

daily activities, social participation, rehabilitation details, maternal health care access, immunization history in children and barriers to health care access.

All data was entered into a database made in MS ACCESS and data was analyzed in STATA 11.0. Both descriptive and inferential statistics were used to present the results. For associations, chi square test were used and for comparisons, logistic regression was used to determine the odds for the associated variables.

## Informed Consent

Informed written consent was obtained from the participating adults. All primary and secondary data collection tools and methods were anonymous, unlinked with no unique identifier like person names. All information collected during the study was kept confidential and not shared with anybody, other than those who were involved in the study. Necessary consent for using the results of the research was obtained for publication and dissemination.

## Ethics Approval

Ethical approval for the study was obtained from the Institute Review Board of Indian Institute of Public Health, Hyderabad.

## Quality Assurance

The processes adopted for quality assurance included:

- a) Specific training inputs by the experts who conducted KI methodology in childhood blindness survey in Bangladesh and Pakistan.
- b) Inter observer agreement during the pilot
- c) A supervised pilot in 1 village in each of the chosen blocks
- d) Developing a Manual of Operations, which was shared with all team members
- e) Regular supervision by Principal/co Investigators at regular intervals
- f) Pre coded data entry forms used to reduce data entry errors
- g) Dedicated data entry module



## Fieldwork Activities

The study used a two stage process. In the first stage, key informants were trained to identify persons with disability using specific criteria (based on physical appearance and brief history) conducting a house-to-house survey. A key informant training kit was developed and the training process was initially piloted in a similar population group. All key informants who participated in the study were persons with disabilities. Each key informant covered a population of 2000-3000 and was assisted by trained field investigators. Field investigators were trained for a week at SACDIR, IIPH and also participated in training of key informants. The field investigators were trained in administering a questionnaire schedule including the short set of WG questions. They also helped to identify the key informants. All field investigators were also persons with disabilities.

After training, the key informants were given a 4-6 week period to identify persons with disability in their catchment area. They listed the persons with disability and shared the information with the field investigators. The field investigators then visited the households and confirmed the details of persons with disabilities. They also identified 1-2 neighborhood controls (for each identified person with disability) without any disability and from those who were not listed by the key informants.

In the second stage, a team of a medically trained physician and a therapist visited all listed individuals and examined them in detail for their underlying impairment and for re-ascertaining the Washington Group criteria. Controls were administered the Washington Group criteria, and those who stated that they had significant difficulty or were unable to do any of the domains or had some difficulty in two or more domains were labeled as WG disabled and they were clubbed with persons with disability identified by the key informants, for comparative analysis. This was done because the comparison with 'controls' would be biased if those who reported disability contaminated the controls. The listed persons with disability using WG criteria were also compared with the Government list of persons with disability as per the SADAREM database and pension records.

The district health system was mobilized to provide care through conducting diagnostic treatment camps and by

providing referral services. List of persons with disabilities was made available to the welfare departments in the concerned areas for follow up action, as appropriate.

## Study Personnel

The field research staff was trained on how to complete the study instruments at the Indian Institute of Public Health, Hyderabad. All data collection staff was persons with a disability. All the Key Informants identified were also persons with disability and they had previous knowledge of disability. They were all trained in areas of:

1. Disability issues
2. Communicating with stakeholders (leaders, service providers, representatives)
3. Usage of flipcharts to identify disabled
4. Logistics and protocols (including questionnaire)

The training focused on specially designed flip books in the local language, handout sheets containing information about targeted impairments and health conditions with visual illustrations, and a list of the key messages required for case finding. KIs spread the messages within their normal working environment (schools, religious venues, community councils, public spaces etc.) and had 4-6 weeks to prepare a list of disabled found and their contact details. Approximately 20 KIs were trained per selected block (approximately 1.5-2 persons per selected village) and their participation was voluntary, without material reward throughout the process.

## Data Instruments

The main data collection instrument, consisted of demographic details, Washington Group disability criteria, general health, activity limitations in daily living, social participation, employment, rehabilitation details, maternal health care access, immunization and barriers to health care access followed by a listing of impairments to be filled by clinicians on confirmation of type of disability identified by KIs for quality purpose.

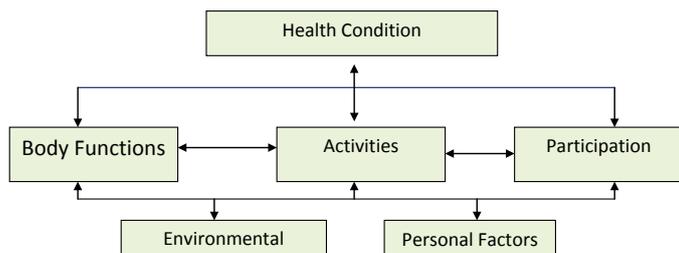
## Definition of Disability

The study followed the definitions by WHO for disabilities. Disability is an umbrella term, covering impairments, activity limitations, and participation restrictions. An



impairment is a problem in body function or structure; an activity limitation is a difficulty encountered by an individual in executing a task or action; while a participation restriction is a problem experienced by an individual in involvement in life situations. Thus disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of the society in which he or she lives [19] (Figure 2).

**Figure 2: ICF Framework**



Person with disabilities as defined by The Government of India (with Equal Opportunities, Protection of Right and Full Participation) Act, 1995 includes:-

1. Blindness;
2. Low vision;
3. Leprosy cured;
4. Hearing impairment;
5. Locomotor disability;
6. Mental retardation;
7. Mental Illness

A person with disability as per the Government definition, means a person suffering from not less than forty percent

of any disability as certified by a medical authority except Hearing Impairment. Hearing Impairment means loss of sixty decibels or more in the better ear in the conversational range of frequencies which corresponds to 85 dBs hearing threshold on the audiogram in the better ear i.e., 85 dB hearing level in audiogram – 25 dB upper limit of normal hearing = 60 dB hearing loss as per provision under “Persons with Disabilities Act, 1995”. The PWDs were checked by the clinical team once the KIs identified them to confirm the impairments [29].

## The Washington Group Questions

The Washington Group of short set of questions covered a set of six domains that focus on key functioning areas or basic actions (seeing, hearing, walking, cognition, self-care and communication). The questions have been shown to produce internationally comparable data that can be used to estimate disability prevalence, and each has four response categories of increasing severity of functioning limitation: (1) No difficulty, (2) Yes, some difficulty, (3) Yes, a lot of difficulty and (4) Cannot do at all.

Several cut-off points can be used for measuring disability.

- WG Criteria 1: At least some difficulty in at least one of the six domains
- WG Criteria 2: At least a lot of difficulty in at least one of the six domains
- WG Criteria 3: Cannot do at all in at least one of the six domains
- WG Criteria 4: A lot of difficulty/ cannot do, in at least one of the six domains or at least some difficulty in two or more domains





# RESULTS

## 1. Profile of Key Informants

A total of 57 key informants were identified. Their socio-demographic characteristics are depicted in Table 1. The mean age of KI was 25 years and 61% were aged 21-35 years.

**Table 1: Characteristics of Key Informants**

Parameters	No.	%
No. trained	57	----
No. with Disability	57	100
Total No. of villages covered	28 (13 villages in Sangareddy, 16 villages in Bidar)	
Mean Age	27.04 (SD± 5.7) years	
Age Groups		
<= 20 yrs	14	24.6
21-35 yrs	35	61.4
>= 36 yrs	8	14.0
Literacy		
Illiterate	15	26.32
Primary Education	19	33.33
Secondary education	15	26.32
> Secondary education	8	14.04

## 2. Persons with disability identified by KI

The key informants listed 978 persons with disabilities in the two districts. They also listed 1317 persons as neighborhood controls (an average of 1.4 controls per case). The recruitment of controls was higher in Sangareddy mandal (1.6:1) compared to Bidar taluka (1:1).



The sex and age characteristics of persons with disability and the neighborhood controls were similar (Table 2).

Analyzing characteristics by district also showed that the populations included were similar and there were no significant differences between persons with disability and the controls with regard to sex composition or age groups included (Table 3).

**Table 2: Socio-demographic characteristics of persons identified by Key Informants**

	Identified as Persons with Disability by KI		Identified as Controls by KI	
	No.	%	No	%
Total	978		1317	
Male	622	63.6	851	64.6
Female	356	36.4	466	35.4
≤ 5 years	11	1.12	9	0.68
6 – 15 years	107	10.9	129	9.8
16 – 20 years	96	9.8	129	9.8
21 – 50 years	584	59.7	821	62.3
51 – 60 years	88	9.0	135	10.3
≥ 61 years	92	9.4	94	7.1

**Table 3: Comparison of population included in the two mandals/ talukas**

Sex	Sangareddy		Bidar	
	Control without Disability (N=839)	Persons With Disability(N=527)	Control without Disability (N=478)	Persons With Disability (N=451)
Male	517 (61.62)	322 (61.1)	334 (69.87)	300 (66.52)
Female	322 (38.38)	205 (38.9)	144 (30.13)	151 (33.48)
	839	527	478	451
	$X^2 = 0.0370$ P= 0.847		$X^2 = 1.2057$ P= 0.272	
Age category				
<5 years	7 (0.83)	5 (0.95)	2 (0.42)	6 (1.33)
5 to 15 years	851 (10.13)	47 (8.92)	33 (6.9)	50 (11.09)
16 to 19 years	41 (4.89)	23 (4.36)	39 (8.16)	42 (9.31)
20 to 49 years	573 (68.3)	365 (69.26)	259 (54.18)	218 (48.34)
≥50 years	133 (15.85)	87 (16.5)	145 (30.33)	135 (29.93)
	$X_4^2 = 0.8599$ ; P= 0.930		$X_4^2 = 8.6969$ ; P= 0.069	



### 3. Characterization of Persons with Disability and neighborhood controls using Washington Group (WG) criteria:

Persons with disability and controls identified by key informants were administered a questionnaire schedule including the WG short questions. There were significant differences in reported disability based on the WG criteria between the two groups (Table 4).

**Table 4: Comparison of Persons with Disability identified by Key Informants and Reported problems using Washington Group criteria**

Core Domains	Persons with Disability		Controls without identified disability	
	No. included	N = 978	43.8%	N = 1317
<b>Difficulty in Seeing</b>				
At least some difficulty	116	11.9	55	4.2
At least a lot of difficulty	67	6.9	28	2.1
Unable to do it at all	54	5.5	20	1.5
$\chi_4^2 = 120.39; p < 0.001$				
<b>Difficulty in Hearing</b>				
At least some difficulty	163	16.8	40	3.0
At least a lot of difficulty	60	6.1	29	2.2
Unable to do it at all	73	7.5	13	1.0
$\chi_4^2 = 241.90; p < 0.001$				
<b>Difficulty in Walking</b>				
At least some difficulty	317	32.4	43	3.3
At least a lot of difficulty	146	14.9	28	2.1
Unable to do it at all	65	6.7	14	1.1
$\chi_4^2 = 649.5; p < 0.001$				
<b>Difficulty in Recognizing</b>				
At least some difficulty	141	14.4	41	3.1
At least a lot of difficulty	84	8.6	18	1.4
Unable to do it at all	69	7.1	7	0.5
$\chi_4^2 = 270.19; p < 0.001$				
<b>Difficulty in Self care</b>				
At least some difficulty	193	19.7	34	2.6
At least a lot of difficulty	103	10.5	26	2.0
Unable to do it at all	66	6.8	10	0.8
$\chi_4^2 = 370.32; p < 0.001$				
<b>Difficulty in Communication</b>				
At least some difficulty	165	16.9	24	1.8
At least a lot of difficulty	86	8.8	6	0.5
Unable to do it at all	45	4.6	1	0.1
$\chi_4^2 = 360; p < 0.001$				



#### 4. Estimated prevalence of disability using KI and WG criteria:

Results were also used to estimate the all age prevalence in the two districts. For this purpose, the denominator was the population covered by the Key Informants in both the districts. The assumption is that all the persons with disability were identified by the KI in the study. Validation of the diagnosis was also done by examining the listed cases and controls by the medical team. It was observed that none of the ‘controls’ had an impairment which was missed. Similarly all the listed persons with disability had some impairment. However when the Washington Group criteria were administered, some of the listed persons with disability stated that they did not have any problem in the 6 domains, while some of the controls reported a significant degree of disability.

**Table 5: Prevalence of Disability defined by Washington Group criteria and KI identified**

Area	Population	Persons with disability		95% CI
		N	Per 1000	
Sanga Reddy (AP)	50,390	527	10.5	9.6 – 11.4
Bidar (Karnataka)	24,890	451	18.1	16.5 – 19.9
Both Regions	75,280	978	13	12.2 - 14.0

It was observed that among the 978 persons with disability, 8.4% (82) did not report any difficulty in the 6 domains (Table 6). It was also observed that among the 1317 matched controls, 4.6% (61) reported significant difficulty even though did not have any visible impairment. Therefore for the rest of the analysis, to reflect their perceived difficulty in the 6 domains, these 61 persons were clubbed with the persons with disability listed by the KI for all the comparative analyses. Therefore the comparative analysis lists 1039 persons as disabled and 1256 persons as matched controls.

**Table 6: Distribution of responses based on Washington Group criteria**

Washington Group criteria	Persons With Disability identified by Key Informants		Controls (Persons without disability) identified by Key Informants	
	N = 978	%	N = 1317	%
At least one domain is scored some difficulty (WG1)	552	56.4	107	8.1
At least one domain is scored a lot of difficulty (WG2)	269	27.5	19	1.4
At least one domain is scored unable to do (WG3)	75	7.7	6	0.5
At least one domain is a lot of difficulty or unable to do it or at least some difficulty is scored in two domains (WG4)	497	50.8	61	4.6

The age distribution of persons with disability and age-matched controls after reclassifying disability after including Washington Group criteria is shown in Table 7. The age distribution was comparable in the two groups.



**Table 7: Age distribution of persons with disability and matched controls**

	Persons with disability % (N)	Matched Controls	Total
<5 years	1.1 (11)	0.7 (9)	0.9 (20)
5 to 15 years	10.5 (109)	10.1 (127)	10.3 (236)
16 to 50 years	68.6 (713)	73.0 (917)	71.0 (1,630)
>50 years	19.8 (206)	16.2 (203)	17.8 (409)
Total	100.0 (1,039)	100.0 (1,256)	100.0 (2,295)

There was a significant difference between the cases and controls on all definitions of Washington Group criteria and these differences were significant both for males and females. This was important as it validates the choice of persons with disability and age-matched controls as appropriate.

**Table 8: Washington Group criteria responses**

Washington group criteria 1-4	Men Without Disability N=816	Men with Disability N=657	Women Without Disability, N=440	Women with Disability, N=382
At least some difficulty in at least one of the six domains	34 (4.17)	378 (57.53)	19(4.32)	228 (59.69)
	$X^2(1)= 413.52, P<0.05$		$X^2(1)=298.22, P<0.05$	
At least a lot of difficulty in at least one of the six domains	0	178(27.1)	0	110 (28.8)
	$X^2(1)= 211.40, P<0.05$		$X^2(1)= 146.28, P<0.05$	
Cannot do at all in at least one of the six domains	0	50 (7.61)	0	31 (8.12)
	$X^2(1)= 56.87, P<0.05$		$X^2(1)=37.11, P<0.05$	
A lot of difficulty/ cannot do, in at least one of the six domains or at least some difficulty in two or more domains	0	340 (51.75)	0	218 (57.1)
	$X^2(1)= 408.45, P<0.05$		$X^2(1)= 341.73, P<0.05$	

## 5. Comparison of educational and current employment status

All study participants were asked about whether they had an opportunity to avail of schooling. This was asked from participants who were aged 5 plus years. There were 98.93 (N=1039) amongst persons with disability and 99.28 (N=1256) amongst matched controls were aged 5+ years. Differences between persons with disability and without a disability were significant for men but not for women (Table 9)



**Table 9: Comparison in Access to Education in Group labeled as Persons with Disability using Washington Group criteria (aged 5 plus years)**

Disability Status	Accessed Education (Population aged 5+ years)		Did Not Access Education (Population aged 5+ years)	
	N	%	N	%
Total number of participants more than age 5 years	1069	46.99	1206	53.01
<b>Males With Disability using WG criteria (n-648)</b>				
Males With Disability	312	48.15	336	51.85
<b>Males Without Disability Using WG criteria (n-811)</b>				
Males without disability	436	53.76	375	46.24
$\chi^2 = 4.54, P = 0.033$				
<b>Females With Disability using WG criteria (n-380)</b>				
Females with Disability	145	38.16	235	61.84
<b>Females Without Disability using WG criteria (n-436)</b>				
Females without Disability	260	59.63	176	40.37
$\chi^2 = 0.415, P = 0.519$				

It was observed that the level of educational attainment was significantly different between the two groups in two tehsils. It was observed that none of the Persons with Disability in either district was educated to beyond the 9th Class and rates of formal education were also lower among the Persons with Disability in comparison with the controls (Table 10). There was a significant difference between persons with disability and their matched controls in both the districts.

**Table 10: Educational Status of Persons with disability identified by Key Informants in AP and Karnataka (School going aged 5 plus)**

Educational Status	Sanga Reddy (Andhra Pradesh)		Bidar (Karnataka)	
	Persons With Disability N (%)	Controls without Disability N (%)	Persons with Disability N (%)	Controls without Disability N (%)
Total	568 (41.94)	786 (58.05)	460 (49.94)	461 (50.05)
No formal school	311 (54.75)	397 (50.50)	260 (56.52)	238 (51.62)
Educated upto 5th class	66 (11.0)	82 (10.43)	45 (9.78)	58 (12.58)
Educated to between 5th to 10th Class	191 (33.62)	232 (29.52)	155 (33.70)	126 (27.33)
Educated to between 10th to 12th Class	0	50 (6.36)	0	29 (6.29)
Educated to Degree level	0	22 (2.80)	0	9 (1.95)
Educated to Post Graduate level	0	3 (0.38)	0	1 (0.21)
	$\chi^2(5)=57.54, P<0.05$		$\chi^2(5)=44.60, P<0.05$	

A total of 559 persons with disability and 774 matched controls were aged 16-60 years and their current employment status was assessed (Table 11). It was observed



**Table 11: Comparison in Employment Status among Persons with Disability and matched controls**

Disability Status and current employment status	Currently Employed (Population aged 16-60 years)		Currently Not Employed (Population aged 16-60 years)	
	N	%	N	%
Currently employment of participants aged 16 to 60 years	1333	71.9	520	28.1
<b>Males without Disability using WG criteria (n-660)</b>				
Males Without Disability	595	90.15	65	9.85
<b>Males with Disability Using WG criteria (n-512)</b>				
Males with disability	309	60.35	203	39.65
$\chi^2_1 = 145.17, P < 0.001$				
<b>Females Without Disability using WG criteria (n-377)</b>				
Females without Disability	290	76.92	87	23.08
<b>Females with disability</b>				

Associations of educational and employment status with disability were assessed (Table 12). Relative to males without disability, females without disability as well as females with disability had a significantly higher risk of not being educated or being currently employed. Women with disability had a 10 times higher risk of not finding employment compared to males without disability.

**Table 12: Association of Access to schooling & Employment**

Access to Schooling		
Categories	OR (95% CI)	P
Men without Disability	1.0	Ref.
Women Without Disability	1.72 (1.36, 2.17)	<0.01
Men with Disability	1.16 (0.945, 1.43)	0.153
Women with Disability	1.69 (1.32, 2.16)	<0.01
Currently Employed		
Categories	OR (95% CI)	P
Men without Disability	1.0	Ref.
Women Without Disability	2.51 (1.79, 3.51)	<0.01
Men with Disability	5.52 (4.13, 7.37)	<0.01
Women with Disability	9.90 (7.18, 13.65)	<0.01



## 6. Concurrence between persons identified as disabled by key informants and Washington group criteria :

Women with disability identified by KI had a 16 times higher risk of being labeled as disabled using WG criteria 1 (At least one domain is scored some difficulty) while with WG criteria 4 (At least one domain is a lot of difficulty or unable to do it or at least some difficulty is scored in two domains) females with disability identified by KI had a risk which was 27 times higher compared to males without any disability (Table 13).

**Table13: Association of Disability Status with Sex**

Disability status	Washington 1	p-value
Men without disability	1.0	Ref
Women without disability	1.20 (0.798, 1.80)	0.383
Men with disability	15.26 (11.32, 20.56)	0
Women with disability	16.42 (11.81, 22.81)	0
Disability status	Washington 2	p-value
Men without disability	1.0	Ref
Women without disability	0.84 (0.32, 2.23)	0.727
Men with disability	23.3 (13.08, 41.4)	0
Women with disability	26.6 (14.70, 42.2)	0
Disability status	Washington 3	p-value
Men without disability	1.0	Ref
Women without disability	1.83 (0.37, 9.1)	0.46
Men with disability	23.12 (7.16, 74.6)	0
Women with disability	24.13 (7.29, 79.91)	0
Disability status	Washington 4	p-value
Men without disability	1.0	Ref
Women without disability	1.38 (0.82, 2.31)	0.23
Men with disability	22.4 (15.45, 32.57)	0
Women with disability	27.30 (18.35, 40.61)	0

## 7. Access to health care

In the entire group of respondents (including persons with disabilities and controls), 12.5% (287) had accessed hospital services in the past year (Figure 3). The differences between persons with disability and matched controls were statistically significant (Table 14).

**Table 14: Hospitalization status among persons with disability and matched controls**

Disability Status	No hospital visits reported		Hospital visits Reported		Total
	N	%	N	%	
No disability	1163	92.6	93	7.4	1256
Persons with disability	845	81.3	194	18.8	1039
X <sup>2</sup> -65.98 p < 0.001					

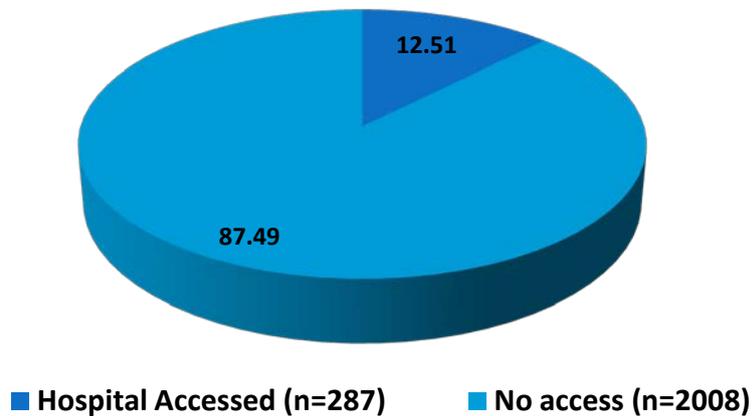
Both females with disability and males with disability accessed hospital services significantly more than males and females without disability in the past year (Figure 4).



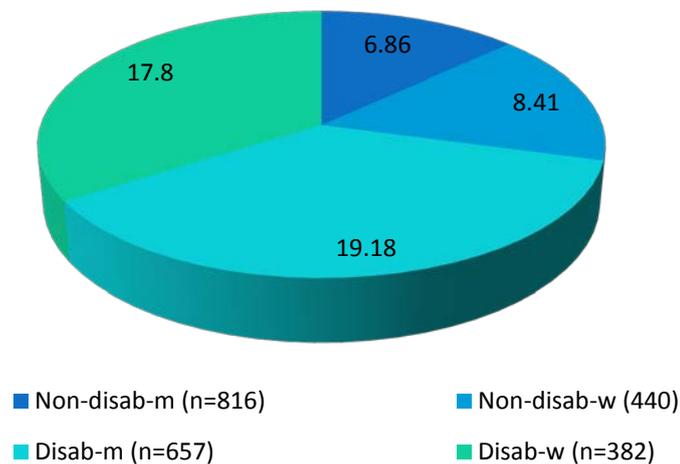
**Table 15: Reported access to health care in the past year (by disability status)**

Disability Status	Hospital accessed in the past year		No access to hospital in the past year	
	N	%	N	%
Hospital access	287	12.51	2008	87.49
<b>Males without Disability using WG criteria (n-816)</b>				
Males Without Disability	56	6.86	760	93.14
<b>Males with Disability Using WG criteria (n-657)</b>				
Males with disability	126	19.18	531	80.82
X <sup>2</sup> (1)= 50.97, P<0.05				
<b>Females Without Disability using WG criteria (n-440)</b>				
Females without Disability	37	8.41	403	91.59
<b>Females With Disability using WG criteria (n-382)</b>				
Females with disability	68	17.80	314	82.20
X <sup>2</sup> (1)=16.19, P<0.05				

**Figure 3: Reported access to health care in the preceding year**



**Figure 4: Reported Access by Disability Status**





Persons with disabilities suffered significantly more from chronic diseases compared to control participants (Table 16)

**Table 16: Reported prolonged illness among those with and those without a disability**

Disability and Sex Status	No reported Prolonged Illness		Reported Prolonged Illness	
	No.	%	No.	%
Men without disability (n-816)	781	95.2	35	4.3
Men With Disability (n-657)	532	80.9	119	19.1
Women Without Disability (n-440)	419	95.2	21	4.8
Women With Disability (n-382)	326	85.3	56	14.7
Total (n-2295)	2058	89.7	231	10.3
$\chi^2_3$ - 100.89 P=<0.001				

Access to hospital/health services were also analysed by age categories (Table 17). There were significant differences by age among males but there were no statistically significant differences among females.

**Table 17: Hospital Access stratified by age categories**

Age category	Non-disabled men (N=816)	Disabled men (N=657)	Non-disabled women (N=440)	Disabled women (N=382)
Less than 20 years	122	76	73	67
21-50 years	484	301	260	191
> 50 years	154	154	70	56
	$\chi^2_2$ =13.14, P=0.001		$\chi^2_2$ =1.34, P=0.51	

It was observed that persons with disability reported significantly higher rates of suffering from prolonged/chronic duration illness compared to persons without a disability (Table 18).

**Table 18: Reported Prolonged Illness by Respondents**

Disability and prolonged illness	No reported Prolonged Illness		Reported Prolonged Illness	
	No.	%	No.	%
Men without disability (n-816)	781	95.7	35	4.3
Men With Disability (n- 657)	532	80.9	125	19.3
$\chi^2_2$ - 50.97, P=<0.005				
Women Without Disability (n- 440)	422	95.9	18	4.1
Women With Disability (n- 382)	326	85.3	56	14.7
$\chi^2_2$ - 106.2 P=<0.005				



The risk of both males and females with disability suffering from a chronic illness was significantly higher compared to males and females without a disability (Table 19).

**Table 19: Comparison of risks of chronic illness among persons with disability with persons without a disability**

Disability status	OR (95% CI)	p
Men without a disability	1.0	
Women without a disability	0.93 (0.53, 1.70)	0.868
Men with a disability	5.24 (3.55,7.75)	<0.005
Women with a disability	3.83 (2.46, 5.96)	<0.005

Respondents (n-234) were also asked about admission in hospital due to a prolonged illness in the past (Table 19). It was observed that persons with disability had a significantly higher admission rate in hospital for a prolonged illness. The main reasons for hospitalization in the entire group was 'gastric problems' (11-0.7%), high fever (67-4.5%), chest/respiratory problems (50 – 3.4%), fits (11-0.7%), tuberculosis (2- 0.1%), malaria (2 – 0.1%) and other unspecified causes (91- 6.1%)

**Table 20: Comparison of hospitalization rates among persons with disability and matched controls**

Disability Status	No reported hospitalization for prolonged illness		Reported hospitalization for prolonged illness		Total
	N	%	N	%	
No disability	1203	95.8	53	4.2	1256
Persons with disability	858	82.6	181	17.4	1039
OR- 4.79 (95% CI: 3.44-6.67); $\chi^2$ -108.22; p <0.001					

Respondents were also asked about their current medication, if any (Table 21). It was observed that persons with disability had significantly higher current medication rate.

**Table 21: Comparison of current medication among persons with disability and matched controls**

Disability Status	No current medication reported		Current medication reported		Total
	N	%	N	%	
No disability	1207	96.1	49	3.9	1256
Persons with disability	936	90.1	103	9.9	1039
$\chi^2$ -33.22; p < 0.001					

Persons with disability (both male and female) had a significantly higher use of current medication (Table 22).

**Table 22: Use of current medication by disability status**

Disability status	OR	P	95% CI
Men without disability	1.0		
Women without disability	0.984	0.96	0.54, 1.79
Men with disability	2.73	<0.05	1.77, 4.23
Women with disability	2.62	<0.05	1.61, 4.23



Respondents were asked about the medical condition for which they were currently under medication (Table 23). Persons with disability suffered significantly more from diabetes, generalized convulsions and a perceived state of depression. There were no differences in relation to other chronic conditions like hypertension, asthma or allergies etc.

**Table 23: Underlying medical conditions for current medication**

Disease	Persons without disability		Persons with disability	
	N	%	N	%
Total Respondents	1256		1039	
Diabetes	7	0.6	117	11.3
X <sup>2</sup> - 127.46; p <0.001				
Fits (Generalized convulsions)	4	0.3	129	12.0
X <sup>2</sup> - 152.36; p < 0.001				
Perceive depressed	14	1.1	214	20.6
X <sup>2</sup> -241.2; p < 0.001				
Hypertension	8	0.6	14	1.3
X <sup>2</sup> -3.02; p=0.08				

Computing odds of these three disease status, it was observed that overall persons with disability were significantly worse compared to those without a disability (Table 24). Additionally, it was also observed that with diabetes, women with disability had a worse outcome compared to the other groups while for generalized convulsions and perceived depression men with disability were significantly more disadvantaged compared to the other groups. Confidence intervals were wide as the number of persons reporting disease was small.

**Table 24: Comparison of odds of different chronic diseases among persons with disability and matched controls**

Disease and Disability Status	Odds Ratio	95% Confidence Interval
Diabetes		
Men without disability	1.0	
Women without disability	0.74	0.14, 3.83
Men with disability	24.43	9.85, 35.57
Women with disability	14.33	5.52, 25.15
Fits (Generalized convulsions)		
Men without disability	1.0	
Women without disability	1.86	0.26, 13.24
Men with disability	67.95	16.7, 276.86
Women with disability	41.05	9.81, 171.63
Perceived Depression		
Men without disability	1.0	
Women without disability	0.74	0.23, 2.07
Men with disability	25.31	13.23, 48.43
Women with disability	14.14	7.13, 28.02



Respondents were asked about their experience with health care services (Table 25). Significantly more persons with disability (both male and female) stated that they could not access health services when they needed them compared to persons without a disability.

**Table 25: Reported experience with health care services**

<b>Status of health care for general health</b>		
<b>Men: (N=1473)</b>	<b>No disability, N=816</b>	<b>Disability, N=657</b>
Sought outpatient care, n=182	56 (6%)	126 (19.18)
Sought inpatient care, n=107	32 (2%)	75 (11.42%)
Needed, but did not get care, n=176	10 (1.2%)	166 (25.27) *
<b>Women: (N=822)</b>	<b>No disability, N=440</b>	<b>Disability, N=382</b>
Sought outpatient care, n=105	37 (8.4%)	68 (17.8)
Sought inpatient care, n=74	18 (4.1%)	56 (14.6)
Needed, but did not get care, n=76	7 (1.60%)	69 (18.1)*
<b>16-20</b>	<b>No disability, N=124</b>	<b>No disability, N=101</b>
Sought outpatient care	5 (4.03)	15 (14.85)
Sought inpatient care	2 (1.61)	12 (11.88)
Needed, but did not get care	0	15 (14.85)
<b>21-50</b>	<b>No disability, N=793</b>	<b>No disability, N=612</b>
Sought outpatient care	63 (7.94)	124 (20.26)
Sought inpatient care	37 (4.66)	117 (19.11)
Needed, but did not get care	15 (1.89)	159 (25.98)
<b>51 plus</b>	<b>No disability, N=203</b>	<b>Disability, N=206</b>
Sought outpatient care	20 (9.85)	30 (14.56)
Sought inpatient care	11 (5.41)	28 (13.59)
Needed, but did not get care	2 (0.98)	35 (16.99)

The proportion of participants in the disabled category not getting health care services when needed is significantly high compared to other categories for men, women and amongst each age categories also.



## 8. Maternal Health

Pregnancy experience and outcome of women with and without a disability in the reproductive age group (15-45 years) was also assessed. There was a significant difference in the proportion of women with disability compared to women without a disability with regard to pregnancy experience (Table 26).

**Table 26: Comparison of pregnancy experience among women with and without a disability**

Pregnancy experience	Women without disability (n=253)		Women with disability (n=209)		Total (n=462)
	N	%	N	%	
Ever Pregnant	167	66.0	98	46.9	265
Never Pregnant	86	34.0	111	53.1	197
$\chi^2=17.1$ ; $p < 0.05$					

Chronic disease in pregnant women according to their disability status was also recorded (Table 27). Out of 98 women who were disabled and pregnant, diabetes, fits and depression were significantly higher compared to females with no disability.

**Table 27: Chronic Diseases Reported during pregnancy among women with and without disability**

Chronic disease	Matched Controls reporting problems in past pregnancies	Women with disability reporting problems in past pregnancies	X2
	N=167	N=98	
Diabetes	1.2	14.29	$\chi^2= 18.65, P<0.05$
Asthma	0.68	2.33	$\chi^2= 1.17, P<0.28$
Hypertension	2.03	2.35	$\chi^2= 0.027, P<0.87$
Fits	0.6	16.33	$\chi^2=25.45, P<0.05$
Allergies	0.68	1.18	$\chi^2=0.159, P=0.690$
Depression	1.8	22.45	$\chi^2= 30.83, P<0.05$

Amongst those women who reported a successful pregnancy, there was no difference in relation to the number of children born to mothers by disability status (Table 28).

**Table 28: Child birth experience of women with and without a disability**

No. of children	Women without disability		Women with disability	
	N	%	N	%
One child	51	30.7	29	30.8
Two children	86	51.8	46	48.9
> 2 children	29	17.4	19	20.2
Total	166		94	
$\chi^2= 0.551, P = 0.759$				



Mothers who reported a pregnancy history were asked about the number of antenatal check-ups they had in their last pregnancy. There was a significant difference based on disability status (Table 29). Women without a disability had significantly more frequent antenatal examinations.

**Table 29: Frequency of antenatal check-ups during the last pregnancy**

Frequency of antenatal check-ups	Women without disability		Women with disability	
	N	%	N	%
Examined only once	19	11.7	27	33.8
Examined twice or more	144	84.3	60	77.0
Total	163		80	
$X^2=11.07, P<0.05$				

Reported complications during their last pregnancy were also recorded (Table 30). There was a significant difference by disability status with regard to complications in pregnancy as reported by the mothers.

**Table 30: Comparison of reported complications in pregnancy by disability status**

Reported Complications	Women without disability		Women with disability	
	N	%	N	%
Complications Reported	29	17.4	34	34.7
No complications reported	138	82.6	64	65.3
Total	167		98	
$X^2 = 10.234, P<0.01$				

Type of delivery reported by the mothers was also recorded. It was observed that there was no significant difference in the type of delivery by disability status (Table 31).

**Table 31: Type of delivery reported by mothers**

Type of delivery	Women without disability		Women with disability	
	N	%	N	%
Normal delivery	102	61.1	58	59.2
Caesarean section	66	38.9	40	40.8
Total	168		98	
$X^2 = 0.093, P=0.076$				

The place of delivery was also assessed (Table 32). Disability status did not make a difference in relation to place of delivery.

**Table 32: Reported place of delivery by disability status**

Place of delivery	Women without disability		Women with disability	
	N	%	N	%
Hospital	87	52.1	55	56.12
Home	80	47.9	43	43.88
Total	167		98	
$X^2 = 0.4026; p = 0.526$				



Compared to non-disabled women, disabled women had more delivery related problems (Table 33).

**Table 33: Reported Health problems during pregnancy**

Place of delivery	Women without disability		Women with disability	
	N	%	N	%
Reported health problems past pregnancies	27	16.17	27	27.55
No problems in past pregnancies	140	83.83	71	72.45
Total	167		98	
$\chi^2 = 4.93; p < 0.05$				

Pregnant and disabled women participants encountered numerous barriers to access reproductive health care services, including inaccessible equipment and facilities, health care providers' attitude and lack of knowledge about disabilities. All the barriers were significantly associated with the disability status in terms of access to health care (Table 34).

The biggest odds were the barrier in having someone to accompany them for accessing reproductive health services. The study showed that the supporting system that pregnant women need from the family and society if they are disabled is very challenging. Accessing reproductive health care services is difficult and therefore women with disability avoid regular gynecologic visits due to the barriers faced by them. This could affect the maternal health and pregnancy outcomes.

**Table 34: Barriers faced by pregnant women in accessing reproductive health services**

Barriers reported	Odd Ratio (Reference women without disability)	P value	95% Confidence Interval
No one to accompany	26.93	< 0.001	9.23 – 78.6
Attitude of health centre staff	7.3	0.013	1.52- 35.27
Lack of awareness on need for repeated check ups	7.13	0.013	1.54 - 35.27
Problems in transportation	4.27	0.041	1.062 - 16.66
Equipment/ Examination not friendly	4.2	0.001	1.06 -16.65
Hospital Infrastructure	4.2	0.031	1.062 - 16.65
Cost in accessing	4.2	0.031	1.062 – 16.65
Access to hospital	1.18	0.508	0.71- 1.97

## 9. History of past immunization

The recall of childhood immunization showed that there was a significant difference in relation to immunization rates among women with disability compared to women without disability. 30% of the disabled men and women had no vaccination in the past to prevent polio, DPT and tuberculosis (Table 35).

**Table 35: History of past immunization among the respondents**

Vaccination history	Men without Disability (%)	Females without Disability (%)	Men with Disability (%)	Females with Disability (%)
	<b>n-816</b>	<b>n- 440</b>	<b>n- 657</b>	<b>n-382</b>
All vaccines	66.3	56.82	37.9	37.43
At least One	27.08	36.59	30.9	32.46
No vaccine	6.62	6.59	31.2	30.1



The immunization history of children aged < 5 years was also recorded. It was observed that there was no significant difference between those with and without a disability (Table 36).

**Table 36: Immunization history among children aged < 5 years**

	At least one immunization received	Not immunized	Total
No disability	8 (100.0)	0	8
Persons with disability	5 (83.3)	1 (16.8)	6
Total	13	1	14
$\chi^2 = 1.4, P = 0.231$			

Health problems among children were analyzed separately (Table 37). It was observed that there was a significant difference in relation to health problems in children between those with and without a disability.

**Table 37: Clinical problems for children in the past year (age less than 16 years)**

Medical problems	Boys without disability N-89	Girls without disability N-47	Boys with disability N-70	Girls with disability N-50
Yes	0	2.13	82.86	82
No	100	97.87	17.14	18
$\chi^2 = 179.12, P < 0.05$				

## 10. Barriers to accessing health services

Information on accessing medical services was assessed, and it was observed that persons with disability had significantly poorer health access compared to those without a disability (Table 38).

**Table 38: Hospital access in participants**

Health service accessed	Men without disability	Females without disability	Males with disability	Females with disability
	816	440	657	382
Accessed health services	72.79	71.59	55.71	56.28
Not accessed hospital previously	27.21	28.41	44.29	43.72
$\chi^2 = 67.13, P < 0.05$				

Disabled people had a 2.1 times higher risk (95% CI 1.73, 2.46) in not accessing health services compared to persons without a disability. Disabled women had a 2 times higher risk in accessing health services compared to men without a disability (Table 39).

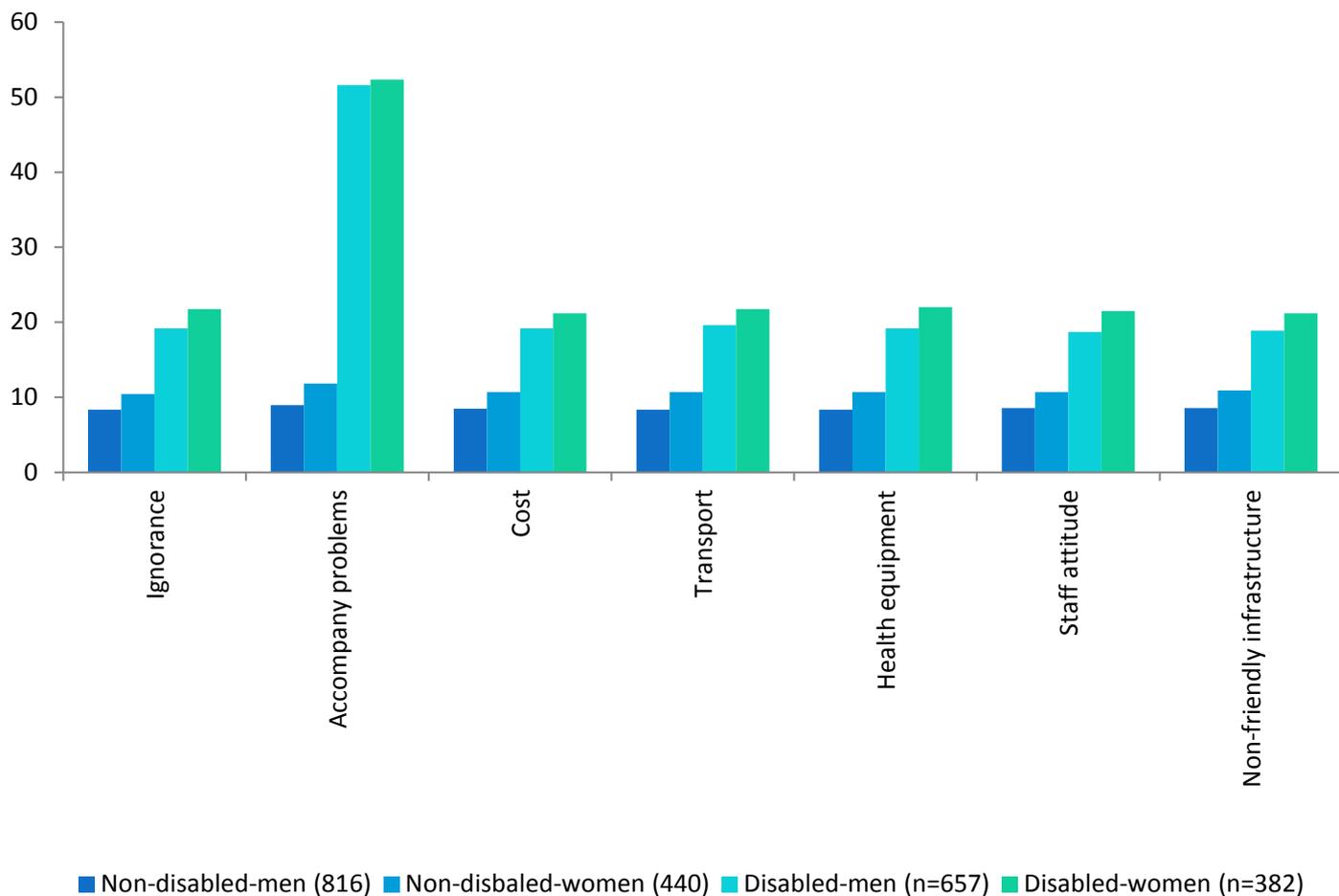
**Table 39: Odds ratio of hospital access and disability stature**

Disability Category	OR	P	OR
Non-disabled men	1.0	Reference	
Non-disabled women	1.06	0.649	0.87, 1.37
Disabled men	2.12	<0.001	1.71, 2.64
Disabled women	2.07	<0.001	1.61, 2.68



People with disabilities encounter a range of barriers in accessing health care facilities including lack of information and physical, inadequate personal assistance, affordability, limitations of resources and inaccessible infrastructure and non-friendly environments. Figure 5 shows the distribution amongst the participants.

**Figure 5: Percentage distribution of different barriers for accessing health services**





The lack of an escort to accompany a person with disability was the biggest barrier reported. Irrespective of sex, if persons had a disability, they faced barriers to access health services (Table 40).

**Table 40: Barriers to health care (Adjusted Odds Ratios)**

Barriers	OR (95% CI)	P-value
<b>Ignorance</b>		
Men without disability	1.0	
Women without disability	1.28 (0.85, 1.90)	0.213
Men with disability	2.61 (1.90, 3.58)	0.003
Women with disability	3.05 (2.16, 4.32)	0.001
<b>Lack of escort</b>		
Men without disability	1.0	
Women without disability	1.36 (.936, 1.99)	0.106
Men with disability	10.85 (8.16, 14.42)	0.000
Women with disability	11.18 (8.18,15.30)	0.000
<b>Cost issues (Affordability)</b>		
Men without disability	1.0	
Women without disability	1.25 (0.86, 1.83)	0.247
Men with disability	2.6 (1.91, 3.55)	0.002
Women with disability	3.04 (2.15, 4.30)	0.001
<b>Transportation issues</b>		
Men without disability	1.0	
Women without disability	1.27 (0.87, 1.86)	0.218
Men with disability	2.72 (1.99, 3.71)	0.04
Women with disability	3.19 (2.25, 4.5)	0.01
<b>Unfriendly equipment</b>		
Men without disability	1.0	
Women without disability	1.29 (0.88, 1.89)	0.191
Men with disability	2.71 (1.98, 3.7)	0.01
Women with disability	3.29 (2.32, 4.65)	0.01
<b>Attitude/ skills of staff</b>		
Men without disability	1.0	
Women without disability	1.27 (0.86, 1.88)	0.222
Men with disability	2.45 (1.79, 3.36)	0.001
Women with disability	2.91 (2.06, 4.12)	0.001
<b>Non-friendly infrastructure</b>		
Men without disability	1.0	
Women without disability	1.30 (0.877, 1.92)	0.2
Men with disability	2.48 (1.81, 3.39)	0.001
Women with disability	2.88 (2.03, 4.06)	0.001



Analyzing the women with and without a disability exclusively, it was observed that women with disability had significantly more barriers in accessing health care compared to women without a disability (Table 41).

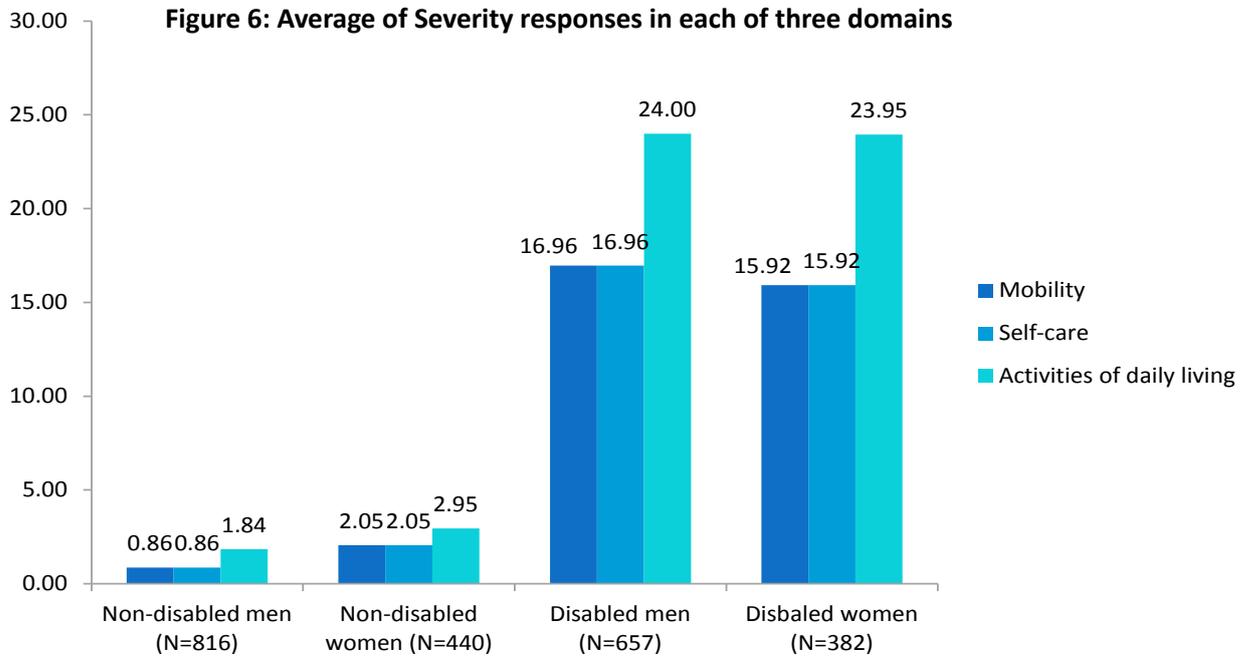
**Table 41: Access to health services among women respondents**

Barriers	OR (95% CI)	P-value
<b>Ignorance</b>		
Women without disability	1.0	
Women with disability	2.38 (1.61, 3.51)	<0.001
<b>Lack of escort</b>		
Women without disability	1.0	
Women with disability	8.20 (5.77, 11.66)	<0.001
<b>Affordability (Cost)</b>		
Women without disability	1.0	
Women with disability	2.25 (1.52, 3.32)	<0.001
<b>Transportation issues</b>		
Women without disability	1.0	
Women with disability	2.32 (1.57, 3.42)	<0.001
<b>Non-friendly equipment</b>		
Women without disability	1.0	
Women with disability	2.36 (1.60, 3.47)	<0.001
<b>Staff attitude</b>		
Women without disability	1.0	
Women with disability	2.29 (1.55, 3.37)	<0.001
<b>Unfriendly Infrastructure</b>		
Women without disability	1.0	
Women with disability	2.20 (1.49, 3.24)	<0.001

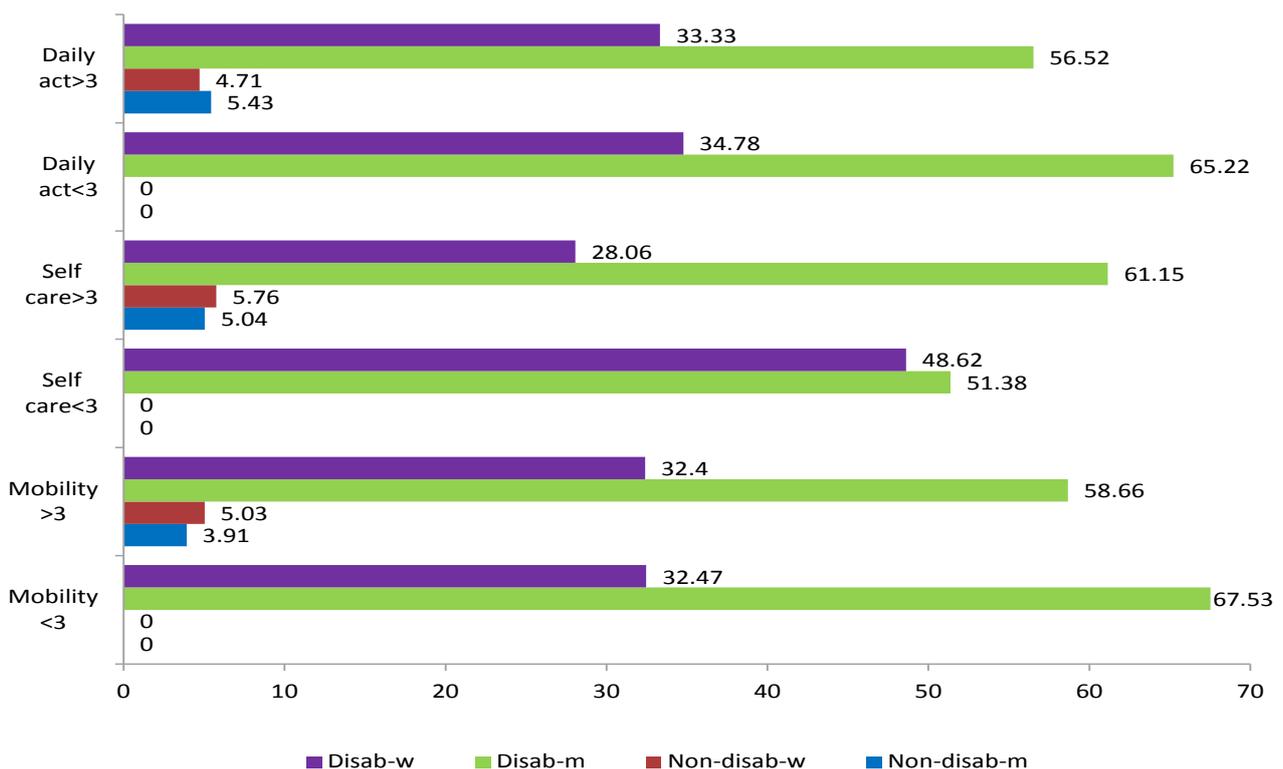


## 11. Activity Limitation

Three domains were assessed in the study. All domains were based on respondent perception which was graded on a score of 1-5. The average of all the three domains in the severe most category (lots of difficulty or cannot do at all) is depicted in Figure 6. Amongst Disabled men around 17% were not able to do mobility related activities and Self-care activities at all. 24% disabled men were not able to perform any of the daily activities in the household. Similar findings were seen with disabled women. 16% women were not able to perform any mobility related activities and Self-care activities at all and 24% disabled women could not perform any of the daily activities in the household.



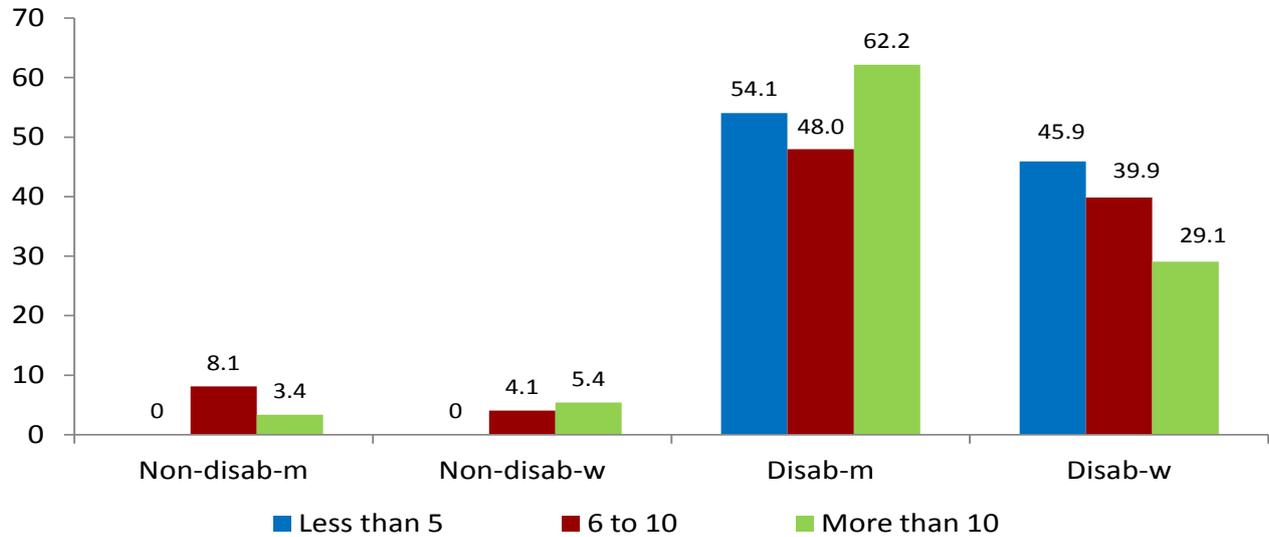
**Figure 7: Severity scale of functioning in persons with disability and persons without a disability**





ive grades of severity (1-5) in each of the three domains (mobility limitation; self-care and activities for daily living were assessed and a severity scale computed to compare the respondents with and without a disability (Figure 7).

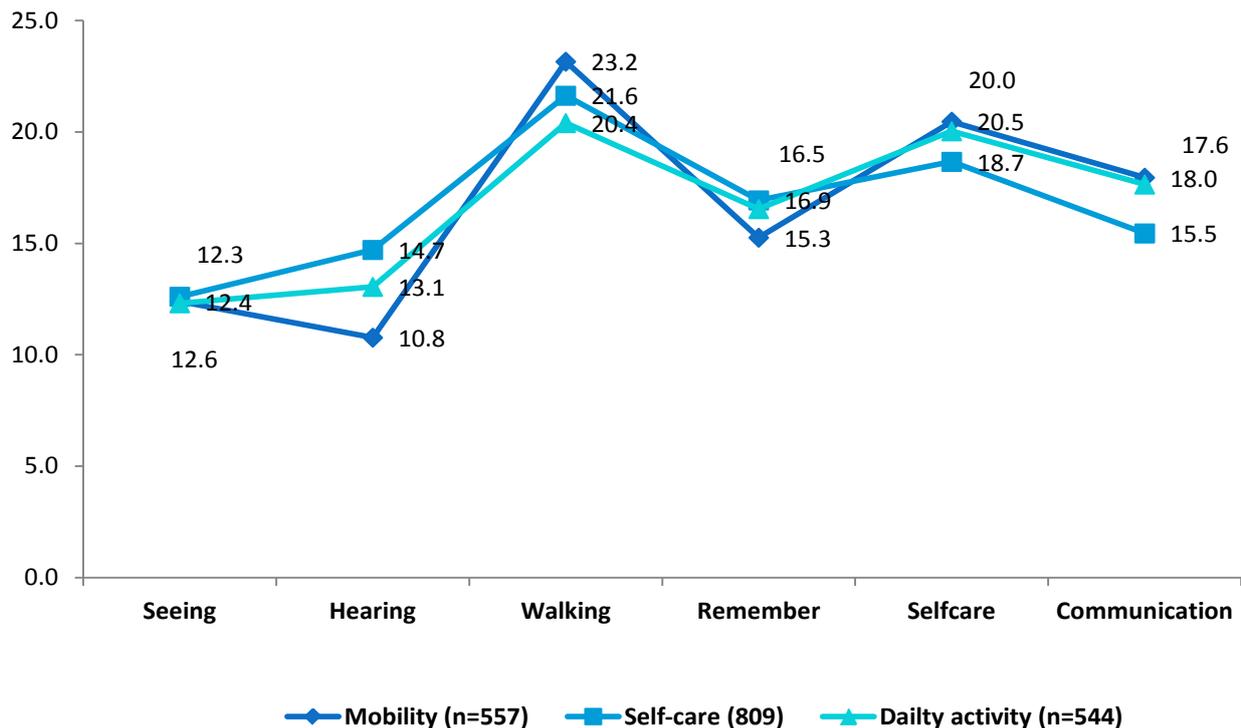
**Figure 8: Activity Scale Comparison between persons with and without disability**



A scoring system was computed combining the daily activities group. The scoring was based on number of activities in each of the main three domains viz., mobility, self-care and activities for daily living. If the cumulative score exceeds 10, it means that the respondent is unable to perform 10 activities or more. Disabled men reported most difficulty with 60% of them unable to perform 10 activities or more as against 25% of women who could not perform 10 activities or more (Figure 8).

Difficulty in performing daily activities, self-care and mobility were assessed in each of the 6 WG domains (Figure 9). It was observed that inability to perform 10 or more activities was seen in relation to each of the WG domains. Respondents reporting difficulty walking were observed to be the most disadvantaged in relation to activity limitation.

**Figure 9: Daily activity with WASHINGTON disability domain**



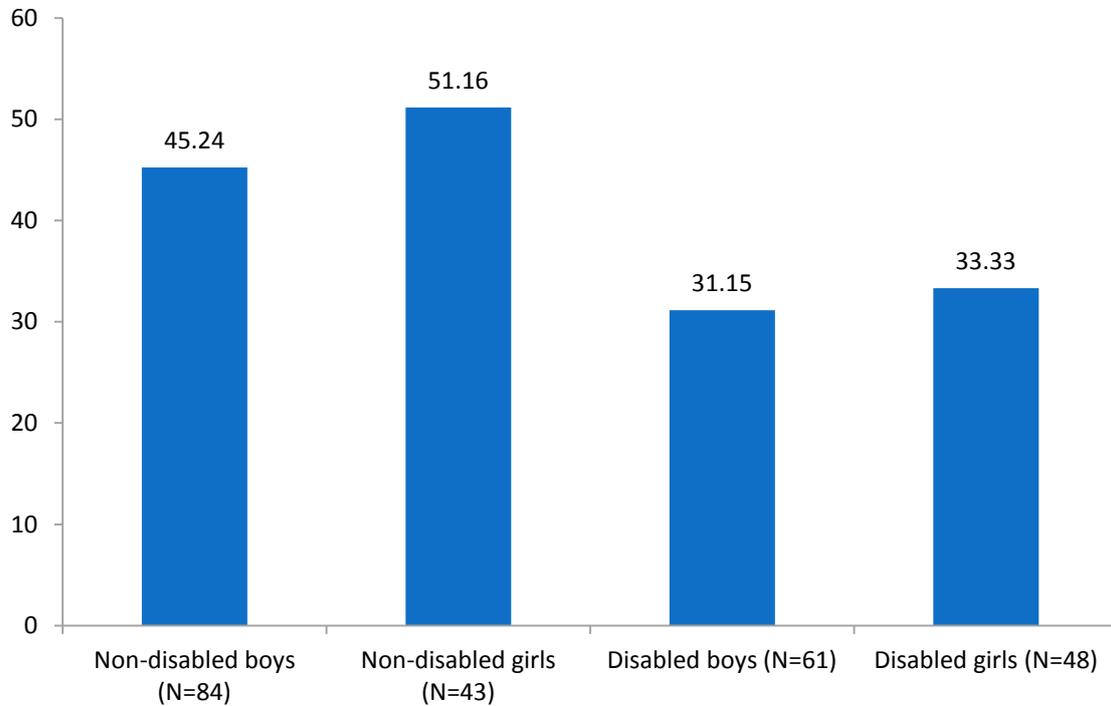


## 12. Social Participation

### Children

A total of 109 children with disability and 127 children without a disability (aged 5-15 years), were available for analysis.

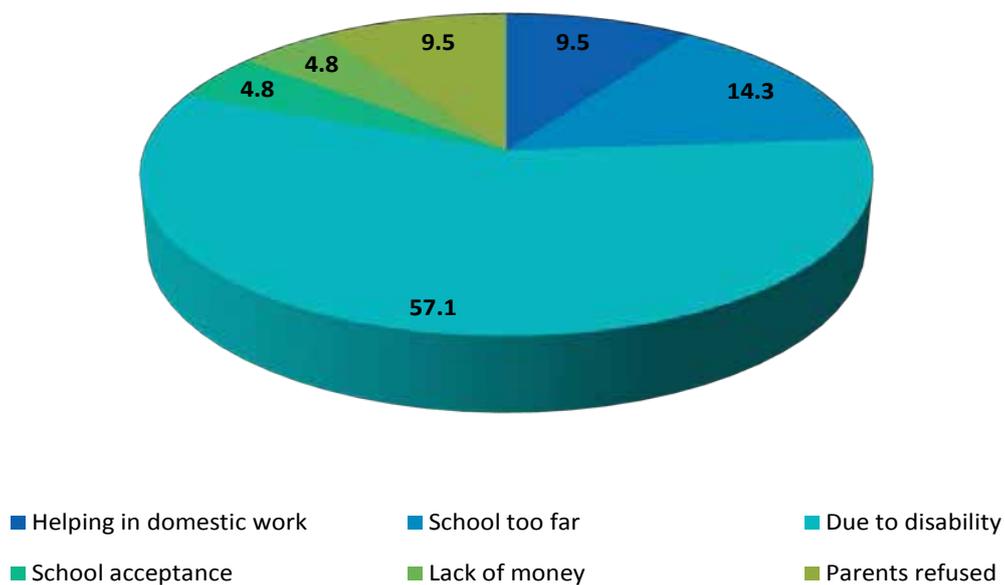
**Figure 10: Distribution of school attendance**



It was observed that school attendance was significantly lower amongst children with disability (Figure 10).

Amongst the 109 children with disability, reasons for not attending school were elicited (Figure 11). Disability status was cited as the commonest reason.

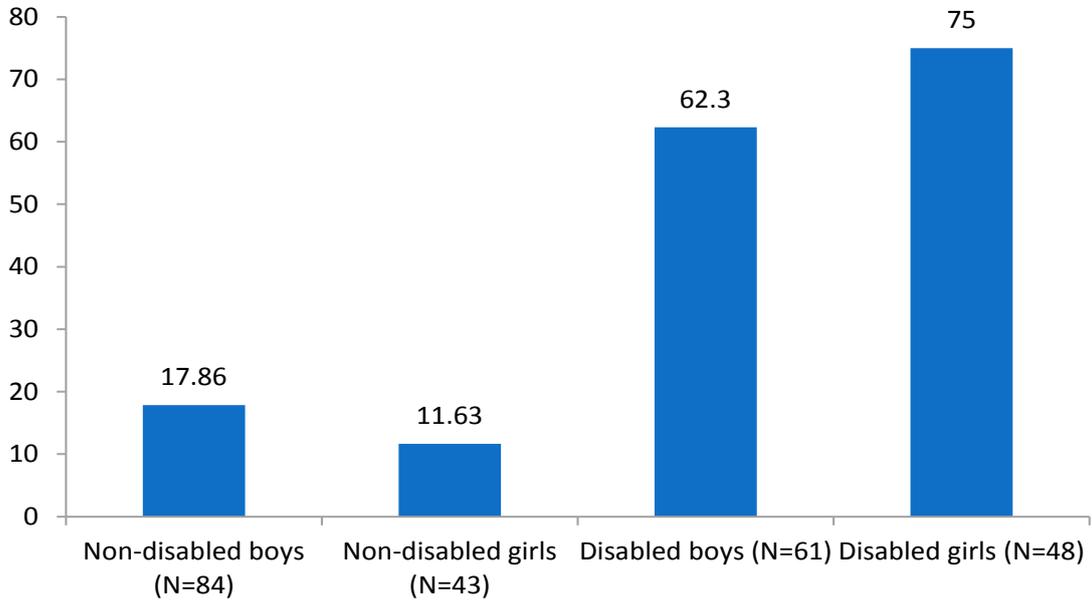
**Figure 11: Reasons for not attending school in 5-15 year old children with disability**





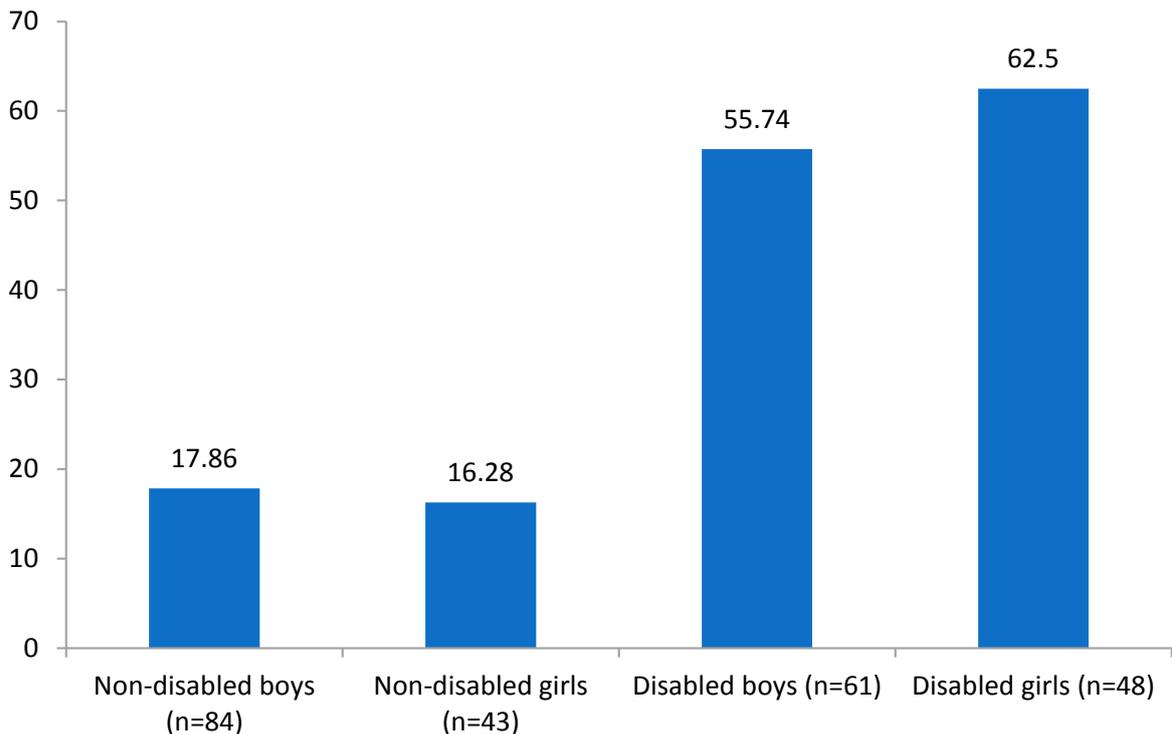
Making friendships and getting along with friends was significantly different among children with a disability and female children were the most disadvantaged in this regard (Figure 12).

**Figure 12: Getting along with friends and peers**



Bullying and abuse were commonly encountered by children with disability and this was significantly higher when compared to children without a disability (Figure 13).

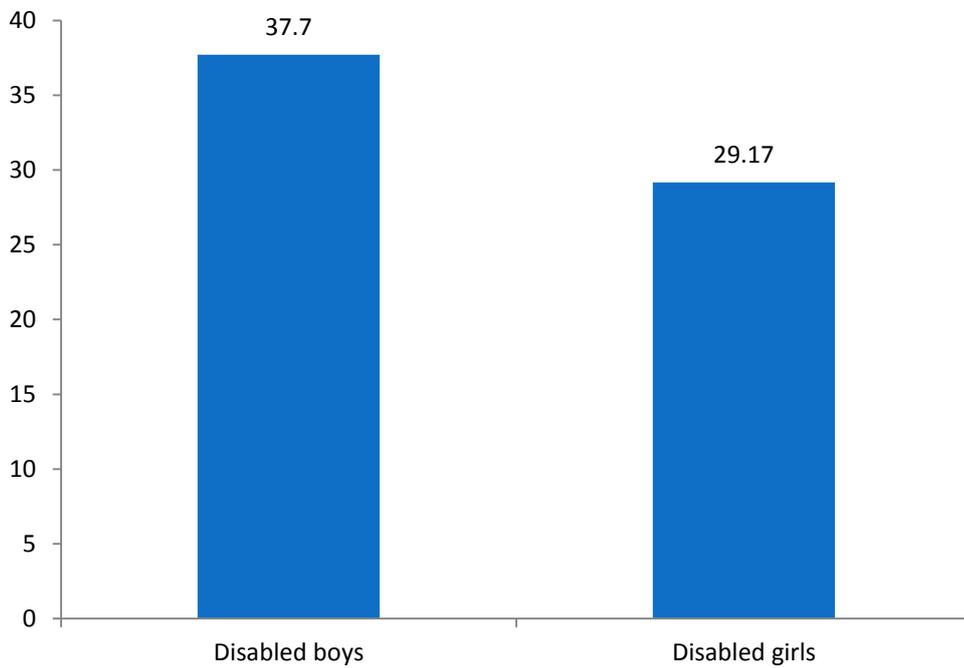
**Figure 13: Children reporting abuse and bullying**





A significant proportion of children with disability stated that they also had peers who were very supportive. A third of the boys with disability and a quarter of girls with disability stated that they did not get support from their peers (Figure 14).

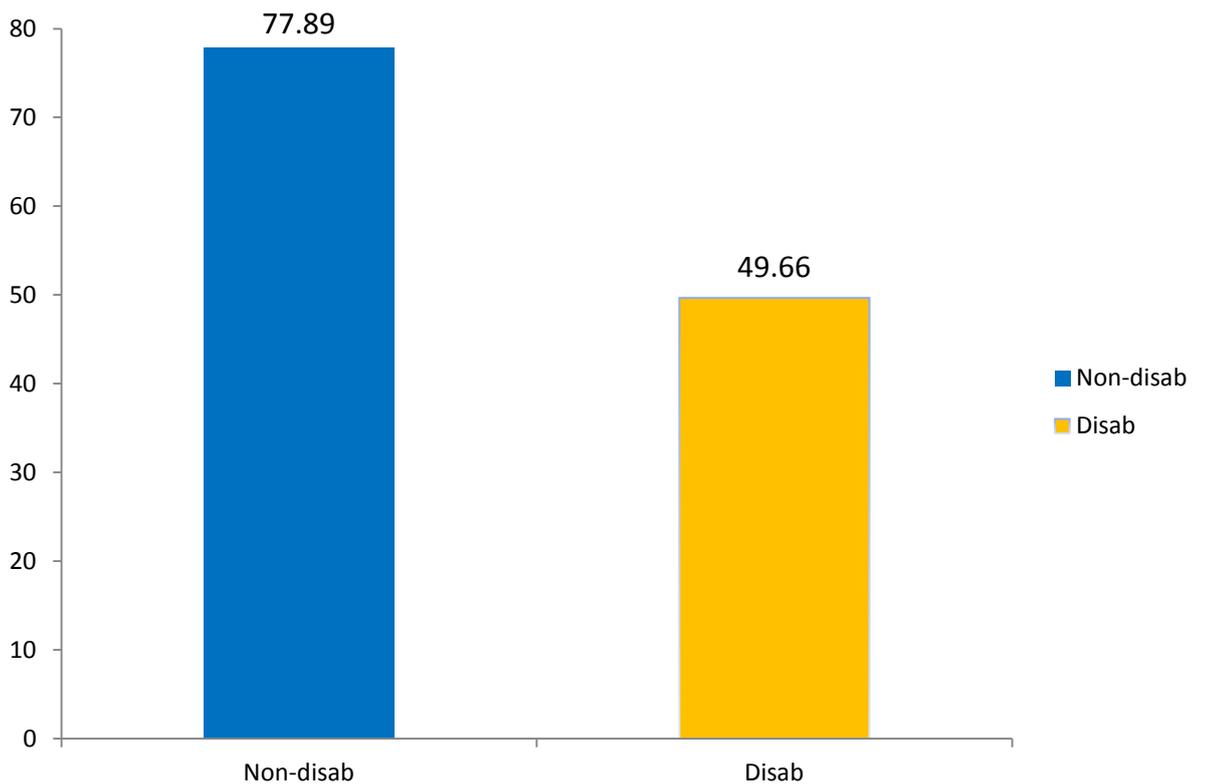
**Figure 14: Lack of support from peers**



### Adults Employment

Employment was observed to be 1.6 times higher amongst persons without disability compared to persons with disabilities (Figure 15).

**Figure 15: Comparison of Employment Status**





The difference in employment status between persons with disability and matched controls was statistically significant (Table 42).

**Table 42: Comparison of employment status between persons with disability and matched controls**

Employment	Controls (N=1256)	KIM Washington disabled (N=1039)
Currently employed	977 (77.79)	516 (49.66)
Currently unemployed	279 (22.21)	523 (50.34)
$\chi^2 = 197.8299; p < 0.001$		

Women with disability had a 7 times higher risk of not being employed compared to men without a disability (Table 43).

**Table 43: Employment Status and Disability Status**

Disability status	OR	P	CI
Males without WG disability, n=669	1.0		
Males without WG disability, n=308	1.95	<0.001	1.49, 2.56
Males without WG disability, n=361	3.73	<0.001	2.95, 4.72
Males without WG disability, n=155	6.67	<0.001	5.08, 8.74

Factors affecting employment were assessed both in persons with disability and their matched controls (Table 44).

**Table 44: Distribution of factors affecting employment potential**

Factors limiting employment	Males without disability (N=595)	Males with disability (N=290)	Females without disability (N=309)	Females with disability (N=139)
Restricted selection of job	45.88	58.25	45.17	61.15
Restricted work time at work	38.32	54.69	33.79	54.68
Special devices need	22.18	42.07	16.90	41.01
Need for assistance	36.97	66.02	30.69	62.59
Choice of job	37.48	64.72	27.93	61.87
Available Health Insurance	43.70	52.43	56.21	55.40
Hospital access at work	48.07	42.39	58.97	41.73



It was observed that people with disabilities are significantly more restricted in terms of getting out and about and in their social lives than people without a disability. Fewer disabled people socialized outside their home. Percentage differences of social participation was made a composite variable wherein people who reported having lots of difficulty or could not participate at all were grouped as ‘not participating group’ and others were categorized as ‘participating group’ (Reported difficulty in social participation of persons without disability: 8.1%; persons with disability:92%). Overall the disabled group were three times more likely to report a difficulty in participation in terms of meeting people, making friends, dealing with strangers, getting along with peer groups, attending social activities (OR=3.4;  $p < 0.005$ , 95% CI: 3.01, 3.80). Persons with disability reported experiences of facing misbehavior from other people in the society and showed a significant difference in terms of living in dignity. Compared to women without disability, women with disability were three times more likely to have reported difficulties for social participation (OR=12.74;  $p < 0.005$ ; 95% CI=8.52- 19.04)( Table 45).

**Table 45: Levels of social participation among the respondents**

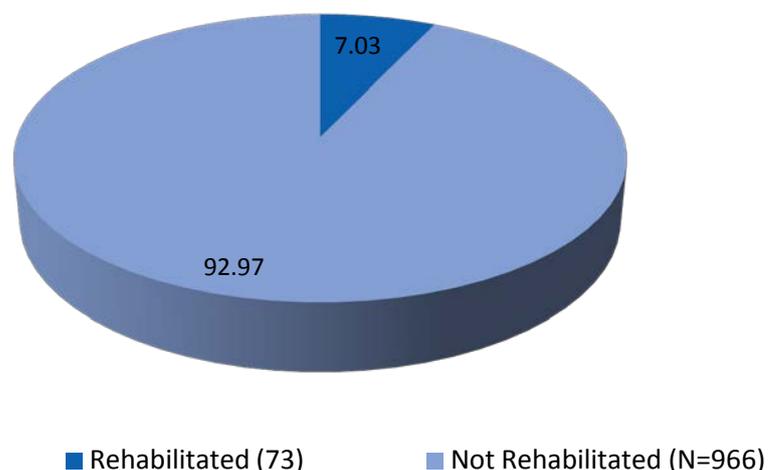
Level of participation	Men without disability	Women without disability	Men with Disability	Women with disability	OR	95% CI
<b>N</b>	<b>816</b>	<b>440</b>	<b>657</b>	<b>382</b>		
Meeting people	2.94	4.32	47.18	46.07	3.28	2.91,3.7
Making friends	2.7	4.32	48.1	46.34	3.35	2.97, 3.78
Dealing with strangers	2.57	4.09	47.79	47.91	3.47	3.07, 3.92
Getting along	2.57	4.09	46.42	46.07	3.34	2.98, 3.81
Participating in community activities	2.94	4.55	52.51	50.26	3.5	3.13, 4.0
Living in dignity	2.94	4.09	48.71	46.6	3.3	2.95,3.75
Misbehavior from community	2.94	3.86	47.34	46.34	3.3	2.94, 3.75

### 13. Rehabilitation Support for persons with disability

Access to rehabilitation services were also assessed during the study. All persons with disability were assessed in relation to rehabilitation.

Among the 1039 persons with disability, only 7% (73) reported accessing rehabilitation support.

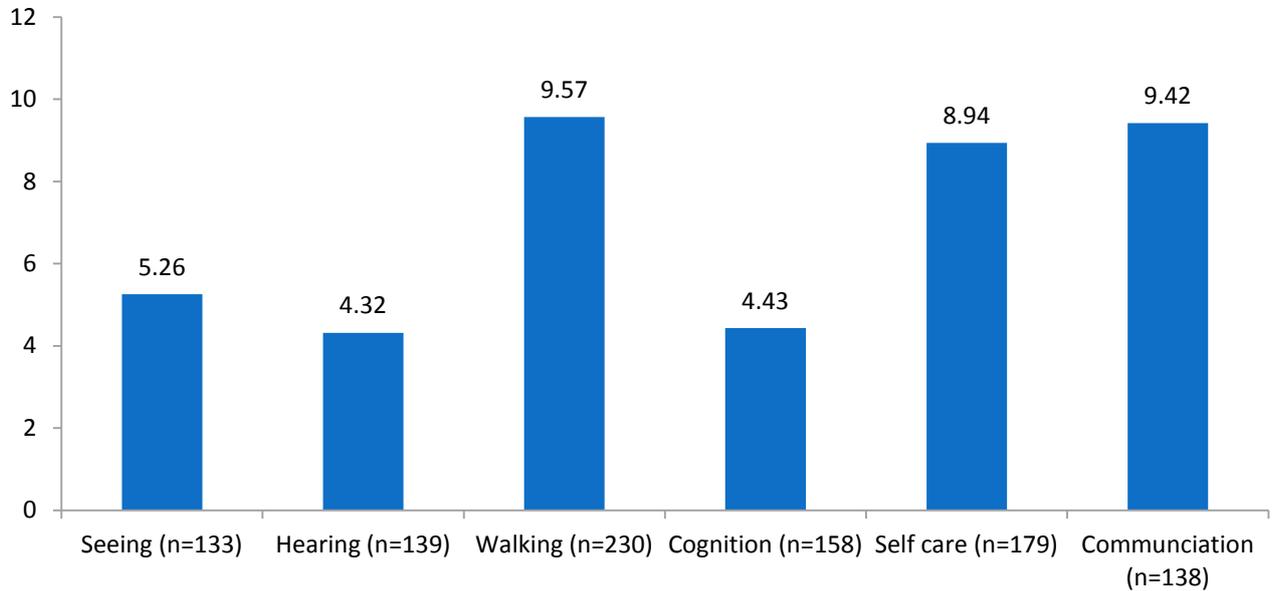
**Figure 16: Accessing rehabilitation support**





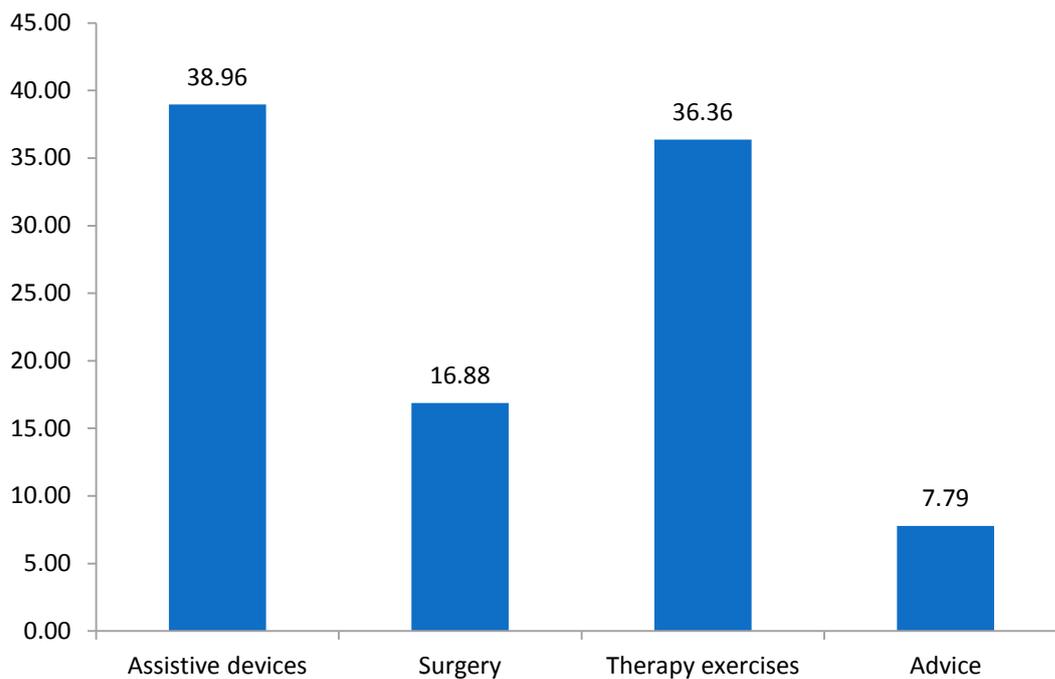
The rehabilitation support accessed in relation to different domains on the WG criteria were analyzed (Figure 17). It was observed that persons reporting disability in relation to mobility, self-care and communication accessed rehabilitation support marginally more than other domains.

**Figure 17: Reported Access to rehabilitation services by WG domains**



The type of rehabilitation support received was also analyzed (Figure 18).

**Figure 18: Type of rehabilitation support received**

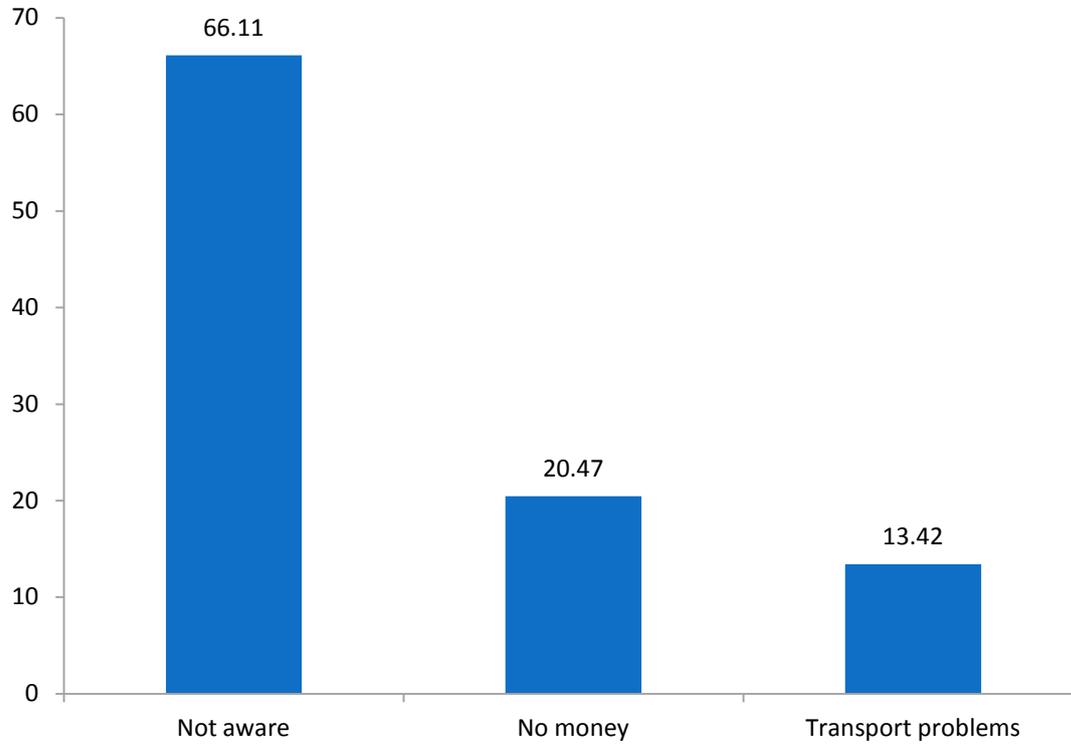




No sex differences were observed in relation to receiving rehabilitation support.

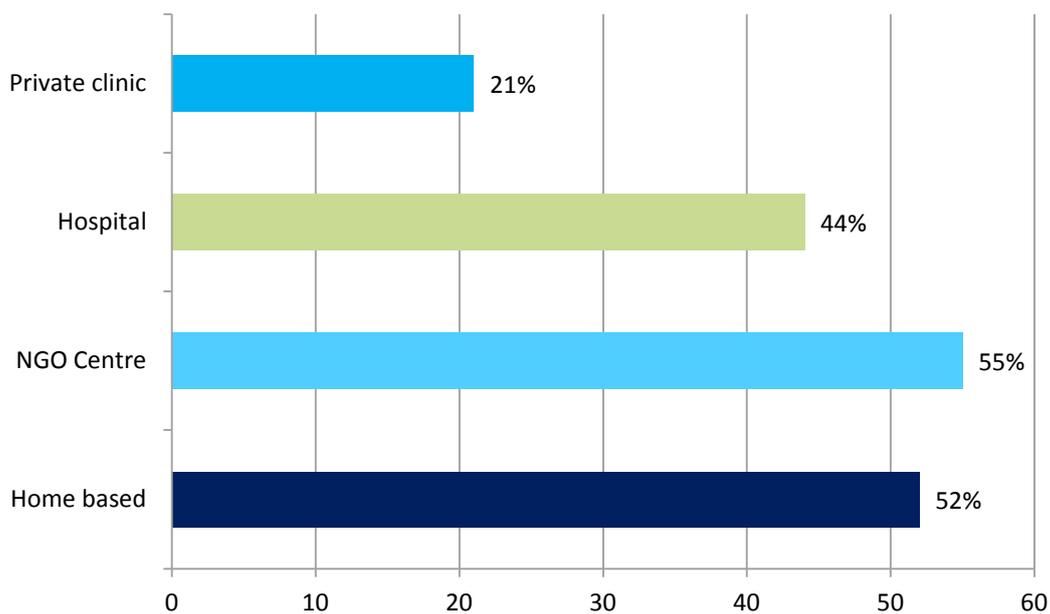
Among the persons with disability, ignorance of where such support was available was the commonest reason for not accessing rehabilitation support (Figure 19).

**Figure 19: Reasons for not accessing rehabilitation support**



Most of the rehabilitation services were provided by NGOs (Figure 20).

**Figure 20: Place where rehabilitation support was accessed**

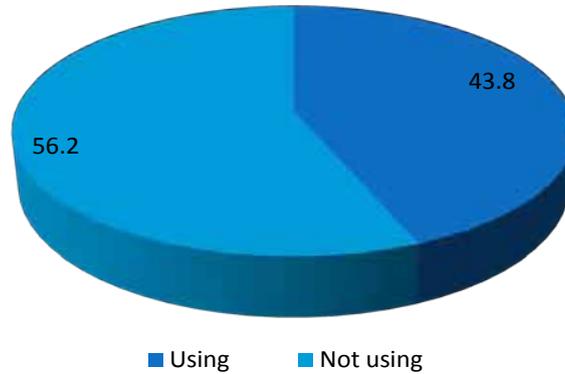




## 14. Use of Assistive Devices

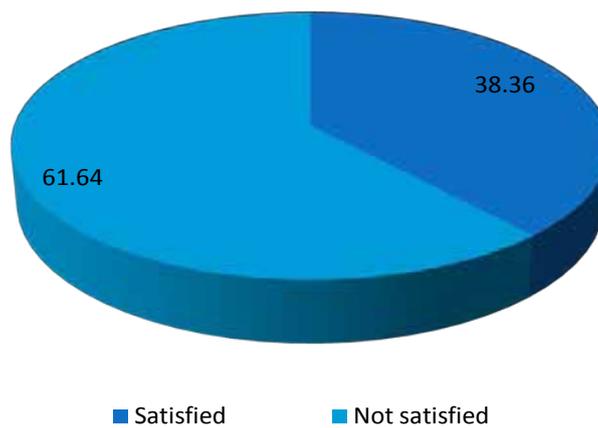
Out of 73 disabled people who got rehabilitated 56.2% of persons with disability were not using any assistive devices (Figure 21)

**Figure 21: Reported Use of Assistive devices**



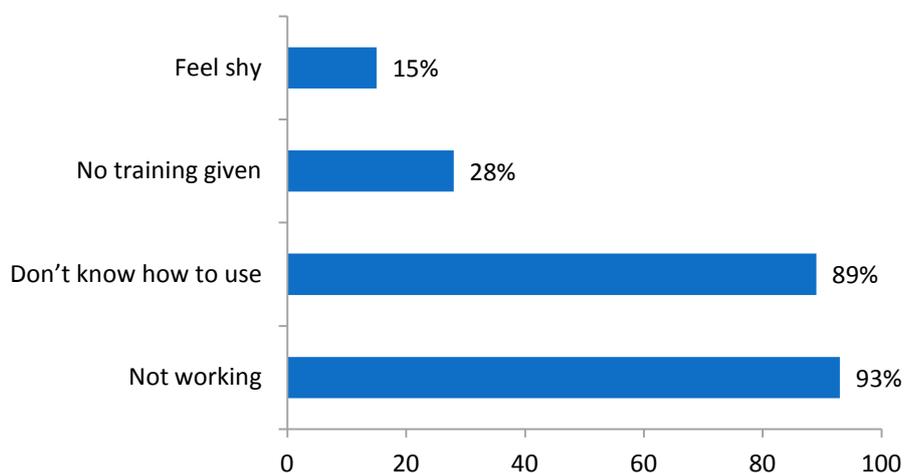
Amongst those using assistive devices, 61.6% were not satisfied with their assistive devices (Figure 22)

**Figure 22: Satisfaction with assistive devices**



Reasons for not using assistive devices was also assessed (Figure 23). Non functioning assistive devices and lack of knowledge on how to use the assistive devices were the two commonest reasons for not using the same. Most of the reasons for not using assistive devices were provider/ system related rather than individual related

**Figure 23: Reasons for not using assistive devices**





## Discussion

### Use of Key Informants

The study was conducted to determine differences, if any between persons with disabilities and an age-matched control group comprised of persons who stated that they did not experience any disability. The categorization was done using Washington Group criteria [19]. A severity scale was constructed based on past literature. An individual was termed as suffering from severe disability if they stated that they had a lot of difficulty or could not do any one of the six domains for which responses were elicited or if they had 'some' degree of difficulty in two or more domains.

The study utilized key informants to first list out individuals with different impairments (physical, visual, hearing and others) and an age-matched group without any impairments. These individuals were then visited by a team of medical personnel and therapists and interviewed using the Washington Group short questions.

The key informants listed 978 individuals with impairments and 1317 individuals as age-matched neighbourhood controls. After administering the WG criteria, individuals who stated that they experienced disability in the control group were clubbed with those with impairments. Therefore the final comparison groups consisted of 1039 persons with disability and 1256 controls without disability.

The analysis was done using sex-disaggregated data and for all persons with reported disability.

### Educational Status of persons with disability

A significant finding was that none of the Persons with Disability included in the study was educated to beyond the 9th Class and rates of formal education were also lower among the Persons with Disability in comparison with the controls. These differences were significant. It has been consistently reported that persons with disability, especially women have poorer access to educational opportunities [30]. The same is true of employment opportunities which was observed in this study and has also been reported from other studies [30,31].

### Health care access among persons with disability

Another major finding of the study was that persons with disability reported visiting a health care facility significantly more than persons without disability. This has been

reported in many other studies from different parts of the world [31-35]. This is likely to be due to the higher risk of chronic diseases among persons with disability compared to persons without a disability. A study in US observed that women with functional limitations had a significantly higher risk of hypertension, obesity, mental health problems and being current smokers [36]. Another study reported that persons with disability had a significantly higher risk of coronary heart disease, diabetes, cancer, obesity and hypertension [37]. Our study showed that Persons with disability suffered significantly more from diabetes, generalized convulsions and a perceived state of depression, but there were no differences in relation to other chronic conditions like hypertension, asthma or allergies etc. Our study also showed that hospitalization rates among persons with disability were significantly higher compared to those without a disability. Women with disability had the highest odds (2.62) of using current medication for 'prolonged illness' compared to men or women without disability.

Persons with disability had a significantly higher risk of reporting chronic illness compared to persons who did not have a disability. This higher risk of chronic diseases has been reported earlier also [37].

A significant proportion of both males and females with disability perceived that they could not access health services whenever they were in need of the same. This difference was observed across all age categories. A study in Korea observed that women with disabilities aged 18-64 years, were more likely to experience lower quality of care in terms of accessibility of care, satisfaction with care and adequate receipt of care [32,38]. Unlike as reported by a study from US, our study showed that men with disability reported poorer access to health services compared to women with disability, whereas in the US, women reported poorer access compared to men [39]. There is therefore an interesting dichotomy as persons with disability report using more health services, especially in-patient care while also stating that they do not receive care when they need it. Similar findings were also reported from Korea [40]. Many persons with disability, especially women with disability state that health facilities are not open when



they need them [39]. Other reasons mentioned included problems related to transportation or costs [33, 40, 41]. People with disabilities encounter a range of barriers in accessing health care facilities including lack of information and physical, inadequate personal assistance, affordability, limitations of resources and inaccessible infrastructure and non-friendly environments. In our study, the lack of an escort to accompany a person with disability was the biggest barrier reported. Irrespective of sex, if persons had a disability, they faced barriers in accessing health services.

## Reproductive Health

There was a significant difference in pregnancy experience between women with and without a disability. Women with disability had significantly lower pregnancy rate compared to women without a disability. Complications during pregnancy were also significantly higher in women with disability compared to women without a disability. This was in contrast to what has been reported from Afghanistan where pregnancy experience of women with disability was similar to pregnancy experience of women without a disability [31]. A study in the US observed that women with moderate-severe physical impairment had significantly higher rates of preterm deliveries [42]. In our study also, we observed that compared to non-disabled women, disabled women had more delivery related problems.

Pregnant and disabled women participants encountered numerous barriers to access reproductive health care services, including inaccessible equipment and facilities, health care providers' attitude and lack of knowledge about disabilities. All the barriers were significantly associated with the disability status in terms of access to health care. Our study showed that the supporting system that pregnant women need from the family and society if they are disabled is very challenging. Accessing reproductive health care services is difficult and therefore women with disability avoid regular gynecologic visits due to the barriers faced by them. This could affect the maternal health and pregnancy outcomes. A study in the US observed that in terms of prenatal visits, women with disability used the services almost as much as women without disability [43]. However hospitalization, emergency room visits and caesarean deliveries were higher among women with disability [43] unlike our study where there were no differences in the type of delivery between women with

and without a disability.

## Health status of children with disability

A total of 14 children were available for analysis, among them 6 were children with disability. Comparison of immunization status of children with disability compared to children without a disability revealed that there were no differences between the two groups.

Amongst children aged 0-16 years, it was observed that there was a significant difference between children with and without a disability in relation to reported health problems. These differences were statistically significant.

Available literature on health status of children with disability shows that children with disability suffer specific health issues. It has been seen that compared with their non-disabled peers, children with disabilities have higher risk of obesity and associated secondary conditions [44]. Work in different countries has looked at the dental health status of children with disability. In Bangladesh it was observed that the dental health status of children with disability was significantly compromised compared to children without a disability [45]. Another study from Croatia stated that dental health status could be considered an indicator of the overall health status of children with disabilities [46]. Analysis of data from the US showed that children with disability used many more services than their counterparts without disabilities in 1999-2000. The largest differences in utilization were for hospital days (464 vs 55 days per 1000), non-physician professional visits (3.0 vs 0.6), and home health provider days (3.8 vs 0.04). As a result of their greater use, children with disabilities also had much higher health care expenditures (2669 dollars vs 676 dollars) and higher out-of-pocket expenditures (297 dollars vs 189 dollars) [47]. Studies have also shown that obesity was commoner in children with intellectual disability [48]. These studies therefore show that health status or health service utilization by children with disabilities is significantly higher than for children without a disability.

## Social participation in children with and without a disability

A total of 109 children with disability and 127 children without a disability (aged 5-15 years), were available for analysis in our study. It was observed that school attendance was significantly lower amongst children with disability. The commonest barrier to not attending school



was the lack of acceptance from the school to admit a child with disability. Social participation was also poor for children with disabilities, especially the girls. Bullying and abuse were commonly encountered by children with disability and this was significantly higher when compared to children without a disability. A study in South Africa observed that the proportion of children attending pre-school (35%) or school (44%) was very low [49].

A significant proportion of children with disability, in our study reported bullying and abuse by their peer groups. Girls with disability suffered more bullying and abuse compared to the boys with disability.

### **Employment among Adults**

It was observed that the risk of not being able to find employment was much higher for a person with disability compared to a person without disability. Women with disability had a 7 times higher risk of not being employed compared to men without a disability.

Among both males and females with disability, the two main barriers cited for employment include need for assistance and the lack of choice of a job which would suit them. Many people with disabilities want to work but the existing barriers prevent them from accessing gainful employment. Persons with disability state that they need to work harder than others to get a job [50]. A study in South Africa reported that employment differed between youth with and without a disability and that disabled youth faced more barriers to employment compared to youth without a disability [51].

### **Social Participation among Adults**

Overall persons with disability were three times more likely to report a difficulty in participation in terms of meeting

people, making friends, dealing with strangers, getting along with peer groups, attending social activities.

Activity limitation was significantly higher in persons with disability compared to those without a disability. It was observed in our study, that the more severe the disability, the greater was the limitation of activities.

### **Use of rehabilitation services and assistive devices**

A very small proportion of persons with disability stated that they had received rehabilitation support. Support for mobility, self care and communication were more commonly reported as rehabilitation support accessed. More than 2/3 of persons with disability did not access services as they were not aware of the available services. Among those who stated that they received support for rehabilitation, less than half were using some assistive devices and 3 out of every 5 such persons stated that they were not happy with the assistive devices provided to them. Most people who were not using the assistive devices were either unaware of how to use them or they device was not functioning.

Promoting the use of assistive devices and providing adequate maintenance support for devices is very important as it is well known that the use of assistive devices by persons with disability leads to improved quality of life of other members of the family/ household as they are freed to do other activities at home [52]. Studies have also shown that the overall quality of life of persons with disabilities is also improved by the availability and use of assistive devices like a wheel chair [53].





## References

1. [http://apps.who.int/gb/ebwha/pdf\\_files/WHA66/A66\\_12-en.pdf](http://apps.who.int/gb/ebwha/pdf_files/WHA66/A66_12-en.pdf) (Accessed on 2nd May 2013)
2. Srivastava DK, Khan JA. Disability Needs Attention Now! *Indian Journal for the Practising Doctor*, 2008; 5: 3-4.
3. World Disability Report, 2011
4. Bowers B et al. Improving primary care for persons with disabilities: the nature of expertise. *Disability & Society*, 2003, 18: 443-455.
5. Drainoni M-L et al. Cross-disability experiences of barriers to health-care access: consumer perspectives. *Journal of Disability Policy Studies*, 2006,17:101-115.
6. McColl MA et al. Physician experiences providing primary care to people with disabilities. *Healthcare Policy = Politiques de Sante*, 2008,4:e129-e147
7. <http://siteresources.worldbank.org/SOCIALPROTECTION/Resources/SP-Discussion-papers/Disability-DP/1109.pdf>
8. Census of India 2001. Disabled population by type of disability, age and sex for India for General (Total). [http://www.censusindia.gov.in/Census\\_Data\\_2001/Census\\_Data\\_Online/disability](http://www.censusindia.gov.in/Census_Data_2001/Census_Data_Online/disability). Accessed 17th August 2010.
9. NSSO, 2002; Disabled Persons in India NSS 58th round 164.100.34.62/ index.php/ catalog/135/download/1533, [http://mospi.nic.in/mospi\\_new/upload/nso/58R\\_26.pdf](http://mospi.nic.in/mospi_new/upload/nso/58R_26.pdf)
10. Ganesh KS, Das A, Shashi JS. Epidemiology of disability in a rural community of Karnataka. *Indian J Public Health*. 2008 Jul-Sep; 52(3):125-9
11. Patel SK. An empirical study of causes of disability in India. *The Internet Journal of Epidemiology*. [http://www.ispub.com/journal/the\\_internet\\_journal\\_of\\_epidemiology/volume\\_6\\_number\\_2\\_26/article/an\\_empirical\\_study\\_of\\_causes\\_of\\_disability\\_in\\_india.html](http://www.ispub.com/journal/the_internet_journal_of_epidemiology/volume_6_number_2_26/article/an_empirical_study_of_causes_of_disability_in_india.html). Accessed 17th August 2010.
12. Kumar SG, Das A, Bhandary PV, Soans SJ, Kumar HNH, Kotian MS. Prevalence and pattern of mental disability using Indian disability evaluation assessment scale in a rural community of Karnataka. *Indian Journal of Psychiatry*, 2008; 50: 21–23
13. Singh A. Burden of disability in a Chandigarh village. *Indian Journal of Community Medicine*, 2008; 33: 113-115
14. Mini GK. Disabled People in Kerala. *Disability Indian Network*. 2006. Available at <http://www.disabilityindia.org/djartaug06A.cfm>
15. R. R. Pati. Prevalence and Pattern of Disability in a Rural Community in Karnataka. *Indian Journal of Community Medicine*, 2004; Vol. 29, No. 4
16. NFHS-2, 2005-2006; <http://www.measuredhs.com/pubs/pdf/FRIND3/FRIND3-VOL2.pdf>
17. Kuruvilla S, Joseph A. Identifying disability: comparing house-to-house survey and rapid rural appraisal. *Health Policy Plan*. 1999 Jun; 14(2):182-90.
18. World Health Organization. International classification of functioning, disability and health. 2001 28th September 2011]; Available from: [www.who.int/classification/icf/en](http://www.who.int/classification/icf/en).
19. Jennifer HM, Loeb ME, Barbara MA. Measuring disability and monitoring the UN Convention on the Rights of Persons with Disabilities: the work of the Washington Group on Disability Statistics; *BMC Public Health*. 2011; 11(Suppl 4): S4.
20. United Nations Enable. Rights and Dignity of Persons with Disabilities. <http://www.un.org/disabilities>
21. Stuijbergen AK, Seraphine A, Roberts G. An explanatory model of health promotion and quality of life in chronic disabling conditions. *Nurs Res*. 2000 May-Jun;49(3):122-9.
22. Coyle CP, Santiago MC. Healthcare utilization among women with physical disabilities. *Medscape Womens Health*. 2002 Jul-Aug;7(4)



23. Turk MA, Scandale J, Rosenbaum PF, Weber RJ. The health of women with cerebral palsy. *Phys Med Rehabil Clin N Am*. 2001 Feb;12(1):153-68
24. Mackey S, Murthy GV, Muhit MA, Islam JJ, Foster A. Validation of the key informant method to identify children with disabilities: methods and results from a pilot study in Bangladesh. *J Trop Pediatr*. 2012 Aug;58(4):269-74.
25. Muhit, M.A., et al., The Key Informant Method: A Novel Means of Ascertaining Blind Children in Bangladesh. *British journal of ophthalmology*, 2007; 91(8): 995.
26. Kalua, K., et al., Causes of blindness among children identified through village key informants in Malawi. *Can J Ophthalmol*, 2008. 43(4): p. 425-7
27. Razavi, H., et al., Prevalence and Causes of Severe Visual Impairment and Blindness Among Children in the Lorestan Province of Iran, Using the Key Informant Method. *Ophthalmic Epidemiology*, 2010. 17(2): 95-102
28. Pal, D.K., T. Das, and S. Sengupta, Comparison of key informant and survey methods for ascertainment of childhood epilepsy in West Bengal, India. *International journal of epidemiology*, 1998; 27(4): 672
29. The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1999. <http://socialjustice.nic.in/pwdact1995.php?pageid=8>
30. Nosek MA, Hughes RB, Swedlund N, Taylor NB, Swank P. self-esteem and women with disabilities. *Soc Sci Med* 2003; 56: 1737-1747
31. Trani JF, Barbou-des-Courieres C. Measuring equity in disability and healthcare utilization in Afghanistan. *Med Confl Surviv*. 2012;28:219-46.
32. Shin J, Moon S. Quality of care and role of health insurance among non elderly women with disabilities. *Women's Health Issues* 2008; 18:238-248
33. DeJong G. Primary care for persons with disabilities: an overview of the problem. *Am J Phys Med Rehabil* 1997; 76:52-58
34. McColl MA. Disability studies at the population level: Issues of health service utilization. *Amer J Occup Therapy* 2005; 59: 516-526
35. Turk MA, Mudumbi SV. The United states' response to the world report on disability. *Am J Phys Med Rehabil*. 2014 Jan;93(1 Suppl 1):S27-35.
36. Chevarley FM, Thierry JM, Gill CJ, Ryerson AB, Nosek MA. Health, Preventive Health Care, and health care access among women with disabilities in the 1994-1995 National Health Interview Survey, Supplement on Disability. *Women's Health Issues* 2006; 16:297-312.
37. Dixon-Ibarra A, Horner-Johnson W. Disability Status as an antecedent to chronic conditions: National Health Interview Survey, 2006-2012. *Prev Chronic Dis* 2014; 11: 130251.
38. Gulley SP, Altman BA. Disability in two health care systems: Access, quality, satisfaction and physician contacts among working age Canadians and Americans with disabilities. *Disability Health J* 2008; 1: 196-208.
39. Smith DL. Disparities in health care access for women with disabilities in the United States from the 2006 National Health Interview Survey. *Disability Health J* 2008; 1:79-88
40. Lee JE, Kim HR, Shin HI. Accessibility of medical services for persons with disabilities: comparison with the general population in Korea. *Disabil Rehabil*. 2013 Dec 16. [Epub ahead of print]
41. Maart S, Jelsma J. Disability and access to health care - a community based descriptive study. *Disabil Rehabil*. 2013 Jul 5. [Epub ahead of print]
42. Morton C, Le JT, Shahbandar L, Hammond C, Murphy EA, Kirschner KL. Pregnancy outcomes of women with physical disabilities: a matched cohort study. *PM R*. 2013 Feb;5(2):90-8.
43. Gavin NI, Benedict MB, Adams EK. Health service use and outcomes among disabled Medicaid pregnant women. *Womens Health Issues*. 2006;16:313-22
44. McPherson AC, Lindsay S. How do children with disabilities view 'healthy living'? A descriptive pilot study. *Disabil Health J*. 2012;5:201-9



45. Nahar SG, Hossain MA, Howlader MB, Ahmed A. Oral health status of disabled children. *Bangladesh Med Res Counc Bull.* 2010;36:61-3.
46. Bakarčić D, Prpić I, Ivancić-Jokić N, Bilić I, Lajnert V, Buković D. Dental status as a quality control health care parameter for children with disabilities. *Coll Antropol* 2009;33:139-42
47. Newacheck PW, Inkelas M, Kim SE. Health services use and health care expenditures for children with disabilities. *Pediatrics.* 2004;114:79-85
48. Slevin E(1), Truesdale-Kennedy M, McConkey R, Livingstone B, Fleming P. Obesity and overweight in intellectual and non-intellectually disabled children. *J Intellect Disabil Res.* 2014 ; 58:211-20.
49. Saloojee G(1), Phohole M, Saloojee H, IJsselmuiden C. Unmet health, welfare and educational needs of disabled children in an impoverished South African peri-urban township. *Child Care Health Dev.* 2007;33:230-5.
50. Jans LH, Kaye HS, Jones EC. Getting hired: successfully employed people with disabilities offer advice on disclosure, interviewing, and job search. *J Occupational Rehabil* 2012; 22: 155-65.
51. Cramm JM, Nieboer AP, Finkenflügel H, Lorenzo T. Comparison of barriers to employment among youth with and without disabilities in South Africa. *Work.* 2013;46:19-24.
52. Mortenson WB, Demers L, Fuhrer MJ, Jutai JW, Lenker J, DeRuyter F. How assistive technology use by individuals with disabilities impacts their caregivers: a systematic review of the research evidence. *Am J Phys Med Rehabil.* 2012;91:984-98
53. Shore S, Juillerat S. The impact of a low cost wheelchair on the quality of life of the disabled in developing world. *Med Sci Monit.* 2012 Sep;18(9):CR533-42.





# ANNEXURES



**Table A.1: List of Impairments Identified**

Impairment	N	%
Blind	21	2.15
Physically handicapped excluding polio	467	47.75
Polio	290	29.65
Visual Impairment	93	9.51
Speech impairment	30	3.07
Hearing impairment	27	2.76
epilepsy	17	1.74
Cerebral palsy	11	1.12
Intellectual Impairment	8	0.82
Speech and Hearing impairment	8	0.82
Mentally ill	5	0.51
Intellectual Impairment and physically impaired	1	0.1

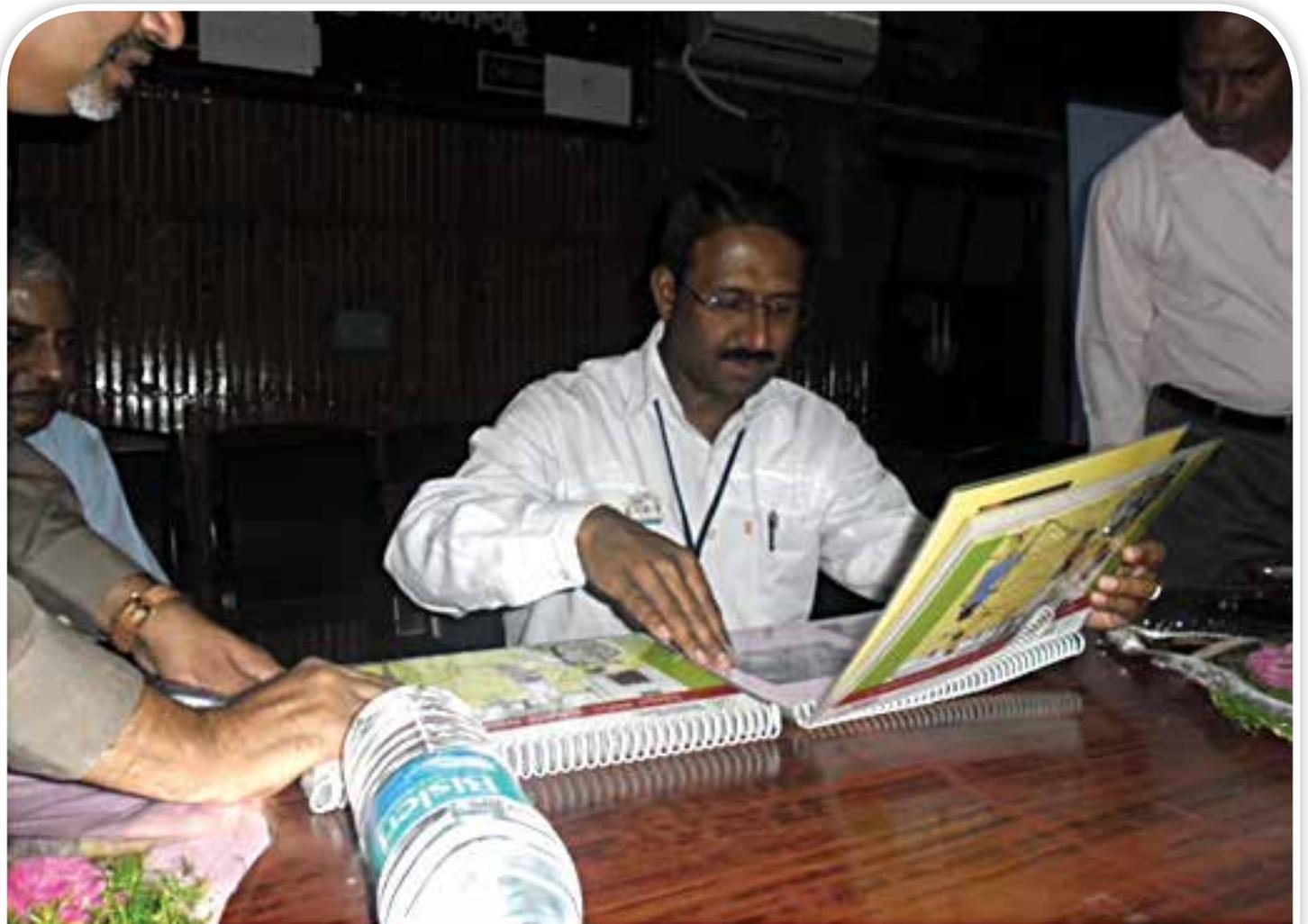
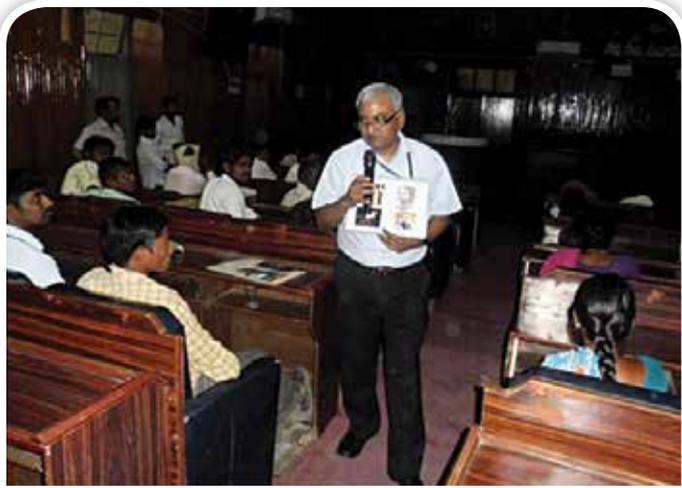
**Table A.2: Glimpses of training and Service provision**

All the Key informants trained were given responsibilities to identify the disabilities hearing, visual, physical impairment and epilepsy with the help of training acquired from LVPEI.

Population covered In Sanga reddy	Number of villages	Total number of KIs trained	Number of KI trained per village
50390 (3000 avg per village)	13	26	1
Population covered in Bidar	Number of villages	Total number of KIs trained	Number of KI trained per village
24890 (850 avg per village)	16	31	2



## Training program



*During KI training program Sanga Reddy district collector looking through the Flip book developed for KI training*

## Services provided:

### 1. Free Eye Camp service:

Community Eye Screening Program Conducted at Laxmi Nagar Community Hall Kandi (V) Sanga Reddy (Mandal) Medak District on 14th April, 2013. 83 persons were screened. Among them, 34 persons were within normal limits and 49 persons identified with eye problems and been referred for further investigations in LVPEI.



*LVPEI Team conducting eye examination*

Services provided	Total people benefited
Total no. of people screened	83
No. of people with Refractive Errors	30
No. of people with Cataract	13
No. of people with other ocular ailments	6
No. of people 'Within Normal Limits'	34
Services	
Prescribed spectacles	26
Advised to continue with same spectacles	4
Referred to LVPEI for further management	6
Counselled self-eye care	34
Diabetic Risk (Indian diabetic risk score form used by LVPEI)	4
Spectacles dispensed	1







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