



Knowledge Assessment of ASHA, ANM & AWW regarding Prevention and Identification of Children with Disability & Developmental Delay

Submitted by:

White Paper Research & Analysis Pvt. Ltd.

Head Office: Ward no. 18, Vidyapuri, Madhepura (Bihar) – 852113, India.

Email: wpraresearch@gmail.com

Content

<i>Acknowledgement</i>	2
1. Introduction	3
2. Objective and Methodology	6
3. Major Findings	8
4. Conclusion and Recommendation	16
<i>References</i>	18
<i>Annexure – I</i>	19
<i>Annexure – II</i>	28

Acknowledgement

We thank to Jan Vikas Samiti, Varanasi for entrusting us to conduct this study. The research team would like to express profound sense of gratitude to Jan Vikas Samiti, Varanasi and its partner organizations for their support and cooperation during the data collection for the study in all the sample states.

Research Team

WPRA

Chapter – I

Introduction

Disability can be defined as any restriction or lack of ability, resulting from impairment, to perform an activity in a manner or within the range considered normal for the human beings. Impairment concerns the physical aspects of health; disability is the loss of functional capacity resulting from an impairment organ; handicap is a measure of the social and cultural consequences of an impairment or disability.

Globally, around 785-795 million persons aged 15 years and older are living with disability based on 2010 population estimates. Of these, the World Health Survey estimates that 110 million people (2.2%) have very significant difficulties in functioning while the Global Burden of Disease Survey estimates 190 million (3.8%) have severe disability. Including children, over a billion people (about 15% of the world's population) were estimated to be living with disability. Thus, a person with any form of disability falls in the world's largest minority group. According to the United Nations report, nearly 8% of the disabled persons belong to the developing countries.

In contrast, the National Sample Survey Organization (NSSO) report and Census data of 2011 estimate that nearly 2.21% of Indian population consists of disabled persons (MOSPI, 2016). A recent community-based study in India found the prevalence of all types of disability as 6.3% out of which mental disability was found to be the most common type of disability (36.7%). The disability prevalence varies in different age groups and urban-rural areas. It is reported that the burden of disability is more among the geriatric (>60 years) age group with 6401 and 5511 per lakh population in rural and urban areas respectively. In India, NSSO reported that a total of 1,40,85,000, and 44,06,000 people are disabled in rural and urban areas, respectively. It depicts the fact that majority of disable people resides in rural part of India where accessibility, availability and utilization of services are major issues to be considered. Lack of education

among disabled is an important barrier for effective delivery of services and 54.7% of disabled belonged to illiterate category according to NSSO 2002 survey findings.

Thorough knowledge, prevention methods, early detection and early intervention on development delay are some key cornerstones that can help in curbing the disability rate in India which is increasing rapidly over the past few decades.

Primary prevention towards disability is the first step to control the disability rate in India.

Prevention of disability can be endeavored in following ways (GOI, 2002):

- i. Prevention at three levels- primary, secondary and tertiary level
- ii. Using general preventive measures
- iii. Care during pregnancy
- iv. Care at the time of birth
- v. Early childhood care

While considering the above methods of preventing disability, the role of the health workers i.e. Accredited Social Health Activist (ASHA), Auxiliary Nurse Midwifery (ANM) and Anganwadi Workers (AWW), becomes hugely prominent towards taking actions prior to the onset of disability of an individual. They are generally responsible for assisting antenatal and postnatal cases of mother and child. These phases play pivotal role in prevention and early detection of disability among children. Therefore, these health workers require having extensive knowledge and awareness to deliver their services regarding identification and prevention of disability.

Chapter – II

Approach, Objective and Methodology

2.1 Approach

Jan Vikas Samiti (JVS), Varanasi, with help of their Partner Organizations, has been focusing on the provision of quality services in the rural area through their Community Based Rehabilitation (CBR) approach. Gradually, JVS is becoming more responsible to work for “Prevention and Early Intervention of Disability and Developmental Delay” in the selected states. Disability is an important public health problem especially in developing countries like India and as per World Health Organization (WHO) rate of disability is very high in India especially, the cases of neurological and genetic disability.

We know that primary prevention (action taken prior to the onset of disability) is very important and essential to control disability and disorders. At the primary level, ASHA, ANM and Aaganwadi workers are majorly responsible to see the matter of Ante Natal and Post Natal Care of mother and their baby. This period is very important for prevention and early identification of disability and developmental delay in child.

Following this, JVS Varanasi has initiated and entrusted us to conduct a study to assess the knowledge of these health workers (ASHA, ANM and AWW) regarding disability in selected states of India. This study also aims to fulfill the gap where detailed study on knowledge assessment of health workers in various Indian states is sparse in the literature. The study tried to assess the knowledge of the HWs on basic and enhanced issues related to disability in children, its early identification and prevention. We hope findings of this study would be of help making strategies for prevention and early identification of disability in children and enhancing the knowledge of health workers on the same.

2.2 Objective of the Study

Major objective of the study is formulated as to assess the knowledge of Accredited Social Health Activist (ASHA), Auxiliary Nurse Midwifery (ANM) and Anganwadi Workers (AWW) regarding prevention and early identification of children with disability and developmental delay in her catchment area

Specific objectives include as:

- i. To assess the general awareness among health workers (ASHA, ANM and AWW) about disability in child
- ii. To assess their knowledge about early identification and prevention of disability
- iii. To measure their knowledge enhancement and its impact

2.3 Methodology

2.3.1 Nature of study: The study used survey methods to get elicit feedback from the concerned stakeholders. Nature of survey was mix of quantitative and qualitative data collection methods. The quantitative findings have been substituted with qualitative feedback. All the selected stakeholders were personally interviewed by field investigators.

2.3.2 Data collection: Data has been collected through semi structured interview schedules with by the experienced field investigators. Interview schedules were translated into English and Hindi languages. To ensure the accuracy of data, both physical and telephonic back checks were conducted during and after the field work.

2.3.3 Selection of Respondents: Respondents (Health Workers i.e. ASHA, ANM and AWW) for this study were selected using random sampling technique in all the four selected states. All the respondents were informed prior to interview to ensure their availability.

2.3.4 Sample Distribution and Geographical Coverage:

State	Health Worker			Total
	ANM	ASHA	AWW	
Bihar	8	16	16	40
Jharkhand	4	13	12	29
MP	8	15	16	39
UP	12	27	29	68
Total	32	71	73	176

Table 2.1

2.3.5 Training of Field Researchers: A two day rigorous training was conducted to make the field researcher familiar with schedules for the study. Prior to training, screening exercise was undertaken to choose able field persons to conduct the study. The due weight was given to experience of field researchers in similar field. The training was divided into two parts. In first part, all the selected field investigators were briefed about the study, data collection techniques and the tools to be used for data collection. In second part, mock interview was conducted to make them familiar with the survey schedule.

2.3.6 Data Analysis: The Computer software CsPro has been used for data entry. Quantified data has been analyzed using SPSS, and wherever necessary, Excel software has also been used for data analysis. Multivariate analysis has been carried out in the study. Mainly descriptive statistics have been used for analyzing sample characteristics. Prior to analysis exercise of data cleaning was carried out. Content analysis of the qualitative responses received during field work from concerned stakeholders has been carried out to ascertain the reasons.

Chapter – III

Major Findings

The study was conducted in four sample states namely Madhya Pradesh, Uttar Pradesh, Bihar and Jharkhand. Total 176 health workers were interviewed to assess their knowledge about prevention and early identification of disability and developmental delay in children.

Major findings of this study are broadly divided into following parts:

- **Awareness level of health workers about their role and responsibility; and their knowledge about disability in child and its early identification and prevention**
- **Health workers participation in training and other awareness programme to enhance their knowledge about disability**
- **Problems faced by health workers during their service and their opinion to fight with disability in child**

3.1 Level of awareness and Knowledge about disability:

Respondents, selected for this study, were having 6-17 years of experience of services in their field. All of them were found mostly aware about their role and responsibility as health worker. Responding to their knowledge about type of disability, most of them were commonly found to be aware about Blindness, Multiple Disabilities including Deaf Blindness, Loco-motor Disability, Speech and Language disability, Hearing Impairment (Deaf and Hard of Hearing), Mental Illness, Intellectual Disability, Low Vision and Dwarfism. Some of them also responded Leprosy Cured persons and Chronic Neurological conditions as type of disability; however, very few of them were found to be aware about rest of the types of disability like Muscular Dystrophy, Cerebral Palsy, Acid Attack Victim, Parkinson's disease, Multiple Sclerosis, Thalassemia, Haemophilia etc. according to the Rights of Persons with Disabilities Act (RPwDs Act), 2016, Govt. of India. It

would have been more contemporaneous, if the health workers had knowledge on all the 21 types of disabilities which could have advanced their knowledge and helped them in early identification and prevention of disability in more specific way.

Responding to providing information and awareness generation regarding disability and its prevention during their service, almost all of the respondents (91.5%) reported that they always provide such information to the people; however, more than two third of the respondents (above 65%) were found not to be aware about any pre natal screening test or diagnostic test for detecting disability in child during pregnancy and about screening test conducted for under 5 age group children for early detection of disability. But with the same, non-availability of such health service centre or test centre in their locality that provides screening test for detection of disability in child was also reported by rest of the respondents who were found to be aware about such screening tests. Most of those health workers, who were aware about such screening test, answered that they always suggest pregnant women to go for this diagnostic test for early detection of disability in the child in their regular visits.

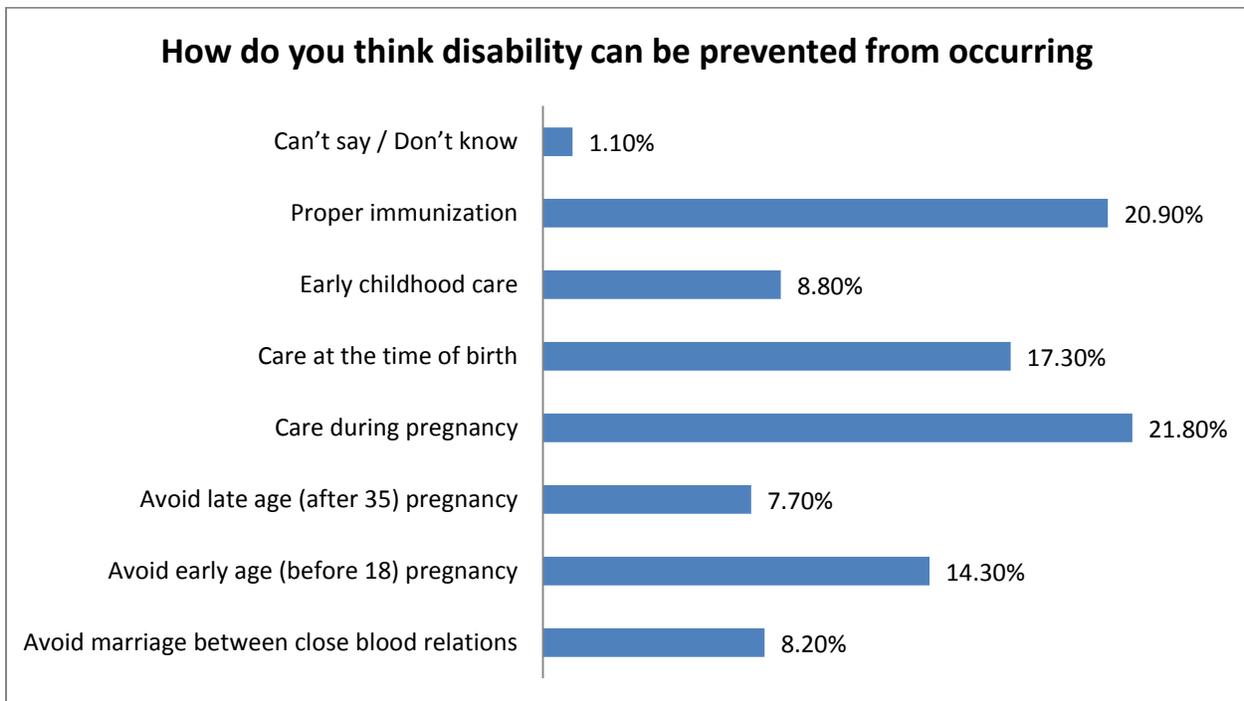


Fig. 3.1

Giving their opinion about how disability in child could be prevented from occurring, most of the respondents opined that care should be taken during pregnancy, proper immunization should be assured and better care at the time of birth should be taken. Some of them also stated that early age pregnancy should be avoided including avoid marriage between close blood relation and early childhood care of children.

Answering to what suggestions they usually give to pregnant women, more than 80% of the respondents answered that they always advised pregnant women to go for institutional delivery, while rest of them reportedly often or sometimes advocated for institutional delivery. However, close to two third of respondents (58.5%) stated that they always advised married women to consult doctor before getting pregnant, whereas more than 17% said often and 14% of them replied sometimes they advised women to consult doctor before conceiving.

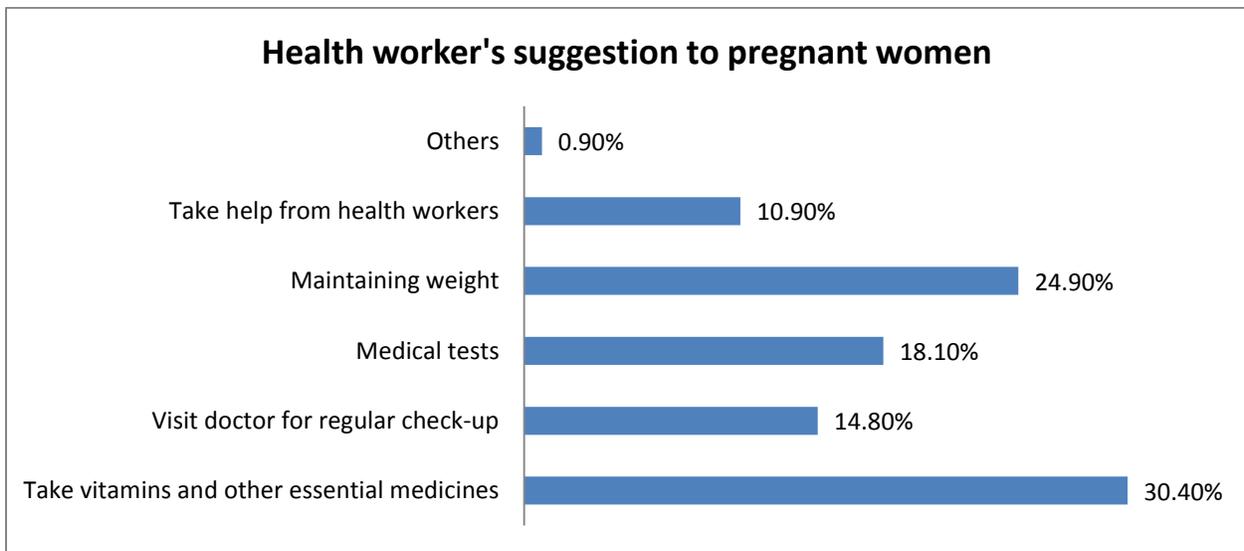


Fig. 3.2

Apart from suggesting for institutional delivery and consulting doctor before pregnancy; close to one third of the respondents stated that they used to suggest taking essential medicine and vitamins and to maintain weight during pregnancy to avoid disability in child. Medical tests, visiting doctor for regular check-up and seek help of health workers in case of problem were also reported as suggestion of health workers to pregnant women to avoid disability in child.

Among all, study also tried to find out that how many cases of pregnant women have been detected with disability in child during pregnancy how many cases of disabled children have been identified in last three years in their catchment areas. Surprisingly very few of the respondents answered to this and number of such cases were reported as 1 to 5 for both pregnant women and early age children. On the contrary, Census 2011 data on disability report shows extreme/high prevalence of disability among children in the sample states. Reasons behind this could be considered as lack of training on disability knowledge, social barriers to detect disability, lack of reporting of cases of disability etc for which instances of disability in child during pregnancy and among children remains under reported.

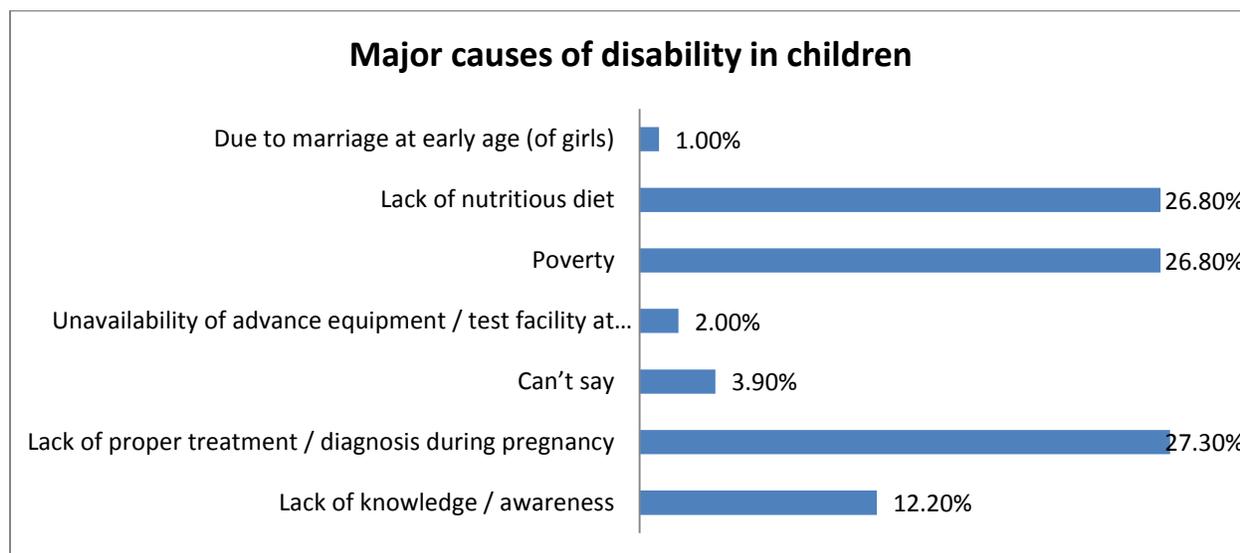


Fig. 3.3

Responding to major causes of disability in children in the area according to them, most of the health workers reported Lack of proper treatment / diagnosis during pregnancy (27.3%), Lack of nutritious diet (26.8%) and Poverty (26.8%) as the major cause according to them. Some of them also stated Lack of knowledge / awareness among people (12.2%) and very few of them reported Unavailability of advance equipment / test facility at health centre and early age marriage of girls as the major reasons.

Answering to major problem they face while assisting cases of disability and developmental delay, close to one fourth of them (above 20%) responded difficulties in convincing people for medical assistance and lack of medical facilities in this area to deal with disability. Financial obstacles (15.9%), resistance from family (13%) and Superstition/stigma in the society towards disability (5.8%) were also reported by the respondents as some of major problem during assisting cases of disability, however, 11% response was reported as no such problems faced.

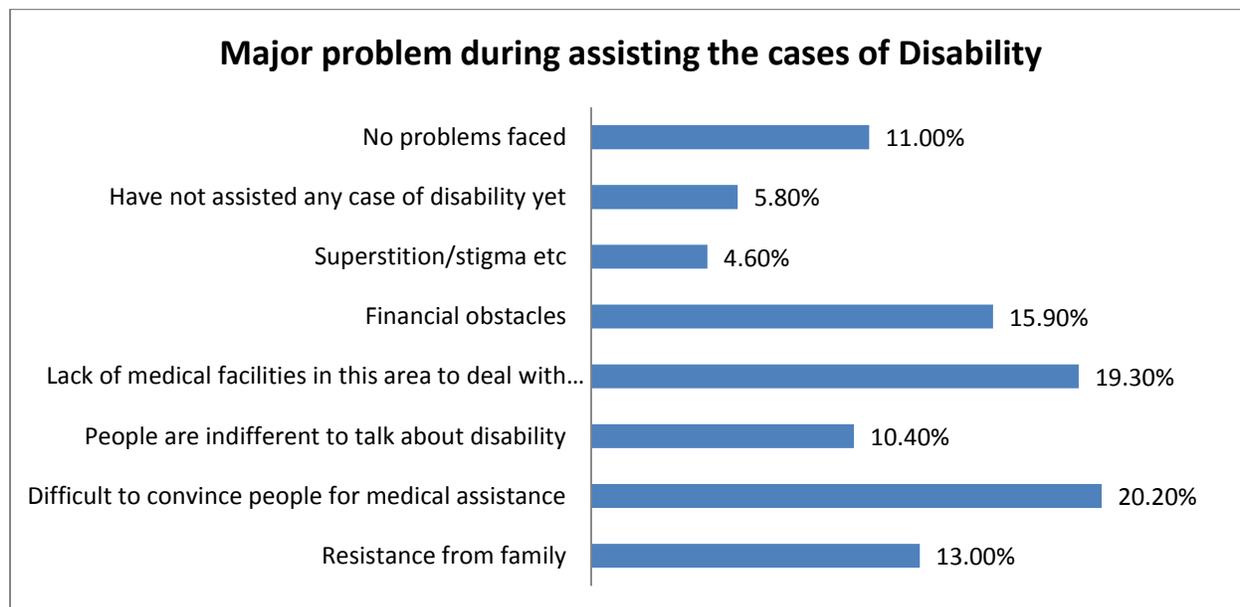


Fig. 3.4

3.2 Training and Knowledge enhancement:

While exploring about specific training or knowledge enhancement programme related to identification and prevention of disability only one fourth of the respondent were found had such training reportedly, however, most of them reported that its been more than a year they received such training and therefore they did not have updated knowledge. Major topics covered in the training programme were reported as knowledge about prevention of disability, early identification of disability and assisting disable person and children. These training

programmes were mostly conducted by non-government organizations and government health department as reported by the respondents.

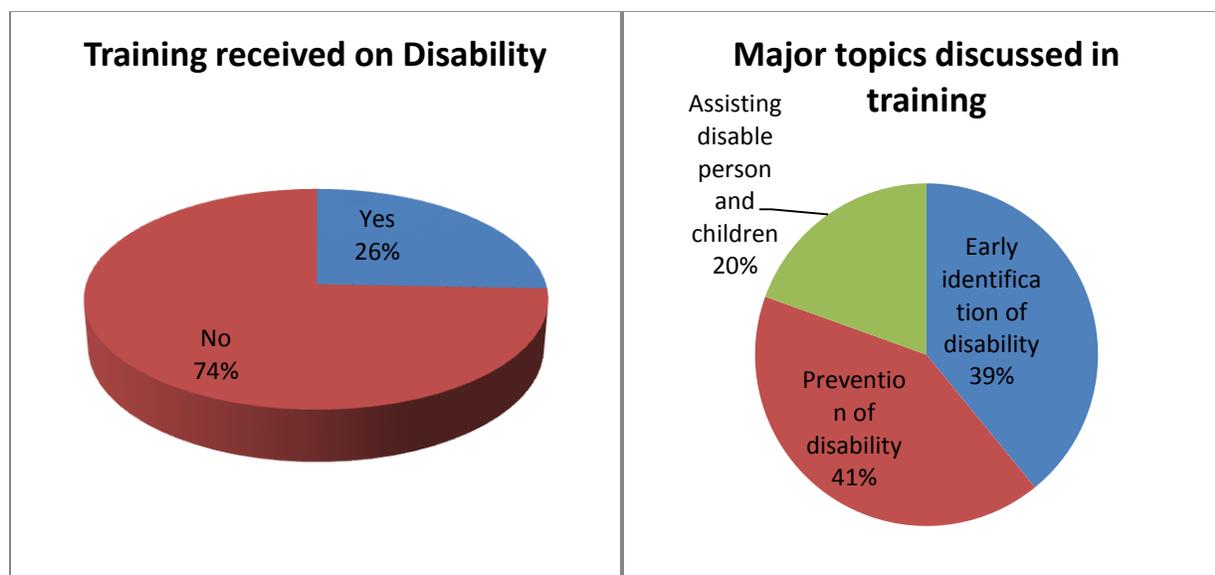


Fig. 3.5

Most of the respondents (health workers) were not found much satisfied with the training they received and major reasons for less satisfaction from training were reported as lack of course material and hand-outs due to which the participants could not remember all the information after the session, inadequate time and sometimes poor quality of trainers; nevertheless, some of them found the training programme helpful in to work on early identification and prevention of disability in children.

Apart from training programme, respondents were also asked if they have been part of any awareness programme on early detection of disability and preventive measure. Assessing the responses to this it was found that close to two third (64.2%) of the respondents were never been part of any such awareness programme related to disability. Besides this, 15.3% of the respondents stated that they have also participated in some assessment/test on disability knowledge, conducted by government/government affiliated agencies, however, when the respondents were asked for self-assessment regarding their knowledge on disability, its early

identification and prevention on the basis of 1 to 10 point scale (1 for very poor and 10 for excellent), most of them have given themselves 5 – 6 point.

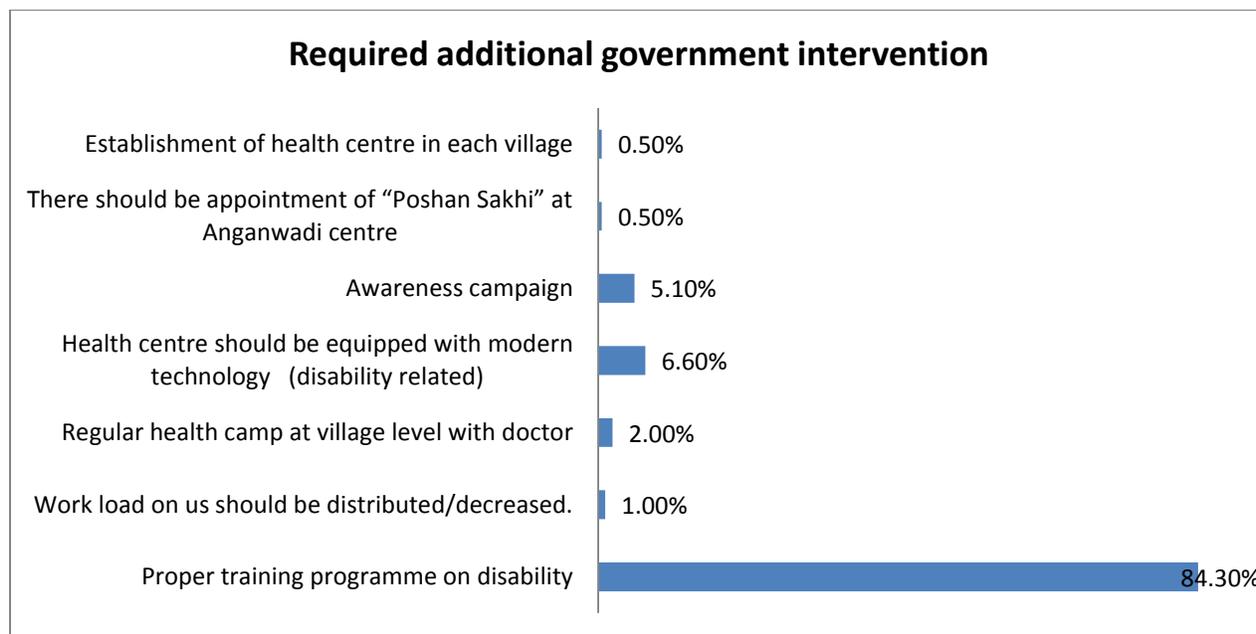


Fig. 3.6

Answering to what additional government intervention they require for enhancing their knowledge about disability more than 84% of them reportedly expressed their need of proper training on early identification and prevention of disability.

3.3 Major problems faced during service and suggestions:

While respondents were asked to tell about major problems they face in general during their service, most of them (65%) reported that there was no such major problem they faced. However, some of them responded difficulties in dealing with illiterate people, transportation problem in case of emergency and otherwise, excessive work load and lower salary as major problems. These stated problems may be considered as factors that may force them to neglect their duty in some cases.

The study tried to capture the respondent's recommendation and suggestions that could be of help, according to them, to fight with disability. These are as follows:

- Health workers recommended for awareness generation programme initiatives to be taken not only by government organizations but also by non-government organizations and other agencies that will make overall improvement in awareness level among the health workers and the local people on disability.
- Health workers reported that in their service area, they come across cases where due to poverty the pregnant women fail to receive adequate vitamin/nutritious food, and proper medical facilities. Health workers suggested that they should be involved in beneficiary activities and provide medical assistance to these persons as part of their assistance work to prevent disability.
- Health workers should be given responsibilities and provision should be made by the authority to provide supplementary nutritious food for children and pregnant women in villages to prevent occurrence of disability.
- Health centre should be equipped with modern technology related to early identification of disability which will help the health workers to provide better solutions to patients with disability.
- Improvement in the sanitation and hygiene condition of the villages.
- There is need for complete training course on immunization which will help the health workers to provide better service and in assisting cases of disability.
- Health workers suggested for specialist doctor appointed in the Primary Health Centre level to whom they can refer or ask suggestions for assisting cases of disability
- Health workers also advocated for restricting early age marriage of girls to prevent disability.

Chapter – IV

Conclusion and Recommendation

The study reveals that health workers, Accredited Social Health Activist, Auxiliary Nurse Midwifery and Anganwadi Workers, selected for this study are having some basic knowledge about prevention and early identification of disability and developmental delay in children, however, they are in urgent need of extensive and specific training on disability in child and prevention measures so that they could work with children with disability more efficiently and help in prevention.

Major recommendations are as follows:

- There is requirement of more rigorous and specific training programme on disability which needs to be adequate in terms of quality and quantity (course materials, handouts, more topics under disability including knowledge about community based rehabilitation programme) etc.
- Time to time evaluation programme for health workers on disability by both Government and other organizations is much needed to motivate and improve the knowledge base of the health workers.
- The health workers should also be provided specific training to serve poor, illiterate people who are more difficult to be convinced on issues of disability and who sometimes refuse to avail medical facilities for treating cases of disability.
- There should be high emphasis on conducting awareness generation programmes, health camps etc. on disability wherein active participation of health workers should be ensured and they could develop experience from field/practical cases of disability.

- There should be improvement in medical facilities to serve the cases of disability. The health centres are required to be equipped with modern equipment and screening test facilities for pregnant mother and children to assist cases of disability which will motivate health workers in advocacy and assisting cases of disability.

References

- ✚ Barbotte E, Guellimin F, Chan N Lorhandicap Group. Prevalence of impairments, disabilities, handicaps and quality of life in the general population: A review of recent literature. Bull World Health Organ.
- ✚ World Report on Disability. Geneva: WHO; 2011
- ✚ Geneva: WHO; 1989. The World Health Organization. Training in the community for people with disabilities
- ✚ A report on disabled persons. New Delhi: Department of Statistics, Government of India; 2003. National Sample Survey Organization
- ✚ Census of India 2011. Data on disability. Office of the Registrar General and Census Commissioner, India
- ✚ http://planningcommission.nic.in/reports/sereport/ser/stdy_ied.
- ✚ http://mospi.nic.in/sites/default/files/publication_reports/Disabled_persons_in_India_2016
- ✚ <http://disabilityaffairs.gov.in/upload/uploadfiles/files/disabilityinindia2011data>

Annexure – I

What are the types of disability you are aware of?

Responses	
Blindness	14.0%
Low Vision	7.5%
Leprosy Cured persons	4.2%
Loco-motor Disability	11.4%
Dwarfism	6.6%
Intellectual Disability	7.8%
Mental Illness	8.6%
Cerebral Palsy	.7%
Specific Learning Disabilities	.7%
Speech and Language disability	10.9%
Hearing Impairment (Deaf and Hard of Hearing)	10.0%
Muscular Dystrophy	.7%
Acid Attack Victim	.9%
Parkinson's disease	.2%
Multiple Sclerosis	.2%
Thalassemia	.4%
Haemophilia	.1%
Sickle Cell disease	.7%
Autism Spectrum Disorder	.2%
Chronic Neurological conditions	2.4%
Multiple Disabilities including Deaf Blindness	11.8%

Do you create awareness related to disability and its detection and prevention during your service?

Responses	
Yes	91.5
No	8.5

How do you think disability can be prevented from occurring?

Responses	
Avoid marriage between close blood relations	8.2%
Avoid early age (before 18) pregnancy	14.3%
Avoid late age (after 35) pregnancy	7.7%
Care during pregnancy	21.8%
Care at the time of birth	17.3%
Early childhood care	8.8%
Proper immunization	20.9%
Can't say / Don't know	1.1%

Are you aware that disability in a child could be detected during pregnancy of women by prenatal diagnostic tests?

Responses	
Yes	34.7
No	65.3

Do you suggest pregnant women to go for diagnostic test for early detection of disability in the child in your regular visit?

Responses	
Always	17.0
Often	12.5
Sometimes	4.0

Rarely	.6
Never	.6
N/A	65.3

What all you suggest to pregnant women to avoid disability in a child?

Responses	
Take vitamins and other essential medicines	30.4%
Visit doctor for regular check-up	14.8%
Medical tests	18.1%
Maintaining weight	24.9%
Take help from health workers	10.9%
Others	.9%

How often you advice women to consult doctors before planning the pregnancy?

Valid Percent	
Always	58.5
Often	17.6
Sometimes	14.8
Rarely	7.4
Never	1.7

How often you advice women to go for institutional delivery?

Responses	
Always	82.4
Often	13.6
Sometimes	3.4
Rarely	.6

Are you aware of the screening tests conducted for under 5 children for early detection of disability?

Responses	
Yes	30.7
No	69.3

Is there any health service centre or test centre in your locality that provides such screening tests for early detection of disability in child?

Responses	
No	96.0
Don't know / Can't say	4.0

How many women you have come to know in last three years who has been detected with disability in child during pregnancy?

Responses	
1 - 5	8.0
None	90.9
Don't know / Can't say	1.1

How many children you have come to know in last three years who have been detected with disability in early childhood?

Responses	
1 – 5	18.8
None	81.3

What are the major problems you face while assisting cases of disability and developmental delay?

Responses	
Resistance from family	13.0%
Difficult to convince people for medical assistance	20.2%
People are indifferent to talk about disability	10.4%
Lack of medical facilities in this area to deal with disability	19.3%
Financial obstacles	15.9%
Superstition/stigma etc	4.6%
Have not assisted any case of disability yet	5.8%
No problems faced	11.0%

In your opinion, what are the major causes of disability in children in your area?

Responses	
Lack of knowledge / awareness	12.2%
Lack of proper treatment / diagnosis during pregnancy	27.3%
Can't say	3.9%
Unavailability of advance equipment / test facility at health centre	2.0%
Poverty	26.8%
Lack of nutritious diet	26.8%
Due to marriage at early age (<i>of girls</i>)	1.0%

Have you got any specific training on disability?

Responses	
Yes	25.6
No	74.4

If yes, what topics were covered in the training programme?

Responses	
Early identification of disability	39.1%
Prevention of disability	41.4%
Assisting disable person and children	19.5%

If yes, when did you get last training on early identification and prevention of disability?

Responses	
Last Month	2.8
Last Year	7.4
More than a year ago	16
Not applicable	73.9

If Yes, please tell us who conducted the training?

Responses	
Government health department	9.1
Private agency	2.8
NGO	10.8
District Hospitals	1.1
Primary Health centres	2.3
Not applicable	73.9

How much are you satisfied with the training you have received on disability?

Responses	
Highly satisfied	4.0
Satisfied	17.6
Moderately Satisfied	2.8
Dissatisfied	.6

Highly Dissatisfied	1.1
N/A	73.9

To what extent did you find the training programme helpful to work on early identification and prevention of disability?

Responses	
Very much helpful	8.0
Helpful	13.1
Not so helpful	4.0
Not helpful at all	1.1
N/A	73.9

Have you ever been a part of any awareness programme on disability or early detection of disability?

Responses	
Yes	35.8
No	64.2

Whom do you refer when you find high risk neonates and children with developmental delay?

Responses	
Primary Health Centre	40.9
District Health Centre	53.4
Private nursing home/Health care professional	4.5
Other_specify	1.1

Have you ever participated in any assessment/test on disability knowledge, conducted by any government/government affiliated agencies?

Responses	
Yes	15.3
No	79.5
Don't Know	5.1

What additional government intervention do you require for enhancing your knowledge about early detection and prevention of disability?

Responses	
Proper training on disability	84.3%
We are already burdened with too much work. Work load on us should be distributed/decreased.	1.0%
Regular health camp at village level with doctor	2.0%
Health centre should be equipped with modern technology (<i>disability related</i>)	6.6%
Awareness campaign	5.1%
There should be appointment of "Poshan Sakhi" at Anganwadi centre	.5%
Establishment of health centre in each village	.5%

In general, what are the major problems you face during your service?

Responses	
No such problem	65.1%
Difficult to deal with illiterate people / hard to make them understand	14.5%
Usually people got involved with quakes (<i>because they are easy accessible</i>)	.5%
We do not get salary in proportion to our work (<i>that means sometimes they use to neglect their responsibilities</i>)	3.2%
Transportation problem	8.1%
Work load on us should be distributed/decreased.	5.4%

Referral hospitals do not take proper care of referred patients (<i>delay in diagnosis/treatment</i>)	.5%
We have not received proper training on disability	2.7%

What are your suggestions to fight with disability?

Responses	
Prevention of early age marriage	1.0%
Due to poverty some families cannot take proper care during pregnancy	18.8%
NGOs should be promoted to create awareness and for other concerned assistance	1.9%
Regular awareness programme	38.0%
Health centre should be equipped with modern technology (<i>disability related</i>)	17.3%
Disability specialist (doctor) should be appointed at PHC	1.9%
Can't say / no comments	.5%
Provision of supplementary nutritious food for children and pregnant women	11.5%
Sanitation and hygiene	5.8%
Complete course of immunization	3.4%

Annexure – II

Photo Album:



Knowledge Assessment of Local Health Workers regarding Identification & Prevention of Disability

