

Research Article

Awareness in Context of own Disabilities in Rural Communities with Extreme Poverty

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- Differently abled
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- Hearing Defect
- Awareness

Abstract

Being differently abled is a complex phenomenon, which reflects interaction between features of a person's body, society in which he or she lives. Such persons are restricted in performing daily activities because of complex interrelating factors, some pertaining to self, others to environment and social/political arrangements in the communities to which they belong.

Objectives: To collect information in the context of disabilities in rural communities with extreme poverty in hilly, forestry region.

Material and Methods: After the ethics committee's approval information was collected from differently abled persons about their own disability, also from those who could have known about disabilities of these differently abled rural people living in extreme poverty in a hilly remote region. It was not a planned study but findings of information collected for services made us share. Information was collected in 100 villages. Neither all houses were visited nor a randomized survey was done. Information was collected by person responsible by identifying persons with disability for services planned with help of Nurse Midwives (NM) of health facility created, responsible for mother child care in villages, Sub Centers' NM, Community Health workers (CHW) etc. Total 226 identified disabled persons and 381, those persons, family members, CHW, NM etc. who were believed to be knowledgeable about the differently abled and were available.

Results: Overall of 226 differently abled persons, only 4 were of less than 10 years, youngest 6 years, eldest was 44 years. Information did not include visually disabled as separate work was going on for visually disabled. It was found that one third of disabled had hearing disability and two third mainly neuromuscular disabilities. No one was from upper and middle upper-economic class and beyond secondary school education. Many did not talk about complaints also.

Conclusions: In rural communities with scarce resources, people lived with disabilities not really realizing about their own disabilities, even persons around them were apathetic. A lot of research is needed, a system for identifying people with disabilities, whatever possible help and awareness creation.

BACKGROUND

Being differently abled is a complex phenomenon, which reflects an interaction between the features of a person's body and the society in which he or she lives. Disability is something which could lead to long-term physical, mental, intellectual or sensory impairment. It hinders the person's effective participation in society in which he or she lives in a way others do. WHO [1], defined 'differently abled, a person with an impairment that produced functional limitations, restrictions in activities or social handicap'. Disability in any part of the body may lead to restriction or impairment of the ability to perform an activity in the manner or within the range considered normal for a person [2]. Such persons are restricted in performing daily activities because of a complex set of interrelating factors, some pertaining to self, others to the environment and social/political

arrangements of the communities they belong. In India rural communities, specifically persons with low resources physical disabilities in families without resources, time and awareness to get required support, are typically at increased risk of lack of quality life.

OBJECTIVES

To collect information about the disabled, their disabilities in rural communities with extreme poverty in a hilly, forestry region with access problems.

MATERIAL AND METHODS

It was not a planned study. Information was collected for services, but findings made us share, so there are many limitations.

Setting

Information was collected with the mission of helping people with disabilities in 100 villages around the village health facility, the area where services were planned.

Design

Sources of information about the disabled and their disabilities were persons themselves, family members, community health workers (CHW), Sub center Nurse Midwives (NM), word of mouth and observations of the differently abled persons during the field visits of NM of the health facility for mother and child care.

Sample

Information was collected from a total of 607 persons, 226 were differently-abled persons and 381 included family members, CHWs and NM depending on availability and willingness to talk (major limitation of information being shared). It was neither planned study nor randomized survey.

Information was collected after the institute's ethics committee's approval, as per the objective which was services to the needy in 100 villages around the village with a health facility. Field assistant met persons with disability, family members, NM, CWHs who so ever were available and were ready to talk about the disability of the person. Purpose was to serve the needy as per needs and availability of services. Any complaints and physical observations were recorded. Awareness information was collected by interviews with predesigned service oriented tools.

RESULTS

Overall of 226 differently abled persons, only 4 were of less than 10 years, the youngest 6 years, 41 were ≥ 10 years to 19 years, 59 of 20-29 years, 49 of 30-39 years and 73 were beyond 39 years, the eldest was 44 years. Of the total 226 differently-abled persons interviewed in context of their disabilities, 203 (89.8%) had awareness in context of their disability but 23 (10.2%) did not have awareness. Of 45 persons of ≥ 10 –19 years with disability, 33 (73.33%) had awareness in context of their disability, while 12 (26.7%) of them did not, significantly more were unaware (P-value 0.05). Over all 103 persons (45.57%) with disability were illiterate and 94 (91.3%) of them had awareness about their disabilities, literacy making little difference as 62 persons with disabilities interviewed had secondary education and 60 (96.8%) of them had awareness significantly more numbers but statistically insignificant. (P value 0.05).

Of the 23 differently-abled persons of middle economic class 21 (91.3%) had awareness and of 108 of lower economic class, 97 (89.8%). No differently abled person during the information collection was found to be belonging to the upper or upper middle economic class. Of 98 differently abled persons who were laborers, 87 (88.8%) had awareness about their disabilities. Of 84 differently abled worked as laborers in their own farms, 76 (93.83%) had awareness in context of their own disability. Of

43 differently abled who were farm owners, 40 (93.00%) had awareness, little difference with occupation, economic status as well as education.

Of the total 226 differently-abled persons, 186 (82.3%) had some complaints. Of 45 persons of ≥ 10 –<20 years, 33 (73.3%) had some complaints. Of 103 illiterate, 84 (81.60%) talked of complaints. Of 62 differently abled secondary school educated, 52 (83.90%) talked of complaints. Of 23 differently abled who were of the middle class, 15 (65.2%) talked about complaints. Of 108 of the lower economic class differently abled, 87 (80.6%) reported complaints. Of 98 differently abled who were laborers, 82 (83.7%) said they had complaints. Of 81, differently abled who were laborers in their own farms, 67 (82.7%) had complaints. Of 43 who were farm owners, 37 (86.00%) talked of complaints. Neither economic status nor job nor education made any difference. All 4 differently abled below 10 years, had neither awareness nor talked of any complaints, one belonged to middle economic class and 3 to lower economic class, the youngest 6 years. All 4 of them were students [Table-I].

Of 381 persons who were believed to be knowledgeable about differently-abled persons in their villages (as put in material methods), interviewed regarding the disabilities and complaints, 213 (55.9%) had awareness regarding disability and others did not. Of 92 persons believed to be knowing details of differently abled of less than 20 years only 34 (37%) had awareness regarding the disability. Of 150 associates of differently abled of 30 to 39 years, 111 (74%) had some awareness and of illiterate of this group only 2 (18.2%) had awareness and nobody knew about complaints of disabled. Of 142 associates of higher secondary education, 98 (69%) had awareness and only 58 (40.8%) knew about differently abled persons' complaints. Family members of those belonging to the middle economic class, only few had realization of disability, but did not know about complaints. Of 186 believed to be knowledgeable about disabled persons of lower economic class, 105 (56.5%) had awareness of disability and 69 (37.1%) about complaints of differently abled. Of 97 believed to be associates of laborers, 33 (34%) had awareness, 10 (10.3%) knew about complaints. Of 91 farm owners, 44 (48.4%) had awareness and 25 (27.5%) knew about complaints. Table II depicts details with demographic features (Table II).

Of 4 differently-abled persons of less than 10 years, one had paraplegia, 3 had monoplegia of the arm. Of 41 differently-abled persons of age ≥ 10 –<20 years, 16 (39%) had hearing problem, 1 (2.4%) paraplegia, 2 (4.9%) had hemiplegia, 7 (17.1%) monoplegia of arm and 19 (46.3%) had monoplegia of leg. Of 35.6% above 39 yrs had hearing disability and 31 (42.5%) had monoplegia in one arm and 3 (4.1%) hemiplegia.

Of 59 differently abled of 20-39 years age, 20 (33.9%) had hearing disability, one (1.7%) paraplegia, one (1.7%) hemiplegia, 16 (27.1%) had monoplegia of arm and 17 (28.8%) had monoplegia of leg. Total 28.6% differently abled in the age group 30-39 years had hearing disability, one (2%) paraplegia, 3 (6.1%) hemiplegia, 17 (34.7%) monoplegia of one arm and

Table I: Awareness in Context of Disabilities in Differently Abled Persons

Variables Age in years	Total	Awareness about Disability				Complaints			
		No	%	Yes	%	No	%	Yes	%
Below 10	4	4	100.0	0	0.0	4	100.0	0	0.0
10-29	45	6	13.3	39	86.7	12	26.7	33	73.3
30-39	56	3	5.4	53	94.6	4	7.1	52	92.9
40and more	121	10	8.25	111	91.75	20	17.5	101	82.5
Total	226	23	10.2	203	89.8	40	17.7	186	82.3
Education									
Illiterate	103	9	8.7	94	91.3	19	18.4	84	81.6
Primary	61	12	19.7	49	80.3	12	19.7	50	82.0
Secondary	62	2	3.2	60	96.8	9	14.5	52	83.9
Total	226	23	10.2	203	89.8	40	17.7	186	82.3
Socio Economic Status									
Middle	23	2	8.7	21	91.3	8	34.8	15	65.2
Upper Lower	95	10	10.5	85	89.5	11	11.6	84	88.4
Lower	108	11	10.2	97	89.8	21	19.4	87	80.6
Total	226	23	10.2	203	89.8	40	17.7	186	82.3
Occupation									
Labourer	98	11	11.2	87	88.8	16	16.3	82	83.7
Own Farm Labourer	81	5	6.2	76	93.8	14	17.3	67	82.7
Farm Owner	43	3	7.0	40	93.0	6	14.0	37	86.0
Other	4	4	100.0	0	0.0	4	100.0	0	0.0
Total	226	23	10.2	203	89.8	40	17.7	186	82.3

14 (28.6%) monoplegia of leg. Of 103 differently abled who were illiterate, 49 (47.6%) had hearing problems, 2 (1.9%) paraplegia, 5 (4.9%) hemiplegia, 37 (35.9%) monoplegia of the arm and 10 (9.7%) reported monoplegia of leg. Of 61 differently abled with primary education, 13 (21.3%) reported hearing problems, 2 (3.3%) paraplegia, 3 (4.9%) hemiplegia, 15 (24.6%) monoplegia of arm and 28 (45.9%) monoplegia of leg. Of 62 differently-abled persons who had secondary school education, 14 (22.6%) reported hearing problems, one (1.6%) paraplegia, 1 (1.6%) hemiplegia, 22 (35.5%) monoplegia of arm and 24 (38.7%) had monoplegia of leg. Of 23 persons who belonged to the middle class, 11 (47.8%) had hearing disability, one (4.3%) paraplegia, 6 (26.1%) monoplegia of arm, 4 (17.4%) had monoplegia of leg. Of 95 differently-abled persons of the lower middle class, 33 (34.7%) reported hearing disability, one (1.1%) paraplegia, 2 (2.1%) hemiplegia, 22 (23.2%) monoplegia of arm and 37 (38.9%) monoplegia of leg. Over all of 102 differently abled persons who were laborers, 36 (35.3%) reported hearing disability, 3 (2.9%) paraplegia, 6 (5.9%) hemiplegia, 33 (32.4%) monoplegia of arm and 24 (23.5%) reported monoplegia of leg. Of 81 differently abled who were laborers on their own farms, 22 (27.21%) reported hearing disability, one (1.2%) paraplegia, 2 (2.5%) hemiplegia, 24 (29.6%) monoplegia of arm and 32 (39.5%) monoplegia of leg. Of 43 differently-abled persons reported owning farms, of which, 18 (41.9%) reported hearing disability, 1 (2.3%) reported paraplegia, one (2.3%) hemiplegia, 17 (39.5%) reported monoplegia of arm and 6 (14%) monoplegia of leg Table III.

DISCUSSION

Being handicapped because of impairment or a disability

that limits or prevents the fulfillment of the role believed to be normal, has many disadvantages for the individual, depending on age, sex, social and cultural factors for that individual. Giulio and Philipov [3], opined that the social concept of disability introduced the notion that society has erected barriers, physical or attitudinal, which affected a differently abled person's life. In the past three decades, the concept of disability has shifted from individual impairment to a more social phenomenon. Needs a holistic approach as there are many Stakeholders. Giulio and Philipov [3], have reported 1.9% incidence of differently abled children, amongst families. Those working in the community have a responsibility to search the local, cultural factors affecting diagnosis and management of differently abled people. A differently-abled person in the household affects the family's quality of life, the parents' gender roles, financial resources, employment status, the use of time, and health. In the U.S. it is estimated that 9% of children younger than 3 years of age had a developmental problem [4], while 13.87% of children of 3 to 17 years of age had a developmental disability [5]. The realization available varies across countries because of lack of community-based data, the lowest rates have been reported from Lithuania (0.58%) and the highest from Poland (4.0%). WHO [6], reported the rate of differently abled among children up to 14 years old in high-income countries as 2.8%. In India, real numbers are not known. There is a lack of awareness, lack of resources, and lack of community-based data Babies born with abnormalities continue to live without attempts at proper diagnosis and possible therapies or if children develop such disorders, action is not taken. Sometimes it goes beyond childhood to adolescence and years beyond, especially in rural communities. Population-based studies are scarce and the real incidence of differently abled in India is not very well known. According to the Census

Table II: Awareness of Disability by Family Members/Ashas/Nm

Variables of disabled Age	Total	Realization about Disability				Presently any Complaints			
		NO	%	YES	%	NO	%	YES	%
Below 10	4	1	25.0	3	75.0	4	100.0	0	0.0
10-29	96	59	63.0	37	37.0	74	76.1	21	22.8
30-39	75	25	33.3	50	66.7	42	56.0	35	46.7
40and more	210	84	50.5	126	45.9	144	77.0	65	32.5
Total	381	168	44.1	213	49.5	260	68.2	121	31.8
Education									
Illiterate	11	9	81.8	2	18.2	11	100.0	0	0.0
Primary	72	55	76.4	17	23.6	60	83.3	8	11.1
Secondary	156	60	38.5	96	61.5	103	66.0	55	35.3
Higher Secondary	142	44	31.0	98	69.0	86	60.6	58	40.8
Total	381	168	44.1	213	55.9	260	68.2	121	31.8
Socio-Economic Status									
Middle	93	34	37.1	58	62.9	65	69.7	28	30.3
Upper Lower	102	52	51.0	50	49.0	78	76.5	24	23.5
Lower	186	81	43.5	105	56.5	117	62.9	69	37.1
Total	381	168	44.1	213	55.9	260	68.2	121	31.8
Occupation									
Labourer	97	64	66.0	33	34.0	87	89.7	10	10.3
Own Farm Labourer	189	53	28.0	136	72.0	103	54.5	86	45.5
Farm Owner	91	47	51.6	44	48.4	66	72.5	25	27.5
Other	4	4	100.0	0	0.0	4	100.0	0	0.0
Total	381	168	44.1	213	55.9	260	68.2	121	31.8

ASHA Accredited Social Health Activist NM Nurse midwife

Table III: Type of Disability

Variable	Type of Disability	Hearing	%	Paraplegia	%	Hemiplegia	%	MONOPLÉGIA ARM	%	MONOPLÉGIA LEG
Age in Year	Total									
Below 10	4	0	0	1	25	0		3	75	0
10-29	41	16	39.0	1	2.4	2	4.9	7	17.1	19
30-39	59	20	33.9	1	1.7	1	1.7	16	27.1	17
40	112	40	28.6	2	2.0	3	6.1	17	34.7	14
									42.5	12
Total		76	33.6	5	2.2	9	4.0	74	32.7	62
Education										
Illiterate	103	49	47.6	2	1.9	5	4.9	37	35.9	10
Primary	61	13	21.3	2	3.3	3	4.9	15	24.6	28
Secondary	62	14	22.6	1	1.6	1	1.6	22	35.5	24
									0.0	0
Total	226	76	33.6	5	2.2	9	4.0	74	32.7	62
										0
Socio Economic status										
Middle	23	11	47.8	1	4.3	1	4.3	6	26.1	4
Upper Lower	95	33	34.7	1	1.1	1	2.1	22	23.2	37
Lower	108	32	29.6	3	2.8	6	5.6	46	42.6	21
Total	226	76	33.6	5	2.2	9	4.0	74	32.7	62
Occupation										
Labourer	102	36	35.3	3	2.9	6	5.9	33	32.4	24
Own Farm Labourer	81	22	27.2	1	1.2	2	2.5	24	29.6	32
Farm Owner	43	18	41.9	1	2.3	1	2.3	17	39.5	6
Total	226	76	33.6	5	2.2	9	4.0	74	32.7	62

2001, approximately 5% of people in India were affected with impairment or disability [7]. The researchers explored the poor representation of differently-abled people in the Indian workforce and economy with the challenges faced during education and employment with the impact of exclusion from society as a whole [8], using a sociocultural management lens and most importantly looked at the exclusion of differently-abled individuals and its large-scale macroeconomic impacts, through extensively estimating the economic impact of exclusion, the issues and consequences can be better understood and valued. The report also suggested potential solutions that could lead to positive change for the differently-abled people in the community. People may be living with various disabilities, with different barriers in getting help as was revealed in the present analysis. In communities with resource problems, differently abled people are not seen as a priority for corrective measures, development, nor included in most of the mainstream development programmes. In the low resource communities, where everyone is struggling for survival, disability is usually not seen as a priority in development, except by differently-abled people and their families. Unfortunately, in rural regions with limited resources families, even the persons with disabilities do not realize their own problems and with some efforts possibilities of change in life. Disability must be seen in the wider context of human development and social justice. Researchers reported that typically, differently abled people were among the poorest of the poor, 90% differently-abled population were most likely to have income below the poverty line, less educated and participate less in society and their employment opportunities were extremely limited being shared. The present information has quite a few limitations as the plan was not to study but to help the community, but results made the author share. Of 226 persons in rural tribal communities who were differently abled were interviewed regarding their disabilities and awareness collected. The total numbers are not known. The mission was to try to help with the resources available, neither sample was calculated nor any planned survey. Also, visual disabilities were not included because cataract and other such visual disabilities were being looked into for services separately so numbers can't be talked about. Total 203 (89.8%) knew about their disability and 23 (10.2%) did not realize about their own disabilities. Many with hearing problems, limb weaknesses did not think of possibilities of help.

An estimated 500 million people worldwide have visual, hearing, mobility or cognitive impairments. Hearing loss, if occurs early in life, can affect speech, language, cognitive skills, social and emotional development, behavior and academic achievements. The condition is a so-called invisible disability and yet more than 20% of the world's population have mild to complete loss, more than 5% have moderate to complete loss that can greatly impede spoken communication assistance and in many cases, even with assistance there may be problems. Hearing loss is the third leading cause of years lived with disability. An important aspect of reducing the burden of hearing loss is the measurement of the burden. Chu et al. [9], reported that hearing problems were

greater than that of several other conditions screened. Around 96% of children with hearing loss have been reported to be born to parents with intact hearing, who may initially know little about deafness or sign language [10]. So their understanding has to be from communities and health workers. In the information being shared, persons with hearing disabilities belonged to all the age groups, one third of all disabled and two thirds were mainly neuromuscular [11].

In the present information, of the 381 persons including family members interviewed regarding knowledge of disability and complaints of persons as were believed to be possibly associated and believed to be knowing about differently-abled people in rural remote communities in hilly region with scarce resources with the person's availability and willingness to provide for the the information, but of these 381 persons also only 213 (55.9%) had awareness about disabled through many had disabilities which should be visible. Visual disabilities were not included. Raising awareness in the community for early diagnosis of problems is essential. Any disability is not only a medical issue and the medical model cannot be used to the complete exclusion of the social model. The problems are many in resource-poor countries [12]. In view of this, there is a need to do community-based research. Melghat region of Maharashtra, Province of India is an underserved, hilly and forested region with tribal population where there is extreme poverty. Not much was known about such issues in these communities, where each day's survival was a struggle. So, attempts were made to find the disabilities. The main mission was to help the differently abled by recognition of disabilities, diagnosis with appropriate and possible treatment plan including devices, necessary surgeries and rehabilitation. People with disabilities face difficulties in accessing services and there is insufficient transparency about the basis for providing health insurance. This jeopardizes families' rights to live in good health and with dignity, taking into account the strong correlation between disability and poverty [13]. In the present information collected mainly for helping people with physical disabilities, rather than research, it was observed that even those aged 40 years lived with disabilities without being aware of any possibilities of change. Many with disabilities were illiterate and of low income [Table II].

CONCLUSION

In rural communities with scarce resources, people live with disabilities with no realization in context of their disabilities and persons around them also do not realize possibilities of change for quality of life by timely diagnosis and therapy. A lot of research is needed and the system to create a lot of awareness too.

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