

Disability, Health and Human Rights

Leni Chaudhari

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Aaram Society Road

Vakola, Santacruz (East)

Mumbai - 400 055

Tel. : 91-22-26673571 / 26673154

Fax : 22-26673156

E-mail : cehat@vsnl.com

Website : www.cehat.org

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FROM THE RESEARCH DESK

Health and Human rights has explicit intrinsic connections and has emerged as powerful concepts within the **rights based approach** especially so in the backdrop of weakening public health system, unregulated growth of the private sector and restricted access to healthcare systems leading to a near-total eclipse of availability and accessibility of universal and comprehensive healthcare. A rights-based approach to health uses International Human Rights treaties and norms to hold governments accountable for their obligations under the treaties. It recognises the fact that the right to health is a fundamental right of every human being and it implies the enjoyment of the highest attainable standard of health and that it is one of the fundamental rights of every human being and that governments have a responsibility for the health of their people which can be fulfilled only through the provision of adequate health and social measures. It gets integrated into research, advocacy strategies and tools, including monitoring; community education and mobilisation; litigation and policy formulation.

Right to the highest attainable standard is encapsulated in Article 12 of the International Covenant on Economic, Social and Cultural Rights. It covers the underlying preconditions necessary for health and also the provisions of medical care. The critical component within the **right to health** philosophy is its realisation. CEHAT's main objective of the project, *Establishing Health as a Human Right* is to propel within the civil society and the public domain, the movement towards realisation of the right to healthcare as a fundamental right through research and documentation, advocacy, lobbying, campaigns, awareness and education activities.

The Background Series is a collection of papers on various issues related to right to health, i.e., the vulnerable groups, health systems, health policies, affecting accessibility and provisions of healthcare in India. In this series, there are papers on women, elderly, migrants, disabled, adolescents and homosexuals. The papers are well researched and provide evidence based recommendations for improving access and reducing barriers to health and healthcare alongside addressing discrimination.

We would like to use this space to express our gratitude towards the authors who have contributed to the project by sharing their ideas and knowledge through their respective papers in the Background Series. We would like to thank the Programme Development Committee (PDC) of CEHAT, for playing such a significant role in providing valuable inputs to each paper. We appreciate and recognise the efforts of the project team members who have worked tirelessly towards the success of the project ; the Coordinator, Ms. Padma Deosthali for her support and the Ford Foundation, Oxfam- Novib and Rangoonwala Trust for supporting such an initiative. We are also grateful to several others who have offered us technical support, Ms Sudha Raghavendran for editing and Satam Udyog for printing the publication. The cover page design and the photograph has been provided by Jhanvi Graphics. We hope that through this series we are able to present the health issues and concerns of the vulnerable groups in India and that the series would be useful for those directly working on the rights issues related to health and other areas.

Chandrima B.Chatterjee, Ph.D

Project In-Charge (Research)
Establishing Health As A Human Right

ABOUT THE AUTHOR

Disability, Health and Human Rights

Leni Chaudhuri has done her M.Phil. in International Studies from Jawaharlal Nehru University. She is an activist researcher working on Human Rights issues for the past decade. Currently she is working for CEHAT as a senior researcher. She is coordinating the study on Public Report on Health for Maharashtra.

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The Disabled: Health and Human Rights

INTRODUCTION

“Disabled people are not only the most deprived human beings in the developing world, they also the most neglected.”

Amartya Sen

Around 400 million disabled persons live in the developing world. It is estimated that at least 10% of the developing world's population is disabled in one way or the other. Most often they are the poorest. Poverty is the most important cause of disability. The WHO estimates that worldwide there are 1.5 million blind children, mainly in Asia and Africa. In developing countries up to 70% of blindness is either preventable or treatable. The WHO also estimates that around 50% of disabling hearing impairment is also preventable. In 1995 this has affected a total of 120 million people worldwide.

The disabled are deprived of all opportunities for social and economic development. The basic facilities like health, education and employment are denied to them. The State infrastructure is grossly inadequate and ill-functioning where disabled are concerned. It is estimated that 40 million of more than 100 million children out of school have disabilities. Around 70% of the disabled are unemployed. Millions are in the verge

of collapsing due to severe disabilities. People with physical disabilities at least get noticed, but those with mental illness not only suffer from physical problems but also bear the brunt of social ostracism and stigma.

The disabled are also not a homogenous group. Each disabled person's problems, needs are different from one another and each one has to be treated and cared for on an individual basis.

In spite of several international and national pronouncements, the rights of the disabled have remained on paper. Given the magnitude of the problem, it is important that disabled persons receive political attention. All the targets and policies of achieving social and economy equality will not be possible to meet if the concerns of the disabled are not addressed. There is need for policy level changes backed by adequate budgetary allocation. This paper is a small step in this direction.

According to the NSSO 58th round survey in 2002 there are 18.49 million people in India who are disabled. This number has increased from 13.67 million in 1981 to 16.36 million in 1991. Out of the 18.49 million disabled people, 10.89 million are males and 7.56 million are females, which constitutes around 59% males and 49% males and females respectively. These

people are suffering from some form of disability.

One of the major problems, which affect any intervention on the issue of the disabled, is the lack of proper data on the number of disabled in the country and the extent and magnitude of the problem. For the first time in 1981, the NSSO data gave the demographic status of the disabled. No evidence-based demographic study has been conducted at the national level to provide reliable and analytical information on the status of the disabled. The NSSO 58th round was indeed a big leap in this direction.

Apart from the fact that there is no data, the other problem is the lack of political will to address the issue of the disabled. Of late, there have been few legislations passed to safeguard the interest of the disabled, but they look more like 'patch work' and 'add ons' rather than an integrated approach. Society is also not in a state of preparedness to accept the disabled population as part of the mainstream. Thus, when the situation is marked by lack of political will as well as social unpreparedness, there is a big challenge ahead.

1. Understanding Disability: Types and Forms¹

Disability is difficult to define since it varies in type, form and intensity. Understanding disability will require understanding these differences. According to the World Health Organization, **"Disability is any restriction**

or lack (resulting from an impairment) of ability to perform in a manner or within the range considered normal for a human being".

The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 is an important landmark and a significant step in the direction of ensuring equal opportunities for people with disabilities and their full participation in the nation building. "The Act provides for both preventive and promotional aspects of rehabilitation like education, employment and vocational training, job reservation, research and manpower development, creation of barrier-free environment, rehabilitation of persons with disability, unemployment allowance for the disabled, special insurance scheme for the disabled employees and establishment of homes for persons with severe disability etc." (The Persons with Disabilities (Equal Opportunities, Protection of Rights & Full Participation) Act, 1995).

Persons with Disability Act 1995 states that a disabled person is one suffering from not less than forty per cent of any disability as certified by a medical authority. The disabilities identified are blindness, low vision, cerebral palsy, leprosy, leprosy cured, hearing impairment, loco motor disability, mental illness and mental retardation as well as multiple disabilities.²

The NSSO considered disability as *"Any restriction or lack of abilities to perform an activity in the manner or within the range*

¹ This section is drawn from WHO 2002, Persons with Disability Act 1995, NSSO 1998 and 2002.

² The Persons with Disability Act 1995.

considered normal for human being". It excludes illness /injury of recent origin (morbidity) resulting into temporary loss of ability to see, hear, speak or move.

1. A. Types of Disability

Loco motor disability is defined as the person's inability to execute distinctive activities associated with moving both himself and the objects, from place to place and such in ability resulting from affliction of musculoskeletal and/ or nervous system. Some common conditions giving rise to loco motor disability could be poliomyelitis, cerebral palsy, autism, amputation, injuries of spine, head, soft tissues, fractures and muscular dystrophies.

Visual Disability or Blindness refers to a person's inability to see either fully or partially. A visually disabled person is known to be suffering from visual impairment. Low Vision or Poor Eye Sight: A person with low vision or poor eyesight is one who continues to have the problem even after going through medically approved corrective measures. This person with poor eyesight is still in a position to continue his/her tasks with appropriate assisted devices.

Mental illness can include both mental ill health and retardation. Mental retardation is defined as a state of arrested or incomplete development of the mind, which is specially characterized by impairment of skills manifested during the development period which contribute to the overall level of intelligence, that is, cognitive

language, motor and social abilities. Mental ill health constitutes of schizophrenia, anxiety disorder and depressive disorder or any other problem, which is caused due to series of chemical changes in the brain.

Speech and Hearing Disability is referred to a condition wherein the person is incapable of speaking and hearing any sound.

Learning Disability is a disorder, which affects the basic psychological processes of understanding or using written or spoken language. This disorder affects development of language, speech, and reading and associated communication skills needed for social interaction. Conditions such as brain injury, minimal brain dysfunction, dyslexia, and developmental aphasia are examples of learning disabilities.

Multiple Disabilities is a combination of two or more disabilities as defined in clause (i) of Section 2 of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995 namely Blindness/low vision Speech and Hearing impairment, Locomotor disability including leprosy cured, Mental retardation and Mental illness.

Given the type and nature of their problem, the disabled are encountered with different types of problems. Some problems are common, while others are disability specific.

2. The Disabled in India: A Demographic Profile³

The NSSO surveys state that over the years there has been a major increase in the disabled population of the country. In the year 1981, there were 13.67 million disabled persons and in 1991, this number increased to 16.36 million.⁴ According to the NSSO 58th round, the magnitude of people with one or more than one of the five-disabilities was 18.49 million in 2002. In this round mental disability was included as a form of disability in addition to the four existing types.

According to the NSSO 58th round in 2002, there were 18.49 million disabled persons out of which 10.89 million were males and 7.59 million were females,

constituting 59% and 41% of males and females respectively. In the 47th round, in 1991 there were 16.36 million disabled persons out of which 9.51 million disabled persons were males and 6.63 million. The proportion of males and females constituted 59 and 41 percent of the disabled persons respectively.

2. A. Gender Distribution of Disability in India

According to the 2002 Census records, among the disabled population in India 10.89 million are males and 7.59 million are females. In terms of percentage, 58% of the disabled persons are males and 42% are females. From 1991 to 2002 the trend has remained very similar also in the case of both the rural and the urban dwelling.

Table No.2.1: The Disabled Population in India, 1981-2002

Year	Rural			Urban			Rural + Urban		
	Female	Both	Male	Female	Both	Male	Female	Both	
1981									13.67
1991	7.44	5.21	12.65	2.07	1.42	3.5	9.51	6.63	16.36
2002	8.31	5.77	14.08	2.58	1.82	4.4	10.89	7.59	18.49

Source: NSSO Rounds 37th , 47th and 58th in 1981,1991 and 2002.

Table: 2.2: Gender Distribution of Disability in India

Year	Sex	Rural	Urban	Rural + Urban
1991	Male	58.81	59.14	58.12
	Female	41.18	40.57	41.88
	Both	100	100	100
2002	Male	59.01	58.63	58.89
	Female	40.99	41.37	41.11
	Both	100	100	100

Source: NSSO Rounds 47th and 58th in 1991 and 2002.

³ This section is drawn from NSSO 1991 and 2002.

⁴ This includes people who are having at least one or more of the four types of disabilities, namely, - loco motor, visual, hearing and speech).

2. B. Disabled Persons: Place of Residence

The magnitude of disabled persons residing in rural areas is very high at 77% as compared to only 23% were residing in the urban areas. This figure is quite intriguing and opens up an area for fresh enquiry. Since the place of residence data, doesn't indicate the proportion of persons with acquired disability and the same since birth, it is difficult to derive anything more.

2. C. Disabled Persons, Prevalence Rate

According to the Census 2002, the prevalence rates⁵ for disabled persons were 1775 as against 1886 in 1991. This reflects a sharp decline in the prevalence rates from 1991 to 2002 which is also a positive trend. Similar trends are observed for both gender groups in case of both rural and urban areas during 1991-2002.

2. D. Prevalence Rate among different Age Groups

Mixed trends are being reflected in terms of the disability prevalence rate. In 2002, for the population below the age group of 14 years decline in the prevalence rate was reflected in both urban and rural areas as compared to 1991. Whereas for the population in the age group of 15-44 years, prevalence rates have increased in both rural and urban areas in 2001 as compared to 1991. The other trend is that of the age group of 60 years and above. Among this age group also there is a sharp decline in the prevalence rate. Another negative factor, which has come into the light, is the increased prevalence rate among the younger population. This is a serious blow on the productive population of the society.

Table No: 2.3: Place of Residence

Year	Sex	Male	Female	Persons
1991	Rural	78.23	78.58	77.32
	Urban	21.77	21.42	22.68
	Both	100	100	100
2002	Rural	76.73	76.02	76.14
	Urban	23.27	23.98	23.86
	Both	100	100	100

Source: NSSO Rounds 47th and 58th in 1991 and 2002.

Table 2.4: Prevalence Rate (per 100,000 persons) 1991-2002

YEAR	RURAL			URBAN			BOTH R+U		
	M	F	M+F	M	F	M+F	M	F	M+F
2002	2118	1556	1846	1670	1331	1449	2000	1493	1775
1991	2277	1694	1995	1774	1361	1579	2144	1609	1886

Source: NSSO Rounds 47th, 1991, and 58th Round, 2002.

⁵ Number of disabled persons per 100,000 person

Table 2.5: Prevalence Rate: Age Group

Age Group	2002		1991	
	Rural	Urban	Rural	Urban
0-4	523	487	533	564
9-May	1167	1015	1578	1430
14-Oct	1549	1317	1605	1510
15-19	1748	1337	1480	1274
20-24	1627	1242	1189	1030
25-29	1487	1000	1105	917
30-34	1448	1054	1258	865
35-39	1444	1138	1300	891
40-44	1594	1309	1708	1149
45-49	1907	1476	2066	1448
50-54	2283	1855	2885	2043
55-59	3025	2571	3521	2766
60+	6401	5511	9184	7623
5 & Above	1846	1499	2217	1702

Source: NSSO Rounds 47th, 1991, and 58th Round, 2002.

2 E. Disability Prevalence: Interstate Variation

According to the Census records, one positive trend which has been noticed through out is that the prevalence rates have declined in 2002 as compared to 1991 in majority of the states. This decline is more visible in urban areas than in rural areas. Prevalence rates for both for men and women registered a sharp decline. States like Orissa, Himachal Pradesh, Haryana reported high prevalence rates among the males in rural areas, whereas the States like

West Bengal and Kerala reported high prevalence rate in the urban areas For females the trends are such that in the rural areas the states of Orissa, Kerala, Tamil Nadu, Andhra Pradesh and some mountain states showed high prevalence rates. In case urban areas the prevalence rate was high for females in Orissa, Kerala, Tamil Nadu, West Bengal and Chattisgarh The table below provides the information about interstate variation in prevalence of Disabled Persons.

Table: 2.6: Disability Prevalence: Interstate Variation Male

States	Rural		Urban	
	1991	2002	1991	2002
Andaman and Nicobar Islands		2766		1290
Andhra Pradesh	2354	1980	1712	1524
Arunachal Pradesh		1861		109
Assam	947	1062	948	1189
Bihar	1125	2098	1071	1725
Chandigarh		865		577
Chhatisgarh		2012		1973
Dadra and Nagar Haveli		990		798
Daman and Diu		649		1500
Delhi		823		642
Goa		2326		1454
Gujarat	1557	2169	1566	1822
Himachal Pradesh	2157	3326	995	1632
Haryana	1665	2256	1105	1537
Jammu and Kashmir		2120		1401
Jharkhand		1614		1352
Karnataka	1891	1977	1307	1245
Kerala	1636	2451	1587	2552
Lakshwadeep		2768		1454
Madhya Pradesh	1794	1969	1113	1749
Maharashtra	1927	2375	1408	1594
Manipur		1092		1090
Meghalaya		1871		1117
Mizoram		855		814
Nagaland		895		602
Orissa	2166	2671	2077	1971
Pondicherry		1817		2310
Punjab	2384	2576	1558	1584
Rajasthan	1355	1826	1168	1596
Sikkim		1860		654
Tamil Nadu	2201	2188	1669	1967
Tripura		748		1176
Uttar Pradesh	1441	2319	1210	1821
Uttranchal		2200		1155
West Bengal	1484	2006	1283	2094
All India	2277	2118	1774	1670

Source: NSSO reports round No. 47th and 58th , 1991 and 2002.

Table: 2.7: Disability Prevalence: Interstate Variation Female

States	Rural		Urban	
	1991	2002	1991	2002
Andaman and Nicobar Islands		1126		604
Andhra Pradesh	2354	1827	1712	1302
Arunachal Pradesh		1471		27
Assam	947	894	948	970
Bihar	1125	1218	1071	1169
Chandigarh		703		549
Chhatisgarh		1582		1743
Dadra and Nagar Haveli		712		610
Daman and Diu		1370		1229
Delhi		451		368
Goa		1039		1650
Gujarat	1557	1556	1566	1325
Himachal Pradesh	2157	2135	995	1025
Haryana	1665	1505	1105	1159
Jammu and Kashmir		1173		1100
Jharkhand		938		726
Karnataka	1891	1521	1307	973
Kerala	1636	2010	1587	2082
Lakshwadeep		1983		2592
Madhya Pradesh	1794	1499	1113	1220
Maharashtra	1927	1677	1408	1398
Manipur		849		850
Meghalaya		1418		677
Mizoram		780		569
Nagaland		944		812
Orissa	2166	2418	2077	1663
Pondicherry		1792		2561
Punjab	2384	1813	1558	1363
Rajasthan	1355	1202	1168	1023
Sikkim		1565		518
Tamil Nadu	2201	1864	1669	1558
Tripura		686		1061
Uttar Pradesh	1441	1574	1210	1320
Uttranchal		1884		665
W. Bengal	1484	1355	1283	1740
All India	1694	1556	1361	1311

Source: NSSO reports round No. 47th and 58th, 1991 and 2002.

2. F. Onset of Disability Since Birth

There are two broad categories in disability, one is *acquired* which means disability acquired because of accidents and medical reasons the other is *disability since the onset of birth*. According to the NSSO 58th round about one-third of the persons with disability have disability since their birth. The reasons for this are diverse, ranging from heredity to defective gene mutation to congenial defects to inappropriate services at the time of delivery and low level of nutrition and healthcare provided to the pregnant mothers during their pregnancy period. The proportion of persons with disability since the onset of birth in both rural and urban areas has been reported around 33%. There are also cases of use of inappropriate methods adopted at the time of delivery, which

were reported through several sample surveys as one of the causes of disability since birth.

2. G. A Disabled Household: Number of Disabled Persons

According to the 2002 Census records, the numbers of disabled persons who have other disabled people in their households are follows: about 92% of these household have one disabled person, 7% households have two disabled persons and the rest 1% of the households have two or more than two disabled persons. In terms of the place of residence there has not been any major change between 1991 and 2002. Nearly 7%-8% households have more than one disabled person in their homes and this was uniform both in rural and urban areas.

Table No. 2.8: Onset of Disability since Birth (per 1000 disabled persons) 1991-2002

Year	Rural			Urban			BOTH R+U		
	F	M+F	M	F	M+F	M	F	M+F	M
2002	335	315	327	303	298	301	328	311	321

Source: NSSO Rounds 58th, 2002.

Table No. 2.9: Disabled Household, Number of Disabled Persons

Number of Disabled Persons in Households having Disability	2002		1991	
	Rural	Urban	Rural	Urban
One	92.3	92.3	92	92.5
Two	7	7.2	7.6	7
More than Two	0.6	0.5	0.4	0.5

Source: NSSO Rounds 47th and 58th, 1991 and 2002.

2. H. Severity of Disability

This section presents information about the severity of disability among persons with disability. The proportion of severely disabled who cannot function even with the help of aid/ appliance is 13.1% in rural areas and 14% in urban areas in 2002. About 60% of the disabled can function without aid/ appliances, while 13% cannot function even with aid and appliance and another 17% can take self care with the help of aid and appliance. Around 10% of the disabled have never had the opportunity to access any aids and appliances and hence cannot take care of their own self.

3. Disabled Persons: Socio-economic Profile⁶

3. A. Age Profile

A substantial portion of the disabled population of India is in the productive age group of 15-44. This is very striking. In terms of rural and urban dwelling, 53 percent from the rural areas and 55 percent from the urban areas are in this age group. The proportion of disabled population in the age groups of 15-44 years has increased during 1991-2002 for both rural and urban areas. For the population above 60 years, the disability prevalence rate has decreased.

Table: 2.10: Severity of Disability (1991-2002 in Percentages)

Degree of Impairment	2002		1991	
	Rural	Urban	Rural	Urban
Cannot function even with aid	13.1	14	25	20.4
Can function only with aid	16.9	18.4	15.7	17.4
Can function without aid	60	61.4	58.5	61.6
Aid/ appliance not tried/not available	9.9	5.9	N.A	N.A
All Disabled	14,085,000	4,406,000	12,652,000	3,502,000

Source: NSSO Rounds 47th and 58th, 1991 and 2002.

Table No. 3.1: Age Profile (Percentage) 1991-2002

Age Group	2002		1991	
	Rural	Urban	Rural	Urban
Less than 4	3.1	3	3.5	3.9
14-May	18.3	16.3	19.1	20.9
15-44	38.2	40.3	29.8	33.6
45-59	14.7	15.1	15.3	13.4
60+	25.7	25.3	32.2	28.2
ALL	14,085,000	4,406,000	12,652,000	3,502,000

Source: NSSO Rounds 47th and 58th in 1991 and 2002 respectively.

⁶ Ibid

3. B. Social Composition

According to the Census data, a substantial proportion of the disabled persons were scheduled castes, out of these 23% were in rural areas and 18% in urban areas. In terms of prevalence, there is not much variation noticed between 1991 and 2002 in the urban and rural context. However, there was a slight increase in the proportion of disabled persons from scheduled castes in the urban areas in 2002 as compared to the number in 1991.

3. C. Marital Status

According to the 2002 Census 43% of the disabled have never married, while 39% are currently married and 15% are widowed and around 1% are divorced or separated. A very high proportion of disabled persons, were never married and that percentage has also increased from 38.3% to 43.2% in rural areas between 1991 and 2002. Significantly 27.8% and 32.4% of the disabled were never married in the age group 'above 15 years' in rural and urban areas respectively in 2002.

Table No. 3.2: Social Composition (Percentage) 1991-2002

Social Group	2002		1991	
	Rural	Urban	Rural	Urban
Scheduled Tribes	8.4	2.5	9.4	2.4
Scheduled Castes	23.2	18.4	22	16.9
Others	68.4	79.1	68.6	80.6
ALL	14,085,000	4,406,000	12,652,000	3,502,000

Source: NSSO Rounds 47th and 58th in 1991 and 2002.

Table No. 3.3: Marital Status (Percentage) 1991-2002

Social Group	2002		1991	
	Rural	Urban	Rural	Urban
Never Married	43.2	45.5	38.3	45.3
Currently Married	39.4	38.1	38.7	35.9
Widowed	15.6	15.2	21.8	17.9
Divorced/Separated	1.8	1.3	1.2	0.8
ALL	14,085,000	4,406,000	12,652,000	3,502,000

Source: NSSO Rounds 47th and 58th in 1991 and 2002.

3. D. Literacy level

According to the NSSO records both 1991 and 2002, 59% of the disabled in rural areas and 40% of the disabled in urban areas were illiterate. Among the disabled who were literate, large sections were only educated up to the primary and middle level. According to the Census 2002, only 7% of disabled persons in rural areas and 17% of disabled persons in urban areas were educated up to the secondary level or above. Only 1.5% of disabled persons in rural areas and 3.6% in the urban areas have received any vocation training through the government initiative.

3. E. Work Status

According to the 2001 Census about 46% of the disabled persons in both rural and urban areas are without any work. The employment status of the disabled persons has not changed much between 1991 and 2002. This is in spite of the PWD Act 1995 which provides for reservation of 3% of all Government jobs for the disabled. Only 1.8% of the disabled in the rural areas and 7.3% in the urban areas were with any regular employer in 2002. This decline in the work force is noticed in all sections, be it self-employment, agricultural sector and casual labor.

Table: 3.4: Educational Status

Educational Status	2002		1991	
	Rural	Urban	Rural	Urban
Non-literate	59	40	70.1	46.2
Primary	24.4	28.8	20.3	29.8
Middle	9.7	13.7	5.3	11
Secondary	3.8	7.8	2.3	6.4
Higher-secondary	2.1	5.1	0.8	2.8
Graduation and above	1	4.6	0.4	3.1
Not Reported	0.1	0.1	0.8	0.8
Vocational Training received	1.5	3.6	1.2	3.1
Engineering	20	25	20.2	26.6
Non-Engineering	80	75	79.8	73.4
ALL	14,085,000	4,406,000	12,652,000	3,502,000

Source: NSSO Rounds 47 th and 58 th in 1991 and 2001.

Table No. 3.5: Work Activity Status (Percentage) 1991-2002

Work Activity Status	2002		1991	
	Rural	Urban	Rural	Urban
Self- Employed in Agriculture	10.6	9.4	13.3	1.9
Self Employed in Non-Agriculture	5.1	2.2	4.2	10.2
Regular Employee	1.8	7.3	2	7.7
Casual Employee	8.8	4.9	9.5	5.5
Attending Educational Institution	13.7	16	11	17.7
Attending Domestic Work	12.8	13.5	13.5	15.2
Begging	0.5	0.9	0.7	0.8
No Work	46	44.5	45.7	41.1
ALL	14,085,000	4,406,000	12,652,000	3,502,000

Source: NSSO 58th Round, 2001

3. F. Disabled Persons in India: Type and Magnitude

The NSSO 47th round, 1991 provides quantitative data about the spread of disability in India in terms of four broad groups, namely visual impairment, hearing impairment, speech impairment and loco motor disability. Amongst all forms of disability, loco motor disability constituted the highest (55.33%) per cent of the disabled, followed by visual disability at 24.79%, hearing disability at 20.06 % and speech disability at 12.17% in 1991.

The 2002 Census, provides detailed information about the disabled in India. It includes mental disability along with the other criteria of disability and categorized it into mental retardation and mental

illness groups. It also categorized visual impairment into blind and low vision groups. According to the 2002 data, 57.50 % of the disabled were suffering from loco motor disability while 10.88% were blind, 4.39% were people with low vision, 16.55 were having hearing impairment, 11.65% had speech disability, 5.37% were mentally retarded and 5.95% were mentally ill. The trends showed a significant rise in the loco motor disability among all other forms. There have been declining trends in speech, hearing and visual impairment. Mentally disabled persons constitute 11.33% of the total disabled persons in out of which 5.37% were mentally retarded with learning and other disabilities, and 5.95% were mentally ill.

Table: 3.6: Type and Magnitude of Disability

Disability Type Numbers	2002		1991	
	Numbers	% age to all disabled	Numbers	% age to all disabled
Visual	2,013,400	10.88	N.A	N.A
Blindness	813,300	4.39	N.A	N.A
Low Vision	2,826,700	15.28	4,005,000	24.79
Both				
Hearing	3,061,700	16.55	3,242,000	20.06
Speech	2,154,500	11.65	1,966,000	12.17
Locomotors	10,634,000	57.5	8,939,000	55.33
Mental	994,600	5.37	N.A	N.A
Mental Retardation	1,101,000	5.95	N.A	N.A
Mental Illness	2,095,600	11.33	N.A	N.A
Both				
ALL	18,491,000	100.00	16,154,000	100.00

Note: The percentages may not add up to 100 % as multiple disabilities was also recorded for a large number of disabled persons.

4. NSSO and Census data on Disability: A Comparative Analysis

The National Sample Survey and the Census both collect data on the nature and magnitude of disability. Though both intend to present quantitative data on disability, the results offered by them are drastically different from each other. The reason behind this is the difference in the definitions adopted by both. The way, the issue is defined determines the information which will be collected there from. The other difference in both the institutions is the method of data collection. So in spite of the fact that both the institutions are providing credible data, they cannot be compared.

If we take the case of visual disability, the Census of India defines seeing disabled as “a person who cannot see at all or has

blurred vision even with the use of spectacles. A person with proper vision in one eye will also be treated as disabled. A person may have blurred vision and had no occasion to test whether his or her eyesight would improve by using spectacles would be treated as visually disabled”. Whereas according to the NSSO definition, visual disability meant, “loss or lack of ability to execute tasks requiring adequate visual acuity. Visually disabled include (a) those who do not have any light perception- both eyes taken together and (b) those who had light perception but could not correctly count the figures of hand (with spectacles/ lenses) from a distance of three meters in good day light with both eyes open. Night blindness was not considered a visual disability. The definitions adopted by the Census of India are broader in coverage than the NSSO definition. This influences the data collected by both.

According to the 2001 Census, there are 10,634,881 persons with disability in India. The NSSO 2002 data showed that there are 2,826,700 persons with visual disability. As per these figures the Census estimates are 3.8 times more than the NSSO estimates. From these estimates it will be wrong to infer that visual disability has declined. Actually the difference in the estimates is because of the difference in the definition used by both the institutions. For example, NSSO includes persons with no light perception or blurred vision, whereas the Census includes, apart from these two categories, people with proper vision in one eye and also people who may have blurred vision and had had no occasion to test whether his/her eyesight would improve by using spectacles.

With regard to persons with speech disability, the 2001 Census estimated that there are 1,640, 868 persons which amounts to 7.49 percent of all persons with disability, whereas the NSSO estimates show that there are 2,154,500 persons with disability which amounts to 11.65 percent of the total disabled. In terms of defining speech disability both the institutions have huge differences. According to the Census of India, a person is recorded as having speech disability, if she/he is dumb, or a listener does not understand speech. A person who stammers but whose speech is comprehensible will not be classified as disabled by speech. NSSO includes those who could not speak, spoke only limited

words or those with loss of voice among the speech disabled. It also includes those whose speech is not understood due to defects in speech such as stammering, nasal voice, hoarse voice and discordant voice and articulation defects. A person with a stammer is classified as disabled by NSSO but not by the Census of India.

It is the same in the case of hearing disability too. According to the Census 2001, there are 1,640,868, people with disability in India, whereas the NSSO estimates 2,154,500 persons with disability. This is primarily because of the definition of hearing disability adopted by both the institutions. According to the Census of India, hearing disabled means all those who cannot hear at all, can hear only loud sounds, cannot hear through one ear but her/his other ear is functioning normally. A person who can hear with a hearing aid will not be considered as disabled under this category. According to the NSSO, if one ear is normal and the other ear had total hearing loss, then the person was not judged as hearing disabled. Similarly, hearing disability was judged without considering the use of a hearing aid. This has resulted in a huge difference in the data collected by both the institutions. Similar cases were observed in the cases of movement disability.

Presented below is a comparison between the NSSO data and the Census data.

Table 4.1: Estimates of Disability in India by Census and NSSO

Estimates of Disability in India by Census and NSSO					
Sr. No.	Types of Disabilities	Census 2001		NSSO - 2002	
		Number	% of Total Disabled	Number	% of Total Disabled
1	Seeing	10,634,881	48.55	2,826,700	15.29
2	Speech	1,640,868	7.49	2,154,500	11.65
3	Hearing	1,261,722	5.76	3,061,700	16.56
4	Movement	6,105,477	27.87	10,634,000	57.51
4	Mental	2,263,821	10.33	2,097,500	11.34
4	Total	21,906,769	100.00	18,491,000	100.00

Source: The Census of India 2001, NSSO 58th round, 2002.

5. Problems Encountered

A. Access: Accessibility is fundamental to the realization and enjoyment of any right. Though the earlier definition of access included only 'physical access' and took only architectural barriers into consideration, the modern day analysis of access is more holistic in nature. It encompasses within itself accessibility to quality education, information and communication, entertainment and technology. Emanating from the Beijing Conference and the Disabilities Act, access now is looked at not only as a means to achieve personal economic development but also as an opportunity to participate in social and political platforms.

A close look at access related issues brings to light that in spite of international conventions and domestic legislations, access has remained as an inadequately addressed concern. Things like public transport, public hospitals toilets, hospitals, government offices, public spaces like parks, educational

institutions, places of worship are still inaccessible to people. So far the interventions which have been made are restricted to the physical access only. Areas like education, teaching aids, books in Braille and interpreters for the hearing and speech impaired are still not available to large sections of the disabled.

C. Employment: According to the Census 2002, disabled people constitute at least 6% of our population; still their basic needs for social security, individual dignity and meaningful employment remain unmet. They are at the mercy of the government and civil society which have a lackadaisical attitude towards them. The Disability Act 1995 provides for 3% reservation in all categories of jobs in government sector. Though it has been three years to this notification, its implementation is still not complete.

D. Education: Education is crucial for any individual's growth. Same is the case for persons with disability. In India, education for the disabled is not part of

mainstream learning, but it is imparted through isolated institutions which operate on a service and charity mode. There are only around 3000 special schools in India today. Of them, only 900 are schools for the hearing impaired, 400 for children with visual impairment, 700 for those with loco motor disability and one thousand for the intellectually disabled. More than 50,000 children with disability are enrolled in the Integrated Education for Children, a government-sponsored programme. Only a few schools have special provisions such as resource rooms, special aids and special teachers. This is restricted only to big cities. Since there are no special schools or special education services in rural India, children with special needs either have to make do with the regular schools in the village or go without education. Pre-vocational and vocational training is provided only in specialized institutions and in select cities.

E. Discrimination: Persons with disability suffer from both social and material discrimination. Society, which is caught up with uniformity, cannot see people with differences with the same eye. There is lot of stigma attached to disability, which hinders their normal social interaction. The other discrimination they face is in terms of access to places. Public buildings, public transport system and other places of importance are not accessible to them. The employment opportunities available to them are also very low. They suffer the triple jeopardy of being

disabled, poor and stigmatized.

6. The Most Vulnerable

Disability impacts the quality of life of all similarly but yet there are certain types of disability and some groups within the population who suffers the most due to disability.

6. A. Children with Disability

It is estimated that one child in every ten is either born with or acquires a physical, sensory or mental impairment in the first year of life. According to this estimate, the world population of disabled children is around 140 million, of which 25 million live in India alone.⁷

According to Child Relief and You (CRY)

Three percent of India's children are estimated to be mentally challenged. Of these 15 million children are below the age of 10 years. Ten million are boys and 5 million are girls. Twenty percent of the disabled children are urban and 80% are in rural areas, 60 percent are males and 40 percent are females.

The data available on disabled children as per the place of residence criteria shows that 20 of every 1000 children in rural India are disabled as compared to 16 out of 1000 urban children. According to a study conducted by NCAER, estimates for various types of physical disability (night blindness, impairments, related to visual, auditory, vocal and loco motor systems) are low

⁷ The Disabled Child, Advocacy Internet, May- June, 2003

in Kerala and Gujarat among the children in the age group of 0-4 years, but high in Bihar and West Bengal. In the West Bengal, in the age group of 5-12 years, the prevalence rate is as high as 6,779 per 100,000, 4,670 in Himachal Pradesh and 4,519 in Tamil Nadu.⁸

6. A. i. Children with Disability: A Health Survey

About 75 percent of the disabilities are preventable either by long term measures like poverty alleviation, access to health care or by short term measures like immunization and vitamin supplementation. The section below takes stock of immunization and vitamin supplementation programs in India.

a. Immunization

In the context of protection of children from disabilities, immunization is a major step. In India, vaccination against diseases like tuberculosis, diphtheria, pertussis, tetanus, poliomyelitis and measles is administered as a package from the public health system. According to NHFS II estimates, full vaccination cover is higher for urban areas (52%) as compared to rural areas (29%). A similar comparison can be drawn between boys (43%) and girls (41%) in rural and urban areas. This indicates that it is not only children in the urban areas but also male children who receive full

vaccination. The data also reflects that immunization cover further goes down for children of illiterate mothers (28%), Scheduled Caste 40%, Scheduled Tribe 26% and other Backward Castes 40%. According to the NHFS data and other government records, the vaccination cover for pulse polio is the higher than for measles and diphtheria. The Government records state that the total percentage of immunized children in India is 53%, the un-immunized in India make up one-third of all the world's un-immunized children. Of the 30 million children born in India, 17.9 million were found to be without any immunization according to the last survey of the Government. According to a review conducted in 2004, by the Health Ministry in collaboration with AIIMS, CDC, Atlanta, WHO, UNICEF, USAID, ICMR and other institutions, about 95% of un-immunized children are concentrated in 15 States. The Southern States are much better off than the Northern States. Forty percent of the un-immunized live in Uttar Pradesh and Bihar. Uttar Pradesh has the highest number (4.6 million) of un-immunized children in the State. In spite of the fact that immunization can check disability substantially, the practice and cover have not yet been made universal. There is lack of both political will and sensitization towards it.

⁸ NCAER, 1999

6. A. ii. Vitamin Supplements

Blindness is the largest disabling factor worldwide. One of the main factors causing blindness is the deficiency of vitamin A. In India the National Program on Prevention of Blindness administers Vitamin A drops to children under the age of five years. The NHFS II data shows that in India as a whole, only three out of ten children in the age group, 12-15 received at least one dose of vitamin A, and only 17 percent received a dose in the past six months. This reflects that a large majority of children in India still do not receive any vitamin A supplements and that even fewer children receive vitamin A supplements regularly (NHFS II).

6. A. iii. Education of the Disabled Children

In India the education scenario for the disabled children reflects a rather grim picture. The issues which are crucial for the education of disabled children is the availability of special schools, access to schools, trained teachers and availability of special educational material.

The situation of special schools in India is quite appalling. According to the Sixth All India Educational Survey Report, of the 6461 town and cities in India, only 334 or 5.1 percent of the towns and cities have the facility of special schools catering to serve disabilities. In these towns, a total of 630 schools are actually functioning of which 97 admit only boys and 33 are for girls and the rest

admit both. Some schools are dedicated exclusively to a particular disability, while others cater to the needs of children suffering from different types of disability.

Categorization of these schools according to their specialization indicates that 215 are for the visually impaired, 290 for hearing impaired, 190 for those orthopedic problems, 173 for the mentally challenged and 60 for those with other locomotive disabilities. The facility of special education is rather skewed. Data shows that of a total number of 586465 villages in the country only 241 have facilities for special education for the disabled. A further look at the state-wise distribution of these schools shows that 83 percent of these schools are in the States of Andhra Pradesh, Bihar, Gujarat, Haryana, Kerala, Madhya Pradesh, Maharashtra, Orissa and the Union Territory of Andaman and Nicobar Islands. Of the 272 available schools, 55 are for boys, 11 for girls and the rest offer coeducation. Categorization of these schools in terms of their specialization shows that 73 are for the visually challenged, 128 for the speech and hearing impaired, 70 are for the mentally challenged and 25 cater to various other handicaps.

In the absence of adequate number of special schools, the other issue that requires discussion is the integration of education of the disabled children with mainstream education. In fact, the Universal Education program envisages

universalizing education by educating the disabled children through the mainstream schools. This is possible only if there are adequate numbers of teachers with special training at the primary level. In the primary schools in India, the number of trained teachers is not adequate. The teacher training programs which provide disability training emphasize that specialization should be sought for a single type of disability. But this is a very expensive proposition. So the situation demands that either the training programs should offer multi-disability training or the general teachers' training courses should be remodeled in a way to equip all the teachers to address the concerns of disabled children.

Another critique of the integrated education system is that it is suitable only for children with moderate disabilities. The system is unable to include children with mental disability. These children are unable to attend the mainstream schools due to stigma and discrimination and also because of their inability to cope with the academic syllabus.

6. A. iv. Policies and Programs for Education of Disabled Children⁹

Relief and rehabilitation of people with disability is one of responsibilities of the government. But it is really unfortunate that initiatives around this are grossly inadequate, badly managed and are done on a service or charity mode rather than from a

rights perspective. The Ministry of Social Justice and Empowerment of the Government of India is the nodal agency for implementing most of the policies and programs. The policies and programs addressing the educational needs of disabled children are mentioned below.

National Policy on Education (1986)

With regard to the Right to Education of the Disabled, the National Policy was a landmark policy. For the first time in India's history, a policy talked about the education of the disabled. Section 4.9 includes the following provisions:

- Inclusive education possibilities for children with mild disabilities in regular schools;
- Provision for the training and education of children with severe disabilities in special schools;
- Vocational training as part of education for the disabled;
- Reorientation of teachers training programmes to include education of disabled.

Integrated Education for Disabled Children (IEDC)

IEDC is a scheme implemented by the Ministry of Human Resource Development. In this scheme trained teachers support the regular class teachers in providing appropriate education to the disabled children.

National Open Schools

The National Open School (NOS) is a program of open education, which

⁹ Report of the Ministry of Social Justice, 2000.

provides the opportunity to intellectually challenged children to join the schools. There are special syllabi for these children and also a provision for vocational training.

The District Primary Education Program (DPEP)

DPEP, a program implemented at the district level aims at providing universal education to the disabled children. Through this scheme, children with special needs can also join the mainstream schools. The scheme attempts to provide primary education to the disabled children through trained teachers, appropriate teaching aids and necessary infrastructural facilities.

6. B. Disability among Women

Disabled women are the most vulnerable in Indian society. This vulnerability exists across class and caste. They suffer because of the triple jeopardy. They suffer because they are women, on account of being disabled and most of the times because of poverty. An excerpt from an interview given below provides deeper insight into the fact that though men and women suffer equally because of disability, some problems affect women differently, perhaps more.

“If disability affects them (boys and girls) in almost identical fashions, but then it’s a patriarchal society. The birth of sons is always celebrated; the birth

of a girl is never celebrated. And the birth of a disabled girl – they say, ‘a girl’, and on top of it, disabled!’ A disabled boy is more acceptable than a disabled girl. If a family has a disabled boy, they will do their best to give him a decent living. Whereas when it comes to girls they say, ‘Why should we do any thing? There are no institutions as such in India. There are residential schools, mostly for the visually impaired girls. (Otherwise) girls are with their families, but what happens is that they are left in a corner, not given enough food and left to die. If the parents can afford one education they would rather educate the boy. Children are lineage capital for families. A boy, even if he’s disabled... If we can find him a cure, or some kind of a job, one day he will be able to look after us.

The rule is not there for girls. I’m afraid that disability movement is patriarchal as any other cultural context, which is what I am fighting. The problem is that, very elite middle class men run the disability movement. As a result their concerns are also issues which affect them.”—Anita Ghai¹⁰

In India, disabled women constitute around 42% percent of the total disabled population. They are most marginalized in terms of their social, economic, political and health status.

They are not considered as a priority group in any kind of research, state policies and

¹⁰ Excerpts from an interview with Dr. Anita Ghai, one of India’s advocates for rights of the disabled women by Laura Hershley in the Disability World.

programs, mass movements, and rehabilitation programs. They are further isolated from social and political participation due to the stigma and discrimination attached to disability. As Irene Feika puts it, “Due to numerous societal standards, they continue to be left out of the decision making processes. This reality is specifically true of women with disabilities in the cultures where the role of wife and mother is considered as a primary role for a female.”¹¹

6. B. i. Education

In a country like India where it's been hard to implement compulsory education to non disabled girl children the condition of the disabled girl child is beyond comprehension. According to the National Sample Survey Organisation 1991 survey, among children in the age group, 0-14 years, approximately 3% of the children are disabled. The data shows that the prevalence rate for physical disability was observed to be higher among boys (22.7/1000) than girls (16.74/1000). This discrepancy in the ratio on the basis of gender, instead of reflecting an advantageous position for girls raises the question of the possibility of underreporting of girl children with disabilities because of the social stigma attached.

Education is one of the fundamental problems disabled girls face. They face problems with regard to access to schools, enrollment in schools

and availing the opportunity of vocational training.

*According to a study conducted by the International Council on Education of People with Visual Disability, only 2 percent of visually challenged children in developing countries receive any formal schooling. In China, where there are 5 million disabled children in the age group of 7 and 15 years, only 6 percent are enrolled in schools. It is understandable that the number of girls who attend these schools will be reasonably low.*¹²

*In the Indian context, a study conducted in Raichur District of Karnataka, states that the literacy rate of disabled women was 7 percent as compared to the general literacy rate of 46 percent for the State.*¹³

Disabled girls have multiple difficulties in availing themselves of education.

- Firstly, since the number of special schools is inadequate, disabled girls are the least likely to attend general schools. In extreme situations, even if parents are prepared to send their disabled male child to the general school, girls are not allowed.
- Secondly, most of the special schools are residential. Usually Indian families are reluctant to allow their girl child to be away from home. At times, these special schools are isolated from the rest

¹¹ Irene Feika, Deputy Chairperson of Underrepresented Groups, Disabled People International.

¹² ICEV, 2004

¹³ Indumathi Rao, 2005, Equity to women with disabilities: Strategy paper prepared for the NCW

of the community and there are major security concerns for students.

- Thirdly, the few special schools that exist in India, are concentrated around big cities, which are inaccessible to a large number of disabled girls who are from the rural areas.
- Fourthly, since most of the special schools function in isolation, the students from these schools find it difficult to adjust with the children from regular schools.
- Fifthly, the most important shortcoming these schools have is that there are educationally inferior. A study of disabled girls, both in special (usually residential) schools and in regular schools, found that those in the special schools were less proficient in basic literacy and numerical skills, had lower expectations about their own capabilities and lacked confidence in the social setting.

Lack of education deprives the disabled girl child from access to information, opportunities for social and political participation, skill development and economic empowerment. Civil society has a great challenge ahead regarding the empowerment of the disabled girl.

6. B. ii. Employment

Education and Employment are closely linked to each other particularly in the context of disabled women, for whom vocational

training is a pre requisite for employment. In India large sections of disabled women are either unemployed or engaged in very low paid jobs. According to the Census 2002 data, the usual work activity status (activity status during last 365 days preceding the survey) for the disabled persons depicts that 62% and 89% males and females respectively in rural areas and 63.5% and 90.5% males and females respectively in urban areas were out of labor force. Though the overall employment scenario for the disabled persons is bad it is more unfavorable in the case of disabled women.

Disabled women have limited scope to get employment because of multiple problems like stigma and discrimination, difficulty in physical access, lack of technical expertise and so on. There are also a number of other difficulties for disabled women to be self-employed. They face problems in obtaining raw material and marketing their products, so they are left with no other option but to take up piecework. Evidence shows that since ages disabled women have been doing routine and ill paid jobs such as weaving, basket making, sewing, assembling of toys and production of handicraft items.

In fact the Census data shows that there has been a decline in proportion of self-employed in non-agricultural sectors in urban areas and in agricultural sector in rural areas during 1991-2002. Even the

proportion of casual employees has declined during 1991-2002 for both rural and urban areas.

6. B. iii. Social Seclusion

Disabled women are the worst victims of social exclusion. Stigma and discrimination attached to disability deprives these women from enjoying their social and cultural rights. In India where marriage is a conventional and near-universal institution, it is also considered as a means to provide social acceptability and status to women. Marriages for disabled persons are a difficult proposition, more so for disabled women. Here again, stigma and discrimination prevents families from entering into marital relations with disabled persons. According to Census 2000, 43% of the disabled have never married, while 39% are currently married and a significant 15% are widowed and around 1% are divorced or separated. Not much variation was recorded in the marital status of the disabled population in both rural and urban areas. But what is surprising is that the proportion of disabled persons, who never married has increased from 38.3% to 43.2% in rural areas between 1991 and 2002. Significantly 27.8% and 32.4% disabled persons were never married in the ages above 15 years in rural and urban areas respectively in 2002. This reflects the reluctance still prevalent in society in marrying persons with disability. Data on the current living arrangement of the disabled persons reveals that about 3% of the disabled persons were

living alone and 6%-7% were staying with relations or non-relations. Only 5.5% of the disabled were staying only with spouses and another 32% were staying together with spouses and others. Significantly nearly 38%-40% of the disabled were staying with parents without spouses. These women are looked upon as a burden to their natal families and are exposed to a lot of ill treatment. Often they are at the mercy of the elderly men in the family and face sexual exploitation.

Disabled women who are single mostly live alone and are exposed to exploitation of various kinds. Same is the condition of disabled women who live in institutions. They are susceptible to sexual exploitation by employers and managers in institutions. The most shocking evidence one has is that of mass hysterectomies of mentally challenged girls in a State run institution in Shirur, Maharashtra. The other issues are abandoning, disowning and elimination of disabled girls. The chances of disabled girls getting adopted is also very slim.

A study conducted by Emily et.al (2002) demonstrated that a culturally appropriate form of independent group-living has a beneficial impact on the women's levels of sociability and their confidence to venture out in public or to social functions. Living among other women with disabilities and in a non-judgmental environment

helped in raising self-esteem and in developing social skills. All of the women who resided in the group-house felt accepted, sociable, and confident to venture. When they were together, confidence in their abilities was strengthened and they could carry out their business with mutual support. Thus independent and group-living helps in social development (increased sociability, public confidence and the ability to support) and personal development (improved self-image, independence and professional motivation).

6. B iv. Health

Like other problems disabled women also face major health problems. As they are not a homogenous group problems they face are also not uniform in nature. Women with different types of disability face different types of health problems. They face these problems on two accounts, one, identifying the health problem and the other is access to health care. In the coming years health problems of disabled women and elderly women is going to be an important issue, which the country has to be able to address.

There is a close association between aging and disability—older women constitute a distinct population that requires interventions very different from a population of younger women. Obviously health problems of women are not homogenous and cannot be addressed through the traditional maternal and child health services.¹⁴

The health of an elderly woman is largely dependent upon her health in her young age, the socio economic strata to which she belongs, marital status, number of children she has and also the place of residence. Her problems are very culture and region specific. The aged are encountered with disabilities such as sight and hearing deficiencies, which happen with age, but other types of disability are brought about by diseases and conditions. For example, some locomotor disabilities are brought about by strokes, weakening of the musculo-skeletal system can cause osteoarthritis which affects movement. About 41 percent of the rural elderly and about 37 percent of urban elderly suffer from one or the other disabilities. (NSSO, 2002). Among all the disabilities, visual disability had the highest incidence followed by locomotor disability. Most visual impairment among elderly is due to cataract and glaucoma (25 percent). The incidence of blindness is higher among women than that in men. The NHFS found that prevalence of partial blindness was 2839 per 100,000 for women of all ages and 2346 per 100,000 for men of all ages (IIPS, 1995). Pregnancy complications and lack of immediate medical attention can also cause cataract, while diabetes, glaucoma and metabolic disorders can increase the risk of cataract. Other potential causes can be vitamin deficient diet (vitamin C, E), severe attacks of

¹⁴ Rao, Equality to women with disability, 2004.

diarrhea and excessive exposure to the ultraviolet rays.

This fact is corroborated by the findings of the World Bank Study 1994, which states that 90 percent of persons above age 65 exhibited signs of cataract. Other micro studies also present similar findings. A study conducted in Tamil Nadu found that 89 percent of the elderly were affected by visual disability. (Rao, 1992). In Asia, nearly three-quarters of Malaysia and Filipino elderly had vision problems, as did a third of the Korean elderly. According to the NSS survey, 40 percent of the elderly reported suffering from at least one disability - slightly higher among females when compared to males. Sex differentials were reported for the prevalence of two and three disabilities; 15 percent suffered from at least two disabilities and another 6 percent suffered from three disabilities in India. Among the elderly, paralysis and dysfunction of joints is a very common occurrence. Along with other things 'stroke' is a major contributor to this.

Elderly women who are disabled have minimal chances of receiving health care. They are encountered with physical and financial problems most of the times access is determined by the willingness and the ability of caregivers to provide treatment. According to a study, women who needed treatment for visual disability reportedly had limited access to health facilities if

they had no sons or could not find alternative escorts. (World Bank, 1994). Finally it is also well established that availability of health services is largely restricted to women in the childbearing age.

6. C. Persons with Mental Disability

Five out of ten leading causes of disability and premature death worldwide are psychiatric conditions.¹⁵ Depression, anxiety and alcohol and drug abuse are the most common mental disorders. Psychotic disorders such as schizophrenia and bipolar disorder, although less common are profoundly disabling. Studies also show that many people with mental illness do not seek help. Both the family and the health system are not equipped enough to cater to the needs of the mentally ill. For those who seek formal medical help often get saddled with either inappropriate or overmedication. They are provided with superficial treatments mostly symptomatic often without addressing the root cause. Specialized treatment and particularly those required for psychological aspects are rarely provided.

The other area of concern is the mental health of the elderly. Increase in life expectancy coupled with economic development has led to an increase in the number of aged people in our country. Dementia and major depression are two of the leading contributors to disease in older people. Dementia, most commonly caused by Alzheimer's disease is characterized by progressive loss of intellectual abilities,

¹⁵ World Health Organization, 2002.

typically leading to death after five to seven years after diagnosis.¹⁶

In terms of health care provisions to persons with mental illness, the State does not have much to talk about. While mental health disorders account for nearly a sixth of all health related disorders, less than one percent of our budget is spent on mental health. India spends just 0.83% of its total health budget on mental health (WHO, 2001a).

India also has high rates of suicides-89000 persons committed suicide in 1995, increasing to 96000 in 1997 and 104000 in 1998, which is a 25 percent increase over the previous year (WHO, 2001b). The two important issues, which are underlined in this estimate, which are of special significance to India, are

- The population in the age group of 15-44 is the most affected. Needless to say, this section is the most economically productive in the community.
- The other issue, which is even more frightening, is the projection that developing countries such as India will see the most substantial increase in the number of mental disorder cases in the next two decades.

Regarding the treatment and cure of mental illnesses, there is gross lack of awareness. For example, nearly 50%-60% of persons with depression will recover with treatment in three to eight months; with schizophrenia, a combination of regular medication,

family education and support can cut the relapse rate from 50% to 10%. There is also no sufficient evidence to show that adequate prevention and treatment of mental disorders can reduce suicide rates, whether such interventions at individuals, families or other sections of the general community (WHO, 2001c).

The Indian situation with regard to treatment of mental illness is a combination of two problems. One is the lack of awareness and stigma attached to mental illness and two, inadequate mental health care facility. The data available on mental health care facility shows that India has 0.25 mental health beds per 10000 population. Of these, a substantial portion (0.20) is in the mental health hospitals occupied by long stay patients. There is also a shortage of mental health professionals. India has 0.4 psychiatrists, 0.04 psychiatrist nurses, 0.02 psychologists and 0.02 social workers per 100000 populations.

In terms of access to health care among mental health patients, gender is the major determining factor. According to a study on gender specific distribution of facilities in two Psychiatric hospitals in Vishakhapatnam city, male patients outnumbered females in both the hospitals from where data was collected. More than 50 percent of the patients in both the facilities were male, the gender gap being wider for the public hospital.¹⁷ (Out of total bed strength of 300 in the public hospital, 225 were for men and

¹⁶ Pathare, Soumitra

¹⁷ Vindhya, kiranmayi, vijaylakshmi, 2001

the remaining 75 for women). This study shows that the mental health care facilities are not geared towards minor and more common illnesses such as depression and so on. Whatever facilities are available for severe mental disorders are in the form of electrotherapy and chemotherapy. More sustained treatment such as counseling is not available in many public health facilities. The public health facilities in India focus more on psychiatric services, and this acts as a deterrent for many women from availing the services due to the stigma attached.¹⁸ The other problem affecting mental health care is lack of adequate number of medical professionals. As mentioned in the earlier paragraph, the proportion of mental health professionals is negligible (0.4 psychiatrists, 0.04 psychiatrist nurses, 0.02 psychologists and 0.02 social workers per 100000 populations). The National Mental Health Programme (NMHP) of 1982 focuses more on severe disorders like epilepsy, mental retardation and schizophrenia with a clinical perspective and the social and community health perspective is completely absent.

6. D. Disability and HIV/AIDS

The sexual and reproductive health of the disabled is an area, which is grossly ignored. They have very little access to reproductive and sexual health services. Often the basic service of maternal health care doesn't reach them. They suffer on multiple accounts such as physical inaccessibility to such

services, lack of information about the health facilities and health professional's lack of knowledge about disability.

The health system goes by the notion that disabled persons are non-sexual. Thus, the mainstream sexual and reproductive health programs have no special component for the disabled. Neither can the disabled avail of any services from these programs. The State and the society fail to realize that the disabled people do have sexual relations and have the right to fulfill healthy sexual relations. In fact, because of their multiple vulnerabilities they are more susceptible to sexual assault and exploitation. According to a study conducted by Swabhiman, a Disabled People's Organization in Orissa, 25 percent of the intellectually disabled women had been raped.¹⁹

Disabled people are at a greater risk of getting affected by HIV/AIDS, often more than the non-disabled persons. This happens because happens because of several reasons. They are more vulnerable to sexual assault than others, their concerns are not included in AIDS awareness programs, counseling and testing facilities are often not available to them. According to studies conducted in Tanzania and Zimbabwe, most of the disabled people were not invited to HIV/AIDS awareness training or events. Prejudice and lack of knowledge about the sexual health issues of the disabled is the prime reason for this.

¹⁸ Davar, B.V. (1999).

¹⁹ Alison Sizer, Disability and HIV/AIDS in Health Link World Wide, 2000

7. Disabled Persons: Human Rights Concerns

Though like all human beings, the disabled too have human rights; not many documents make a special mention about the disabled persons not even the Universal Declaration of Human Rights. The European Social Charter, adopted by the European Social Council in 1961 was the first to talk about the rights of the disabled persons in Europe. It supplements the European Convention for Protection of Human Rights and Fundamental Freedoms. The Charter contains rights relating to employment policy, working conditions, worker's protection, freedom of association and collective bargaining, social security, family policy and other matters. The clause on Human Rights of Disabled Persons is mentioned exclusively in Point 15 of the first section, which says **“Disabled persons have the right to vocational training, rehabilitation and resettlement, whatever the origin and nature of disability.”**²⁰

In November 2000, The European Council adopted a directive which states that “Any discrimination based on religion or belief, disability and age or sexual orientation may undermine the achievement of the objectives of the Treaty, in particular the attainment of a high level of employment and social protection, raising the standard of living and quality of life, economic and social cohesion and solidarity, and free movement of persons.”²¹

The other Treaty, which reinstates the right of the disabled, is the Treaty of Amsterdam. The Inter Governmental Conference that drew up the Treaty of the Amsterdam passed a declaration saying “the community institutions take accounts of the needs of persons with disabilities when adopting measures to approximate Member States’ legislation.”²²

This Treaty is indeed very significant because it not only mentions economic opportunities but also about greater participation in social, cultural and political life.

7. A. United Nations Provisions

- ***Rights of the Disabled Child***

United Nations Conventions on the Rights of the Child is the most comprehensive and widely accepted document regarding the rights of the child. Two articles of the convention makes explicit provisions for the rights of disabled children. *Article 23* mentions that “*State parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions that ensure dignity, promote self-reliance and facilitate the child’s active participation in the community.*”

The Article 2 of the convention mentions that “*State parties shall respect and ensure the rights set forth in the present convention to each child within their jurisdiction without discrimination of any*

²⁰ European Social Charter 1961

²¹ Ibid

²² Treaty of Amsterdam

kind, irrespective of the child's or his parent's or legal guardian's race, colour, sex, language, religion, political or other opinion, national ethnic or social origin, property, disability, birth or other status."

Being ratified by all the member states excepting the United States and Somalia, UNHRC is by far the most widely accepted UN provision.

- **Universal Declaration of Human Rights**

The Universal Declaration of Human Rights affirms the right of all people, without discrimination of any kind, to marriage, property ownership, public services, social security, and the realization of economic and social cultural rights. The International Covenant on Human Rights, the Declaration on the Rights of the Mentally Retarded Persons, and the Declaration on the Rights of the Disabled Persons give specific expression to the principles contained in the Universal Declaration of Human Rights.

- **UN Standard Rules**

UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities, 1993, has inspired many countries to frame their own disability related laws. This document aims to provide for equality and participation of disabled people in all walks of life. The 22 rules define the prerequisites of participation and equality, the essential main policy areas and the means whereby changes can be brought about.

- **United Nations Children's Fund (UNICEF)**

The UNICEF has adopted principles to emphasize strengthening family and community resources to assist disabled children in their natural environment.

- **United Nations High Commissioner for Refugees (UNHCR)**

The UNHCR has an exclusive set of programs for the refugees who are disabled.

- **United Nations Relief and Works Agency for Palestine Refugees in the Near East (UNRWA)**

UNRWA, is concerned, among other things, with the prevention of impairment among Palestine Refugees and the lowering of social and physical barriers, which confront disabled members of the refugee population.

- **Office of the United Nations Disaster Relief Coordinator (UNDRO)**

The UNDRO adopts specific measures for disaster preparedness and prevention for those already disabled, and also the prevention of permanent disability as a result of injury or treatment received at the time of disaster.

- **The United Nations Center for Human Settlements (UNCHS)**

The UNCHS is concerned concern about physical barriers and general access to the physical environment; the United Nations Industrial Development Organization's activities cover the production of Drugs essential for prevention of disability as well as of technical devices for the disabled.

7. A ii. Domestic Provisions

The Constitution of India right from its origin does include clauses, (though implicitly) which can be used to establish the rights the disabled persons have.

● **Right to Equality:** The Fundamental Right to Equality under Article 14 of the Indian Constitution which states that “The State shall not deny to any person equality before the law and or the Equal protection of Laws within the territory of India,” is the most crucial for establishing the rights of the disabled persons. This article talks about “substantial” equality and not “formal” equality. This means that different people have different needs because of physiological, social, historical or any other reason and there cannot be universal application of laws for all persons. It also means that different classes of people have specific needs and require specific treatment. The only condition is that the separate treatment should be rational and must further the objective of the law. The substantive equality paradigm provides for affirmative action. This means that special laws, policies and programs can be made for people who need special treatment. The right of persons with disabilities, any discrimination, which is on the basis of disability of the person, is therefore, within this mandate of Right to Equality under Article 14 of the Constitution of India.

● **Right to Life:** The Fundamental

Right to Life guaranteed under Article 21 of the Indian Constitution is an important right which encompasses within itself several other rights. Some of the important fundamental rights which have been recognized as part of right to life and which are of special significance to the disabled are as follows:

- Right to Housing
- Right to Education
- Right to Health
- Right to Food

● **Directive Principles of State Policy:** These are directives, which the Constitution provides, to the States, to use as parameters on the basis of which policies should be prepared. Unlike the Fundamental Rights, the Directive Principles are not *justiciable*, but they are a set of very progressive principles which uphold the spirit of human rights. Some Directive Principles specially mention the rights of persons with disability. For instance, Article 41 specifically provides for effective provision made by the State for securing the right to work, to education and to public assistance in cases of “disablement”. Article 39A envisages equal justice and free legal aid to all citizens and that opportunities for securing justice are not denied to any citizen by reason of economic or other disabilities. Articles 46 and 47 also have the potential for raising the standard of living education and development of persons with disabilities.

8. Legal Provisions

1. Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995.

This Act is guided by the philosophy of empowering the persons with disability and their associates. The Act aims to introduce instruments for promoting equality and participation of persons with disability on the one hand, and eliminating discriminations of all kinds, on the other.

2. Rehabilitation Council of India Act, 1992.

The Act was created to provide for the constitution of the Rehabilitation Council of India for regulating training of the rehabilitation professional and maintaining of Central Rehabilitation Register and for matters related to these issues.

3. Mental Health Act, 1987.

This is an Act to consolidate and amend the law relating to the treatment and care of mentally ill persons, to make better provision with respect to their property and affairs and for matters connected therewith or incidental thereto.

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

The government has also introduced a National Trust for Welfare of Persons with Mental Retardation and Cerebral Palsy Bill, 1995. The trust aims to provide total care to persons with mental retardation and cerebral palsy and also manage the properties bequeathed to the trust.

5. Employees State Insurance Act, 1948. This provides the facilities for persons employed in Government agencies and public sector organizations to avail of various benefits.

8. A. Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995

Education of Disabled persons: The Act addresses the issues related to the education of the disabled persons in a very comprehensive way. The Act imposes several duties on the Government and the Local Authorities to ensure free and compulsory education of the disabled persons. The Act provides for a quota of 3% seats for persons with disability in Government educational institutions and other educational institutions receiving aid from government. The government is supposed to issue notifications to all regarding the provisions for non-formal education, announcing comprehensive education schemes. The governments are expected to set up the adequate number of teachers' training institutions and assist other voluntary organizations to develop teachers' training programs.

The Act has certain shortcomings, which ultimately affects its proper implementation. A few of those are listed here.

- Section 39 which mentions reservation of 3 percent of the seats in government institutions and government-aided institutions, is mentioned under the employment chapter and not under that of

education. In order to deny seats to the disabled, the convenient excuse made by educational institutions is that the act talks about reservation of jobs and not admissions in educational institutions.

- In spite of the constitutional provision of free and compulsory education to all the children below the age of fourteen, the government has not yet included the clause of education of disabled children explicitly in the 'Education for all' program.
- Education for non disabled children comes under the Ministry of Education, whereas for the disabled children it comes under the Ministry of Social Justice. This shows that all the discourse around inclusive education and mainstreaming the issue is only at a theoretical level, the reality reflects something else.
- The Act does not define the parameters of segregationist, integrationist, and inclusive education. The lack of ideological commitment of the government towards this issue is reflected in the various forms.

The greatest advantage of the Education clause in the Act is that it provides the opportunity to every disabled child to dream of and demand for education.

The Employment Act covers the issue of employment of the disabled in various sections. It not only provides for reservation of jobs in the government institutions but also in the private sector though in a limited way. It talks

about long term steps like government-sponsored research about job identification and on site modifications in offices and factories. Also worth mentioning are the welfare schemes are the payment of "unemployment allowance". In spite of the above-mentioned provisions the Act also has severe shortcomings.

- The Act provides for employment to only those people who come under loco motor, hearing impaired and visually impaired stated categories of disability. The persons with mental illness and mental disability are expressly left out of it irrespective of the extent and severity of their illness.
- On the one hand, the Act provides for the employment of the disabled persons in government sector on the other hand provides for an "exemption clause". In case of the private sector the provision for reservation of jobs has remained at recommendation level where the Act talks about the "Incentive policy" which has not been worked out so far. And again the incentive provision has been made conditional to the Government's "economic capacity and development".
- Another area of contention is the "rights against disability based discrimination". This clause deals with disability acquired during service and doesn't encompass within itself rights against any form of disability- based discrimination. This section of the Act comprises of the most progressive, egalitarian and empowering provision for the persons with disability. This is actually a major

step to provide social and economic rights to the disabled.

Access: The Disability Act gives a broader definition of access. It provides for access not only physical access, but also to education, media, communication, entertainment and technology etc. Sections 44 to 46 talks about access, to public transport, public buildings and adapted toilets, etc.

- The greatest critique of this Act is that the entire Act does not have a special chapter on access. It provides for it in the chapters on non-discrimination. The Act fails to address that access and non-discrimination are two different things and call for two different kinds of action.
- Without physical access, reservations in educational institutions, government organizations do not have any value any will not give any tangible results. Still, a large section of India's public transport system, public amenities, parks, entertainment centers etc, are disabled unfriendly.
- Educational opportunities to children do not make sense when there are not enough primary schools admitting disabled children, schools not having enough trained teachers and reading material not being available in Braille, and there is a dearth of sign language interpreters, assistive aids and appliances.

Housing: The law recognizes the right to housing for the disabled, whether independent or familial, and the need

to provide for it. The Act aims to make special provisions for the integration of persons with disabilities into the social mainstream. The National Trusts Act was created with a huge Corpus for supporting programs that promote independence and address the concerns of those who do not have family support. Both these enactments address the need and rights of the disabled to adequate and suitable housing. This clause is undoubtedly a very important provision towards improving the quality of life for the disabled, but it has several shortcomings.

- The Act fails to include all the facets of residential and independent housing in its purview. Important issues like framing schemes allotment criteria and other important details are left to the local authorities.
- Access to residential housing becomes difficult without disabled specific housing loans.

Mental Health: The Act includes in two of its sections the provisions of mental illness and mental disability. Though it is a major victory for the persons with mental disability to be included in the Act, they are up set with the insensitive and sectarian treatment meted to them. One of the examples is the use of terms such as "unsoundness of mind" and lunacy. Besides, persons with learning disability are also not included in this section.

8. B. Available Services for the Disabled

Relief and rehabilitation of people with disability is one of the major

responsibilities of the government. Disabled persons need assistance for diverse needs of theirs like education, housing, health care and most importantly access. But it is really unfortunate that initiatives around this are grossly inadequate, badly managed and are done on a service or charity mode rather than from a rights perspective. The section below lists the provisions made by the government for the benefit of the disabled. The

Government Rehabilitation Services²³

The Ministry of Social Justice and Empowerment is the nodal agency of the Central Government that promotes services for the people with disabilities through its various schemes. The Ministry aims to promote services for disabled persons through government and non-government organizations, so that disabled are encouraged to become functionally independent and productive members of the nation through opportunities of education, vocational training, medical rehabilitation, and socioeconomic rehabilitation. It also emphasizes on coordination of services particularly those related to health, nutrition, employment, sports, cultural, art and craft and welfare programs of various government and non-government organizations.

Some rehabilitation services are mentioned here:

● District Rehabilitation Center (DRC) Project

The DRC project was launched in 1985 to provide comprehensive rehabilitation

services to the rural disabled. The aims and objectives of the DRC include surveys of disabled population, prevention, early detection and medical intervention and surgical correction, fitting of artificial aids and appliances, therapeutic services-physiotherapy, occupational therapy and speech therapy, provision of educational services in special and integrated schools, provision of vocational training, job placement opportunities, awareness generation for involvement of family to create a cadre of multidisciplinary professionals to take care of major categories of disabled in the district. Currently there are 11 DRCs functioning in 10 States in India.

● Regional Rehabilitation Training Center (RRTC)

RRTC has been launched in the year 1985 to provide training to village level functionaries, DRC professionals, orientation and training of government officials, research on service delivery and low cost aids.

● National Information Center on Disability and Rehabilitation (NICDR)

The NICDR was established in 1987 to provide database for comprehensive information on all facilities and welfare services for disabled within the country. It also acts as a nodal agency for awareness creation, preparation, collection and dissemination of materials on disability.

● National Council For Handicapped Welfare

The NCHW was launched to ensure

²³ Ministry of Social Justice, 2004.

coordinated and comprehensive approach to research, training and services for the disabled population. The other areas of work are to evolve a National Plan of Action, review National Plan of Action, and evolve policy guidelines for rehabilitation of disabled persons.

● **National Handicapped Finance and Development Corporation**

The corporation was set up with a corpus of Rs. 400 crores to make persons with disability self reliant, economically productive and to bring them to the mainstream economic activity.

In spite of such great pronouncements in the national and international documents, the rights of the disabled have remained in paper. The government policies, legislative actions, schemes, rehabilitation programs show that the government is committed to the rights of the disabled people, but in practice all this is far from reality. The government's interventions fail on various accounts. First and foremost, some of the rehabilitation programs have a welfare mode instead of a rights based approach. Secondly, not much effort is put into spreading of awareness about disability, particularly about the stigma and discrimination attached to disability and also the preventive aspects of disability. Thirdly, programs for prevention have been very medical oriented and do not talk about community based rehabilitation. Fourthly the medical intervention is also slanted in favour of only certain

types of disability. For example, the efforts made in pulse polio are much more than those for deafness and neurological disabilities. Fifthly, sometimes the government departments, which are designated as nodal agencies to implement these programs themselves, lack the required expertise. Sixthly, the schemes and programs for the disabled do not receive adequate budgetary allocation and monitoring or evaluation, which grossly affects their performance.

9. Disability can be prevented

Not all disability is from birth. A large number of them are acquired in the course of time. Accidents, illnesses, nutrition related issues, conflicts situations and several other factors cause disability. This means that if the above mentioned factors can be controlled then disability can also be prevented. A large proportion of disability is caused by illness.

Because of the disability movement and the international covenants the concept of prevention has now acquired an expanded meaning. It not only means control or elimination of disabling factors but also initiating actions which empower disabled people to realize their full potential and to lead a productive life. This section presents the illness which can cause disability and also the other factors which have disabling impact on the lives of people.

9 A. Illnesses and Disability²⁴

The section below presents some of the major illness which have the potential

²⁴ This section is based on the paper prepared by the National Institute on Disability and Rehabilitation Research, US Department of Education.

to disable, people suffering from these diseases.

Arthritis: Arthritis is defined as pain in joints, usually reducing range of motion and causing weakness. Rheumatoid arthritis is a chronic syndrome. Osteoarthritis is a degenerative joint disease.

ALS (Amyotrophic Lateral Sclerosis) is a fatal degenerative disease of the central nervous system characterized by slowly progressive paralysis of the voluntary muscles. The major symptom is progressive muscle weakness involving the limbs, trunk, breathing muscles, throat and tongue, leading to partial paralysis and severe speech difficulties. This is not a rare disease (5 cases per 100,000). It strikes mostly those between age 30 and 60, and men three times as often as women. Duration from onset to death is about 1 to 10 years (average 4 years).

Cerebral Palsy (CP): Cerebral palsy is defined as damage to the motor areas of the brain prior to brain maturity (most cases of CP occur before, during or shortly following birth). CP is a type of injury, not a disease (although it can be caused by a disease), and does not get worse over time; it is also not “curable.” Some causes of cerebral palsy are high temperature, lack of oxygen, and injury to the head. The most common types are: (1) spastic, where the individual moves stiffly and with difficulty, (2) ataxic, characterized by a disturbed sense of balance and depth perception, and (3) athetoid, characterized by involuntary,

uncontrolled motion. Most cases are combinations of the three types.

Spinal Cord Injury: Spinal cord injury can result in paralysis or paresis (weakening). The extent of paralysis/paresis and the parts of the body effected are determined by how high or low on the spine the damage occurs and the type of damage to the cord. Quadriplegia involves all four limbs and is caused by injury to the cervical (upper) region of the spine; paraplegia involves only the lower extremities and occurs where injury was below the level of the first thoracic vertebra (mid-lower back).

Head Injury (cerebral trauma): The term “head injury” is used to describe a wide array of injuries, including concussion, brain stem injury, closed head injury, cerebral hemorrhage, depressed skull fracture, foreign object (e.g., bullet), anoxia, and post-operative infections. Like spinal cord injuries, head injury and also stroke often results in paralysis and paresis, but there can be a variety of other effects as well.

Parkinson’s Disease: This is a progressive disease of older adults characterized by muscle rigidity, slowness of movements, and a unique type of tremor. There is no actual paralysis. The usual age of onset is between the age of fifty and seventy and the disease is relatively common.

Stroke (cerebral vascular accident; CVA): The three main causes of stroke are: thrombosis (blood clot in a blood

vessel blocks blood flow past that point), hemorrhage (resulting in bleeding into the brain tissue; associated with high blood pressure or rupture of an aneurysm), and embolism (a large clot breaks off and blocks an artery). The response of brain tissue to injury is similar whether the injury results from direct trauma (as above) or from stroke. In either case, function in the area of the brain affected either stops altogether or is impaired.

Muscular Dystrophy (MD): Muscular dystrophy is a group of hereditary diseases causing progressive muscular weakness, loss of muscular control, contractions and difficulty in walking, breathing, reaching, and use of hands involving strength.

Age-Related Disease: Alzheimer's disease is a degenerative disease that leads to progressive intellectual decline, confusion and disorientation. Dementia is a brain disease that results in the progressive loss of mental functions, often beginning with memory, learning, attention and judgment deficits. The underlying cause is obstruction of blood flow to the brain. Some kinds of dementia are curable, while others are not.

Loss of Limbs or Digits (Amputation or Congenital): This may be due to trauma (e.g., explosions, mangle in a machine, severance, burns) or surgery (due to cancer, peripheral arterial disease, diabetes). Usually prosthetics are worn, although these do not result in full return of function.

Poliomyelitis: It is spread by contact with the feces (bowel movement) of an infected person. Symptoms can include sudden fever, sore throat, headache, muscle weakness and pain. Poliomyelitis is the most flagrant example. In fact, this disease could have been eradicated several years ago if efficient immunization programmes and sufficient hygienic conditions were put in place.

Leprosy: A bacillus, *Mycobacterium leprae*, that multiplies very slowly and mainly affects the skin, nerves, and mucous membranes. Deformities are the most striking manifestation of leprosy. The impairments seen in leprosy-affected persons range from a mild degree such as a small area of anaesthesia on the hand, to a very severe degree such as shortening of fingers and thumbs in both hands, bilateral wrist drop, ulceration and fixed deformities of both feet rendering them useless for walking, and loss of vision in both eyes. However, the milder ones are more common.

9. B. Disability is also caused due to other factors, if these factors are controlled then disability can be prevented.

- i. Poverty is the greatest cause and effect of disability. Malnutrition resulting from Poverty is the greatest single cause of disability. Pregnant women and children are at greater risk of being disabled by this cause. This can be prevented if people have more access to resources.

- ii. Lack of Safe Drinking Water and Proper Sanitation are the key elements in the spread of infectious diseases that may result in impairment and disability.
- iii. Lack of Vitamin A cause millions of children to lose their eyesight each year. Proper and adequate nutrition can prevent this from happening.
- iv. A large proportion of people are disabled due to accidents. Traffic accidents alone account for 30 million disabilities world over. Another 45% of the injuries take place at home and about 19% happen at work out side home.
- v. Disabilities also result from hazardous working conditions. Accidents in factories and mines account for large number of disability. Other occupations like electronics industry, carpet making and weaving also cause very high proportion of visual impairment. Here again women and children are the hardest hit, since they predominate in these meticulous and unskilled jobs.
- vi. Old age is a prime cause of disability. This affects both men and women but women are at greater risk. Since, they have higher life expectancy and have less access to health care.
- vii. Disability is also caused by drug and alcohol abuse.
- viii. Wars are disabling. They are fought for human interest and can kill and impair millions. Yet the world spends billions on wars every year.
- ix. Depression, anxiety and other psychological disorders when not

treated on time results in chronic mental health cases. Social support and timely medical aid can prevent a lot of people from becoming mentally ill.

- x. Ignorance and negative attitude towards disability is more disabling than impairment. The stigma and shame attached to disability prevents many people from seeking help. This often turns minor illness into major handicaps.

10. Recommendations

Disability is a major problem in the developing world which affects large sections of the society. Disabled persons suffer on multiple accounts not only because of the physical handicap but also from stigma and social ostracism. Earlier care and support for the disabled was not a priority for the governments and whatever little was done was on service or charity mode. Off late, there has been a change in the perspective and disability care is receiving a social and human rights approach. The other issue is that *disability* or *disabled people* are not a homogenous category. Different disabilities affect people differently and are influenced by all the social factors likes like caste class and gender. This implies that the same treatment cannot be provided for all the people with disability.

The recommendations made in this section are an elaboration of the same argument stating that all disabled people have different needs and specific programs should be designed according to their needs.

Disability and HIV/AIDS

- Targeting specific interventions designed and implemented for disabled people to address the issues of HIV/ AIDS and disability, empowerment and gender issues and sexual reproductive health.
- Advocating that the disabled are vulnerable to HIV/AIDS.
- Providing HIV/AIDS related information to the disabled in a format relevant to them.
- Raising awareness among health workers about the sexual and reproductive health rights of the disabled persons.

Persons with mental disability

- The most important thing about mental health care in India is the issue of accessibility to treatment.
- The first and foremost step in this regard is increase in the budgetary allocation to mental health issues within the health system.
- Mental health care can be made available to a large number of people by providing it through primary health care facility. Integrating primary health care and mental health is an important step.
- The other issue which is closely linked to that of access to mental health is adequate number of health professionals. In India, there is a need to increase the number of mental health professionals. There should be an all-round increase in the number of doctors, psychiatric nurses, counselors etc.
- Given the magnitude of the problem, it may not be possible for the health system alone to cope with it. It calls

for an inter-sectoral collaboration between the health system, the civil society groups, the public and private sector.

- It is necessary to involve the community in designing and delivery of the services. No efforts in addressing the problem will be successful without the participation of the community. If community participation is sought the problems of stigma and discrimination can also be managed.
- It is essential to develop effective mental health policies and programs. This will not only increase access to health care but also promote the respect of human rights.

Access

- Access is the most fundamental right of the disabled and enjoyment of all other rights is dependent upon it.
- Even though the Disability Act talks about making all public buildings and places of importance accessible to the disabled the government is far from achieving it. The government should set a dead line and immediately work upon the physical accessibility part.
- The Standard Rules on the Equalization of Opportunities for persons with Disabilities which were adopted in the 48th session of the United Nations General Assembly, December 1993, should be considered as a guideline and strict implementation of the same has to done.

- The Disability Act expanded the concept of access from physical access to other things like information, communication, media, entertainment etc. The spirit of the act has to be translated into action.
- Safety measures such as road safety, safety in residential areas, public transport system etc, should be taken up on a priority basis.
- Access to education is the key to development. Not only physical access to schools but also reservation of seats, access to reading material on Braille, appliances like hearing aids should be made available to all disabled children.

Social Security

- For persons with disability social security measures are extremely important because they provide the opportunity for greater mental and physical well-being. They provide the opportunity for vocational rehabilitation, protection against unemployment, other facilities like insurance, compensation, loans, maintenance of dependants etc.
- In India most of the social security measure are available to all those who are employed and that too in the organized sector. Large sections of the disabled are not only unemployed but also in the unorganized sector. These people are any way left out of the chain of social security. The ones who really need it are the most vulnerable.

- The government should take it as a priority that all disabled people are brought within the network of social security.

Employment

- Employment related issues are the key to lives of the disabled. In fact right to life and right to employment are closely related. In absence of employment and sustenance all other rights are peripheral.
- In India even though there is legislation in place, which talks about employment security, still there is no provision in theory or in practice, which gives employment guarantee to all the disabled persons.
- There is no provision by which the mentally disabled persons can have employment.
- The existing provisions of reservation of jobs are restricted to only government establishments. In reality, this doesn't translate much action because the public sector is shrinking very fast and most of the people are employed in the private and unorganized sector.
- The other issue is that of disability based discrimination at work place. There are gross violations of human rights of disabled people at their work place. This issue has to be addressed at the earliest if the employment rights of the disabled are to be protected.
- The recommendations of the Disability Act with regard to employment should be implemented.

Prevention of Disability

- Evidence shows that large number of cases of disability is preventable. Disability caused due to poor nutrition, contaminated soil and water, accidents, wars etc are highly preventable. Data shows that 70% of the visual impairment is caused either due to poor nutrition or clinical problems like cataract surgery. Concrete programs should be made so that disability caused by these can be prevented.
- Another thing, which causes disability, is old age. The incidence of disability can be significantly reduced through well-designed social and medical attention.
- The government's focus should be towards removing the factors causing disability rather than only providing clinical corrections.
- Poverty is the most important cause of disability. Every year millions of people go below the poverty line. This makes them more vulnerable to disability. The WHO estimates that worldwide there are 1.5 million blind children, mainly in Asia and Africa. In developing countries up to 70% of blindness is either preventable or treatable. The WHO also estimates that around 50% of disabling hearing impairment is also preventable. In 1995 this affected a total of 120 million people worldwide.

Women with Disability

- Women with disability suffer on both accounts, for being women and also for being disabled. The government and the civil society do not

adequately take up their causes. Women's movement in India has not specially looked into the problems of the disabled. The government programs either take women as a homogenous group or disabled as another group. Programs especially for the disabled women, cutting across all identities is not available. This is a priority and needs to be taken up.

- Within the disabled women's organization also the focus is on women with physical or visual disabilities. Adequate attention is not paid to the women with other disabilities such as mental illness and cerebral palsy. Growing number of cases of mental illness make it all the more important to be taken up specifically.
- Awareness and education has to be facilitated about disabled women and their rights. Efforts should be made to promote a positive attitude towards women with disability.
- Women are to be provided with career-oriented education, job reservation, credit facilities to start entrepreneurship and other forms of economic self-reliance.
- The health system should be geared to address the needs of the disabled women. Among other rights they should have the right to control their own fertility. Accessible, well equipped resource centers and clinics that will provide information on the issues affecting the disabled women should be made.
- The social security system should be geared towards the needs of the disabled women. Young women and

disabled mothers should be brought under the ambit of the scheme. The entire program for rehabilitation should have a component of economic empowerment and a right-based approach to the same.

- Organizations like National Commission for Women, Human Rights Commission and other Civil Society Groups should be consulted before making policies for disabled

women.

- More efforts should be made towards increasing the political participation of disabled women, the reason being, disabled women are the best to represent the interests of the disabled.
- Disability issue should receive political attention. The manifestos of political parties should mention the concerns of the disabled.

References

1. **Abidi. Javed**, (1995), No Pity. Health for the Millions, Vol.21 No.6. Voluntary Health Association of India (VHAI) New Delhi.
2. **Baquer. Ali**. (1994), Disabled, Disablement, Disablism, VHAI, New Delhi.
3. **Bhargava. Mahesh**, (1994), Introduction to exceptional Children: Their Nature and Educational Provisions. Sterling Publishers Pvt. Ltd., New Delhi.
4. **Bhushan. Shashi et al**, (1998), The situation of the handicapped in India. Institute of Social Studies. New Delhi.
5. **Davar,. B.V.**, (1999), Mental Health of Indian Women: A feminist agenda. New Delhi: Sage Publications
6. **Mani. D. Rama**, The Physically Handicapped in India: Policy And Program, Ashish House, New Delhi.
7. **Marfatia. J. C.**, (1966), Mental Retardation. Popular Prakashan, Bombay.
8. **Pandey. R. S. Advani**, (1995), Perspectives in Disability and Rehabilitation. Vikas Publication Ltd. New Delhi
9. **Sen. Anima**, (1992), Mental Handicap Among Rural Indian Children. Sage Publications Limited. New Delhi.
10. **Shiley. Oliver ed**, (1983), A Cry for Help: Poverty and Disability in the Third World. Group for Disabled People, Somerset.
11. **Vindhya. U., A. Kiranmayi, V.Vijayalakshmi**, (2001), Women in psychological distress: Evidence from a hospital based study. Economic and Political Weekly, 36(43), pp.4081-4087.

Reports

1. Annual Report, 1995-96, Ministry of Health and Family, Govt. of India.
2. A Report of Disabled Persons, 47th Round 1991 and 58th Round 2002, National Sample Survey Organisation.
3. The Persons with Disabilities (Equal Opportunities, Protection of Rights & Full Participation) Act, 1995.
4. The Standard Rules on the Equalization of Opportunities for persons with Disabilities, 1994.



**Centre For Enquiry Into Health And Allied Themes
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CEHAT’s objectives are to undertake socially relevant research and advocacy projects on various socio-political aspects of health; establish direct services and programmes to demonstrate how health services can be made accessible equitably and ethically; disseminate information through databases and relevant publications, supported by a well-stocked and specialised library and a documentation centre.

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	Year of Publication
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3 Health Facilities in Jalna: A study of distribution, capacities and services offered in a district in Maharashtra	2004
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