

Disability in India

Issues and Concerns

Leni Chaudhuri *

The disabled are deprived of all opportunities for social and economic development. Basic facilities like health, education and employment are denied to them. In spite of several international and national pronouncements the rights of the disabled has remained on paper. Given the magnitude of the problem it is important that disabled persons receive political attention.

***Centre for Enquiry into Health and Allied Themes (CEHAT), Mumbai. Email: cehat@vsnl.org**

“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. Most often they are the poorest. 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 per cent of blindness is either preventable or treatable. The WHO also estimates that around 50 per cent of disabling hearing impairment is also preventable. In 1995 this has affected a total of 120 million people worldwide. It is estimated that at least 10 per cent of the developing world's population is disabled in one way or the other.

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 per cent 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 the others with mental illness are just written off. Along with the physical problems they also bear the brunt of social ostracism and stigma.

Disabled are also not a homogenous group. There are different types of disabilities, with different requirements. Each once problems, needs and help required are different from the other.

In spite of several international and national pronouncements the rights of the disabled has remained on paper. Given the magnitude of the problem it is important that disabled persons receive political attention. It is important to note that 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 males and 7.56 million are females, which constitutes of around 59 per cent males and 41 per cent females respectively. These are the people who are suffering from some form of disability. The World Health Organization defines disability as 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.

One of the major problems, which affect any intervention on the issue of disabled, is the lack of proper data on the number of disabled in the country and the extent and magnitude of the problem. As late as 1981, the NSSO data for the first time gave the demographic status of the disabled. There is no evidence based demographic study conducted at the national level to provide reliable and analytical information on the status of disabled in the country. The NSSO 58th round was indeed a big leap in that 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 a few legislations passed to safeguard the interest of the disabled but they look more like ‘patch work’ and ‘add on’ rather than an integrated approach. The society is also not in a state of preparedness to accept the disabled population as part of the mainstream. Most often the disabled are looked at as not normal. Given the situation of lack of political will as well as social unpreparedness there is a big challenge ahead.

I **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”.

Persons with Disability Act 1995 defined as a person 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, locomotor 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 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.

Types of Disability

Locomotor Disability:

Locomotor 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 inability resulting from affliction of musculoskeletal and/ or nervous system. Some common conditions giving raise to locomotor disability could be poliomyelitis, cerebral palsy, autism, amputation, injuries of spine, head, soft tissues, fractures, muscular dystrophies etc.

Visual Disability:

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 tasks with appropriate assisted devices.

Mental Illness:

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, i.e., 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:

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

Learning Disability:

It 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:

A combination of two or more disabilities as defined in clause (i) of section 2 of the Person with disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995 namely Blindness/low vision Speech and Hearing impairment Loco motor 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 others are disability specific.

II Demographic Profile

1. Disabled in India: Demographic Profile³

The NSSO surveys, state that there were 13.67 million disabled persons in 1981 and 16.36 million disabled persons in 1991 (who were having at least one or more of the four types of disabilities viz. - loco motor, visual, hearing and speech). The NSSO survey 58th Round in 2002, covered mental disability in addition to the above stated four disabilities. According to the NSSO 58 th round the magnitude of the one or more than one of the five-disabilities was 18.49 million in 2002.

**Table I.1
1981-2002**

Year	Rural			Urban			Rural + Urban			
	Male	Female	Both	Male	Female	Both	Male	Female	Both	
1981										13.67
1991	7.44	5.21	12.65	2.07	1.42	3.50	9.51	6.63		16.36
2002	8.31	5.77	14.08	2.58	1.82	4.40	10.89	7.59		18.49

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

According to the NSSO 47 th round in 1991 there were 16.36 million disabled persons were registered out of which 9.51 million disabled persons were males and 6.63 million disabled persons were females. The proportion of males and females constituted 59 and 41 percent of the disabled persons respectively. According to the NSSO 58 th round in 2002 there were 18.49 million disabled persons out of which 10.89 million were males and 7.59 million were females, again constituting 59 per cent and 41 per cent males and females respectively. (Ref. Table No.II.1.1)

2. 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 per cent of the disabled persons were males and 42 per cent were females. Similar trends were noticed in 1991 and 2002 in case of both the rural and the urban areas. (Ref. Table No.II.1.2)

Table: 1.2
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 47 th and 58 th in 1991 and 2002.

3. Disabled Persons: Place of Residence

The magnitude of disabled persons residing in rural areas is very high at 77 per cent as compared to only 23 per cent were residing in the urban areas. Ref: Table No. II.1.3

Table No: 1.3

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 47 th and 58 th in 1991 and 2002.

3. Disabled Persons, Prevalence Rate:

According to the Census the prevalence rates (number of disabled persons per 100,000 persons) recorded for disabled persons was 1886 in 1991 and 1775 in 2002. This reflects a sharp decline in the prevalence rates from 1991 to 2002. Similar trends are observed for both gender groups in case of both rural and urban areas during 1991-2002. (Ref. Table No.II.1.4)

Table 1.4**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 47 th, 1991, and 58 th Round, 2002.

4. 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, which is reflected, 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. (Ref: Table 1.5).

Table 1.5**Prevalence Rate: Age Group**

Age Group	2002		1991	
	Rural	Urban	Rural	Urban
0-4	523	487	533	564
5-9	1167	1015	1578	1430
10-14	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 47 th , 1991, and 58 th Round, 2002.

5. Disability Prevalence: Interstate variation

The table below provides the information about interstate variation in prevalence of Disabled Persons.

Table: 1.6
Disability Prevalence: Interstate Variation
Males

STATES	RURAL		URBAN	
	1991	2002	1991	2002
Andaman & N.Isl			2766	1290
Andhra Pradesh	2354		1980	1712
Arunachal Pradesh			1861	109
Assam	947		1062	948
Bihar	1125		2098	1071
Chandigarh			865	577
Chhatisgarh			2012	1973
D & N Haveli			990	798
Daman & Diu			649	1500
Delhi			823	642
Goa			2326	1454
Gujarat	1557		2169	1566
H.P.	2157		3326	995
Haryana	1665		2256	1105
J&K			2120	1401
Jharkhand			1614	1352
Karnataka	1891		1977	1307
Kerala	1636		2451	1587
Lakshadeep			2768	1454
Madhya Pradesh	1794		1969	1113
Maharastra	1927		2375	1408
Manipur			1092	1090
Meghalaya			1871	1117
Mizoram			855	814
Nagaland			895	602
Orissa	2166		2671	2077
Panichery			1817	2310
Punjab	2384		2576	1558
Rajasthan	1355		1826	1168
Sikkim			1860	654
Tamil Nadu	2201		2188	1669
Tripura			748	1176
Uttar Pradesh	1441		2319	1210
Uttranchal			2200	1155
W. Bengal	1484		2006	1283
All India	2277		2118	1774

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

Table: 1.7
FEMALES

STATES	RURAL		URBAN	
	2002	1991	2002	
Andaman & N.Isl		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
D & N Haveli		712		610
Daman & Diu		1370		1229
Delhi		451		368
Goa		1039		1650
Gujarat	1557	1556	1566	1325
H.P.	2157	2135	995	1025
Haryana	1665	1505	1105	1159
J&K		1173		1100
Jharkhand		938		726
Karnataka	1891	1521	1307	973
Kerala	1636	2010	1587	2082
Lakshadweep		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
Panichery		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
Uttanchal		1884		665
W. Bengal	1484	1355	1283	1740
All India	1694	1556	1361	1311

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

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 the urban areas than in the 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 in the urban areas the States like West Bengal and Kerala reported high prevalence rate. 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.

6. Onset of Disability since Birth:

Around 1/3rd of the persons with disability have acquired 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. (Ref. Table No.II.1.8). Both rural and urban areas have reported around 33 per cent disability cases since birth. 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. Onset of Disability since Birth (per 1000 disabled persons) 1991-2002

Table No. 1.8

YEAR	RURAL			URBAN			BOTH R+U			
	M	F	M+F	M	F	M+F	M	F	M+F	
2002		335	315	327	303	298	301	328	311	321

Source: NSSO Rounds 58th, 2002.

7. Disabled Household, Number of Disabled Persons:

According to 2002 Census records the numbers of disabled persons who have other disabled people in their households are the following. About 92 per cent of these household have one disabled person, 7 per cent households have two disabled persons and the rest 1 per cent households have two or more than two disabled persons. No significant variations were registered in the rural and urban areas during 1991 and 2002. A significantly large proportion, 7-8 per cent households have more than one disabled person in their homes and this was uniform both in rural and urban areas.

Table No. 1.9

Disabled Household, Number of Disabled Persons

Number of Disabled Person in Households having Disability	2002		1991	
	Urban	Rural	Urban	Rural
One	92.3	92.3	92.0	92.5
Two	7.0	7.2	7.6	7.0
More than Two	0.6	0.5	0.4	0.5

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

8. Disabled Persons, Severity:

This section presents information about the severity of disability among persons with disability. About 60 per cent disabled persons can function without aid/appliances, while 13 per cent cannot function even with aid and appliance and another 17 per cent can take self care with the help of aid and appliance. Around 10 per cent of disabled have neither tried nor have access to aids and appliance and hence cannot take self-care. Significantly the proportion of severely disabled who cannot function even with the help of aid/ appliance is 13.1 per cent in rural areas and 14 per cent in urban areas in 2002. (Ref: Table No. 1.8)

Table: 1.10
1991-2002 (Percentages)

Degree of Impairment	2002		1991	
	Rural	Urban	Rural	Urban
Can not function even with aid	13.1	14.0	25.0	20.4
Can function only with aid	16.9	18.4	15.7	17.4
Can function without aid	60.0	61.4	58.5	61.6
Aid/ appliance not tried/nor 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.

III

Disabled Persons- Socio-Economic Profile⁴

Age Profile

A substantial portion of the disabled population of India (53 per cent in rural areas and 55 per cent in urban areas) is in the productive age group of 15-44. Significantly the proportion of disabled population has increased during 1991-2002 for the age groups of 15-44 years for both rural and urban areas. What is even more striking is that a significant proportion of disabled persons are in the age group of 5-14. For the population above 60 years the disability prevalence rate has decreased. (Ref: Table No. 2.1)

Age Distribution (Percentage)
1991-2002

Age Group	2002		1991	
	Rural	Urban	Rural	Urban
Less than 4	3.1	3.0	3.5	3.9
5-14	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 47 th and 58 th in 1991 and 2002 respectively

10. Disabled Persons: Caste Composition

The caste composition of disabled persons in India depicts that a substantial proportion of them were scheduled castes (23 per cent in rural areas and 18 per cent in urban areas). About 8.5 per cent and 2.5 per cent disabled persons were scheduled tribes in rural and urban areas respectively. In terms of the prevalence rate not much variation was noticed between 1991 and 2002 in the urban and rural context. However there was a slight increase in the proportion of scheduled caste disabled persons in the urban areas in 2002 as compared to 1991.

Table No. 2.2
Caste Composition (Percentage) 1991-2002

Social Group	2002		1991	
	Urban	Rural	Urban	Rural
Scheduled Tribes	8.4	2.5	9.4	2.4
Scheduled Castes	23.2	18.4	22.0	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 47 th and 58 th in 1991 and 2002.

12. Disabled Persons, Marital Status:

According to the 2002 Census 43 per cent disabled have never married, while 39 per cent are currently married and a significant 15 per cent are widowed and around 1 per cent are divorced or separated. A very high proportion of disabled persons, were never married and that percentage has also increased from 38.3 per cent to 43.2 per cent in rural areas between 1991-2002. Significantly 27.8 per cent and 32.4 per cent disabled persons were never married in the ages above 15 years in rural and urban areas respectively in 2002. (Ref: Table No. 2.3)

Table No. 2.3
Marital Status (Percentage) 1991-2002

Social Group	2002		1991	
	Urban	Rural	Urban	Rural
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 47 th and 58 th in 1991 and 2002.

11 Disabled Persons, Literacy level:

According to the NSSO records both 1991 and 2002, 59 per cent of disabled persons in rural areas and 40 per cent disabled persons in the 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 per cent of disabled persons in rural areas and 17 per cent disabled persons in urban areas were educated up to secondary level or above. Only 1.5 per cent of disabled persons in rural areas and 3.6 per cent in the urban areas has received any vocation training through the government initiative.

Table: 2.4
Educational Status

Educational Status	2002		1991	
	Rural	Urban	Rural	Urban
Non-literate	59.0	40.0	70.1	46.2
Primary	24.4	28.8	20.3	29.8
Middle	9.7	13.7	5.3	11.0
Secondary	3.8	7.8	2.3	6.4
Higher-secondary	2.1	5.1	0.8	2.8
Graduation and above	1.0	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

13. Disabled persons and work status:

According to the 2001 Census about 46 per cent 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 per cent of all Government jobs for the disabled. Only 1.8 per cent disabled persons in the rural areas and 7.3 per cent in the urban areas are with any regular employer in 2002. This decline in the work force is noticed in all sections, like, self-employed, agricultural sector and casual labors.

Table No. 2.5
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	2.0	7.7
Casual Employee	8.8	4.9	9.5	5.5
Attending Educational Institution	13.7	16.0	11.0	17.7
Attending Domestic Work	12.8	13.5	13.5	15.2
Begging	0.5	0.9	0.7	0.8
No Work	46.0	44.5	45.7	41.1
ALL	14,085,000	4,406,000	12,652,000	3,502,000

14. 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 the forms of disability loco motor disability constituted the highest (55.33 per cent) percentage of the disabled, followed by visual disability at 24.79 per cent, hearing disability at 20.06 per cent and speech disability at 12.17 per cent in 1991.

The 2002 Census provided more detailed information about the disabled in India. It included mental disability along with the other criteria's 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 per cent of the disabled were suffering from loco motor disability while 10.88 per cent were blind, 4.39 per cent were people with low vision, 16.55 were having hearing impairment, 11.65 per cent had speech disability, 5.37 per cent were mentally retarded and 5.95 per cent were mentally ill. The trends showed a significant rise in the loco motor disability among all other forms. Whereas, there have been declining trends in speech, hearing and visual impairment. Mentally disabled persons constitute 11.33 per cent of the total disabled persons in out of which 5.37 per cent were mentally retarded with learning and other disabilities, and 5.95 per cent were mentally ill. (Ref: Table: 2.6)

Table: 2.6
Type and Magnitude of Disability

Disability Type	2002		1991	
	Numbers	per cent age to all disabled	Numbers	per cent 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	57.50	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 per cent as multiple disabilities was also recorded for a large number of disabled persons.

IV Problems Encountered

1. Access: Accessibility is fundamental to realization and enjoyment of any right. Though the earlier definition of access included only 'physical access' and took only architectural barrier 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, this understanding of access provides the scope for not only full personality development but also participation in social and political life.

A close look at the access related issues brings into light that in spite of international conventions and domestic legislations access is an issue of concern. Access to public transport, toilets, hospitals, government offices, public spaces like parks, educational institutions, places of worship are still in accessible to people. Still whatever interventions are made are restricted to the physical access. The 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.

2. Employment: According to the Census 2002, Disabled people constitute at least 6 per cent of our population; still their basic needs for social security, individual

dignity and meaning full employment remain unmet. They are at the mercy of the government and the civil society, which have a lacsidical attitude towards them. The disability Act 1995 provides for 3 per cent reservation in all categories of jobs in government sector. Though it has been three years to this notification, its implementation is still not complete.

3. Education: Education is yet another thing crucial for the persons with disability. In India education to the disabled is not provided as part of the mainstream but through other isolated institutions which operate on a service and charity mode. Most of the times these institutions are not fully integrated into the mainstream education system. 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 like 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.

4. Discrimination: Persons with disability suffer from both social and material disability. The 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.

V

The Most Vulnerable

a) Children with Disability:

According to the Child Relief and You (CRY), the figures on disability are as follows: 3 percent of India's children are estimated to be mentally challenged. Of these 15 million children are below the age of 10 years. 10 million are boys and 5 million are girls. 20 percent of the disabled children are urban and 80 per cent are in rural areas. 60 percent are males and 40 percent are females.

It is estimated that 1 child in every 10 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.⁵

The data available on the 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 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 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.⁶

Children with disability and their health

a. Immunization

In the context of protection of children from disabilities immunization is considered as 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 2 estimates, full vaccination cover is higher for urban areas (52 per cent) as compared to rural areas (29 per cent). A similar comparison can be drawn between boys (43 per cent) and girls (41 per cent) in both rural and urban areas. This indicates that 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 per cent), scheduled caste 40 per cent, scheduled tribe 26 per cent and other backward caste 40 per cent. According to the NHFS data and other government records the vaccination cover for pulse polio is the higher than the others like measles and diphtheria. According to the Government records the total percentage of the immunized children in India is 53 per cent, the un immunized in India make up for 1/3rd 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 as per the last survey of the Government. According to review conducted in 2004, by the Health Ministry in collaboration with AIIMS, CDC, Atlanta, WHO, Unicef, USAID, ICMR and other institutions, about 95 per cent of un immunized children are concentrated in 15 States. The Southern States are much better off than the Northern States. 40 per cent of the un immunized live in Uttar Pradesh and Bihar. Uttar Pradesh leads the charts with 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 has not yet been made universal. There is lack of both political will and sensitization towards it.

b. 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 2 data shows that in India as a whole only 3 out of 10 children age 12-15 received at least one dose of vitamin A, and only 17 percent received a dose within the past six months. This reflects that large majority of children in India still do not receive vitamin A supplementation at all and even fewer children receive vitamin A supplementation regularly. (NHFS-2)

Education of the disabled children

In India where education of the non-disabled is challenge to achieve, the education scenario for the disabled children reflects a rather grim picture. The issues which are crucial for the education of disabled children which need a closure look are the availability special schools, access to schools, trained teachers, availability of educational material for the disabled.

The situation of special schools in India is quite appalling. According to the Sixth All India Educational Survey report, of the 6,461 town and cities, only 334 or 5.1 percent towns and cities have the facility of special schools catering to severe 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. Of these some schools may be dedicated exclusively to a particular disability, while others cater to needs of children suffering from different types of disability.

Categorization of these schools according to there specialization indicates that 215 are for the visually impaired, 290 for hearing impaired, 190 for orthopaedical problems, 173 for the mentally challenged and 60 for other locomotive disabilities. The facility of special education is rather skewed. Data shows that of a total number of 586,465 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 pwercent of these schools are in the States of Andhra Pradesh, Bihar, Gujarat, Haryana, Kerala, Madhya Pradesh, Maharashtra, Orissa and Union Territory of Andaman and Nicobar Islands. Of the 272 available schools, 55 are for boys, 11 for girls and the rest are for co education. Categorization of these schools in terms of there specialization shows that 73 are for the visually challenged, 128 for speech and hearing impaired, 70 are for mentally challenged and 25 cater to various other handicaps.

In the absence of adequate number of special schools the other issue, which requires discussion, is of integration of education of the disabled children in mainstream education. In fact, the Universal Education program envisages to universalize 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 only inadequate. The teacher training programs which provide disability training emphasize that specialization should be sought for single type of disability. But this is a very expensive proposition for the Indian situation. So the situation demands that either the training programs should offer multi disability training or the general teachers training courses are re modeled in a way to equip all the teachers tom 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 the 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.

Policies and Programs for Disabled Children⁷

1. 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 any 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;
- Provisions for the training and education of children with severe disabilities in special schools;
- Vocational training as being as part of education for the disabled;
- Reorientation of teachers training programmes to include education of disabled.

2. Integrated Education for Disabled Children:

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.

3. The National Open Schools

The National Open School (NOS) is a program of open education, which provides the opportunity to intellectually challenged children to join the schools. There are special syllabuses for these children and also a provision for vocational training.

4. The District Primary Education Program:

DPEP is 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, teaching aids, infrastructural the facility etc.

b) Disability and 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 the account of being disabled and most of the times because of poverty. The excerpt of an interview mentioned below provides deeper insight into the fact that, though men and women suffer equally because of disability, some problems are exclusively women's problems.

“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 it off 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. Where as 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.”⁸

In India disabled women constitute around 42 per cent 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 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.”⁹

Education:

As mentioned earlier as education is crucial to development so is the case with disabled women. 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 of 0-14 years, approximately 3 per cent of the children are disabled. The data shows that the prevalence rate for physical disability was observed to be higher among boys i.e. 22.7/1000 than girls i.e. 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 under reporting of girl child with disability because of the social stigma attached to it.

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 the Visually Handicapped, 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.

According to another study in Raichur District of Karnataka, literacy rate of such women was 7 percent as compared to the general literacy rate of the State of 46 percent.

Disabled girls have multiple difficulties in availing 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 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 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 the 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. The civil society has a great challenge ahead regarding the empowerment of the disabled girl.

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. 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 per cent and 89 per cent males and females respectively in rural areas and 63.5 per cent and 90.5 per cent males and females respectively in urban areas were out of labour force. Though the overall employment scenario for the disabled persons is bad it is more unfavorable in case of disabled women.

Disabled women have limited scope to get employment because of the multiple problems like stigma and discrimination, physical access, lack of technical expertise etc. There are also a lot of problems for disabled women to be self-employed. They face problems in obtaining raw materials and marketing their products, so they are left with no other option but to take up piecework. Evidences show that since age's disabled women have been doing routine and ill paid jobs like 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.

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.

India where marriages are universal, they are also considered as means of social acceptability and provide social status to the women. Marriages for disabled persons are a difficult proposition particularly for disabled women. Here again stigma and discrimination prevents families from making marital relations with disabled persons. According to the census 2000, 43 per cent disabled have never married, while 39 per cent are currently married and a significant 15 per cent are widowed and around 1 per cent are divorced or separated. Not much variation was recorded in the marital status of disabled population both in case of the rural and urban areas. But what is surprising is that the proportion of disabled persons, who never married has increased from 38.3 per cent to 43.2 per cent in rural areas between 1991-2002. Significantly 27.8 per cent and 32.4 per cent 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 the society in marrying persons with disability. Data on the current living arrangement of the disabled persons reveals that about 3 per cent disabled persons were living alone and 6-7 per cent were staying with relations or non-relations. Only 5.5 per cent -disabled people were staying only with spouses and another 32 per cent were staying together with spouses and other. Significantly nearly 38-40 per cent-disabled persons were staying with parents without spouses. These women are looked 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, managers in institutions etc. 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 less.

A study conducted by (Emily.et.al 2002) demonstrated culturally appropriate form independent group living to have 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 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. 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).

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.

Aging and Disability have a close association; 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.¹⁰

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. 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 eg, some locomotor disabilities are brought about by strokes, a weakening musculo-skeletal system can cause osteoarthritis, which affects movement. About 41 per cent percent of rural elderly and about 37 percent of urban elderly suffer from one or other disabilities. (NSSO 2002). Among all the disabilities, visual disability had highest incidence followed by locomotor disability. Most visual impairment among elderly are due to cataract and glaucoma (25 percent). The incidence of blindness is higher among women than 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 diarrhoea and excessive exposure to the ultraviolet rays.

This fact is corroborated by the findings of the World Bank Study 1994, which states that 90 per cent of persons above age 65 exhibited signs of cataract. Other micro studies also present similar findings. A study conducted in Tamil Nadu found that visual disability 89 per cent 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 Korean elderly. According to the NSS survey, 40 percent of the elderly reported suffering from at least one disability - slightly higher among females 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 very 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.

Mental Health

Five out of ten leading causes of disability and premature death worldwide are psychiatric conditions.¹¹ 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. 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 are often provided with a cocktail of treatments for example, sleeping pill for sleep problems, vitamins for tiredness etc. 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, typically leading to death after five to seven years after diagnosis.¹²

In terms of health care provisions to persons with mental illness the State doesn't 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 per cent of its total health budget on mental health (WHO 2001a).

India also has high rates of suicides- 89,000 persons committed suicide in 1995, increasing to 96,000 in 1997 and 104,000 in 1998, which is a 25 per cent 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 per cent 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 per cent to 10 per cent. 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 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 10,000 population. Of these, a substantial portion (0.20) are in the mental health hospitals occupied by long stay patients

and really accessible to the general population. There is also shortage of mental health professionals. India has 0.4 psychiatrists, 0.04 psychiatrist nurses, 0.02 psychologists and 0.02 social workers per 100,000 population.

In terms of access to health care among mental health patients gender is the major determining factor. According to study by Vindhya, Kiranmayi, and Vijaylaxmi (2001) male patients outnumbered females in both the hospitals from where data was collected. More than 50 per cent of the patients in both the facilities were male, the gender gap being wider for the public hospital. (Out of total bed strength of 300 in the public hospital, 225 were for men and the remaining 75 for women). Evidences from this study show that the mental health care facilities are not geared towards minor and more common illnesses like depression etc. Whatever facilities are available are in the form of electrotherapy and chemotherapy for severe mental disorders. More sustained treatments like counseling are 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 to that.¹³ 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 100,000 population). 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.

Disability and HIV/AIDS

The sexual and reproductive health of the disabled is an area, which is majorly ignored. They have very little access to reproductive and sexual health and maternal health services. This is primarily because of physical inaccessibility to such services, lack of information about the health facilities and health professional's lack of knowledge about disability.

The disabled persons are considered 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 full 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 Swabhimani, a Disabled People's Organization in Orissa, 25 percent of the intellectually disabled women had been raped.

Disabled people are at a greater risk of getting affected by HIV/AIDS often more than the non-disabled persons. This happens because, they are more vulnerable sexual assault, they are not excluded from AIDS awareness programs, counseling and testing. According to studies conducted in Tanzania and Zimbabwe, most of the disabled people were not

invited to HIV/AIDS awareness training or events. Prejudices and lack of knowledge about the sexual health issues of the disabled is the prime reason for this.

VI

Disabled Persons: Human Rights Concerns

Though like all human beings, the disabled also 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."¹⁴

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."¹⁵

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."¹⁶ This Treaty is indeed very significant because it not only mentions economic opportunities but also about greater participation in social, cultural and political life.

Other UN 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 make 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 second Article 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 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 United States and Somalia UNHRC 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 the 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 expressions 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 environments.

- United Nations High Commissioner for Refugees (UNHCR):

The UNHCR has 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 impairments 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 of 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, with its concern about physical barriers and general access to the physical environment; the United Nations Industrial Development Organisation's activities cover the production of Drugs essential for prevention of disability as well as of technical devices for the disabled.

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 people have different needs because of physiological, social, historical or any other reason and there can’t 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 Principle of State Policy:** As the name suggests these are directives, which the Constitution provides, to the State along which they should prepare its policies. The Directive principles are not justifiable as the fundamental rights but a set of very progressive principles, which upholds the spirit of human rights. Some directive principles specially mention the rights of persons with Disability. For e.g. 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. Article 46 and 47 also has the potential for raising the standard of living education and development of persons with disability.

VII

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 there 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
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.

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 per cent 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 etc. Additionally the governments are expected to set up the adequate number of teachers training institution 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 states reservation of 3 per cent 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 taken 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 some thing else.
- The Act doesn't define 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 Education clause in the Act is that it provides the opportunity to every disabled child to dream and demand for education.

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 three 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 this Act is that the entire Act does not have a special chapter on Access. It provides for 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 un friendly.

- Educational opportunities to children don't make sense without enough primary schools admitting disabled children, schools not having enough trained teachers and reading material not available in Braille, sign language interpreters, assistive aids and appliances.

Housing: The law recognizes the right to housing for the disabled persons, whether independent or familial, and the need to provide for it. The Acts aims to make special provisions for the integration of persons with disabilities into the social mainstream. The National Trusts Act was created with a Corpus of 100 crores, for supporting programs that promote independence and address the concerns of those who do not have family support. FN. 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's 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. Persons with learning disability are also not included in this section.

Services for the Disabled

Government Rehabilitation Services¹⁷¹⁸

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 socio economic 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, etc.

- National Information Center on Disability & 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 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 & 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 such great pronouncements in the national and international documents rights of disabled has remained in paper. The government policies, legislative actions, schemes, rehabilitation programs etc show that the government is committed to the rights of the disabled people but in practice all this is far from the reality. The governments' 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 e.g. 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.

IX

Disability is preventable:

1. 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.
2. 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.
3. Lack of Vitamin A cause millions of children to lose their eyesight each year. Proper and adequate nutrition can prevent this from happening.
4. A large proportion of people are disabled due to accidents. Traffic accidents alone account for 30 million disabilities world over. Another 45 per cent of the injuries take place at home and about 19 per cent happen at work out side home.
5. 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.
6. 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.
7. Disability is also caused by drug and alcohol abuse.
8. Wars are disabling. They are fought for human interest and can kill and impair millions. Yet the world spends billions on wars every year.
9. 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.
10. 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.

Recommendations

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.

Mental Health

- 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 the 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. An inter- sectoral collaboration between the health system, the civil society groups, the public and private sector.
- No efforts in addressing the problem will be successful without the participation of the community. It is necessary to involve the community in designing and delivery of the services. If community participation is sought then the problems of stigma and discrimination can also be managed.
- Last but not the least, 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 like 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 once 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 of human rights violations 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 per cent 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 per cent of blindness is either preventable or treatable. The WHO also estimates that around 50 per cent 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.

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² The Persons with Disability Act 1995

³ This section is drawn from NSSO 1991 & 2002

⁴ Ibid

⁵ The Disabled Child, Advocacy Internet, May- June,2003

⁶ NCAER, 1999

⁷ Report of the Ministry of Social Justice 2000

⁸ 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.

⁹ Irene Feika, Deputy Chairperson of Underrepresented Groups, Disabled People International.

¹⁰ Rao, Equality to women with disability,2004.

¹¹ World Health Organisation 2002

¹² Pathare, Soumitra

¹³ Davar,B.V. (1999).

¹⁴ European Social Charter 1961

¹⁵ Ibid

¹⁶ Treaty of Amsterdam

¹⁷ Ministry of Social Justice 2004

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