

DISABILITY

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Background

An estimated 10% of the world's population experiences some form of disability or impairment (WHO Action Plan 2006-2011). The term 'disability' has many different meanings; the *Global Burden of Disease* (GBD) however, uses the term disability to refer to loss of health, where health is conceptualized in terms of functioning capacity in a set of health domains such as mobility, cognition, hearing and vision (WHO 2004). The number of people with disabilities is increasing due to population growth, ageing, emergence of chronic diseases and medical advances that preserve and prolong life, creating overwhelming demands for health and rehabilitation services (Srivastava and Khan 2008). In South-east Asia, the prevalence of disability ranges from 1.5 – 21.3% of the total population, depending on definition and severity of disability (Mont 2007). Despite the increase in prevalence of disability worldwide, due to various reasons, not much attention has been paid to its evaluation, management and prevention (WHO 2002).

This fact sheet will attempt to describe disability and present data on the prevalence and distribution of disability globally as well as in India. The various causes of disability and the risk factors of various types of disabilities will be reviewed. Current management practices and government policies for disability in India will be presented and attempts will be made to identify the gaps in its knowledge and research.

Prevalence of disability

Global Prevalence:

*4%-10% (Yeo 2001)

*4% in developing countries and 7% in industrialised countries (Metts 2000)

India and South Asia Prevalence:

*1.5-21.3% in WHO South East Asia member countries (<http://www.searo.who.int/>)

*1.8% -2.2% for India (Census 2001, NSSO 2002)

What is Disability?

The World Health Organization (WHO 1976) draws on a three-fold distinction between impairment, disability and handicap:

- **Impairment** is any loss or abnormality of psychological, physiological or anatomical structure or function.
- **Disability** is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.
- **Handicap** is a disadvantage, for a given individual, resulting from impairment or a disability, which prevents the fulfilment of a role that is considered normal (depending on age, sex and social and cultural factors) for that individual.

In 1980, the WHO reaffirmed this classification (WHO 1980), and in 2001 issued the *International Classification of Functioning, Disability and Health* (ICF). The ICF distinguishes between body functions (physiological or psychological, e.g. vision) and body structures (anatomical parts, e.g. the eye and related structures) (WHO 2002). Impairment in bodily structure or function is defined as involving an anomaly, defect, loss or other significant deviation from certain generally accepted population standards, which may fluctuate over time (WHO 2002). Since an individual's functioning and disability occur in a context, the ICF also includes a list of environmental factors. The ICF lists 9 broad domains of functioning which can be affected (WHO 2002):

- Learning and applying knowledge
- General tasks and demands
- Communication
- Mobility
- Self-care
- Domestic life
- Interpersonal interactions and relationships
- Major life areas
- Community, social and civic life

The ICF was officially endorsed by all 191 WHO Member States in the Fifty-fourth World Health Assembly on 22 May 2001 (resolution WHA 54.21).

Prevalence of disability

The *United Nations* (UN) *Disability Statistic's Compendium* (DISTAT) noted that disability rates are not comparable across the world because of differences in survey design, definitions, concepts and methods, as the proportion of disabled people per national population varies between less than 1% in Peru and 21% in Austria (UN 1990). In 1981 UN/WHO studies estimated that on average 10% of all national populations were disabled. However in 1992, this

estimate was modified to 4% for developing countries and 7% for industrialised countries (Metts 2000). There is no consensus as to which figures to use, for example: The UN Development Program estimates a total global proportion of disabled people of 5% (Coleridge 1993), USAID at 10% and DFID at 4-7% (Yeo 2001). Depending on survey or census data different estimates are derived across the world with the United States census data estimating a disability prevalence rate of 20% in 2000 and a survey data estimating a 5% rate in China in 1987. (Mont 2007; Table 1) Differences are also seen across member states of the WHO South-East Asian Region (Table 2).

Table 1: Prevalence of disability in the different countries of the world

<u>Censuses</u>			<u>Surveys</u>		
Country	Year	Percent of population with a disability	Country	Year	Percent of population with a disability
United States	2000	19.4	New Zealand	1996	20.0
Canada	2001	18.5	Australia	2000	20.0
Brazil	2000	14.5	Uruguay	1992	16.0
United Kingdom	1991	12.2	Spain	1986	15.0
Poland	1988	10.0	Austria	1986	14.4
Ethiopia	1984	3.8	Zambia	2006	13.1
Uganda	2001	3.5	Sweden	1988	12.1
Mali	1987	2.7	Ecuador	2005	12.1
Mexico	2000	2.3	Netherlands	1986	11.6
Botswana	1991	2.2	Nicaragua	2003	10.3
Chile	1992	2.2	Germany	1992	8.4
India	2001	2.1	China	1987	5.0
Colombia	1993	1.8	Italy	1994	5.0
Bangladesh	1982	0.8	Egypt	1996	4.4
Kenya	1987	0.7			

Source: Mont (2007)

In the 2001 and 2002 survey data, Bangladesh had the highest prevalence rates of 5.6% compared with a 1.5% rate in Timor-Leste. (Table 2) Census data suggests that Thailand had a prevalence rate for disability in 2007 of 2.9% compared with a rate of 1.6 in Sri Lanka in 2001.

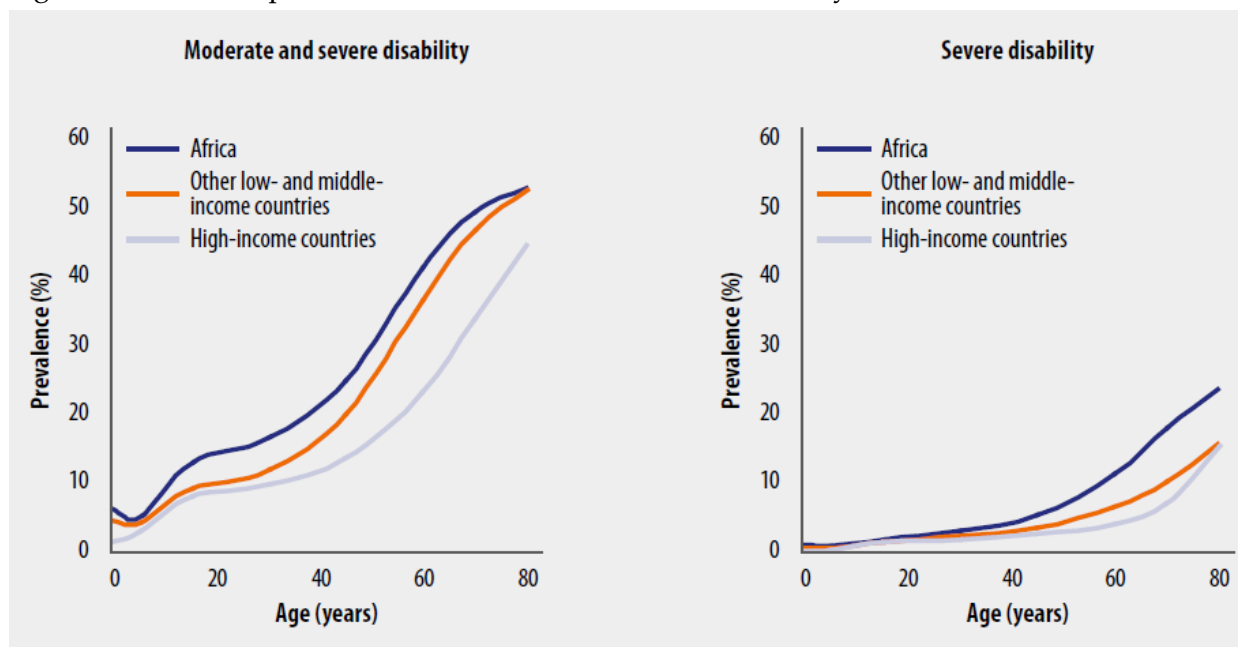
Table 2: Prevalence of disability in the Member countries of the WHO South-East Asia Region

Country	Prevalence	Year	Source
Bangladesh	5.6%	2001	National Forum of Organizations Working With The Disabled Handicap International survey.
Bhutan	3.5%	2005	UN Economic & Social Commission (UNESCO) for Asia and the Pacific
India	1.8%	2002	UNESCO for Asia and the Pacific
Indonesia	21.3%	2007	Ministry of Health, Republic of Indonesia
Maldives	3.4%	2003	UNESCO for Asia and the Pacific
Myanmar	2%	2007	Ministry of Health
Nepal	1.6%	2001	UNESCO for Asia and the Pacific
Sri Lanka	1.6%	2001	National Statistical Office
Thailand	2.9%	2007	National Statistical Office
Timor-Leste	1.5%	2002	UNESCO for Asia and the Pacific

Source: http://www.searo.who.int/en/Section1174/Section1461_15167.htm#table2

WHO estimates of global prevalence of moderate and severe disability, as defined by the *Global Burden of Disease*, is expected to increase as depicted in Figure 1 (WHO 2004).

Figure 1: Estimated prevalence of moderate and severe disability in the world 2004



Source: WHO (2004)

Prevalence of Disability in India

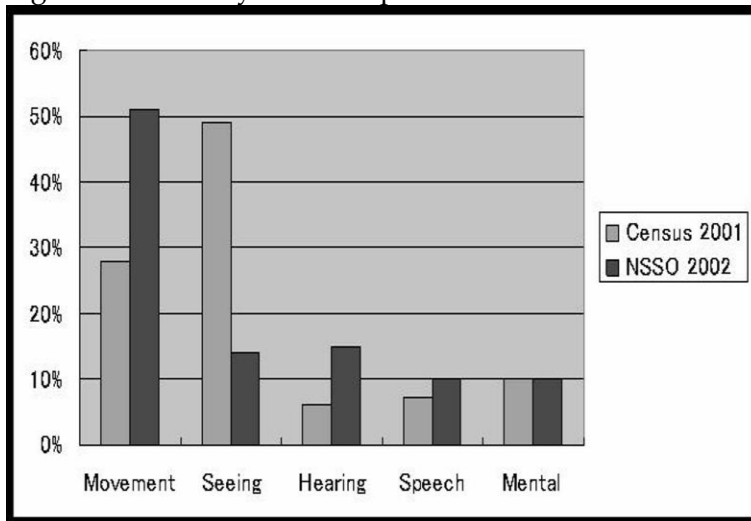
Different prevalence rates for disability are available in India. According to the *Census 2001*, there are 2.19 thousand people with disabilities in India who constitute 2.13 % of the total population (Census 2001). Out of the 21,906,769 people with disabilities, 12,605,635 are males and 9,301,134 females and this includes persons with visual, hearing, speech, locomotor and mental disabilities (Census 2001).

In contrast, the *National Sample Survey Organization* (NSSO) estimated that the number of persons with disabilities in India is 1.8% (49-90 million) of the Indian population (NSSO 2002), that 75% of persons with disabilities live in rural areas, 49% of the disabled population is literate and only 34% are employed (NSSO 2002). NSSO also includes the persons with visual, hearing, speech, locomotor and mental disabilities, but the distribution in each category according to the two surveys differs drastically (Table 3 and Figure 2). The difference in estimates of Census (2001) and NSSO (2002) for different types of disabilities can be explained by the lack of universal definitions and criteria of disabilities used during the surveys.

Table 3: Prevalence of different types of disability in India

Type of Disability	Census of India (2001)	NSSO (2002)
Movement (Locomotor)	28%	51%
Seeing (Visual)	49%	14%
Hearing	6%	15%
Speech	7%	10%
Mental	10%	10%

Figure 2: Disability data comparison between Census 2001 and NSSO 2002



Census 2001 v/s NSSO 2002

Source: <http://www.disabilityindia.com/html/facts.html>

About 10.63 per cent of the disabled persons suffer from more than one type of disability. Prevalence rates have shown declining trends during 1991-2002 for all disability types except locomotor disability. Significant decline was registered for visually impaired persons during 1991-2002 (NSSO 2002).

Patel et al. (2009) using NSSO 2002 data, observed that locomotor disabilities are the most prevalent type of disabilities affecting of all ages in India. Mental disabilities are the highest in the working age population, whereas visual and hearing disabilities are the highest in the aged. Further, onset of locomotor and speech disabilities mainly occur at early ages, whereas onset of visual and hearing disabilities are highly concentrated at later ages. Onset of mental disabilities peaks at early ages and younger working age population. Severe disability is broadly concentrated at later ages (Patel et al. 2009).

In addition to the Census of India and NSSO there are also other studies which report in disability rates for different parts of India. These are summarized in Table 4.

Table 4: Prevalence of Disability in various states of India

Region	Reference	Major findings
Karnataka	Ganesh et al. (2008)	Prevalence = 6.3%. 80% of the disabled had multiple disabilities. Knowledge and occupation plays a major role as determinants of disability. Chronic medical conditions are also more common among disabled.
Karnataka	Pati (2004)	Prevalence rate = 2.02%, higher in 45-59 years age groups, higher in females (2.14%) than males (1.89%). Locomotor disability was the most common..
Karnataka	Kumar et al. (2008)	Prevalence of mental disability = 2.3%, more prevalent among females (3.1%) than males (1.5%), significantly higher among elderly people and illiterates.
Kerela	Mini (2006)	Prevalence rate = 2.7%. Highest number of visually disabled followed by movement disability. Literacy rate = 67% among the disabled people, otherwise the state highest literacy rate of 90.9%. The male-female gap in literacy rate of general population is 6.5 which widens to 15.8 among the disabled population.
Chandigarh	Singh (2008)	Prevalence rate = 4.8%, disability rate significantly more in aged 55 years or more (31%) compared to 25-54 years (5.4%) and <25 years (0.1%) (p<0.001). Rates were higher in females compared to males (p<0.001).
Delhi, Jaipur, Lucknow	ICMR (2007)	Disability rates in children below 6 years of age were 8.8 per 1000 in Delhi, 6.5 per 1000 on Jaipur & 12.6 per 1000 in Lucknow.

Gender and region specific distribution

Between the two sexes, the prevalence of disability was marginally higher among males than among females with a prevalence rate for males at 2% and for women 1.5% (Census 2001; NSSO 2002). According to NSSO (2002), about 8.4% and 6.1% of the total estimated households in rural and urban India, respectively, reported to have at least one disabled person. Among the rural residents, the prevalence of disability was 1.85% and that among the urban was 1.50%. Table 5 presents the actual numbers. The distribution of different types of disabilities among the

urban and rural areas is depicted in Figure 3 which indicates that locomotor disability is the most prevalent type.

Table 5: Estimated number (in '000) of disabled persons by type of disability and sex for rural and urban India

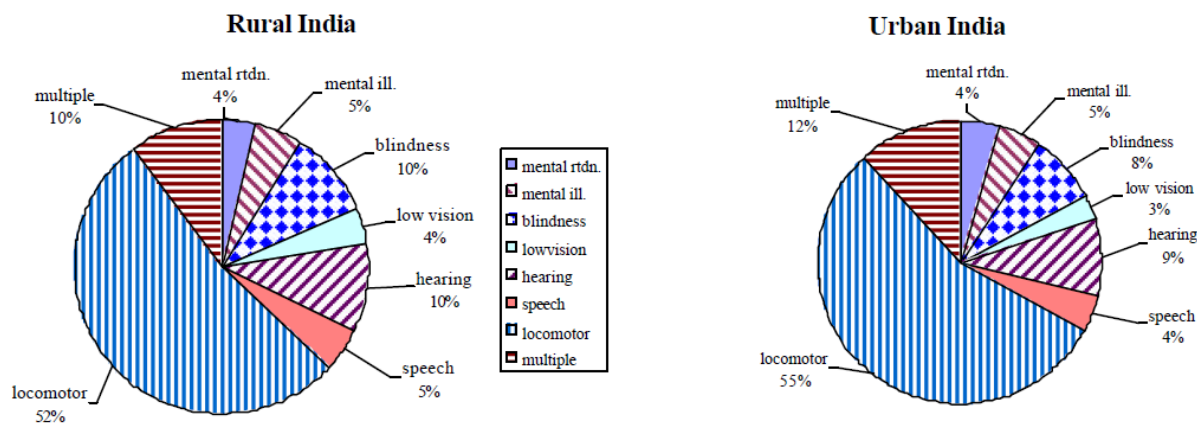
type of disability	rural			urban		
	male	female	persons	male	female	persons
(1)	(2)	(3)	(4)	(5)	(6)	(7)
any disability**	83102	57748	140850	25811	18249	44060
<i>mental disability:</i>						
mental retardation	4434	2561	6995	1824	1128	2951
mental illness	5022	3377	8399	1623	988	2611
<i>Physical disability:</i>						
<i>visual disability:</i>						
blindness	7494	8536	16030	1793	2311	4104
low vision	2982	3563	6545	711	877	1588
hearing disability	12516	11171	23687	3617	3313	6930
speech disability	9495	6532	16027	3416	2102	5518
locomotor disability	49987	29839	79826	16352	10162	26514
estd. (00) total persons	3923611	3711319	7634930	1545555	1391996	2937551

* estimates are obtained by using survey proportions on the projected population.

** at least one of mental, visual, hearing, speech and locomotor disability.

Source: NSSO (2002)

Figure 3: Percentage distribution of disabled persons by type of disability in rural and urban India

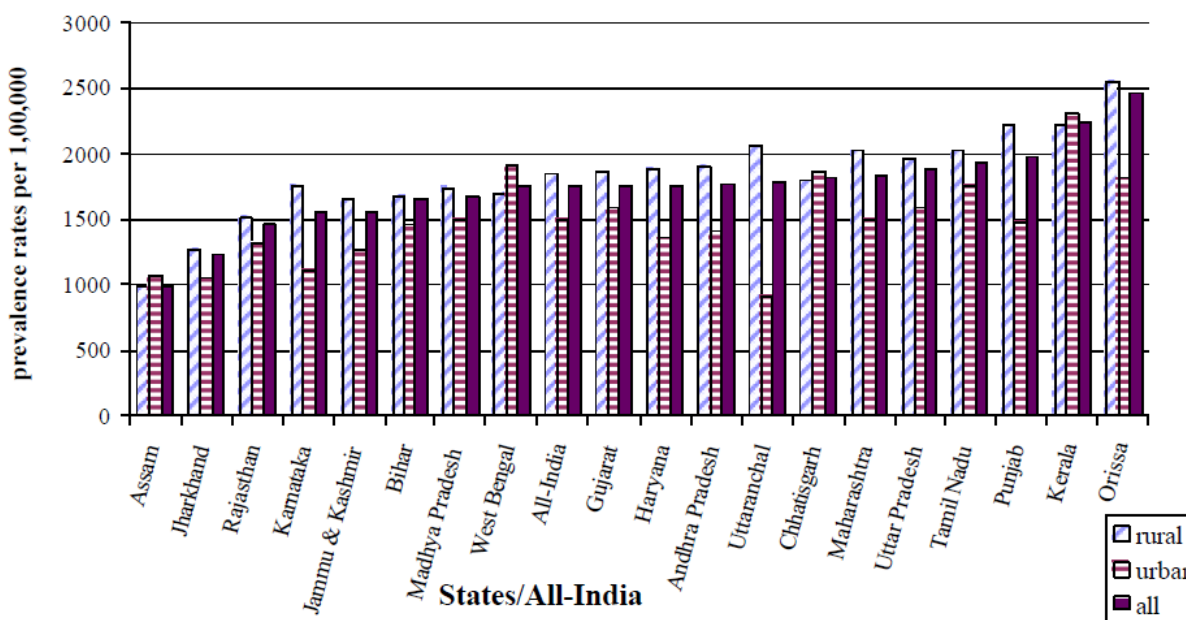


Source: NSSO (2002)

The inter-state prevalence rates for disability vary and variations are also observed between urban and rural areas. (Figure 4) In the rural areas the disability prevalence rates ranges from 0.67% in Delhi to 2.71% in Himachal Pradesh whilst in the urban areas it ranges from 0.52% in Delhi to 2.61% in Lakshadweep (excluding Arunachal Pradesh where the rate was only 27 per

1,000,000). The prevalence rates among males were higher than among females in all the states (NSSO 2002).

Figure 4: Prevalence rates of disability on major Indian states



Source: NSSO (2002)

Age specific distribution

Table 6 indicates a decline in prevalence of different disability types in age groups of less than 15 years and above 45 years (NSSO 2002). It illustrates an increasing trend of prevalence rate for locomotor impairment for the 15-44 age groups.

Incidence of disability in India

In 2002, the NSSO estimated that the incidence rates for males were 77 and 75 per 100,000 respectively in rural and urban India as against 61 and 58 per 100,000 respectively among females during 2001-2002. (NSSO 2002) Urban/rural differences varied, ranging from 2 to 117 per 100,000 persons in rural India and from 11 to 132 per 100,000 persons in urban India. The incidence rate was highest in Andhra Pradesh and lowest in Assam (Figure 5) (NSSO 2002). Incidence rates have declined during 1991-2002 for all types of disability groups in lower and high age groups, however, the incidence rates for locomotor disabilities among the age groups of 15-29 years have increased.(NSSO 2002)

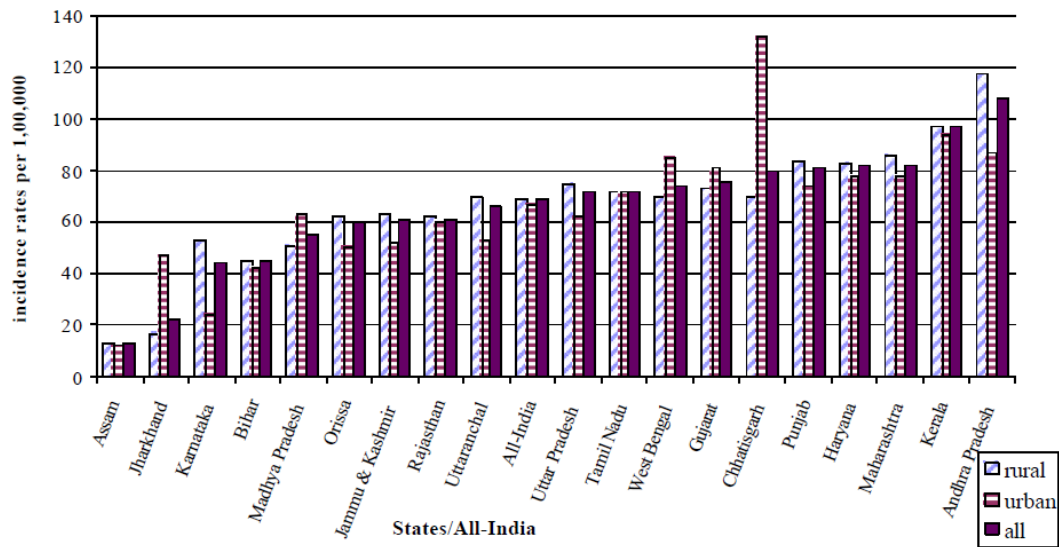
Table 6: Age and sex differentials in different types of disability in India

Types of disability***	Age								
	<15			15-59			60+		
	Male	Female	N	Male	Female	N	Male	Female	N
Mental	63.0	37.0	2872	62.2	37.8	7665	47.1	52.9	745
Visual	53.2	46.8	925	54.8	45.2	3748	41.9	58.1	6250
Hearing	55.6	44.4	2036	54.4	45.6	6153	50.3	49.7	4605
Speech	59.7	40.3	3809	62.1	37.9	5452	57.0	43.0	697
Locomotor	60.8	39.2	9082	66.6	33.4	24392	56.3	43.7	8314
Total	60.0	40.0	18724	62.9	37.1	47410	50.2	49.8	20611

Note: Chi-square test (***) 1% level of significance)

Source: Patel (2009)

Figure 5: Incidence rates of disability in major Indian states



Source: NSSO (2002)

Poverty and Disability

The British *Department for International Development* (DFID) has recognized that, 'disability is a major cause of social exclusion and it is both the cause and consequence of poverty' (DFID 2000). Recent World Bank studies contend that "half a billion disabled people are undisputedly amongst the poorest of the poor" (Metts 2000) and are estimated to comprise "15 to 20% of the poorest in developing countries" (Elwan 1999). Yeo argues that the relationship of chronic poverty with disability and impairment is dependent upon the disabled individual's experience of discrimination from birth (or from time of disablement) which leads to lack of resources, lower expectations, poor health and poor education. In turn, the chronic poverty conditions enhance the risk of illness, injury and impairment, and thus disability.(Yeo 2001) It is also clear from several studies that the prevalence of disability is lower in relatively privileged socio-economic groups in both developed and developing countries. (Parker et al 1994; Melzer et al 2000; Rautio et al 2001; Seeman et al 2001)

It is argued that poverty is the biggest cause of disability in India because disabled persons are more likely to suffer from malnutrition, live in crowded & unsanitary conditions (increasing risk of infectious disease) have limited access to medical care, be poorly educated, not immunise their children, lack adequate care during pregnancy and birth and have multiple pregnancies. (Thomas 2005a) A South Indian study was able to demonstrate that disability was found to be more common among the children of families with monthly incomes of US\$ 10-15 (17.2%) when compared with children of families with monthly incomes of US\$ 32-42 (8.4%); odds ratio (OR) of 2.36 (95% CI = 1.08-3.64). The bivariate and multiple logistic regression analysis showed a significant and meaningful relationship between area of residence as an indicator of social status and childhood disability (OR = 2.39; 95% CI = 1.85-3.09). The results suggested that comparatively small differences in social status can be associated with significant differences in the health status. (Natale et al 1992)

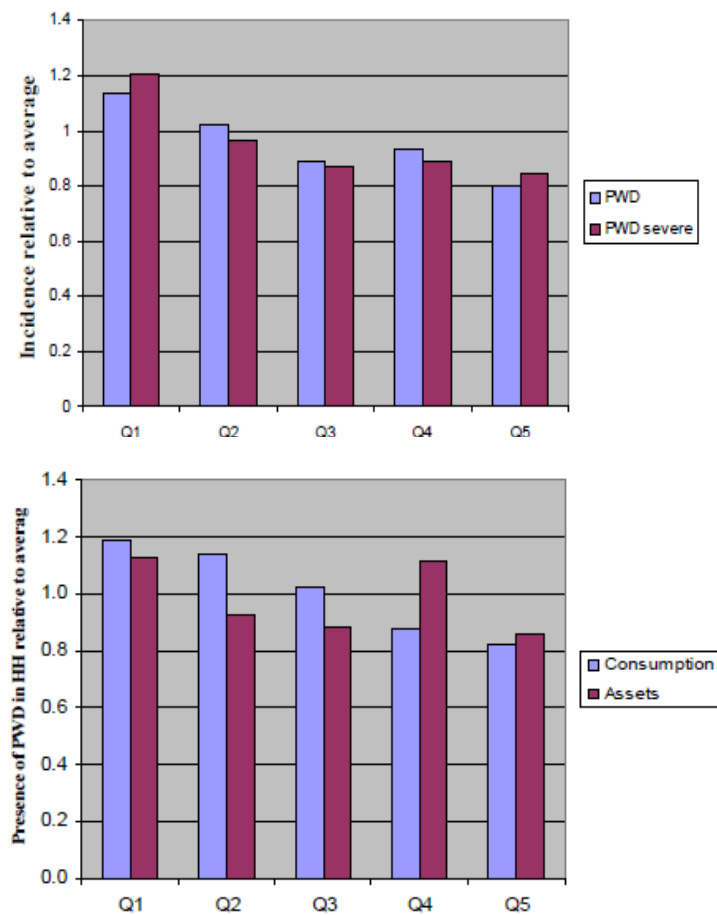
Similarly, the World Bank reported in 2007 that in India, disability is associated with lower socio-economic status. Survey data from villages in Uttar Pradesh and Tamil Nadu in 2005 showed a clear decline in the proportion of people with disabilities of all severity as the wealth of households rises (figure 6) and a similar pattern can be seen where the measure of disability is by community identification of whether or not a household has a disabled member (World Bank Report 2007).

Socio-Economic burden of disability

The financial impact of disablement in a child on the family/household is significant. A recent cross-sectional study conducted in Delhi reveals that locomotor disability poses a severe socio-economic burden on parents of the disabled children (Laskar et al 2010). More specifically, a south Indian study evaluating the economic burden of families with disabled children indicated that the mean expenditure of the families with a disabled child was \$254 per year compared with an expenditure of \$181 per year of families with normal children, ($t= 10.2$, $P<.00001$). (Kandamuthan and Kandamuthan 2004) It further reported that of the disabled children, 80% were not getting any social security payments and 90% had no special concessions for medical

and other educational purposes. Of the mothers of the disabled children, 21% were unemployed as against 12% in the case of normal children. Parents of disabled children estimated that they would require, on average, an additional amount of \$203 per year as social security payments from the Government to meet the essential necessities of their disabled children. (Kandamuthan and Kandamuthan 2004)

Figure 6: Relative share and severity of people with disability by asset quintile in Uttar Pradesh and Tamil Nadu 2005 (top) and Relative household share with people with disability consumption and asset quintiles (bottom)



Source: World Bank report (2007) Q1=poorest and Q5 richest quintiles.

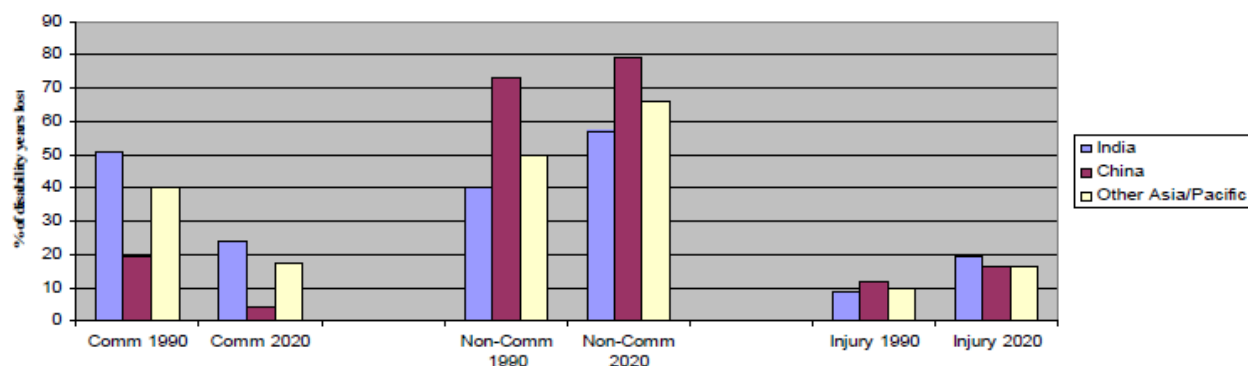
Causes and Risk Factors of Disability

The most common causes of impairment and disability include chronic diseases such as diabetes, cardiovascular disease and cancer; injuries such as those due to road traffic crashes, conflicts, falls, landmines, mental impairments, birth defects, malnutrition, HIV/AIDS and other communicable diseases.

Disability transition

Figure 7 depicts the disability transition in South Asia between 1990-2020. (Murray and Lopez 1997) The pace of transition in India is predicted to be most rapid (World Bank Report 2007) as is the percentage of disability years lost due to non-communicable diseases and injuries from 1990s to 2020s. Between 1990 and 2020, there is predicted to be a halving of disability due to communicable diseases, a doubling of disability years due to injuries/accidents, and a more than 40 percent increase in the share of disability years due to non-communicable diseases (e.g. cardiovascular and stroke). Half the disability rates from non-communicable disease for South Asia are estimated to be due to neuro-psychiatric disorders (mainly mental illness and mental retardation) suggesting that 30 percent of total years lost to disability in India by 2020 could be due to these causes alone.(World Bank 2007)

Figure 7: Disability transition in various Asian countries, 1990-2020



Source: World Bank Report (2007)

The NSSO survey data of 2002 on the various causes of the different types of disability are presented in Tables 7 to 11 (NSSO 2002). Old age, cataract, glaucoma and other eye disease are the main causes of visual problems in India (see Table 8). Similarly old age, ear discharge, other illness and injury other than burns are the main causes of hearing problems (see Table 9). Paralysis, mental illness/retardation, voice disorder and injury other than burns are the main causes for speech problems (see Table 10). Mental disability is found to be mainly due to serious illness during childhood, head injury in childhood and pregnancy and birth related causes (see

Table 11). Home transport agricultural field and other work site-related accidents are the main reasons behind causing injury which leads to disability afterwards.

The World Bank report (2007) similarly provides graphic information on the age of onset of different types of disabilities (based on NSSO 2002) (figure 8). The onset of mental disabilities is concentrated in childhood and the 20-30 age-groups, resulting in the lowest average age of onset. In contrast, visual disabilities are more associated with ageing. While hearing disabilities exhibit a more pronounced dual peak, they are also, on average, subject to later average onset. Both locomotor and speech disabilities are more concentrated in younger ages also, with the highest onset in the early years of life in both cases, and a more noticeable second wave of onset for speech disabilities around age 60.

Table 7: Percentage distribution of causes of locomotor disability by age, India, 2002

Causes of locomotor disability**	Age			Total
	<15	15-59	60+	
Cerebral palsy	1.5	2.2	3.8	2.5
Polio	62.4	31.9	3.4	28.9
Leprosy cured	-	0.9	1.1	0.8
Leprosy not cured	-	1.2	1.7	1.2
Heart stroke	1.3	5.6	15.3	7.5
Arthritis	-	2.3	6.5	3.1
Cardio-respiratory disease	-	0.3	0.7	0.4
Cancer	-	0.3	0.3	0.3
Tuberculosis	-	0.4	-	0.3
Other illness	11.0	12.4	12.6	12.3
Burns	2.7	2.4	0.7	2.0
Injury other than burns	9.8	27.9	29.9	25.7
Medical/surgical intervention	2.4	2.5	1.4	2.2
Old age	-	0.2	12.2	3.3
Not known	4.3	4.7	4.7	4.6
Other reasons	3.2	4.8	5.5	4.7
N	100 (4410)	100 (17865)	100 (7847)	100 (30122)

Note: () indicates number of cases; - indicates number of cases <20; Chi-square test (**5% level of significance)

Source: NSSO (2002)

Table 8: Percentage distribution of causes of visual disability by age, India, 2002

Causes of visual disability**	Age			Total
	<15	15-59	60+	
Sore eyes during the 1 st month of life	-	-	-	0.2
Sore eyes after one month	-	1.3	-	0.6
Severe Diarrhea before the age of 6 years	-	2.1	-	0.9
Cataract	-	14.8	27.8	23.0
Glaucoma	-	4.8	5.7	5.3
Corneal opacity	-	3.0	2.2	2.4
Other eye diseases	31.0	25.2	11.9	16.6
Small pox	8.1	7.2	1.3	3.3
Burns	-	0.8	-	0.3
Injury other than burns	8.4	8.7	2.8	4.8
Medical/surgical intervention	-	3.4	2.6	2.9
Old age	-	3.2	33.8	23.4
Not known	19.4	14.8	6.6	9.5
Other reasons	11.6	10.4	4.6	6.6
N	100 (310)	100 (2819)	100 (6115)	100 (9244)

Note: () indicates number of cases; - indicates number of cases <20; Chi-square test (** 5% level of significance)

Source: NSSO (2002)

Table 9: Percentage distribution of causes of hearing disability by age, India, 2002

Causes of hearing disability**	Age			Total
	<15	15-59	60+	
German measles/rubella	-	1.2	-	0.9
Noise induced hearing loss	-	2.6	1.9	2.1
Ear discharge	36.5	19.6	8.5	14.5
Other illness	32.1	31.4	18.9	24.6
Burns	-	-	-	-
Injury other than burns	4.6	7.2	3.8	5.2
Medical/surgical intervention	-	2.5	1.1	1.7
Old age	-	2.2	45.0	25.5
Not known	11.1	21.5	13.5	16.5
Other reasons	9.3	11.6	6.7	8.8
N	100 (452)	100 (3061)	100 (4260)	100 (7773)

Note: () indicates number of cases; - indicates number of cases <20; Chi-square test (** 5% level of significance)

Source: NSSO (2002)

Table 10: Percentage distribution of causes of speech disability by age, India, 2002

Causes of speech disability**	Age			Total
	<15	15-59	60+	
Hearing impairment	4.3	3.9	-	3.2
Voice disorder	11.4	9.4	-	8.5
Cleft palate/lip	-	1.9	-	2.1
Paralysis	-	17.6	48.4	20.8
Mental illness/retardation	14.9	9.3	-	9.4
Other illness	26.3	26.0	20.3	24.8
Burns	-	-	-	-
Injury other than burns	-	7.5	-	5.6
Medical/surgical intervention	-	2.5	-	2.8
Old age	-	-	5.5	1.2
Not known	21.0	14.1	5.8	14.0
Other reasons	8.6	6.5	5.1	6.7
N	100 (491)	100 (1033)	100 (434)	100 (1958)

Note: () indicates number of cases; - indicates number of cases <20; Chi-square test (** 5% level of significance)

Source: NSSO (2002)

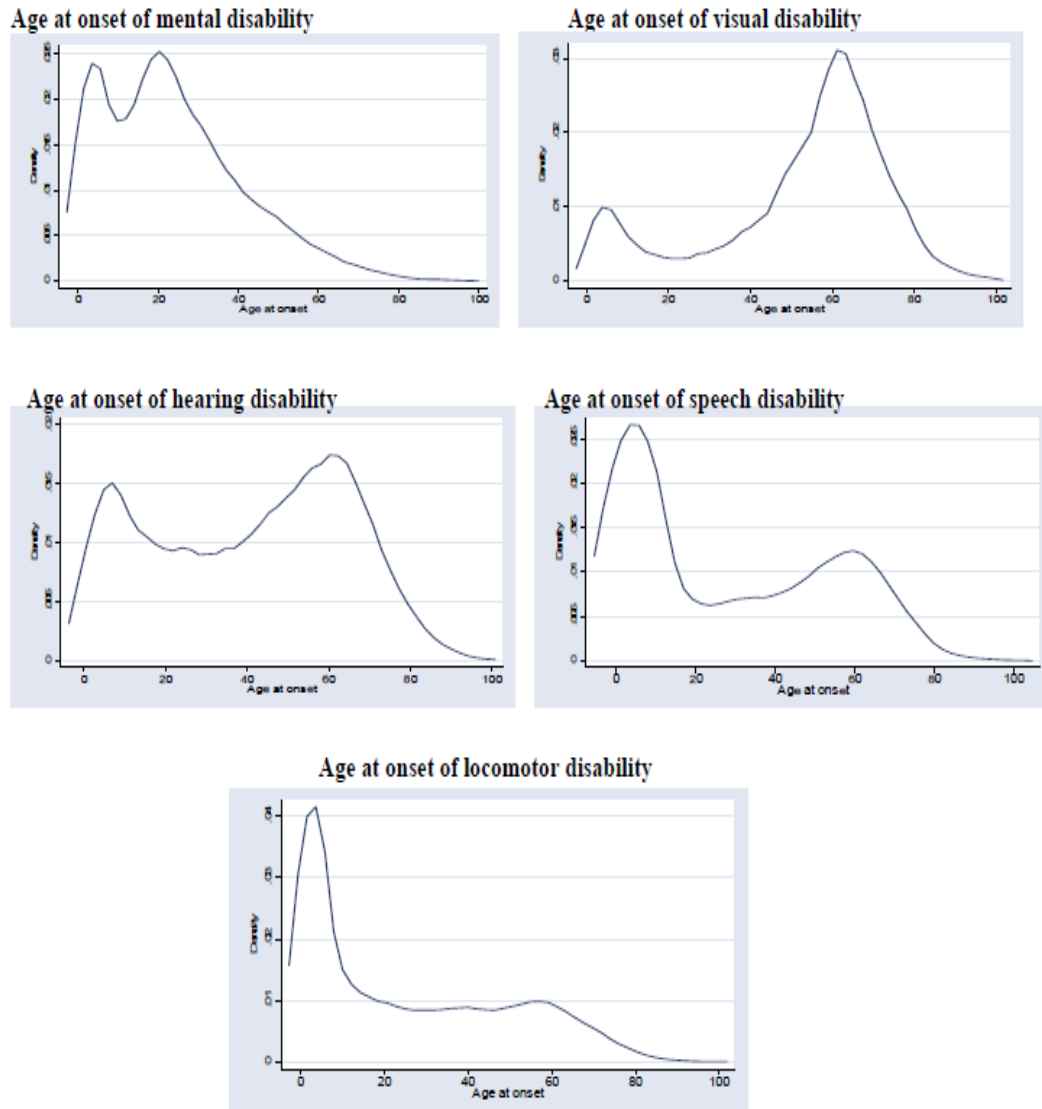
Table 11: Percentage distribution of causes of mental disability by age, India, 2002

Causes of mental disability**	Age			Total
	<15	15-59	60+	
Pregnancy and birth related	4.2	3.4	-	3.3
Serious illness during childhood	48.6	12.8	-	15.0
Head injury in childhood	7.7	4.0	-	4.0
Heredity	-	3.0	4.0	2.9
Not known	22.4	34.9	35.9	33.8
Other reasons	16.0	41.8	56.3	40.9
N	100 (568)	100 (4301)	100 (682)	100 (5551)

Note: () indicates number of cases; - indicates number of cases <20; Chi-square test (** 5% level of significance)

Source NSSO 2002

Figure 8: Age at onset of different types of disabilities



Based on Das (2006), using NSS 58th round

Source: World Bank Report (2007)

Other causes of disability

Article 40 of the World Programme of Action (WPA) concerning disabled persons lists out a comprehensive range of causes of disability which take into consideration factors like wars, civil conflicts, poverty, overcrowding and unhygienic living conditions; constraints of resources, geographical distance and physical and social barriers, industrial, agricultural, and transportation-related accidents, natural disasters, stress and psycho-social problems (NHRC 2005). In addition, the Sarva Shiksha Abhiyan programme reports high incidences of disabilities in children (post-polio paralysis, cerebral palsy) attributed to reduced coverage of immunisation programmes and poor access to medical services (Sarva Shiksha Abhiyan 2005).

The disability manual by National Human Rights Commission elaborately describes various indirect causes of disability (NHRC 2005).

Malnutrition: in its various forms is a major cause of disability in India as well as a contributory factor in other ailments that increase susceptibility to disabling conditions. It is estimated that currently 515 million Asians are chronically undernourished, accounting for about two thirds of the world's hungry people (NHRC 2005). Common micro-nutrient deficiencies that affect disability include:

- Vitamin A deficiency – blindness
- Vitamin B complex deficiency – beri-beri (inflammation or degeneration of the nerves, digestive system and heart), pellagra (central nervous system and gastro-intestinal disorders, skin inflammation) and anemia
- Vitamin D deficiency – rickets (soft and deformed bones)
- Iodine deficiency – slow growth, learning difficulties, intellectual disabilities and goitre
- Iron deficiency – anaemia, which impedes learning and activity, and is a significant cause of maternal mortality
- Calcium deficiency – osteoporosis (fragile bones)

Conflict: War has been the single largest factor responsible for causing permanent disablement not only to combatants in the battlefield but also to civilians who are forced to bear the hazards of lethal, chemical and nuclear weapons. Based on figures from a study carried out in 206 communities, including Afghanistan and Cambodia, landmine triggered disability rate among survivors is about 0.9% (NHRC 2005)

Occupational Hazards: Around 90% of the workforce in India is in the unorganized sector, which is characterized by low levels of technology, low standards of safety and hazardous working conditions. Wheat harvesting and amputations, paddy sowing and muscular diseases, coconut picking and spinal cord injuries are some common hazards associated with typical agricultural activities (NHRC 2005).

Traffic Hazard: It is estimated that by 2020, road traffic accidents will be ranked as the third leading cause of disability in the Asian and Pacific region. Quadriplegia, paraplegia, brain damage and behavioural disorders are some common disabilities among survivors of traffic accidents. (NHRC 2005)

Risk Factors

The risk for disability are both non-modifiable and modifiable are illustrated in Table 12. A study among aged people in Scotland demonstrated that locomotor disabilities increase as the number of chronic conditions increase (Adamson et al., 2003). Similar studies have been

reported worldwide where stroke, heart and respiratory diseases, incontinence and arthritis were found to be related with disability (Ford et al., 1988; Verbrugge et al., 1989; Barberger-Gateau et al., 1992; Guccione et al., 1994; Boulton et al., 1994). Stuck et al. (1999) lists various behavioral and health factors that at an individual level, contribute to the development of disability in old age. The risk factors associated with old age disability, usually related to different chronic diseases, include hypertension, elevated blood lipids and glucose, low bone density, alcohol and drug misuse (Goldberg and Chavin, 1997; Wagner, 1997; Vischer and Seidell, 2001; Infeld and Weissert, 2002). Research has also shown that certain psychological and psychosocial characteristics such as poor self-efficacy, coping strategies, depression and social integration predict the development of disability (Camacho et al., 1993; Femia et al., 1993).

Age: Adamson et al. (2003) examined the relationship between different measures of morbidity and locomotor disability in old age. After adjusting for several measures of morbidity, sex and social class, frequency of pain from CVD conditions (OR 5.49, 95% CI 2.64-11.39), frequency of pain from musculo-skeletal conditions (OR 2.79, 95% CI 1.76-4.44) and self-assessed health compared to other people the same age (OR 2.76, 95% CI 1.64-4.65) were the most important predictors of locomotor disability.

Lifestyle: Ebrahim et al. (2000) examined the impact of lifestyle and disease on locomotor disability in British men cohort (table 12). The study reflected that smoking (OR=1.7, CI=1.2-2.3), obesity (OR=1.6, CI=1.0-2.5), physical activity (OR=0.8, CI=0.6-1.2) and heavy drinking (OR=1.4, CI=0.8-2.3) in middle age are strong predictors of locomotor disability in later life.

Balzi et al. (2010) aimed at identifying cross-sectional correlates of disability and risk factors for the development activities of daily living (ADL) and instrumental ADL (IADL) disability in a cohort study conducted among the 65 – 102 years old people in North Italy. The study suggested that the higher level of physical activity and lower energy intake may be protective against the development in ADL and IADL disability in older persons. In a fully adjusted model, high level of physical activity compared to sedentary state was significantly associated with lower incidence rates of both ADL and IADL disability at the 3-year follow-up visit (OR= 0.30; 95% CI=0.12–0.76 for ADL disability and OR= 0.18; 95% CI= 0.09–0.36 for IADL disability).

The Indian context: Joshi et al (2003) conducted a study to determine the relationship of morbidity with disability and distress among the elderly population of North India (table 13) and found that 87.5% of the elderly people were reported to have minimal to severe disabilities and 66% that were distressed either physically or psychologically, or both. Correlating morbidities with disability and psychological well being showed increasing numbers of morbidities were associated with increasing disability ($r=0.52$, $d.f.=198$, $p<0.01$) and also increasing distress ($r=0.72$, $d.f.=198$, $p<0.01$).

Table 12: Risk factors reported to be associated with disability worldwide

Risk Factors		Effect Size	Reference
Non-modifiable risk factors			
Age		OR=1.2, CI=1.1-1.2	Tas et al. (2007)
Chronic Disorders			
Depression	Men	OR=2.4, CI=1.4-4.1	Tas et al. (2007)
	Women	OR=1.7, CI=1.2-2.5	
Hypertension	Men	OR=0.8, CI=0.5-1.4	
	Women	OR=1.1, CI=0.8-0.6	
Stroke	Men	OR=4.6, CI=1.6-13.5	
Osteoarthritis	Women	OR=1.5, CI=1.0-2.2	
Joint Complaints	Men	OR=1.6, CI=1.0-2.5	
	Women	OR=1.8, CI=1.2-2.6	
Morning Stiffness	Women	OR=1.3, CI=0.9-1.9	
Falls	Men	OR=0.3, CI=0.1-1.2	
Comorbidities	Men	OR=1.0, CI=0.5-1.9	
Psychological Distress due to chronic disorders	Myocardial Infarction	RR=2.34, CI=1.17-4.69	Manninen et al. (1997)
	Depression	RR=2.50, CI=1.09-5.72	
	Neck-Shoulder Disorders	RR=1.98, CI=1.26-3.11	
	Low back disorders	RR=1.76, CI=1.24-2.49	
	Knee osteoarthritis	RR=1.55, CI=0.91-2.63	

Modifiable Risk Factors

BMI	OR = 1.6 to 2.8	Launer et al. (1994), Ebrahim et al. (2000),
Smoking	OR= 1.8 to 2.0	Tas et al. (2007)
Heavy Drinking	OR= 1.3 to 1.7	Balzi et al. (2010)
Higher Energy Intake	OR=1.09, CI=1.02-1.15	

ADL – activities of daily living, IADL – instrumental ADL, BMI – body mass index, RR – relative risk, OR – odds ratio, CI – confidence interval

Table 13: Risk factors associated with disability in North Indian rural and urban population

Morbidity	N	Disability		Psychological distress	
		Mean (SD) score	P-value	Mean (SD) score	P-value
No. of morbidities					
0-3	34	22.0 (4.6)		3.9 (4.2)	
4-6	85	24.4 (4.6)	< 0.001	8.2 (4.8)	< 0.001
7-9	46	27.4 (6.9)		13.7(5.7)	
>9	35	32.3 (7.8)		18.3 (5.7)	
Medical condition					
Asthma					
Yes	12	30.3 (8.1)		15.9 (7.5)	
No	188	25.8 (6.5)	< 0.05	10.2 (6.8)	< 0.05
Chronic obstructive airway disease					
Yes	84	29.2 (7.7)		13.3 (6.5)	
No	116	23.7 (4.7)	< 0.001	8.4 (6.5)	< 0.001
Tuberculosis					
Yes	7	25.5 (5.7)		16.4 (8.4)	
No	193	26.1 (6.7)	0.8	10.2 (6.8)	< 0.05
Hypertension					
Yes	98	27.0 (7.1)		11.9 (7.1)	
No	102	25.1 (6.1)	< 0.05	9.0 (6.5)	< 0.01
Osteoarthritis					
Yes	66	27.1 (7.2)		12.4 (6.9)	
No	134	25.4 (6.3)	0.044	9.3 (6.7)	< 0.01
Gastrointestinal disease					
Yes	41	26.6 (5.7)		14.6 (7.3)	
No	159	25.9 (6.9)	0.096	9.4 (6.5)	< 0.001
Anaemia					
Yes	133	26.8 (6.9)		11.8 (7.1)	
No	67	24.3 (5.9)	< 0.01	7.4 (5.6)	< 0.001

Source: Adapted from Joshi et al. (2003)

Policies and Guidelines in India

The legislative framework for the protection of the rights of disabled people is covered by four acts in India (Thomas 2005a):

- Mental Health Act 1987
- Rehabilitation Council of India Act 1992
- Persons with Disabilities Act 1995
- The National Trust Act 1999

The Mental Health Act 1987 (<http://www.disabilityindia.org/mentalact.cfm>) Mental Health Act came into effect in all the states and union territories of India in April 1993 and replaced the Indian Lunacy Act of 1912. This Act consolidated and amended the law relating to the treatment and care of mentally ill persons and to make better provision with respect to their properly and affairs. The objectives of the Act include to:

- regulate admission to psychiatric hospitals or psychiatric nursing homes of mentally ill-persons who do not have sufficient understanding to seek treatment on a voluntary basis, and to protect the rights of such persons while being detained;
- protect society from the presence of mentally ill persons who have become or might become a danger or nuisance to others;
- protect citizens from being detained in psychiatric hospitals or psychiatric nursing homes without sufficient cause;
- regulate responsibility for maintenance charges of mentally ill persons who are admitted to psychiatric hospitals or psychiatric nursing homes;
- provide facilities for establishing guardianship or custody of mentally ill persons who are incapable of managing their own affairs;
- provide for the establishment of Central Authority and State Authorities for Mental Health Services;
- regulate the powers of the Government for establishing, licensing and controlling psychiatric hospitals and psychiatric nursing homes for mentally ill persons;
- provide for legal aid to mentally ill persons at State expense in certain cases.

In 2002, the Act was implemented in 25 out of 30 states and Union Territories. Under the Mental Health Act 1987, each state is required to constitute a State Mental Health Authority (SMHA) to ensure effective and equitable enforcement of the provisions of the Act. The primary role of the SMHA is in planning, implementation and monitoring of mental health programme/activities (WHO 2006).

The Rehabilitation Council of India Act 1992 (http://rehabcouncil.nic.in/pdf/about_rci.pdf) This Act sets out to regulate the training of professionals in rehabilitation and sets out a framework for a Central Rehabilitation Register. Specifically it sets out:

1. training policies and programmes;
2. to standardise the training courses for professionals dealing with persons with disabilities;
3. to grant recognition to the institutions running these training courses;
4. to maintain a Central Rehabilitation Register of the rehabilitation professionals;
5. to promote research in Rehabilitation and Special Education.

In order to give statutory powers to the Council for carrying out its duties effectively the Rehabilitation Council of India Act was passed by the Parliament which came into force with effect from 1993. The amendment in the Act in 2000 gave the additional responsibility of promoting research to the Council. The major functions of the council include the recognition of qualifications granted by Universities in India for Rehabilitation Professionals and also the recognition of qualification by Institutions outside India.

The Persons with Disabilities (Equal Opportunities, protection Of Rights And Full Participation) Act 1995 (<http://www.disabilityindia.org/pwdacts.cf>)

This act provides 3% reservations for disabled people in poverty alleviation programmes, government posts, and in state educational facilities, as well as other rights and entitlement. The specific objectives of the Act are:

- Prevention and Early Detection of Disabilities
- Education
- Employment
- Affirmative Action
- Non-Discrimination
- Research And Manpower Development
- Recognition of Institutions for Persons with Disabilities
- Institution for Persons with Severe Disabilities
- The Chief Commissioner and Commissioners for Persons with Disabilities
- Social Security

A study conducted by *Disability Knowledge and Research Group* in India assessed the impact of this Act and tried to evaluate its implication (Thomas 2005a). It was found that those eligible had difficulties in obtaining disability certificates, benefit entitlements varied across the India and that only 3% per cent had received monetary support from the government on a regular basis (UNNATI 2004).

The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act 1999 (<http://www.disabilityindia.org/trustact.cfm>)

This Act provides for the constitution of a national body for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities. The main objectives are:

- to enable and empower persons with disability to live as independently and as fully as possible within and as close to the community to which they belong;
- to strengthen facilities to provide support to persons with disability to live within their own families;

- to extend support to registered organization to provide need based services during the period of crises in the family of persons with disability;
- to deal with problems of persons with disability who do not have family support.

National Policy for Persons with Disabilities Act 2005

(<http://www.disabilityindia.org/nationalpolicyfordisable.cfm>)

The National Policy, released in February 2006 recognizes that Persons with Disabilities are valuable human resource for the country and seeks to create an environment that provides them equal opportunities, protection of their rights and full participation in society. Its aim is to ensure better coordination between various wings of the State and Central Governments (Kumar 2005). The focus of the policy is on the following:

- Prevention of Disabilities
- Rehabilitation Measures
- Physical Rehabilitation Strategies
- Early Detection and Intervention
- Counselling & Medical Rehabilitation

In addition to the legal framework, extensive infrastructure has been developed in India for disabled persons under this Act and includes the establishment of the following institutions:

- Institute for the Physically Handicapped, New Delhi.
- National Institute of Visually Handicapped, Dehradun
- National Institute for Orthopaedically Handicapped, Kolkata
- National Institute for Mentally Handicapped, Secunderabad.
- National Institute for Hearing Handicapped, Mumbai
- National Institute of Rehabilitation Training & Research, Cuttack.
- National Institute for Empowerment of Persons with Multiple Disabilities, Chennai

In addition, to these parliamentary acts, India draws support from international bodies to compliment the legal framework. It is a signatory to the Declaration on the Full Participation and Equality of People with Disabilities in the Asia Pacific Region, the Biwako Millennium Framework for action towards an inclusive, barrier free and rights based society and India is currently participating in the negotiations on the UN Convention on Protection and promotion of the Rights and Dignity of Persons with Disabilities. For example:

- *The Disability and Rehabilitation WHO Action Plan 2006-2011* document provides the overview of WHO's future plan of activities, which will be carried out or coordinated by the Disability and Rehabilitation team located in the Department of Injuries and Violence Prevention, in the Non-communicable Diseases and Mental Health.
- One of the four strategic areas of the *Bibikova Millennium Framework* is the development of a national system of disability-related data collection and analysis, and the establishment of a definition of disability, which would enable internationally comparable analysis. (UN-ESCAP 2006). A 2004 survey in India revealed the following:
 - Limited information on the definition of disability
 - Limited information on access to education to disabled people
 - No mention on disability in the Indian constitution
 - No standardized sign language

Management and Treatment of Disability

Many international organizations vary in their approach to the management and treatment of disabled people's needs: for example the WHO promotes a medical rehabilitation approach to disability issues; UNESCO promotes inclusive education policies; the International Labor Organization (ILO) has a policy of including disabled people in their employment; UNICEF focuses on prevention of impairment in children through health and immunization programmes.

However, disabled people themselves are rarely involved in the policy making of these organizations. This makes it difficult to form effective strategies of full inclusion (Yeo 2001). Metts (2000) further argues that the lack of comparable information on disability and chronic poverty makes it difficult for the World Bank and other international organizations to form cost-effective disability policies or to evaluate different approaches towards tackling chronic poverty and disability.

It has been reported that although the overall burden of diseases was 20.9% in India the proportion of health expenditure was less i.e. 1% in 1990 (Murray and Lopez 1997). In the period 1998-2003, just under Rs. 1042 crore was spent by MSJE on the 'welfare of persons with diasbalties', with the largest expenditure category the national institutions and corporations for disability (World Bank 2007). This represents a negligible portion of total budgetary spending. While precise comparisons are difficult, for 2000-2001 budget year, MJSE's spending on disability would account for around 0.07 percent of total Government of India expenditure, and for 2002-03, it accounted for around 0.05 percent of total. In the most recent budget year (2005-06), the share had fallen even further to only 0.047 percent of total allocation.

Ministry of Social Justice and Empowerment (MSJE), Government of India, is the key line ministry with responsibility for disability, though there are several other ministries and government departments that are directly engaged with addressing the problem of disability in India, and many have earmarked funds to develop activities concerning disabled people. Disability activists see disability issues as somewhat ghettoised within the MSJE. For example, they argue that all education initiatives for disabled children and adults should be under the Ministry of Human Resources. Currently, there is a lack of government oversight on the operations and activities of special schools (Thomas 2005a).

NGOs report the current system is bureaucratic and difficult to access, and that when grants are given, the amount is often considerably less than that originally requested and that payments are slow and irregular (Thomas 2005a). Anecdotal evidence suggests that the slow disbursement of funds has resulted in NGOs having to lay off staff and close programmes. The MSJE budget for disability is consistently under-spent (Times of India 2005). In 2003, a committee was established to review the guidelines and procedures for the administration and monitoring of MSJE grants. Despite new guidelines being issued by the MSJE before the committee reported, and, according to disability NGOs, the committee's recommendations have never been made public (Thomas 2005a).

Current health care provision is managed within the outpatient departments of Institute for the Physically Handicapped, the National Institute of Visually Handicapped, National Institute for Orthopaedically Handicapped, National Institute for Mentally Handicapped, National Institute for Hearing Handicapped, National Institute of Rehabilitation Training & Research. These clinics include diagnostic, therapeutic and remedial services, educational, pre-school and vocational services. Outreach programmes with multi-professional rehabilitation services to the slums, tribal belts, foothills, semi-urban and rural areas have been developed. Through outreach services, communities are sensitized on early-identification, prevention, intervention and rehabilitation of the disabled. Technical know-how and information are also provided to NGOs, on infrastructure requirement for established service centers for the disabled (Zutshi 2010).

The analysis of these outpatients services was undertaken and revealed that the majority of organizations providing special education for the impaired children are only doing so up to primary level with 9.9% of the disabled population having attended vocational training in 2002 (Zutshi 2010). Even among the disabled persons who received the vocational training, the nature of training received was in non-engineering skills, which fetch lower profile jobs and have lower income generation prospects. Thus the majority of them lacked earning capacity through the training provided to them. Only 1.2% disabled persons had received vocational training in engineering skills and only 10% NGOs and other organizations provide aid and appliances to the impaired (Zutshi 2010).

Joshi et al. (2003) in a study conducted among disabled people in Chandigarh and Haryana, North India found that treatment seeking was more common in the urban (58%) than the rural

area (19%). The most popular type (system) of medicine preferred by those who were seeking treatment was allopathic, which was adopted by nearly 92.2% people. The rest, 7.7% of the elderly people, rely on either ayurvedic or homeopathic medicine (Joshi et al., 2003).

Research Programmes in India

Ongoing research programmes on disability are limited in India. Although, one of the objectives of National Policy for PWD 2006 and the PWD Act 1995 is to support the research in prevention and management of disability, the major focus is on the social upliftment, monetary benefits (like job opportunities, exemption from taxes, pensions, etc.) and providing rehabilitation facilities to disabled people.

Other major projects are run by international organizations which include the *Disability Knowledge and Research (KaR) Programme* funded by DFID, UK. Its focus is on mainstreaming disability in India and have adopted a wide range of approaches in order to bring together knowledge and research on international disability issues. The different areas of the programme include:

1. Disability research projects; examples of these research projects are:
 - Data and Statistics on Disability in Developing Countries (Eide and Loeb 2005)
 - Research Gaps in Disability and Development (Albert et al. 2005)

2. DFID policy project, managed by Healthlink Worldwide, was created to assist DFID to develop policies and processes to support the mainstreaming of disability and to ensure that the Disability KaR's knowledge and research outputs are responsive to DFID's needs and effectively communicated to DFID (Thomas 2005b).

3. The other components of the Disability KaR group included
 - Disability equality training.
 - A knowledge and communication strategy, including a number of publications and online communication tools and face-to-face events to encourage dialogue between different stakeholders in India.
 - Competition projects aimed to develop and support sustainable technologies that combat the effects of disability and poverty.

There are numerous NGOs working for disabled people, but these predominantly focus on the medical or charity model of disability (Yeo 2001) in terms of providing medical care and vocational training to disabled. Recently, *South Asia Centre for Disability Inclusive Development and Research* has been launched by *Public Health Foundation of India* (The Hindu 2010). One of the first aims of this institute would be to:

- (i) screen diseases, nutritional disorders and disability in both rural and urban schools
- (ii) examine and certify disabled people in the Andhra Pradesh state.

This exercise would help in bringing out data on various parameters of the disabled population which can be utilized for various research purposes (The Hindu 2010).

Gaps to be filled

Lack of Surveillance Systems: The preliminary step to conduct research in any field demands a baseline data about the prevalence, incidence and distribution of a disease. Due to the lack of a universal definition of disability and its types and categories, there are no reliable figures available for the prevalence of disability in India. The differences seen in the estimates of Census (2001) and NSSO (2002) are the best indications of the discrepancies in understanding and the conceptualization of the term 'disability'. There is a major issue of under reported cases of disability in the country because of the lack of national level registration and identification system of the persons with disability. There are numerous examples of excluded disability categories, including autism, thalassemia, haemophilia, and many learning disabilities in both census (2001) and NSSO (2002). The social stigma attached to the disability is also likely to contribute to under-estimation.

Management and Treatment: There is a need of systematic and organized community based rehabilitation facilities to identify and take care of persons with disability wherein they can be managed and treated. There is a need to develop the evidence based guidelines to provide services for the effective diagnosis, care, understanding the cause, management, treatment and prevention of various types of disabilities; along with the need to evaluate these health systems at the both primary and secondary levels.

Lack of Priority: As there is no direct mortality associated with the various types of disabilities, they remain at the bottom of the government's priority list. There is no mention of "disability" either in the constitution or the millenium development goals (MDG), thus the treatment and prevention of disability does not demand much attention. Groce and Trani (2009) pointed out the reason for their neglect as the thought by experts and organizations that the needs of people with disabilities will be taken care of by some disability-specific group or programme. The

greatest barrier to inclusion of people with disability in MDG is stigma and prejudice (Lang 2009, UN Enable 2009).

Evaluation and audit of the guidelines: The results of the survey conducted by ESCAP in 2004 (UN ESCAP 2004) demands an evaluation of the regulation of international and national policies and guidelines for persons with disability to ensure their correct, effective and fruitful functioning. The World Bank report (2007) also highlights the different institutional and other issues which hinder the implementation of the disability policies.

Integrated Research Programmes: There are numerous NGO's conducting small scale research activities on disability like Monovikas Kendra (West Bengal), Handicapped Development Foundation (Manipur), Mobility India (Uttar Pradesh), Disability India Network (Din), Disability India Information Resources (DIIR). There is a need to identify co-ordinate such organizations and actively involve them in policy formulation, planning, implementation, monitoring in disability in India.

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