

RETA 5956

Identifying Disability Issues Related to Poverty Reduction

India Country Study

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ABBREVIATIONS

ACA	–	Additional Central Assistance
ADP	–	Association of People with Disability
AP	–	Andhra Pradesh
ATC	–	Advanced Training Centre
AUWSP	–	Accelerated Urban Water Supply Programme
BPA	–	Blind People's Association
CBR	–	community based rehabilitation
CCC	–	Central Coordinating Committee
CEC	–	Central Executive Committee
CRSP	–	Central Rural Sanitation Programme
CTS	–	Craftsmen Training Scheme
DANIDA	–	Danish Agency for International Development
DFID	–	Department of International Development
DGE&T	–	Directorate General of Employment and Training
DMC	–	developing member country
DPEP	–	District Primary Education Programme
GO	–	government organization
GOI	–	Government of India
HBP	–	home-based program
HDR	–	Human Development Report
HP	–	Himachal Pradesh
HPI	–	Human Poverty Index
IAY	–	Indira Awaas Yojana
ICDS	–	Integrated Child Development Services
IDSMT	–	Integrated Development of Small and Medium Towns
IEC	–	Information, Education and Communication
ILO	–	International Labour Organization
IRDE	–	Integrated Rural Development and Employment
ITI	–	Industrial Training Institutes
LIG	–	low income groups
MP	–	Madhya Pradesh
MP	–	members of parliament
NCPEDP	–	National Center for Promotion of Employment for Persons with Disability
NCVT	–	National Council of Vocational Training
NFHS	–	National Family and Health Survey
NGO	–	Non-Government Organization
NHFDC	–	National Handicapped Finance and Development Corporation
NMBS	–	National Maternity Benefit Scheme
NMMP	–	National Mid-day Meals Programme
NOAPS	–	National Old Age Pension Scheme
NPRPD	–	National Programme for Rehabilitation of Persons with Disabilities
NSAP	–	National Social Assistance Programme
NSSO	–	National Sample Survey Organization
NTC	–	New Training Centre
PHC	–	primary health centres

PMGSY	–	Pradhan Mantri Graam Sadak Yojana
PMGY	–	Pradhan Mantri Gramodaya Yojana
PMR	–	Physical Medicine and Rehabilitation
PRI	–	Panchayati Raj Institutions
PWD	–	Persons with Disabilities
RREC	–	Rural Rehabilitation Extension Centres
RRTC	–	Regional Rehabilitation Training Centres
SCVT	–	State Council for Vocational Training
SGSY	–	Swarnjayanti Gram Swarozgar Yojana
SPASTN	–	Spastics Society of Tamil Nadu
SRC	–	State Referral Centres
SSEI	–	Spastics Society of Eastern India
TRYSEM	–	Training for Rural Youth for Self Employment
ULB	–	urban local bodies
UN	–	United Nations
UNDP	–	United Nations Development Program
UNESCAP	–	United Nations Economic and Social Commission for Asia and the Pacific
UNESCO	–	United Nations Educational, Scientific and Cultural Organization
UNICEF	–	United Nations Children’s Fund
UT	–	Union Territories
UWEP	–	Urban Wage Employment Programme
VRC	–	Vocational Rehabilitation Centre
WHO	–	World Health Organization

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FOREWORD AND ACKNOWLEDGEMENTS

On March 8, 2002, the Foundation for International Training (FIT) entered into a contract with the Asian Development Bank (ADB) to provide technical assistance through RETA 5956, "Identifying Disability Issues Related to Poverty Reduction". The objectives of the Project were to:

- (i) familiarize developing member countries (DMC) with the ADB's overarching objective of poverty reduction and other related ADB policies to help address the vulnerability and poverty situation of disabled peoples;
- (ii) identify and analyze the DMC's national policies, programs, projects and initiatives concerning disabilities and poverty to be used as a basis for action plans;
- (iii) provide a forum for ADB, Government and disabled peoples' groups/organizations to identify and discuss disabled peoples' needs and concerns, particularly those related to poverty; and
- (iv) develop a disability checklist for the ADB.

The project was carried out in four countries: Cambodia, India, the Philippines and Sri Lanka. In each country, FIT mobilized a two-person team of multi-disciplinary specialists in disability and poverty reduction policy and participatory development. These local consultants carried out the research, documentation, and policy activities at the country level. The results of this work are documented in Country Study Reports and Recommendations prepared for each country.

The Project was led by an international team leader, Dr. Lorna Jean Edmonds. Dr. Edmonds provided invaluable guidance and direction in the structure and development of the country study reports. This Country Study Report was produced by Ms. Geeta Chaturvedi, the Project's Disability and Poverty Policy Specialist for India. Ms. Chaturvedi was assisted by a Participatory Specialist, Ms. Monica Ramesh. Together Ms. Chaturvedi and Ms. Ramesh organized a series of provincial and national-level workshops; the recommendations that emerged from this process form an integral component of this Country Study. This work benefited from support and cooperation from the Ministry of Social Justice and Empowerment. The editing of the Country Study Report and Recommendations was carried out by the team at FIT led by Ms. Michelle Sweet, Project Manager.

COUNTRY BRIEF

A. Population/Surface Area

General Data

- Capital: New Delhi
- Official Languages: Hindi and English
- Currency: Rupees
- Surface Area: 3,287,263 Sq. Km
- Population: 1,027,005,247 persons in 2001 Census
- Population growth rate (1991-2001): 21.34%
- Female: 0.49 billion
- Male: 0.53 billion
- Population in rural areas: 0.74 billion
- Population in urban areas: 0.28 billion

B. Administration

- The country has 29 states and 6 union territories.

C. Demography:

- Density: 324 persons per Sq. km.
- Highest population density: In the state of Uttar Pradesh

D. Economic indicators

- GNP (per capita) – net national product: Rs 16,486.6 (current prices)
- GDP in US Dollar (2000-2001): \$42 billion
- Annual income of the country: Rs 16.8 billion

E. Health

- Annual income of the country: Rs 16.8 billion
- Life expectancy at birth: 61.1 years
- Birth rate (per '000): 26.1
- Death rate (per '000): 8.7
- Infant mortality rate (per '000 life birth): 70

F. Literacy

- Adult literacy (2001): 65.4 percent

I. INTRODUCTION

1. One out of three Asians is poor and survives on less than US\$1 a day. According to the World Health Organization (WHO), it is estimated that one out of ten persons has a disability. More than three out of four of these live in a developing country and are among the poorest of the poor. In India, a comprehensive survey conducted by National Sample Survey Organization indicated that an estimate of 32 million people were likely to be disabled and that an estimated 130 million people are indirectly affected by physical disability of a family member. Lack of comprehensive information on the poverty of disabled people is an important indicator of their marginalization and invisible status in society. Many disabled people are disadvantaged by social, economic, physical and political conditions. Together, these conditions constitute barriers to freedom of movement and full participation in society. These barriers include stigma attached to disability and a poor understanding of abilities and aspirations of disabled people by the rest of society. Because of this, disabled people often face a life that is segregated and debased. Women and girls with disability suffer from double discrimination. Poverty and disability reinforce each other as both contribute to increase vulnerability and exclusion. The goal of eliminating world poverty cannot be reached unless the rights and needs of excluded people—including people with disabilities—are taken into account.

2. An Asian Development Bank (ADB) fact-finding mission visited India from 18 to 21 July 2000 in order to plan for the Asian Development Bank's (ADB) Regional Technical Assistance project "Identifying Disability Issues Related to Poverty Reduction". Its primary aim was to provide greater understanding of how to address disability needs in the development of country strategies and action plans, and for the ADB to develop recommendations for a regional approach to mainstreaming disability issues within programs for poverty reduction and social development. In April 2002, RETA 5956 was formally launched with an inception meeting at Manila, Philippines. The Study was conducted in four Developing Member Countries (DMCs): India, Sri Lanka, Cambodia and Philippines.

3. The National Focal Agency for the country study review was Ministry of Social Justice and Empowerment, Government of India. The Study aimed to assist the Government of India in assessing the adequacy of national disability policies and relevant strategies and develop a clear disability-poverty link in India. It also assessed country experience in addressing the needs of disabled people through the government's development programs.

4. The process involved a series of consultations and visits to project sites to develop an adequate and relevant strategy for the country. Four provincial workshops were held between June-July 2002 and one National Workshop took place in August 2002. The methodology used at the workshop adhered to a complete participatory approach. The process also involved an interface with relevant and related government departments, UN agencies and NGOs to analyze the strength and the capacity of the implementing agencies with special reference to inclusion of persons with disabilities at the times of designing, planning, decision making and implementing. The workshops were attended by 185 participants representing Central and State governments, UN-agencies, disability specific NGOs, development NGOs, CBOs, corporate sector, financial institutions and disabled people's organizations. Out of a total number of participants, 25 persons with disabilities and parents of persons with disabilities participated in the workshops.

5. The Country Study Report is an attempt to analyze the realities of the country in the wake of its unique diversity in language, religion, culture and ethnicity. The key areas addressed in the report focus on the overall profile of the country with distinct country needs. The report also consists of the poverty profile along with the poverty reduction schemes in rural and urban

areas, social protection programs for disabled people and the policy and legislative initiatives to include the needs of persons with disabilities. The end of the document consists of the recommendations drawn from consultations, developed over provincial workshops and finally concretized at the National Workshop.

6. India continues to be the middle of its demographic transition. For the country as a whole, the crude death rates have been declining since 1921, but the decline in crude birth rates has been remarkably slow, beginning only after 1941. The gap between the fertility and mortality rates has resulted in rapid growth of India's population over the last five decades. The country's population stood at 1,027.02 million in March 2001, according to the most recent census. There has been an increase of nearly 181 million during the 1990s alone. This figure is quite striking when one compares it to the population of Brazil (168.2 million), Russian Federation (146.2 million), Pakistan (137.6 million), Bangladesh (134.6 million) or Japan (126.8 million) for the year 1999, as indicated in UNDP's Human Development Report (HDR) for 2001. India is, in fact, adding nearly the equivalent of Australia's population to its own population every year.

7. Overall, human development as reflected in the Human Development Index (HDI) has improved significantly between 1980 and 2001. At the national level, during the 1980s the index has improved by nearly 26 percent, and by another 24 percent during the 1990s. There has been an improvement in both rural and urban areas. Though the rural-urban gap in the level of human development continues to be significant, it has declined during the period.

A. Incidence of Poverty

8. In general, poverty is identified by examining the gap between personal expenditure required to enable the individual to meet minimum needs and actual income levels. Using such an approach the Planning Commission, Government of India, has been estimating the Head Count Ratio of the poor at the State level, separately for rural and urban areas for over three decades. It currently uses a minimum consumption expenditure, anchored in an average (food) energy adequacy norm of 2400 and 2100 kilo calories per capita per day to define State specific poverty lines, separately for rural and urban areas.

9. Using this method, the incidence of poverty on the Head Count Ratio declined from 44.48 per cent in 1983 to 26.10 per cent in 1999-2000. It was a decline of nearly 8.5 percentage points in the ten years period between 1983 and 1993-94 followed by a further decline of nearly 10 percentage points in the period between 1993-94 and 1999-2000. In absolute terms, the number of poor declined from about 323 million in 1983 to 260 million in 1999-2000. This decline has not been uniform either across States or across rural and urban areas.

10. Poverty rates as measured by the Human Poverty Index (HPI) declined during the 1980s, from nearly 40 percent in the early 1980s to about 39 percent in the early 1990s. In terms of the rural and urban incidence, as well as at the State level, there are considerable variations. The rural-urban ratio for the proportion of the poor on the HPI is nearly twice as high as those on the head count ratio of poverty. The magnitude of HPI in early nineties had declined in all the States. However, the relative positions of different States remained quite similar to the earlier period.

B. Prevalence of Disability in India

11. The National Sample Survey Organization (NSSO) conducted a survey of disability in 1991. In this survey people were classified as "disabled" if they had less than 40% "normal"

functions and concentrated primarily on physical disabilities. The concept of “normal functions” was not clearly defined. The findings of this survey included:

- 9% of rural households and 7% of urban households have at least one person with disability (average household size was 5.8 people).
- 1.9% of the Indian population had severe or profound physical disabilities.
- 12% of the disabled people identified had multiple disabilities.
- 80% of people with disabilities live in rural areas.
- 4% of children aged 0-4 years living in rural areas and 3.3% of those in urban areas had a hearing loss.

The survey concluded that prevalence rates for the total population are: visual impairment 0.5%; hearing and speech impairment 1%; and motor disabilities 1.05%.

12. UNICEF suggests the following figures, using these labels, though these labels may not have been chosen to be quoted by other authors as they are derived from a medical view of disability:

Blind	12 million
Low Vision	28 million
Deaf and Speech Impaired	12 million
Orthopaedically Handicapped	6 million
Mentally Retarded	24 million
Mentally Ill	8 million
Leprosy (cured)	1 million

13. The Indian Council for Medical Research in 1974 suggested a prevalence rate of 1.4% of blindness and WHO, in 1986, estimated a prevalence rate of blindness of 1.5%. The Indian Council for Medical Research further estimates that there are 5 low vision children for every blind child. The national program to counteract blindness primarily through a cataract operation scheme cannot perform enough surgeries to reduce the backlog of people needing this operation, suggesting that the national prevalence rates for blindness may be rising.

14. Around 22.77 per thousand males and 16.94 per thousand females have a physical disability. There is a higher prevalence rate than the national average in Andhra Pradesh (AP), Himachal Pradesh (HP), Karnataka, Madhya Pradesh (MP), Orissa, Punjab and Tamil Nadu. Physical disability prevalence rates in urban populations is 16.75, and in rural populations 19.75, per thousand. About 9.14% of rural households, and 6.77% of those in urban areas include at least one person with disability. Around 36% of disabled people are over 60 years of age. According to the 1991 Survey, for every 1,000 persons with disabilities, 290 were employed and 110 were attending educational institutions. Of those employed, 7% were in regular employment. The percentage of disabled people seeking and available for work in urban areas was 1.7%, and 0.7% in rural areas.

15. The Census figures for the present decade, starting from 2000-2001 are yet to be published. Table 1 is based on estimated numbers/percentages of people with disabilities as per the 1991 NSSO. (All India figures)

Table 1: Estimated Numbers/Percentages of People with Disabilities, Based on the 1991 NSSO (All India Figures)

Type of Disability	Rural			Urban			Total Rural + Urban
	Male	Female	Total	Male	Female	Total	
	(1)	(2)	(3)	(4)	(5)	(6)	(3)+(6)
Visual	1.539	1.796	3.335	0.308	0.362	0.670	4.005
	46.15%	53.85%	83.27%	45.97%	54.03%	16.73%	
Hearing	1.409	1.164	2.573	0.339	0.330	0.669	3.242
	54.76%	45.24%	79.36%	50.67%	49.33%	20.64%	
Speech	0.942	0.557	1.499	0.298	0.169	0.467	1.966
	62.84%	37.16%	76.25%	63.81%	36.19%	23.75%	
Hearing and Speech	2.009	1.490	3.499	0.557	0.426	0.983	4.482
	57.42%	42.58%	78.07%	56.66%	43.34%	21.93%	
Loco-Motor	4.369	2.411	6.807	1.370	0.762	2.132	8.939
	64.58%	35.42%	76.16%	64.26%	35.74%	23.85%	
Physical (at least one of the above)	7.442	5.210	12.652	2.078	1.424	3.502	16.154
	58.82%	41.18%	78.32%	59.34%	40.66%	21.68%	

Note the figures in columns (1) and (2), in columns (3) and (6), and in column (4) and (5) add up to 100.

Table 2: Estimated Number of Persons with Disability in India-1991 (In Millions)

Type of disability	Rural			Urban			Total Persons (R+U)
	Male	Female	Person	Male	Female	Person	
Visual	1.54	1.80	3.34	0.31	0.36	0.67	4.01
Hearing	1.41	1.16	2.57	0.34	0.33	0.67	3.24
Speech	0.94	0.56	1.56	0.30	0.17	0.47	1.97
Hearing and/or Speech	2.00	1.49	3.50	0.56	0.43	0.98	4.48
Loco-Motor	4.40	2.41	6.81	1.37	0.76	2.13	8.94
Physical (at least one of the above)	7.44	5.21	12.65	2.08	1.42	3.50	16.15

C. Distinct Country Issues

16. India is a country of 28 States and 7 Union Territories (UTs) spread over difficult and diverse geographical terrain, which makes planning and implementation of various national programmes very difficult. Indian communities are heterogeneous, with wide differences in socio-economic status, educational attainment, religion, and ethnicity. This diversity can cause friction and affect services as different groups in a community have widely differing needs and priorities. Often the needs of disabled people, who are in a minority, are not considered priorities by other groups. Disabled people living in poverty have always suffered from double disadvantage and are also at higher risk of becoming even poorer. The same is true for all people living in poverty, who have a higher risk of facing a disabling condition due to their limited access to basic services such as health, education, and sanitation and higher rates of exposure to hazardous working conditions.

17. Poor nutrition during pregnancy, generic factors, infectious diseases, poor sanitation and crowded living conditions together with poor food, lack of basic health and rehabilitation services, lack of immunization against diseases such as polio and rubella are among of the major causes of disability. Modernization itself is also a causal factor, such as in the cases of infants born with a disability as a result of inappropriate medications used during pregnancy, traffic accidents resulting in loss of limbs and blindness and leprosy infections as a result of pesticide and fluoride poisoning. Aging is another major contributing factor; 36% of disabled people in India are over the age of 60.

18. Women with disabilities face certain unique disadvantages, such as difficulties in performing traditional gender roles, participating in community life, and accessing rehabilitation services that are dominated by male service providers.

II. COUNTRY NEEDS: POVERTY PROFILE

19. There are seven main elements of India's Five Year Plans. These are: (i) assessment of the potentialities of the constraints on growth in the economy, (ii) growth profiles based on this assessment, (iii) investment requirements and its mobilization, (iv) priorities and objectives of the plan, (v) deployment or allocation of investments, (vi) physical targets and (vii) plan proposals.

20. The approach to the Tenth Plan prepared by the Planning Commission, Government of India and approved by the National Development Council on September 1, 2001, has thrown up a major challenge for each state in the country. It has set out an ambitious target of 8% annual for growth in the national economy. This Plan considers this level of growth feasible, but at the same time observes that this sharp increase is possible only if there is a significant improvement in the growth rates of slow-growing states. The Plan will meet its target only if a higher growth target is sought to be achieved with a continuation of low growth rates observed in some of the most populous states; it would necessarily imply a very large increase in inter-State inequality with serious consequences.

21. The process of liberalization was started in the country about a decade ago to ensure increased participation of the private sector in development activities. However, while developed states have been able to attract private investors through their superior socio-economic infrastructural network, less developed states have not been able to take advantage of this economic liberalization.

22. Creating and strengthening infrastructural facilities—particularly power, road and transport—throughout each State is required to promote the flow of private investment and growth. The Central Planning Commission is fully aware of this prerequisite of private investment. With recent indications from the Central Planning Commission that greater freedom and choice of location that is now available to industry, it is more likely that some states would be able to attract more private investment than others. In such a situation, it will be necessary to deliberately bias public investment in infrastructure in favor of less well-off states.

23. India needs to fulfill its foremost obligation of making investments in critical infrastructures such as rural electrification, the development of irrigation and water management systems, land development, state highways, district and rural roads and social sectors such as education and health. The establishment of minimum levels of basic socio-economic infrastructure facilities throughout the Nation will have a reinforcing effect on growth.

A. Shelter and Quality of Housing

24. At the national level, nearly 73 per cent of the households were living in houses with two or less rooms in 1981. The proportion was identical for rural and urban areas. In 1991, the proportion of households living in houses with two or less rooms declined marginally to 71 per cent at the national level. The proportion was marginally higher in rural areas in comparison to urban areas. At the national level, while the share of households living in kutcha and semi pucca houses declined by around 9 percentage points between 1981 and 1991, those living in pucca houses increased from around 33 per cent to 42 per cent. Nearly 30 per cent of rural households and 73 per cent of urban households lived in pucca houses in 1991 as compared to 23 to 65 per cent respectively, in 1981.

B. Sanitation—Access to Toilet Facilities

25. As per the 1991 Census, less than one-fourth of the households in the country had toilet facilities within their places of residence; the proportion was less than 10 per cent for rural households and around 64 per cent for urban households. Access to toilet facilities for Scheduled Castes and Scheduled Tribes households were lower than that of other households in almost all States. A majority of India's population does not have access to toilet facilities in their dwellings and lack of sanitation facilities for disposal of wastewater, which is one of a main causes of prevailing ill health and morbidity levels in the country.

26. At the household level in rural areas, problems related to sanitation are not caused by a shortage of resources, but essentially by a lack of awareness and education. The situation is reversed in the case of urban sanitation and solid waste management with a special reference to sewage disposal. In urban areas, poor solid waste management practices pose a significant threat to safe drinking water.

C. Access to Safe Drinking Water

27. The Census of India defines access to safe drinking water when a household has access to drinking water supplied from a tap or a hand pump/tube well situated within or outside the premises. Millions of people in the country suffer from water borne diseases on account of lack of access to safe drinking water. People living in poverty suffer from a higher prevalence of such diseases. Studies undertaken in many metropolitan cities show a higher rate of diseases and longer duration per illness due to poor quality of drinking water supply in the slum areas. In

terms of population segments, access to safe drinking water varies between the Scheduled Caste and Scheduled Tribe households in India.

28. The National Family and Health Survey (NFHS) provides more recent information on the accessibility of the population to safe drinking water. As per NFHS II, the share of population having access to safe drinking water was nearly 78 per cent in 1998-99 as against 62 per cent in 1993-94. As with the Census data, the proportion of population having access to safe drinking water was significantly higher in urban areas at nearly 93 per cent as against rural areas where it was around 72 percent. The NSS 52nd Round 1995-96 gives the distribution of households by major source of drinking water at the State level separately for rural and urban areas. At the national level, nearly 77 per cent of the households had access to water from tap or tube-well/hand-pump and about 18 per cent of the households had access to pucca wells. In the hilly States, however, tap water was the predominant source of safe drinking water. These surveys do not provide any information on accessibility of safe drinking water or accessibility to the water points for persons with disabilities.

D. Access to Electricity

29. As per the 1991 Census, only 42 per cent of households had access to electricity in their homes, as against 26 per cent in 1981. At the national level, three-fourth of the urban households in the country had access to electricity, whereas only 30 per cent of those living in rural areas had access to this facility.

E. Road Connectivity

30. Road connectivity is a useful indicator of the inclusiveness of the development process and, perhaps, reach of the market as well. It is particularly relevant in the Indian context where over 70 per cent of the population continues to live in rural areas, and where over 50 per cent of villages with population of less than 1,000 are yet to be connected by roads.

31. The Planning Commission has been tabulating data on State level coverage of roads. The road length per hundred square kilometers has increased at the national level from about 45 kilometers in 1981 and 61 kilometers in 1991 to about 75 kilometers in 1997. During the same period, road length per million population has increased from 21.68 kilometers to 25.82 kilometers.

III. LEGISLATIVE AND POLICY FRAMEWORK

A. Definition of Disability in India

32. The RCI-Rehabilitation Council of India Act, 1992, defines disability as:

- **Hearing handicap:** means deafness with hearing impairment of 70 decibels and above in the better ear or total loss of hearing in both ears.
- **Locomotor disability:** means a person's inability to execute distinctive activities associated with moving, both himself and objects from place to place, and such inability resulting from affliction of either bones, joints, muscles and nerves.

- **Mental retardation:** means a condition of arrested or incomplete development of mind of a person which is specially characterized by sub-normality of intelligence.
- **Visually handicapped:** means a person who suffers from any of the following conditions, namely:
 - total absence of sight; or
 - visual acuity not exceeding 6/60 or 20/200 (sentinel) in the better eye with correcting lenses; or
 - limitation of the field of vision subtending an angle of degree 20 or worse.

33. Planning Commission of India's definition: a person with disability means a person who is 1. blind; 2. deaf; 3. having orthopedic disability; or 4. having neurological disorder; 5. mentally retarded. The definition includes any person who is unable to ensure him/herself, wholly or partly, the necessities of a normal individual or social life including work, as a result of deficiency in his/her physical or mental capability.

34. The new Law – Persons With Disabilities (PWD) Act, 1995 established the following definitions:

- **Person with disability:** means a person suffering from not less than forty percent of any disability as certified by the medical authority.
- **Blindness:** refers to a condition where a person suffers from any of the following conditions, namely:
 - total absence of sight; or
 - visual acuity not exceeding 6/60 or 20/200 (sentinel) in the better eye with correcting lenses; or
 - limitation of the field of vision subtending an angle of 20 degrees or worse.
- **Cerebral palsy:** means a group of non-progressive conditions of a person characterized by abnormal motor control posture resulting from a brain insult, or injuries occurring in the prenatal, peri-natal or infant period of frequencies.
- **Hearing impairment:** means loss of sixty decibels or more in the better ear in the conversational range of frequencies.
- **Locomotor disability:** means disability of bones, joints or muscles leading to substantial restriction of the movement of the limbs or any form of cerebral palsy.
- **Leprosy cured person:** means any person who has been cured of leprosy, but is suffering from:
 - Loss of sensation in hands or feet as well as loss of sensation in the eye and eye-lid but no manifest deformity.
 - Manifest deformity or paresis but having sufficient mobility in their hands and feet to enable them to engage in normal economic activity;
 - Extreme physical deformity, as well as advanced age which prevents him from undertaking any gainful occupation and the expression – 'Leprosy Cured' shall be construed accordingly.

- **Mental retardation:** means a condition of arrested or incomplete development of mind of a person, which is specially characterized by subnormality of intelligence.
- **Mental illness:** means mental disorder other than mental retardation.
- **Person with low vision:** means a person with impairment of visual functioning even after treatment of standard refractive correction, but who uses or is potentially capable of using vision for the planning or execution of appropriate assistive device.

B. National Legislation for Persons with Disabilities

35. The policy framework in the area of disability is enshrined in 3 legislative enactments:

- The Persons with Disability (Equal Opportunities, Protection of Rights and Full Participation) Act 1995.
- The Rehabilitation Council of India Act, 1992.
- The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999.

36. The Persons with Disability Act 1995 is a comprehensive piece of legislation which aims to spell out the responsibility of the State towards the prevention of disabilities, protection of rights of persons with disabilities and provision of medical care, education, training, employment and rehabilitation of persons with disabilities. The Act also includes a commitment to create barrier-free environments for persons with disabilities, owns the responsibility to remove any discrimination of persons with disabilities in sharing of development benefits and to counteract any situation resulting in abuse and exploitation of persons with disabilities. The Act established a framework for comprehensive development of strategies, programs and service for equalization of opportunities for persons with disabilities and makes special provisions for their integration into the social mainstream. The Act also provides for better protection of rights of persons with disabilities and for their social security.

37. The office of the Chief Commissioner for Persons with Disability emerged as a statutory authority having quasi-judicial powers under the Persons with Disabilities Act, 1995. The functions and duties of the Chief Commissioner include coordinating the work of State Commissioners for persons with disabilities and monitoring the utilization of funds disbursed by the Central Government. It is also mandated to take steps to safeguard rights and facilities made available to persons with disabilities and acts as a grievance redressal forum in the event of denial of such rights, addressing various issues such as access to education, physical accessibility, employment opportunities, discrimination etc.

38. The Act also mandates appointment of Commissioners at the State levels for effective implementation of the Persons with Disabilities Act. In reality there are only 9 States where independent Commissioners have been appointed. In the rest of the States it is only given as an additional charge to the Secretary of the State Social Welfare or Women and Child Welfare Departments. The rationale given by the government authorities is that it may not be feasible for the state governments to appoint independent commissioners where the population of a State is less than a million (particularly North-East states and Himanchal Pradesh).

39. The Rehabilitation Act 1992 provides for regulation and monitoring of the training of professionals and personnel in the field of rehabilitation, promoting research in the field of

rehabilitation and special education and the maintenance of the Central Rehabilitation Register. The Rehabilitation Council of India Act, 1992 among other things, relates to the training of professionals in the field of rehabilitation for disabled people. It is relevant that this Act links health with other social issues such as hygiene, sanitation etc. Similarly, the training of teachers needs to be linked with other social issues since the professionals produced as a result of this training are linked to the services rendered to persons with different disabilities. All Acts related to the social Sectors are prepared after consultation with experts and organizations working in the field. They are referred to different Departments and Ministries for their comments and are approved by the legislative department and the Cabinet before they are tabled in the Parliament. Normally, the Houses of Parliament refer these to the Standing Committees comprising Member of Parliament (MPs), who then consider the matter clause by clause, and only after extensive discussion are these again placed for passing before the Lok Sabha and the Rajya Sabha. There are further opportunities for debate at this stage before the Bill is passed.

40. NGOs in the disability sector have expressed concern that The Rehabilitation Council of India Act, 1992 was passed without consultation and discussion. In fact, non-profit organizations and NGOs in the sector were only informed of the act two years after it was passed in parliament. From 1988 onwards, the Rehabilitation Council of India had started advertising extensively in the national dailies and sending messages to NGOs working in the area of disability stating that professionals working and/or practicing in the disability sector without having registered with the Central Rehabilitation Register would face punitive action. NGOs are still clarifying the constructs of the Act and trying to determine how these requirements will impact on their work. The professionals working in the area of disability are concerned that maintaining a Central Rehabilitation Register is not practical and that the threat of imprisonment for those professionals who are not registered is both unenforceable and highly discouraging. The presence and implementation of The Rehabilitation Council of India Act, 1992 has brought about serious debate on the basic concept and agenda behind the Act and the mechanism for its implementation.

41. The National Trust Act responds to one of the most important concerns of parents and family members of persons with autism, mental retardation and multiple disabilities: who will care for people with these disabilities and manage their affairs after parents or other family members are no longer able to provide care. Under this Act, provisions have been made for persons during their lives following the death or illness of their primary caregiver by appointing guardians under this Act for persons with autism, mental retardation and multiple disabilities over the age of 18 years. The National Trust began with a corpus fund of Rs 100 crore, i.e., 1 billion Rs from the Government of India.

C. National Policy Addressing Disability Through Integrated Programs

1. Education

42. Education is perhaps the single most important means for individuals to improve personal endowments, build capability levels, overcome constraints and, in the process, enlarge their available set of opportunities and choices for sustained improvement in well-being. Education is not only a means to enhance human capital, productivity and, hence incomes, but is equally important for enabling the process of acquisition, assimilation and communication of information and knowledge, all of which augments a person's quality of life. Education is important not merely as a means to other ends, but has intrinsic value. More importantly, it is

critical to bringing about social, economic and political inclusion and a durable integration of people, particularly those 'excluded' from the mainstream of any society.

43. In India, the responsibility of educational development and spread of literacy rests largely with State governments. The Central Government has also been taking initiatives, under its Constitutional obligations, to supplement the efforts of State governments by meeting some critical gaps in public funding for literacy improvement, particularly in the educationally backward States. Education is a concurrent area, which means that both State and Central Governments have the authority to develop education legislation. Where there are discrepancies, legislation of the Government of India (GOI) would prevail. These efforts have taken the shape of an enabling policy framework – for instance, the National Education Policy 1986, and the more recent step of introducing a bill in the Parliament to make primary education compulsory. Other national initiatives include the Total Literacy Campaign, District Primary Education Programme (DPEP), Mahila Samakhyas and the present Sarva Shiksha Abhiyan initiative.

44. The policy for making elementary education universal has to focus on access and enrolment; retention of children up to 14 years of age; and a policy framework for bringing about substantial improvement in the quality of education—including improvements in the educational infrastructure, standardization and regular review of curricula, improvement in teaching aids, practices and training that will enable all children to achieve essential levels of learning.

45. Article 45 of the Constitution enjoins that the State shall endeavor to provide, within a period of 10 years from the commencement of this Constitution, free and compulsory education for all children up to 14 years of age. This Constitutional obligation has been time and again deferred successively to 1970, 1980, 1990 and then to 2000. The Tenth Five Year Plan (2002-07) has set the target of all children completing five years of schooling by 2007.

46. According to the 2001 Census, Rajasthan, Madhya Pradesh and Andhra Pradesh, followed by Orissa and Uttar Pradesh, have made unprecedented improvements in raising their respective literacy rates. Rajasthan and Madhya Pradesh have literacy rates more than 20 percentage points higher than that at the national level.

47. Improving access to schooling and increasing enrolment rates have been backed in some cases by visible measures to improve qualitative aspect of schooling. These efforts have led to improvements in student retention rates and, therefore, better performance on educational indicators.

48. The Sarva Shiksha Abhiyan is a time-bound initiative of the Central Government in partnership with the States, the local governments and the community to provide elementary education to all children in the age group 6-14 years by 2010. It recognizes the importance of community owned systems organized in a mission mode for improving reach and performance of the school system.

49. The Sarva Shiksha Abhiyan seeks to bring about convergence of existing institutional frameworks at the State and district levels. The Programme seeks functional decentralization right down to the school level in order to improve community participation. In addition to involving the Panchayati Raj Institutions/Tribal Councils in Schedule Areas, the States are encouraged to strengthen accountability in implementation of the Programme by involving NGOs, teachers, activists and women's organizations. According to board assessments made by the Department of Elementary Education and Literacy, Government of India, nearly Rs.

60,000 Crore additional budgetary resources are required from the Central and the State governments over the next ten years to implement this initiative.

50. The Compulsory Education Act was enacted in the States and Union Territories and has largely remained un-enforced due to prevailing socio-economic conditions. At the same time, some North Eastern States and Himachal Pradesh, in particular, have made rapid strides in improving their literacy rates without having the support of such an Act. All State governments have, however, abolished tuition fees in government schools up to upper primary level. Education in schools run by local bodies and private aided institutions is also mostly free. Other costs of education such as text books, uniforms, school bags, transport fees, etc. are not borne by States except in a few cases by way of incentives for children from poor and deprived segments of population including, in some cases, girls.

51. The National Policy on Education considers children with disabilities in the 5-14 age group as a vulnerable population. Clause 39 of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full participation) Act 1995 establishes a 3% reservation in all educational institutions to provide a basis for ensuring better education for disabled people. Even though this provision does not discuss the private sector, it could be used to put pressure on private schools and colleges to accommodate children and adults with disabilities into educational institutions. With the help of these provisions in the Act, the Courts have admitted two cases concerning the admission of a student with disability in the Indian Institute of Management, Bangalore and the promotion of an employee with disability at the Indian Institute of Technology, New Delhi. These decisions demonstrate that the law concerning disability could be implemented effectively in an atmosphere of greater sensitivity regarding the rights of disabled people.

2. Health

52. The National Health Policy, 1983 and the draft National Health Policy, 2002 statements have highlighted the need for a time-bound program to establish networks of comprehensive primary health care services, linked with extension and health education. The draft policy proposes service delivery through 'health volunteers' with the appropriate knowledge and skills and emphasizes the establishment of a referral system to prevent needless load on higher levels of health care hierarchy. At the same time the policy proposed to create a network of highly specialized services by encouraging private health care facilities for patients with the ability to pay for health services. While there has been noteworthy success in the eradication of some communicable diseases, and some are expected to be eliminated in near future, the sustainability of India's health care system, as it stands today, is uncertain. Moreover, there is an urgent need to ensure an equitable access to health care services and attain acceptable standards of good health for the population in the country. The broad objective of National Health Policy 2002 is to achieve an acceptable standard of good health amongst the general population of the country. The approach to achieving this objective is to increase access to the decentralized public health system by establishing new infrastructure and upgrading the existing one where necessary. Overriding importance is given to ensuring a more equitable access to health services across the social and geographical expanse of the country.

53. As per the Constitutional allocation of responsibilities between the Central and State governments, health and family welfare has been identified as a State subject. The main responsibility for infrastructure and human resources rests with the State governments. However, over the last five decades the Central Government has provided supplementary funds

for control of major communicable, as well as non-communicable diseases, by initiating national level programs, in some cases with the help of assistance from foreign agencies.

54. National initiatives, on some non-communicable diseases that were perceived as major public health problems, have also been taken. Among these the National Goitre Control Programme (launched in 1962), the National Blindness Control Programme (launched in 1976), the National Cancer Control Programme (launched in 1975-76), National Mental Health Programme (launched in 1982) and Integrated Non-Communicable Disease Control Programme (launched on a pilot basis in the Ninth Plan) are some of the major initiatives of the Central Government. In addition, the Central Government supports bio-medical research in a number of areas. The Indian Council for Medical Research is the nodal organization for undertaking and supervising this work.

55. At the State level, apart from the overall responsibility of providing preventive and curative health care, the Integrated Child Development Services (ICDS) program, the National Mid Day Meals Programme (NMMP), various micro nutrient schemes, including those targeted for improving intake of iron-folate, vitamin A and iodized salt, as well as food for work through various anti poverty programs are some important initiatives aimed at addressing the problem of malnutrition and women and child health. The ICDS program provides services like supplementary feeding, immunization against preventable childhood diseases, health checkups, health and nutrition education to women and pre-school education for children and has recorded significant success in many areas, particularly in States where the primary level health care infrastructure is relatively well developed. The States that have done well include, Kerala, Tamil Nadu, Karnataka and Andhra Pradesh in the South, Maharashtra and Gujarat in the West and West Bengal in the East. Himachal Pradesh, Haryana and Punjab have also done well but it is Rajasthan and Madhya Pradesh that have made significant strides in improving the implementation of ICDS program in their State. The National Mid Day Meal Programme (NMMP) was initiated in 1995 to improve nutritional status and learning achievements of school-going children and, more importantly, their enrolment and attendance in schools.

56. At present, the national norms envisage a Sub-Centre for population of three to five thousand; a Primary Health Centre for population of twenty to thirty thousand; and a Community Health Centre for the four Primary Health Centres. The number of Primary Health Centre doctors at the national level exceeds the requirement as per the norms. There are, however, shortages in the availability of para-medics, as well as specialists at the Community Health Centres, which undermines their functioning as referral units. The disparities across States and within states between regions for infrastructure, as well as for manpower are quite striking.

57. Physical Medicine and Rehabilitation (PMR) emerged as a Medical Specialty in the post-independence era underlining the need of interdisciplinary teamwork among rehabilitation specialists such as physiatrists, physical therapists, occupational therapists, medical social workers, speech therapists, psychologists, prosthetists and orthotists. Only a few institutes have been established with all the above professionals under one roof. Such centres are also required to take up the responsibility of training and research in the field of rehabilitation. However the number of trained rehabilitation professionals—and the number of institutions that offer education and training in these fields—is not sufficient to meet the needs of the country. Mass emigration of rehabilitation professionals has further aggravated this scarcity.

58. With the exception of states such as Kerala and Tamil Nadu, Departments of Rehabilitation, with all the constituent disciplines, have not come into existence, even in the Medical College Hospitals, District Hospitals or cottage hospitals and PHCs.

59. Although the Ministry of Health and Family Welfare is not the focal Ministry for disability issues, it does have an important role in early detection and prevention of disability, and also in the implementation of programs for persons with disabilities under the Act of 1995. As the Ministry has a number of programs that have a direct bearing on disability, its role needs to be strengthened and emphasized.

60. Ongoing national health programs that have a direct bearing on prevention of disability are: (i) Leprosy Eradication Programme; (ii) Blindness Control; (iii) Iodine Deficiency Disorders Control Programmes; (iv) National Mental Health Programme; and (v) Universal Immunization Programme, including the Maternal Child Health Programme. These programs may be further strengthened and attention will be given towards preventive and rehabilitation aspects. A central council was established within the Ministry of Health and Family Welfare to take stock of the status of implementation of health-related policies in the PWD Act 1995. This council meets every two years; recent recommendations include:

- establishing a center for Basic Rehabilitation Services in each State and in every district for people with disabilities;
- identification of and enhanced cooperation with institutions and bodies engaged in research and investigation of cause, occurrences and early symptoms of disability;
- making training programs for medical, paramedical and field workers a top priority with State governments taking advantage of the existing Central schemes for this purpose;
- establishment of a screening mechanism to identify high risk groups among school and pre school children in the States & UTs so that they can be identified and provided with early access to rehabilitation services;
- ensuring proper physical facilities for disabled people in hospitals and health institutions such as special toilets and ramps to increase their access to medical facilities.
- ensuring that State has at least one medical college with a Department of Physical Medicine and Rehabilitation;
- the Medical Council of India should re-circulate its mandatory recommendation, which should be made time bound for starting Department of Physical Medicine and Rehabilitation in all medical colleges (private and government). To meet the requirements of the new curriculum for under-graduate medical education.
- developing facilities for chronically disabled patients with health problems in each state.

The Council also suggested an increase in budgetary support from the State with equal attention to the rural and urban poor.

3. National Commission for Women

61. The National Commission for Women is a statutory body established in 1992 to safeguard the rights and interests of women. The Commission reviews legislation that affects women specifically and advises the government to bring forth necessary amendments from time to time. The Commission has conducted a nation-wide investigation of issues for women belonging to socially and economically disadvantaged groups specially those from the Scheduled Castes and Scheduled Tribes and other target groups such as women/child-sex workers, women in custody/asylum, and women with disabilities.

62. The Commission has adopted open public hearings (open adalats) to enquire into cases of grievance and abuse. In the process, it has taken the system of justice to the doorsteps of women. Based on its recommendations, the government has already initiated an action to amend the Commission of Sati (Prevention) Act, 1987; the Immoral Traffic (Prevention) Act, 1956; the Indecent Representation of Women (Prohibition) Act, 1986; the Child Marriage Restraint Act, 1929; the Guardians and Wards Act; Family Codes Act; the Foreign Marriage Act; and sections of the Penal Code relating to rape.

4. Employment

63. Under the Constitution of India, labor is a subject in the Concurrent List where both the Central and State governments are competent to enact legislation subject to certain matters being reserved for the Center. The Ministry has four attached offices and ten subordinate offices, four autonomous organizations, seventeen adjusting bodies and one arbitration body.

64. Under the Constitution of India, vocational training is a concurrent subject for both the Central and State levels of government. The Central Government has responsibility for developing training schemes at the national level; policy development; and establishing training standards, procedures, conducting trade tests and certification, whereas implementation of the training schemes largely rests with the State and UT governments. The National Council of Vocational Training (NCVT), a tripartite body with representatives from employers, workers and Central and State governments acts in an advisory capacity. Similar Councils, known as State Councils for Vocational Training (SCVT), have the same role with respect to State governments.

65. The Directorate General of Employment and Training (DGE&T) is a Department of the Ministry of Labour. In 1950 the Directorate initiated the Craftsmen Training Scheme (CTS), establishing about 50 centers to develop skills in various vocational trades and to meet the skilled manpower requirements for technology and industrial growth of the country. The growth of industrial and vocational training in India has been dramatic. In 1980, there were 831 such industrial training institutes (ITIs), currently there are 4465 ITIs, 1733 government facilities and 2732 in operated by the private sector. The objectives of the CTS are:

- to ensure a steady flow of skilled workers;
- to raise the quality and quantity of industrial skills; and
- to reduce unemployment among educated youth by equipping them with suitable skills for industrial employment.

66. Seats are reserved for SC/ST candidates in proportion to their population in respective State/UT. Guidelines for reserving 3% seats for persons with disabilities and 25% for women candidates have been issued to State governments, and these could be filled based on the general reservation policy of each State/UT, with a total reservation limited to 50% of seats. It should be noted that participation rates for disabled people in vocational and industrial training does fall below the target of 3%.

67. The Women's Vocational Training Programme in the Ministry of Labour was launched in 1974 with the aim of promoting social development and economic opportunities for women through vocational and skill training. A separate women's occupational training directorate is responsible for formulating long-term policies related to Women's Vocational Training in the country. A network of institutes, both under the Central and State Sector, have been set up for extending skill training facilities to women and aim to stimulate employment among women of

various socio- economic levels and different age groups. Under the Central Sector the Institutional Network includes

- A National Vocational Training Institute for Women; and
- Ten Regional Vocational Training Institutes for Women.

Both Institutes provide facilities for structured long-term, regular advanced skill and post advanced training for women.

68. For skill training to poor women (those below poverty line), the International Labor Organization (ILO) has undertaken a project on Decent Employment for Women; DGE &T is the focal point agency from GOI.

69. The program will focus on enhancing productive employment and income earning opportunities for women as well as on promoting awareness of their rights in the workplace and as women workers in the non-formal sector. This is a pilot program and will be implemented in New Delhi and Bangalore.

70. There are 938 Employment Exchanges at the State level, including 42 Special Employment Exchanges for persons with disability throughout India. Forty-one special cells for persons with disability have also been created within mainstream Employment Exchanges. Most States have a Directorate of Employment located in the State capital.

71. While employment services continued to make efforts to meet the special needs of disabled job-seekers, they are unable to keep pace with the consistently rising numbers. To date, employment exchanges have succeeded in placing only 100,000 disabled people.

Table 3: Performance of Employment Exchanges with Respect to Disabled Job-Seekers (in thousands)

Year	Registration	Placement	Live Register
1993	49.3	4.5	337.6
1994	43.7	4.5	340.3
1995	48.3	3.7	352.7
1996	52.1	3.9	359.1
1997	51.6	4.5	392.6
1998	54.9	3.6	415.3
1999	62.7	4.2	455.9

72. There are currently 17 Vocational Rehabilitation Centres for Disabled People located in 16 states. Out of these, the Vocational Rehabilitation Centre at Vadodara has been set up

exclusively for women with disabilities. Rehabilitation services are also extended to persons with disabilities living in rural areas through mobile camps (the quality and the sustainability of such mobile camps is always questionable) and Rural Rehabilitation Extension Centres (RRECs) set up in 11 Blocks under 5 VRCs.

D. National Policy Addressing Disability through Targeted Programs

73. The Ministry of Social Justice and Empowerment monitors the implementation of the Persons with Disability Act 1995 and National Programme for Rehabilitation of Persons with Disabilities delivered at the State level, and has established a number of composite resource centers and rehabilitation centers. The Ministry has also created and manages national trusts for persons with various disabilities, such as Spinal Injuries, Autism, and Cerebral Palsy. It plays a vital role in the coordination, networking and collaboration with other related departments for inclusion of disability issues in the mainstream.

74. There are over half a dozen government departments that are directly engaged in addressing the problem of disability in India. A coordinated approach to build synergies across the various interventions could substantially improve the effectiveness of public action in this area. Each Ministry and Department of the government has earmarked funds to develop activities concerning persons with disabilities in its area of operation.

75. In the field of health a National Programme for the Control of Blindness was launched in 1976. Applying a variety of strategies, this Programme succeeded in reducing the prevalence of blindness from 1.4% to 0.3%. The Leprosy Eradication Programme with Multi-Drug Therapy also had an impact on the incidence rate and prevention of disability. The National Immunization Programme expanded to uncover areas and increased the number of children immunized. The National Mental Health Programme seeks to run training programs and information, education and communication (IEC) activities within the District Mental Health Programmes.

76. Under the ICDS network, special attention was given to the needs of pregnant women and nursing others living below the poverty line in socially and economically marginalized villages and urban slum areas.

77. The Department of Women and Child Development has been given special responsibility in the field of prevention. Health-related programs that prevent some disabilities continue to be strengthened and implemented through a multi-sectoral and collaborative approach. In the Maternal Health Programme, emphasis is laid on pre-natal and post-natal health of the mother and infant.

78. Pre and Post-natal screening for prevention, coupled with timely intervention and treatment, could also avoid occurrence of severe and secondary disabilities. Corrective and rectifying surgery and medical intervention could be provided to prevent permanent disabilities. Training of Anganwadi workers and ANM for early detection and timely prevention of disabilities is also undertaken by the same department.

1. Funding for National Policies

79. Financial support for inclusion of disability concerns within national programs is largely supported by UN organizations and allocated through the recommendation of the Ministry of Finance to the relevant ministry who in turn hands it over to the state departments. In other words, implementation is the responsibility of the State, although programming decisions may

be made by the National Government, and are funded by UN or allied agencies. Recently, implementing agencies have begun seeking support from various NGOs for the implementation of development programs.

80. The programming priorities of international funding agencies in India are varied, but focus largely on issues related to poverty, gender, and children. Of late, disability concerns have begun to be included in the mandates of funding agencies as well. The World Bank has supported the Government of India's inclusive education initiative in 16 States and UTs. UNICEF was a pioneer in promoting the integration of children with special needs along with funding for Braille production. UNESCO has also funded programs for inclusive education while UNESCAP has supported the inclusion of disabilities strategies within rural development initiatives. The WHO initiated the Community-Based Rehabilitation (CBR) model in India and has supported programs for the prevention of leprosy and blindness.

81. Disability issues are also being addressed through projects and programs funded by bi-lateral agencies. The Danish Agency for International Development (DANIDA) has long been associated with programs to control of leprosy and cure blindness, and has recently supported advocacy initiatives promoting the rights of disabled people. The German Government supports the MISEROR CBR forum, which primarily funds organizations working in the field of disability through a community-based approach. The Netherlands has also funded programs for district rehabilitation centers in India, while the Government of Norway has funded income generation programs for women with disabilities in CBR network.

82. The National Handicapped Finance and Development Corporation (NHFDC) was incorporated on 24th January 1997 under Section 25 of the Companies Act for channeling funds through agencies and NGOs authorized by the State governments and Union Territory Administration. The Corporation aims to promote economic empowerment of Persons with Disabilities through financing self-employment ventures. It also extends loans for pursuing general/professional/technical education at the Graduate and Higher levels. NHFDC also assists in the upgrading of technical and entrepreneurial skills of persons with disabilities to manage their production units efficiently. While there are channeling agencies of NHFDC in various states and UTs, insufficient operational capacity is a cause of concern.

2. Rehabilitation Programs

83. The National Programme for Rehabilitation of Persons with Disabilities (NPRPD) was launched with a view to providing comprehensive rehabilitation services to persons with disabilities, especially those living in rural area. There is a four-tier structure for service delivery at Gram Panchayat, Block, District and State levels. The focus is on provision of identification, early detection and intervention at the grassroots level and on provision of referral services at the district and state levels. The NPRPD has been implemented as a State Sector Scheme since 1999-2000, when funds were released to set up the State Referral Centres (SRCs). The Scheme will ensure local capacity building and better utilization of available resources while providing a much needed rehabilitation structure from the panchayat level upwards.

84. During 2000-2001, five Composite Regional Centre for Persons and Disabilities (CRCs) were set up in Srinagar, Lucknow, Bhopal, Sundernagar, Guwahati. These are housed in facilities provided by the respective State governments with assistance of National Institutes. Four Regional Rehabilitation Centres for Spinal Injured at Mohali, Cuttack, Jabalpur and Bareilly have also started providing services in the temporary accommodation given by the State governments.

85. There are 11 District Rehabilitation Centres in the country. Their objective is to provide comprehensive rehabilitation services to people with disabilities in rural areas through a camp approach in the villages. These centers provide services for prevention and early detection, medical intervention, surgical correction, fitting artificial aids and appliances, physiotherapy, occupational and speech therapy, vocational training, and job placement in local industries. There are also Four Regional Rehabilitation Training Centers (RRTCs) located in Chennai, Cuttack, Lucknow and Mumbai for training and manpower development in the field of rehabilitation.

86. The Science and Technology Project in Mission Mode was established in 1986 to support research and development of appropriate and innovative technological appliances to improve the quality of life of people with physical disabilities. The scheme aims to coordinate, fund and direct application of technology in the development and utilization of suitable and cost effective aids and appliances, as well to promote education and skill development, easier living and mobility, communication, recreation and social integration. Full funding is provided to researchers, engineers, doctors, scientific departments autonomous bodies and research laboratories. Over 30 aids and appliances/products have been developed through this program. These include plastic aspheric lens for persons with low vision, the myo electric hand control system and a motorized, joystick-operated wheelchair.

87. The Government of India facilitates delivery of various rehabilitation services to persons with disabilities by both public institutions and voluntary organizations. Financial assistance and technical and administrative support is given to promote voluntary action to enlarge the scope of vocational and professional opportunities, and income generation through formal as well as non-formal employment and placement opportunities.

IV. DISABILITY ORGANISATIONS AND DEVELOPMENT AGENCIES

88. The quality of life of disabled people is very low. Facilities provided by the government and NGOs are inadequate, which has increased the dissatisfaction levels of disabled people and their caregivers. The majority of people with disabilities are poor and the incidence of disability among the poor is also higher than that found in middle or high income groups.

89. The impact on quality of life is particularly significant among people who have lived with a disability from birth or early childhood. In such cases the means to acquire literacy, education and skills are often significantly reduced, thereby affecting their capability to participate effectively and productively in society. Not only does a person with disability require resources and assistance to overcome physical barriers, but he or she may also require additional resources to meet specific education, training and skills needs in order to realize their fullest potential. The on-set of disabilities with age have in most cases a direct bearing on the economic well being of the person through reduced work participation rates and a decline in productivity of the affected person. As a result, employment and income levels tend to be a fraction of those of non-persons with disability. People with disabilities face physical, social and attitudinal barriers that may restrict their livelihood opportunities and access to basic public services or social transfers.

90. The emergence of Persons with Disability Act in 1995 was no doubt a landmark moment in the history of disability in India. Through the Act, the Government of India explicitly recognized and realized the potential and dignity of persons with disabilities for the first time, and accorded disabled people status as contributing members of society. The Act also provides

for grievance mechanisms in relation to the protection of rights of persons with disabilities and non-implementation of related laws, rules, regulations, executive orders, guidelines etc. The implementation of the provisions of the Act is being undertaken through a multi-sectoral, collaborative approach, as related ministries and departments of the Central Government, the State governments and other appropriate authorities continue to take steps towards effective implementation of the various provisions of the Act. The Act mandates the formation of two statutory committees: the Central Coordination Committee (CCC), which is a policymaking body consisting of 33 members with representation from five NGOs; and the Central Executive Committee (CEC), which is the decision making body consisting of 23 members with representation from three NGOs. While these bodies provide an excellent opportunity for inter-agency coordination and government-NGO collaboration, they do not meet frequently enough to fully achieve this potential. While CCC ought to meet once every quarter, and the CEC should be meeting once every six months, in fact the CCC has only met five times in the past 16 years, and the CEC has met only eight times. Similar bodies are active at the State level as well; to date only a few States have convened such committees.

91. NGOs working in the field of disabilities and development along with community-based organizations are also important stakeholders. Disabled people's organizations are also very important stakeholders and national institutions, United Nations agencies and international donor agencies can play a very important role to ensure the inclusion of persons with disabilities in various development programs. The private sector in India has taken few initiatives by providing employment to persons with disabilities; the potential for more active engagement of the private sector in actively creating employment opportunities for people with disabilities makes it an important stakeholder as well. It is to disabled people's organizations and parents' organizations that Indians owe their gratitude for the enactment of legislation for persons with disabilities. Disabled people's organization and NGOs working in the field of disability have to their credit inclusion of disability related items in the 2001 Census.

92. With the shift from a medical model to the social model for addressing disability issues, the emphasis today is on integrating disability into development processes. It is more cost-effective, and promotes better social integration by ensuring that people with disabilities have access to the same benefits and services as others in the community. As well, community participation is likely to be greater in a program that benefits the majority, rather than a minority group. At the same time, people fear that unplanned integration of disability into other development programs can ignore 'real rehabilitation' needs, such as mobility, special education, vocational rehabilitation etc., and inadvertently contribute to increased marginalization of people with disabilities, rather than their integration into the mainstream.

93. Integration of disability issues into development programs requires a high degree of coordination and collaboration between different sectors such as health, education, and employment. Often, such co-ordination works better at local, 'grass-roots' levels, but fails at higher regional or national levels. Multi-sectoral collaboration is difficult for a number of reasons. For example, the management cultures of government organizations and non-governmental organizations (NGOs) are quite different, with the government operating in a top-down manner while the NGOs are usually 'bottom-up' and democratic in their management style. These differences can become a barrier to effective collaboration. Also, multi-sectoral collaborations can become mired in power and control issues between the different sectors. Lack of commitment to stated goals from all partners can also be a problem in multi sectoral collaborations.

94. It is estimated that 70% of people with disabilities could be supported at the community level, while the remaining 30%, i.e. people with severe and multiple disabilities, would require specialist interventions that are not available in the community. CBR programs face many difficulties in dealing with severe disabilities. Many of those who establish programs are external agents, who must build a rapport with the community and still show quick results. Also, many CBR programs are not staffed by specialists with the training needed to work with people with severe and/or multiple disabilities. Sometimes, in the process of promoting 'community participation' and the 'rights' of persons with disability, the severely persons with disability get neglected. No valid methods to effectively address the needs of this group at the community level have been devised.

95. The Government has the financial and human resources to address issues of quantity, while NGOs have the capacity to provide quality services for persons with disabilities. Therefore, government-NGO collaboration could result in a synergy that promotes more effective coverage as well as quality of services. NGOs and community-based organizations (CBOs) not only have the benefit of presence and acceptance at the grassroots, but also possess technical know-how and stability that can enhance the cost effective delivery of programs and services in partnership with government.

V. RELATIONSHIP BETWEEN DISABILITY AND POVERTY

A. Government Poverty Reduction Strategy

96. The Government of India's anti-poverty strategy is comprised of a wide range of poverty alleviation and employment generation programs, many of which have been in operation for several years and have been strengthened to generate more employment, create productive assets, impart technical and entrepreneurial skills and raise the income level of the poor. Under these schemes, both wage employment and self-employment are provided to people living below the poverty line. In 1998-99, various poverty alleviation and employment generation programs were grouped under two broad categories of Self-Employment Schemes and Wage Employment Schemes. Funding and organizational patterns are also rationalized to achieve better impacts. These programs are primarily meant for poverty alleviation, but have generally not been successful in achieving sustainable employment generation.

1. Urban Development

97. Urban poverty has become an area of concern, as almost one-third of the urban population in the country falls below the poverty line. By 2025, well over 50% of the population will be urban-based, and the number of people living below the poverty line will increase in both absolute and relative terms. Therefore, the need to attend to deficiencies in urban infrastructure, such as water supply and sanitation, will continue to increase. To overcome the shortage of potable water issues such a better distribution, proper storage, improved water management practices, and conservation of ground water resources have to be tackled by resource deficient Urban Local Bodies (ULBs). Similarly sanitation and environmental hygiene need urgent attention. Disposal of solid water, proper sewerage and drainage facilities, regular conservancy and effective public health measures are other priority areas.

98. It is evident that the New Economic Policy launched in India in 1991-92 did see several important initiatives in the urban sector designed to encourage private sector participation in urban infrastructure projects. These initiatives would need to be taken to their logical conclusion.

A series of new Reform Measures are being put together for implementation during 10th Plan Period. There is a hope to reverse the declining standards of urban infrastructure in the country.

99. Centrally-sponsored schemes under the urban development department include

- scheme for Infrastructure Development In mega cities;
- Integrated Development of Small and Medium Towns (IDSMT);
- Accelerated Urban Water Supply Programme (AUWSP). The Accelerated Urban Water Supply Programme (AUWSP) is a Centrally Sponsored Scheme initiated with the objective of solving the drinking Water Problems in Towns having population of less than 20,000 as per 1991 census; the scheme is funded by the Central and State governments in the ratio of 50:50;
- Low Cost Sanitation Scheme for Liberation of Scavengers; the main objective of the scheme is to convert the existing dry latrines into low cost pour flush latrines and to provide alternative employment to the liberated scavengers; and
- Urban Mapping Scheme.

100. Urban Transport is another crucial component of urban infrastructure with a direct bearing on poverty reduction as it provides access to opportunities, supports urban economic activities, and facilitates social interactions. A good network of roads and an efficient Mass Urban Transport System makes a significant contribution to improve the working efficiency of a city and its environs, while underdeveloped transportation systems degrade quality of life through congestion, pollution, accidents etc. The extent to which Indian cities can maximize economic performance and reduce poverty will be closely linked to how efficiently the transport system moves people and the goods upon which their socio-economic activities depend.

101. The major responsibility for urban road transport infrastructure and service delivery rests with the State government and local bodies, At present the major initiative by this Ministry in the area of urban transport is in the form of a grant of 40% of the cost to be given to the State governments for the preparation of comprehensive Traffic System Management. The Delhi Metro Rail Transport System Project was approved 'in principal' by the Union Government in 1994. The project envisaged introduction of a metro rail system of about 55.3 km, comprised of 11 km of underground rail corridor and 44.3 km of elevated-cum-surface rail corridor. Construction began in 1998 and the project is scheduled to be completed by March 2005. Care has been taken to ensure accessibility for persons with disabilities on the metro rail system. Since managing road transport is a state subject, and most of the states do not have substantial financial resources, the needs of disabled people are not being addressed through current road transport projects.

102. The National Housing and Habitant Policy was formulated to address the issues of sustainable development and infrastructure and to promote strong public-private sector partnerships for shelter delivery. The objectives of the policy are to create surpluses in housing stock and facilitate construction of 2 million additional dwelling units each year. This program has a special focus on meeting housing needs among Economically Weaker Sections (EWS), Low Income Groups (LIG) and other vulnerable groups. Out of 2 million additional houses, 0.7 million houses will be constructed in urban areas and remaining 1.3 million in rural areas. Pursuant to the National Agenda for Governance, which identifies "Housing For All" as a priority area, the Policy also seeks to ensure that housing—along with supporting services—is treated as a priority sector at par with infrastructure development.

103. The Urban Wage Employment Programme (UWEP) seeks to provide wage employment to beneficiaries living below the poverty line, within the jurisdiction of urban local bodies, by utilizing their labor for construction of socially and economically useful public assets. Under this program, there is no restriction on educational qualification. This program applies to urban local bodies, the population of which was less than 5 lakhs, as per the 1991 Census.

104. Additional Central Assistance (ACA) is being released to States and UTs for the development of urban slums. The objective of this program is to provide adequate and satisfactory water supply, sanitation, primary education facilities, health care, community empowerment, garbage and solid waste management in addition to improvements to slum dwellings themselves. The program also aims to improve different social sector programs through creation of sustainable support systems. The focus will be on community infrastructure, provision of shelter, empowerment of urban poor women, training, skills up-grading and advocacy and involvement of NGOs, CBOs, Private institutions and other bodies.

2. Rural Development

105. Rural development is also a priority for the Government of India. The National Government has invested in a number of programs aimed at sustainable holistic development of rural areas. A Strategic Pro-poor Policy in which the rural poor are treated as a net resource replete with their own ideas and experience forms an integral part of the Development Strategy. In the process, the disadvantaged sections of society receive a high priority. The Panchayati Raj Institutions constitute the bedrock for the implementation of Programmes. Accordingly, sustained efforts have been made to strengthen local governance institutionalizing people's participation and empowering women through the Panchayati Raj Institutions.

106. The enactment of the Constitutional 73rd Amendment Bill, 1992 has paved the way for the creation of statutory institutional structures for releasing the goals of self-governance under the Panchayati Raj system. The explicit objective of this initiative for democratic decentralization of governance is to accelerate the socio-economic development of the rural areas within the participatory framework at a grass root level. The Amendment has given statutory recognition to a 3-tier system of governance with Panchayati Raj Institutions (PRIs) at the district (Zila Parishads), intermediary (Mandal Panchayats) and village levels (Gram Sabhas/Panchayats).

107. Five elements of social and economic infrastructure, critical to the quality of life in rural areas are health, education, drinking water, housing and roads. To impart greater momentum to the efforts in these sectors, the government launched the Pradhan Mantri Gramodaya Yojana (PMGY). The Ministry of Rural Development has been entrusted with the responsibility of implementing the drinking water, housing and roads component of PMGY.

108. There is a close link between Rural Connectivity and Growth, be it in the area of trade, employment, education or healthcare. The Pradhan Mantri Graam Sadak Yojana (PMGSY), launched on 25th December, 2000 seeks to provide all-weather roads to all unconnected rural habitations with a population of more than 500 persons in the next seven years.

109. For sustainable habitat development at the village level, and to meet the growing housing needs of the rural poor, the Additional Central Assistance is released to the State governments and Union Territories on their submitting specific project proposals. These proposals are then scrutinized by a Committee on whose recommendations funds are released by the Ministry of Finance.

110. A comprehensive Action Plan for Rural Housing envisaging construction of 25 Lakh houses annually in rural areas and upgrading unserviceable Kutcha houses. The Action Plan is being implemented through various programs such as the Indira Awaas Yojana (IAY) Credit-cum-Subsidy Scheme for Rural Housing, the Innovative Stream for Rural Housing and the Habitat Development Rural Building Centres.

111. Under the Rural Drinking Water Programme a minimum of 25% of the total allocation is to be utilised by the respective States or UTs on projects and schemes for water conservation, water harvesting, water recharge and sustainability of the drinking water. The Programme intends to expedite availability of potable drinking water to all habitations of the country.

112. The Accelerated Rural Water Supply Programme has been revamped and aims to institutionalize community participation in the rural water supply sector with a view to gradually replacing the government-oriented, centralized, and supply driven Rural Water Supply Programme with one that is people-oriented, decentralized, demand driven and community-based.

113. The Central Rural Sanitation Programme (CRSP) is community-led and people-centered and aims to provide adequate sanitation facilities to the rural poor and generate awareness of health issues. A Rural School Sanitation Programme has also been introduced as a major component and as an entry point encouraging wider acceptance of sanitation by the rural masses.

114. The National Social Assistance Programme (NSAP) consists of three schemes: the National Old Age Pension Scheme (NOAPs), the National Family Benefit Scheme (NFBS), and National Maternity Benefit Scheme (NMBS). The NSAP is a 100 percent centrally-sponsored Programme and extends benefits in the form of an old age pension of Rs. 75 per month to aged destitute, Rs. 10,000 to the bereaved (poor) family on the death of its primary breadwinner and Rs. 500 as maternity benefit to poor women, up to the first two live births.

115. The Jawahar Gram Samridhi Yojana provides demand driven rural infrastructure at the village level to enable village communities to create durable assets such as school buildings, roads, etc.

116. The Employment Assurance Scheme provides employment to persons below the poverty line in lean agriculture seasons and during the period of acute shortage of wage employment. Its secondary objective is to create durable community, social and economic assets for sustained development.

117. The Swarnjayanti Gram Swarozgar Yojana (SGSY) is a comprehensive self employment program that aims to raise the family incomes of the rural poor and provides for flexibility of design at the grassroots level to suit the local needs and available resources. The SGSY emphasizes the group approach, enabling rural poor to face various challenges in self-employment such as skills development, marketing, handling finances etc.

B. Institutional Framework

118. Planning is an important tool as the nation allocates its resources for development and poverty reduction. The extent to which planning takes place—and the issues addressed through a planned approach—depends largely on the priorities set by political leaders as well as the size and scope of the issue. National policy formulation is always done at the Central level

with inputs from the States and UTs. Funding for development projects from UN agencies is received by the Central Government, which becomes the executing agency for different development programs. These funds are then released to State governments for implementation. The Central Government also funds projects through the National budget; again the States and UTs implement these initiatives. Regardless of the original source of funds, the State and UT governments are expected to sustain the programs with their own resources after the project period is completed. Because most development programs are designed and conceptualized at the Central level, most meet an untimely end when funding is no longer in place.

119. Currently the formulation and execution of social welfare programs at the Central level is scattered over various ministries, departments and agencies. There are many States that have not been able to formulate or develop adequate social welfare programs to commensurate to the needs of the different target groups. Most State programs do not have proper linkages, inter-sectoral coordination mechanisms, or state-wise assessment of the various problems needed to prepare suitable schemes.

120. Sometimes, when the schemes are proposed by the Centre for the States to implement, there are no takers, as priorities and vision are not always shared. The role of the State needs to be conceptually repositioned. It can neither be a completely minimalist role nor an entirely proactive one. It has to be directed at building personal capabilities and community capacities for human development through the use of all the means at its command. There are, however, aspects of governance and the contingent instruments that have to be taken up on priority. The issue of improving Central and State Governance in the country has to be addressed at multiple levels. The relevance and the operation of institutions to direct social, economic and political processes towards the goals of human development will have to be re-examined.

C. Program Initiatives for Disabled People

121. While the links between disability and poverty are well known and understood, there is an absence of statistical data to quantify the scale and scope of the problem. At the most basic level, there is a lack of accurate data to measure the number of persons with disabilities in India. While the Report of the National Health and Family Survey provides data on the standard of living of poor people and their access to potable water, health services and toilet facilities, no mention is made of the availability of these basic services for persons with disabilities or of the incidence of disability among persons who are poor. Though most poverty reduction programs of India have a mandatory reservation of 3 percent in all their schemes in the wake of PWD Act 1995, there is no data on the numbers of disabled people who are reached through these programs.

122. Service delivery with respect to health, education, employment and welfare is the responsibility of State and UT governments. In spite of existence of national legislation, the degree to which it is implemented varies among the different states. Also, the task forces mandated by the Act have not been constituted in all states, and to date only nine states have struck independent commissioners. Lack of awareness about the Act is apparent among the poorest of the poor; even lawyers, judges and officials remain unaware of its provisions.

123. Bureaucracy in India is a highly rigid hierarchized system, which carries the risk that issues such as disability can be overlooked as social programs move from the national to the State and local levels. However, if properly utilized, this same system can create wonders through convergence. The Deputy Commissioner is the administrative and bureaucratic head at

the district level with maximum concentration of powers, thereby able to play an important role in ensuring the implementation of programs under the education, health, rural and urban departments.

124. Programs targeting poor persons with disabilities in India suffer from poor implementation, especially with respect to decentralization. Resources allocated through urban and rural poverty alleviation departments are rarely utilized fully. For example, many seats reserved for persons with disabilities within government-sponsored employment and vocation training programs remain unutilized because program staff do not have the relevant information or are not motivated to promote these opportunities among people with disabilities. In spite of regular government orders and office memorandum, the needs and concerns of persons with disabilities have not been taken up as a priority by the local implementing offices. There is also a lack of knowledge and understanding of the rights of disabled people among local government personnel.

125. Despite the systemic challenges posed to addressing the needs of disabled people within the National Poverty Reduction Strategy, there are a number of initiatives that are providing some measure of social security to people with disabilities.

1. Special Benefits (Pensions and Health Allowances)

126. Under the country's social protection structure, persons above the age of 18 with a disability more than 40% are entitled to a disability pension, the amount of which varies from state to state. The amount of disability pension depends on the prosperity and the commitment of the state towards disability concerns. There are 28 States and UTs in the country providing disability pensions and seven States and UTs that have no disability pension program. Pension amounts range from Rs. 50 to Rs. 300 per month. Only 12 States and UT's provide an unemployment allowance. There is a provision of concessional telephone connection on priority to blind persons. Goa is the only state granting tax exemptions on purchases of equipment for self-employment for people with disabilities, up to Rs 30,000.

127. Under the National Social Assistance Programme Old Age pensions are given to people over the age of 60 living below the poverty line. There is also provision under this pension scheme to cover disabled people who are over 45, and under certain conditions age restrictions can be relaxed by the District Committee headed by the District collector. However, not all States have such Committees.

128. As health services are provided free of cost, there is no special health allowance given to persons with disabilities or those below the poverty line. Departments of Welfare in many States operate programs for free distribution of assistive aids and appliances for persons with disabilities, with the help of National Ministry of Social Justice and Empowerment. Some states have also taken the initiative to conduct free surgeries for correctable conditions.

2. Housing and Transportation

129. There are 22 States and UTs that provide a Conveyance Allowance to disabled State government employees. Bus Concessions are given in 26 States and UTs. Persons with 100% visual impairment or more than 80% locomotor disability are eligible for concession on air travel. Under the Poverty Reduction Schemes and Programmes in the urban and rural areas, disabled people can access housing through Indira Awas Yojana. Some states, such as, Tamil Nadu

have established proactive programs, providing free housing sites or agricultural land to those disabled people who are living below the poverty line.

130. Disabled government employees with disabilities, as well as those suffering a serious illness, may get adhoc allotment within the general pool of the government's residential accommodation. A request for government housing must be made to a Special Recommendation Committee and be approved by the Urban Development Ministry. For those disabled employees who have been provided with government accommodation within a distance of one kilometer from the place of work, or within a campus housing the places of work and residence, the allowance shall be admissible for normal rates as applicable under the orders. The Fifth Central Pay Commission has recommended that a Transport Allowance be given to Central Government Employees with Disabilities to suitably compensate them for the cost incurred on account of commuting between the place of residence and the place of duty.

3. Family Benefits

131. Disabled children of government employees are eligible for the family pension benefit, even if they have been born after the retirement of the government servant.

4. Others

132. Section 33 of the Persons with Disabilities Act 1995 provides that in every establishment the government shall hire disabled people to fill no fewer than 3% of all vacancies. There are provisions under the Ministry of Rural Areas and Employment for 3% reservation of total coverage of beneficiaries for Persons with Disabilities under the Training for Rural Youth for Self Employment (TRYSEM) Program, Integrated Rural Development and Employment (IRDE) Scheme and organized separate groups of disabled women. Under the department of Rural Employment and Poverty Alleviation, out of 60% funds earmarked for general works, 3% of funds are to be utilized for the creation of barrier-free infrastructure with an annual allocation of 3% for this purpose at the intermediate and village level Panchayats. There is also scope for convergence of funds of the intermediate and village Panchayats to be used according to the needs of the area concerned.

4. Community-based Rehabilitation

133. In the early 1980s, community-based rehabilitation (CBR) emerged as an important approach to addressing disability issues in the wider social context. CBR evolved primarily as a medically-focused service delivery method, since the WHO had recommended that it be integrated into the established primary health care (PHC) system. The early CBR programs tended to focus on restoring functional ability in disabled individuals in order to 'fit' them into their community. During the 1980s and 1990s there was substantial growth in the number of CBR programs. Along with the quantitative growth, there were also major changes in the way it was conceptualized. One of the early changes was the shift from a medical focus to a more comprehensive approach. With the realization that stand-alone medical interventions did not complete the rehabilitation process, CBR programs gradually began to incorporate interventions such as education, vocational training, social rehabilitation and prevention. Along with this shift came the recognition that CBR needs to deal with issues related to disabled people's lives at all times and to seek to change not only the disabled individual, but the context in which he or she is located. Addressing these contextual factors involved changing attitudes of non-persons with disability in the community to accept people with disabilities, promoting their social integration, and promoting equal opportunities in education and employment, in the same way that they are

available to non-persons with disability. Empowering communities to manage their programs was another important contextual evolution in the CBR approach. Thus, CBR has moved beyond the medical model of service provision and today follows a social model.

134. Lack of organizational ability and knowledge about disability on the part of community development organizations acts as a major barrier to integration. Disability is seen as a 'specialist' issue, and hence many organizations feel that they do not have the expertise to address it. Further, disabled people tend to be recognized only by their disability and not by any other parameter such as gender, poverty level, ethnic status and so on, resulting in their exclusion from the benefits of integrating disability into mainstream development programmes. Lack of mobility, education and skills continue to prevent disabled people from participating in development programs as full stakeholders and equal partners.

VI. FRAMEWORK OF THE PARTICIPATORY PROCESS

135. RETA 5956 was carried out using within a framework based on key participatory development and research principles. The participatory framework was developed to ensure that disability issues related to poverty reduction highlighted in this study reflect the experiences, knowledge, understanding and perspectives of the widest possible range of stakeholders.

136. The importance of adopting the participatory framework as a process for the development of the country study report in all four project countries (Cambodia, India, Philippines and Sri Lanka) emerged from the Disability and Development Workshop that took place in 1999. The participatory framework was considered the most important factor to ensure participation in the study from all the key stakeholders in the field of development and disability. It was also realized that there was a need to provide a forum for persons with disabilities with scope of valued participation.

137. Focus group discussion was among the methods used to ensure participation. During the launch of the project in each country, the International Team Leader and local specialists carried out these meetings with important actors in the field of disability and development from government, the NGO sector, international donor agencies, United Nations agencies, and, most importantly, representatives of disabled people's organizations.

138. Four Provincial-level Workshops and one National Workshop were organized in India during the execution of the RETA. More than 185 representatives from all related fields of development, including Central and State governments, UN agencies, disability specific NGOs, development NGOs, community based organizations, the corporate sector, financial institutions and disabled people's organizations participated in these workshops. Out of total number of participants, 25 persons with disabilities and parents of persons with disabilities participated in the workshops.

139. Locations for the Provincial Workshops were decided on the basis of geographical coverage of all the states & union territories of India. Four provincial workshops were held at Chennai, Mumbai, Kolkata and Delhi, finally culminating in a National Workshop in Delhi. The workshops were designed to give an opportunity for maximum interaction and participation among the participants. Participants interacted primarily through plenary sessions and group discussions in the provincial workshops whereas the future search conference methodology was used in a structured way at the National Workshop. It helped to build a common ground

and collectively analyze past and the present with overall aims of establishing a vision to contribute toward a National Action Plan. Small groups discussed sector-specific issues and developed relevant recommendations for mainstreaming disability issues in the development programs. Strengths, weaknesses, opportunities and threats to mainstreaming disability issues were discussed democratically in groups. Participants explored core values, and came to an agreement on the values that will guide an action plan for mainstreaming disability issues in poverty reduction. These core values included equal opportunities, mutual respects, openness, accountability, transparency, integrity and sensitivity. The workshops also gave an opportunity to discuss values and attitudes that were influenced by culture and have contributed to the status of persons with disabilities. There were differences of opinion among the participants regarding the strengths of joint family norms.

140. A Country Background Paper was drafted and shared with participants at the Provincial and National workshops for validation by actors in the field of disability and development. It provided a forum for key stakeholders to build commitment to and a common vision for a National Action Plan for mainstreaming disability issues in poverty reduction programs. The process helped to create a better understanding and awareness of disability. It also increased interest in the issues and ownership of the study and networking among stakeholders. The process ensured the validation of the report along with development of a comprehensive report to be discussed at the regional level among countries, donors and international agencies.

141. The participatory process was instrumental in developing a series of recommendations that form the basis of this study report, and in building momentum among stakeholders to continue to advance disability issues in their respective communities. The recommendations that came out strongly from the workshops were “Nothing about us, without us” and could be a good principle and guideline for all policy planning. Perhaps an advisor on disability concerns and issues at the highest-level, for example the Prime Minister’s Office, could make a difference. Last but not least, real “Political Will” could make a change in the decisions regarding the implementation of disability-related policy in our country. For example, inclusion in the Census cemented the outlook for a “Human Rights Approach” for concerns of persons with disabilities. The Government of India and disabled community realized the strength of positive and constructive lobbying. The issue of Census brought together many cross-disability organizations and parents’ organizations; this unified approach led to a constructive pressure resulting in Inclusion.

VII. CONCLUSION AND ANALYSIS

A. Issues in Targeting Particular Groups

142. Different age groups among disabled people need to be targeted, with their specific issues addressed. In spite of the presence of the National Education Policy, only two percent of children with disabilities in the age group of 6-14 years are able to access mainstream education. Means need to be found to ensure that children with disabilities are reached through the new “Sarva Shiksha Abhiyan” to increase access to and retention in the mainstream education, at least for primary education.

143. When targeting youth with disabilities, focus could be on access to higher education, vocational training and employment opportunities. There are often many seats reserved for persons with disabilities lying vacant in the vocational training system. There is also an urgent need to upgrade the existing vocational training opportunities to enhance employment prospects

for persons with disabilities. Employment exchanges need to play a more proactive role, in collaboration with DGE&T, to match the pace of the increasing numbers, such as strengthening counseling services and identifying employment opportunities. The government could play an active role by announcing targeted incentives to the private sector to promote employment opportunities for persons with disabilities.

144. Older people with disabilities require social security mechanisms to ensure dignified living standards. In India the amount given through old age pensions, widow pensions and disability pensions varies from states to states, since welfare is a state subject. These amounts also depend upon the prosperity and the priorities of the State. Lack of uniform standards leave many older disabled people vulnerable.

B. Crosscutting Issues and Priorities

145. The usage of the term rehabilitation has become integral when speaking about meeting the needs of disabled people. A more appropriate framework would be the “Human Rights Approach”. Strengthening access to education, health services, employment, accessibility are important stepping-stones on the continuum of empowerment, while conceptually rehabilitation addresses a narrow range of issues. A human rights approach could be realized through National Policy that addresses and targets empowerment, rather than rehabilitation, through involving each of the related departments.

146. Health services in India have the largest network. Services for persons with disabilities have for past several decades been delivered under the aegis of Ministry of Health and Family Welfare. While the Ministry plays a significant role in providing rehabilitation services, disabled people continue to have difficulty gaining access to basic health services as a result of inaccessible infrastructure of the primary health centers in the rural as well as the urban areas. There is also a significant shortage of expertise at the grassroots level for early identification and intervention for infants born with a disability or disabling condition.

147. The education needs of the children with disabilities have become more widely recognized and acknowledged in recent years. But sadly, the focus has so far been for the age group between 6-14 years; there are very few early childhood education facilities rural poor children with disabilities between 3-6 years. Opportunities for higher education are also very limited in rural areas, and even in urban areas the physical infrastructure of most higher education institutions continue to pose accessibility challenges. While a few prosperous states of the country provide scholarships for higher education for disabled children and youth from the departments of welfare, this is controversial as education is the responsibility of Departments of Education under the Ministry of Human Resources Development.

C. Coordination Among Stakeholders

148. There are many successful community development initiatives, in various parts of the country, founded on a unique partnership of local people with the State governments, often catalyzed and mediated by motivated individuals and non-governmental organizations (NGOs). The recent success of such initiatives, particularly in the areas of water shed management and minor irrigation in the States of Gujarat, Rajasthan and Maharashtra, have considerably improved income levels at the community level and strengthened the capacities of communities to become self reliant. More importantly, it has fostered a sense of ‘ownership’, ‘responsibility’ and ‘progress’ among the people.

149. There is an urgent need to re-look at the structure, composition, functions and role of civil administration in the development of the country. There is a dire need for amendment of the constitution to enable states, if they so wish, to abolish either the district or the block level tier of the Panchayats and retain only one out of these two in addition to the village level body. Also, restrictions should be imposed on the devolution of Central Finance Commission funds and from other sources to the states unless administrative and financial powers are effectively devolved to the PRIs. PRIs need to be strengthened with revenue raising powers of their own in order to reduce their excessive dependence on the Central and State governments. They need to be encouraged to mobilize local resources to access matching grants from the Central and State governments. Accountability of the local body and their standing committees may also be improved to help evolve a code of conduct. Simplification of rules and procedures could also make transactions simpler and strengthen financial management and audited procedures.

150. A major area of concern is that respective State acts have, by and large, failed to take into account the implications of the Constitutional status of the Panchayats. Under State laws, wide powers of suspension and dismissal have been vested in the State bureaucrats. This places PRIs in a position of disadvantage vis-a-vis even the middle level functionaries of the State government. Most State governments have retained adequate financial and administrative powers to deal with PRIs. This directly affects the concept of democratic decentralization, on the one hand, and autonomy of PRIs on the other. Gram Panchayat Sarpanchas have to spend considerable time in visiting block level functionaries for technical and administrative approvals. These administrative concerns have a direct bearing on the ability of disabled people and their communities to take action and initiate community-based approaches to disability and poverty issues.

D. Analysis of Current Paradigms

151. Culture and tradition have played an important role in the shaping of rehabilitation for disabled people in India. Social and religious institutions guided by the charity model played a pivotal role through history, in providing essential care to needy. In India, religion and family have remained at the core of community life and the primary institutions to guide various movements and changes.

152. Culture, traditions and family are viewed as strengths rather than impediments in improving the quality of life of people with disability. In recent times, rehabilitation policies and programs have increasingly emphasized participatory models. These have as their objectives: to ensure active participation of the local communities at all levels of program planning and implementation; and to identify indigenous knowledge and resources in achieving the ultimate objective of improving the life conditions of people with disabilities and their families.

153. Ambivalent attitudes towards people with disabilities have always been prevalent. Manu Smriti, the ancient charter of social conduct, compelled people to spare a part of their material resources for their less fortunate fellow-beings and to support their daily living. Dharmashastra prescribed householders to look after the weak and disabled. Disability is also held to be a punishment for the sins of previous births. Families and other community members attribute physical disability to cosmic factors, fate, God's will and Karma.

154. Religious beliefs thus seem to be providing important explanations for both disease and disabilities. Karma is so deeply ingrained in the minds of the people, that any effort to dismiss or dislodge it can be counterproductive. Acceptance of disability as Karma gives people some explanation for their suffering that cannot be otherwise justified. Belief in Karma keeps the faith

in a just world alive, even under very adverse conditions; it reinforces hope that good deeds will ultimately result in good outcomes. In traditional Indian families, children were the shared responsibility of everyone. Children were considered dependent, immature, and incapable of taking decision about their own lives, with the family meeting their basic needs for security, food and affection. Unless they doubly prove themselves and assert their rights as equal, these children of the lesser gods were rarely taken seriously.

155. Disability rehabilitation was always primarily considered as a responsibility of the family, which was to provide essential physical, emotional and economic support to its members with disabilities. The economic and caste status of the family and its networks also determined the quality of the well being of its members with disabilities. Concept of rehabilitation initially implied routine care.

156. Prior to the 1980s, people with disabilities in India had little or no access to rehabilitation services. Rehabilitation services available were limited to institutions, which obviously had limited coverage. Since India had limited resources to provide high quality institutional services, the emphasis was not on developing a method capable of providing high quality institutional services, but on developing a method that provided wide coverage, at costs that were affordable to governments. In CBR, interventions were to be shifted from institutions to home and communities of people with disabilities, carried out by minimally trained people, such as families and other community members, thereby reducing the costs. CBR appears to be the only viable and practical solution for the massive problem of disability in India. It envisages a social environment in which a community shows awareness and sensitivity to the special needs of its disabled members and feels responsible for bringing about the desired changes. The efficacy of CBR lies in the fact that a highly developed sense of community has always been the strength of Indian society. Local communities have taken care of their members with disabilities. Though in its present incarnation CBR is a product of the western scientific tradition, conceived by international agencies, as adopted by urban NGOs, it also has an inherent component of community participation, belongingness and involvement. Efforts to address disability and poverty issues through the CBR model with equal partnership between the Government of India and the NGO sector could result in profound changes in the quality of life for people with disabilities.

157. The disability movement in India has made considerable progress promoting the need to integrate people with disabilities in the social mainstream. There has also been an ideological shift in the developmental planning—from welfare to human resource development. The National Committee on the International Year of the Persons with disability was set up under the chairmanship of the Prime Minister. Central Ministries established several working groups and task forces to give high priority to the development of action plans to address the needs of disabled people. But, in a country like India, with its geographical, cultural, religious and social diversity, there was no way the Central Government and NGOs could meet the vast challenge of disability in rural areas. There was a need to mobilize local resources and support to sustain disability rehabilitation programs. There was also pressure from international organizations in national programs on disability. International agencies indeed brought a change in service culture, ideology and ways of functioning of governmental and voluntary organizations. Service organizations went through major transitions, which were in line with the international movements. A major event was the enactment of Persons with Disabilities Act 1995 by the Indian Parliament. Through this Act, the government itself made a shift from the charity and welfare based models of rehabilitation, toward a human rights based approach. Good governance to ensure timely and time bound implementation of the legislation is the next step.

158. The effort of the past decades brought a qualitative change in the lives of many people with disabilities. There has been a growth in the number of people with disabilities who are educated, professionally successful and able to provide leadership. This new generation of leaders is playing an active advocacy role and asserting the right of people with disabilities to participate in all decision-making that affects their lives. Though the partnership model appears incompatible with the traditional practices, the success of partnership approaches in the recent years is a clear indication of changing attitudes of the society, the government and the service organizations.

VIII. RECOMMENDATIONS

159. The analysis of the relationship between disability issues and development led to the identification of four main common areas for strategic action. They are inclusion, participation, access and quality. These four areas for addressing the need for targeted mainstreaming of disability issues in country programming are described as follows:

- **INCLUSION:** People with disabilities must be visible. Inclusion identifies the disability initiatives that need to be taken into account in the design, implementation and evaluation of strategies, policies, programs and projects. Areas to consider are the extent to which disability is supported and included through policies and programs that dedicate financial resources through lending and budget allocations by banking, development, governmental and non-governmental agencies; ensure that material resources are committed to disability issues; ensure that organizations and their personnel are knowledgeable and ensure the accountability of decision makers and program implementers to advance disability issues as a poverty reduction and growth strategy in their area(s) of development.
- **PARTICIPATION:** People with disabilities and their organizations must have a voice. Participation ensures that people with disabilities and their respective organizations are given a voice in decisions that affect their lives and their communities. Strategies to promote effective participation, including consultation and decision-making that involves representatives of people with disabilities including beneficiaries, are the priorities.
- **ACCESS:** Removing barriers and creating opportunities to access all services and resources within a community is essential for people with disabilities. Access requires that people with disabilities and other stakeholders are informed and aware of disability issues and have access to available data (i.e. demographics) on disability. It requires that services and resources reach the most vulnerable in rural and urban communities and reach all persons with disabilities, irrespective of age, sex, ethnicity, geography, language and disability. It requires that the built environment and systems of communication are barrier-free.
- **QUALITY:** People with disabilities deserve quality of life through knowledge and capacity building. Quality identifies the priority for all sectors and services to be designed and developed according to needs, meet universal standards of practice and are effective. Core dimensions of quality through knowledge is raising the capacity of persons with disabilities and other stakeholders to ensure independent living through technical and functional interventions. It requires the development of

critical awareness to influence policy development by increased understanding of the factors impacting on a barrier-free environment including community access, attitudes towards disability and human rights. Thirdly, persons with disabilities and other stakeholders need to develop the capacity for social action through the development of skills and experience in participatory management and inter-sectoral and multi-stakeholder approaches to development.

160. In order to address these areas of priority for disability and development, a series of recommendations have been identified according to the four categories of Inclusion, Participation, Access, and Quality.

A. Inclusion

161. The Government of India should include in their deliberation with regards to the disability sector recognition of their formal obligation and commitment. This commitment could be most effectively projected through a comprehensive policy on the issues concerning the disabled people. All national policies should address cross cutting themes such as gender, disability, and poverty. Policies should also include specific indicators with respect to its target group for its objective evaluation. Policy could also be made time bound or with riders like periodic reviews to assess the need for continuity.

162. The Government of India has formal obligations and commitments to disability issues and poverty reduction. It is recommended that these direct Strategic Planning for disability and development and that disability and rehabilitation should be a priority issue.

163. The government and donors, including the Asian Development Bank, should consider further increases and allocation of human and financial resources to the disability and rehabilitation sector. They should insist that the needs of people with disabilities are considered as an integral part of all-planning programs and projects, and not viewed as a separate issue. All projects, especially those addressing basic needs such as rural development, education or health should not only conceptualize inclusion, but ensure that such inclusion of disability issues is integral to project implementation.

164. Although there are budgetary allocations to address disability concerns in development programs at the central and state levels, the optimal utilization of these resources remains an area of concern. Initiatives could be taken to ensure that funding to promote inclusion achieves this objective. Multi-sectoral and multi-stakeholder collaboration should be encouraged to enhance and cement effective utilization of resources. Mandatory inclusion of persons with disabilities in all programming, and strict utilization of 5% of budgets for rural and urban development schemes enhanced to support effective inclusion in socio economic and political life should be established as important targets.

165. As disability is a crosscutting theme, similar to gender or environment, awareness of disability issues could be targeted through all development programs. Disability should also become a core component of curriculum of the related fields, such as medicine, social work and architecture.

166. The Asian Development Bank and funding agencies could support the disability sector in India through lending resources and collaborating with the government to mainstream disability issues in sub-sectored projects. Additional and longer term funding should be further devoted to this sector so that comprehensive planning for the development and implementation of services

can be created and implemented by government in collaboration and co-operation with other sectors.

167. Efforts need to be made to ensure that persons with disabilities who possess the capacity and skills to enter mainstream society be provided with the opportunity to do so. People with disabilities must be integrated in public and private sector, professional and non-professional positions. Demonstrating through example their capacity to participate would strengthen the perception of their ability to constructively contribute to national life and development.

168. Measures should be adopted for midterm reviews and a periodic evaluation to ensure the inclusion of disability concerns in all the development programs. Inclusion of disability concerns could also be a parameter or variable through which to evaluate development programs.

169. World Disabled Day, December 03 should be celebrated by each and every department, as is International Women's Day, or May Day.

170. Although laws are made with good intentions and high hopes, however, it is important that the disability sector be very vigilant and proactive to ensure appropriate implementation of laws and policies. Effective channels of communication between the disability sector, the legal profession and other sectors are crucial for greater awareness and sensitivity towards disabled people in society. There is a dire need to create awareness amongst NGOs in how to use the law to empower persons with disabilities. Communication and information campaigns with national coverage could also play an important role in the promotion and inclusion by building awareness of human rights issues related to disability.

171. The cost of supporting disabled people in India is huge and poses a severe drain on the economic resources, according to leading organizations working for the rights of persons with disabilities. For approximately 6 crore (60 million) number of disabled people in India, the minimum cost of living for a person (per month) is Rs. 1,000; the cost to the country to support disabled people per month is Rs. 6,000 crore (Rs 6 billion). Hence, the cost to the country to support disabled people per year is Rs. 80,000 crore (Rs.80 billion). Therefore if disabled people could be made self-sufficient, wealth-creation in India could increase significantly.

172. In spite of its diversity, there are many common disability issues among countries in the Asia and Pacific Region. Therefore streamlining support and assistance from international funding agencies could benefit all disabled people in the region. The focus for such coordination could be through involvement of NGOs and CBOs at the time of negotiating with the Government of India. Greater participation of NGOs and CBOs could be secured through allowing them to act as implementing agencies for certain program components, with the government assuming responsibility for monitoring and evaluation with pre-determined and structured indicators.

B. Participation

173. The government and disability sector NGOs should join in an effort to support the establishment and strengthening of self-help and advocacy organizations of persons with disability at all levels. Participation of persons with disabilities should be promoted by establishing a role for self help groups within government run or aided poverty reduction schemes of the country.

174. Participation of persons with disabilities in decision making should be guaranteed at all levels of development programming, from project designing to implementation, by government ministries, local authorities, and NGOs in the development sector. Representation and participation of person with disabilities at the highest levels of policy planning is also very crucial and should be an important prerequisite of any National Policy Planning initiative.

175. There is a need to orchestrate the positive outcomes of mainstreaming disability concerns and positive stories of persons with disabilities with a special focus on the rural areas.

176. Lack of awareness of disability issues among people at the highest levels is an area of concern. Educating officials, using successful approaches applied in the model of gender sensitization can contribute to ensuring participation of persons with disabilities in the capacity of advisors or consultants in all major decisions impacting their lives.

177. There are 650 organizations receiving grants in aid from the Ministry of Social Justice and Empowerment, and at least four times as many that are not. The number of NGOs in the disability sector, and an absence of coordination within the sector, can limit effective participation. There is a pressing need among NGOs, CBOs, disabled people's organizations and parents' organization to remain united and lobby for the realization of rights guaranteed under the Act 1995. There is also a need for cross disability consensus on priority issues for persons with disabilities.

178. There is a fair amount of consensus among the experts and the implementers of public policy and programs that only decentralized community-centered approaches can overcome the scourge of hunger and poverty by taking into consideration the disability and gender issues.

C. Access

179. Ensuring access to education for children with disabilities is an important step in reducing marginalization among disabled people. Education is a human right and a basic need. Social and educational sectors must give more attention to this matter and implement education policies that provide children with disabilities access to basic education without discrimination and/or free of barriers. Promotion of non-formal education and literacy programs for persons with disability should be encouraged. Primary and higher education would become more accessible to persons with disabilities if the national policy for elementary education of children and the age group of 6-14 years is strictly adhered to. There is a need to include the concerns of persons with disabilities and their aspiration for higher education. Increased momentum could be built by making the infrastructure available for education accessible and fostering attitudinal changes at the management levels.

180. Awareness of accessibility for people with disabilities is minimal outside of organizations working on the promotion of rights of people with disabilities. However, some adaptations to the built environment and the external environment can be achieved at a minimal cost with creative thinking and careful consideration given to people's needs.

181. The government should enact strict measures, with punitive actions attached to enforce the implementation of laws with regards to accessibility and safety features at the time of construction of buildings for public use.

182. Focused efforts are needed to ensure disabled people's access to safe drinking water, toilets (lavatories), sewage and drainage, general sanitation (disposal of solid waste) with barrier-free features.

183. There is a dire need to develop a central database on disability that includes information on the numbers of persons with disability, the nature and extent of their disabilities, and their needs. This information should be analyzed and disseminated to all relevant institutions, including NGOs. The government should make a time-bound commitment to develop such a database to support efforts to ensure disabled people's access to services.

184. The government, the entire UN system and many funding agencies have recognized the need to develop a universal sign language in India. Eliminating this barrier to communication among people with impaired hearing would make a significant contribution to providing greater access to opportunities for social and economic participation.

185. Incorporation of accessibility features in the built environment could be promoted as a preventive measure as well. It should be an inherent component at health delivery, telecommunication and banking services facilities. Access requires enforcement of barrier-free features on roads, pavements, public places (parks, markets, recreational, and spiritual places) zebra crossings, subways and public toilets. Persons with disabilities could also receive priority with respect to accessing services at hospitals, housing allotments, education, pensions and micro-credit based training schemes.

D. Quality

186. Quality needs to be considered as a prime component for mainstreaming disability issues so that it is applicable, enjoyable and accessible. Quality includes ensuring that technical interventions impact on mainstreaming in a targeted way.

187. Imparting management skills, with specific reference to mainstreaming disability issues in the field of development, could be an effective tool to ensure mainstreaming. There is a need to strengthen the potential implementing organizations and agencies that have disability awareness activities in terms of capacity, management and methodologies to develop project activities.

188. A multidisciplinary and inter-sectoral team of stakeholders could be involved to effectively deliver mainstreaming through a coordinated and practical approach. This approach could also help in sharing the onus for mainstreaming among sectors.

189. There is a need to recognize professionals in the disability sector commercially as well with special reference to their approved salaries by government aided programs. This could play a crucial role in improving the quality of services delivered to persons with disabilities.

190. Disabled people need to be able to sustain themselves economically. Hence, there is a need to provide them with equal earning opportunities. Trades that have been traditionally identified as appropriate for disabled people need to be redefined. There is an urgent need to improve the quality of the training facilities available for persons with disabilities, and ensure that training is consistent with the current market trends. The private sector in India provides the majority of job opportunities. Defined incentives to this sector could enhance their commitment to disability concerns, which in turn could further increase the employment opportunities for persons with disabilities.

191. Disabled people themselves can be effectively trained to become trainers to promote universal access.

192. There is a need to develop standards for the provision of services for persons with severe disabilities. Standardized training to build knowledge and skills among local service providers with respect to the needs of disabled people would improve the quality of programs in all sectors.

OUTCOMES FROM THE NATIONAL WORKSHOP

A. The National Workshop

1. The National Workshop represented the culmination of four months' of research, stakeholder analysis, and the four provincial-level workshops held in Chennai, Mumbai, Kolkata and Delhi. The workshop was designed to build consensus around critical issues and, through this consensus, develop a tentative action plan agreed upon by various stakeholders in the field of disability and poverty. Key stakeholder groups were represented at the Workshop, including Government of India ministries and departments, State and Union Territories Governments, development NGOs, disability NGOs, disabled people's organizations, United Nations agencies, international funding agencies, and international NGOs. The following recommendations and action plan are the collective effort of these participants and reflect their knowledge, expertise and wisdom.

2. Vision of a Just Society for All:

- (i) Inclusive society where ALL PEOPLE, including people with disabilities are valued and provided equal opportunities for utilization of their potentials, OR
- (ii) A society where each person is valued, recognized, provided an opportunity for equal participation and contribution to self and society.

3. Target group and beneficiaries:

- (ii) ALL PEOPLE with disabilities (including children with disability, women and men with disability, people with different disabilities, including mental, intellectual); AND
- (iii) Other stakeholders (including families, communities, friends, professionals, service providers, policy makers, leaders).

4. Legacy after 5-10 years:

- (i) Meaningful partnership on the levels of society, community, family;
- (ii) Values and principles – such as acceptance and compassion, human rights, equal opportunities, equal access, equal participation;
- (iii) Demonstration and celebration of achievements: examples of good practices; and
- (iv) Change of attitudes.

5. Major stakeholders:

- (i) Disabled people, their families and communities;
- (ii) Governments;
- (iii) Professionals, and service providers; and
- (iv) Nation as a whole.

6. Uniqueness of our Plan:

- (i) Participatory;
- (ii) Realistic;

- (iii) Culturally based;
- (iv) Needs based; and
- (v) Comprehensive.

7. Constraints and opportunities in the environment for achieving the vision was also discussed in smaller groups and presented in a comprehensive way as follows:

8. Following were opportunities agreed upon by the forum:

- (i) Landmark legislation for people with disabilities;
- (ii) Corporate, bilateral, and multilateral resources;
- (iii) Chief Commissioner's office for redressal as a quasi-judicial body;
- (iv) Democratic vocal and articulate media;
- (v) Panchayati Raj Institutions promoting a bottom up approach in planning;
- (vi) Availability of ample financial resources;
- (vii) Global pressure for mainstreaming disability issues; and
- (viii) Systematic schemes floated by Ministry of Social Justice and Empowerment like RRTC, NPRPD and DRCs.

9. Constraints as discussed and consented upon were as follows:

- (i) Mental and attitudinal barriers;
- (ii) Lack of access to information;
- (iii) Lack of well devised Social Security System;
- (iv) Long and time consuming process;
- (v) Judiciary system;
- (vi) Lack of professional recognition to rehabilitation;
- (vii) Commercialization of the disability issues;
- (viii) Marginalized status of disabled people;
- (ix) Disability a low priority issues; and
- (x) Lack of political and bureaucratic will.

10. After the session sector-specific recommendations drawn from the Provincial Workshops were shared with the participants and they were again grouped into smaller groups to refine these recommendations in order to develop a concrete National Action Plan.

11. Participants were grouped according to the choice of their sectors.

12. The sector-specific National Action Plan, which emerged from the three day National Workshop was presented before the State Minister, Mr. Satya Brata of the Ministry of Social Justice and Empowerment.

13. Immediate Actionable Points agreed upon by the whole group from all the sectors related to persons with disabilities on the basis of priority were as follows:

- (i) To enforce barrier-free features on roads, pavements, public places (parks, markets, recreational, spiritual places) zebra crossing, subways and public toilets.

- (ii) Persons with Disabilities to receive priority handlings in:
 - Hospitals
 - Housing allotment
 - Education
 - Assistive devices
 - Pension
 - Travel (Bus, Metro)
 - Micro-credit of training schemes
- (iii) Mandatory inclusion of persons with disabilities and strict utilization of 5% allocated resources in Rural and Urban development schemes with their enhanced and effective inclusion in socio economic and political life.
- (iv) Provision of safe drinking water, toilets (lavatories), Sewerage / drainage, general sanitation (disposal of solid waste) with barrier-free features.
- (v) Prevention of disabling factors by reducing 50% of accidents, maximizing attended births and achieving 100% immunization in 2 years.
- (vi) Preparation of an exhaustive and comprehensive database of all marginalized groups of society to ensure accessibility of services for their development.
- (vii) Social communication to be enhanced to cover the nation through wide media and traditional campaign with increased displays on public places – i.e. schools /temples /corporate for awareness of disability concerns.
- (viii) Promoting economic status through organizing placements, training, micro credit, marketing group activities, with increased responsibilities on Ministry on Social Justice and Empowerment, DGE & T, employment and placement offices, NHFDC, corporate sector and NGOs.
- (ix) Social Security, with streamlined coordination in the Ministry of Health and Family Welfare, Ministry of Social Justice and Empowerment, Ministry of Railways and State Road Corporations, to achieve the following coverage within two years:
 - Rs. 500 per month for every person with disability;
 - Scholarship Rs. 250/ - 1880 per month for every disabled student;
 - Old age pension for people with disabilities over the age of 45, Rs. 500 per month;
 - Bus concession to all persons with disability;
 - Train concession to all persons with disability.
- (x) Bound enforcement of all provisions in the Persons with Disabilities Act 1995 and implementation of the Amendments proposed for the Act with penal provisions for non-compliance.

B. Recommendations that Emerged from the National Workshop.

14. **National Coordination.** There are 650 organizations receiving grants in aid from the Ministry of Social Justice and Empowerment, and at least four times that number who are not.

This suggests that there are a large number of NGOs in the disability sector, yet their activities and programs are not coordinated and effective collaboration among organizations is low. There is a pressing need among NGOs, CBOs disabled people's organizations and parents' organizations to remain united and lobby for the realization of rights guaranteed under the Act 1995. There is also a need for cross disability consensus on priority issues for persons with disabilities. A fair amount of representation and participation of person with disabilities at the highest levels of policy planning is also very crucial and could be an important prerequisite of any National Policy Planning. Mandatory inclusion of persons with disabilities and strict utilization of 5% allocated resources in rural and urban development schemes with their enhanced and effective inclusion in socio economic and political life.

15. **Awareness Raising.** World Disabled Day, December 3, should be celebrated by each and every department, as International Women's Day, or May Day are celebrated. Although the laws are made with a lot of good hope and intention, it is important for the disability sector to be very vigilant and proactive to ensure their appropriate implementation through building strict factor of accountability and professionalism failing which, the Acts cannot succeed. Effective channel of communication between the disability sector, the legal fraternity and other sectors of social development is crucial for greater awareness and sensitivity towards the disabled in society. There is a dire need to create awareness amongst NGOs regarding using the law to empower persons with disabilities. Social communication to be enhanced to cover the nation through wide media and traditional campaign with increased material displays in public places—schools, temples, corporate institutions—for awareness of disability concerns.

16. **Accessibility and Communication.** To enforce barrier-free features on roads, pavements, public places (i.e., parks, markets, recreational, spiritual places) zebra crossing, subways and public toilets. Persons with disabilities to receive priority handlings at: i) hospitals, ii) housing allotment, iii) education, iv) assistive devices, v) pension, vi) travel (bus, metro), and vii) micro-credit of training schemes.

17. **Information and Database.** Preparation of an exhaustive and comprehensive database of all marginalized groups of society to ensure accessibility of services for their development.

18. **Prevention of the Causes of Disabilities.** Provision of safe drinking water, toilets (lavatories), sewage and drainage, general sanitation (disposal of solid waste) with barrier-free features. Prevention of disabling factors by reducing 50% of accidents, maximizing attended deliveries and achieving 100% immunization in 2 years.

19. **Education.** Primary and higher education could become accessible to persons with disabilities, if the national policy for elementary education of children and the age group of 6-14 years is strictly adhered to. There is a need to include the concerns of persons with disabilities and their aspiration for higher education. This could get an increased momentum even through making the infrastructure available for education accessible and attitudinal changes at the management levels.

20. **Vocational Training and Employment.** Promoting economic status through organizing placements, training, micro credit, marketing groups activities, with increased responsibilities on the Ministry on Social Justice and Empowerment, DGE&T, employment and placement offices, NHFDC, corporate sector, and NGOs. Four enablers for strategic planning which would facilitate employment opportunity would be, by increasing public awareness about the causes of disabilities; extending opportunities to disabled people through legislation; equipping disabled people with educational qualification and skills; and ensuring easy and convenient access to

relevant places. It is envisaged that the four enablers would then lead to ensure an equal status of people with disabilities in society leading dignified lives.

21. **Social Security.** Social Security to cover in two years with streamlined coordination with the Ministry of Health and Family Welfare, Ministry of Social Justice and Empowerment, Ministry of Railways and State Road Corporations; a) Rs. 500 per month for every person with disability, b) Scholarship ranging between Rs. 250/ - 1880 per month for every disabled student, c) Old age pension for disabled people over the age of 45 of Rs. 500 per month, d) bus concession to all people with disabilities, and e) Train concession to all people with disabilities.

22. **Regional Cooperation.** The issues and concerns in the asia and pacific region, in spite of the diversity, are relatively similar owing to the developing economies. Hence, streamlining of the support and assistance from the international funding agencies is essentially a need. The focus for such cooperation could be through involvement of ngos and cbos at the time of negotiating with the government of india. A greater participation of the ngos and cbos could be sought rather than government being the implementing agency of the area programmes. Instead, the government could take on roles of monitoring and evaluation with pre-determined and structured indicators.

23. **Effective Implementation of Legislation.** Time bound enforcement of provisions in the Persons with Disabilities Act 1995 and implementation of the Amendments proposed for the Act with penal provisions for non-compliance.

CASE STUDIES IN INDIA

A. Association of People with Disability (APD)

1. Realizing the importance of economic rehabilitation of people with disabilities to gain recognition, acceptance and dignity in society, the APD was started as a training center for enhancing employability and motivation for self employment. The New Training Centre (NTC) to provide formal technical training as per NCVT syllabus and Advanced Training Centre (ATC) to provide advanced technical skills with shop floor experience were set up in 1975 to fulfill the needs of economic rehabilitation of trainees with physical disabilities. Despite some inherent set backs they served useful purpose of enabling the disabled to develop confidence and competence to enter into mainstream employment.

2. The idea of a home-based program (HBP) was conceived in 1976 for the purpose of economic rehabilitation of people who were home bound due to various factors such as severity of disability, inaccessibility due to geographical and logistic constraints, etc. The development of disabled through the process of building capabilities and utilization of their potentiality for achieving economic independence and self reliance was the guiding principle of the HBP.

3. HBP envisages APD to act as a mediator between the industry and workers based in their home or in small ancillary cooperatives. Support of the family members was an essential ingredient. Several experiments were tried out to achieve the objectives of the HBP and income generation activities. It did have its positive impact on promotion of self-employment among the people with disabilities.

4. Consolidating the practical experience gained by APD during almost two decades, APD developed three ancillary units formed by people with disabilities of different types under its HBP over a period of eight years since 1994. Among them, Ability in Disability was the first one set up in 1994 for supply of mechanical sub assemblies to Motor Industries Co. (MICO) a prominent industry in the automobile sector. The APD Utpadana Society is the Second unit in the series set up in 1999 engaged in supply of electronic sub assemblies and components to major electronic industries such as Indian Telephone Ltd., Bharath Heavy Electricals Ltd., (ECD), Bangalore. The third one is the Creative Skills Society with 14 persons working to meet requirements of a small scale electronic industry in Bangalore.

5. Mr. Sarangadharan, an Executive of APD played a pivotal role and was always a motivating force for the progress achieved by these units. The process of withdrawal of APD from these units is being implemented in a phased manner to serve the real purpose of developing into a self managed industrial unit owned by people with disabilities and prove their entrepreneurial and managerial capabilities. The principle of cross-disability integration and integration with able-bodied persons have been achieved in the real sense.

6. Major challenges encountered by the APD in fulfilling the task were; change in mind set, building competence, instilling confidence, removal of attitudinal barriers, paradigm shift in perception of persons with disabilities and society, reduction in perpetual dependence on APD, fear of failure, lack of entrepreneurial capabilities, maintenance of quality of products, abuse of facilities offered by the government, and undue expectation of persons with disabilities from society. APD had to muster great courage to meet these challenges effectively.

1. Ability in Disability

7. 15 persons run this unit of whom three have locomotor disabilities and 10 are visually impaired. Among the 15, ten are women. The unit developed a capability to carry out more than 25 sub assemblies for fuel injection pumps with stringent specifications conforming to international standards, to the Motor Industries Co., a German company set up in India having works at Nasik (Maharashtra), Jayapura (Rajasthan) and two major units in Bangalore. The Ability in Disability is being subjected to audit conforming to ISO standards by the MICO. It has been adjudged as an excellent unit in the class and was rewarded in year 1998. It started earning profit in its third year itself and its turnover is about Rs.10 lakhs p.a. The unit marches ahead to secure ISO 9001-2000 Certification.

2. APD Utpadana Society

8. This unit was set up in April 2000 to be engaged in electronic and electrical sub assemblies, catering to the requirements of Indian Telephone Industry Ltd., and Bharath Heavy Electricals Ltd., both being Government of India undertakings in the field of electronics. 32 people work in the unit. Among these, 24 have locomotor disabilities and two are hearing impaired. Here again cross-disability integration has been achieved.

9. The unit suffers erratic inflow of sub contracts due to the adverse effect of industrial recession prevalent all over the country. The unit was able to achieve a record turnover of about Rs.1.85 lakhs in September 2001 and proved its capabilities if proper opportunity is provided and rising to the occasion.

3. Creative Skill Society

10. This unit was set up a year ago to meet the assembling requirements of an SSI unit - Nikhara Electronics, in the private sector. Among the 14 workers, 10 have a hearing impairment and four have locomotor disabilities. They are able to run the unit successfully with the patronage of the parent unit. It is anticipated that the unit could reach the level of Rs.30,000 per month, leaving adequate margin.

11. The APD enlarged its area of operations gradually over a period of four decades to encompass physiotherapy, orthotic appliances, horticulture, CBR, urban slum outreach, community health, integrated education. Its achievement in all these areas is unique and unequivocal. APD became a role model by its exemplary efforts and experience in empowering people with disability to attain economic self-reliance and lead dignified lives. With its pragmatic policy, realistic action strategy and firm commitment to its avowed objectives, APD could meet all challenges successfully. It proved its might to enable people with disability as positive contributors and find pride of place in society.

B. District Primary Education Programme

12. This program is funded by the World Bank has and been launched in 19 States of India.

13. Rajasthan is one of the States where the project has been functional covering 10 districts by the Second Phase. The funding principle is "Education for All" in the age group of 6-14 yrs.

14. The Nodal Agency for implementation of DPEP is the State Primary Education Council, which, at its core, adopted a very flexible strategy to address the needs of all the children in the age group 6-14 yrs.

15. The program has successfully integrated disability issues within the wider framework of education sector, using community-based approaches. Activities undertaken by Rajasthan Primary Education Council have been quite varied based on the area specific needs of the community, including:

- (i) Alternate schools;
- (ii) Madarsa education for children belonging to minority section;
- (iii) Residential and Non residential bridge courses focusing on non-formal education;
- (iv) Residential facility of children of nomadic families;
- (v) Education-friendly schemes with special target girls who are not enrolled in either formal /non-formal education system;
- (vi) Inclusive education for the disabled aiming at children with disabilities to be included in regular education system with substantial provision assistive devices for the locomotion of children with disabilities;
- (vii) Primary education center to be strengthened for 100% enrollment for children, retention and quality education.

16. **Major Strengths**

- (i) Community mobilization;
- (ii) Decentralization through effective village level committees;
- (iii) Partnership with voluntary organizations;
- (iv) Partnership in planning and decision making at all levels;
- (v) Flexibility in implementation;
- (vi) Effective integration with voluntary organizations; and
- (vii) Multisectoral approach.

17. Major strength of the DPEP program in Rajasthan is its association with UNICEF for civil workers at school to:

- (i) Renovate dilapidated buildings of primary schools in Rajasthan;
- (ii) Construction of school building at some remote villages where schools were initially functioning under trees;
- (iii) Schools and toilets in the schools made accessible for children with disabilities;
- (iv) Availability of water in all the schools through boring;
- (v) Effective village level committees which has representation from parents, parents of children with disabilities, school headmaster/teachers, Anganwadi Workers;
- (vi) Scope for capacity building for resource teacher to focus on children with special needs;
- (vii) Scope for in-service sensitization and training to manage children with disabilities.

C. Inclusive Education for Children with Disabilities, Uttar Pradesh

18. Uttar Pradesh is one of the backward States of the country. U.P. has been far behind most states in per capita income as well as in respect of the levels of socio-economic development. An estimated 33 Lac persons with disabilities live below the poverty line in U.P. Out of 16.55 Crore population of U.P. there are an estimated 82.5 Lac people with disabilities

19. Education has always been a primary development activity in India. UNDP is presently supporting 2 States i.e. Uttar Pradesh and Karnataka with coverage of 8 blocks in each State for inclusive education of children with disabilities. In U.P. the UNDP program has been launched in 8 blocks of Lucknow District where it is providing supportive services in the areas of:

- (i) Assistive devices;
- (ii) Barrier-free schools;
- (iii) Transportation;
- (iv) Teaching learning materials;
- (v) Sensitization of teachers;
- (vi) Sensitization of parents; and
- (vii) Sensitization for school readiness.

20. The implementing agency for this program is the State Department of Handicapped Welfare.

21. The program aims to reach children with disabilities in the school going age of 6-14 years with the objectives of:

- (i) Zero rejection;
- (ii) Home based education services for children with severe to profound disabilities;
- (iii) Including children with disabilities in mainstream education;
- (iv) Special schools for children with specific needs to make them ready for regular formal schooling.

22. Major strengths

- (i) It has undertaken a detailed house to house survey in 8 blocks where the program is likely to be implemented;
- (ii) It has mobilized school head masters and sensitized them on the need for inclusive education for children with disabilities;
- (iii) It has also developed indigenous techniques to make the primary schools barrier-free for children with disabilities with availability of grants of Rs. 10,000/- for each school;
- (iv) It has worked extensively in capacity building of field level workers to identify children with disabilities for early intervention.

23. Limitations

- (i) Community mobilization has not been exploited extensively;
- (ii) Realist allocation of funds could have borne better results;
- (iii) Wider coverage would ensure implementation of education for all; and
- (iv) Home-based education for children with severe to profound disabilities is not being addressed in a qualitative way.

D. The Spastics Society of Eastern India

24. The Spastics Society of Eastern India (SSEI) was set up in 1974 to establish, manage and run an educational and rehabilitation center, providing comprehensive facilities for children with cerebral palsy. Initially it was a state organization operating in West Bengal only. Over the years its activities have increased beyond the borders of the State and has emerged as a national institute with the following objectives:

- (i) Establish, manage and run an educational and rehabilitation center, providing all round facilities for children with cerebral palsy;
- (ii) To recruit qualified staff and specialists in various fields to ensure the quality of education and treatment imparted to children with cerebral palsy;
- (iii) To establish, equip and run a vocational training center for people with cerebral palsy;
- (iv) To impart training in specialized methods and techniques to meet the educational, therapeutic and social needs of people with cerebral palsy and their families;
- (v) To render financial and other assistance to poor or distressed families of children or adults with cerebral palsy, who are users of SSEI services;
- (vi) To obtain official recognition from the Government of India, and affiliation with other centers set up for people with cerebral palsy;
- (vii) To network with other agencies involved with community development projects in order to support, initiate and extend community based services for people with cerebral palsy;
- (viii) To conduct research, which is action and need based, in order to extend the knowledge base of issues (educational, therapeutic or social) related to cerebral palsy;
- (ix) To create awareness amongst the community at large about people with disabilities;
- (x) To advocate the rights of people with disabilities;
- (xi) To contribute to manpower development and practice in order to improve the quality of life of people with multiple disabilities and their families;
- (xii) To enhance the training capacity of the Indian Institute of Cerebral Palsy in order to meet the diverse manpower needs of rehabilitation of personnel and professionals working in the field; and
- (xiii) To act as a catalyst for supporting center-, outreach- or community-based services for people with cerebral palsy, specifically focusing on West Bengal and Eastern India.

24. In 1994, with the experience gained over two decades, SSEI came to the realization that it needed to enhance its capacity as a catalyst agency, in order to make a greater contribution towards supporting people with disabilities. SSEI approached the Department for International Development, (DFID) Government of UK, for financial assistance to support such a project. The project was initiated in 1994 and the duration was five years ending 31st March 1999.

25. The goal of this project was to contribute to national policy development and practice in order to improve the quality of life of people with multiple disabilities and their families through service provision and reduction of attitudinal, institutional and organizational barriers.

26. The purpose of the project was for SSEI to act as a catalyst for persons with disabilities, their families, and communities in the development of CBR and other needs-based programs appropriate to the needs of beneficiaries, and able ultimately to reach all people, especially the poor with cerebral palsy (Project Logical Framework, June 1997).

27. The project was carefully planned in order to meet the specified objectives. The project has five components, each one linked to the other, yet independent in its own right. The first two projects were intended to be directly linked to service provision while three were intended to be linked to developing or extending the knowledge-base of both trainers at SSEI, and trainees from different sites. Specific objectives of the different projects are given below. It is important to note the carefully planned linkages between the projects.

28. Specific Objectives of each Project Component

- Project 1: To initiate community based services in the 16 districts of West Bengal
- Project 2: To initiate 8 sustainable affiliate services in eastern India to provide need-based services to persons with disabilities, with a special focus on people with cerebral palsy.
- Project 3: To establish a training centre at Bolpur, Birbhum District.
- Project 4: To develop and disseminate needs based training and awareness material.
- Project 5: To develop and enhance SSEI's capacity as an apex institution for the transference of knowledge, skills and experience to persons with disabilities, their families and communities.

1. Lessons Learned During Implementation

29. At the outset it needs to be stated that all the activities specified in the original proposal have been carried out. The only exception is the development of the eighth affiliate center in Eastern India, scheduled for the last year of the project. This was due to disastrous flooding in the state during that year.

30. Many lessons have been learnt along the way. Constant monitoring and review of the five project components, along with the production of quarterly and annual reports has enabled SSEI to maintain a focused yet flexible approach to the development of services, training and materials. SSEI has been able to model this process of development, learning over the course of the project that community participation, innovation and the ability to adapt the process to the needs in each area, are core elements for success. SSEI has been able to promote sustainability by enhancing the strengths of the local organizations and by increasing the capacity of staff, volunteers and families with disabilities so that they gradually need less input over time. In June 1997, on the basis of its work in the first three years of the project, SSEI recognized the need to review the original project objectives (June 1993). In the latter, its role may be described as that of an indirect 'implementer'. In the reviewed project logical framework SSEI emphasizes more explicitly, its catalyst role in helping partners to become core resource agencies in the districts of West Bengal and states outside West Bengal. This meant that project partners have been gradually able to take a more dominant role in planning, implementation, determining training needs and monitoring their own projects.

31. Over the duration of the project, the total number of families who have used services in Project 1 is 10,192, Project 2 is 8,608 and in Project 3, 3836. Since the approach is family-centered, these figures represent individual child beneficiaries multiplied by a family with average of four members. Individual child beneficiaries have included those with cerebral palsy,

learning difficulties, specific learning problems, hearing impairment, visual impairment, polio and rare syndromes. Children with visual and hearing impairment and polio have been referred to specialist agencies wherever possible. A total of 444 persons have been trained in formal training courses at SSEI and in training placements in the Rural Training Center during the projects.

D. Blind People's Association

32. Blind People's Association (BPA) Ahmedabad in the State of Gujrat is one of the largest and oldest disability organizations in the country. Apart for implementing its own programmes directly, the organization also provides professional consultancies and appraises and monitors projects funded by international agencies. BPA has worked intensively to facilitate linkage of blind welfare organizations with mainstream organizations. In the process, selection of appropriate workers, effective training and workable mode have been identified as critical factors in the success of any CBR programme.

33. **Mission.** An organization devoted to comprehensive rehabilitation of persons with all categories of disabilities through their education, training, support services, research and community based interventions.

34. BPA supports both institutional and community-based programs. A wide range of learning / training material has been developed. Experience has shown that small organizations require support in terms of training and funding, in order to initiate CBR activities. While BPA is not a funding organization, it plays an active role in helping organizations it supports to liaise with funders.

35. BPA promotes a cross-disability and multi-agency approach, with a focus on convergence of available services and integration in mainstream development. Programmes are designed to provide a balance between interventions at the community level, and referrals to specialist institutions.

36. Major Areas of Intervention

- (i) Education and comprehensive rehabilitation for people with disabilities;
- (ii) Development of aids and appliances;
- (iii) Interventions for special education needs of children with disabilities;
- (iv) Community Based Rehabilitation Program;
- (v) Creating employment opportunities for disabled people;
- (vi) Strengthening other NGOs through networking.

37. Major Strengths

- (i) Addressing cross disabilities issues;
- (ii) Promoting decentralization;
- (iii) Good example of NGO-GO alliance;
- (iv) Facilitating linkages between government and local community based organizations;
- (v) Resource mobilization for sustaining other NGOs;
- (vi) Networking with various Government ministries;
- (vii) Lobbying with Government;
- (viii) Addressing the needs of the disabled;

- (ix) Diversifying from one disability to cross disability;
- (x) Promoting employment of disabled people;
- (xi) Capacity building of NGOs;
- (xii) Skill up-grading for disabled people;
- (xiii) Inclusive constitution of BPA;
- (xiv) Reaching out to the parents of the disabled through grass root level organizations and motivating them to organize themselves;
- (xv) Integrated education programs;
- (xvi) Practicing the CBR model – promoting and facilitating home based interventions for people with disabilities;
- (xvii) Acting as an intermediary for providing accessibility to information for disabled people;
- (xviii) Networking with the private sector to promote expanded employment opportunities for disabled people;
- (xix) Networking with NGOs for monitoring their programs.

38. **Future Areas for Mainstreaming**

- (i) Convergence with the Department of Rural Development;
- (ii) Lobbying with the Department of Health for improved health delivery services; and
- (iii) Lobbying with the Ministry of Labour for ensuring 3% reservation for disabled people in all jobs, and making the work environment accessible to persons with disabilities.

E. Sulabh Sanitation Movement: A Low Cost Solution to Success

39. Nearly 80 per cent of the country's population still either defecate in open or use unsanitary bucket latrines or smelly public toilets. This is true even in urban areas where less than 20 per cent of the population has access to water/flush toilets connected to a sewerage system, and only 14 per cent enjoy water toilets connected to septic tanks or leach pits. In rural areas a mere 3 per cent of the population has access to sanitary toilets. This lack of adequate sanitation is responsible for severe health problems. Cholera, dysentery, typhoid, infectious hepatitis and many other diseases can be traced to the unsanitary disposal of human excreta. Lack of sanitation also has grave social consequences; the need to have 'night soil' removed has given rise to the profession of 'scavenging' or collecting it from bucket latrines, the streets and other locations. Although this practice has been banned and the Indian Constitution bans the segregation of those who service this profession, there are many pockets in the country where the practice continues unabated.

40. Sulabh International Social Service Organization, a non-governmental organization, founded by Dr. Bindeshwar Pathak, has in partnership with local governments, demonstrated the success of low cost sanitation technology throughout the country. Their solution, called the Sulabh Shauchalaya, is a low cost, pour flush, water-seal toilet with twin leach pits for onsite disposal of human waste. The technology has many advantages. It is affordable, even by the economically weaker sections of the society, and is designed to suit different levels of income. Flushing requires only two liters of water, instead of 10 liters needed by a conventional toilet. The toilet can never be out of commission, since one of the two pits can always be used while the other is being serviced. The latrine can be built with locally available material. It can be conveniently upgraded as it is a stand-alone on-site unit that can be connected to a sewer system as and when the latter is introduced in the area. So far, more than 700,000 units have

been constructed or substituted for existing latrines in houses and more than 3000 have been installed as pay-and-use public toilets. The latter are staffed by full time attendants and provide facilities including soap powder for washing hands, for bathing and for laundry and offer free services to children, disabled and poor. Thus, nearly 10 million people have been provided with improved, low cost sanitation and at the same time nearly 50,000 employment opportunities have been created in a commercially viable enterprise. As a social spin-off the enterprise has resulted in liberating about 50,000 scavengers from their enforced profession.

41. A key to the success of Sulabh Shauchalaya lies in creating public awareness and seeking community participation in implementing and maintaining the infrastructure. The organization is also working with local groups on production of biogas from human excreta accessed from community toilets, and on generation of electricity. Its research and development activities are geared to seeking practical, low cost solution for solid and liquid waste disposal, including re-cycling in a financially sustainable manner.

E. Parent Role Model – Mrs. Gajalakshmi

42. This is a story of the strength of a determined mother Gajalakshmi, who not only has empowered her disabled daughter Anusuya, but is also being a role model to the parents in her area. The story is shared by the Spastics Society of Tamil Nadu (SPASTN).

43. Mrs. Gajalakshmi has three daughters and her youngest daughter, Anusuya, now aged 12 years, is a severe quadriplegic child. When this was initially revealed by the doctor to the family, her in-laws and her husband held her responsible for their child's disability. To make matters worse, her husband had left them for another woman not bothering to support his family. It was at this juncture that Gajalakshmi took it up as a personal challenge and sought help for her child's rehabilitation services.

44. Knowing that SPASTN has a center at Redhills PHC she took her daughter there and out of her interest in the activities learnt all the therapy activities and speech interventions needed to help her child. On finding Gajalakshmi so motivated, the CBR team has transferred rehabilitation skills and know how to her.

45. She now runs the services at the center and educates other parents on their children's rehabilitation needs. Her valuable contribution is promoting the ideologies of low cost rehabilitation aids and appliances, made of mud, bricks, clay, plantain barks, etc. This has helped most of the parents in rural areas in following up program at home to maintain the functional position required by their children e.g. corner chair, standing frame, splints, prone wedge parallel bars etc. Gajalakshmi is also a strong advocate of inclusion of disabled children in balwadis and schools, which she looks after with periodic follow ups.

46. When the CBR team started working on promoting Self Help Groups in the villages, she took up the responsibilities and helped in forming a self-help group of 18 women with disabilities from her village. By this she brought to focus on the empowerment of women with disabilities.

47. She has also given her own land to the Sangam collective income generating activities and has put up a small hut on it with community contributions. Through the self-help group she takes up social causes to the village leaders about the concerns of persons with disabilities. This serves as a model to all other women mahila mandrams.

48. As a remarkable milestone Mrs. Gajalakshmi stood for the ward member post in the Panchayat elections, nominated by the village panchayat leader himself.

49. There is a twist to the tale: recently in an illicit liquor tragedy her husband, Mr. Palani became totally blind due to its toxicity. Now he is fully dependent on his wife who he had totally rejected earlier. Being a kind hearted person she has accepted him back to her life and family.

50. In spite of having to look after two people with disabilities in her own house, Gajalakshmi runs the Redhills center and the Sangam and continues to be a role model to everyone bringing out the message.

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