DISABLED PEOPLE IN DEVELOPMENT

INDIA COUNTRY REPORT

Foundation for International Training and
Regional and Sustainable Development Department

June 2005

A companion publication of the *Disabled People and Development* and *Disability Brief: Identifying and Addressing the Needs of Disabled Persons in ADB Operations. Disabled People and Development* describes the evolution of the global response to disability as well as the concepts and tools for addressing disability issues. The publication is accompanied by the *Disability Brief,* which focuses on the concepts and tools for addressing disability issues in development for ADB operational staff as well as their government counterparts.

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FOREWORD

In 1999, the Asian Development Bank (ADB) adopted poverty reduction as its overarching goal. This goal is highly relevant to disability issues including the prevention of the causes of disability, generation of appropriate support services and structures, equalization of opportunities for people with disabilities to contribute to poverty reduction, and social and economic development. In 2001, ADB approved its Social Protection Strategy to address the needs of the most vulnerable, including people with disabilities.

In March 2002, ADB approved a regional technical assistance (RETA 5956) project on Identifying Disability Issues Related to Poverty Reduction. The objectives of the project were to

(i) familiarize developing member countries (DMCs) with ADB's overarching objective of poverty reduction and other related ADB policies to help address the vulnerability and poverty situation of people with disabilities;

(ii) identify and analyze the DMCs' 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 disability-related groups/organizations to identify and discuss the needs and concerns of people with disabilities, particularly those related to poverty; and

(iv) develop a disability checklist for ADB.

The project was carried out in 4 countries—Cambodia, India, Philippines, and Sri Lanka—and was undertaken by the Foundation for International Training (FIT). In each country, FIT mobilized a two-person team of multidisciplinary 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 the present series of reports prepared for each country. The country studies were presented at a regional conference on disability and development held at ADB in October 2002.

In India, the project began in April 2002 and involved a series of consultations and visits to project sites; four provincial workshops were held during June–July 2002. An assessment of the current institutional framework and stakeholders' capacity to mainstream disability issues in poverty reduction programs was also included in the work. The outcomes of this process (see Appendix 1) were presented at a national workshop held in August 2002.

This report describes the major factors that affect the life of persons with disabilities: the legislative framework; the country's social protection structure, disability organizations and development agencies; and the relationship between disability and poverty. In addition, the participatory process conducted resulted in the experiences and advice of the key stakeholders, particularly persons with disabilities, being incorporated in the report and in the recommendations developed. Collectively, this report and the process completed have served to focus attention on the imperative for addressing disability issues in India as well as in ADB poverty reduction and growth strategies.

ACKNOWLEDGMENTS

The Project on Identifying Disability Issues Related to Poverty Reduction was led by Dr. Lorna Jean Edmonds, who provided invaluable guidance and direction in the structure and development of the country study reports. This 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 the report. The work benefited from support and cooperation from the Ministry of Social Justice and Empowerment.

We would like to thank for their valuable inputs all those interviewed, as well as the 185 participants at the workshops—25 persons with disabilities, and representatives of disabled people's organizations, central and state governments, United Nations agencies, disability-specific nongovernment organizations (NGOs), development NGOs, community-based organizations, private sector, and financial institutions.

The report and recommendations were edited by a team at the Foundation for International Training led by Ms. Michelle Sweet, Project Manager.

ABBREVIATIONS

AP	–	Andhra Pradesh
APD	–	Association of People with Disability
BPA	–	Blind People's Association
CBO	–	community-based organization
CBR	–	community-based rehabilitation
DGE&T	–	Directorate General of Employment and Training
HPI	–	human poverty index
ICDS	–	Integrated Child Development Services
ILO	–	International Labour Organization
ISO	–	International Standards Organization
NGO	–	nongovernment organization
NHFDC	–	National Handicapped Finance and Development Corporation
NPRPD	–	National Programme for Rehabilitation of Persons with Disabilities
NSSO	–	National Sample Survey Organization
SPASTN	–	Spastics Society of Tamil Nadu
SSEI	–	Spastics Society of Eastern India
UN	–	United Nations
UNDP	–	United Nations Development Programme
UNICEF	–	United Nations Children's Fund
UP	–	Uttar Pradesh
UT	–	Union Territory
WHO	–	World Health Organization

NOTE:

In this report, "$" refers to US dollars.

COUNTRY BRIEF

A. Population and Demographic Data

- Population : 1.055 billion (2002)
- Population growth rate : 2.1 % (2002)
- Rural population (% of total population) : 72 (2001)
- Population density : 321 persons per square kilometer (2002)

Socio-economic Indicators

- GDP growth rate : 4.6 % (2002)
- GDP per capita growth rate : 3.0 % (2002)
- Life expectancy at birth : 63 years (2001)
- Crude birth rate (per '000) : 25 (2001)
- Crude death rate (per '000) : 9 (2001)
- Infant mortality rate (per '000 live births) : 65 (2002)
- Adult literacy : 65.4% (2001)

C. Poverty Data

	1983	1999
• Poverty incidence, %, (head count ratio)	44.5	26.1
• Number of poor (in million)	323	260
• % of population below $1 (PPP) a day		34.7

D. Disability Statistics (1991 data)

- 9% of rural households and 7% of urban households have at least one disabled person (average household size, 5.8 people);
- 1.9% of the population have severe or profound physical disabilities;
- 12% of disabled people have multiple disabilities;
- 80% of disabled people live in rural areas;
- 4% of children aged 0-4 years living in rural areas and 3.3% in urban areas have a hearing loss; and
- prevalence rate for visual impairment is 0.5%, hearing and speech impairment 1%, and motor disabilities 1.1%.

E. Others

- Capital New Delhi
- Official Languages Hindi and English
- Currency Rupee
- Surface Area 3,287,263 square kilometers

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I. COUNTRY NEEDS: POVERTY PROFILE

A. Incidence of Poverty

1. 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 more than 3 decades. It currently uses a minimum consumption expenditure, anchored in an average (food) energy adequacy norm of 2,400 and 2,100 kilocalories per capita per day to define state-specific poverty lines for rural and urban areas, respectively.

2. Using this method, the incidence of poverty on the head count ratio declined from 44.5% in 1983 to 26.1% in 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.

B. Prevalence of Disability

3. A comprehensive survey conducted by the National Sample Survey Organization (NSSO) indicated that some 32 million people in India are 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; both cause 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.

4. India continues to be in 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 fertility and mortality rates has resulted in rapid growth of India's population over the last five decades. The country's population stood at around one billion in March 2001, according to the most recent census. There was an increase of 180 million during the 1990s alone.

5. Overall, human development in India, as reflected in the human development index (HDI), improved significantly between 1980 and 2001. At the national level, the index improved by nearly 26% during the 1980s, and by another 24% during the 1990s. There has been an improvement in both rural and urban areas, although the rural-urban gap in the level of human development continues to be significant.

6. The NSSO conducted a survey of disability in 1991, in which people were classified as "disabled" if they had less than 40% "normal" functions and the focus was primarily on physical

disabilities. The concept of “normal functions” was not clearly defined. The findings of this survey included:

(i) 9% of rural households and 7% of urban households have at least one person with disability (average household size was 5.8 people);
(ii) 1.9% of the Indian population had severe or profound physical disabilities;
(iii) 12% of the disabled people identified had multiple disabilities;
(iv) 80% of people with disabilities live in rural areas;
(v) 4 % of children aged 0–4 years living in rural areas and 3.3 % of those in urban areas had some hearing loss; and
(vi) prevalence rates for the total population were visual impairment 0.5%, hearing and speech impairment 1%, and mobility impairment 1.05%.

7. The United Nations Children’s Fund (UNICEF) suggests the following figures; note that the terminology is not the one currently recommended:

(i) blind - 12 million
(ii) low vision - 28 million
(iii) deaf and speech impaired - 12 million
(iv) orthopedically handicapped - 6 million
(v) mentally retarded - 24 million
(vi) mentally ill - 8 million
(vii) leprosy (cured) - 1 million

8. The Indian Council for Medical Research in 1974 suggested a blindness prevalence rate of 1.4%. The World Health Organization (WHO) estimated a blindness prevalence rate of 1.5% in 1986. The Indian Council for Medical Research further estimated 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 rate for blindness may be rising.

9. Around 23 per thousand males and 17 per thousand females have a physical disability. The prevalence rate is higher than the national average in Andhra Pradesh (AP), Himachal Pradesh, Karnataka, Madhya Pradesh, Orissa, Punjab, and Tamil Nadu. The physical disability prevalence rate per thousand in urban populations is 16.75, and in rural populations, 19.75. About 9.1% of rural households and 6.8% of urban households 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 proportion of disabled people seeking and available for work in urban areas was 1.7%, and 0.7% in rural areas.

10. The census figures for the present decade, surveyed in 2000–2001, are yet to be published. Table 1 is based on estimated numbers/percentages of people with disabilities nationwide as per the 1991 NSSO.

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

Type of Disability	Rural			Urban			Total Rural + Urban
	Male	Female	Total	Male	Female	Total	
	(1)	(2)	(3)	(4)	(5)	(6)	(3)+(6)
Visual (No.)	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 (No.)	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 (No.)	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 (No.)	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	
Locomotor (No.)	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 above) (No.)	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: Percentage figures in columns (1) and (2), in columns (3) and (6), and in columns (4) and (5) add up to 100.

11. The cost of supporting disabled people in India is huge and poses a severe drain on economic resources, according to leading organizations working for the rights of persons with disabilities. If the number of disabled people in India is conservatively estimated at 60 million and the minimum cost of living for a person (per month) estimated at Rs1,000, the cost to the country to support disabled people per year is Rs80 billion. If disabled people could be made self-sufficient, wealth creation in India could increase significantly.

C. National Issues

12. India is a country of 28 states and 7 union territories (UT) spread over diverse geographical terrain, which makes planning and implementation of various national programs very difficult. Indian communities are heterogeneous, with wide differences in socioeconomic status, educational attainment, religion, and ethnicity. This diversity can cause friction and affect services because 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 a double disadvantage and are also at high risk of becoming even poorer. The same is true for all people living in poverty, who have a high risk of facing a disabling condition because of their limited access to basic services, including health, education, and sanitation, and higher rates of exposure to hazardous working conditions.

13. Poor nutrition during pregnancy, genetic factors, infectious diseases, poor sanitation, and crowded living conditions together with poor food, lack of basic health and rehabilitation services, and lack of immunization against such diseases as polio and rubella are among the major causes of disability. Modernization itself is also a causal factor, as in the cases of infants born with a disability as a result of inappropriate medication used during pregnancy, traffic accidents resulting in loss of limbs and blindness, and infections as a result of pesticide and fluoride poisoning. Aging is another major contributing factor.

14. 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.

15. At the national level, 71% of households were living in houses with two or less rooms in 1991; the proportion was slightly higher in rural areas than in urban areas. Also, less than one quarter of the households in the country had toilet facilities within their places of residence; the proportion was less than 10% for rural households and around 64% for urban households. Access to toilet facilities for Scheduled Castes and Scheduled Tribes households was lower than that of other households in almost all states. The lack of facilities for disposal of wastewater is one of the main causes of prevailing ill health and morbidity levels in the country.

16. 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, especially sewage disposal. In urban areas, poor solid waste management practices pose a significant threat to safe drinking water. Millions of people in the country suffer from water-borne diseases because of lack of access to safe drinking water. People living in poverty suffer from a higher prevalence of such diseases.

II. LEGISLATIVE AND POLICY FRAMEWORK

A. Definitions of Disability in India

17. The RCI-Rehabilitation Council of India Act, 1992, defines disabilities in the following terms.

(i) *Hearing handicap*: deafness with hearing impairment of 70 decibels and above in the better ear or total loss of hearing in both ears.
(ii) *Locomotor disability*: a person's inability to execute distinctive activities associated with moving, both himself/herself and objects from place to place, and such inability resulting from affliction of either bones, joints, muscles and nerves.
(iii) *Mental retardation*: a condition of arrested or incomplete development of the mind of a person, which is specially characterized by subnormality of intelligence.
(iv) *Visually handicapped*: a person who suffers from any of the following conditions:
    (a) total absence of sight,
    (b) visual acuity not exceeding 6/60 or 20/200 (sentinel) in the better eye with correcting lenses, or
    (c) limitation of the field of vision subtending an angle of 20 degrees or worse.

18. The Planning Commission of India's definition of a person with disability refers to a person who is blind; is deaf; has orthopedic disability; has a neurological disorder; or is 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.

19. A new law, the Persons with Disabilities (PWD) Act, 1995, established the following definitions.

(i) *Person with disability*: a person suffering from not less than 40% of any disability as certified by the medical authority.
(ii) *Blindness*: a condition where a person suffers from any of the following conditions:
    (a) total absence of sight; or
    (b) visual acuity not exceeding 6/60 or 20/200 (sentinel) in the better eye with correcting lenses; or
    (c) limitation of the field of vision subtending an angle of 20 degrees or worse.
(iii) *Cerebral palsy*: a group of nonprogressive conditions in a person characterized by abnormal motor control posture resulting from a brain insult, or injuries occurring in the prenatal, perinatal or infant period of frequencies.
(iv) *Hearing impairment:* loss of 60 decibels or more in the better ear in the conversational range of frequencies.
(v) *Locomotor disability*: disability of bones, joints or muscles leading to substantial restriction of the movement of the limbs or any form of cerebral palsy.
(vi) *Leprosy-cured person*: any person who has been cured of leprosy, but is suffering from

(a) loss of sensation in hands or feet as well as loss of sensation in the eye and eye-lid but no manifest deformity;
(b) manifest deformity or paresis but having sufficient mobility in their hands and feet to enable them to engage in normal economic activity; or
(c) extreme physical deformity, as well as advanced age which prevents him/her from undertaking any gainful occupation and the expression "leprosy cured" shall be construed accordingly.

(vii) *Mental retardation*: a condition of arrested or incomplete development of the mind of a person, which is specially characterized by subnormal intelligence.
(viii) *Mental illness*: mental disorder other than mental retardation.
(ix) *Person with low vision*: a person with impairment of visual functioning even after treatment of standard refractive correction, but who uses or is potentially capable of using vision with an appropriate assistive device.

B. National Legislation for Persons with Disabilities

20. The policy framework in the area of disability is enshrined in 3 Acts:

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

21. The Persons with Disabilities Act, 1995, is a comprehensive legislation that spells out the responsibility of the State toward the prevention of disabilities; protection of rights of persons with disabilities; and provision of medical care, education, training, employment, and rehabilitation to persons with disabilities. The Act also includes a commitment to create barrier-free environments for persons with disabilities, and owns the responsibility to remove any discrimination against persons with disabilities in sharing 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 services for equalization of opportunities for persons with disabilities and makes special provisions for their integration into the social mainstream. The Act also provides for protection of rights of persons with disabilities and for their social security.

22. The office of the Chief Commissioner for Persons with Disabilities is a statuary authority having quasi-judicial powers under the Persons with Disabilities Act. The functions and duties of the chief commissioner include coordinating the work of state commissioners for persons with disabilities and monitoring the use of funds disbursed by the central Government. The position is also mandated to take steps to safeguard rights and facilities made available to persons with disabilities and acts as a forum to redress grievances in the event of denial of such rights, addressing such issues as access to education, physical accessibility, employment opportunities, and discrimination.

23. The Act also mandates appointment of commissioners at the state level for its effective implementation. Independent commissioners have been appointed in only 9 states. In the others, it is an additional responsibility of the secretary of the state social welfare or women and child welfare departments. The rationale given by 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 1 million (particularly the northeastern states and Himachal Pradesh).

24. The Rehabilitation Council of India 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 Act links health with other social issues, such as hygiene and sanitation. Similarly, the training of teachers needs to be linked with other social issues because the professionals produced from this training are linked to the services rendered to persons with various disabilities**.**

25. 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 standing committees comprising members of parliament, who then consider the matter clause by clause, and only after extensive discussion are these again placed before parliament.

26. Nongovernment organizations (NGOs) in the disability sector have expressed concern that the Rehabilitation Act was passed without consultation and discussion. In fact, nonprofit 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 began 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 affect their work. 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 who are not registered is both unenforceable and highly discouraging. The presence and implementation of this Act have brought about serious debate on the basic concept and agenda behind the Act and the mechanism for its implementation.

27. 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 to appoint guardians for persons over the age of 18 years with autism, mental retardation, or multiple disabilities in the event of death or illness of their primary caregiver. The National Trust began with a corpus fund of Rs1 billion from the Government.

C. National Policy Addressing Disability through Integrated Programs

1. Education

28. 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 opportunities and choices for sustained improvement in well-being. Education is not only a means to enhance human capital, productivity and incomes, but is also important for enabling the process of acquisition, assimilation, and communication of information and

knowledge, all of which augment 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 the durable integration of people, particularly those excluded from the mainstream of any society.

29. In India, the responsibility for 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 prevails. These efforts have taken the shape of an enabling policy framework—for instance, the National Education Policy, 1986, and the more recent introduction of a bill to make primary education compulsory. Other national initiatives include the Total Literacy Campaign, District Primary Education Programme, Mahila Samakhya, and the present Sarva Shiksha Abhiyan initiative.

30. The policy for making elementary education universal focuses on access and enrollment; 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, and improvement in teaching aids, practices, and training that will enable all children to achieve essential levels of learning.

31. Article 45 of the Constitution states that the State shall endeavor to provide, within a period of 10 years from the commencement of the Constitution, free and compulsory education for all children up to 14 years of age. This constitutional obligation has been deferred successively to 1970, 1980, 1990 and then to 2000. The Tenth Five Year Plan (2002–2007) has set the target of all children completing 5 years of schooling by 2007.

32. 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.

33. The Compulsory Education Act was enacted in the states and UTs and has largely remained unenforced because of prevailing socioeconomic conditions. At the same time, some northeastern states and Himachal Pradesh, in particular, have made rapid strides in improving their literacy rates without the support of the 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 privately funded institutions is also mostly free. Other costs, such as text books, uniforms, school bags, and transport fees, are not borne by states except in a few cases as incentives for children from poor and deprived segments of the population including, in some cases, girls.

34. 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 Act, 1995, establishes a 3% reservation in all educational institutions 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. With the help of these provisions in the Act, the courts have required 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

35. Statements in the National Health Policy, 1983, and the draft National Health Policy, 2002, 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; the policy emphasizes the establishment of a referral system to prevent a needless load on higher levels of the health care hierarchy. At the same time, the policy proposes to create a network of highly specialized services by encouraging private health care facilities for patients with the ability to pay for them.

36. 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 all people. The broad objective of the draft National Health Policy, 2002, is to achieve such an acceptable standard of good health by increasing access to the decentralized public health system through upgraded and new infrastructure. Overriding importance is given to ensuring more equitable access to health services across the social and geographical expanse of the country.

37. Under 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 5 decades, the central Government has provided supplementary funds for control of major communicable and noncommunicable diseases, by initiating national-level programs, in some cases with assistance from foreign agencies.

38. National initiatives on some noncommunicable diseases that are perceived as major public health problems have also been taken. Among these are the National Goitre Control Programme (launched in 1962); the National Blindness Control Programme, which was launched in 1976 and has succeeded in reducing the prevalence of blindness from 1.4% to 0.3%; the National Cancer Control Programme (launched in 1975–76), National Mental Health Programme, which was launched in 1982 and runs training programs and information, education, and communication activities within district mental health programs; and the Integrated Non-Communicable Disease Control Programme, which was launched on a pilot basis in the Ninth Plan. In addition, the central Government supports biomedical research. The Indian Council for Medical Research is the nodal organization for undertaking and supervising this work.

39. At the state level, apart from the overall responsibility of providing preventive and curative health care, some important initiatives are the Integrated Child Development Services (ICDS) program, the National Midday Meals Programme (NMMP), various micronutrient schemes—including those targeted for improving intake of iron-folate, vitamin A, and iodized salt— and food for work through various antipoverty programs. The ICDS program provides supplementary feeding, immunization against preventable childhood diseases, health checkups, health and nutrition education to women, and preschool education for children. The program has had significant success in many areas, particularly in states where the primary health care infrastructure is relatively well developed. The states that have done well include Kerela, 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, and especially Rajasthan and Madhya Pradesh have significantly improved their respective ICDS programs. The NMMP was initiated in 1995 to improve nutritional status and learning achievements of school children and, more importantly, their enrollment and attendance in schools.

40. There should be a health subcenter for every 3,000–5,000 persons; a primary health center for populations of 20,000–30,000; and a community health center for the 4 primary health centers. The number of primary health center doctors at the national level exceeds these requirements. There are, however, shortages of paramedics, as well as specialists at the community health centers, which undermine their functioning as referral units. The disparities across states and within states for infrastructure and personnel are quite striking.

41. Physical medicine and rehabilitation emerged as a medical specialty in the post-independence era, underlining the need of interdisciplinary teamwork among physiatrists, physical therapists, occupational therapists, medical social workers, speech therapists, psychologists, prosthetists, and orthotists. Only a few institutes have all the above professionals under one roof. Such centers 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.

42. With the exception of such states 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, cottage hospitals, and primary health centers.

43. Although the Ministry of Health and Family Welfare is not the focal ministry for disability issues, it has 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. The ministry has programs with direct bearing on disability and its role needs to be strengthened and emphasized.

44. Ongoing national health programs related to prevention of disability, apart from those mentioned above on noncommunicable diseases, are the Leprosy Eradication Programme with multidrug therapy, which has had an impact on the incidence rate and prevention of disability; Iodine Deficiency Disorders Control Programmes; and Universal Immunization Programme including the Maternal Child Health Programme, which has expanded and gradually increased the number of children immunized. These programs may be further strengthened and attention will be given toward preventive and rehabilitation aspects.

45. 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 Persons with Disabilities Act, 1995. This council meets every two years; recent recommendations include

(i) establishing a center for basic rehabilitation services in each state and in every district for people with disabilities;
(ii) identification of and enhanced cooperation with institutions and bodies engaged in research and investigation of cause, occurrences, and early symptoms of disability;
(iii) 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;
(iv) establishing a screening mechanism to identify high-risk groups among school and preschool children in the states and UTs so that they can be provided with early access to rehabilitation services;
(v) 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;
(vi) ensuring that each state has at least one medical college with a department of physical medicine and rehabilitation;
(vii) urging the Medical Council of India to recirculate its mandatory recommendation, which should be made time bound, for starting departments of physical medicine and rehabilitation in all medical colleges (private and government) in order to meet the requirements of the new curriculum for undergraduate medical education; and
(viii) developing facilities in each state for chronically disabled patients with health problems.

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

3. Women

47. 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 make necessary amendments from time to time. The commission has conducted a nationwide investigation of issues for women belonging to socially and economically disadvantaged groups, especially those from the Scheduled Castes and Scheduled Tribes and other target groups, such as women/children sex workers, women in custody or asylums, and women with disabilities.

48. The commission has adopted open public hearings (open *adalats*) to enquire into cases of grievance and abuse. Based on its recommendations, the Government has already initiated action to amend the Commission of Sati (Prevention) Act, 1987; Immoral Traffic (Prevention) Act, 1956; Indecent Representation of Women (Prohibition) Act, 1986; Child Marriage Restraint Act, 1929; Guardians and Wards Act; Family Codes Act; Foreign Marriage Act; and sections of the Penal Code relating to rape.

4. Employment

49. Under the Constitution of India, labor is a subject where both the central and state governments are competent to enact legislation, subject to certain matters being reserved for the central Government. The Ministry of Labour has 4 attached offices and 10 subordinate offices, 4 autonomous organizations, 17 adjusting bodies, and an arbitration body.

50. Vocational training is also subject to both central and state levels of government. The central Government has responsibility for developing training schemes at the national level, policy development, establishing training standards and procedures, and conducting trade tests and certification. Implementation of training schemes largely rests with the state and UT governments. The National Council of Vocational Training, 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, have the same role with respect to state governments.

51. 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. Currently, it comprises 4,465 industrial training institutes. 50.Seats are reserved for scheduled caste (SC) and scheduled tribe (ST) candidates in proportion to their number in the population in the respective state. The guideline to reserve 3% seats for persons with disabilities and 25% for women candidates has been issued to state governments. The participation rate for disabled people in vocational and industrial training is below the 3% target.

52. 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 in both central and state sectors have been set up for extending skill training facilities to women and to stimulate employment among women of various socioeconomic levels and age groups. Under the central sector, the institutional network includes a National Vocational Training Institute for Women; and 10 regional vocational training institutes for women.

53. For skills training of poor women (those below the poverty line), the International Labour Organization (ILO) has undertaken a project on Decent Employment for Women; DGE &T is the focal point agency. The program focuses 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 nonformal sector. This is a pilot program implemented in New Delhi and Bangalore.

54. There are 938 employment exchanges at the state level, including 42 special employment exchanges for persons with disabilities, throughout India. There are also 41 special cells for persons with disabilities within mainstream employment exchanges. Most states have a directorate of employment located in the state capital.

55. 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 gives recent data from the exchanges.

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

Year	No. Registered	No. Placed	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

*Note: Live register refers to persons with disability who are alive and have still not been absorbed in any gainful employment.

56. There are currently 17 vocational rehabilitation centers for disabled people, located in 16 states. One, the Vocational Rehabilitation Centre at Vadodara, was 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); rural rehabilitation extension centers have been set up in 11 areas under 5 vocational rehabilitation centers.

D. National Policy Addressing Disability through Targeted Programs

57. The Ministry of Social Justice and Empowerment monitors the implementation of the Persons with Disabilities Act, 1995, and the 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 coordination, networking, and collaboration with other related departments for inclusion of disability issues in their ongoing programs.

58. At least 6 government departments are directly engaged in addressing disability. Each ministry and department has funds to develop activities concerning persons with disabilities in its area of operation. A coordinated approach to build synergies among them could substantially improve the effectiveness of public action in this area. For example, health-related programs that prevent some disabilities continue to be strengthened and implemented through a multisectoral and collaborative approach.

59. The Department of Women and Child Development has been given special responsibility in the field of prevention. In the Maternal Health Programme, emphasis is laid on prenatal and postnatal health of the mother and infant. Pre- and postnatal 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 personnel in early detection and timely prevention of disabilities is also undertaken by this department.

1. Funding for National Policies

60. Financial support for inclusion of disability concerns within national programs is largely from United Nations (UN) organizations and allocated through the recommendation of the Ministry of Finance to the relevant ministry, which hands it over to the state departments in turn. Recently, implementing agencies have begun seeking support from various NGOs for the implementation of development programs.

61. The programming priorities of international funding agencies in India 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. The World Bank has supported the Government'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. The United Nations Educational, Scientific and Cultural Organization has also funded programs for inclusive education, while the United Nations Economic and Social Commission for Asia and the Pacific has supported the inclusion of disabilities strategies within rural development initiatives. WHO initiated the community-based rehabilitation (CBR) model in India and has supported programs for the prevention of leprosy and blindness.

62. Disability issues are also being addressed through projects and programs funded by bilateral agencies. The Danish International Development Agency (DANIDA) has long been associated with programs to control 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 disability through a community-based approach. The Netherlands has also funded programs for district rehabilitation centers in India, while Norway has funded income-generation programs for women with disabilities.

63. The National Handicapped Finance and Development Corporation (NHFDC), incorporated in 1997, channels funds through agencies and NGOs authorized by the state governments and UT Administration. The Corporation aims to promote economic empowerment of persons with disabilities by financing self-employment ventures. It also extends loans for pursuing general/professional/technical education at the graduate and higher levels. NHFDC also assists in upgrading 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

64. The National Programme for Rehabilitation of Persons with Disabilities (NPRPD) was launched to provide comprehensive rehabilitation services to persons with disabilities, especially those living in rural areas. There is a 4-tier structure for service delivery at gram panchayat, block, district, and state levels. The focus is on 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, when funds were released to set up state referral centers. The scheme will ensure local capacity building and

better use of available resources while providing a much needed rehabilitation structure at all levels.

65. During 2000–2001, five composite regional centers for persons and disabilities were set up in Srinagar, Lucknow, Bhopal, Sundernagar, and Guwahati, respectively. These are housed in facilities provided by the respective state governments with assistance of national institutes. Four regional rehabilitation centers for persons with spinal injuries—at Mohali, Cuttack, Jabalpur, and Bareilly, respectively—have also started providing services in temporary accommodation given by the state governments.

66. There are 11 district rehabilitation centers. Their objective is to provide comprehensive rehabilitation services to people with disabilities in rural areas through a mobile camp approach in villages. These centers provide services for prevention and early detection, medical intervention, surgical correction, fitting of artificial aids and appliances, physiotherapy, occupational and speech therapy, vocational training, and job placement in local industries. There are also 4 regional rehabilitation training centers located in Chennai, Cuttack, Lucknow, and Mumbai, respectively, for training and personnel development in rehabilitation.

67. 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 the application of technology in the development and use of suitable and cost-effective aids and appliances, as well to promote education and skills 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. More than 30 aids and appliances/products have been developed through this program, including a plastic aspheric lens for persons with low vision, the myo-electric hand control system, and a motorized, joystick-operated wheelchair.

68. The Government 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 nonformal employment and placement opportunities.

III. DISABILITY ORGANIZATIONS AND DEVELOPMENT AGENCIES

69. The quality of life of disabled people is very low. Facilities provided by the Government and NGOs remain inadequate. Most people with disabilities are poor and the incidence of disability among the poor is also higher than that in middle- and high-income groups.

70. 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 his or her potential. The onset of disabilities with age has in most cases a direct bearing on a person's economic well-being through reduced work participation and decline in productivity. As a result, employment and income levels tend to be a fraction of those of the general working population. People with disabilities face physical, social, and attitudinal barriers that may restrict their livelihood opportunities and access to basic public services or social transfers.

71. The emergence of the Persons with Disabilities Act, 1995, was no doubt a landmark in the history of disability in India. Through the Act, the Government 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 nonimplementation of related laws, rules, regulations, executive orders, guidelines, etc. The provisions of the Act are being implemented through a multisectoral, collaborative approach by related ministries and departments of the central Government, the state governments, and other appropriate authorities. 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 5 NGOs; and the central executive committee (CEC), which is the decision-making body consisting of 23 members with representation from 3 NGOs. While these bodies provide an excellent opportunity for interagency coordination and government-NGO collaboration, they do not meet frequently enough to fully achieve this potential. While the CCC should meet quarterly and the CEC once every 6 months, the CCC has only met 5 times in the past 16 years, and the CEC has met only 8 times in the same period. Similar bodies are active at the state level, although only a few states have convened such committees to date.

72. NGOs working in the field of disabilities and development, community-based organizations (CBOs), and disabled people's organizations are very important stakeholders. National institutions, UN 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 in providing employment to persons with disabilities; the potential for more active engagement of the private sector in creating employment opportunities for people with disabilities makes it an important stakeholder as well. Indians owe a debt of gratitude to disabled people's organizations and parents' organizations for the enactment of legislation for persons with disabilities. Disabled people's organizations and NGOs working in the field of disability were able to have disability-related items included in the 2001 Census.

73. 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.

74. 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 coordination works better at local levels but fails at regional or national levels. Multisectoral collaboration is difficult for a number of reasons. For example, the management cultures of government organizations and 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, multisectoral collaboration 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 multisectoral collaboration.

75. 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 disabilities, persons with severe disabilities are neglected. No valid methods to address the needs of this group effectively at the community level have been devised.

76. 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 CBOs not only have the benefit of presence and acceptance at the grassroots level, but also possess technical knowledge and stability that can enhance the cost-effectiveness of programs and services in partnership with government.

IV. RELATIONSHIP BETWEEN DISABILITY AND POVERTY

A. Government Poverty Reduction Strategy

77. The Government's antipoverty strategy comprises a wide range of poverty reduction 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, the various poverty reduction and employment-generation programs were grouped under two broad categories: self-employment schemes and wage employment schemes. Funding and organizational patterns were also rationalized to achieve better impact. These programs are primarily meant for poverty reduction, but have generally not been successful in achieving sustainable employment generation.

1. Urban Development

78. Urban poverty is an area of concern—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, such issues as better distribution, proper storage, improved water management, and conservation of groundwater resources have to be tackled by resource-deficient urban local bodies. Similarly, sanitation and environmental hygiene need urgent attention. Disposal of solid waste, proper sewerage and drainage facilities, and effective public health measures are other priority areas.

79. The New Economic Policy launched in India in 1991–92 saw several important initiatives designed to encourage private sector participation in urban infrastructure projects. These initiatives need to be further strengthened. A series of new reform measures is being put together for implementation during the 10^{th} plan period. There is hope that the declining standards of urban infrastructure can be reversed.

80. Urban transport has a direct bearing on disability and poverty reduction by providing potential access to opportunities, supporting urban economic activities, and facilitating social interaction. The major responsibility for urban road transport infrastructure and service delivery rests with state governments and local bodies, One major initiative is the Delhi Metro Rail Transport System Project. Care has been taken to ensure accessibility for persons with disabilities on the metro rail system. However, managing road transport is a state subject, and most states do not have substantial financial resources; hence, the needs of disabled people are not being addressed in current road transport projects.

81. The National Housing and Habitat Policy aims 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, low-income groups, and other vulnerable groups. Of the 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.

82. The Urban Wage Employment Programme seeks to provide wage employment to beneficiaries living below the poverty line, within the jurisdiction of urban local bodies, by using their labor for construction of socially and economically useful public assets.

83. There is a National Social Assistance Programme (NSAP) comprising the National Old Age Pension Scheme, the National Family Benefit Scheme, and National Maternity Benefit Scheme. The NSAP is a 100% centrally-sponsored program and extends benefits in the form of an old-age pension to the aged destitute, a lump sum to the bereaved (poor) family on the death of its primary breadwinner, and a small maternity benefit to poor women for the first two live births.

84. Additional central assistance is being released to states and UTs to develop urban slums through 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, advocacy, and involvement of NGOs, CBOs, private institutions, and other bodies.

2. Rural Development

85. Rural development is also a priority for the Government, which 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 implement the programs. Accordingly, sustained efforts have been made to strengthen local governance, institutionalizing people's participation and empowering women through the Panchayati Raj institutions.

86. 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 a development program, the Pradhan Mantri Gramodaya Yojana. The Ministry of Rural Development has been entrusted with the responsibility for implementing the drinking water, housing, and roads components of the program.

B. Institutional Framework

87. National policy formulation is 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 to be implemented by the states and UTs. Regardless of the original source of funds, the state and UT governments are expected to

sustain the projects with their own resources after the funding ends. Because most development programs are designed and conceptualized at the central level, most meet an untimely end when funding is no longer in place.

88. At the central level, the formulation and execution of social welfare programs at the central level are currently done by various ministries, departments, and agencies. Many states do not have adequate social welfare programs; the programs lack proper linkages, coordination mechanisms, and assessment of the development problems.

89. While the role of the State needs to be redefined, 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 toward the goals of human development will have to be reexamined.

C. Program Initiatives for Disabled People

90. While the links between disability and poverty are well known and understood, there is an absence of statistical data to determine 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. 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, but 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. Although most poverty reduction programs have a mandatory reservation of 3% for the disabled in all their schemes as a result of the Persons with Disabilities Act, 1995, there are no data on the numbers of disabled people who are reached through these programs.

91. Service delivery with respect to health, education, employment, and welfare is the responsibility of state and UT governments. However, the degree to which national legislation is implemented varies among the different states. Also, as mentioned earlier, the task forces mandated by the Act have not been constituted in all states. Lack of awareness of the Act is apparent; even lawyers, judges, and officials remain unaware of its provisions.

92. Bureaucracy in India is a highly rigid hierarchical system. On the one hand, this means that such issues as disability can be overlooked as social programs move from the national to the state and local levels. On the other hand, if properly utilized, this system can create wonders through convergence. The deputy commissioner, the administrative and bureaucratic head at the district level, has maximum concentration of powers, and is thereby able to play an important role in ensuring the implementation of programs under the education, health, rural, and urban departments.

93. At present, programs targeting poor persons with disabilities are poorly implemented, 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 empty 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 memorandums, 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.

94. Despite the systemic challenges 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

95. Under the country's social protection structure, persons above the age of 18 who are more than 40% disabled 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 toward disability concerns. Seven states and UTs have no disability pension program. Only 12 states and UTs provide an unemployment allowance. Goa is the only state granting tax exemptions on purchases of equipment for self-employment for people with disabilities.

96. The National Social Assistance Programme has provisions to cover disabled people who are over 45-years old and, under certain conditions, age restrictions can be relaxed by the district committee. However, not all states have such committees.

97. Health services are provided free of cost; hence, there is no special health allowance for persons with disabilities or those below the poverty line. Departments of welfare in many states provide free distribution of assistive aids and appliances for persons with disabilities, with the help of the National Ministry of Social Justice and Empowerment. Some states have also taken the initiative to conduct free surgery for correctable conditions.

2. Housing and Transportation

98. Twenty-two states and UTs 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 programs in 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 disabled people living below the poverty line.

99. Disabled government employees, as well as those suffering a serious illness, may receive housing 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. The fifth central Pay Commission has recommended that a transport allowance be given to central government employees with disabilities to compensate them for the cost of commuting between residence and place of duty.

3. Family Benefits

100. Disabled children of government employees are eligible for a family pension benefit, even if the children are born after the retirement of the employee.

4. Other Benefits

101. The provision in the Persons with Disabilities Act, 1995, that in every establishment the Government shall hire disabled people to fill no fewer than 3% of all vacancies, has had flow-on in other schemes. For example, there are provisions under the Ministry of Rural Areas and Employment for 3% reservation for persons with disabilities among beneficiaries under the Training for Rural Youth for Self Employment Programme and Integrated Rural Development and Employment Scheme. Under the Department of Rural Employment and Poverty Alleviation, out of the 60% of funds earmarked for general works, 3% are to be utilized for the creation of barrier-free infrastructure with an annual allocation of 3% for this purpose at 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.

5. Community-based Rehabilitation

102. In the early 1980s, 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, because WHO had recommended that it be integrated into the established primary health care 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 quantitative growth, there were 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 education, vocational training, social rehabilitation, and prevention. Along with this shift came the recognition that CBR needed to deal with issues related to disabled people’s lives at all times and to seek to change not only the disabled individual, but also the context in which he or she lived. Addressing these contextual factors involved changing attitudes of other persons in the community to accept people with disabilities; promoting their social integration; and promoting equal opportunities in education and employment. Empowering communities to manage their programs was another important contextual step in the CBR approach.

103. Lack of organizational ability and knowledge about disability on the part of community development organizations remain a major barrier to integration. Disability is seen as a “specialist” issue; 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, and ethnic status. Lack of mobility, education, and skills continue to prevent disabled people from participating in development programs as full stakeholders and equal partners.

V. CONCLUSIONS

A. Issues in Targeting Particular Groups

104. Different age groups among disabled people need to be targeted and their specific problems addressed. In spite of the National Education Policy, only 2% of children with disabilities in the 6–14 age group 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, which aims to increase access to and retention in mainstream education, at least for primary education.

105. When targeting youth with disabilities, the focus could be on access to higher education, vocational training, and employment opportunities. There are 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 increasing numbers of these people, such as by 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.

106. Older people with disabilities require social security mechanisms to ensure dignified living standards. The amount given through old age pensions, widow pensions, and disability pensions varies from states to states, because welfare is a state subject. These amounts also depend on the prosperity and the priorities of the state. The lack of uniform standards leaves many older disabled people vulnerable.

B. Crosscutting Issues and Priorities

107. Use of the term *rehabilitation* has become integral when speaking about meeting the needs of disabled people. Conceptually, rehabilitation addresses a narrow range of issues. A more appropriate framework would be a human rights approach that includes strengthening access to education, health services, employment, and the built environment, important stepping-stones on the continuum of empowerment. A human rights approach could be realized through a national policy that addresses and targets empowerment, rather than rehabilitation, by involving all the related departments.

108. Health services in India have the largest network. Services for persons with disabilities have in recent decades been delivered under the aegis of the 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 because of inaccessible infrastructure in the primary health centers in both rural and urban areas. There is also a significant shortage of expertise at the grassroots level for early identification of and intervention for infants born with a disability or disabling condition.

109. The education needs of children with disabilities have become more widely recognized and acknowledged in recent years. But sadly, the focus has so far been on the 6–14 age group; there are very few education facilities for young children with disabilities (3–6 years) in rural areas. Opportunities for higher education are also very limited in rural areas, and even in urban

areas the physical infrastructure of most higher education institutions continues to pose accessibility challenges. A few prosperous states provide scholarships for higher education for disabled children and youth from the departments of welfare, but this is controversial because education is the responsibility of departments of education under the Ministry of Human Resources Development.

C. Coordination Among Stakeholders

110. 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 NGOs. Recent successful initiatives, particularly in watershed management and minor irrigation in the states of Gujarat, Rajasthan, and Maharashtra, have considerably improved incomes at the community level and strengthened the capacities of communities to become self-reliant. More importantly, they have fostered a sense of ownership, responsibility, and progress among the people.

111. However, the need for decentralized governance and different relationships between central and state governments is an issue that affects the pace of development in general and the welfare of persons with disability in particular. The present administrative hurdles and lack of coordination have a direct bearing on the ability of disabled people and their communities to take action and initiate appropriate community-based approaches to disability and poverty issues.

D. Analysis of Current Paradigms

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

113. 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, which seek to ensure active participation of local communities at all levels of program planning and implementation, and to identify relevant indigenous knowledge and resources to help achieve the ultimate objective of improving the quality of life of people with disabilities and their families.

114. Ambivalent attitudes toward people with disabilities have always been prevalent. Manu Smriti, the ancient charter of social conduct, compelled people to spare some of their material resources for those less fortunate and to support their daily living. Dharmashastra prescribed householders to look after the weak and disabled. However, disability is also held to be a punishment for the sins of previous lives. Families and other community members attribute physical disability to cosmic factors, fate, God’s will, and karma.

115. Religious beliefs provide 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.

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

117. Prior to the 1980s, people with disabilities had little or no access to rehabilitation services, which were limited to institutions and obviously had limited coverage. India had limited resources to provide high-quality institutional services; the emphasis instead was on developing a method that provided wide coverage at costs affordable to governments. Through the CBR approach, interventions shifted from institutions to home and communities of people with disabilities and carried out by minimally trained people, such as families and other community members, thereby reducing costs. CBR appears to be the only viable and practical solution for the massive problem of disability in India. The approach envisages a social environment in which a community shows awareness of and sensitivity to the special needs of its disabled members and feels responsible for bringing about the desired changes.

118. The efficacy of CBR lies in the highly developed sense of community that has always been the strength of Indian society. Local communities have generally taken care of their members with disabilities. Although CBR in its present form is a product of the western scientific tradition, conceived by international agencies and adopted by urban NGOs, it also has inherent components of community participation, a sense of belonging, and involvement. Efforts to address disability and poverty issues through the CBR model with equal partnership between the Government and the NGO sector could result in profound changes in the quality of life for people with disabilities.

119. The disability movement in India has made considerable progress in promoting the need to integrate people with disabilities in the social mainstream. There has also been an ideological shift in developmental planning—from welfare to human resource development. The national committee on the International Year of Persons with Disabilities 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, given the geographical, cultural, religious, and social diversity, the central Government and NGOs were unable to meet the vast challenge of disability in rural areas. There was a need to mobilize local support to sustain disability rehabilitation programs. There was also pressure from international organizations for national programs on disability. International agencies indeed brought a change in service culture, ideology, and ways of functioning of government and voluntary organizations. Service organizations went through major transitions, in line with international movements. The Persons with Disabilities Act,1995, was a major result, through which, the Government itself made a shift from the charity and welfare 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.

120. The efforts 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. Although the partnership model appears incompatible with traditional practices, its success in recent years is a clear indication of changing attitudes of society, government, and service organizations.

VI. RECOMMENDATIONS

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

122. *Inclusion*: People with disabilities must be visible. Inclusion identifies the disability initiatives needed 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, government, and nongovernment agencies; to ensure that material resources are committed to disability issues; to ensure that organizations and their personnel are knowledgeable; and to 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.

123. *Participation*: Participation ensures that people with disabilities and their respective organizations are given a voice in decisions that affect their lives and their communities. The priorities are to promote effective participation, including consultation and decision making that involve representatives of people with disabilities.

124. *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.

125. *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 be effective. Quality includes raising the capacity of persons with disabilities and other stakeholders to ensure independent living through technical and functional interventions. It requires increased understanding of the factors needed for a barrier-free environment, including community access, attitudes toward disability, and human rights. Also, 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 intersectoral and multistakeholder approaches to development.

126. In order to address these areas of priority for disability and development, a series of recommendations was made according to the four categories above.

A. Inclusion

127. The Government should include recognition of its formal obligation and commitment in its deliberations on the disability sector. This commitment could be most effectively projected through a comprehensive policy and strategic planning on issues concerning disabled people. All national policies should address crosscutting themes, such as gender, disability, and

poverty. Policies should also include specific indicators with respect to target groups for objective evaluation. Policy could also be made time bound or subject to periodic review to assess the need for continuity.

128. The Government and donors should consider further increases and allocation of human and financial resources to the disability and rehabilitation sector, which should be treated as a priority sector. These agencies should insist that the needs of people with disabilities be considered as an integral part of the planning of all programs and projects and not viewed as a separate issue. All projects, especially those addressing such basic needs as rural development, education, or health should not only conceptualize inclusion of disability issues, but ensure that such inclusion is integral to project implementation. An important target is to set aside 5% of budgets for rural and urban development schemes to support effective inclusion of persons with disabilities in socioeconomic and political life.

129. Although there are budget allocations to address disability concerns in development programs at the central and state levels, the use of these resources remains an area of concern. Initiatives could be taken to ensure that funding to promote inclusion achieves its objective. Multisector and multistakeholder collaboration should be encouraged for optimum use of resources**.**

130. Because disability is a crosscutting theme, awareness of disability issues could be targeted through all development programs. Disability should also become a core component of the curriculum in related fields, such as medicine, social work, and architecture.

131. Funding agencies could support the disability sector in India by lending resources and collaborating with the Government to mainstream disability issues in subsector 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 cooperation with other sectors.

132. 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 into the public and private sector in professional and nonprofessional positions. Demonstrating through example their capacity to participate would strengthen the perception of their ability to constructively contribute to national life and development.

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

134. World Disabled Day, 3 December, should be celebrated by all departments, as is International Women’s Day or May Day.

135. Although laws are made with good intentions and high hopes, 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 toward disabled people in society. There is a dire need to create awareness amongst NGOs on 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 of inclusion by building awareness of human rights issues related to disability.

136. 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 by allowing them to act as implementing agencies for certain program components, with the government assuming responsibility for monitoring and evaluation using predetermined and structured indicators.

B. Participation

137. 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 disabilities at all levels. Participation of persons with disabilities should be promoted by establishing a role for self-help groups within government-supported poverty reduction schemes.

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

139. Lack of awareness of disability issues among people at the highest levels is an area of concern. Educating officials by using an approach similar to the successful model of gender sensitization can contribute to ensuring participation of persons with disabilities as advisors or consultants in all major decisions that affect them.

140. 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 Persons with Disabilities Act, 1995. There is also a need for cross-disability consensus on priority issues for persons with disabilities.

141. There is some 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 disability and gender issues.

C. Access

142. Ensuring access to education for children with disabilities is an important step in reducing marginalization of disabled people. Education is a human right and a basic need. The social and education sectors must give more attention to this matter and implement education policies that provide children with disabilities access to basic education without discrimination and free of barriers. Promotion of nonformal education and literacy programs for persons with disabilities should be encouraged. Primary and higher education would become more

accessible to persons with disabilities if the national policy for elementary education of children in the age group 6–14 years were strictly followed. 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 accessible education and fostering attitudinal changes at management levels.

143. Awareness of accessibility for people with disabilities is minimal outside 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.

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

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

146. There is a dire need to develop a central database on disability that includes information on the numbers of persons with disabilities, 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.

147. Incorporation of accessibility features in the built environment could be promoted as a preventive measure as well. They 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), road crossings, subways, and public toilets. Persons with disabilities could also receive priority with respect to accessing services at hospitals, housing allotments, education, pensions, and microcredit-based training schemes.

148. 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.

D. Quality

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

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

151. 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.

152. 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 them, and ensure that training is consistent with the current market trends. The private sector provides the majority of job opportunities. Defined incentives to this sector could enhance their commitment to disability concerns, which in turn could further increase employment opportunities for persons with disabilities.

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

154. 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 these people would improve the quality of programs in all sectors.

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DESIGN AND METHODOLOGIES OF THE STUDY

1. 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.

2. The study was carried out using 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.

4. Focus-group discussion was among the methods used to ensure participation. During the launching of the study, the team leader and local specialists carried out these meetings with important actors in the field of disability and development from government, the nongovernment organization (NGO) sector, international donor agencies, United Nations (UN) agencies, and, most importantly, representatives of disabled people's organizations.

5. Four provincial-level workshops and one national workshop were organized during the project. More than 180 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. Of the total, 25 persons with disabilities and parents of persons with disabilities participated in the workshops.

6. Locations for the provincial workshops were determined on the basis of geographical coverage of all the states and UTs. They were held at Chennai, Mumbai, Kolkata, and Delhi, culminating in the 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 the past and the present with overall aim 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.

7. 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.

8. 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 view that came out strongly from the workshops was “Nothing about us without us,” which could be a good principle and guideline for all policy planning.

OUTCOMES OF THE NATIONAL WORKSHOP

A. The National Workshop

1. The national workshop represented the culmination of 4 months of research, stakeholder analysis, and 4 provincial-level workshops held in Chennai, Mumbai, Kolkata, and Delhi, respectively. The national workshop (in Delhi) was designed to build consensus around critical issues and, through this consensus, develop a tentative action plan agreed on by various stakeholders in the field of disability and poverty. Key stakeholder groups were represented, including Government of India ministries and departments, state and Union Territory governments, nongovernment organizations (NGOs) in development, disability NGOs, disabled people's organizations, United Nations agencies, international funding agencies, and international NGOs. The following outcomes 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) An inclusive society where all people, including people with disabilities, are valued and provided equal opportunities to use their potentials.

3. **Target group and beneficiaries**

(i) All people with disabilities (including children with disability, women and men with disability, and people with different disabilities including mental and intellectual); and
(ii) other stakeholders (including families, communities, friends, professionals, service providers, policymakers, and leaders).

4. **Legacy after 5–10 years**

(i) Meaningful partnerships at the levels of society, community, and family;
(ii) values and principles, such as acceptance and compassion, human rights, equal opportunities, equal access, and equal participation;
(iii) demonstration and celebration of achievements, and 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 the plan**

(i) Participatory;
(ii) realistic;

(iii) culturally based;
(iv) needs based; and
(v) comprehensive.

8. **Opportunities**

(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, such as regional rehabilitation training centers, the National Programme for Rehabilitation of Persons with Disabilities, and district rehabilitation centers.

9. **Constraints**

(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 of rehabilitation;
(vii) commercialization of disability issues;
(viii) marginalized status of disabled people;
(ix) disability a low priority issue; and
(x) lack of political and bureaucratic will.

10. Sector-specific recommendations drawn from the provincial workshops were shared with the participants, who formed small groups to refine these recommendations in order to develop a concrete action plan. The sector-specific plan that emerged from the 3-day workshop was presented before the State Minister Mr. Satya Brata of the Ministry of Social Justice and Empowerment.

11. Immediate points for action that were agreed on by the whole group from all the sectors related to persons with disabilities, on the basis of priority, were as follows:

(i) Enforce barrier-free features on roads, pavements, public places (parks, markets, recreational, spiritual places) road crossings, subways, and public toilets.
(ii) Persons with disabilities should receive priority handling in hospitals, housing allotments, education, assistive devices, pensions, travel (bus, metro), and microcredit for training schemes.
(iii) Inclusion of persons with disabilities should be mandatory, with strict utilization of 5% of resources in rural and urban development schemes for their effective inclusion in socioeconomic and political life.
(iv) Provide safe drinking water, toilets, sewerage/drainage, and general sanitation (disposal of solid waste) with barrier-free features.

(v) Prevent disabling factors by reducing the accident rate, maximizing attended births, and achieving 100% immunization in 2 years.

(vi) Prepare an exhaustive and comprehensive database of all marginalized groups of society to ensure accessibility of services for their development.

(vii) Social communication should be enhanced to cover the nation through media and traditional campaigns, with increased displays of disability concerns in public places, such as schools, temples, and corporations.

(viii) Promote the economic status of persons with disabilities through placements, training, microcredit, and marketing group activities, with increased responsibilities of the Ministry on Social Justice and Empowerment, Directorate general for Employment and Training (DGE&T), employment and placement offices, National Handicapped Finance and Development Corporation (NHFDC), corporate sector, and NGOs.

(ix) Apply 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:

(a) Rs500 per month for every person with disability;

(b) scholarships of Rs250 per month for every disabled student;

(c) old-age pensions for people with disabilities over the age of 45, at Rs500 per month;

a. (d) bus and train concessions to all persons with disability.

(x) Enforce all provisions of the Persons with Disabilities Act, 1995, and implement the amendments proposed for the Act, with penal provisions for noncompliance.

B. Draft Action Plan

12. *National coordination*. 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. This suggests that there are many 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, community-based organizations (CBOs), disabled people's organizations, and parents' organizations to remain united and lobby for the realization of rights guaranteed under the 1995 Act. There is also a need for cross-disability consensus on priority issues for persons with disabilities. Adequate representation and participation of persons with disabilities at the highest levels of policy planning is also very crucial and could be an important prerequisite of any national policy planning. There should be mandatory inclusion of persons with disabilities, with strict utilization of 5% of resources in rural and urban development schemes for their effective inclusion in socioeconomic and political life.

13. *Awareness Raising*. World Disabled Day, 3 December, should be celebrated by all departments as are International Women's Day and May Day. It is important for the disability sector to be very vigilant and proactive to ensure the appropriate implementation of laws by including strict accountability and professionalism, without which the laws cannot succeed. Effective channels of communication between the disability sector, the legal fraternity, and other sectors of social development are crucial for greater awareness and sensitivity toward the disabled in society. There is a dire need to create awareness among NGOs regarding use of the law to empower persons with disabilities. Social communication should be enhanced to cover

the nation through media and traditional campaigns, with increased displays in public places of the concerns of persons with disabilities.

14. *Accessibility and Communication*. Enforce barrier-free features on roads, pavements, public places, road crossings, subways, and public toilets. Persons with disabilities should receive priority handling in hospitals, housing allotments, education, assistive devices, pensions, travel (bus, metro), and microcredit for training schemes.

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

16. *Prevention of the Causes of Disabilities*. Provide safe drinking water, toilets (lavatories), sewage and drainage, and general sanitation, with barrier-free features. Prevent disabling factors by reducing the accident rate, maximizing attended births, and achieving 100% immunization in 2 years.

17. *Education*. Primary and higher education could become accessible to persons with disabilities if the national policy for elementary education of children and the 6–14 age group were strictly followed. There is a need to include the concerns of persons with disabilities and their aspirations for higher education. Momentum would be increased by making the infrastructure available for accessible education and attitudinal changes at the management level.

18. *Vocational Training and Employment*. Promote economic status through placements, training, microcredit, and marketing group activities, with increased responsibilities of the Ministry on Social Justice and Empowerment, DGE&T, employment and placement offices, NHFDC, corporate sector, and NGOs. Four enabling factors for strategic planning that would facilitate employment opportunities are increasing public awareness about the causes of disabilities, extending opportunities to disabled people through legislation, equipping disabled people with educational qualifications and skills, and ensuring easy and convenient access to relevant places. It is envisaged that these four factors would lead to ensuring equal status for people with disabilities in society.

19. *Social Security*. Apply 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:

(i) Rs500 per month for every person with disability;
(ii) scholarships of Rs250 per month for every disabled student;
(iii) old-age pensions for people with disabilities over the age of 45, at Rs500 per month; and
(iv) bus and train concessions to all persons with disabilities.

20. *Regional Cooperation*. The issues and concerns of countries in the Asia and Pacific region, in spite of their diversity, have many similarities because of the similarity of their developing economies. Hence, streamlining support and assistance from international funding agencies is possible. National cooperation could be achieved through involvement of NGOs and CBOs when these agencies are negotiating with the Government. Greater participation of NGOs

and CBOs could be sought in implementing programs. The Government could take on the roles of monitoring and evaluation with predetermined and structured indicators.

21. *Effective Implementation of Legislation*. There should be time-bound enforcement of provisions of the Persons with Disabilities Act, 1995, and implementation of the amendments proposed for the Act, with penal provisions for noncompliance.

CASE STUDIES

A. Association of People with Disability

1. Realizing the importance of economic rehabilitation of people with disabilities to gain recognition, acceptance, and dignity in society, the Association of People with Disability (APD) was started as a training center for enhancing employability and motivation for self-employment. Two training centers to provide formal technical training through the national vocational training syllabus and advanced technical skills with shop-floor experience, respectively, were set up in 1975.

2. A home-based program was conceived in 1976 for economic rehabilitation of people who were home bound because of the severity of their disability, inaccessibility to the training centers, etc. The program envisages APD to act as a mediator between industry and workers based in their home or in small ancillary cooperatives. Support of the family members is an essential ingredient. The program has had a positive impact on promotion of self-employment among these people.

3. Three ancillary units have been formed by people with disabilities of different types under the home-based program since 1994. Ability in Disability was the first, set up in 1994 for supply of mechanical subassemblies to Motor Industries Co. (MICO), a prominent industry in the automobile sector. The APD Utpadana Society was second, and supplies electronic subassemblies and components to major electronic industries. The third is the Creative Skills Society, with 14 persons working to meet requirements of a small-scale electronics industry in Bangalore.

4. APD is withdrawing from these units in a phased manner to serve the real purpose: developing self-managed industrial units owned by people with disabilities to prove their entrepreneurial and managerial capabilities. The principles of cross-disability integration and integration with able-bodied persons have been achieved in the real sense.

5. APD has gradually enlarged its area of operations to encompass physiotherapy, orthotic appliances, horticulture, community-based rehabilitation, urban slum outreach, community health, and integrated education. Its achievements in all these areas are unique and unequivocal. APD has become a role model by its exemplary efforts and experience in empowering people with disability to attain economic self-reliance and lead dignified lives.

6. Major challenges encountered by the APD in fulfilling the task were changing mind sets, building competence, instilling confidence, removal of attitudinal barriers, a paradigm shift in the perception of persons with disabilities and society, reduction in 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 from society of persons with disabilities. Descriptions of the three ancillary units follow.

1. Ability in Disability

7. Fifteen persons run this unit, of whom 3 have locomotor disabilities and 10 are visually impaired; 10 are women. The unit developed a capability to carry out more than 25 subassemblies for fuel injection pumps with stringent specifications conforming to

international standards for MICO, which has factories at Nasik (Maharashtra), Jayapura (Rajasthan), and Bangalore. Ability in Disability is being subjected to audit conforming to ISO standards by MICO. It has been judged to be an excellent unit in the class. It became profitable in its third year and is working toward ISO 9001-2000 certification.

2. APD Utpadana Society

8. This unit was set up in April 2000 to be engaged in electronic and electrical subassemblies, catering to the requirements of Indian Telephone Industry Ltd., and Bharath Heavy Electricals Ltd., both being government undertakings in the field of electronics. There are 32 people in the unit, of whom 24 have locomotor disabilities and 2 are hearing impaired.

9. The unit suffers erratic inflow of subcontracts because of the industrial recession prevalent in the country. However, through its output, the unit has proved its capabilities to perform when proper opportunity is provided.

3. Creative Skills Society

10. This unit was set up in 2003 to meet the assembling requirements of a private company, Nikhara Electronics. Among the 14 workers, 10 have a hearing impairment and 4 have locomotor disabilities. They are able to run the unit successfully with the patronage of the parent unit. It is anticipated that the unit can become profitable.

B. District Primary Education Programme

11. This program is funded by the World Bank and has been launched in 19 states. The funding principle is “education for all” in the 6–14 age group. The nodal agency for implementation in Rajasthan is the state Primary Education Council, which has adopted a very flexible strategy to address the needs these children.

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

(i) alternate schools;
(ii) Madarsa education for children belonging to minority groups;
(iii) residential and nonresidential bridge courses, focusing on nonformal education;
(iv) residential facility for children of nomadic families;
(v) education-friendly schemes, with special focus on girls who are not enrolled in either formal or nonformal education;
(vi) inclusive education for the disabled, aiming at children with disabilities to be included in the regular education system, with substantial provision of assistive devices; and
(vii) strengthening of the primary education center for 100% enrollment of children, better retention, and higher-quality education.

13. The major strengths of the program are

(i) community mobilization,
(ii) decentralization through effective village committees,
(iii) partnership and integration with voluntary organizations,
(iv) partnership in planning and decision making at all levels,
(v) flexibility in implementation, and
(vi) multisectoral approach.

14. A further strength of the program in Rajasthan is its association with the United Nations Children's Fund (UNICEF) for civil workers in schools to

(i) renovate dilapidated buildings in primary schools;
(ii) construct school buildings in remote villages where schools were initially functioning under trees;
(iii) make buildings and toilets in the schools accessible for children with disabilities; and
(iv) make water available in all the schools through well construction.

15. In addition, the association with UNICEF has provided for effective village-level committees, with representation from parents, parents of children with disabilities, school headmaster/teachers, and Anganwadi workers. It has also provided scope for capacity building for resource teachers to focus on children with special needs, and scope for in-service sensitization and training to manage children with disabilities.

C. Inclusive Education for Children with Disabilities, Uttar Pradesh

16. Uttar Pradesh is one of the least developed states of the country. It has been far behind most states in per capita income and socioeconomic development. Out of the 165.5 million population of the state, an estimated 8.25 million are people with disabilities. Out of which an estimated 3.3 million are people with disabilities living below the poverty line.

17. The United Nations Development Programme (UNDP) is presently supporting Uttar Pradesh and Karnataka for inclusive education of children with disabilities, with coverage of 8 blocks in each state. In Uttar Pradesh, the UNDP program is in Lucknow District, where it is providing supportive services in the areas of assistive devices, barrier-free schools, transportation, learning materials, and sensitization of teachers and parents. The implementing state agency for this program is the Department of Handicapped Welfare.

18. The program aims to reach children aged 6–14 years with disabilities, with the objectives of zero rejection, provision of home-based education services for children with severe to profound disabilities, inclusion of children with disabilities in mainstream education, and provision of special schools for children with specific needs to make them ready for regular formal schooling.

19. The program has undertaken a detailed house-to-house survey in 8 blocks where the program is implemented. It has mobilized school headmasters and sensitized them on the need for inclusive education for children with disabilities, and developed indigenous techniques to make the primary schools barrier-free for children with disabilities through grants for each

school. Also, the program has worked extensively in capacity building of field workers to identify children with disabilities for early intervention.

20. However, some aspects need further attention: community mobilization has not been exploited extensively; allocation of funds could have been more realistic; wider coverage would ensure implementation of education for all; and 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

21. 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 extended beyond the borders of the state and the society has emerged as a national institute with the following objectives:

(i) To 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 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 action- and needs-based research, in order to extend the knowledge base of issues (educational, therapeutic, or social) related to cerebral palsy.
(ix) To create awareness among the community 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 needs of rehabilitation personnel and professionals working in the field.
(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.

22. During 1994–1999, SSEI undertook a project, supported by the Department for International Development of the United Kingdom, 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.

23. 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.

24. The project had 5 linked components: two projects were intended to be directly linked to service provision and the other three were intended to be linked to developing or extending the knowledge-base of trainers both at SSEI and elsewhere. Specific objectives of the different projects are given below.

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

25. All the specified activities were carried out, with the exception of the last affiliate center in eastern India, which was planned for the last year of the project but was not constructed because of disastrous flooding.

26. Many lessons were learnt. Constant monitoring and review of the 5 project components, along with the production of quarterly and annual reports, enabled SSEI to maintain a focused yet flexible approach to the development of services, training, and materials. SSEI learned over the course of the project that community participation, innovation, and the ability to adapt the process to the needs in each area, were core elements for success. SSEI was able to promote sustainability by strengthening the local organizations and increasing the capacity of staff, volunteers, and families with disabilities so that they gradually needed less input over time. After the first 3 years of the project, SSEI recognized the need to review its role from that of an indirect implementer to that of a catalyst, helping partners to become core resource agencies. This meant that project partners gradually took a more dominant role in planning, implementation, determining training needs, and monitoring their own projects.

27. Over the duration of the project, the total number of families who used the services in Project 1 was 10,192; Project 2, 8,608; and Project, 3, 3836. The approach was family-centered and these figures represent individual child beneficiaries multiplied by four—a family with an average of four members. Individual child beneficiaries included those with cerebral palsy, learning difficulties, specific learning problems, hearing impairment, visual impairment, polio, and rare syndromes. Children with visual and hearing impairments and polio were referred to specialist agencies wherever possible. A total of 444 persons were trained in formal courses at SSEI and in placements in the rural training center during the projects.

E. Blind People's Association

28. The Blind People's Association (BPA) of Ahmedabad in Gujarat is one of the largest and oldest disability organizations in the country. Its mission is comprehensive rehabilitation of persons with all categories of disabilities through education, training, support services, research, and community-based interventions. Apart for implementing its own programs directly, the organization provides professional consultancies and appraises and monitors projects funded by international agencies. BPA has worked intensively to link blind welfare organizations with mainstream organizations.

29. BPA supports both institutional and community-based programs. A wide range of learning and training material has been developed. The critical factors for success of CBR programs were found to be selection of appropriate workers, effective training, and appropriate implementation mode. 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 the organizations it supports to liaise with donors.

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

31. The major areas of intervention are education and comprehensive rehabilitation for people with disabilities, development of aids and appliances, interventions for special education needs of children with disabilities, CBR, creating employment opportunities, and strengthening other NGOs through networking.

32. The major strengths of BPA are

(i) addressing cross-disability issues,
(ii) promoting decentralization,
(iii) providing a good example of NGO-government alliance,
(iv) facilitating linkages between government and CBOs,
(v) resource mobilization for sustaining other NGOs,
(vi) networking with various government ministries,
(vii) lobbying government,
(viii) addressing the needs of the disabled,
(ix) promoting employment of disabled people,
(x) capacity building of NGOs,
(xi) skill up-grading for disabled people,
(xii) outreach to parents of the disabled through grassroots organizations and motivating them to organize themselves,
(xiii) integrated education programs,
(xiv) practicing the CBR model—promoting and facilitating home-based interventions for people with disabilities,
(xv) acting as an intermediary for providing accessibility to information for disabled people,

(xvi) networking with the private sector to promote employment opportunities for disabled people, and
(xvii) networking with NGOs to monitor their programs.

33. Future activities include convergence with the Department of Rural Development; lobbying the Department of Health for improved health delivery services; and lobbying the Ministry of Labour to ensure 3% reservation for disabled people in all jobs, and making the work environment accessible to persons with disabilities.

F. Parent Role Model: Mrs. Gajalakshmi

34. This is a story of the strength of a determined mother who has not only empowered her disabled daughter, but has also become a role model to the parents in her area. The story is from the Spastics Society of Tamil Nadu (SPASTN).

35. 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 left them for another woman, not bothering to support his family. At this juncture, Mrs. Gajalakshmi sought help from a SPASTN center for her child's rehabilitation services.

36. At SPASTN, she learned all the therapy activities and speech interventions needed to help her child. On finding Mrs. Gajalakshmi so motivated, the CBR team transferred rehabilitation skills and knowledge to her.

37. She now runs the services at the center and educates other parents on their children's rehabilitation needs. Her valuable contribution is promoting low-cost rehabilitation aids and appliances made of mud, bricks, clay, plantain bark, etc. This has helped many parents in rural areas to follow up programs at home—to maintain the functional position required by their children, e.g., a corner chair, standing frame, splints, or parallel bars. She is also a strong advocate of inclusion of disabled children in balwadis and schools, and makes periodic follow-ups concerning inclusion in the schools.

38. When the CBR team started working on promoting self-help groups in the villages, she helped in forming a self-help group of 18 women with disabilities from her village. She has also given her own land for Sangam collective income-generating activities and has erected a small hut on it with community contributions. Through the self-help group, she takes the concerns of persons with disabilities to the village leaders.

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

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

41. In spite of having to look after two people with disabilities in her own house, Mrs. Gajalakshmi runs the SPASTN center and the Sangam and continues to be a role model.

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