

DISABILITY MANAGEMENT IN INDIA

CHALLENGES & COMMITMENTS



EDITED BY
C S MOHAPATRA



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Challenges and Commitments

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National Institute for the Mentally Handicapped
Ministry of Social Justice and Empowerment
Secunderabad

In collaboration with



Indian Institute of Public Administration
New Delhi

Disability Management in India
Challenges and Cominitments

Edited by : C S Mohapatra

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List of Abbreviations

AAC	Augmentative and Alternative Communication
ABR	Auditory Brainstem Response
ADIP	Scheme for Purchase and Fitting of Aids and Appliances
AICB	All India Council of Blind.
AICTE	All India Council of Technical Education.
AIIMS	All India Institute for Medical Sciences
AIISH	All India Institute of Speech and Hearing
AIPMR	All India Institute for Physical Medicine and Rehabilitation
ALIMCO	Artificial Limbs Manufacturing Corporation of India
AMIS	Adaptive Multimedia Information System
AWW	Anganwadi Worker
AYJ.NIHH	Ali Yavar Jung National Institute for the Hearing Handicapped
BASLP	Bachelor in Audiology, Speech and Language Pathology
BHU	Banaras Hindu University
BIS	Bureau of Indian Standards
BMF	Biwako Millennium Framework
BOT	Bachelor in Occupational Therapy
BPO	Bachelor in Prosthetics and Orthotics
BPT	Bachelor in Physiotherapy
BTE	Behind the Ear Hearing Aid
CABE	Central Advisory Board of Education
CAI	Computer Assisted Instruction
CBM	Christofel Blind Mission
CBR	Community Based Rehabilitation
CBSE	Central Board of Secondary Education
CAI	Computer Assisted Instructions
CCC	Central Coordination Committee
CCD	Chief Commissioner for Persons With Disabilities
CD	Compact Disc
CEC	Central Executive Committee
CIC	Completely in the Canal Hearing Aid
CII	Confederation of Indian Industries
CRC	Composite Regional Centre for Persons With Disabilities
CRE	Continuing Rehabilitation Education
CSIR	Council of Scientific and Industrial Research.
DAISY	Digital Accessible Information System.

DBT	Department of Bio Technology.
DDRC	District Disability Rehabilitation Centre
DFA	DAISY For All
DGHS	Director General of Health Services.
DIC	District Industry Centre
DIT	Department of Information Technology
DMT	District Management Team.
DOPE	Diploma Course In Prosthetic and Orthotic Engineering
DOPT	Department of Personnel and Training
DPEP	District Primary Education Programme
DPEP-IED	District Primary Education Programme - Integrated Education for the Disabled
DPO	Disabled Persons Organization.
DPOE	Diploma in Prosthetic and Orthotic Engineering
DRC	District Rehabilitation Centre
DSE(MR)	Diploma in Special Education (Mental Retardation)
DST	Department of Science and Technology
DWCD	Department of Women and Child Development.
EGS	Education Guarantee Scheme
ENT	Ear, Nose and Throat.
ESCAP	Economic and Social Commission for Asia and Pacific
FICCI	Federation of Indian Chambers of Commerce and Industries.
FM	Frequency Modulation
G2C	Government to Citizen
GO	Governmental Organization
GOI	Government of India
HI	Hearing Impaired.
HQ	Head Quarters
HRD	Human Resource Development
IAPMR	Indian Association of Physical Medicine and Rehabilitation.
ICDS	Integrated Child Development Scheme
ICEVI	International Council for Education of People with Visual Impairment
ICF	International Classification of Functioning
ICMR	Indian Council of Medical Research
ICT	Information and Communication Technology.
IEC	Information Education and Communication
IED	Integrated Education for Disabled
IEDC	Integrated Education for Disabled Children
IGNOU	Indira Gandhi National Open University
IIT	Indian Institute of Technology.
IIS	Indian Institute of Science
ILO	International Labour Organisation
IPH	Pt. Deendayal Institute for the Physically Handicapped

ISIC	Indian Spinal Injury Centre.
ISO	International Standards Organization
IT	Information Technology.
ITI	Industrial Technical Institute.
JSRPD	Japanese Society for Rehabilitation of Persons With Disability
LAN	Local Area Network
LEA	Local Education Authority
MAMC	Moulana Azad Medical College.
MCH	Maternity and Child Health.
MCI	Medical Council of India
MEDLARS	Medical Literacy Analysis and Retrieval System
MHRD	Ministry of Human Resource Development
MOT	Master in Occupational Therapy
MPBOU	Madhya Pradesh Bhoj Open University.
MPT	Master in Physiotherapy
MR	Mental Retardation
MRW	Multipurpose Rehabilitation Worker
MSJ and E	Ministry of Social Justice and Empowerment
NAB	National Association of Blind
NABP	Norwegian Association for Blind and Partially Sighted
NCERT	National Council for Education Research and Training
NCTE	National Council for Teacher Education
NCVT	National Council of Vocational Training
NFE	Non Formal Education
NGO	Non Governmental Organization
NHFDC	National Handicapped Finance and Development Corporation
NI	National Institutes
NICNET	National Information Centre Network.
NIHH	National Institute for the Hearing Handicapped
NIMH	National Institute for the Mentally Handicapped
NIMHANS	National Institute of Mental Health and Neuroscience.
NIOH	National Institute for the Orthopaedically Handicapped
NIRTAR	National Institute for Rehabilitation, Training and Research
NISH	National Institute of Speech and Hearing
NIVH	National Institute for the Visually Handicapped
NOS	National Open School
NP	Non - Poor
NPE	National Policy on Education
NPRPD	National Programme of Rehabilitation for Persons With Disabilities
NSSO	National Sample Survey Organization
OAE	Oto-Acoustic Emission
OBC	Other Backward Classes
OCR	Optical Character Recognition
P	Poor

PC	Personal Computer
PGDDR	Post Graduation Diploma in Developmental Rehabilitation.
PGDRP	Post Graduation Diploma in Rehabilitation Psychology.
PGIBMS	Post Graduate Institute of Biomedical Sciences.
PGIMER	Post Graduate Institute of Medical Education and Research.
PHC	Primary Health Centre.
PIED	People's Initiative for Empowerment of Disabled
POA	Programme of Action
PPI	Permanent Physical Impairment
PSU	Public Sector Unit.
PVA	Private Voluntary Agencies
PWD	Persons with Disabilities
PWD Act	Persons with Disabilities (Equal Opportunities, Protection of Rights And Full Participation) Act, 1995
RCI	Rehabilitation Council Of India
RDP	Rehabilitation of Disabled Persons.
Rh -ve	Rhesus Negative
RRTC	Regional Rehabilitation Training Centre
RSIC	Regional Spinal Injury Centre
S and T	Science and Technology
SAFA	Screen Access For All
SC	Scheduled Caste
SCVT	State Council of Vocational Training.
SE	Special Education
SISI	Small Industries Service Institute.
SJSY	Swarna Jayanti Rojgar Swarv Yojana.
SSA	Sarva Shiksha Abhiyan
ST	Scheduled Tribe
SUPW	Socially Useful Productive Work
TOT	Training of Trainers
TV	Television
TIS	Text to Speech
UEE	Universal Elementary Education.
UGC	University Grants Commission.
UNDP	United Nations Development Programme
UNESCO	United Nations Educational, Social and Cultural Organisation
UNICEF	United Nations International Children's Emergency Fund
UT	Union Territory
UV	Ultraviolet
VIP	Very Important Person
VRC	Vocational Rehabilitation Centre
WBU	World Blind Union
WCD	Women and Child Development
WHO	World Health Organisation



Message

We in the Ministry are happy to learn that the book on “Disability Management in India Challenges and Commitments” is coming out shortly, a collaboration between our Ministry and the Indian Institute of Public Administration (IIPA), New Delhi:

This book gives updated estimates of NSSO 2002 and identifies sustainable strategies for management of various categories of disability in India, keeping the Biwako Millennium Framework for action towards an inclusive, barrier-free and rights based society in mind. The book looks at issues and strategies for the support and empowerment of persons with challenging needs and their integration into family and community life. It chronicles the tremendous growth in the provision of services for persons with disabilities during the past three decades, and points out that while significant gains have been made, there is much more ground to cover. The issues and challenges facing the disability sector need to be addressed in an integrated manner and the component plan approach as promised in the Tenth Five Year Plan need to be given effect to for speeding up the process of empowerment of persons with disabilities.

We appreciate the incessant and untiring efforts made by Shri C.S.Mohapatra, former Director, Disability Division of our Ministry who has promoted the cause of disability through organizing the workshop, editing the book as also pursuing his dissertation work in the field of disability. We support the initiative taken by Dr.L.Govinda Rao, Director, National Institute for the Mentally Handicapped, Secunderabad for making efforts to publish the book in a short time.

This book will help enrich the knowledge and research base in the field of disability, and would, it is hoped, sensitize and generate awareness amongst all those who are directly or indirectly involved in our common endeavour.

(B.S. Baswan)

New Delhi
30th March, 2004

Secretary to the Government of India
Ministry of Social Justice & Empowerment

Foreword

'Disability' in any form restricts the functional capacity, space and opportunity for full participation in society. In India, welfare of persons with disabilities has gained significance since the 1970s. From the 90's, these efforts have been consolidated, expanded and oriented towards empowerment of persons with disabilities with a 'rights approach'. The enactments for promoting the accompanied empowerment of persons with disability by the recent adoption of BMF framework for action during 2003-2012 on the one hand and increased attention of the Government along with increase in non-governmental activities on the other are welcome forays in the right direction. However, it is disheartening that we are yet to reach a large number of persons with disability in remote areas, with sustainable rehabilitation services. Decentralization efforts that have started at right earnest, need to be expedited to improve the outreach achieve the same.

This section of population is yet to benefit from the vast potential of information, communication and technological revolution to the fullest extent. Education and employment opportunities guaranteed to them in the statutes also need to be ensured. The dimension of disability and poverty along with its established linkages requires to be understood and schemes/programmes of the Government - Central, State or Local mounted in an integrated manner. Dissemination of information and awareness generation is needed for prevention and early detection of disabilities in rural and urban areas alike.

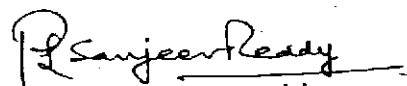
The Indian Institute of Public Administration (IIPA) is engaged in conducting a number of training courses as also pursues academic excellence in all fields directly or indirectly related to public administration and public policy. As a part of its social commitments, IIPA has been keen to involve itself for the cause of the disadvantaged and marginalized sections of society, bringing them to the mainstream and ensuring them due dignity of life and protection of their rights which still remains an unfulfilled dream. It is towards this endeavour that IIPA in collaboration with the Ministry of Social Justice and Empowerment had organized a two-day workshop titled 'Disability Management In India- Challenges, and Perspectives' during March 2004. The papers presented in the workshop have culminated in the form of this book with modifications wherever necessary. The book has been edited by Shri C. S. Mohapatra, a senior bureaucrat and former Director (Disabilities Division) in the Ministry of Social Justice and Empowerment who is undergoing the 29th Advanced Professional Programme on Public Administration (APPPA) course 2003-04.

This book comes at a time when the paradigm shift from welfare based approach to a right based approach is getting established into the societal norm. The Tenth Plan document has reaffirmed the commitment for effective implementation of the Persons with Disabilities Act, 1995 and provision of component plan for the Disability Sector in related Ministries and Departments. India, along with other ESCAP countries has adopted the Biwako Millennium Framework for Action in the decade 2003 - 2012 and finally the NSSO 2002 data on disability which has just been released. The workshop organized in collaboration with the Ministry of Social Justice and Empowerment and participation of senior bureaucrats, professionals, NGOs and experts generated very useful inputs and insights which form the essence of this book.

This edited book contains a wide range of subjects of interest to the professionals, students, bureaucrats ,non-governmental organisations and all those who have a deep concern and commitment to the welfare of the persons with disabilities.

The book focuses on NSSO survey, 2002 on disability and raises pertinent issues. It analyses various dimensions of disability management in India along with the challenges and linkages between poverty and disability and strategies for empowerment of the physically and mentally challenged. Other areas covered include education, employment, human resource development, role of information and communication technology, barrier-free environment, social security for persons with disabilities, public- private partnership, sustainable rehabilitation management strategies for persons with locomotor disability, visual disability, hearing disability and mental retardation. Issues concerning the persons with cerebral palsy, autism, and multiple disabilities have been dealt with in a separate chapter. The book also addresses various issues related to rehabilitation and ensuring human rights for persons with disabilities. The coverage of the subject is comprehensive, cogent, and compassionate.

This book is a significant contribution to heighten the awareness and understanding of disability management in India with an updated rights based approach and latest information on the status and issues involved in disability management. I am confident that this will be a very valuable document in the field of disability related research, an excellent guide for future action providing appropriate solutions to the multidimensional and multi-sectoral issues of empowerment of persons with disabilities. I wish to commend the partnership and collaboration of the Ministry of Social Justice and Empowerment and the National Institute for Mentally Handicapped, Secunderabad in bringing out this valuable book. I appreciate the efforts and commitment of Shri Mohapatra and Dr. L.Govinda Rao of NIMH in facilitating insightful discussions leading to this publication on a highly relevant and socially sensitive subject.



Dr. P.L.Sanjeev Reddy

Director

Indian Institute of Public Administration

New Delhi
30 March 2004

Preface

The last decade witnessed a phenomenal rise in institutional infrastructure accompanied by reaffirmation of the commitment to the cause of promoting empowerment of persons with disabilities. The Government and NGO activities got a boost during the period and the paradigm shift from welfare based approach to a right based one towards issues pertaining to persons with disabilities was apparent. Recent decentralization efforts coupled with thrust on outreach services through a camp approach, in addition to improving coverage, have raised the expectations of persons with disabilities from Government and civil society in general. The planners and implementers at this critical juncture have in front of them, on one hand, the statutes and the Biwako Millennium Framework for Action in the future decade (2003-2012) and on the other, the recently released NSSO (2002) data which throws light on various dimensions of disability status in India.

It was felt that there is a necessity to deliberate on major emergent issues confronting the disability sector under the changed paradigm and to formulate and suggest strategies that are sustainable and futuristic in approach with an aim to fulfill the dream of empowering the persons with disabilities. IIPA was also keen to promote the cause of this disadvantaged section of society on the occasion of its Golden Jubilee Year. These factors gave birth to a two-day workshop titled "Disabilities Management in India: Challenges and Perspectives" conducted by National Institute for the Mentally Handicapped in collaboration with Indian Institute of Public Administration (IIPA) at New Delhi, during 4-5th March, 2004. The workshop had active participation of top senior Government bureaucrats involved in implementation of policies and programmes for persons with disabilities, NGOs, academicians, experts and senior officials from various other Ministries/Departments then undergoing the APPPA course at IIPA. The workshop was inaugurated by Dr.P.L.Sanjeev Reddy, Director, IIPA and closed with a half-day long discussion on sustainable strategies for management of disabilities in India followed by valedictory address by Shri B.S.Baswan, Secretary, Ministry of Social Justice and Empowerment.

This book contains a rich collection of papers contributed by eminent experts, policy makers and NGOs that have been edited and presented in the form of chapters in five parts. Part One discusses the context that gives the summary of findings of NSSO survey, 2002 in the introductory chapter followed by a chapter that discusses the poverty and disability links and summarises the primary data based on a research study undertaken by the editor of the book. This study of

persons accessing the Government institutional services was completed in less than two months time as a part of the Advanced Professional Programme in Public Administration (APPPA) course being undertaken at IIPA. It shows various dimensions of the linkages and gives an indication about the socio-economic costs of disability. In Part Two, the agenda for the future has been delineated by taking the Biwako Millennium Framework priority areas of action as the guideline for completing unfinished task. It also gives a futuristic approach to promoting employment opportunities for persons with disabilities.

Part Three discusses emergent issues relating to the disability sector including human resource development, inclusive education, role of information, communication and technology as a tool for empowerment of persons with disabilities and finally, issues relating to social security for persons with disabilities.

Part Four deals with the sustainable strategies for disability management for persons having different categories of disabilities, i.e., locomotor disability, visual disability, hearing disability and mental retardation, each in separate chapters. A chapter on management of persons with cerebral palsy, autism, mental retardation, multiple disabilities has also been incorporated. This part of the book also analyses the challenges involved in disability management while keeping in view the commitments made by the Nation, proposes strategic action areas for sustainable management with a futuristic approach. Part Five covers the area of public-private partnership in the field of disability rehabilitation, which is an essential prerequisite for efficient and sustainable outcomes. The evolution of human rights for the persons with disabilities in India and the international conventions and declarations have been discussed in the context of the emerging rights based paradigm. The last chapter of the book contains the view point of Major H.P.S.Ahluwalia as regards the future challenges for persons with disabilities and the issues that need to be addressed in future.


C.S.Mohapatra

New Delhi
30th March, 2004.

Acknowledgements

At this moment when the book is going to press, I cannot believe that this maiden and arduous endeavour has been completed in such a short span of time. This has become possible due to all the highly cooperative and inspiring people around me who provided support. I would like to convey my deep gratitude to Dr.P.L.Sanjeev Reddy, Director, Indian Institute of Public Administration who inspired me and provided the confidence and support to first undertake the workshop, and then, this voluminous book that contains seventeen edited papers transformed into chapters. I am equally thankful to Smt Rajwant Sandhu and Smt. Jayati Chandra, both Joint Secretaries in the Ministry of Social Justice and Empowerment, Government of India for their enthusiastic support and guidance in going ahead with the job which was in addition to the load of assignments and papers to be submitted for the course I was undertaking at IIPA.

I would like to express profound gratitude to the Secretary, Ministry of Social Justice and Empowerment for having made this workshop to materialize and thereafter the publication of the book to be published and also for his valuable presence and precious contributions during the closing session of the workshop. I am obliged to Ms. Aloka Guha, Chairperson, National Trust, Dr.Uma Tuli, Chief Commissioner for Persons with Disabilities and Major H.P.S.Ahluwalia, Chairman, RCI for their sincere cooperation, advice and blessings. I am highly thankful to Dr.L.Govinda Rao, Director, NIMH for lending his ever willing cooperation and invaluable suggestions for achieving excellence in this endeavour. I am equally thankful to Shri R.Rangasayee, Dr. Dharmendra Kumar, Dr.Ratnesh Kumar and Dr.S.R.Shukla, Directors of the National Institutes, for their unstinted support in this challenging initiative.

There have been times of crisis. Whenever I felt the deadline to be too deadily to meet, my wife Mamata and loving kids, Saurabh and Shrusty came to the rescue and supported me all through in every possible manner they could. I am highly indebted to them. Words cannot express my gratitude towards my parents and family for their profound love, affection, inspiration and constant encouragement. The level of excellence and quality that the book has been endowed with would not have been possible but for the untiring work of all the contributors of the papers to each of whom I am extremely grateful. I am highly thankful to the referee of the book for his valuable suggestions.

I owe special obligation towards my Professor and Guide Ms.Aasha Kapur Mehta for putting right kind of intellectual input and confidence in carrying through my research work while undertaking the study, and guidance during the workshop. I specially thank Dr.R.K.Hora and the staff of NIMH Regional Centre, New Delhi for their sincere help and assistance in conducting the workshop. I am equally obliged to the officers and staff of NIMH, Secunderabad for lending their valuable assistance without which this book could not have taken shape in such a short period. I am thankful to Ms.Vijaya and Shri Keshavan for their assistance. The printers of this book M/s.Sree Ramana Process Pvt. Ltd., Secunderabad, deserve special commendation for being able to take out this quality publication within the available time frame.



C.S.Mohapatra

New Delhi,
30th March, 2004.

Part One

THE CONTEXT

Chapter 1

Introduction

Rajwant Sandhu

This chapter gives a brief preview of the national commitments for empowerment of persons with disabilities and attempts to summarize the latest survey of NSSO carried out during July–December, 2002 in which the coverage was extended to include mental disability. It highlights important facets of challenges to be met by the planners and implementers in the emerging disability scenario.

Background

The closing years of the twentieth century have seen rapid advancements in the areas of biotechnology and technology. Advanced diagnostic techniques and corrective surgery that even includes prenatal interventions are now available. Genetic mapping and counseling coupled with genetic manipulation and gene therapy are now helping doctors address some of the causes of disability. Due to the progress made in this direction, coupled with the excellent health care facilities, the incidence of congenital disabilities in developed countries is very low now. In India too the incidence of disability has been reduced in recent years due to better primary health care facilities and improved coverage under the universal immunization program particularly the pulse polio campaign. Besides, national programs for the control of blindness and leprosy, iodisation of common salt, nutrition support etc. have helped in tackling some of the primary and secondary causes of disability.

According to the experts, 50percent disability is preventable provided the quality of air and water is satisfactory, and immunization and nutrition get adequate attention. However, much of disability can also be attributed to accidents, ageing and lifestyle diseases. The persons affected are often in the productive and older age group and require appropriate rehabilitation services to enable them to lead as normal a life as possible. This implies that they should be able to attend to the activities of daily living, regain mobility if they have lost it and reintegrate with the workplace. Infants, children and adolescents with disability require early intervention services and education and training in an appropriate environment for the world of work.

Commitments

To address the needs of the disabled persons we have been guided by the Constitution of India and the UN instruments such as the Universal Declaration of Human Rights (1948), the Declaration on the Rights of Mentally retarded Persons (1971) and the Declaration on the Rights of the Disabled Persons (1975). The promotion by the United Nations through the adoption of the World Program of Action concerning Disabled Persons (1983), the declaration of the Decade of the Disabled Persons (1983-92) and development of the Standard Rules for the equalization of opportunities for Persons with Disabilities (1993) along with the observance of the Asian and Pacific Decade of Disabled Persons (1993-2002) have had a significant effect on the development of policy and programmes regarding persons with disabilities.

The paradigm shift from the welfare and charity approach to a rights based one towards the issues concerning persons with disabilities is encapsulated most effectively through the landmark enactment of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995. The Act establishes the responsibility on the appropriate Governments and society to ensure free education for the persons with disabilities up to the age of 18 years, preference in employment in the public sector through the reservation of 3% of vacancies against identified posts and accessibility to buildings, roads, transport and other public services. The Act also prohibits discrimination in every sphere on the ground of disability.

This was followed in 1999 by the enactment of the National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999. The objective of this enactment is to enable and empower persons with these disabilities to live as independently and as fully as possible within or close to the community to which they belong. It also addresses the needs of those persons who do not have family support and provides for their care and protection.

Estimates of Disability in India

How many disabled persons are there in India? The figure of 100 million has been freely quoted on the assumption that the World Health Organization estimates that ten percent of the population suffers from some disability or the other and we are a nation of a billion people. Yet it is necessary to have an idea of the numbers disability wise, age-wise, sex-wise and to know where the disabled persons are before realistic planning can take place regarding the need for aids and appliances, rehabilitation services and other support. To address the need for data the National Sample Survey (NSSO) made its first attempt to collect information on the number of physically handicapped persons in the 15th round during July 59 to June 60. The enquiry was exploratory in nature and was confined to rural areas only. However, in the 16th round (July 60 – June 61), the geographical coverage was extended to urban areas. The subject was again taken up in the 24th (July 69 – June 70) and in the 28th (October 73 – June, 74) rounds of the NSS. The objective of these early enquiries was only to provide estimates of the number of persons in

the country who suffered from certain specified physical handicaps. However, the types of physical handicap covered in these rounds were not always same.

The NSSO undertook a comprehensive survey of disabled persons in its 36th round during the second half of 1981, the International Year of the Disabled Persons. After a gap of ten years, a second survey on the disabled was carried out in the 47th round during July-December 1991. In these surveys, the objective was to provide data base regarding the incidence and prevalence of disability in the country. The basic frame-work of these surveys including the concepts, definitions and operational procedures of the 36th and 47th round was kept the same.

A question on disability was included in Census 2001 and the data compilation is still in progress. However, again after a gap of eleven years, at the request of the Ministry of Social Justice & Empowerment, the third survey on the disabled was carried out by the NSSO in the 58th round during July-December, 2002. In this round, the coverage was extended to include mental disability. Along with the particulars of physical and mental disabilities, the socio-economic characteristics of the disabled persons such as their age structure, literacy, vocational training, employment, cause of disability, age at onset of disability etc. were collected. In the following paragraphs, the findings of the NSSO survey have been analyzed with a view to identify some of the issues that arise in the context of the provisions of the PWD Act.

NSSO Survey: 2002

The survey in the 58th Round has shown that the number of disabled persons in the country was 1.85 crore and they formed 1.8% of the total estimated population*. About 10.63% of the disabled persons suffered from more than one type of the following disabilities, (i) mental disability in the form of (a) mental retardation or (b) mental illness, (ii) visual disability in the form of (a) blindness or (b) low vision, (iii) hearing disability, (iv) speech disability and (v) locomotor disability.

Table 1.1 Estimated number of disabled persons by type of disability and sex separately for rural and urban India

(in lakh)

Type of disability	Rural			Urban			Rural + Urban
	Male Persons		Female	Male Persons		Female	
(1)	(2)	(3)	(4)	(5)	(6)	(7)	(8)
Any disability	83.10	57.74	14.85	25.81	18.24	44.06	184.91
Mental disability:	2	8	0	1	9	0	
Mental retardation	4.34	2.561	6.995	1.824	1.128	2.951	9.946
Mental illness	5.022	3.377	8.399	1.623	0.988	2.611	11.01
Physical disability:							
Visual disability:							
Blindness							20.13
Low vision	7.494	8.536	16.030	1.793	2.311	4.104	81.33
Hearing disability	2.982	3.563	6.545	0.711	0.877	1.588	30.67
Speech disability	12.51	11.17	23.687	3.617	3.313	6.930	21.545
Locomotor disability	6	1	16.027	3.416	2.102	5.518	
	9.495	6.532	79.826	16.35	10.16	26.51	106.44
	49.98	29.83		2	2	4	
	7	9					

* *The total estimated population for 1st October, 2002 was obtained by applying decennial growth rate of population for 1991-2001 on 2001 population.*

Prevalence of disability

For the purpose of the NSS, a person with restrictions or lack of abilities to perform an activity in the manner or within the range considered normal for a human being was considered disabled. An attempt was made to train the enumerators so that they brought only those persons with disability over 40%, as per the PWD Act, into the count of disabled persons. Persons with speech disability were also included, although this is not one of the disabilities covered by the PWD Act, since it is seen that many of the persons who suffer from hearing impairment from birth or infancy are also mute. Also, speech disability was included in the earlier survey rounds. The survey has revealed that for every one lakh persons in India, there were 1755 who were either mentally or physically disabled. Among the rural residents, the prevalence of disability was 1.85% and that among the urban based persons was 1.50%. The prevalence of disability was marginally higher among males than among females. The inter state variations in the prevalence rate are significant. In the rural areas, it ranged from 0.67% (Delhi) to 2.71% (Himachal Pradesh) while in the urban areas it ranged from 0.52% (Delhi) to 2.61% (Lakshwadeep). The following table gives the number of disabled persons per one lakh population for each sector:

Table 1.2 Number of disabled persons per 1,00,000 persons for each sex and sector.

Disabled persons per 1,00,000 persons			
Type of disability	Rural + Urban		
	Male	Female	Persons
Mental retardation	115	72	94
Mental illness	122	86	105
Blindness	171	214	192
Low vision	68	87	77
Hearing disability	296	285	291
Speech disability	237	169	204
Locomotor disability	1217	785	1008
Any disability	2000	1493	1755

Incidence of disability

This is the number of persons whose onset of disability (by birth or otherwise) had been during the specified period of 365 days preceding the date of survey per one lakh persons. About 69 persons were born or otherwise became disabled per one lakh persons in rural India during the reference year. The incidence rate was almost the same in urban areas. The incidence rate was highest in Andhra Pradesh (108). Other States which showed high incidence rate of disability were Kerala (97), HP(96), Maharashtra and Haryana (82 each).

Disability since birth

Prevalence of disability by birth is shown in the table below by type of disability separately for each sex and sector. It is seen that about 84% of the mentally retarded and 82% of the persons having speech disability were born with the disability. For persons with other type of disability, the incidence at birth is not as significant as in the case of the mentally retarded or persons with speech disability. Most of them became disabled in the later stage of life. Incidence for the other disabilities is largely associated with old age.

Table 1.3 Number of disabled persons with onset of disability since birth per 1000 disabled persons by type of disability for each sex and sector.

Onset of disability since birth			
Type of disability	Rural + Urban		
	Male	Female	Persons
Mental retardation	834	851	840
Mental illness	228	230	229
Blindness	182	133	155
Low vision	120	60	87
Hearing disability	393	345	370
Speech disability	807	827	815
Locomotor disability	268	288	275
Any disability	328	311	321

Extent of physical disability The table below shows the classification of persons with disabilities into one of the four categories, viz., (i) those not able to take self care even with aid/appliance, (ii) those able to take self care only with aid/appliance, (iii) can take self care without aid/appliance and (iv) aid/appliance not tried/not available.

Table 1.4 Per 1000 distribution of physically disabled persons by extent of physical disability by sex and sector.

Extent of physical disability					
Disabled persons	Cannot take self care even with aid/appliance.	Can take self care only with aid/appliance	Can take self care without aid/appliance	Aid/ Appliance not tried/ not available	Total
Male	118	181	613	86	1000
Female	154	160	588	96	1000
Persons	133	160	603	90	1000

Marital status of the disabled

The survey shows that at the All India level, out of 1000 disabled males residing in rural areas, 471 were never married, while in the urban areas the figure is 484. Amongst the females, the never married were 376 and 415 respectively. In the case of the mentally retarded, it is seen that most of them have to lead an unmarried life.

Literacy among the disabled

The distribution of disabled persons (age 5 years and above) shows that about 55% of the disabled in India were illiterate. The figure is highest amongst the mentally retarded (87%) followed by the visually disabled (74-77%). The proportions of illiterates were about 59% in rural areas and 40% in the urban areas. Delhi followed by Kerala showed the highest literacy among the disabled while the lowest literacy level is found in Arunachal Pradesh followed by Sikkim, Jharkhand, Bihar and Orissa.

Table 1.5 Per 1000 distribution of disabled persons of age 5 years and above by level of general education and sector.

Type of disability	Rural + Urban			
	Not literate	upto primary	middle	secondary & above.
Mental retardation	866	106	24	3
Mental illness	591	215	102	89
Blindness	773	141	45	41
Low vision	738	172	45	43
Hearing	646	231	70	50
Speech	670	235	57	38
Locomotor disability	447	292	136	124
Any disability	547	254	106	92

It is seen that the current enrolment ratio per 1000 disabled children in the ordinary schools was higher in the rural than in the urban areas, i.e. 475 and 444 respectively for the two sectors. The enrolment ratio was the highest among those with locomotor disability and the lowest amongst the mentally retarded. It was also higher among the boys than among the girls. In the case of enrolment in the special schools, it was extremely urban-biased – about 11% were enrolled in the special schools in the urban areas as compared to even less than 1% in the rural areas.

Work activity of the disabled

The situation is depicted in the following Table.

Table 1.6 Per 1000 distribution of disabled persons by activity status for each sector.

Type of disability	Rural + Urban		
	Employed	Unemployed	Out of labour force
Mental retardation	56	0	943
Mental illness	126	1	873
Blindness	91	2	907
Low vision	188	3	809
Hearing	343	4	653
Speech	263	7	730
Locomotor disability	282	10	708
All disabled	257	7	735

Prevalence of disability

Although a comparison between the 36th and 44th rounds and the data from the 58th round is not feasible since mental disability was not covered in the earlier rounds, it is worthwhile to see that the prevalence of disability has declined significantly since 1991 when the last NSSO survey took place in spite of the years of survival beyond sixty years of age going up.

Table 1.7 Prevalence of disabled persons per 100,000 persons obtained from NSS 36th, 47th and 58th rounds.

	36 th round (July-Dec.'81)	47 th round (July-Dec.'91)	58 th round (July-Dec.'02)
	Rural		
Male	2045	2277	2118
Female	1632	1694	1556
Persons	1844	1995	1846
	Urban		
Male	1532	1774	1670
Female	1297	1361	1311
Persons	1420	1579	1499

Mental Disability

Persons who had difficulty in understanding routine instructions, who could not carry out their activities like others of similar age or exhibited behaviours like talking to self, laughing/crying, staring, violence, fear and suspicion without reason were considered as mentally disabled for the purpose of the survey. The "activities like others of similar age" included activities of daily living and social skills. The mentally disabled were categorized into two groups, viz., mentally retarded and mentally ill. In the survey probing questions were asked and based on the information so obtained; the persons were categorized into mentally retarded and mentally ill. The table below shows the prevalence rate for mental disability.

Table 1.8 Number of persons with mental retardation and mental illness per 100,000 persons for each sex and sector.

Mentally disabled	Rural + Urban		
	Male	Female	Persons
Mental retardation	116	72	94
Mental illness	124	86	105

Unlike the other disabilities, mental retardation is a phenomenon whose manifestation is observed since birth or at the very early ages of life. About 87% of the mentally challenged were reported to have the problem since their birth and about 8% in the age group 0-4 years. On the other hand, the problem of mental illness is more of an old age problem. The possibility of onset of mental illness increases as one becomes older. The Table below depicts the position:

The Table below indicates the age at the onset of visual disability.

Table 1.11 Per 1000 distribution of persons 60 years and above with blindness or low vision by age at onset of disability.

Category Disability since birth		0- 4	5- 9	10- 14	15- 19	20- 24	25- 29	30- 34	35- 44	45- 59	60 & above	Tot- al
Blindness												
All male	21	5	7	7	4	2	2	12	41	214	683	1000
All female	15	8	9	8	6	5	7	5	25	246	666	1000
All persons	18	7	8	8	5	4	5	8	32	233	673	1000
Low vision												
All male	13	2	5	4	3	2	0	2	7	233	729	1000
All female	2	7	4	3	0	2	1	0	14	258	708	1000
All persons	6	5	4	3	1	2	1	1	11	248	717	1000

The tables also show that both in rural and urban sectors, regarding the age for onset of visual disability, the percentages tend to be higher in the first three age groups, (birth to four years) than that in age groups upto thirty five years. This also shows that apart from old age, visual disability tends to manifest itself during the early years.

Hearing Disability

Inability of a person to hear properly is considered as hearing disability and is judged taking into consideration the ability of the better ear. The prevalence rate is higher in rural India (310) as compared to that in urban India. Between the two sexes, the prevalence of hearing disability is marginally higher among males than among females. The Table below indicates the position:

Table 1.12 Number of persons with hearing disability per 100,000 persons by degree of disability for each sex and sector.

Degree of disability	Rural + Urban		
	Male	Female	Persons
Profound	96	88	92
Severe	113	114	113
Moderate	86	82	84
All	296	285	291

The probable cause of hearing disability are listed in the table below :

Table 1.13 Per 1000 distribution of persons with hearing disability by cause hearing disability for each sex and sector.

Causes of hearing disability	Rural + Urban		
	Male	Female	Persons
German measles/ rubella	8	5	7
Noise induced hearing loss	25	15	20
Ear discharge	162	154	158
Other illness	220	235	227
Injury other than burns	3	1	2
Burns	56	42	49
Medical/surgical intervention	13	18	15
Old age	254	272	263
Other reasons	79	85	82
Not known	175	168	172
Total	1000	1000	1000

The important causes are old age, ear discharge and other illnesses. Nearly 1% of the disabled persons reported rubella as the cause of hearing disability. The table below indicates also the age at onset of hearing disability. The survey reveals that about 7% of persons with hearing disability are born with it and for about 57% onset is reported at the age of 60 years and above.

Table 1.14 Per 1000 distribution of persons 60 years and above with hearing disability by age at onset of disability for each sex and sector.

Category		0-4	5-9	10-14	15-19	20-24	25-29	30-34	35-44	45-59	60 & above	Total
Disability since birth												
All male	77	8	7	16	5	14	5	14	41	227	585	1000
All female	53	5	10	12	6	15	7	18	51	267	557	1000
All persons	65	6	9	14	6	14	6	16	46	247	571	1000

Locomotor Disability

The survey estimated 1.064 crore persons as having locomotor disability in the country. Of them, about 80 lakh are in rural areas and 26.60 lakh in the urban areas. About 4% of those who had locomotor disability are reported to have either multiple locomotor disability or two or more other disabilities. The prevalence rate for locomotor disability is given in the table below.

Table 1.15 Number of persons with locomotor disability per 100,000 persons for each sex and sector.

Sector	Male	Female	Persons
Rural	1274	804	1046
Urban	1058	730	901
Rural and Urban	1217	785	1008

The type of locomotor disability is indicated in table below:

Table 1.16 Per 1000 distribution of persons with locomotor disability by type of disability for each sex and sector.

Type of locomotor Disability	Rural + Urban		
	Male	Female	Persons
Paralysis	142	148	145
Deformity of limb	460	444	454
Loss of limb	93	50	77
Dysfunction of joints of limb	210	259	228
Others (deformity of body)	94	97	95
All	1000	1000	1000

The probable causes of locomotor disability have been identified in the table below.

Table 1.17 Per 1000 distribution of persons with locomotor disability by cause locomotor disability for each sex and sector.

Cause of locomotor disability	Rural + Urban		
	Male	Female	Persons
Cerebral palsy	23	26	24
Polio	290	286	289
Leprosy cured	15	12	14
Leprosy not cured	15	13	14
Stroke	71	68	70
Arthritis	22	46	31
Cardio respiratory disease	4	2	3
Cancer	3	3	3
Tuberculosis	4	2	3
Other illness	108	141	120
Burns	19	21	19
Injury other than burns	295	199	260
Medical/surgical intervention	22	20	21
Old age	20	59	34
Other reasons	42	49	44
Not known	41	47	43
Total:	1000	1000	1000

These indicate that polio has been a major cause while another is injury. The age at onset of locomotor disability is depicted in the following table.

Table 1.18 Per 1000 distribution of persons 60 years and above with locomotor disability by age at onset of disability for each sex and sector.

Category Disability since birth		0- 4	5- 9	10- 14	15- 19	20- 24	25- 29	30- 34	35- 44	45- 59	60 & above	Tot- al
All male	54	20	20	14	11	18	11	21	66	291	472	1000
All female	53	20	11	14	4	6	3	14	42	274	557	1000
All persons	54	20	16	14	8	13	7	18	55	284	511	1000

Planning for Persons with Disabilities

While improved health services have contributed to reducing disability amongst the younger age groups, the prevalence can increase due to increased incidence amongst the older age group. This is perhaps inevitable on account of more people surviving longer beyond the age of 60 years. Analysis of the data regarding causes of disability, age at onset and regional variations can provide insights that can help in developing appropriate medical interventions for minimizing disabilities particularly those of a congenital nature. Accepting however that in terms of numbers, the persons with disabilities form a substantial chunk of the population, rehabilitation services have to be planned and developed. The gap between the number of therapists and special educators required and those actually available is large and needs to be bridged through HRD programs and institution building. The need for decentralized availability of rehabilitation services also needs to be addressed.

The age-wise data available for the prevalence of all disabilities in the 58th round is particularly valuable for facilitating planning in the area of education. Between the age of 0-18 years, there are an estimated 49.91 lakh children with disabilities. The 86th amendment to the Constitution casts the responsibility on the State to ensure that all children up to the age of 14 years attend school. Under the PWD Act, the State is required to ensure that all children up to the age of 18 years get access to education in the appropriate mode free of cost. The data shows that there are 26.18 lakh children with locomotor disability in the age group of 5-18 years. How many of these children can attend regular schools after fitment of appropriate devices and with facilities for transportation to school being ensured? How many are so severely disabled that they cannot attend regular schools since getting to the school would be too difficult for them? For such children the State has to plan for residential facilities within regular schools so that they can either attend classes there or separate classes are organized for them.

The survey reveals that the estimate of children with visual impairment (blind) in the age group of 5-18 years points to a figure of 1.56 lakh. These children require school readiness programmes and mobility training before they can be integrated with regular schools and even then some resource support has to be provided for subjects such as mathematics. There are another 0.48 lakh children estimated to suffer from low vision. Aids and appliances and resource support programmes can facilitate their education too in regular schools. Teachers need

training in handling low vision children as their needs are different from normal children and also different from children who are totally visually impaired.

The hearing impaired children in the age group of 5-18 years are estimated to number 2.13 lakh. Yet this is a group for which access to special education programmes is much lower than for visually impaired children while they are not able to do well in regular schools particularly if they have not developed speech. Special education is an extremely costly option and the need for the same would perhaps not exist if our early intervention programmes get due attention. The hearing impaired children in the age group of 0-4 years are estimated to number 0.107 lakh and early intervention programmes combined with fitment of hearing aids could ensure that these children are later able to pursue their education in regular schools. If the promise of the 86th Constitutional amendment and Section 26 of the PWD Act is to be a reality, the State needs to plan for early intervention and school readiness programs for the children with disabilities. It must plan for funding and fitment of aids and appliances for children who need them. Capacity building for teaching children with disabilities needs particular attention at the primary level. Scholarships, books, uniforms, transportation must be covered through comprehensive schemes for integrated and special education in the States. All this will require detailed planning and substantial commitment of resources.

The work participation rate for the persons with disabilities is rather low and this is an area demanding the attention of rural and urban employment planners. Perhaps this points to the need to ensure access to vocational training of adolescents who have never attended school and those who are not pursuing education at the higher level. The vocational training must have adequate linkage with industry and business enterprises so that placement levels improve. Education amongst MR persons is non-existent/low and they can only acquire limited skills. Although work not requiring literacy and high skills is available, community support is vital for their accommodation in the workplace on tasks within their capacity. The expansion of programmes for advancement of micro credit and credit to persons with disabilities to enable them to set up their own small enterprises can also ameliorate their lot.

The data clearly indicates that disability afflicts a large proportion of the older persons. With the life expectancy rising and also the years of survival beyond 60 increasing, the needs of elderly persons will need special care and issues of access keeping in view their physical capacity will require attention. This points to the need for adopting the principles of Universal Design while planning for buildings, transport systems, etc. so that life is easier for persons with disabilities as well as the elderly.

Planning for and delivery of services required by the disabled persons is a major challenge for this decade. This is particularly so in the context of the Biwako Millennium Framework of Action adopted by the member nations of ESCAP in September, 2003 which lays down targets in the areas of education, poverty alleviation, vocational training, access, etc. The Planning Commission has also advised that Ministries of the Government of India and States must prepare a Special Component Plan for the disabled persons and earmark adequate resources to implement the plan. The NSSO survey is a valuable data base for planners and

must be utilized to strengthen their case for allocation of funds particularly for the development of the full range of rehabilitation facilities. The countries of the world are moving towards finalization of the Comprehensive and Integral Convention on the Rights of Persons with Disabilities. India should now prepare itself to comply with the standards on which it will be monitored when this Convention is ratified.

Reference

Report No. 485 of National Sample Survey Organization(2002) 58th Round; Survey on Disabled Persons in India, New Delhi; NSSO

Chapter 2

Poverty and Disability in India

C S Mohapatra

Poverty and Disability dynamics is complex and multidimensional. The author delineates the various facets of the linkages with the help of a Link Model highlighting the multiple deprivations suffered by a person with disability who is also poor. The factors that accentuate the state of poverty of a person with disability and brings downward mobility has been identified in the chapter gives a brief summary of the author his study, "Poverty and Disability Links: A study of Persons Accessing Government Institutional Services" that establishes the linkage and also gives an idea about the socio-economic cost borne by the persons with disabilities. Government interventions and support over the Five Year Plans and specifically, the Tenth Plan commitments have also been indicated. Finally, the author gives valuable policy suggestions including E-Governance for Disabled Persons (E-GOD) that will help ameliorate the conditions of persons with disabilities.

Introduction

The physically and mentally challenged persons of our country suffer from social, economic and psychological burden that needs to be understood by the policy makers, implementers and the society in general in right perspective. This disadvantaged section of our society has to bear additional costs of disability some of which are difficult to compensate. The physical and attitudinal barriers they face and the additional expenditure they have to incur for management of their disability are few dimensions of their hardship. When a disabled person is poor, the problems get added on, the challenges and costs they face becomes magnified - more often than not, to an unmanageable degree. Makes an attempt to look at various dimensions of the poverty and disability linkage ,more particularly, in the Indian context .To substantiate the linkage, which is often discussed in general terms, the author gives a brief summary of the research work conducted on the basis of primary data collected from the disabled persons who, for accessing rehabilitation services, visited the fourteen selected Institutes/ Centres of the Government located in different parts of the country.

Poverty

Poverty is seen differently by different experts. It has many dimensions and these include standard of living, assetlessness, lack of basic security, lack of entitlement, multiple deprivation, exclusion, inequality, class, dependency and unacceptable hardship, (Gordon & Spickler, 1999). Poverty can be transient, structural or chronic in nature. In the international sphere, poverty index is related to human development and contains the basic aspects as delineated below:

Table: 1 Poverty Index

1)	Health Deprivations (3):
	(i) Life expectancy less than 40 years (ii) Lack of access to basic medical services (iii) Non-immunized children
2)	Educational Deprivations (2):
	(iv) Illiteracy rate (v) Un-enrolled children
3)	Economic Deprivations (5):
	(vi) Below poverty line (vii) Katcha dwelling (viii) Lack of sanitation facilities (ix) Lack of safe drinking water (x) Lack of electricity connection

Source: National Human Development Report, 2001.

Broadly (1) poverty is seen as lowness of income, and (2) poverty is seen as the inability to meet some elementary and essential needs. Since we are ultimately concerned with the lives we can lead (and income is only instrumentally important in helping us to lead adequate lives), the case for taking the latter view of poverty is quite strong. (a) poverty can be defined in terms of capability deprivation (the connection with lowness of income is only instrumental); and (b) there are influences on capability deprivation other than lowness of income. (Sen and Foster, 1999)

Disability

'Disability' and 'Handicap' are often used interchangeably. Whereas 'Disability' refers to different functional limitations physical, intellectual or sensory impairment, medical conditions or mental illness, 'Handicap' means the loss or limitation of opportunities to take part on an equal level with others due to shortcomings in the environment such as information, communication, education. Disability may be defined as any restriction or lack of ability (resulting from impairment) to perform an activity in the manner or within the range considered normal for a human being as defined by the World Health Organisation (WHO). International Labour Organisation (ILO) defines a disabled person as an individual whose prospects of securing, retaining and advancing in suitable employment are substantially reduced as a result of a duly recognized physical or mental impairment. While the former highlights the functionality aspect, the ILO approach focuses on the employment perspective. Depending on the context, disability has been defined in terms of medical, economic, social or psychological aspects. Disability can be physical or mental. It can be broadly categorized as (a) locomotor (b) visual (c) hearing and (d) mental disability.

Disability may exist from birth or may be acquired during a person's lifetime. A certain degree of disability also comes as a natural process of aging called as geriatric conditions that can be at the most delayed but cannot be avoided. A number of factors can cause disability. These include: heredity, birth defects, lack of care during pregnancy and childbirth due of lack of coverage or ignorance, insalubrious housing, natural disasters, illiteracy and the resulting lack of information on available health services, poor sanitation and hygiene, congenital diseases, malnutrition, traffic accidents, work-related accidents and illnesses, sports accidents, the so-called diseases of "civilization" (cardiovascular disease, mental and nervous disorders, the use of certain chemicals, change of diet and lifestyle, etc.), marriage between close relatives, accidents in the home, respiratory diseases, metabolic diseases (diabetes, kidney failure, etc.) drugs, alcohol, smoking, high blood pressure, old age, Chagas' disease, poliomyelitis, measles, etc. Non-governmental sources also place particular emphasis on factors related to the environment, air and water pollution, scientific experiments, violence, wars, intentional physical mutilations carried out by the authorities and other attacks on the physical and mental integrity of persons, as well as violations of human rights and humanitarian law in general. (Kishan, Dutt and Rao, 2001)

Poverty and Disability

Poverty restricts the choice and availability to persons due to multiple deprivations. Disability, physical or mental, further narrows down the range of choices available to a person due to functional limitations and social discrimination. When these disabilities significantly restrict the activities that would otherwise have been available to the persons, they will, all other things being equal, constitute reductions in the person's quality of life.

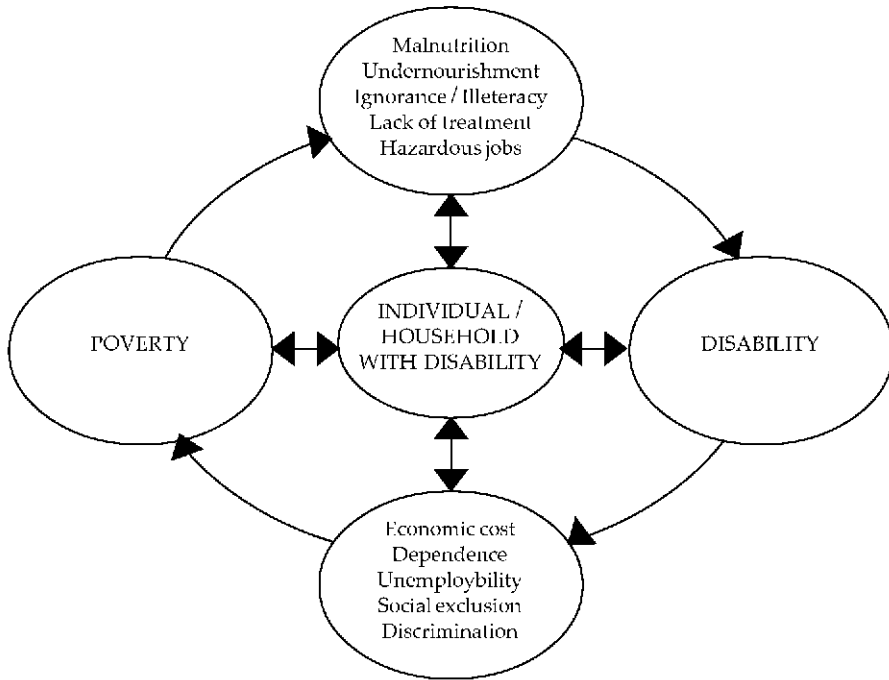
Though the positive association between poverty and disability in India has been much discussed, research in this field is quite limited. The study undertaken by Susan Erb and Barbara Harriss-White in the Indian context clearly brings out a positive association between poverty and disability. This was a census of three villages in northern Tamil Nadu. They have worked with people's own definition of chronically sick and disabled household members and have estimated that between 17 and 30 per cent of households had at least one chronically sick or disabled member and there existed wide inter-village variation. A slightly higher proportion of these households were found to be below the income poverty line. It was found that households with chronically sick and disabled people tended to have smaller family sizes, smaller operational landholding sizes, lower grain consumption from own production and greater market dependence for food. (Harris-White and Subramanian 1999). The study mentions that disabilities were self-reported based upon rural peoples' own definitions of disability and not classified according to the medicalised criteria employed by government and international agencies.

The fact that disability increases dependence not only among children and the elderly but also among adults of working age has been brought out by that study which contends that "poverty is believed both to cause and be a consequence of disability. Impoverished households are perceived as being more susceptible to disabling circumstances. Malnutrition (as a predisposing factor to blindness (vitamin A deficiency) and certain types of physical deformities (cretinism), inadequate access to preventative and curative medical care (including immunization), risks of accidental and/or occupational injury (labouring, carrying heavy loads, pesticide poisoning, etc.) all conspire to increase poor households' susceptibility to disabling conditions. The inverse, however, is also expected to hold true. Disability is believed to combine with poverty to create situations of downward mobility". (Erb and Harriss-White, 2002).

Narsing Rao holds the view that disability and poverty are closely related. While disability causes poverty, in a country with mass poverty it is also possible that poverty causes disability (Narsing Rao, 1990 as cited by Susan Erb and Barbara Harriss-White, 2002). There is a strong and definite, vicious cycle of poverty and disability. The propensity for the poor to be disabled and for disabled people to be poor is very strong. People living in poverty tend to become disabled because of aggravating factors such as malnutrition and squalid housing, hazardous occupations and so on. (Arora, 2003).

Due to multiple deprivations faced by them, disabled persons, once poor, are likely to suffer from chronic poverty or long duration poverty. A cumulative lack of basic capabilities would make it extremely difficult for the poor to emerge from poverty by their own efforts. (David and Shephard 2003). Chronic poverty seems to be disproportionately high among historically marginalized groups such as Scheduled Castes, Scheduled Tribes, the elderly, women and the disabled. The multiple deprivations suffered by them make it harder for them to escape from poverty. (Kapur and Shah, 2003). Different forms of disadvantages tend to be mutually reinforcing so that people in groups 'jammed' by one log are likely to face others as well. (Haan and Lipton, 1998). Poverty combined with disability traps a person in a downward spiral that pulls him downwards economically, socially, psychologically and functionally.

Some authors hold the view that prevalence of disability and poverty are rather inversely related due to high mortality rates of poor and disabled persons. There is evidence for a disability transition during which disabilities due to malnutrition and infectious/ contagious diseases are eradicated, but more than offset by reduced mortality rates, survival of para- and quadri - plegics and increases in disabilities due to trauma and old age, such that the total incidence of disability increases. (Mohan, 1998). However, the view even if opposite, hints at a definite poverty- disability linkage. It rather strengthens the case for special poverty alleviation interventions and better health care for persons with disabilities.

Figure: 2.1 Poverty and Disability Links Model

The Indian Context

According to the latest 58th Round National Sample Survey of India the number of disabled persons in the country was 18.49 million and they formed about 1.8 per cent of the total estimated population. Prevalence of disability in India as per the Survey is marginally higher among rural residents as compared to urban residents. About 10.63 per cent of the disabled persons suffered from more than one type of following disabilities, (i) mental disability in the form of (a) mental retardation or (b) mental illness, (ii) visual disability in the form of (a) blindness or (b) low vision, (iii) hearing disability, (iv) speech disability, and (v) locomotor disability (NSSO, 2002).

In the Indian context, poverty estimated in terms of people below or above the poverty line as per the recommendations of the Expert Group on Estimation of Proportion and Number of Poor constituted by Planning Commission in 1989. This method captures the cost of living in each state through state-specific poverty

line. Per capita monthly consumption expenditure of Rs. 49.09 in rural areas and Rs. 56.64 in urban areas, anchored in the per capita daily intake of 2400 K Cal in rural areas and 2100 K cal in urban areas with reference to the consumption pattern as obtained in 1973-1974 is adopted as the basis for defining poverty line (K.L Datta and Savita Sharma - Facets of Indian Poverty, 2002). In India, poverty is seen as an absolute concept indicating a minimum of provisions required to keep up health and working capacity in order to survive and maintain physical fitness and efficiency. This method of estimating poverty ratio does analyze the depth and severity of poverty.

In India, disability often results in a person remaining idle and becoming dependant on the working population. Disability reduces the social status of a person and the implications vary depending on his/her sex, age, marital status, family size, extent of social network, whether he was self employed or an employer. These costs of disability are borne by the persons with disabilities regardless of whether or not rehabilitation services are available. These costs may however decrease if rehabilitation services are provided. This may result in increased productivity & income, independent living etc. The following factors however, accentuate the state of poverty of a person with disability:

- Lack of educational facilities including educational aids
- Shortage of trained and sensitive teachers
- Absence of barrier free school
- Inadequate vocational training
- Lack of employment opportunities in terms of availability as well as reservation of jobs
- Absence of barrier free environment
- Low coverage of rehabilitation services by both govt. and non-government organizations
- Less sophisticated/ maneuverable assistive devices etc.
- No effective implementation of reservation provisions in education and employment
- Lack of earmarking of funds in related developmental activities for rural development

As disability accentuates poverty due to the economic , social and psychological costs involved, so also poverty accentuates disability due to lack of access to any or all of the rehabilitation services that are essentially required for a person with disability to survive. Poor nutritional status and health of pregnant mother due to poverty can lead to a low birth weight baby who is a prospective candidate for one or multiple disability. Besides, lack of access to health care and lack of awareness about the causes of disability which has a greater likelihood of occurrence amongst poor families, can lead to disability in children/ adult which otherwise could have been prevented. The poverty-disability dynamics is complex.

The Study

In order to delve deeper into these seemingly complex inter-linkages in the Indian context, a study was undertaken by the author with the following broad objectives in mind:

- i. To gain insight into the linkages between disability and poverty.
- ii. To ascertain whether there exists a correlation between poverty and disability.
- iii. To ascertain what is the proportion of poor people among those who are accessing the governmental institutional rehabilitation services.
- iv. To critically review the Government policies and programmes for persons with disabilities.

Primary data was collected from the disabled persons accessing Government rehabilitation facilities by administering questionnaires to a modest sample of 426 persons accessing each type of facility such as physiotherapy, occupational therapy, speech therapy, vocational counseling, training, surgery & hospital facility. Disability was broadly categorized into four types locomotor, visual, hearing and mental. The persons categorized as locomotor disabled included the persons with Cerebral Palsy suffering from locomotor disability. Mentally disabled category, for the purpose of the study, only included the mentally retarded and autistic persons and did not include the mentally ill who primarily need health and psychiatric care. The questionnaire focused on disability and poverty. Income as well as expenditure data were collected and matched with the asset profile of the household. The emphasis was on looking at the disabled poor vs. disabled non-poor. The respondents were categorized as Poor (P) and Non poor (NP) depending on the whether the per capita per month expenditure of the household is below the poverty line (BPL) or above the same, respectively. To arrive at the BPL criteria, the State specific poverty line was taken for rural/urban areas/ and multiplied with the individual number of households, case by case and the poverty status ascertained.

The questionnaire was circulated to five National Institutes i.e. NIRTAR, IPH (both relate to locomotor disabled), NIMH (Mentally Retarded), NIVH (Visually Handicapped), and NIHH (Hearing Handicapped). To cover the rural areas, a few District Centres were chosen covering all parts of the country. Besides, two Composite Regional Centres (CRCs) and one Regional Spinal Injury Centre (RSIC) were also included. The questionnaires were administered by the author by personally visits to some of the Institutes. Wherever the same was not possible, the help of Institute's research staff was taken to ensure better response. As a set of questions on the performance of the Centre/ Institute was also included, that made the organisations to participate enthusiastically. Besides, such an exercise was done for the first time after decentralization efforts took place in 1999-2000.

The details of the locations of Centres/Institutions covered under the study is indicated below:

- Composite Regional Centres (Bhopal and Guwahati) at the Regional level and District Centres (Jalpaiguri - West Bengal; Kolhapur - Maharashtra; Surat - Gujarat and Gangtok - Sikkim) at the district level. These centres provide composite services i.e. services for all types of disabilities.
- Five National level Institutions each catering to a specific type of disability were included in the sample as follows:
 - Locomotor Disability - IPH, New Delhi and NIRTAR, Cuttack, Orissa .Data from one of the four newly set-up Regional Spinal Injury Centre (RSIC) located at Cuttack that caters in general to locomotor disability and spinal injury in particular, was also collected.
 - Visual Disability - NIVH, Dehradun
 - Hearing Disability - NIHH, Mumbai alongwith its regional offices at Delhi and Bhubaneswar
 - Mental Retardation - NIMH, Secunderabad

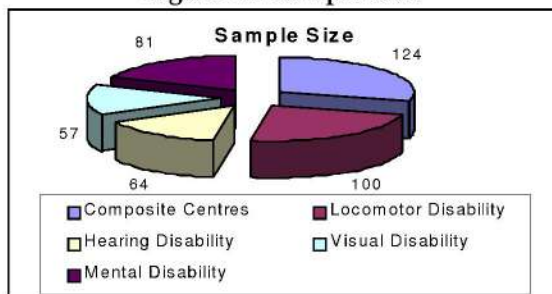
The Sample

The number of persons surveyed in the Composite Centres/Disability Specific Centres is given in Table 6.1 below:

Table 1.3 Sample Size

Centre / Institute	No. of Respondents
Composite Centres	124
Locomotor Disability	100
Hearing Disability	64
Visual Disability	57
Mental Disability	81
Total	426

Figure 1.1 Sample Size



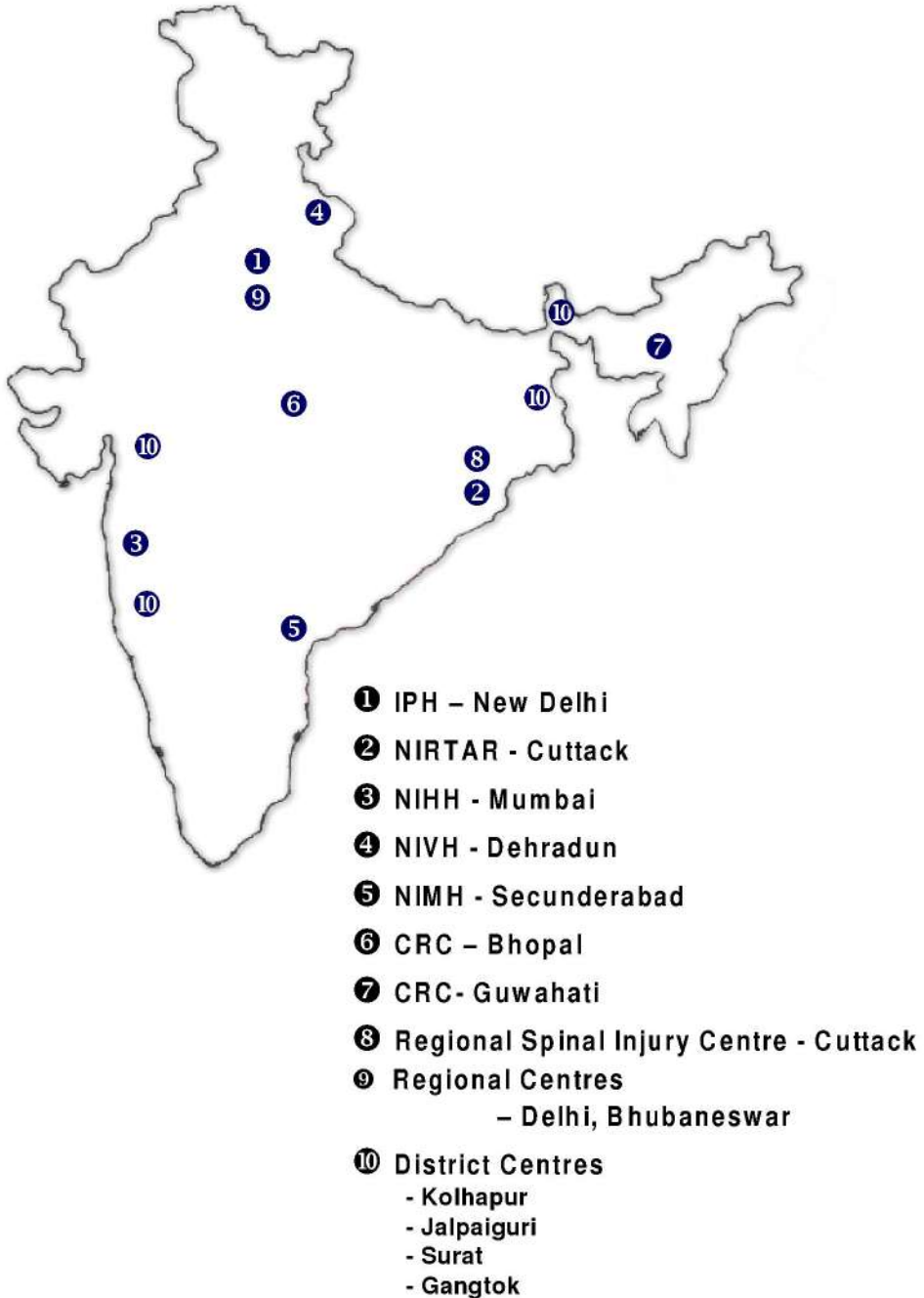
Data collected from each of the centres represent persons accessing different types of services provided in various departments/units of each of these centres.

Unstructured interviews with the Directors of the National Institutes, prominent NGOs, some persons with disabilities, key resource persons in the Government were also conducted to gain insight into the dynamics of poverty and disability.

Spatial Distribution

The spatial distribution of the data sample is mapped as given below:

Figure 1.2 Mapping Coverage of Study



Limitations of the Study

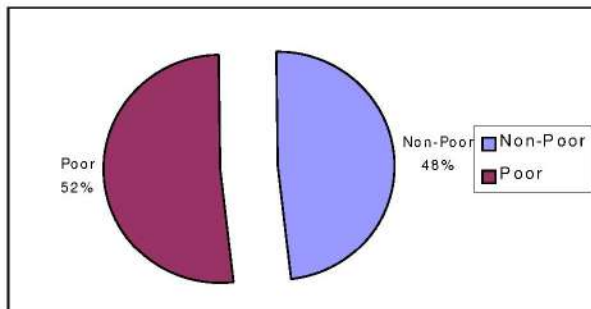
The study covers only a sub-set of persons with disabilities who have accessed the Governments' Institutional Rehabilitation Services. Keeping in view the limited time frame available while undertaking the study under the Advanced Professional Programme in Public Administration (APPPA) course, inclusion of persons with disabilities accessing services of NGOs or outreach services of the Institutes under the camp approach was not possible. An in-depth village study was also not feasible. The sample thus constitutes only disabled persons who access different services provided by the selected Centres/Institutions of the Government.

Major Findings of the Study

Poverty

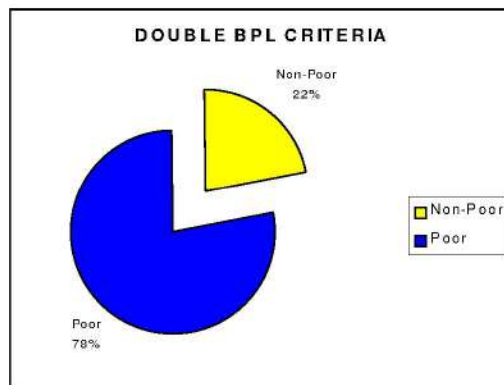
Depending upon the location of the Centre and number of members in the households the state specific poverty line criteria used for the study ranged between Rs 319 and Rs. 540 per capita per month. There was large variation in the total monthly expenditure of the households which ranged from as low as Rs. 250 in case of a nuclear family to a joint family having monthly expenditure as high as Rs. 40,000 with average of Rs. 3620. It was found that over half i.e. 51.88 percent of the population was poor in terms of the poverty line criteria of Planning Commission of 1999. Assuming a modest inflation rate of 4 percent per annum and adjusting the BPL criteria, the number of poor respondents increase to 59 percent. Asset analysis showed that over 67percent of the respondents are Asset Poor. About two third of the respondents were landless and of those who owned land, majority (67 percent) belonged to rural areas.

Figure 2.1 Poverty



A person with disability, however resource poor he/she is, has to undertake a bare minimum amount of expenditure for functional independence, mobility and activities of daily living. This brings us to the question whether the poverty line as applicable to non-disabled persons is an appropriate measure to judge poverty status of a person with disability. Some experts feel that, the poverty line is higher for persons with disabilities as compared to the rest of the population. As a result, using the conventional poverty line is likely to give a much lower estimate of the number of persons with disabilities living below the poverty line. (Arora, 2003). Keeping in view the additional financial direct costs and indirect costs that a disabled person is destined to bear, if one takes, roughly, double the official BPL criteria of Planning Commission 1999 as the poverty line criteria for the disabled persons, the percentage of respondents who were poor increased to 77.7 percent even without adjusting for inflation.

Figure 2.2



Socio- Economic Profile

Results of the study show that 55 percent of the respondents belonged to rural areas, and the remaining 45 percent hailed from urban areas. About 68.51 percent of the rural respondents were poor as against 31.41 percent of the urban respondents. The average family size of the sample was six which matches with that of NSSO survey figure of 5.7. In rural as well as urban areas 60.43 percent and 67.54 percent of sample respectively had a nuclear family to support. This corroborates the fact that even in rural areas; the joint family system is eroding.

Figure 2.3 Rural / Urban Background

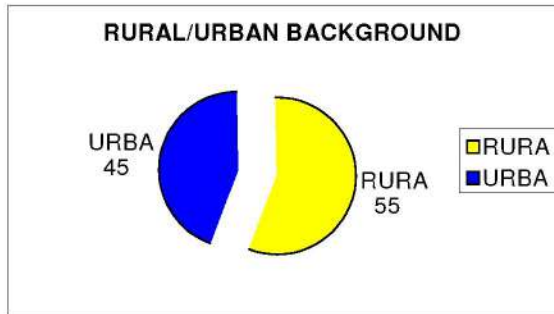
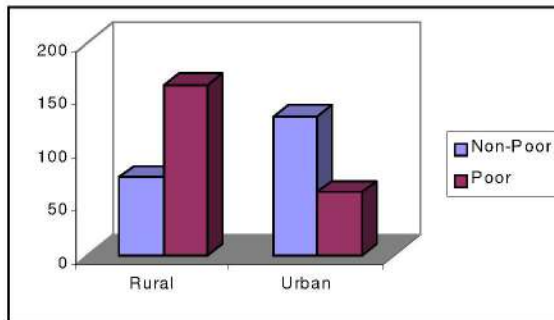
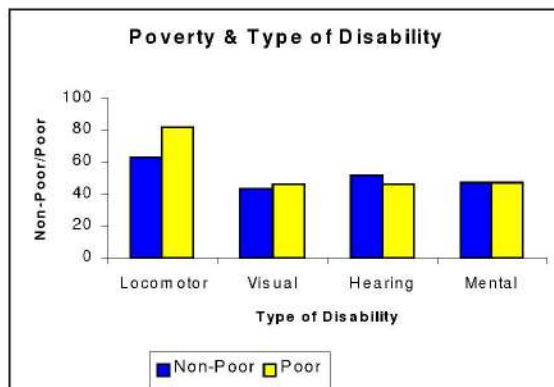


Figure 2.4 Poverty & Rural / Urban Background



Locomotor disability being the most prevalent in the country, the survey had representation of 145 persons who had locomotor disability (34% of the sample) followed by Hearing Disability (23%), Mental Disability (22%) and Visual Disability (21%).

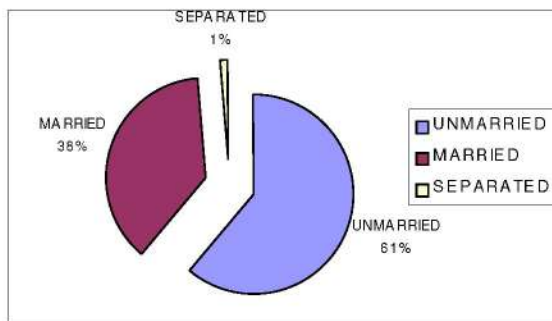
Figure 2.5 Poverty & Type of Disability



Male representation was uniformly dominant at about 71% amongst poor as well as non-poor respondents. The NSSO survey also found male dominance in all categories of disability except for visually disabled where females were higher. However such dominance was more pronounced in the study undertaken by the author. This suggests that there exists a significant gender bias in terms of accessing rehabilitation services of the Government institutions which was uniform across income and locations.

The overall marital status for persons with disabilities covered under the study shows that out of the total number of respondents above 18 years of age, 61% were unmarried, 38% married and 1% separated.

Figure 2.6 Marital Status



Out of the sample, 58 percent of males and 74 percent of females above 18 years are unmarried. About 96.6 percent of the unmarried respondents lie in the age range of 18 -40 years. Analysis of marital status according to different types of disability in the age range of 18 years & above reveals that the percentage of unmarried persons is highest (85 percent) in case of mental disability implying that the problem of marriage due to disability is most prominent in this category. NSS-2002 also contends that most of the mentally retarded seem to lead an unmarried life.

The literacy rate of disabled persons in India is estimated at 60 percent in urban areas and 41 percent in rural areas. About 81.5 percent of the respondents under the study however were found to be literate suggesting that higher proportion of literate disabled persons approach the institutional rehabilitation facilities of the Government. Those with graduation or higher degree of qualification constituted 13 percent of the literate respondents. The level of literacy in case of non-poor respondents was higher at 85.5 percent whereas in case of poor persons it was about 78.1 percent. A major proportion i.e. 67.86 percent poor persons among those who were literates without formal schooling. At higher levels of education, percentage of non-poor population was more as compared to poor. Female population had higher proportion of illiterates (23.15 percent) as compared to males (16.84 percent). Amongst graduates, 56.4 percent were males and 43.6 percent were females. Analysis according to type of disability suggests highest percent of illiteracy amongst persons with mental retardation which is in agreement with the NSSO findings.

Principal family occupation of majority of respondents was wage labour (42 percent) followed by self-employment (32 percent). About 32 percent of the respondents were employed. Among the poor, 26.02 percent people were employed as against 38.37 percent in case of non-poor.

Poverty and Disability Links

Poor persons constituted a higher proportion than non-poor persons in both the age groups of 7-18 years and 19-40 years. In the most dominant age group i.e. 19 - 40 years, poor persons constituted 55.5 percent.

A majority of 245 persons out of the total sample suffered from 60 percent and above degree of disability. As against the national estimates that show only 13 percent of disabled population suffering from severe disability, persons with severe disability (above 80 percent) under the study constituted 31.69 percent (highest percentage) of persons who accessed services of the centres/institutions which was followed by 26 percent of sample who had disability ranging from 60 percent to 80 percent. These figures indicate that relatively higher proportion of severely disabled persons benefit from the Government rehabilitation services.

The various facets of this linkage have been brought out in Chapter I that delineates the causative factors of how, on the one hand, disability accentuates poverty due to the additional cost of social exclusion and consequentially downward mobility and how poverty results in malnutrition, undernourishment, lack of timely detection and lack of treatment. Chi-square test has been applied separately (a) by taking all the five ranges of degrees of disability and (b) by taking only 2 broad ranges i.e. 20 percent to 60 percent and 60 percent & above degrees of disability. In both the situations, the hypothesis of poverty and disability linkage is proved at 0.05 and 0.01 levels of significance. The results are given as below:

Table 2.2 Poverty and Degree of Disability in Two Broad Groups

	Upto 60%	60%+	Total
Non-Poor	101	104	205
Poor	80	141	221
Total	110	135	426

The hypothesis concerning linkage between disability and poverty was established at two different levels of significance at 0.05 percent and 0.01 percent respectively and in both the situations, the null hypothesis of no association has been disproved under the chi-square test.

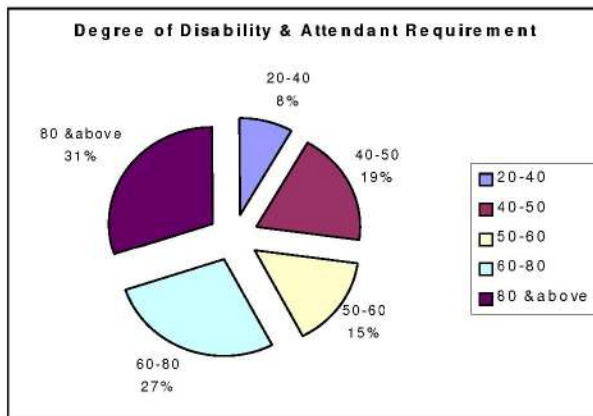
Table 2.3 Poverty & Degree of Disability

	20%-40%	40%-50%	50%-60%	60%-80%	80%+	Total
Non-Poor	24	40	37	32	72	205
Poor	11	43	26	78	63	221
Total	35	83	63	110	135	426

Stating alternatively, it is statistically proved that there exists an interdependence between poverty and degree of disability. This supports the hypothesis of the study that poverty and disability are closely linked with each other. Many more dimensions of the linkages between poverty and disability discussed in subsequent paragraphs lend further support to the hypothesis.

About 45.5 percent of the sample required an attendant of whom majority were locomotor disabled (62.76 percent) and mentally disabled (58.51 percent). In terms of attendant requirement of poor and non-poor persons, having over 60 percent disability, it was found that the percentage of persons (61.64 percent) who required attendant care in case of poor was more than the non-poor. Only 23.47 percent of hearing disabled and 28 percent of the visually disabled admitted that they needed an attendant.

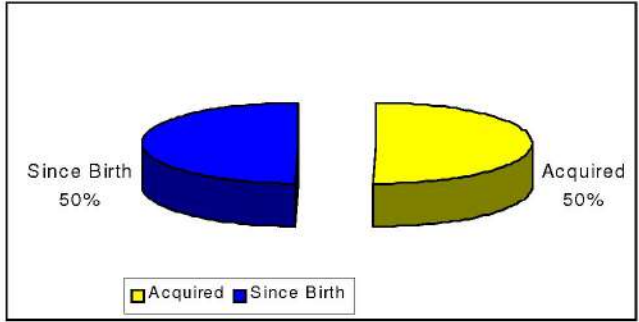
Figure 2.7 Degree of Disability & Attendant Requirement



In the category of persons who had more than 60 percent disability, poor respondents, in both children (0-18 yrs) and adult (18 yrs and above) category were higher in number than non-poor indicating that poor suffered higher degree of disability on an average. When analyzed in terms of attendant requirement of all persons, poor and non-poor having over 60 percent disability, it is found that the percentage of respondents who require attendant care is higher in case of poor than the non-poor. This only shows that the poor persons have a more disabling environment due to poverty and resourcelessness which makes them more attendant-needy than the non-poor. Also the relative opportunity cost of the family attendant who has to abstain from work may be higher in the case of poor persons.

Respondents were almost equally divided on the question as to since when he/she has been suffering from the disability as a marginally higher percentage of them (50.5%) cited that they have acquired disability after birth.

Figure 2.8 Cause of Disability



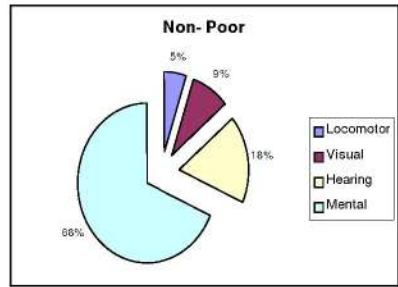
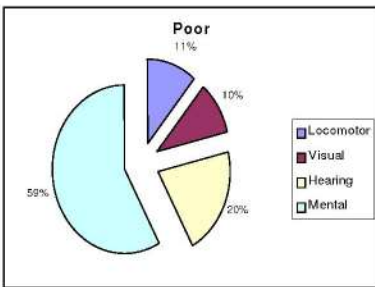
Majority of responses confirmed that accident was the most common reason for acquiring disability (41.2 percent) followed by lack of treatment (28.24 percent). Amongst persons who acquired disability a higher percentage of poor (43.4 percent) cited, next to accident, either lack of treatment or timely detection as the cause of disability as against a corresponding figure of only 29 percent in case of non-poor. The number of respondents who cited lack of treatment was more than double of the number of non-poor who gave the same reason.

About 86 percent of persons with mental disability covered under the study stated that they had disability since birth which corroborates the fact that mental retardation is birth related. This interestingly, matches with the comparable figure of 87 percent of the national estimates of NSSO 2002. The study found that 64.3 percent hearing disabled and 42.7 percent visually disabled persons had such disability since birth. Locomotor disability since birth was observed in only 20.7 percent cases and was more prominent in poor persons (11.22 percent) as compared to non-poor (5.26 percent). The proportion of poor who had visual disability (10.2 percent) and hearing disability (20.4 percent) since birth was higher in case of persons below poverty line. This signifies that higher percentage of poor persons suffer from disability since birth due to reasons of under nourishment, malnutrition, poor hygienic condition, lack of care during pre-natal, peri-natal and post natal stages in case of poor households. Poverty and disability are thus closely interlinked.

Figure 2.9 Poverty and Type of Disability since Birth

(a)

(b)



Amongst people who had disability since birth, 63.67 percent of people stated that they were ignorant about the cause of disability. Of the people who cited a cause, 22 percent felt that they had disability since birth due to malnutrition and 26 percent felt that disability was caused due to genetic factors. Amongst those who cited malnutrition as the cause, poor people comprised the majority at 65 percent.

While 40 percent of males were employed; only a meager 8.4 percent of females had employment. Whereas 53 percent of locomotor disabled persons could find jobs, only 26 percent of hearing disabled could manage one. The mentally disabled and visually disabled persons were worst sufferers as only 17 percent and 14 percent of them respectively were reported to be employed. Percentage of unemployment increased from 59 percent to 73 percent with increase in degree of disability implying that higher the severity of disability, more difficult it is to get work.

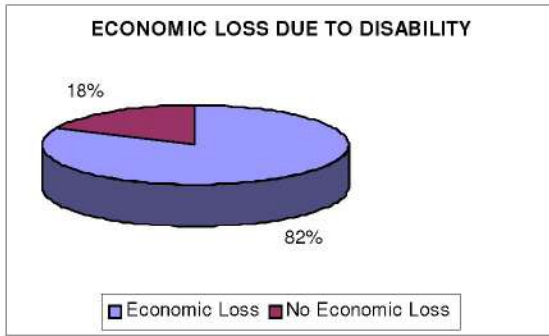
Of those employed, 38 percent earned their livelihood from wage labour or casual labour, 34 percent of them were self employed. While 12 percent of them had Government service, 14 percent worked in the private sector.

Table 2.4 Disability Type & Category of Employment

	Self Employment	Casual Labour	Wage Labour	Salaried Government Employment	Salaried Pvt. Employment	Others	Total
Locomotor	28	13	19	6	7	0	73
Visual	2	1	0	1	6	2	12
Hearing	9	5	2	3	3	0	22
Mental	1	3	2	4	0	0	10
Total	40	22	23	14	16	2	117

Onset of disability in a person who has a job sometimes results in loss of the job or change of work. The official national estimates of 2002 records that 37 percent of persons were working before onset of disability. The disabled population covered under the study were asked whether they were doing any job before the onset of disability. They were also asked if disability had been acquired and whether it had resulted in either loss of job or reduction in their earning due to change of work. 21.6 percent were doing some job or other before onset of disability of which about 82 per cent persons admitted that it has cost them the job or resulted in a change of job with reduced income levels. More than half (53.3 percent) of the respondents who were affected by total job loss or change of job with reduced income, reported having acquired disability levels of 60 percent or above. They constituted 61.53 percent of those employed at the time of study.

Figure 2.10 Economic Loss Due to Disability

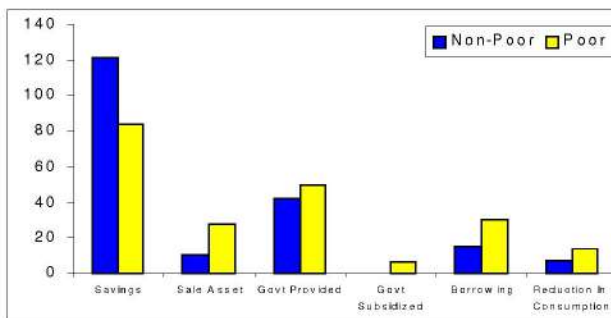


This points to the fact that on account of disability as also downward economic mobility, significant percentage of disabled persons were found accessing Government facilities which is subsidized or free.

Among the respondents, 26% had taken loan from some source or other, one fourth of whom had taken loan from money lenders. About 66.66 % of persons, who had to borrow for managing their disability, were poor. About two third of indebted poor had more than 60% disability.

Cost of treatment and care of disability was reported to be mostly met out of savings (50.4%) or by Government (22.6%). Borrowing was the third major source (11%) for both poor and non-poor. About two third of respondents who had to borrow money for managing their disability, were found to be poor. Poor respondents constituted 73.68% and 66.66% of the persons who had to go for sale of assets or reduction of consumption as a means to meet the cost of treatment and care.

Figure 2.11 Poverty & Sources of Meeting Cost of Treatment / Care



An overwhelming 72% of the respondents stated that timely attention and/or treatment would have reduced the extent of disability. Such feeling was more rampant in case of persons from rural areas accessing rehabilitation services they constituted about 71.49% of the rural population 62% stated that the impact would have been significant. Overall, 56% of the respondents felt that money would have helped in reducing disability. Two third felt that it could had played a significant role. Lack of awareness of parents or self was considered by 61% of the respondents as being responsible for increasing their degree of disability.

Economic Costs of Disability and the Link

A person with disability, however poor, has to undertake the hardship of meeting the cost of minimum aids & appliances, as also for its maintenance/ replacement etc. It was a difficult task to get the cost of disability quantified not only because the 'hurting' costs are social and psychological in nature that needs a different type of subjective analysis which this study did not envisage, but also the 'spending' costs or direct costs were difficult for respondents to calculate and quote. In a number of cases the respondents were unable to quantify the figures and therefore, only where concrete and precise figures were given, the same were taken for estimation of the cost. Average costs had to be worked out by considering each entry under specified components as discussed below.

The fixed variety of costs included the cost of identification and issue of certificate of disability that guarantees further benefits and concessions, cost of purchase of aids and appliances, travel cost for purchase of the aids and appliances as also for fitting of the same and the cost of preparing documents such as income certificate, any other affidavit etc. which are required to be produced for assistance from Government and NGOs.

The regular recurring costs included cost of repair of the aids / appliances used, travel cost involved in getting it repaired, fitted or replaced along with boarding and lodging cost in case he/she has to stay, opportunity cost of the person who accompanies the disabled person and above all, the consultation and medicine charges required for managing his disability.

Besides this, there exists other economic costs (categorized as special additional costs under the study) i.e. cost of special education, separate transport for education, if necessary, cost of making house barrier free for making it livable, cost of keeping a full time/ part time attendant or even taking the help of family member (full time/ part time) who may have an opportunity cost equivalent to the income which the latter would have otherwise earned etc.

Though the cost varies substantially depending on the degree of disability, nature and quality of aids and appliances required/ used, distance between place of stay and consultation/ service centers, availability of repair facility in the place of stay, extent of need for an attendant (full time/ part time) etc., an aggregate average cost has been estimated to determine the level of additional expenditure borne by the persons due to disability.

The responses of locomotor disabled persons reveal that on an average, they bear Rs.5771 as nonrecurring cost and Rs.4510 as recurring cost per annum due to their disability. The monthly recurring cost of a locomotor disabled person was thus estimated to be Rs 376. However, this does not include the cost for education and opportunity cost for the attendant which has been given separately for all categories of disabilities.

A visually disabled person spent on an average Rs.1073 per annum on recurring basis after incurring an initial non recurring amount of Rs.5223. For the hearing disabled persons, higher amount of Rs.10161 was estimated as the non-recurring cost as they claimed to have spent higher amount ,on an average Rs.5362 towards initial cost of aids/appliances purchased and towards

identification and issue of certificate of disability (Rs 1512) as compared to other categories of disabled respondents. Hearing disabled persons incurred about Rs.6193 per annum towards recurring expenditure. The mentally disabled had spent Rs.5738 as the nonrecurring expenditure and cited that they incurred Rs.8485 on an average, towards the recurring items of expenditure. There existed wide variation in quoting the opportunity cost of the attendants by the respondents.

Across all disabilities, the average spending of the respondents against the specific components of recurring and nonrecurring expenditure along with other costs such as cost on special education and opportunity cost of attendant are given in the table below:

Table 2.5 Major Economic Costs of Disability

Type of Disability	Non-Recurring Cost	Recurring Cost	Cost on Education	Opportunity Cost of Attendant
Locomotor	5771	4510	3000	8611
Visual	5223	1073	3365	3450
Hearing	10161	6193	4715	1952
Mental	5738	8485	6617	4568
All	6659	5056	4424	4645

The regular recurring cost incurred by the person with disabilities every year, on an average, comes to about Rs. 5056, as cited by the respondents which means that the additional monthly expenditure of a disabled person on an average, was Rs.421/-, which was approximately equivalent to the average of the official state specific poverty lines (Rs.441) used for the study .If education and opportunity cost of attendants are added to this, the recurring cost of the disabled person on an average comes to Rs.1176. The nonrecurring costs are of course, to be separately considered for understanding the total implications of the economic cost of a disabled person.

Social Cost of Disability and the Link

The cost of social and psychological burden of a disabled person is significant. In order to ascertain the degree of social exclusion, questions were asked covering aspects such as whether they think non-disabled persons have more respect in society, whether they feel ashamed or cursed due to disability and also whether they avoid attending social functions, melas and public gatherings due to disability. Wherever a respondent answered in affirmative in at least any one of the three questions, he/she was categorized as facing social exclusion due to disability. The results show that 74.8% out of the total sample feel socially excluded. Marginally higher percentage of people (77%) at higher degree of disability felt that they are not included in their society due to disability. As high as 80% poor-respondents felt that they were socially excluded as against 69% in case of non-poor respondents.

As regards discrimination at home, workplace, school, community, access to education or access to livelihood/employment, analysis shows that about 57%

felt discriminated in at least one of these areas, with proportion of such persons being higher in case of poor respondents (65.6%) than the non-poor (47.3%). A higher percentage of persons with mental disability felt discriminated (61.7%) as compared to other types of disabled persons.

Poverty, Rehabilitation Services & Benefits

Disability Certificate was issued in 61.03% cases only. Aids and Appliances were received by 75% respondents from government agencies of which only 27% were females. 21.67% claimed that they or their family members had purchased it.

There exists provision of various concessions and benefits to the disabled persons by the Central/ State Governments such as concessions and facilities in travel, loan, education, scholarships and reservation in employment etc. It was found that even amongst those who come to Government centres; a little less than half of them had not taken any benefit. Travel concession has been availed by the most but there was no single respondent who claimed to have availed all the benefits. Only two persons out of those accessing the centres had availed the concessional loan facility.

Impact of rehabilitation services was almost uniform across poverty and degree of disability and to some extent across different types of disability in which case it ranged from 85% to 96%.

Over 70% of those who used aids and appliances felt that their life had improved significantly after using aids and appliances. Half of the respondents stated that income and standard of living had perceptively gone up and their earning capacity had gone up due to use of aids and appliances.

About 78% of the respondents felt that there was some impact of rehabilitation services taking into account the dimensions such as financial burden on family, mobility, productivity, income potential, social status and confidence. 61.4% felt that their condition has improved significantly after the rehabilitation services were provided. Two third felt that financial burden on family has reduced due to rehabilitation services of which 54 % felt that it has affected them significantly. Over four fifth conveyed that their mobility has increased due to rehabilitation services availed by them. About 70% of the respondents felt that rehabilitation services had actually increased productivity and income potential. As regards increase in social status and confidence, an overwhelming percentage (92%) suggest that the confidence increases with rehabilitation services as against 83% respondents supporting the contention that social status increases consequent to providing rehabilitation services to any person with disability

The study has traced the causative factors of how, on the one hand, disability accentuates poverty due to the additional cost, social exclusion and consequentially downward mobility and how poverty hits a person with malnutrition, undernourishment, lack of timely detection and lack of treatment. Disability results in limiting ones functional capacity in daily living as also at work to varying degrees depending upon the nature and extent of disability on the one hand and the aids and appliances as also other rehabilitation services available on the other. Disability

impoverishes and pulls the disabled person economically downward. An income-poor household with a disabled member in it suffers from multifarious problems such as lack of money for adequate food and nutrition, lack of timely attention and treatment and above all high level of ignorance and lack of awareness about the causes of disability that affects before, during and immediately after birth. The poor persons have a more disabling environment due to poverty and resourcelessness which makes them more vulnerable than the non-poor. Also the relative opportunity cost of the family attendant as a proportion of household income is more for poor than in the case of non-poor persons.

Government Interventions and Support over the Five Year Plans

During the three first three five year plans (1955-69), the sole support to the disabled persons comprised grants in aid to NGOs and the establishment of National Training Institutes (Erb and Harris-White, 2002). The outlay for the disability sector as well as NGO assistance for welfare of the persons with disabilities is given in Table 3.2 below:

Table No. 2.6 Plan Outlays for Disability Sector (Rs. Million)

Plans	4 th Plan	5 th Plan	6 th Plan	7 th Plan	8 th Plan	9 th Plan	10 th Plan
Years	1969-74	1974-78	1979-83	1985-90	1992-97	1997-2002	2002-2007
Outlay	97.5	245(151)	425(73)	460(8)	2140(365)	9509(344)	14541(53)
NGO Assistance	60	111(85)	185(67)	210(14)	1085(417)	3765(247)	8575(128)

N.B. Brackets indicate percentage increase over previous plan periods

Source: Susan Erb and Barbara Harris-White 'Outcast from Social Welfare 'till 7th Plan and MSJE from 9th Plan onwards

It can be observed that the outlay for the disability sector increased substantially in the Eighth Plan and Ninth Plan by 365% and 344% over the previous plan period respectively against only eight per cent increase in Seventh Plan clearly indicating the effect of rise of national awareness and decision of the policy makers that was coupled with the historic and ambitious Persons with Disabilities Act, 1995.

The NGO sector also got the increase in the Eighth Plan and Ninth Plan by 417% and 247% over the previous plan period respectively against only 14% increase in Seventh Plan. The tenth plan promises a further quantum jump in the activities in this sector through committing an outlay that is 128 per cent higher than the 9th plan outlay.

The year wise outlays and expenditure for the Ninth Plan is given in Table 3.3 Analysis shows that the annual outlay for the disability sector as a whole as a percentage of the total outlay of the Ministry of Social Justice and Empowerment which is responsible for schemes and programmes for the disadvantaged, has increased from 10.08 percent in 1997-98 to 19.67% in 2000-01 and thereafter, to 19.45 % in 2001-02. During the entire plan period however, the expenditure in disability sector constituted 14.97% against the targeted 15.77 %. As regards the NGO sector, the allocation as a percentage of disability sector fluctuated between 26.61% and 51.22%. However, at the end of the plan period, the share of Government assistance to the NGO sector was 48.58% as against the envisaged 39.59%.

Table No 2.7 Year wise Plan Outlay & Expenditure for Disability Sector Schemes-1997-02

(Rs. Million)

Years	1997-98 Outlay	1997-98 Expndr.	1998-99 Outlay	1998-99 Expndr.	1999-2000 Outlay	1999-2000 Expndr.	2000-01 Outlay	2000-01 Expndr.	2001-02 Outlay	2001-02 Expndr.	1997-02 Total 9thplan Outlay	1997-02 Total 9thplan Expndr.
MSJE/ Social Welfare Sector	10630	7256	11517	9439	11472	10780	13336	10981	13327	11931	60282	50409
Disability Sector *	1071 (10.08)	567 (7.81)	1420 (12.33)	1076 (11.40)	1802 (15.71)	1348 (12.50)	2623 (19.67)	2178 (19.83)	2592 (19.45)	2379 (19.94)	9509 (15.77)	7548 (14.97)
NGO Disability Sector **	285 (26.61)	291 (51.32)	710 (50)	598 (55.58)	923 (51.22)	824 (61.13)	837 (31.91)	911 (41.83)	1010 (38.97)	1043 (43.84)	3765 (39.59)	3667 (48.58)

* Brackets indicate percentage share of social sector outlay/expenditure

** Brackets indicate percentage share of disability sector outlay/expenditure

BE is taken as outlay

N.B. Social Welfare sector outlay pertains to MSJE outlay that excludes tribal development schemes

Source: MSJE

Tenth Plan Commitments and Perspectives

Tenth Plan 2002-07 commits for ensuring rights of disabled persons through effective implementation of the Disabilities Act, 1995 and rehabilitation of Disabled during the Plan period. Under the policy imperatives and programme initiatives of the Government of India for the tenth plan, it is proposed to introduce a Component Plan for the Disabled in the budget of all the related Ministries/ Departments, in order to ensure flow of adequate financial resources to the un-reached, so as to make as many disabled as possible active, self-reliant and productive.¹⁴The outlays allocated for the Tenth Plan are given in Table 3.4 below:

Table No. 2.8 Year wise Proposed Plan Outlay for Disability Sector Schemes-2002-07 (Government of India, Planning commission)

(Rs. Million)

Years	2002-03 Outlay	2003-04 Outlay	2004-05 Outlay	2005-06 Outlay	2006-07 Outlay	2002-07 Total 9th Plan Outlay
MSJE Social Welfare Sector	14100	15375	17079	18701	20145	85300
Disability Sector *	2295 (16.28)	2584 (16.81)	2947 (17.26)	3237 (17.31)	3478 (17.26)	14541 (17.05)
NGO Disability Sector **	1270 (55.34)	1480 (57.28)	1729 (58.67)	1965 (60.70)	2131 (61.27)	8575 (58.97)

* Brackets indicate percentage share of social sector outlay

** Brackets indicate percentage share of disability sector outlay

N.B. Social welfare sector outlay pertains to MSJ E outlay that excludes tribal development schemes.

Suggestions

(i) Rigorous Policy Analysis

India has made major strides in the field of disability rehabilitation efforts in the 1990s in terms of enacting laws, increasing funds availability for aids and appliances and NGO support, building institutions and decentralizing delivery units. However, there appears to be no rigorous academic effort for analysis of the policy. There is a need for the Government to engage in a serious policy analysis including diagnosing the underlying problem of rehabilitation, exploring whether alternatives for policy choice exist, evaluating the policy outcomes and forecasting the consequences and making a preferred choice after looking at the alternatives and their implication. This will place the public authorities in a stronger ground than pushing through the beaten path in a traditional manner with sub-optimal delivery of rehabilitation services and empowerment outcomes.

(ii) Participatory Policy (PPA) Analysis

An Integrated Policy Analysis of the Disability sector covering both retrospective and prospective analysis is required. PPA has a number of benefits. Policy makers could have greater confidence that a more complete spectrum of evidence had been incorporated into the analytic exercise, thereby providing a greater likelihood of policy's or programmes (that is, personal) success. (Peter De Leon, 1992). However, there is a risk involved in choosing the representatives of the target population, which in this case, are disabled persons. Right selection of representatives who can make meaningful contributions while participating in policy deliberations will make a successful analysis and thus, lead to better outcomes.

(iii) Effective Evaluation

The basic rationale for evaluation in the first instance, is fixing accountability followed by learning from the implementation of a policy. Some stakeholders may be more interested in accountability while others may be more interested in learning, particularly in using the evaluation to improve processes and outputs or to make an impact on policy and social change both locally and nationally; in practice, many will be interested in both. It is a curious fact that despite the widespread support for evaluation, there is also deep seated resistance to it within many organizations. The reasons for this are complex and diverse, but it is possible to find a pattern to the resistance which seems to be based on some core beliefs held by organizations in different sectors. These beliefs are myths because they are so deep-seated and pervasive but influence behaviour in subtle and decisive ways - are to be found in the private sector, the public sector and the voluntary sector and provide separate rationales for resistance to being fully accountable to all their stakeholders (Kieran, 1999). There exist myths about the sincerity of performance amongst the implementers. The NGOs have the myth of good intentions: 'we mean well'. The Government and Statutory agencies, similarly have the myth of competence: 'we know best'. Mayo called the myth of good

intentions of voluntary organizations as the 'fantasy of improvement' (Mayo, 1996). This myth holds on the fact that good intentions always leads to good actions and good results because it is presumed that those who mean well do well in reality. This feeling has to be shed away and a proper and critical evaluation of performance may be initiated and corrective measures, if needed be taken. The development of appropriate indicators to measure performance is also equally important. Evaluation of Disability Policy with all its dimensions including the actual and desired role of the various Ministries/Departments of the Central Government, State Governments and Local Administrations, scope of change of policy elements, change in implementational approaches etc. will help streamline the policy as well as implementation perspectives. Regular internal evaluations interspersed with unbiased external evaluations together with analysis of qualitative and quantitative data will improve the policy performance manifold. Formative evaluation (which influences the intervention as it is occurring) will be more relevant in this case than summative evaluation (which takes place when the intervention is completed) as rehabilitation governance is mostly an ongoing process.

(iv) Developing Electronic Governance for Disabled Persons (E-GOD) in India

The present performance monitoring system is ridden with the weaknesses such as disorganized information system, often duplicated with multiple channels and redundancies, repetitive flow of information, time lag, limited use of electronic-mailing, discrepancies in information and above all, a proper MIS. It is proposed that E-Governance for Disabled Persons (may be called as E_GOD, hereafter) can immensely benefit this marginalized section of the society. It will also improve accountability, efficiency and effectiveness of the delivery system. The commitments of Disability Act are many but the delivery system is not as efficient and as adequate so as to ensure equal opportunities and full participation of persons with disabilities in the mainstream activities of the society in a speedy manner. The aims of Electronic Governance for disabled persons can be formulated to include the following:

- Increasing efficiency and effectiveness of government delivery systems.
- Improving transparency and monitoring of disability welfare activity.
- Increased public interfaces such as Government - Disabled interface, Government - NGOs interface, Central Government - State Government interface, etc.
- Dissemination of complete information on all aspects of prevention, early detection, availability of rehabilitation services, aids & appliances, government schemes and concessions, R&D in the field of disability, etc.
- The thrust should remain in covering remote rural areas and poor - disabled persons.
- Special consideration/information for severely disabled i.e. disability with greater than 80% needs to be built into system.

- Electronic Governance to be developed for persons with disabilities to have SMARTER features such as decentralization and empowerment of people at the grassroots, an equitable honest system which can be easily tracked, an accessible responsive and transparent system with efficiency and features that can be strategically reengineered in view of the dynamic information society.

The Government needs to get into the information stage after creating an MIS for following up its own activities. At the first stage, a static website may be created engulfing all the organisations of the Central Government, with expansion of networking up to District level. Information (G2C) through internet presence is the District Centres/ Institutes regarding various aspects including general information on disability, disability statistics, prevention, early detection, availability of specialized rehabilitation services, NGOs/Health Organization working in the field along with their specialties, availability of aids and appliances, availability of aids and appliances and their cost inside and outside the country, recent applied research going on in the field and likely benefits, educational facilities (schools/colleges/higher education in the field of disability ,Central/State Government Concessions for disabled persons, details of Acts such as Persons with Disabilities Act, 1995, National Trust Act, 1999, RCI Act, 1992, List of identified posts for persons with disabilities (persons with disabilities), Guidelines for evolution of disability, details of services available in all government/private institutions etc.

The data base on the internet website can be made a dynamic one with wide data base connectivity. Interaction levels of the E-GOD may involve a complex two way system encompassing all actors/stakeholders i.e. Central Government, State government, Local Administration (District Level), Civil Society, National Institutes, DDRCs/DDRCs/RRTCs/RSICs/CRCs, ALIMCO, NHFDC, National Trust, o/o CCD, RCI and the persons with disabilities. The interactive dynamic website models can help serving the following purpose:

- Interactive knowledge data bases can be created and accessed amongst all the service providing Government Institutions, all major NGOs working in the Disability Sector and the Ministry (G2G).
- Complaints and suggestions of NGOs can be handled by the Ministry or through the Specialized National Institutions. (G2G).
- Disabled persons should be able to download various forms from this interaction based website including on-line help for filling forms such as Income-Tax returns, issue of disability certificate, application for special scholarships and concessions granted to the disabled (G2C).
- Consultation/Referral services can be provided by the National Institutes through this website to the Disabled persons
- Suo-moto information on special services initiated by the Government, concessions granted that involves a feedback from eligible disabled persons, can be provided (G2C).

(v) Contextual Challenges

Five major dimensions of the policy-context in India, which appear crucial to defining the parameters of expectation regarding public policy as well as its actual effects, deserve to be discussed in this context. These pertain to extreme resource disparities, uneven representation in governance, knowledge -power network, discursive context and institutional relations (Dolly, 2002). In the context of Disability Policy these challenges are reflected in the phenomena such as higher incidence and prevalence of disability amongst the rural poor, inextricable poverty and disability links, skewed representation of the urban-centric disabled persons and grant receiving organisations in the policy/decision making bodies of the Government, discursive impact of international developments for a rights based paradigm and above all, the complexities of coordinated activities amongst the seemingly water-tight Ministries/ Departments of the Centre, State Governments and local bodies for ensuring speedy and effective implementation of the Disability Policy. All these complex challenges are to be recognized with all seriousness and suitably addressed.

(vi) Sensitization of Implementers

Rigorous training and orientation needs to be imparted to the rehabilitation staff at the grassroots about the real policy objectives and the final goal they aim to achieve. The NGOs need to have a broader perspective about their goal and role. All the bureaucrats directly or indirectly involved in welfare of the disabled, be it education, employment, economic upliftment or rehabilitation, need to get the big picture and the vision and mission of the policy.

(vii) Disability Certificates

Issue of Disability Certificates needs to be attended to on priority basis by appropriate Governments with special emphasis on persons staying in remote and rural areas.

(viii) Rehabilitation Services

There exists a substantial gender bias in terms of persons who access the Government institutional rehabilitation services as male representation was observed to be uniformly dominant at about 71% amongst poor as well as non-poor respondents. Females constitute only 27% of persons who received aids and appliances from the Government. There is a dire need for expanding outreach services for the poor persons in rural areas by the Government. Besides, female population needs to be targeted through an effective, if necessary, special intervention strategy.

(ix) Integrated Approach

Poverty and disability are closely inter-woven and therefore there is a need for an integrated approach to handle the same. Besides making the disabled get the minimum three per cent benefit of all the rural development programmes

which is statutory, the poverty line criteria for the disabled-poor needs to be specially looked into in depth and prima-facie, increased to cover this doubly economically and socially disadvantaged group and provide them access to the poverty amelioration programmes.

(x) Safety Norms

The study reveals that accident was the most common reason for acquiring disability followed by lack of treatment which makes a case for stringent measures to reduce traffic related accidents, strengthening and providing more number of trauma centres, and strict adherence of safety norms in hazardous jobs.

(xi) Awareness Generation & Information Dissemination

Ignorance about the cause of disability since birth was observed in majority cases under the study conducted by the author. Information dissemination and generation of awareness about prevention and early detection of disability, especially in rural areas needs to be taken up in a mass scale. Integrating efforts of all related wings of the Central, State, Local as also NGOs will yield better results. Early detection, early intervention and education about the causes of disability should be taken up in a mass scale with the help the grass-root level functionaries.

(xii) Training & Employment

Vocational training taken up for persons with disabilities are mostly in traditional areas and does not lead to a sustainable employment strategy, with advent of ICT, non-traditional areas including those involving use of computers should be encouraged. Employment opportunities in the Government and private sector need to be expanded. The revised list of identified posts for persons with disabilities taken out by the Government less than three years ago needs to be earmarked as the starting point and more jobs can be identified and added with advancement of technology. Reservation provisions on employment needs stricter monitoring. Self employment through concessional loans from NHFDC and its channelizing agencies need to be promoted effectively.

(xiii) Poverty Alleviation Programmes

There exists a strong linkage between poverty and disability. Therefore, poverty alleviation programmes for capacity-building, social security and sustainable livelihood programmes etc. need to be taken up effectively in an integrated manner so as to ameliorate the conditions of persons who are poor as well as disabled.

(xiv) Research

Research in the field of disability is quite limited. Functional research need to be expanded. Academic research leading to better planning and policy needs to be encouraged and supported.

Conclusion

This chapter has clearly brought out the strong linkages between poverty and disability. The study undertaken by the author also corroborates the same. The three per cent reservation provisions in jobs, in education and in all poverty alleviation schemes are to be implemented in right earnest to ameliorate the conditions of the poor physically and mentally challenged population. Private sector initiatives in organized sector coupled with effective delivery system for making the concessional facilities available to the poor and disabled persons will help breaking the vicious cycle of poverty and disability. Increasing the poverty line criteria for the disabled persons also needs consideration by the planners. Problem of mobility and physical barriers are the road-blocks for the disabled in accessing facilities, accessing people and accessing information. Mitigating the problem requires resources and attention. Equally important is the social exclusion and discrimination that a disabled person faces in life which makes it miserable for him to live in society, not to talk of getting equal opportunity and full participation in mainstream activities which is far from real, even today. The study, based on perceptual responses, corroborates the general feeling that majority of disabled feel socially excluded and discriminated. The attitudinal barriers are therefore, the real barriers that need to be crossed over in the first place. Higher inflow of resources to the sector to the schemes and programmes run in the social welfare sector as also through the tenth plan committed component plan approach coupled with capacity building of NGOs for working in the remote rural areas are required to be ensured in order to materialize the commitment of an inclusive, barrier-free and rights-based society.

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Part Two

AGENDA FOR

FUTURE

Chapter 3

Biwako Millennium Framework for Action - A Guide for Future

L. Govinda Rao

Paradigm shift in the rehabilitation of the persons with disability is imperative, which is founded on the rights based and empowerment approach. This chapter draws a comprehensive road map touching each target point of Biwako Millennium Framework for Action (2003-2012). The author believe that there is greater need for convergence of actions by various developmental agencies in the country and the Government need to inject support led programmes while inspiring the community to come up with growth mediated initiatives. He stresses that existing programmes and schemes of all the Ministries of Union and State Governments should extend to the persons with disabilities as a special component as envisaged in the Tenth Five Year Plan document.

Introduction

Disability is embedded as another variation in God's creation of mankind itself. Kofi Annan, U.N. Secretary General has aptly stated that we must remember disabilities are another manifestation of human diversity. Finklestein (1980) has divided the history of disability into three distinct and sequential phases. The period before the European industrial revolution was termed as first phase which was characterized by agrarian feudalism and some cottage industries. During this period, there was scant social mobility and the mode of production did not exclude disabled people from active participation in their local communities. The second phase was associated with the industrial revolution and immediate aftermath, when disabled people were effectively excluded from being engaged in paid employment. This was due to the fact that they were not able to maintain the pace set by the factory system. As a consequence, disabled people were separated and socially excluded from mainstream social and economic activity. Finklestein maintains that during the third phase, which relates to the current period, disabled people will witness and experience their liberation from social oppression (Lang, 2000), which is rights based and empowerment oriented.

Paradigm Shift - A Rights Based and Empowerment Approach

Success of the rehabilitation programmes largely depends on the quality of life of the persons with disabilities. In accordance with the International Association for the Scientific Study of Intellectual Disabilities (IASSID) (Schalock et.al. 2003), the conceptualization principles of the quality of life are as under:

- It is composed of those same factors and relationships for people with intellectual disabilities that are important to those without disabilities.
- It is composed of a person's needs and wants are met and when one has the opportunity to pursue life enrichment in major life settings.
- It is composed of both subjective and objective components; but it is primarily the perception of the individual that reflects the quality of life he/she experiences.
- It is composed of individual needs, choices and control.
- It is composed multidimensional construct influenced by personal and environmental factors such as intimate relationships, family life, friendships, work, neighborhood, city or town of residence, housing, education, health, standard of living, and the state of one's nation.

Historically, being an agrarian country, India is endowed with a large population living in rural area. Indian villages are traditionally known for their culture of community living. Persons with disabilities were treated as equals and part of the community and they are eventually included. They were provided due care and rehabilitation services through the institution of family and village. Indeed, many of the mild and moderate ones used to get mingled and had the social acceptance in the mainstream. The institution of family used to be a major strength in the care of the persons with severe and profound disability in the rural India, which is seen to be wanting now. Rehabilitation services for the persons with disability in an organized manner started as a movement after Independence, particularly with the influence of urbanization and industrialization. In the subsequent times many developmental programmes have been launched in which both the government and non-government organizations have worked together to create facilities for the rehabilitation services for the persons with disabilities. Gradually, a paradigm shift (Rao, 2002) is taking place.

Figure 3.1. Typology of Paradigm Shift (Rao 2002)

Area	Traditional Approach	Contemporary Approach
Philosophy	Charity	Rights
Model	Medical	Socio-Medical and holistic
Goal	Transaction i.e. pain-relief or providing assistive device	Transformation on life-cycle basis
Responsibility of Environment and Society	Not owned	Owned as the handicap situation is felt as the creation of environment and society
Values	Maintenance of the disabled is adequate	Empowering is the ultimate goal of the disability rehabilitation
Attitude	Burden on the society are not employable	Part of the society and employable
People working in NGOs	Voluntary minded	Career minded
Process involved	Adhocism	Professionalism

International Scenario

Systematic efforts have started only after the International Year of Disabled Persons (IYDP) in 1981 although in the last quarter of 19th Century there were voluntary organizations working in areas of education, training and rehabilitation of the disabled. Government of India is a signatory to various UN resolutions concerning the disabled persons. The UN resolution 37/52 of 3rd December, 1982 is a very significant UN instrument, aimed at achieving full participation and equality and protection of rights of persons with disabilities, which followed the International Year of Disabled Persons in 1981. Subsequently, the Asian and Pacific Decade of Disabled Persons (1993-2002) was observed immediately after the UN Decade of Disabled Persons (1983-1992). The Asia and Pacific Decade has focused on twelve policy areas viz., national coordination, legislation, information, public awareness, accessibility and communication, education, training, employment, prevention of causes of disability, rehabilitation services, assistive devices, self-help organizations and regional cooperation.

Recently, the Biwako Millennium Framework for Action towards an inclusive, barrier-free and rights-based society for persons with disabilities in Asia and the Pacific was adopted in the 58th session for Resolution 58/4 on 22nd May, 2002 in Japan. The resolution proclaimed extension of the Asian and Pacific Decade of Disabled Persons 1993-2002, for another decade, 2003-2012.

Constitutional Provisions

Not only being the signatory to the UN resolution, but being aware of its constitutional obligations, Government of India has introduced various programmes and schemes for the welfare of the persons with disabilities. The Constitution of India itself affords protection to the rights of persons with disabilities through Articles 15 and 41. Under the Constitution the disabled persons have been guaranteed the Fundamental Rights as available to other citizens of the country viz., equality of opportunity, no discrimination, no untouchability, no traffic in human beings, provision of employment of children, freedom of religion, right to the language, script or culture, right to franchise, right to property, right to enforce fundamental rights, access to education in any educational institution, right to work.

The State has also the obligation to apply the Directive Principles of State Policy of securing a social order in promotion of the welfare of the people. The State Policy has to be directed to minimize inequalities, secure right to an adequate means of livelihood and also secure that the operation of legal system promotes justice. The State shall secure that free legal aid is provided to ensure that opportunities for securing justice are not denied to any citizen by reason of economic or other disabilities. The State shall make provisions for ensuring the right to work to education and public assistance in false of unemployment, old age, sickness and disablement and in other cases of underserved want. The State shall endeavour to provide for free and compulsory education for all children until they complete the age of 14 years. The State also has the responsibility of promoting with special care the educational and economic interests of the weaker sections of the people.

Government Initiatives

The initiatives of the Government can be summarized as under:

- National Institutes in various areas of the disabilities, National Handicapped Finance Development Corporation, Composite Regional Centers, Regional Rehabilitation Centres for Persons with Spinal Injuries, ALIMCO, District Disability Rehabilitation Centres and work towards capacity building in the area of disability rehabilitation apart from ensuring delivery of services to the persons with disabilities.
- Creating infrastructure for capacity building in terms of human resource development, rehabilitation services model development, research and development, promotion of NGO's for direct delivery of services, providing technical assistance, etc.
- Support for scientifically manufactured aids and appliances, under Science and Technology Mission Mode.
- Providing Education through Integrated Education of the Disabled (IED) and Sarva Siksha Abhiyan (SSA).
- Developing programmes for providing aids and appliances, benefits and concessions directly to the persons with disabilities, developing programmes

for extending financial assistance to the NGOs to promote rehabilitation services for the persons with disabilities.

- Bringing out legislations to ensure rights based society for the persons with disabilities, quality and standards in the Human Resource Development Programmes, delivery of services and reaching the services for the persons with disabilities. Provision for empowerment for independent living is covered in three i.e. Rehabilitation Council of India Act, (1992), Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, National Trust for Welfare of Persons with Autism, Cerebral palsy, Mental Retardation and Multiple Disabilities Act, 1999. The office of the Chief Commissioner for Persons with Disabilities (1998) and the National Commission for Persons with Disabilities (2003) has been set up.

These initiatives of Government of India are called support-led strategies for creating a base for the development and growth of rehabilitation services, which will be discussed in subsequent chapters.

Role of NGOs

The growth-mediated strategies are usually seen in the formation of voluntary organizations engaged in the disability rehabilitation programmes. These voluntary organizations are also called Non-Government Organizations. The World Bank defines NGOs as "private organizations that pursue activities to relieve suffering, promote the interests of the poor, protect the environment, provide basic social services, or undertake community development". Green and Mathias (1997) defined NGOs as "Organizations that are formally constituted, with a primarily non-profit-seeking objective of a group or community wider than the direct membership of the organization and with a decision-making authority independent of government. They may achieve their aims in a variety of ways ranging from direct service provision through to the support of other NGOs". Korten (1990) classifies NGOs into a wide variety of organizations. They include: (1) Voluntary organizations that pursue a social mission driven by a commitment to shared values; (2) Public Service contractors that function as market oriented non-profit business serving public purposes; (3) People's organizations that represent their members' interests, have member accountable leadership, and are substantially self-reliant; and (4) Governmental-nongovernmental organizations that are creations of government and serve as instruments of government policy. Non-government organizations are an essential part of the change and development in the society in many countries. The scale and diversity of NGOs is remarkably varied and some chief characteristics are:

- Promotion of non-profit seeking objectives of specified groups.
- Focus on programmes and activities aimed at providing relief and empowerment to the disabled and disadvantaged.
- Organize activities that are generally aimed at relieving the suffering and promote the interests of the poor.
- Organize and execute community development programmes in select functional areas and having membership beyond regional confines.

- Enjoy operational freedom in decision-making process free from the clincher of government control.
- Self-reliant with regard to resources for pursuing social programmes.
- Exhibit high degree of commitment for organizing social service involving the community.

The UNESCAP/UNDP (1991) document on NGOs clarifies four ways in which the government might make use of NGOs in any country:

- NGOs may substitute for the government in the formal delivery of specific services.
- NGOs may supplement the service delivery role of the government, either through delivering certain services for which government structures are not suited or by delivering the same types of services as the government but to population sectors to which the government structures find it difficult to reach.
- NGOs may engage in community development work that is often essential for ensuring that normal service delivery achieves its objectives.
- NGOs can assist in ensuring that statutory development reflects grassroots realities by contributing their experience directly to the planning process, acting as a pressure on the government to be responsive and facilitating the people's own access to all stages in the planning and delivery of services.

Robinson (1992) described the following factors for the success of NGOs.

- Beneficiary participation in planning design and implementation of projects (the objectives should correspond with the priorities of the poor and the beneficiaries regularly consulted).
- Strong and competent leadership, skilled management and overall vision of the project goals (leaders were able to maintain communication with the government, circumvent problems and mobilize resources; excessive, centralised decision-making undermined staff commitment).
- Staff commitment and their empathy with intended beneficiaries (well-trained and educated staff motivated by a reasonable level of remuneration and decent working conditions).

NGOs have the capacity to substitute the government efforts in the formal delivery of specific services. As they are locally based and provide scope for beneficiary participation, their commitment and empathy to the services is beyond doubt in majority of the cases. The NGO programmes are less expensive without bureaucratic hassles and with direct action in the field. Although NGOs movement in India has increased manifold, there is inadequacy in the capacities available in terms of number of organizations in various fields of social development and regions when compared with the countries abroad, particularly in the field of disability rehabilitation. As observed by Kalam and Rajan (1998):

- "Many NGOs and youth organizations can be fruitfully utilized to fulfill major life-saving missions.
- There are many NGOs and a number of local initiatives that work well.

- In order to realize the potential of NGOs and its usefulness HRD cannot remain an exclusive domain of the corporate sector, but be a participating process of the NGO sector”.

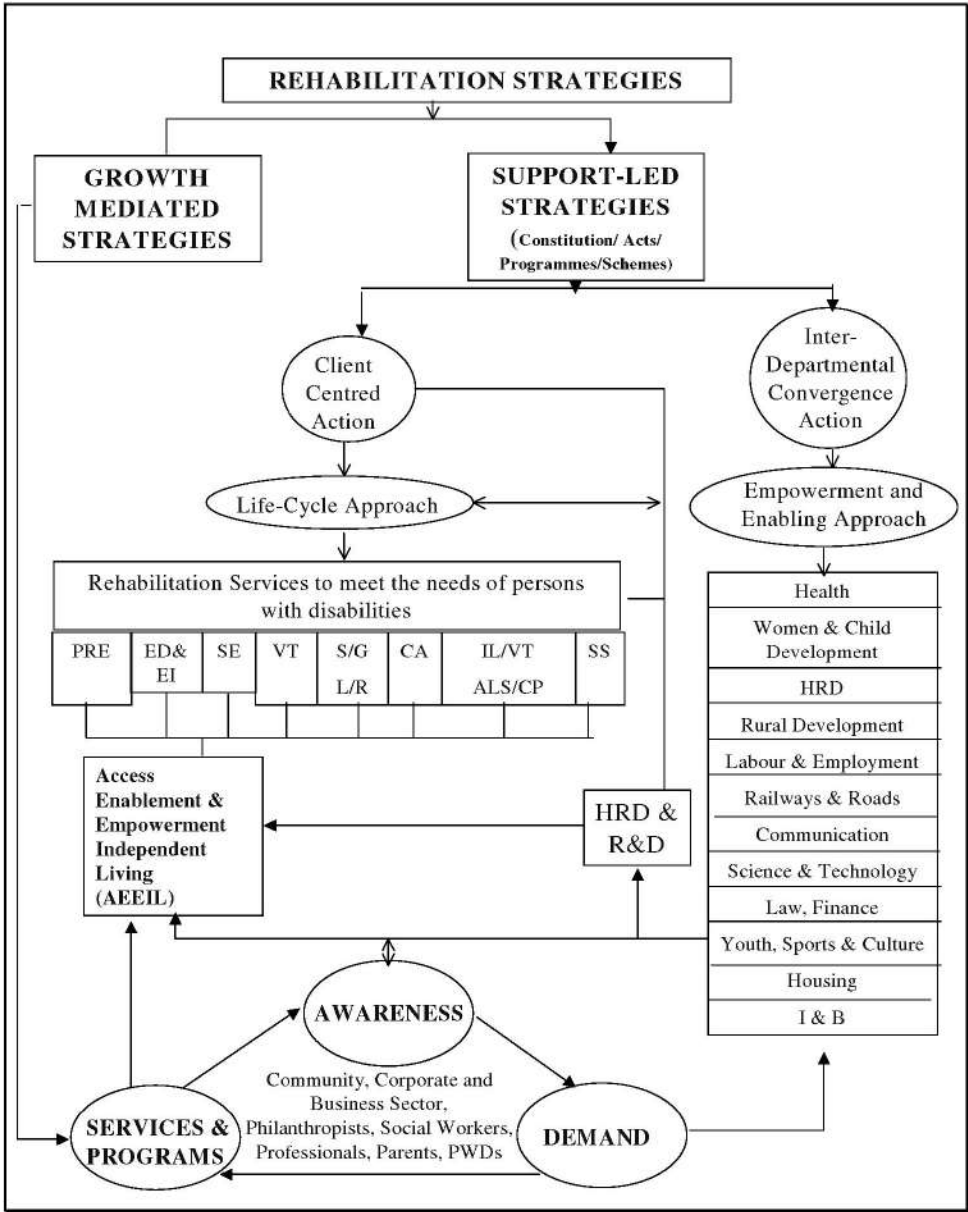
Convergence of Rehabilitation Strategies - A Model

As per NSSO 58th round, the number of disabled persons estimated is 18.53 million forming 1.8percent of the total population. In a developing country like India, the support-led strategies from all developmental departments are essential to ensure enabling conditions and empowerment of the persons with mental retardation and their families, for which the government initiatives in various areas of the life-cycle needs are to be increased further. The support led strategies will also help in inducing growth-mediated strategies, which in any case related to the economic health of the country. Government’s role in taking the advantage of the economic growth and social development needs no emphasis.

Convergence between the support-led and growth-mediated strategies will be successful only when in-house convergence among the various Ministries of the Government of India and the Departments of State Government takes place. Based on the approach to convergence, endeavours should be made to bring in fusion in the support led strategies and growth mediated strategies, for which there is a need for a planned effort to develop programmes interfacing the Government and community. Similarly there is a need to develop action plans right from District level to State and Central level for convergence of various schemes and programmes in vogue in the country including community initiatives.

In addition to the specific programmes and schemes in vogue, the programmes meant for Scheduled Castes, Scheduled Tribes, Backward Classes, Minorities, and persons benefited under Social Defence programmes being implemented by the Ministry of Social Justice and Empowerment should definitely cover the persons with disabilities. Similarly, the programmes under various Ministries viz., Health, Human Resource Development, Women and Child Development, Labour and Employment, Rural Development, Urban Development, Information and Broadcasting and Information Technology should strive to focus on extending the benefits of the persons with disabilities through their respective schemes. The list of the existing Government of India schemes and programmes of various Ministries is given in Appendix-1.

Figure-3.2: Graphical presentation of Rehabilitation Strategies (Rao, 2003)



PRE - Prevention, ED and EI - Early Detection and Early Intervention, SE - Special Education, V/T - Vocational/Training, S/G - Sports/Games, L/R- Leisure and Recreation, CA - Cultural Activities, IL - Independent Living, ALS-Adult Living Skills, CP-Community Preparation, SS - Social Security

Source: Rao, L.G. (2003) Rehabilitation Strategies – An Approach to Convergence – Karavalamban Vol.16, Issue-1, June 2003

Based on the above concept, the systematic framework of the strategies to be adopted for India is shown below.

Fig. 3.3 - Support-led Strategies

Area	Support led strategies	
	Concentrated action	Convergence action
Awareness	<ul style="list-style-type: none"> • Constitution • Legislation • National bodies • Sensitization and orientation of state government and central government organizations, community workers and public. 	Various Departments - <ul style="list-style-type: none"> • Health and Medical • Women and Child Development • Education • Labour • Labour • Rural and Urban Development • Science and Technology • Culture and Youth • Information and Broadcasting
Needs	<ul style="list-style-type: none"> • Prevention • Early detection and intervention • Special education • Vocational and employment • Sports and games • Cultural activities • Social security 	<ul style="list-style-type: none"> • Sensitization • Orientation • Identification of needs of persons with disabilities in respective sector • Working out programmes relating to the persons with mental retardation
Programmes and Process	<ul style="list-style-type: none"> • Service models • HRD - long term courses in various areas, short term courses, fellowships, certificate courses, development of textbooks, models, publicity materials. • RandD - development of models, early intervention packages, educational material, assistive devices, adaptive materials, vocational models. 	<ul style="list-style-type: none"> • Early detection and early intervention for health people • Inclusion and integration in education • Providing vocational training in ITIs • Including disability rehabilitation as a course in all higher professional programmes • Providing training to the employers • Development accessible work environment and removing the psychological barriers • Developing the rural programmes • Development of jobs in the rural area - agricultural and allied fields • Developing jobs in urban areas • Providing housing in the rural and urban areas • Share in the scientific and technological field towards development of educational materials, assistive materials • Adaptation and restructuring of the work environment • Orientation and augmentative devices for independent living of the persons with mental retardation

		<ul style="list-style-type: none"> • Promoting cultural and sports and games for the persons with mental retardation • Creating public awareness and preparing the community for a rights based society • Fast track treatment to the families with disabilities. • Adaptation and restructuring of the work environment • Orientation and augmentative devices for independent living of the persons with mental retardation • Promoting cultural and sports and games for the persons with mental retardation • Creating public awareness and preparing the community for a rights based society • Fast track treatment to the families with disabilities.
Outcome	<ul style="list-style-type: none"> • Access • Empowerment • Enablement • Independent Living • (AEEIL) 	<ul style="list-style-type: none"> • Access • Empowerment • Enablement • Independent Living • (AEEIL)

Fig. 3.4 - Growth mediated Strategies

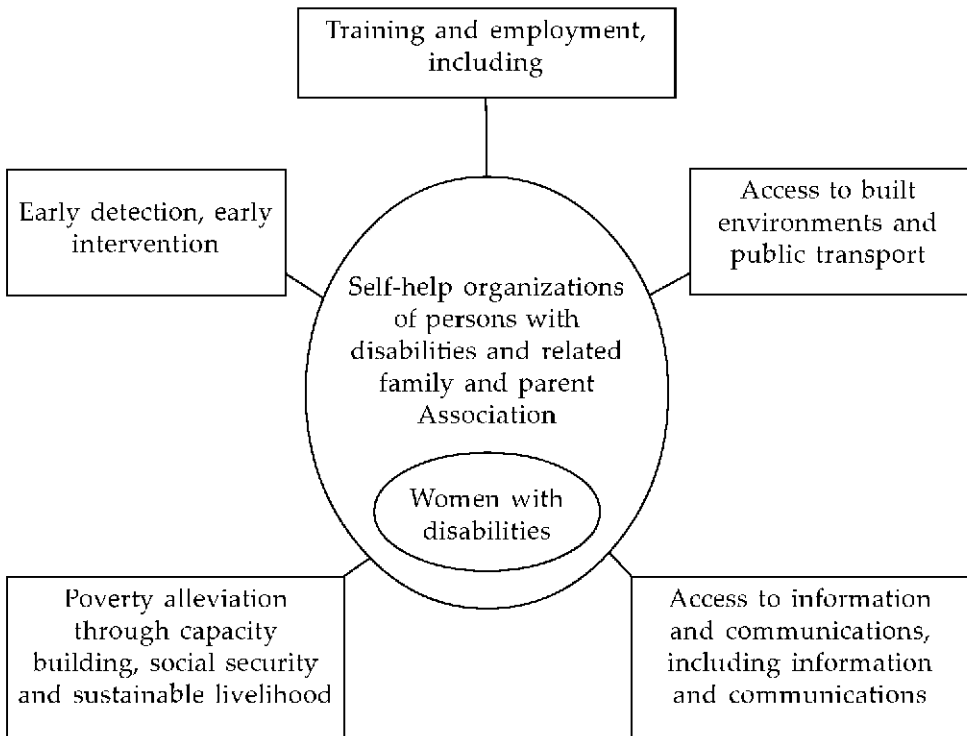
Players	Awareness	Programmes	Outcome
<ul style="list-style-type: none"> • Corporate sector • Philanthropists • Social workers • NGOs • Community 	<ul style="list-style-type: none"> • Educating the corporate people, social workers • Community 	<ul style="list-style-type: none"> • Educating the IIRD people and corporate CEOs • Sponsorships in the cultural and sports activities for the persons with mental retardation, for example Abylimpics, dance and music and sports and games • Adaptation of specific disability services Social security measures for the employees having children with disabilities Facilitation by government in providing rent, electricity, tax exemptions Recognition and incentive for the people involved in rehabilitation in addition to the present National Awards 	<ul style="list-style-type: none"> • With the greater participation of community, the persons with mental retardation will be further benefited in the empowerment process

Over three-fourth of the population lives in rural area, which includes the persons with disabilities. Therefore, the people with disabilities are naturally in the community itself. Many persons with mild and moderate mental retardation are in the social milieu. The educational and rehabilitation programmes can become successful when the regular departments engaged in developmental programmes include the disability component compulsorily and obligingly in their programmes as a social mandate. So far in India, the momentum has yet to pick up, which however, is visible in the education sector. These programmes have to be properly planned in consultation with the people and departments concerned including the persons with disabilities. Despite the need for inclusion, efforts of 85 percent of the children with disabilities in the regular settings, special settings are still needed for the remaining 15percent of the severe and profound categories. It is a well known theory that persons with disabilities trained in the community based vocational training set up will have more acceptance and more likely to be employed as adults than those who receive vocational training in simulated work settings. Disability is the product of not merely of the individual's limitations but also the barriers of built environment, viz., physical, social, cultural, political and psychological. The vicious triad of poverty, disability and illiteracy has colossal impact on the population living in rural area and urban slums. Exclusion from education has a cascading and consequential exclusion effect in all aspects of individuals life viz., lack of opportunities for further personal development, diminishing access to vocational training, employment, income generation and business development. Disability limits active participation in their families. They are liable for economic and social dependence. Their vulnerability becomes a cause for self-perpetuating and inter generational cycle affecting the lives of the persons with disabilities and their families. When education is denied the lives become hopeless and powerless.

*Biwako Millennium Framework for Action - Inclusive,
Barrier Free and Rights Based Society.*

The World Summit for Social Development held at Copenhagen in March 1995 in its Copenhagen Declaration on Social Development noted that people with disabilities, as one of the world's largest minorities, are often forced into poverty, unemployment and social isolation. At the regional review meeting in 1995, the commission adopted 107 specific targets in 12 policy areas of Asian and Pacific Decade of Disabled Persons - 1993-2002, which was further, strengthened in 1999 and endorsed by the Commission at its 56th session in 2000. The Asian Pacific Decade of Disabled Persons was extended for another decade, 2003-2012 in order to promote an inclusion, barrier free and rights based society for people with disabilities in the Asian and Pacific region in the 21st Century. It is now popularly known as Biwako Millennium Framework for Action (BMFA). It has 7 priority areas for action, 21 targets and 62 actions.

Fig. 3.5 -Graphic presentation of the priority areas of Biwako Millennium Framework for Action



For each priority area, the following have been identified: (a) critical issues, (b) millennium development goals, where applicable, (c) targets of the Biwako Framework and (d) action required to achieve those targets

Four of the priority areas concern with direct empowerment to the persons with disabilities while the remaining three addresses the issues related to enabling conditions. Together these actions would certainly realize the goals of inclusive, barrier free and rights based society for persons with disabilities for which the targets set in Biwako Millennium Framework for Action are as under:

Self-help organizations of persons with disabilities and related family and parent associations:

Target 1. Governments, international funding agencies and non-governmental organizations (NGOs) should, by 2004, establish policies with the requisite resource allocations to support the development and formation of self-help organizations of persons with disabilities in all areas, and with a specific focus on slum and rural dwellers. Governments should take steps to ensure the formation of parents associations at local levels by the year 2005 and federate them at the national level by year 2010.

Target 2. Governments and civil society organizations should, by 2005, fully include organizations of persons with disabilities in their decision-making processes involving planning and programme implementation which directly and indirectly affect their lives.

Women with disabilities

Target 3. Governments should, by 2005, ensure anti discrimination measures which safeguard the rights of women with disabilities.

Target 4. National self-help organizations of persons with disabilities should, by 2005, adopt policies to promote the full participation and equal representation of women with disabilities in their activities, including in management, organizational training and advocacy programmes.

Target 5. Women with disabilities should, by 2005, be included in the membership of national mainstream women' associations.

Early detection, early intervention and education

Target 6. Children and youth with disabilities will be an integral part of the population targeted by the millennium development goal of enduring that by 2015 all boys and girls will complete a full course of primary schooling.

Target 7. At least 75 per cent of children and youth with disabilities of school age will, by 2010, be able to complete a full course of primary schooling.

Target 8. By 2012, all infants and young children (birth to four years old) will have access to and receive community based early intervention services, which ensure survival, with support and training for their families.

Target 9. Governments should ensure detection of childhood disabilities at a very early age.

Training and employment, including self-employment

Target 10. At least 30 per cent of the signatories (member States) will ratify the Vocational Rehabilitation and Employment (Disabled Persons) Convention, 1983, by 2012.

Target 11. By 2012, at least 30 per cent of all vocational training programmes in signatory countries will be inclusive of persons with disabilities and provide appropriate support and job placement for business development services for them.

Target 12. By 2010, reliable data that measure the employment and self-employment rates of persons with disabilities will exist in all countries.

Access to built environments and public transport

Target 13. Governments should adopt and enforce accessibility standards for planning of public facilities, infrastructure and transport, including those in rural/agricultural contexts.

Target 14. All new and renovated public transport systems, including road, water, light and heavy mass railway and air transport systems, should be made fully accessible by persons with disabilities and older persons; existing land, water and air public transport systems (vehicles, stops and terminals) should be made accessible and usable as soon as practicable.

Target 15. All international and regional funding agencies for infrastructure development should include universal and inclusive design concepts in their loan/grand award criteria.

Access to information and communications, including information, communication and assistive technologies

Target 16. By 2005, persons with disabilities should have at least the same rate of access to the Internet and related services as the rest of citizens in a country of the region.

Target 17. International organizations (e.g. International Telecommunication Union, International Organization for Standardization, World Trade Organization World Wide Web Consortium, Motion Picture Engineering Group) responsible for international ICT standards should, by 2004, incorporate accessibility standards for persons with disabilities in their international ICT standards.

Target 18. Governments should adopt, by 2005, ICT accessibility guidelines for persons with disabilities in their national ICT policies and specifically include persons with disabilities as their target beneficiary group with appropriate measures.

Target 19. Governments should develop and coordinate a standardized sign language, finger Braille (tactile sign language), in each country and to disseminate and teach the results through all means, i.e. publications, CD-ROMs, etc.

Target 20. Governments should establish a system in each country to train and dispatch sign language interpreters, Braille transcribers, finger Braille interpreters, and human readers and have them employment.

Poverty alleviation through capacity building, social security and sustainable livelihood programmes

Target 21. Governments should halve, between 1990 and 2015, the proportion of persons with disabilities whose income/consumption is less than one dollar a day.

A Guide for Future Action

A National Consultation Meeting has been organized by the Ministry of Social Justice and Empowerment, Government of India at New Delhi on 9th and 10th October, 2003 in which recommendations for various areas of action have been made for consideration of the Government of India. Based on the model of convergence for rehabilitation strategies and strengths of Government of India programmes and schemes, a guide is formulated for future action, which can be

developed into viable schemes and programmes. These supported programmes are expected to cover the targets given in Biwako Millennium Framework for Action.

Self-help organizations of persons with disabilities and related family and parent associations:

- Schemes to promote self-help groups.
- Preference to self-help groups under Deen Dayal Rehabilitation Scheme
- Some DDRCs to be given to self-help groups.
- Training on capacity building to the self-help group leaders.
- Development of master trainers for capacity building of self-help groups.
- Fast track treatment to the persons with disabilities and families in Government schemes.
- Promoting partnership between persons with disabilities and NGOs.
- Guidance and counselling to persons with disabilities and their families.

Women with disabilities

- Literacy level of women is 50percent as against 73percent of males. Women literacy to be promoted.
- Only 37percent of the women with disabilities avail services. Special interventions needed.
- Measures to enhance enrolment of women with disabilities in special schools and in Sarva Shiksha Abhiyan.
- Inclusion of disability component in gender related education.
- Gender-just representation of the disabled in all fora including Government machinery.
- Educate women organizations to associate women with disabilities in their programmes.
- DWACRA groups to cover women with disabilities.
- Orientation programmes to all public services on women with disabilities and their needs.
- Enactment and implementation of proper laws to protect rights of women with disabilities.
- Support machinery for legal remedies for women with disabilities.
- Concessions and tax benefits for women with disabilities.

Early detection, Early intervention and education

- All the 20,000 and odd Primary Health Centres and 1,37,000 and odd sub-centres need to be strengthened with early intervention services.
- Inclusion of disability rehabilitation in the degree programmes of nursing and medical sciences.

- Master trainers to be developed to train 5 lakh physicians and 10 lakh nursing staff in the country.
- To begin with, at least weekly or fortnightly early intervention services to be provided at PHCs and Sub-centres.
- Promotion of admission of children with mild and moderate levels in 41,738 pre-primary schools.
- Training of pre-school staff.
- Promoting Sarva Siksha Abhiyan covering 6,10,763 primary schools.
- Promoting admission of students with disabilities in 1,85,506 secondary schools.
- 100percent utilization of the capacities of the special schools in the country - studies indicated 25percent shortfall in the utilization.
- Inclusion of special education as a compulsory subject both theory and practical in all the teacher training courses.
- One master trainer to be posted in each DIET with Masters in Disability studies.
- Strengthening teacher training on special education.
- Increase in the intake of Master's Degree Courses.

Training and employment, including self-employment

- Engineering the shift from traditional to non-traditional items for the vocational training.
- Develop models to fit in the rural set.
- Introduce vocational training to the adults with disabilities in all the 6,560 technical institutes in the country.
- DRDA and CAPART to promote vocational training for the persons with disabilities in the rural area.
- Orient the corporate sector for employment of the persons with disabilities.
- Licenced job coaches to be created for extending technical guidance and facilitation of the employment of persons with disabilities in the factory settings and corporate offices.
- Encourage and promote open employment for persons with disabilities by introducing incentives, tax concessions to the entrepreneurs.
- Promoting HRD and Research and Development programmes.

Access to built environment and public transport

- Removal of psychological and social barriers.
- Orientation programmes for the community through various developmental programmes.
- Orientation to college and high school students on disabilities.

- Inclusion of a subject on disability in the high school curriculum.
- Orientation to the employees of public utility departments on disabilities.
- Comprehensive acts and other labour laws to extend the benefits to the persons with disabilities on priority basis.
- Inclusion of barrier features in the plans of new buildings.
- Atleast one of the existing government buildings per year should be made barrier free.
- Modification of recruitment rules to cover the barrier free features.

Access to information and communications, including information, communication and assistive technologies

- Promoting e-rehabilitation services.
- Developing softwares for reading, writing and arithmetic.
- Promoting extensive use of internet with free access to internet facilities.
- Concessional rates for procurement of hardware by persons with disabilities.
- Citizen charters to cover comprehensive facilities to the persons with disabilities.
- Orientation to the media.
- Promotion of IT education to the eligible persons with disabilities.
- Promoting Research and Development in assistive and augmentative devices.
- Ensuring supplying of assistive devices through self-help groups.

Poverty alleviation through capacity-building, social security and sustainable livelihood programmes

- Extensive spread of NHFDC to provide soft loans to the persons with disabilities.
- Impact studies to indicate correlation between supply of assistive devices and the economic inputs.
- Developing capacity building training programmes to cover NGOs and self-help groups.
- Developing community resource centres for extending help to the persons with disabilities in employment guidance and employment generation.
- Developing infrastructural facilities to provide inputs for various rural based commercial activities and extend help in the sale and distribution of the products.
- Developing schemes for compulsory insurance coverage of persons with disabilities and their families.
- Developing rural and agro based livelihood programmes through DRDA/CAPART.
- Extending support through nationalized banks for financial support for livelihood programmes of persons with disabilities.

- Developing monitoring and evaluation programmes in each area.
- Developing quality indicators.
- Inclusion of community in every programmes.

Conclusion

Monitoring and evaluation is an integral part of programme in the disability rehabilitation area. In order to evaluate the performance in the above mentioned priority areas we have to develop outcome indicators. Quality is an essential index of developmental programmes. Numbers and amounts though represent the seriousness and commitment of the programmes, research evidence (Rao, 2002) indicates that money is not the single factor for the success of programmes, which depends on the involvement of the community, the quality of professional inputs and the effective role of parents in the realization of the goals. Certainly these tasks are difficult but not unfathomable to reach the goals. With people's commitment and involvement for a common cause, it is possible for us to achieve inclusive, barrier free and rights based society for persons with disabilities in our country.

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Appendix

Government of India

Schemes and Programmes

Ministry of Social Justice and Empowerment

Disabilities

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

- Preventive and Promotional aspects of rehabilitation of persons with disabilities like education, employment and vocational training, job reservation, research and manpower development, development of barrier-free environment, rehabilitation, unemployment allowance, establishment of homes for persons with severe disability etc.
- Grievance redressal mechanism in relation to deprivation of rights of persons with disabilities and non-implementation of related laws, rules, regulations, executive orders, guidelines etc.
- Being implemented with a multi-sectoral collaborative approach and related ministries/departments of the Central Government, the State Governments and other appropriate authorities.
- Office of Chief Commissioner for Persons with Disabilities
Shall:
 - (a) coordinate the work of the Commissioners;
 - (b) monitor the utilization of funds disbursed by the Central Government
 - (c) take steps to safeguard the rights and facilities made available to persons with disabilities.
 - (d) Submit reports to the Central Government on the implementation of the Act at such intervals as the Government may prescribe.

National Institutes/Apex level Institutions:

National Institute for the Mentally Handicapped (NIMH)

Ali Yuvar Jung National Institute for the Hearing Handicapped (AYJNIHH)

National Institute for the Visually Handicapped (NIVH)

National Institute for the Orthopaedically Handicapped (NIOH)

National Institute for Rehabilitation, Training and Research (NIRTAR)

Pandit Deen Dayal Upadhyaya Institute for the Physically Handicapped (IPH)

The objectives of these institutions are as under:

- Human Resource Development
- Research and Development
- Development of models of services
- Consultancy services to voluntary organizations
- Documentation and Dissemination
- Extension and outreach programmes

National Commission for Persons with Disabilities

- To recommend to the Central Government specific programmes of action towards elimination of inequalities in status, facilities and opportunities for disabled persons so that they are assessed for their abilities despite disabilities and given the right education, vocational training and poverty alleviation packages, employment, and other support services to achieve the goal of psycho-social acceptance and full participation in the social and economic life of the country;
- To review the status and conditions of institutions delivering services in the disability sector and make recommendations; and
- To make annual reports to the Central and State Governments on matters concerning disabled persons, with its recommendations
- To discharge any other work assigned by the Central Government from time to time.

ALIMCO

- To manufacture components and aids and appliances
- To distribute aids and appliances
- To undertake research and development

National Handicapped Finance and Development Corporation (NHFDC)

- To finance self-employment ventures for the persons with disabilities
- To extend loans for pursuing general/professional/technical education at graduate and higher levels for the persons with disabilities.
- To assist upgradation of technical and entrepreneurial skills to enable beneficiaries to manage their production units efficiently.

Rehabilitation Council of India (RCI)

- Statutory body set up under the Rehabilitation Council of India Act, 1992.
- Amended in 2000 to include promotion of research in rehabilitation and special education.
- Responsible for regulating training policies and programs for various categories of professionals in the area of disability.

- Entrusted with the responsibility of maintaining a Central Rehabilitation Register (CRR) for all professionals/personnel and promotes research in rehabilitation and special education.

Composite Regional Centers for persons with Disabilities and Regional Rehabilitation Centers for Persons with Spinal Injuries

- Human Resource Development
- Delivery of Rehabilitation Services
- Research and Development
- Documentation and Dissemination
- Consultancy and network with other organizations.

Indian Spinal Injury Centre (ISIC)

- To provide comprehensive rehabilitation management services to the persons with spinal cord injuries and other neuromuscular skeletal disabling disorders.
- Surgical intervention- reconstructive operations - stabilization operations
- Physical rehabilitation
- Psycho-social rehabilitation
- Vocational rehabilitation Services

National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities

- To enable and empower persons with disability to live as independently and as fully as possible within or close to the community where they belong
- To strengthen facilities to provide support to persons with disabilities to live within their own families
- To extend support to registered organizations to provide need based services during periods of crises in the family of the person with the disability
- To promote measures for the care and protection of these persons in the event of death of their parents or guardians.

District Rehabilitation Centers - 11 DRCs and 4 RRTCs

- To provide comprehensive rehabilitation services to the rural disabled through a camp approach in the villages.
- To provide services for prevention, early detection, medical intervention, surgical correction, fitment of artificial aids and appliances, physiotherapy, occupational speech therapy, vocational therapy, job placement in local industries and rural settings.

National Programme for Rehabilitation of Persons with Disabilities

- A State Sector Scheme
- A four tier structure for service delivery at Gram Panchayat, Block, District and State levels.
- To provide comprehensive rehabilitation services to persons with disabilities, especially those living in rural areas.
- Identification, early detection and intervention at the grassroot level and referral services at District and State level.

Pt. Deen Dayal Upadhyaya Scheme to promote voluntary action for persons with disabilities.

- To provide financial assistance technical and administrative support to promote voluntary action for delivery of various rehabilitation services to persons with disabilities by public institutions and voluntary organizations.
- Financial assistance upto 90percent of the project cost given to such organizations with at least two years in the field. Projects supported are:
 - Vocational training centers
 - Sheltered workshop (for 40-50 beneficiaries)
 - Special schools for the persons with disabilities
 - (a) Special school for the mentally challenged
 - (b) Special school for the hearing and speech impaired
 - (c) Special school for the visually challenged
 - Project for cerebral palsied children
 - Project for preschool and early intervention training
 - Home based rehabilitation programme/Home management programme
 - Project for rehabilitation of leprosy cured persons (LCPs)
 - Project relating to survey identification, awareness and sensitization
 - Project for community based rehabilitation
 - Projects for Human Resource Development
 - Seminars/workshops/rural camps
 - Project for legal literacy, including legal counseling. Legal aid and analysis and evaluation of existing laws.
 - Environment friendly and eco-promotives projects for the handicapped
 - Grant for purchase of vehicle
 - Construction of building
 - Grant for Computer
 - Project for low vision centers
 - Half way home for psycho-social rehabilitation of treated and controlled mentally ill persons

Scheme of Assistance to Disabled Persons for purchase/fitting of Aids and Appliances (ADIP)

- To assist the needy persons with disabilities in procuring durable, sophisticated and scientifically manufactured, standard aids and appliances that can promote their physical, social and psychological rehabilitation by reducing the effects of disabilities and enhancing their economic potential.
- To implement through implementing agencies like voluntary organizations, national institutes under the ministry, ALIMCO, Zilla Panchayats, DRDAs, Red Cross Society, District societies headed by the District Collector, etc.
- To distribute Aids and appliances worth ranges from Rs.50/- and more than Rs.6000/-.
- To cover persons with disabilities in the areas of visual, mental, speech and hearing or multiple disabilities the limit is Rs.8000/- during their study upto 12th Standard.
- 100 percent free - for the beneficiaries having income upto Rs.5000/- per month.
- 50 percent cost is charged for beneficiaries having income between Rs.5000/- and Rs.8000/- per month.

District Disability Rehabilitation Centers - More than 85 Districts have been established out of 130 identified.

The rehabilitation services include;

- Facilitation and provision of disability certificate
- Assessment on the need of assistive devices
- Provision/fitment/followup/repair of assistive devices
- Therapeutical services
- Promotion barrier free environment
- Prevention, early detection and early intervention
- Providing supportive and complimentary services to promote education, vocational training and employment for persons with disabilities.

Barrier Free Access

The concerned Central Ministries/Departments of Urban Development, railways, surface transport, civil aviation, human resource development, labour, rural development, health and family welfare etc. and States/Union Territories are pursued to provide barrier free access to public facilities for the persons with disabilities.

Scheduled Castes

Special Central Assistance (SCA) subsidy out of SCA and loan from National Scheduled Castes Finance and Development Corporation and Banks -

- SC families living BPL from one window viz State SC Development Corporation.
- Projects implemented in Karnataka and Andhra Pradesh.

NSFDC

- SCDC -
- Additional channelizing agencies - State level agencies dealing with specific activities like promotion of handloom, handicrafts, dairying and women's development -
- Micro-credit program geared to form SHGs

National Scheme of Liberation and Rehabilitation of Scavengers and their dependents (NSLRS)

- Provides training and assistance -
- Sanitary marts commercially functioning in AP, Gujarat, Rajasthan and Tamil Nadu.
- National Safai Karamcharis Finance and Development Corporation (NSKFDC)

Scholarship for students -

- Post-Matric scholarship
- Pre-Matric scholarship

Scheme of coaching to Scheduled Caste youth for getting into educational institutions as well as for employment in Group A and B posts.

National Overseas Scholarship Scheme for SC, ST etc. students for higher studies abroad (Master level courses, Ph.D., and Post Doctoral Research Programs abroad in specified fields like engineering, technology and science only.

- Financial Assistance @ US \$ 7700/- per annum or Pounds Sterling 5000/- per candidate for maintenance.
- Contingency allowance US \$ 500 or UK Pound 325/- per annum per candidate.
- For a maximum period of 4 years.

Hostels for SC Boys and Girls

Book Banks for Scheduled Castes Students -

- Assistance for purchase of text books for medicine (including Indian Systems of Medicine and Homeopathy), Veterinary, Engineering, Agriculture and Polytechnic courses, Law, CA, MBA and Biosciences.
- Financial Assistance from Rs.2400/- to Rs.7500/- for Books and for cupboard Rs.2000/-

Special Educational Development Program for Girls belonging to SCs in low literacy districts.

Scheme of grant-in-aid to voluntary organizations working for Scheduled Castes.

Backward Classes

National Backward Classes Finance and Development Corporation

Pre-matric scholarship for OBCs

Hostels for OBC Boys and Girls.

Preexamination coaching.

Assistance to voluntary Organizations for Welfare of OBCs.

Minorities

Moulana Azad Education Foundation assisted over 86 organizations by releasing Rs.5.31 crore

- Organizes special training for imparting higher education to teachers.

National Minorities Development and Finance Corporation

- Micro financing and assisting traditional artisans.

Assistance for pre-examination coaching (a combined scheme for SCs, OBCs and Minorities)

Social Defence

Integrated Programme for Older Persons

- To provide financial assistance to NGOs upto 90percent of the project cost for establishing and maintaining old age homes, day care centres, mobile medicare units and to provide non institutional services to older persons.

2.0 Ministry of Health

Chapter IV of the PWD Act lays down that appropriate government shall undertake preventive measures:

Health Ministry is a nodal ministry with regard to prevention, which has the following programmes:

National Programme for the control of blindness and visual impairment (1976)

- To establish regional institutes of ophthalmology, make provision for mobile eye units, offer ophthalmic services to trained ophthalmic assistants
WHO project to promote prevention of child blindness (2001)

National Leprosy Eradication Programme (1983)

- To eliminate leprosy as a public health problem
- To create mass awareness
- National goitre prevention programme
- National Malaria Eradication Programme
- National Filaria control programme
- National Mental Health Programme
- Pulse polio immunization
- National Immunization Programme
- Nutrition programmes
- Medical rehabilitation

Ministry Human Resource Development

- Elementary Education
- Free and Compulsory Education to all children upto the age of 14 years.
- Non formal education
- National Open School - 1989
- Integrated Education for disabled children - 1974
- District Primary Education Programme
- Sarva Siksha Abhiyan

Ministry of Women and Child Development

Integrated Child Development Scheme - 1974

- To control nutritional and health problems
- It has linkages with health and immunization programmes

Ministry of Labour and Employment

- Special employment exchanges,
- Vocational rehabilitation centers for persons with disabilities
- 3percent reservation of vacancies for persons with disabilities in the areas of visual impairment, hearing impairment and handicap in the ITIs ,

Ministry of Rural Development

Swarn Jayanthi Grameen Swarojgar Yojna

Council for Advancement of People's Action and Rural Technology (CAPART)

- To promote economic rehabilitation of persons with disabilities
- Other poverty alleviation programmes

Ministry of Urban Development

- Poverty alleviation programmes
- Barrier free access to buildings

Ministry of Information and Broadcasting

- Awareness programmes
- Education programmes
- Training programmes

Ministry of Information Technology

- Tele-rehabilitation
- e-rehabilitation

Chapter 4

Employment for Persons with Disabilities: A Futuristic View

C S Mohapatra
Bhusan Punani

This chapter discusses various dimensions of the issue of employment of persons with disabilities in three sections. It mentions in brief, about the wide range of avenues and types of employment in both organized and unorganized sectors that include self-employment, professional employment, home-workers, cooperatives, community based rehabilitation, Open Employment, Special Employment, Sheltered Workshops, Transitory Employment Workshops, and On-the-job Training Centres. While dealing with the policy framework and Government initiatives for promotion of employment of the physically and mentally challenged persons, the strategy of the Government as reflected in the Tenth Five Year Plan policies and programmes have also been discussed. The authors, address the challenges ahead and provide a wide range of suggestions for a better employment scenario for the persons with disabilities in future.

Introduction

Productive employment raises the standard of living of a person and also adds to the Gross Domestic Product of the country. However, employment to a disadvantaged person means much more than economic upliftment of the individual concerned. It not only brings about improvement to their quality of life socially and economically and mainstreams them, but also ensures dignity and recognition in the family and society. When employment is provided to any disadvantaged person, such as a person with disability, the outcome is therefore, multidimensional. Work is essential for every human being; for the sake of earning money and for economic independence as also because it contributes to self-esteem and self-dignity leading to an abiding joy for life. For persons with disabilities, it is still more important as the self-esteem and financial gains generated out of it would offset to a great extent the negative impact of disdainful attitude of the society. (Pandey & Advani, 1995)

There is a general consensus the world over that employment is the most essential but the toughest aspect of rehabilitation. Employment of the disabled is a more potent problem in India due to near non-existence of social security benefits; limited education and training facilities; and high rate of illiteracy amongst the disabled population. Most disabled persons and their families come from the poorest rungs of society. In fact, studies have revealed that there exists an association between poverty and disability. The cost of maintaining such persons in the family adds to the financial burden. Thus their economic rehabilitation does not remain an individual need; many a times it becomes a question of survival of the family.

Vicious Cycle

It has been observed that a vicious cycle of the following components is an obstacle to the employment process of persons with disabilities:

- Low levels of literacy
- Lack of educational facilities
- Absence of comprehensive identification of services
- Lack of job-oriented training facilities
- Irrelevant training in non-viable trades
- Lack of training of employment officers/ trained instructors
- Lack of an implementing machinery and absence of a system of delivery of services
- Apathy and apprehension of employers and Government officials.
- Non implementation of legislative provisions
- Lack of mainstream vocational training opportunities.

The Biwako Millennium Framework points out the challenge of integrating and including persons with disabilities in the economic mainstream has not been met. Despite international standards and the implementation of exemplary training and employment legislation, policies and practices in some countries, persons with disabilities, and especially women, youth and those in rural areas, remain disproportionately undereducated, untrained, unemployed, underemployed and poor (ESCAP, 2002).

To expedite the employment process, it is essential therefore to direct all efforts at breaking the vicious cycle at some stage; extend appropriate job-oriented training and career counselling facilities; prepare the person for suitable employment; convince the employers to extend him employment; counsel family members and community in this regard; ensure effective implementation of legislative measures; and involve Government machinery actively in the process.

Economic and Vocational Rehabilitation

Economic rehabilitation aims at developing and enhancing the functional abilities of a person with disabilities so that he/she is gainfully occupied resulting in economic contribution to self and the family. Economic rehabilitation includes any trade, economic activity or profession which enables an individual to make any tangible or intangible contribution; any monetary or non-monetary service support to the family or community in the organized as well as unorganized sector. Income generation activities are a sub-set of economic rehabilitation and these mean direct monetary or tangible gains derived on a regular basis for services rendered or goods provided. Vocational training should generally lead to promotion of income generation or many a times economic rehabilitation. In general parlance, vocational training aims at promoting open employment of the individual. It refers to skill development through a structured and formal training programme, which aims at placement of a person in open competitive wage employment in the organized sector.

Vocational rehabilitation is an outcome of the employment process. It may be achieved through open, self or sheltered employment, gainful occupation or income generation. ILO Recommendation No. 99, Paragraph 1 (a) reads: "For the purpose of this recommendation the term 'vocational rehabilitation' means that part of the continuous and coordinated process of rehabilitation which involves the provision of those vocational services e.g. vocational guidance, vocational training and selective placement, designed to enable a disabled person to secure and retain suitable employment"

Avenues of Employment

Remaining idle and unemployed are probably the major causes for the resultant isolation, depression and rejection in a disabled person. It has been established that persons with disabilities can perform competitively in various professional, semi-professional and industrial jobs; rural crafts, trades and agricultural operations. It has been observed that when incentives for work motivation and recognition of high performance are available, their performance is comparable to that of a non-disabled person.

The term employment, by definition, includes any trade, economic activity or profession in the organized as well as unorganized sector or any trade that would provide with some monetary remuneration. It may be recognized that the community itself offers a wide spectrum of opportunities. In India, the employment opportunities for persons with disabilities in the organized sector, particularly in the rural areas are almost non-existent. This employment crisis, both for the disabled as well as the non-disabled, has resulted due to exclusive dependence on the organized sector which accounts for only a small proportion of the workforce. The unorganized sector which is the major avenue of employment for the non-disabled may prove to be the most appropriate avenue of employment for the persons with disabilities also, if suitably exploited through a coordinated approach, need based training, and an effective system of delivery of services.

Unorganized Sector

In the unorganized sector, the major types of employment include self - employment, professional employment, home-workers, cooperatives and community based rehabilitation.

Self Employment

Becomes a feasible and successful mission subject to availability of a launching grant, coverage of the occupation under the existing schemes, financial viability of the venture, availability of training facilities, existence of an organizational network, Informational database, business acumen, foresight, required expertise etc. The capacity and willingness of the persons with disabilities to work besides the much-needed support from the family and community also play a crucial role.

Getting persons with disabilities into the arena of Professional Employment needs initiative and hard work, mobility, suitable orientation, acquiring specific skills through higher education and appropriate training, availability of appropriate assistive devices, adaptations & techniques, involvement and coordination of research, industrial training and higher education institutes and universities in the process and above all, Governmental, administrative and institutional support.

Home-work

Home-work is the most important avenue of economic rehabilitation for persons with disabilities who are home-bound due to nature of their disability, age, lack of mobility, physical incapacity, social constraints, particularly in case of women, lack of education or specific production skills. The Helen Keller International has defined industrial home work as "A service to be rendered by an accredited agency - designed and developed with the intention of adhering to health and labour laws - to offer regular work training and remunerative work opportunities to those eligible disabled persons who cannot for physical, psychological or geographical reasons leave their homes to travel to and from a place of business". However there are also problems in this type of employment as observed in a module initiated and implemented at the Blind People's Association, Ahmedabad for the training and employment of persons with disabilities of all categories in domicilliary occupations as home workers.

According to the ILO publication "Employment of Disabled Persons - Manual on Selective Placement" some essential features of a good home workers programme are:

- adequate transport facilities for the supply of raw material and collection of finished products;
- availability of raw material;
- availability of training facilities;
- effective sales organization;

- sufficient supervisory staff to visit the stake holders at their homes;
- variety of suitable work to suit skills and aptitude of workers;
- support of family members and community.
- prevalence of occupation, production activity or craft in the area;
- adequate remuneration for the work.

Additional features of such type of employment are financial viability, professional approach, availing of following benefits, bulk buying, low cost of investment, financial assistance for initial training, incentives, subsidy, low-interest rate loan from the Government, identification of occupation especially for each category of disabled persons and Institutional and administrative support to the activity.

Employment in a Cooperative framework in India, in general have success stories in fields like credit, consumers, housing, dairy, irrigation, agriculture and allied pursuits only. The cooperatives exclusively for persons with disabilities have serious limitations due to heterogeneous backgrounds & scatteredness of the target group, lack of infrastructure and organizational support, limited choice of products, lack of initiative, risk taking ability, awareness and self confidence and absence of any organized schematic and institutionalized effort for encouraging cooperatives of the disabled persons.

Community Based Rehabilitation

Community Based Rehabilitation (CBR) is cost effective, individual need based and result oriented approach of promoting complete integration of the individual into his community. Once rehabilitated, individual should lead a more productive life, thus helping community economically. This approach calls for full and coordinated involvement of all levels of society, community and intermediate and national. It seeks the integration and intervention of all relevant sectors - education, health, legislative and vocational - and aims at the full representation and empowerment of persons with disabilities (Punani 1997).

Organized Sector

Organized Sector includes a variety of employment types such as Open Employment, Special Employment, Sheltered Workshops, Transitory Employment Workshops, and On-the-job Training Centres. True economic independence of the disabled person, realizing their limitations in self and professional employment opportunities would mean exploring the world of employment, a secured one, in the organized sector. It requires preparing them for employment and convincing the employers to extend them suitable employment opportunities.

Open Employment

Open Employment is created by State as well as Central Government; institutions, corporations and companies; establishments, factories, production units, schools, colleges, universities and research organizations etc. Government intervention in terms of augmenting training facilities; encouraging placement services; enforcing laws on employment; supporting production cum training centres and extending administrative support are prerequisites for a successful employment interventionist strategy. Institutional support for developing training programmes; seeking Government intervention; creating public awareness; developing vocational guidance and counselling services and motivating the capable and educated disabled persons to compete for open employment will also help. Involvement of Trade Unions, Employers' Federations, Local administration and Service Clubs will prove useful for extending employment opportunities. Availability of suitable employment assistive devices for persons with disabilities is also necessary. Open employment of the disabled persons helps towards their social integration into the community, gives financial security and possibility of savings besides making the society awareness regarding their potentials.

The Persons with Disabilities Act (1995) also intends reservation of 3 percent of jobs for persons with disabilities in the identified posts. A large number of State Governments and number of Ministries of the Central Government have already issued notifications and office orders reserving 3 % jobs for persons with disabilities. The Ministry of Social Justice & Empowerment has identified a large number of posts for such persons and has issued appropriate notification in this regard.

Special Employment

Special Employment is being provided in the country for providing special employment, which could be classified as Sheltered Workshops, Transitory Employment Centres and On-the-job Training Centres

The first two categories have been the most commonly initiated. There are other centres which have initiated training in a few trades which are certificate level courses recognized by the relevant governmental authorities. The vocational training centres offer training, which is generally informal, not very structured, is traditional and not very systematic. The stipend offered to trainees is just enough for sustenance. The latest trend, which is welcoming, is to admit the persons with disabilities, in regular ITIs, technical school or professional training centres, which ensure integration of the individual. A large number of State Councils for Vocational Training (SCVTs) have now started recognition a variety of crafts and trades for persons with disabilities. A large number of State Governments have already reserved 3 percent of seats in the State run it is and Polytechnics for persons with disabilities to encourage their vocational training.

Sheltered workshop

Sheltered workshop is a work-oriented rehabilitation facility with a controlled working environment and individual vocational goals, which utilizes work experience and related services for assisting a visually impaired person to progress towards normal living and a productive vocational status. It is also considered a permanent or semi-permanent vocational placement for individuals who are unable to find jobs in the community. It is to be considered a job and a place to go to work every day. It is a vocational setting, geared to take advantage of whatever vocational assets a client might have. It is meant to provide a resource in which an individual can make a contribution to the community. It sometimes suffers from limitations such as lack of legal status and trades selected not having compatibility with the existing job scenario due to controlled environment. However, this approach is suitable for the aged, disabled persons and persons with multiple disabilities.

Transitory Employment

Transitory Employment is given through a transitory workshop within a controlled working environment with the ultimate objective of open employment. Its distinguishing features include emphasis on movement of the individual whether his destination is the open labour market or extended employment. This type of employment is specifically structured as a work setting leading to open employment and is a middle path approach of providing on-the-job training for a limited duration. It encourages open employment provided the trades selected are compatible with the employment opportunities. As training is provided in simulated industrial settings, it becomes easier for a person to adjust to new environment when placed outside.

This is to suggest that wherever possible, the sheltered workshops should be transformed into the transitory employment workshops. At the same time, open employment is the most desirable mode of providing economic rehabilitation and restoring dignity to visually impaired persons.

On-the-Job training centres

On-the-Job training centres aim at providing work placement in simulated industrial settings. It is a production activity and resembles an industrial set-up, which has a primary objective of imparting employment oriented and task-based training to the individuals. It is a step ahead of sheltered workshop in respect of nature of placement and training opportunities. In this case, placement is provided for a limited duration, which depends upon nature of production activities or skills of individuals. Its major focus is imparting skill training and actual work experience to individuals who due to lack of requisite qualification and age cannot be enrolled under the formal vocational training programmes. This programme is designed to provide actual work experience for individuals who have not been able to get jobs due to limited vocational potential, lack of employment opportunities and poor condition of general economy. The ultimate goal is to

prepare the individuals for open placement or self-employment on completion of on-the-job training. Such programme is more desirable - socially as well as financially. Despite all its merits, it is to be admitted that on-the-job training is provided under simulated conditions. It may always not be possible to find appropriate competitive wage employment for every individual if the quality of on-the-job training is not upto the mark or the nature of training may not be in tune with employment opportunities.

Every category of disability, locomotor, visual, hearing or mental retardation, casts its typical functional limitation on the disabled person. When multiply disabled, the problem becomes more complex. In case of disability of severe order, again, the problems get compounded. However, with the advent of the modern aids and appliances, any type of physical disability can be won over to a substantial degree as regards the individual's functional capacity is concerned. The basic problem of a locomotor disabled person is mobility and being able to function normally with the aids and appliances concerned. The hearing disabled needs a hearing aid to overcome the disability and show his ability. Similarly, given right type of assistive device for work that includes IT based tools and computers as also mobility aids, the persons with disabilities can show their caliber in the work they will be assigned. However, there is a fundamental difference when it comes to the question of persons with mental retardation, because the problem is of mental capability to do a job, which is internal. The approach for building up facilities, identifying jobs, preparing the mentally retarded from school to work is there fore, different. In the following few paragraphs, the issues concerning mentally retarded persons are touched upon.

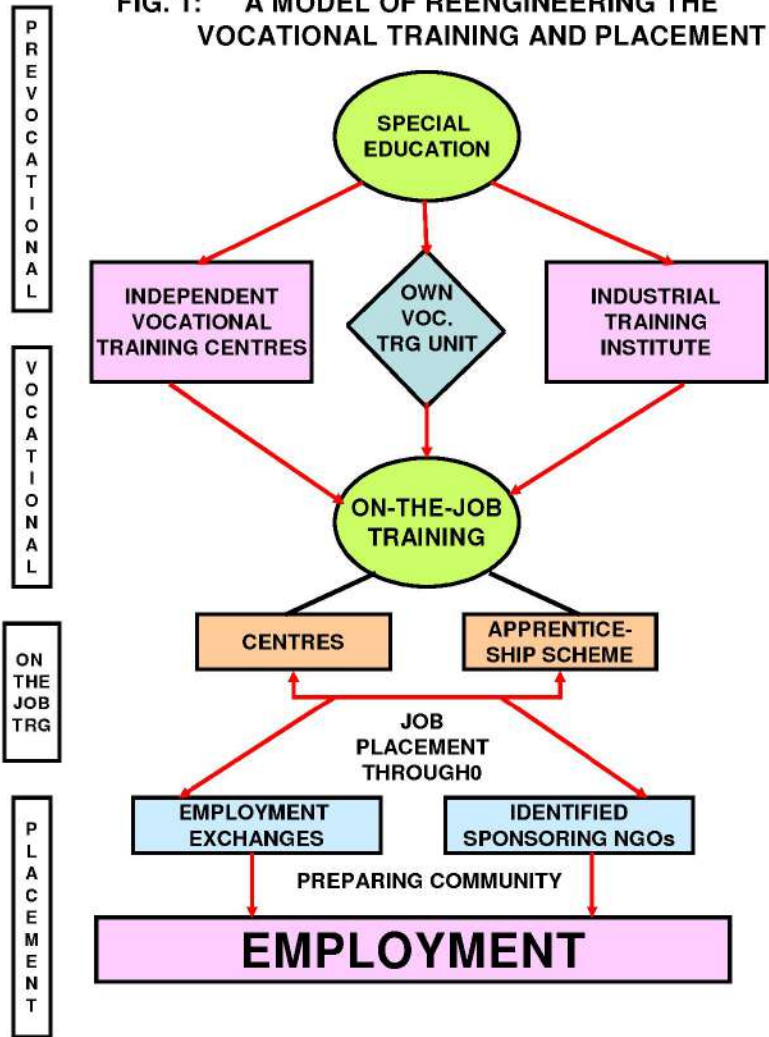
It is roughly calculated that there are 70 lakh adults in a population of 170 lakhs of persons with mental retardation in our country. Approximately 3000 adults are currently receiving vocational training at 16 Vocational Rehabilitation Centres and 200 Non Government Organizations in India. The transition of persons with mental retardation from school to work suitable to Indian conditions has been attracting attention as the ultimate aim of rehabilitation services to the persons with mental retardation employability and independent living and the trend of increasing number of adults with mental retardation in special schools due to the absence of vocational training facilities.

The National Institute for the Mentally Handicapped, based on the experiences and experiments conducted by during the past sixteen years has developed a guide that gives details of the transition from school to work that includes functional assessment, job identification, job matching, job training, and work place preparation etc. The ILO believes that the best opportunities for women and men with mental handicap in developing countries are the same as those for the working age population in general: i.e. Inclusive work in support of family farming, household and productive activities, and work in the fast growing informal sector of the economy.

Vocational training and placement of persons with mental retardation in India has evolved from the purely sheltered workshop to the open employment system. This shift has helped them to move from seclusion to inclusion. Competitive jobs improve the quality of life of persons with mental retardation

when compared with sheltered workshop employment. Supported employment also provides job satisfaction, self-worth, the value of pay and relationships. For the mild and moderate categories, instead of over-emphasis on academic achievement, exposure to more beneficial functional training for work and job locations will benefit them and support successful rehabilitation in jobs and independent living. The traditional and non-traditional occupations in which vocational training is presently given to the persons with mental retardation include, paper based, cloth based, chemical based, food items, engineering, agro based, service/open employment and novelty items. The NIMH has identified 66 jobs suitable for persons with mental retardation on the basis of cognitive and work behaviour and physical requirements. Following model of reengineering of vocational training and placement puts the approach to placement of persons with mental retardation in clear perspective (Rao and Sivakumar, 2004).

FIG. 1: A MODEL OF REENGINEERING THE VOCATIONAL TRAINING AND PLACEMENT



Policy Framework and Initiatives for Promotion of Employment of Persons with Disabilities

The nation is committed to providing employment including self-employment to persons with disabilities as enshrined in the Persons with Disabilities Act (1995). There exists an institutional mechanism for providing employment including self-employment to persons with disabilities. Though the Government sector establishments and PSUs have made some progress, there are a lot more initiatives that need to be taken in the private sector. Besides, special focus also needs to be given to persons with disabilities for whom any type of engagement including activities of daily living also brings about significant change in the life of the person in the form of relatively independent living and relieving their escorts for other productive purposes means addition to the National Income.

Employment Opportunities

The opportunities available for persons with disabilities along with various measures taken by the Government in promoting employment of persons with disabilities directly or indirectly are briefly given hereunder:

Employment in Government Sector

The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 is very comprehensive and encompasses provision relating to monitoring and implementation machinery, prevention of disability, education, employment, affirmative action, non-discrimination, research and manpower development and recognition of institutions for the persons with disabilities. The Chapter VI on employment envisages the following main provisions:

- Identification of posts in the establishments, which can be reserved for persons with disabilities (S-32).
- Job reservation to the extent of 3 percent of the vacancies in every establishment in the posts identified for each disability (S-33).
- Seeking information from each establishment relating to appointments of persons with disabilities in such vacancies (S-34).
- Empowering Special Employment Exchanges to have access to any relevant record or documents in the possession of establishments as regard such reservation (S-35).
- Provision for vacancies not filled to be carried forward (S-36).
- Maintenance of records by the employers as regards filling of identified posts (S-37).
- Formulation of special schemes by the local authorities and the appropriate Governments for ensuring employment of persons with disabilities (S-38).

- Reservation of 3 percent in all poverty alleviation schemes benefits for such persons (S-40).
- Incentives to employers both in public and private sectors to ensure that at least five percent work force is composed of such persons (S-41).

The Persons with Disabilities Act has made very bold provisions for promoting competitive employment for the persons with disabilities. The outcome of these provisions would, however, depend upon its effective implementation.

In pursuance of the provisions, the Government has stressed upon all the Ministries/Departments that vacancies reserved for persons with disabilities in Group A, B, C posts are intimated to the UPSC/SSC as the case may be. In the case of Group D posts, it has also been stressed upon them that all out efforts should be made to fill up the vacant posts at the earliest. For clearing backlog of vacancies reserved for the blind, all the Ministries/Departments have been requested to furnish the same to the UPSC/SSC, as the case may be so that special examinations could be organised by them for filling up of the same. To ensure strict compliance of the instructions issued from time to time, all the appointing authorities have been requested to furnish a certificate to the recruiting agencies that the policy relating to 3% reservation for persons with disabilities has been taken care of. DOPT has brought amendment in providing points No.1, 34 & 67 in cycle of 100 vacancies in the 100 point register for reservation for the disabled persons, instead of point No. 33, 67 & 100 prescribed earlier, for the persons with disabilities in the posts filled through direct recruitment/promotion. The Govt. of India in the Department of Personnel & Training (DOPT) have issued instructions providing relaxation of upper age limit for persons with disabilities in Group C & D posts filled through employment exchanges, to the extent of 10 years. DOPT vide their instructions dated 27.7.1995 has allowed age relaxation of 5 years (10 years for SC/ST and 8 years for OBC) to persons with disabilities for appointment to Group A and B posts/ services except where recruitment is made through open competitive examination.

As per the review undertaken and information available with the Department of Personnel & Training, which is the nodal Department concerned with reservation in posts/services under the Central Government, the status of reservation for persons with disabilities in various Ministries/ Departments of Government of India with reference to the identified posts in Group A, B, C & D, is 3.07%, 4.41%, 3.76% and 3.18% respectively. The position of PSUs numbering 237 with reference to identified posts in Group A, B, C & D is 2.78, 8.54, 5.04 and 6.75 respectively.

Expansion of Scope of Government Employment

With a view to expand the list of posts identified for persons with disabilities, the Government on the recommendation of an Expert Committee, has identified more than 1900 categories of posts for persons with disabilities in Government establishments and Public Sector Undertakings. This is an indicative list and similar/ analogous posts can also be included under the identified category by the employers.

Employment in Private Sector

The Government, in order to identify jobs suitable for persons with disabilities in private sector, had also constituted a Committee of Experts including representatives from the Corporate Sector. The Committee has identified 120 occupations at Executive/ Management/ Supervisory levels and 945 occupations at skilled/ semi-skilled/ un-skilled levels. The report has been made available to Central Ministries/ Departments, States/ UTs/ PSUs and various other organizations/ institutions, including FICCI, ASSOCHAM, CII, NGOs in an effort to promote employment of persons with disabilities in the private sector.

Self - Employment

Economic empowerment of the persons with disabilities is facilitated by the **National Handicapped Finance & Development Corporation (NHFDC)** which provides concessional financial assistance to persons with disabilities through the State Channelising Agencies (SCAs) and micro credit programmes. The Corporation provides loans to persons with disability of 40% or above with annual income less than Rs.1, 00,000/- per annum in urban areas and Rs.80, 000/- per annum in rural areas. Loans are provided for setting up small business in service or trading sector, small industrial units, manufacturing/ production unit of assistive devices for disabled persons and also for agricultural activities, higher studies/ professional training etc. A rebate of 1% on interest for disabled women is being given. Applications for financial assistance are routed through the concerned State Channelising Agency for sanction by NHFDC.

Under **micro financing scheme of NHFDC**, loans are given to NGOs for further disbursement to individual beneficiaries or through Self-Help Groups (SHGs) for starting or augmenting income generation activities like small business/ trade, tiny/cottage industry or service activity, artisan activities, agricultural and allied activities and transport sector activities. Under this scheme, loan upto an amount of Rs.5 lakhs is given to an NGO for further disbursement to individual beneficiary with a ceiling of Rs.15, 000/- per beneficiary at a rate of interest not exceeding 5% per annum on convenient repayment period of 24 months and on convenient terms. The NHFDC has disbursed Rs.1284.32 lakh to 3015 beneficiaries during 2001-2002. Under Micro Finance Scheme, an amount of Rs.39.78 lakhs has been disbursed to 24 NGOs to benefit 640 persons with disabilities. NHFDC has disbursed (cumulative) Rs.4546 lakhs to 11294 beneficiaries in 31 States/ UTs till 31.10.2002.

Assistance for Vocational Training

Under the Scheme to Promote Voluntary Action for Persons with Disabilities, Government gives assistance to voluntary organizations for providing facilities of education, training, including vocational training and a wide range of rehabilitative services for the disabled including the mentally challenged. The extent of assistance given is up to a maximum of 90% of the eligible amount of grant. Assistance within the aforesaid ceiling is given for recurring items such as honorarium for human resource personnel, stipend, transportation allowance,

hostel maintenance, contingencies and non recurring items such as furniture, equipment, construction of building etc. as indicated in the scheme.

The Ministry of Labour, through the Directorate General of Employment & Training (DGE&T) extends its services to persons with disabilities through a number of schemes. DGE&T runs 17 **Vocational Rehabilitation Centres (VRCs) for the disabled persons** (including 7 skill development centres) throughout the country covering all types of disability. This training is not only free of cost, but the Government of India also lends support to the training programme of VRCs by providing stipends to the trainees.

Rural Rehabilitation Extension Centres

Rural Rehabilitation Extension Centres and a Central Institute for Research and Training in employment service. The Ministry of Labour is planning to establish at least one VRC in each State. Ministry of Labour has also instructed the State Governments to ensure that 3% of the seats reserved for the persons with disabilities in the ITI, are fully utilized. It has further instructed that all the State Directors dealing with craftsmen training scheme to include an exclusive ITI for the disabled in the Plan schemes of the State Government.

The Government has taken up a scheme to select and up grade 50 existing **polytechnics** spread all over the country to undertake technical/ vocational and continuing education programme for persons with disability. The All India Council for Technical Education (AICTE) has allotted 25 extra seats to the selected polytechnics. 35 additional polytechnics have been selected and the remaining 15 polytechnics is being selected from amongst the Women's Government Polytechnics preferably, which are conducting the courses in Hotel management with a view to benefit female students with disabilities.

Employment Through Poverty Alleviation Programmes

Three per cent reservation is available under Swarnjayanti Gramin Swarozgar Yojana (SGSY) being implemented by Ministry of Rural Development. Similar programmes are also being run in urban areas. However, 3% reservation has not been achieved so far.

According to the Guidelines of **Swarnjayanti Gram Swarozgar Yojana (SGSY), Jawahar Gram Samridhi Yojana (JGSY) and Indira Awaas Yojana (IAY)**, 3% of the beneficiaries assisted under the Programme are to be from the category of physically disabled persons. During 1999-2000, 8529 disabled persons have been assisted which forms 0.91% of the total Swarozgaris. During 2000-2001 (January, 2001), 3615 disabled persons were assisted which forms 0.64% of the total Swarozgaris. Under the Jawahar Gram Samridhi Yojana (JGSY), during 1999-2000, 7753 works have been taken up for disabled persons, which forms 0.01% of the total works completed. During 2000-2001, 6878 works have been taken up for the disabled persons which forms 0.02% of the total works completed. Under the Indira Awaas Yojana (IAY), 3,196 disabled persons have been provided houses during 1999-2000, which forms 0.96% of the total houses constructed. During 2000-

2001, (December, 2000), 3435 disabled persons have been provided houses which forms 0.65% of the total houses constructed.

The Ministry of Urban Development and Poverty Alleviation implements the unified urban poverty alleviation scheme called **Swarna Jayanti Shahari Rozgar Yojana (SJSRY)** with effect from 1st December, 1997 for the benefit of urban poor. This programme seeks to provide gainful employment to them through encouraging the setting up of self-employment ventures. It has a provision of 3% reservation for persons with disabilities and till 31.12.2000, out of 2, 67,034 persons assisted under the self-employment ventures, 13,547 were persons with disabilities, which works out to 5%.

Information Technology for Persons with Disabilities

The National Programme for Braille Literacy with the application of Information Technology of Ministry of Information Technology plans to provide various opportunities to the visually impaired population. The text and supplementary reading material in Braille form will be developed. The material will be prepared at the Resource Centers (RCs) which are networked together for sharing information in electronic form for keeping education standard uniform. Further, RC will distribute information to the respective Training Centre (TC) over the network. It is envisaged that many NGOs and voluntary organizations would also be offering their services for content creation under coordination of RC. Computer based training material integrating with tactile device will be developed for teaching Braille to students. For self-learning, speech and multimedia will also be incorporated. Resource Centers will have a repository of reading material like magazines, newspapers and books for the visually impaired. The material will be stored mainly in the electronic media with a facility to take a Braille print. RCs will also compile and distribute information like welfare schemes of the Govt., employment opportunities for the blind, health bulletin, news highlights etc. This will be available to the end user at Nodal Centers over the network. The blind for writing articles etc can also use the facilities at the RCs and TCs.

At training Centers, visually impaired students will be trained in Braille while in Resource Center teaching material will be generated and electronic library will be maintained. These materials will be made accessible to TCs through networking. Various RCs will also be connected to each other through networking so that uniform standard of teaching material can be maintained among them. At present software has been developed, which translates text in English, Devnagari, Bengali, Oriya etc. to Braille. Further, tactile device for reading text line wise has also been developed. For the benefit of Blind Schools in NE Region, on a pilot scale, the Computerized Braille Transcription system with present development has been implemented in five Blind schools of Assam. The systems that have been installed are working satisfactorily. Students are regularly using the system for education. With the new Computerized Braille system, an ordinary typist with no knowledge of Braille can transcribe books and other text materials into Braille form. Work on information technology for disabled persons has just started and there is vast scope of harnessing IT for the differently abled.

National Trust Initiatives

The National Trust is a statutory body under the Ministry of Social Justice and Empowerment, Government of India, set up in 2000 under the "National Trust for the Welfare of persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities" Act, in December, 1999. Its prime objectives include enabling persons with disability to live as independently and as fully as possible within and as close to the community to which they belong, strengthening facilities to provide support to persons with disability to live within their own families, extending support to registered organizations to provide need based services during period of crisis in the family of persons with disability. It also promotes measures for the care and protection of persons with disability in the event of death of their parent or guardian. The Trust provides assistance for undertaking projects for training of caregivers, day care centers, respite care and residential programmes. Out of 574 districts in the country, 347 districts have formed Local Level Committees in 29 States/ UTs. The activities of Trust empower the severely disabled to live independently, learn activities of daily living and in some cases, contribute to the society as much as it can. The "feel good factor", a severely disabled person derive from this transformation has to be felt to be believed. It releases the escort for doing other productive work, such 'engagement' of a severely disabled person, is no less than 'employment' and it indirectly helps increasing the standard of living of the family when escorts go out for work.

Tenth Five Year Plan Perspective

The 10th Plan projects 8% GDP growth during the period. The plan along with various other policy measures and promotion of labour intensive sectors promises to create more employment opportunities in general. Various anti-poverty programmes and employment generation programmes such as Swarna Jayanti Gram Swarojgar Yojana (SGSY) and Sampoorna Gramin Rojgar Yojana (SGRY) aims at creating self-employment/wage employment.

Recognising the need of special attention to the disadvantaged groups, the 10th Plan envisages empowering the socially dis-advantaged groups economically through promotion of employment-cum-income generation activities with an ultimate objective of making them economically independent and self-reliant.

Policies and Programmes in Tenth Five-Year Plan

According to the Tenth Five Year Plan, "Arrangements will be made to utilize the training facilities available at the National Vocational Training Institutes (NVTI), Regional Vocational Training Institutes (RVTIs), District Rehabilitation Centres, it is, and Craft Training Centres. Efforts will also be made to expand the existing Scheme of Vocational Rehabilitation Centres (VRCs) in each State/Union Territory, besides modernizing the existing VRCs to keep pace with the merging market trends. The VRCs are also expected to provide help and guidance to persons with disabilities in getting placements. Also, while planning for training programmes for such persons, every effort will be made to diversify the trades besides giving priority to up-coming trades, keeping in view the trends and demands in the

employment market. Inter-se priority will be given to disabled women and adolescent girls in all training and employment programmes, through identifying specific trades/vocations with suitable training inputs. For people with severe disabilities, efforts will be made to expand the on-going programme of Sheltered Workshops-cum-Production Centres to be spread all over the country with a special priority in rural areas".

The tenth Plan Document envisages that "simultaneously, efforts will be made to tie-up with all concerned Ministries/Departments to ensure flow of benefits to persons with disabilities in all the employment-cum-income generation programmes, especially meant for those living below the poverty line. They include 3 per cent reservation in wage and self-employment opportunities and other asset-endowment benefits created under various poverty-alleviation programmes viz. SJSRY for the urban disabled and SGSY, SGRY, IAY for the rural disabled. In addition, measures like concessional finance, land allotment, etc. will also be provided to create income-generation activities to person with disabilities. To help them, SHGs or Viklang Sangams will also be empowered to start their own employment units and cooperatives. Necessary tie-ups will also be encouraged to develop both backward and forward linkages to keep the SHGs gainfully employed and self-reliant. Agencies like the National Bank for Agriculture and Rural Development (NABARD), Council for Advancement of People's Action for Rural Technology (CAPART) and Rashtriya Mahila Kosh (RMK) can play a major role in extending credit to these Groups. The Placement of persons with disabilities in Government jobs will receive an added thrust through more of pro-active role of the Special Employment Exchanges/Special Cells under the general employment exchanges. To ensure effective implementation, periodic evaluation of their performance will be undertaken. Also, the reserved quota/preferential selection for the disabled in Group A, B, C and D services of the Government need to be filed up promptly. For this purpose, all Ministries/State Governments and Public Sector Undertakings will identify posts to be reserved for them as mandated under the Persons with Disabilities Act, 1995, the corporate sector, with adequate opportunities to employ disabled persons will be encouraged to do so. Various Legislations like the Workmen Compensation Act, 1923, Industrial Disputes Act, 1947, and Apprentice Act, 1961, will be suitably reviewed/amended to make them enabling instruments for the employment of disabled persons." These planned agenda for the future, if implemented effectively will see a remarkable change in the employment situation of the disabled persons .

Challenges Ahead and Suggestions : A Futuristic View

Looking at the institutional mechanism and the Government initiatives, though prima-facie, it appears that significant strides have been made in the right direction, yet there are many areas that need attention. While employment is a general socio-economic problem that needs to be tackled, there is a case for laying special focus for ensuring more employment opportunities for persons with disabilities.

Some of the challenges and issues that needs to be addressed on priority by the Government, NGOs, media and society at large, are delineated as under:

(i) With globalization, the scope of **Government employment** has shrunk. Therefore, there is need to provide employment opportunities for persons with disabilities through initiatives in the **private sector** as also through promoting self-employment ventures. In the Government, there are backlogs in many Ministries that need to be filled. Review needs to be done by each Ministry/ employer on an annual basis to ensure filling up the vacancies directly in terms of the instructions of the Department of Personnel and Training which has a provision of carry forward of vacancies for three years in case of non availability of candidates with disability and also interchange of category of disability.

(ii) The **revised list of identified posts** has been notified in June 2001 after lapse of one and half decades and encompasses over 1900 categories of posts. It has also been clarified that this is an indicative list, thereby encompassing similar/ analogous posts in the ambit of identified posts for persons with disabilities. This has been notified in June 2001 and placed on the website of Ministry of Social Justice & Empowerment at www.socialjustice.nic.in The Central Government Ministries/Departments need to take this revised list as a guide before planning to achieve the 3% reservation target. Now, three percent of this expanded list will mean more number of posts for disabled persons.

Besides, the anomalies and bottlenecks in implementing the reservation provisions need to be sorted out. For example, The DOPT needs to revise the definition of hearing impaired in accordance with the section 2 (l) of the Persons with Disabilities Act, 1995. Due to non-revision, majority of hearing impaired persons are not able to get employment in spite of fulfilling other conditions. Till date the Banking Sector, Railways and Public Sector Undertakings are insisting that the person should have 90 dB (in some cases 70 dB) hearing loss in the better ear to be eligible for the posts reserved for the hearing handicapped. Whereas, under Section 2 (l) of Act, it is defined that 'hearing impaired' means loss of 60 dB in the better ear. This type of discrepancy needs to be corrected.

(iii) Most **State Governments** have not yet identified posts for persons with disabilities, which need to be done as provided in the Disabilities Act, 1995. All States should notify identified posts in State Government jobs/State PSUs on the lines done by Central Government. There is a need to review the progress on a regular basis.

(iv) **The Private Sector** should come forward to employ persons with disabilities taking the private sector identified list as the guide. The organisations like FICCI, CII and PHDCCI etc. should take a lead role in creating awareness on

potential abilities of the persons with disabilities. To enhance the employment prospects for the Persons with disabilities in Private Sector, the Persons with Disabilities Act, 1995 made the provision of incentives to be given to the employers for employing at least 5% of the employees with disabilities. Such an incentive is still awaited from the Government. The incentives like tax rebates, excise concession, tax holidays, preferential allotment of land, soft loans, easy payment terms etc. could be thought of.

(v) Enabling the persons with disabilities to work in a **congenial atmosphere** in the Government/private organizations still remains a challenge. Many Government buildings are yet to have **barrier free** features. Assistive devices for enabling the persons with disabilities to work efficiently are also not being provided adequately in many organizations thereby suppressing the hidden talent of persons with disabilities. A differently abled person, due to the natural gift of God or may be due to his higher level of concentration, sincerity of purpose and dedication, commitment to the society and a drive to acquire dignity in this world (which generally looks at a person with disability as a liability) always tries to give his/her best in the work situation which need to be harnessed in full.

(vi) In general, the **mental barriers** are even more challenging than the physical barriers when it comes to accepting an employee with disability in the workplace. This needs to be removed through orientation programmes, workshops, social integration and awareness generation programmes. The role of **media** including the **electronic media** is significant in this direction.

(vii) At present **vocational training** is being given in many age-old trades, which has out-lived its utility and/context. For example, the traditional trades that were and are being imparted to the visually handicapped include: chair canning, knitting, chalk - piece making, agarbathi making, and instrumental and vocal music. All these and more such traditional trades and skills have very limited employment opportunities. The advent and growth of Braille in Indian languages with contractions and short - hand system and computers with compatible software for visually impaired has made many a trade and jobs accessible for them. Telephone operating, stenography, light mechanical engineering, physiotherapy, medical transcription, caller services computer operations & programming skills are the new additions of avenues for the employment of persons with disabilities. With IT revolution, the scope for employment of persons with disabilities has expanded. Hon'ble President of India Dr. A.P.J. Abdul Kalam in his address to the nation on the eve of Republic Day 2003 have aptly mentioned *"I had met many physically and mentally challenged children at Rashtrapati Bhavan and also during my visits to various States. My belief all along was reconfirmed that these children like all others have an equal urge to pursue their studies and WORK. We have to provide solutions to their problems with the aid of Information Technology, by developing audio books, talking websites, voice assistive interfaces and other devices. Public buildings and educational institutions need to provide friendly facilities that offer easy access and reach"*.

(viii) Vocational training per se is not a guarantee for employment. They have to be given preliminary training of entrepreneurial development, provided with all kinds of information and back-up support for taking up self-employment

ventures, including forming Self-help Groups (SHGs).

Also, existing **VRCs** of every state are to be strengthened to assess and evaluate the persons with disabilities to match their individual ability and the job requirement and to take up imparting vocational skills in the most modern trades. Existing **Community Based Rehabilitation (CBR)** programmes are also to be strengthened to provide self-employment and gainful placement of the persons with disabilities. **Concessional loans** of NHFDC available for various purposes may be given to large number of beneficiaries with necessary backup support including marketing and infrastructure.

(ix) At present there is no thrust on **placement services** for persons with disabilities though there exists Special Employment Exchanges of the Government, placement service facilities by few NGOs and placement advices/assistance that are provided by the Government's institutions like the National Institutes in the disability sector.

(x) **Inclusive education** of children with disabilities has started in the country but we have miles to go in that regard. Ensuring inclusive education for children with disabilities will bring the necessary changes in the society towards acceptance of an educated person with disability for employment purposes and also improve the confidence level of prospective employees/entrepreneurs of the future.

(xi) The existing **placement services** in the organized sector must emerge as centres of excellence for initiating, promoting and coordinating integrated training of the target group. Wherever possible, sheltered workshops must redefine their roles and progressively emerge as skill development centres aimed at promotion of gainful occupation of the individual.

(xii) A **nation-wide study and evaluation** of the existing employment services may be carried out for establishing and evaluating their objectives and the strategies. The centres should redefine their objectives; modify their strategies and approach to emerge as employment oriented, skill development, economically viable units. It may require introduction of new vocations, new equipment, new curricula and new procedure of evaluation and certification. These centres should emerge as skill development cum placement centre. A time bound Plan of Action should be evolved to convert these Skill Development Centres in a phased manner to be promoters of integrated training, they becoming resource centres.

(xiii) **New programmes of vocational training, income generation or economic rehabilitation** should adopt integrated approach from the beginning itself. In this case, developmental organizations engaged in welfare of the disabled persons should become the resource centres, programme implementation centres, advocacy agencies or support systems.

(xiv) The **placement centres** should develop and supply special equipment, carry out task analysis and provide information, extend individual preparatory services and coordinate admissions, supply of educational material and promote appropriate employment. These centres must emerge as properly equipped, well-maintained, appropriately staffed training and placement centres with structured training and suitable certification. There should be in-built provision for continuous evaluation and self-monitoring of the process and outcome of the

activities. While core staff should be appointed on regular basis, part time and visiting professionals should be involved for up gradation of services.

(xv) Economic independence and social integration of the persons with disabilities should generally be achieved through their competitive and open employment. It certainly requires preparing them for appropriate employment through suitable training and exploring all avenues of employment. Apart from administrative measures and institutional support, it requires adoption of appropriate, result-oriented and relevant **modern placement techniques**, which include the following, which has been explained in detail in the Appendix to this Chapter:

- Vocational Assessment and Work Preparation
- Selective Placement
- Job Clubs
- Work Stations
- Social Reinforcement
- Job Camps
- Institutional Placement Services

(xvi) Looking at the poverty profile of the disabled population of the country, it is a ray of hope one sees in the recently launched scheme for awarding **National Scholarship** to disabled students for pursuing post-metric and higher technical education. However, coverage of such schemes needs to be expanded and providing of **Scholarships from the school level**, need to be made by all State Governments.

(xvii) There are other **generic issues/challenges** that needs to be tackled for ensuring better employment opportunities for persons with disabilities in future years. The level of **literacy** of disabled population in general is quite low and that of **rural and/or female disabled population** is dismal. Special focus needs to be given through the Sarva Shikshya Abhiyan (SSA) and through other non-Governmental efforts to increase the level of literacy. This should be coupled with better opportunities in the technical/professional education including **IT education** for children with disabilities.

(xviii) At present, there is lack of **coordination** between educational/technical institutions, Institutions/NGOs in the disabilities sector, and prospective private and Government employers as also producers of assistive devices for the persons with disabilities to ensure that the educated person with disability gets the employment it deserves. Mechanisms need to be evolved to effectively employ the person with disability with necessary facilitating devices and environment.

Conclusion

The authors have brought out in this Chapter, various avenues of employment for all categories of persons with disabilities while highlighting the special case of mentally retarded persons. Analysing the policy framework and Government initiatives for promotion of employment of the disabled persons, it has been shown that whereas there exists a framework, yet the scope and opportunity in the Government sector is limited. It is suggested that while effective implementation of the reservation provisions need to be ensured by the Central and State Governments and the list of identified posts revised in every three years, thrust should be given towards harnessing the private sector opportunities for employment in organized as well as unorganized sectors. Promoting self employment through concessional loans from the National Handicapped Finance and Development Corporation has to be taken up in a big way which may call for great amount of involvement and cooperation of the State Governments and strengthening of the State Chanellising Agencies. Vocational training in non-traditional areas with thrust on sustainable employment and placements need serious attention. Capacity building of NGOs, Self Help Groups and Parent associations is crucial in promoting employment of the physically and mentally challenged. Access to educational facilities, barrier-free environment, in both physical and mental terms supported by right kind of modern assistive devices are the needs of the day for ensuring gainful employment for the persons with disabilities. Harnessing benefits of Information and Communication Technology for the benefit of this disadvantaged section of society in a mass scale, will revolutionize the employment scenario for the persons with disabilities.

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Appendix

Modern Techniques of Promoting Employment of Persons with Disabilities

Vocational Assessment and Work Preparation

Vocational rehabilitation may be achieved with or without work testing, aptitude testing, psychological testing, extensive and prolonged vocational guidance, reconditioning or vocational training.

Services:

The promotion of vocational rehabilitation in the organized sector will necessitate provision of the following services:

- a. **Assessment:** Obtaining a clear picture of a person's remaining physical, mental and vocational abilities and possibilities.
- b. **Evaluation:** Evaluating level of skill, aptitude, functional and occupational abilities.
- c. **Guidance:** Advising the person accordingly in the light of vocational training and employment possibilities.
- d. **Training:** Providing any necessary reconditioning, toning-up or formal vocational training or work preparation.
- e. **Assistive Devices:** Organizing appropriate vocational assistive devices to enhance mobility, functioning capabilities and capacities of the individual.
- f. **Placement:** Assisting individual to find appropriate and suitable work or service opportunities in the open or sheltered environment.
- g. **Follow up** until complete rehabilitation is achieved.

Outcome

Vocational assessment of this nature can:

- evaluate work performance under actual work conditions;
- indicate the degree of work tolerance, the hours a person can work without fatigue, his ability to stand noise and other environmental stresses, interruptions etc.;
- assist to develop his self-confidence, self-reliance and personal adequacy;
- assist the person to realize and accept his own potentials and limitations;
- assist in vocational orientation.

Aims

The procedure followed for vocational assessment, work preparation and placement would achieve the following objectives:

- To assist a person to gain or recover the habit of work
- To give advice on any social problems, which emerge in the process
- To provide physical reconditioning
- To provide medical, physical, psychological and vocational assessment of work capacity.
- To build up person's morale, help him to recognize his abilities and to think positively about his future
- To place the person in employment or in suitable course of vocational training as a prelude to employment.

Pre-requisites

In order to benefit from the procedure of promoting employment in the organized sector, an individual should:

- be of a working age, or approaching it, but not too old to secure appropriate placement at the end of the course;
- have, or likely to have at the end of the procedure, the physical and mental capacity to work;
- have reasonable prospects of getting a job at the end of the course.

The benefits of vocational assessment and work preparation would be lost unless the person concerned obtains appropriate placement on termination, either with or without suitable vocational training.

Selective Placement

Introduction

The selective placement involves:

- using all the normal services and provisions; and
- adjusting them as necessary to their known and carefully assessed needs.

It is the next step after assessment, vocational guidance, vocational training or on-the-job training and involves three distinct processes i.e.

Knowing the individual,

Knowing the job and

Matching following qualities of the individual with the job:

- Educational background, work experience and age
- Family background, economic and social status and occupation
- Level of training in orientation and mobility and activities of daily living.

Basic Principles

- Meeting the physical requirements of the job
- Compatibility between the training availed and job provided
- Matching between the potentials of the individual and job requirement
- Placement not resulting to any occupational hazard or risk to the visually impaired or fellow workers
- Enhanced social integration
- Conducive working conditions and environment
- Placement on grounds of suitability for the job, not pity, charity or sympathy.

Job Clubs

Introduction

A group of visually impaired persons meets everyday, in a structured meeting supervised by a counsellor using a 'lesson plan' schedule of daily activities. Half a day is spent in obtaining job leads and interviews in the office; the other half is spent in going out to these interviews. The counsellor closely observes and supervises as the client is engaged in obtaining leads, calling employers and writing letters.

Essential Features

- Train the counsellor to provide adequate counselling.
- Emphasize creation of job leads.
- Encourage a person to maintain the job once he is placed.
- Rapidity of obtaining job is dependent upon:
 - number of new job leads created
 - number of interviews attended
 - interest of counsellor
- Involve other employment agencies, concerned Government departments, voluntary development organizations and employers' federations actively.

Work Stations

Introduction

The Work Station is a step between open placement and the training or the sheltered employment. The aspirant is placed under the conditions of actual employment but without formal employment. He is expected to:

- perform actual work;
- follow all the rules as applicable to other workers in terms of timings, uniform, work performance and other conditions of employment
- However, the employer has no obligation in terms of payment of wages, maintenance of attendance cards, incidental expenses, compensation for hazards and insurance coverage

The local implementing agency or the Government department may provide the payment in terms of stipend, local transport, incidental expenses and insurance coverage. At the end of the training, it has been observed that the employer normally absorbs the person in his firm or unit.

Merits

It serves as an excellent arrangement wherein a person is under direct observation of the prospective employer who gets an opportunity to study his potentials, talents and adaptability to the job. The approach has the following merits:

- Demonstrates production potentials of the visually impaired.
- Convinces the co-workers regarding his production skills
- Enables the employment officers to:
 - perform task analysis
 - do individual planning
 - assist the VIP to adjust to the job
- Economical and cost effective as compared to other modes of training
- Ideal for a person who had no formal training
- Reduces the gap between on the job training or transitory employment and open placement
- Establishes direct contacts between the trainee and the prospective employer and improves chances of open employment

Factors Affecting Success

While the work station approach seems to be practical, result-oriented and cost effective, its success depends upon the following aspects:

- Proper selection of the job depending upon:
 - ability,
 - skills,
 - potentials and
 - interest.

- Proper supervision by the employer and the placement officer
- Willingness of the employer to extend open employment on completion
- Involvement of the concerned officials
- Willingness of the implementing agency to incur expenditure on stipend, transportation and incidentals
- Most important, adoption of this approach by the employment exchanges, vocational rehabilitation centres, district rehabilitation centres and voluntary placement organizations.

Social Reinforcement

Definition

The Social Reinforcement approach portrays the employment process as an informal job information net-work in which the person with early knowledge of job openings selectively passes this information on to unemployed persons who are then likely to reward the job informants in a social way.

Merits

- Prevalent for employment in unorganized sector, small units where recruitment process has not been streamlined
- Effective where employment per se does not pose a very serious problem
- May be adopted as a supplementary tool for encouraging employment
- May enable the aspirants to seek employment under legal provisions for which they are otherwise eligible

Job Camps

Definition

It involves inviting the prospective employers and unemployed disabled persons en masse and providing them appropriate conditions for mutual interaction for expediting the employment process. It has been adopted by special employment exchanges and the disabled welfare voluntary organization for the person with disabilities.

Merits

- Employer gets to meet, examine and interview a large number of disabled persons and to select the most suitable ones
- Person with disability faces a large number of interviews on the same day
- Suitable for developing countries where there is lot of unemployment and lengthy selection procedures are involved.

Limitations:

- A strong 'employer-pull' is essential
- Not a complete process by itself
- Merely one aspect of the employment process
- Incentives, motivation and follow-up are essential

Institutional Placement Services

Procedure

- Circulate a detailed resume of the individual giving following details among the prospective employers:
 - educational qualification
 - past experience
 - area of specialization
 - age and areas of interest
- Display the offers received from the employers
- Encourage the individuals to apply for the job
- Provide facilities and infrastructure for the interviews
- Arrange initial interviews.

This approach has proved very effective for the placement of various professionals, particularly in case of well established and reputed institutions and universities offering professional courses. The development institutions and placement agencies may adopt this technique for expediting employment in the following areas:

- physiotherapy, massage
- stenography, touch typing
- telephone operating
- computer programming, data entry
- social work, office management, marketing

Part Three

EMERGENT ISSUES

Chapter 5

Human Resource Development in Disability Management

K C Panda

This chapter gives a comprehensive picture about the human resource development for disability rehabilitation in India for different categories of disability. The author discusses the emerging role of distance learning in HRD in the disability while dealing it in other initiatives taken by various agencies for catering to the increase in demand for rehabilitation professionals in the country. A brief review of activities of Rehabilitation Council of India in so far as HRD is concerned, including the courses conducted and recent initiatives taken have been discussed. The author highlights the role of humanistic element such as Service and human values, Understanding the needs and rights of the disabled, Paying individual attention, Developing and using resources, Resource Management and Collaborative working in increasing effectiveness.

Introduction

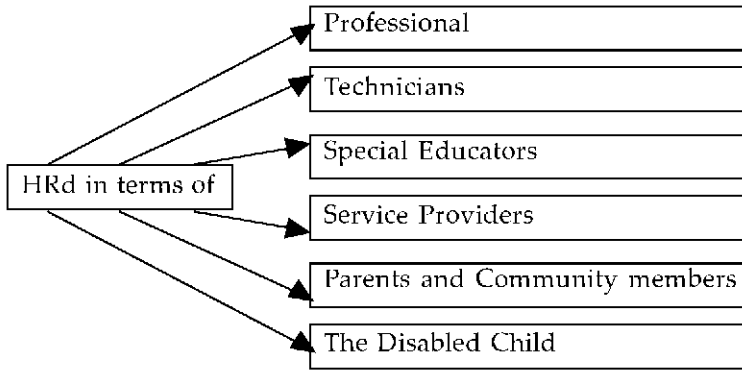
Human Resource Development deals with creating conditions that enable people to get the best out of themselves and families. Development is a never ending process As people develop themselves in new directions, new problems and issues arise enabling them to new competences to meet the changing requirements, aspirations, and problems. There are however, some universal goals towards which all HRD efforts aim to achieve the most important and common objective at all levels being competence (capacity) building. It is a process of competency development in people and creation of conditions through public policy, programmes & intervention to help people to apply there competencies for their own benefit and for that of others. Competence may include, knowledge, skills, attitudes and values. The core of HRD depends upon the context in which items are used (Pareek & Rao, 1981). UNDP has given a broad meaning to it. It defines policies and programmes that support and sustain equitable opportunities for continuing acquisition and application of skills, attitudes and competences which promote individual autonomy and one that is mutually beneficial to individuals the community and the larger environment of which they are a part (UNDP, BPPE 1991). The term HRD have come into popular usage during the 1990's. Prior to that emphasis was on development. Literature had been on the terms "human capital", the social "psychology based" & "poverty driven" aspects.

All three stress human competency development and the role of education in developing and human competencies.

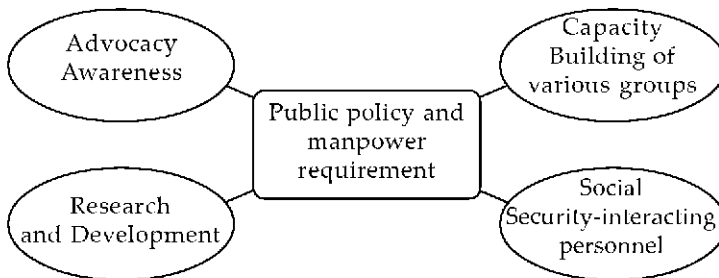
Human Resource Development and Disability Rehabilitation in India

Disability rehabilitation in India has a long past but a short scientific history. Groups and individuals initiated measures for betterment and improvement of the disabled persons but unfortunately these efforts were individualistic and perhaps unorganized and ad-hoc in nature though they were committed to improve the condition of disabled persons. There was little concern for systematic and scientific efforts in this direction. Systematic efforts has started as of IYDP 1981.

Disability though to a large extent inherited, environment has a substantial role to play in growth and development. One can visualize disability Rehabilitation and HRD



UN (1992) in its report on Regional Framework for human resource development refers as “the totality of skills and knowledge available to any given society as well as the prevailing attitudes and resource persons of members of that society to manipulate natural and physical resources towards the production of socially & economically valuable goals and practices. HRD concept depends upon the focus in which it is used. The following model would explain the range of activities in relation to HR:



In India, the term HRD was first introduced by Pareek and Rao in 1981, to professionals and academicians. It prepares people, professionals, technicians

- To acquire and sharpen capabilities to perform various functions – present and future roles.
- To develop their general capabilities as individuals and discover and explicit their own potentials for their own and organizational development purposes.

HRD ensures a steady supply of competent and well trained people at all levels to the different areas spelt out. HRD is also required for NGO management purposes in disability organizations particularly for NGOs working in the area of disability.

The Rehabilitation Courses in the field of disability are broadly classified as courses for Master Trainers, clinical and Technical Assistants, Special Educators and other technicians. For master Trainers the courses are offered at the Masters level and for clinical and technical assistants at Graduate level, for special teachers at Diploma level. There are 22 graduate and PG level courses and 14 at Diploma level coming the functional areas in all disabilities. These functional areas include rehabilitation psychology and speech pathology, and audiology, orthotic & prosthetic Engineering, Physiotherapy OT, vocational, Rehabilitation Engineers and technicians including ear-mould technicians, Rehabilitation Workers, CBR workers and mobility specialists, rehabilitation managers. The trained manpower of all categories taken together upto 2001-2002 is 18000.

Considering the magnitude of requirement of the manpower requirement, RCI has launched a distance mode education of the rehabilitation courses through various training institutes in the country. The RCI has also come up with Bridge courses & MRW training programmes so that the gap in trained man power Development can be covered to some extent. Simultaneously plans are afoot to develop CBR workers programme and other rehabilitation workers who could take up the rehabilitation work at the grass-root level as the studies reveal that 80% of the resources with disabilities could be met from & within the community itself and 20% of the needs, the qualified professionals intervention will be needed.

Human Resource Development in Visual Impairment

The RCI has recognized a large number of teacher preparation courses. At present there are four courses for training of secondary level teachers at NIVH, Dehradun; Blind People's Association, Ahmedabad; Ramakrishna Mission Ashram, Narendrapur; and Blind Relief Association, New Delhi. Similarly, the NIVH has sanctioned 16 courses for the training of teachers at the primary level. Training Course for the Deaf blind which is run at the Helen Keller Institute for the Deaf and Deaf blind, Mumbai.

In recent years, there has been noteworthy progress in the field of cure of blindness, comprehensive rehabilitation, education and development of support services for the people with visual impairment and blindness. During last few years, the number of teacher preparation facilities went for a major expansion with 22 diploma courses and number of degree courses, all recognized by the RCI. The country at the moment has training facilities for training of 700 teachers every year.

The National Association for the Blind took the lead in starting a nation-wide programme on community based rehabilitation, which has covered more than 50,000 blind persons till date. A large number of NGOs have also initiated and supported a variety of programmes on rehabilitation of the rural disabled. During the recent years, the Ministry of Social Justice & Empowerment have also introduced programmes, for the benefit of persons with disabilities including visually impaired:

A few leading eye care agencies, viz., L.V. Prasad Eye Institute, Venu Eye Hospital, and Arvind Eye Hospital have also established low vision centers for assessment, provision of low vision devices and training of low vision professionals.

Teacher Training :

- (a) The first ever Teacher Training Course for the Deaf blind sponsored by Sense International (India) started at the Helen Keller Institute for the Deaf and Deaf blind, Mumbai in the month of July, 2000. In the first batch, eight teachers successfully completed the course recognized by the RCI. In the second batch (2001) and third batch (2002), 8 and 7 students have been admitted respectively. From the academic year 2002-2003, another such course has been started at the Clarke School for the Deaf & Deaf blind, Chennai.
- (b) Inclusion of Deaf blindness in the Teacher Training : The RCI has upgraded the teachers training courses for the primary as well as secondary level teachers of the blind including one-third of a paper on deaf blindness. Thus all the teachers of the blind will be provided appropriate information about deaf blindness.

Continuing Education

The RCI has sanctioned a few projects for upgrading skills of the teachers of the visually impaired under the mode of continuing education with the following objectives :

- To impart advance training to special teachers in teaching of science and mathematics to the teachers.
- To review the status of teaching of science and mathematics to the blind students.
- To evolve mechanism of promoting learning of science and mathematics among blind students.
- To review use of Nemeth Code for Mathematics among blind students.

There is a need for the RCI, NIVH and other educational institutes for the blind should adopt a system of continuing education as a regular programme for upgrading skills of special teachers of the blind.

The RCI has introduced a national programme for imparting orientation to the Medical officers about all types of disabilities. All the Medical Officers working at the District and Block level in the rural areas will be covered under this programme which includes definition, limitations and causes of visual

impairment; socio-psychological implications of blindness, effects of visual impairment on personality development; and an overview of education and rehabilitation of the visually impaired.

This course is programme very effective in respect of screening, identification and referral of people with eye problems and visual impairment.

The RCI has developed a vocational training module for the instructors of the blind under the Science & Technology Mission. This module will standardize and improve quality of training for such instructors. (Punani , 2003)

Human Resource Development in Hearing Impairment

Manpower in speech and hearing is the professionally qualified women and men who deal with the speech and hearing handicapped. This group includes those with B.Sc., M.Sc. and Ph.D. degrees in speech and hearing one offered in general in India.

The introduction of internship subsequent to the completion academic training, but prior to the award of degrees as per the RCI guidelines is an important step. The professionals in the field have voiced their feelings that an undergraduate program of four-year duration in keeping with other professional courses would increase their promotional opportunities. This step would also pave the way for providing services in the rural areas. It is pertinent to recall at this point that at the AIISH, those enrolled in the Master's program had to complete one year of internship prior to receiving their degrees. The present program of internship is at the Bachelor's level of one-year duration and of shorter duration for shorter programs.

Subsequently, In the year, 1983, the Ali Yavar Institute for the Hearing Handicapped was started. The AIISH and AYINHH have played a signal role in developing manpower in the area of speech and hearing in the country.

The professionals in speech and hearing perform various functions; those of formal and non-formal teaching, diagnosis of speech and hearing problems, selection of suitable amplification and / or assistive devices, recommendation, initiation and implementation of intervention procedures. They are also involved in conducting surveys, camps, and screening programs aimed at educating the layman and in identifying the problem in its early stages.

Manpower in speech and hearing also includes those personnel who may not have professional degree in speech and hearing but who assist the professional in the management of the speech and hearing handicapped. They include ear-mold technicians, technicians who repair hearing aids. Training of these personnel is done through short-term programs lasting for a month or two for those who have completed tenth standard education. AIISH and the AYJNIHH have conducted these programs, the latter doing so at different parts of the country. The Rehabilitation Council of India has standardized a training program in ear-mould making and hearing aid technology with the entry requirement of ten plus two.

The training programs at levels below the bachelor's degree approved by the RCI for the CBR workers for varying duration, short term program for sign

language, and the programs for the VRWs, MRWs and programs for family members conducted by the Directorate of the Disabled Welfare, Govt. of Karnataka, are some of the programs that are intended to generate manpower to help the hearing impaired.

There are no programs for training professionals in the engineering and technical institutions for giving expertise in performing installation and calibration. Hence there is need for a course of study including repair & maintenance.

The speech and hearing professionals need involvement in research activities. The course of study especially at Master's level includes both theoretical and practical training to inculcate in the trainees the inclination for conducting research. The outcome of these research activities help in the overall betterment of the speech and hearing handicapped. No such Research & Development Centre exist in the country.

There is a need for specialist manpower of higher technical capability. Recognizing this need, those programs which started off with an undergraduate degree, have added on the Master's degree program subsequently. The Ph.D. degree program was started in the Mysore University in 1978 and later also the Bangalore University. Doctoral studies have also been pursued at the Indian Institute of Science, Bangalore, PGIMR, Chandigarh by candidates with their basic degree in speech and hearing.

The need of the hour is not only to have sizeable numbers which are capable of meeting the requirements in professional settings, but a force that is capable of adapting itself to new emerging situations. The need is also for ensuring overall high caliber of these forces and their ready availability to meet the demand. The government programs such as the NPRPD to provide more attention to the rural masses and the emphasis on community based rehabilitation constitute other emerging areas that lay emphasis on the development of suitable manpower.

The individual speech and hearing professional is the prime source in providing relief to the communicatively handicapped. In tune with this, the policies for development of manpower should have the following goals :

- i) Increasing number of professionals to meet the increasing demands in various categories.
- ii) There is a growing concern that the existing training programs are not able to get the requisite number of candidates to fill up the sanctioned number of seats.
- iii) Assigning each individual so as to utilize his / her highest potential. The rigorous training imparted to the trainees is not being fully utilized for want of the infrastructure facilities including audiometric rooms, diagnostic test instruments. Added to it is the lack of orientation of the other professionals to the needs and contribution of the speech and hearing professional as a member of the interdisciplinary diagnostic team.

Questions are being raised whether the tools used in professional practice are appropriate in a developing country and if scaling it down might help in retaining and increasing the available manpower in the country.

- iv) Shortage of human resources to man the training programs is an added woe. Charges are traded that the fresh graduates are recruited to man the training programs with little or no experience. There is thus a vicious circle of manpower not being available to generate fresh manpower.
- v) Development of suitable instruction modes. The relevant processes and procedures may be explained through lectures. Patient participation may be used in demonstration. Preparation of aids such as models, audio-visual material, programmed instructional material must form part of the manpower development process.
- vi) Development of criteria for determining the level of competency reached in the various skills expected of them, and at the various levels of training.
- vii) A close evaluation of training programs must also be undertaken periodically in the light of current potential employment opportunities.

Resource Materials are important inputs into HRD programmes. Publications, mostly from abroad, in the form of books, journals, monographs, etc., pertaining to the field of speech and hearing and allied areas, linguistics, electronics, acoustics, psychology, and in medical subjects - neurology, pediatrics, anatomy, physiology serve as resource material.

Audio-visual cassettes prepared by some of the training institutions such as the S. R. Chandrashekar Institute, the AIISH and the AYJNIHH also make good resources. Computer and internet facilities are made available to the trainees in the respective institutions examples being AIISH, AYJNIHH and SRC Institute of speech and hearing.

There is urgent need for developing resource material indigenously instead of depending on overseas publications even at the undergraduate entry level.

Continuing Education :

In addition to the formal programs affiliated to the universities, short-term programs have also been conducted by the national institutes. These programs were planned to meet the demands of allied professionals for orientation to the field of speech and hearing. At the AIISH, Mysore, more than sixty such programs were attended by allied professionals instruments were limited. They were of short duration conducted on demand from enough number of candidates on a specific Topic.

The speech and hearing professionals are also involved in training programs of short-term to the CBR workers, Anganwadi workers, Nurses etc.

The population in the country is large enough to provide the quantitative needs, but the requirement for qualified, skilled and human manpower is not so readily met. The days of relying for manpower is not so readily met. The days of relying for manpower in speech and hearing on large number of men and women trained only in simple tasks of identifying the speech and hearing impaired and providing therapy is far behind us. In modern times, the handicapped is to be dealt with as a whole person.

Efforts Since 1981 (IYDP)

It was the setting up of Ali Yavar Jung National Institute for the Hearing Handicapped (AYJNIHH) in Mumbai in 1983, gave an impetus to the Teacher Training Programmes and other technical services for the deaf in the country. At that time, eight centers were only conducting teacher training programmes as reported by Dr. Rita Mary, in 1993.

Besides conducting D.Ed. and B.Ed. in (H.I.), at AYJNIHH and its regional centers, it also runs collaborative centers, involving the State Governments and the NGOs.

The AYJNIHH also realized that (a) there is dearth of qualified professionals for these centers to appoint as Lecturers (b) the level of model teaching schools, where the D.Ed. trainees did their practice teaching was also very low. Therefore, with concentrated efforts and persuading the Universities of Osmania at Hyderabad and Calcutta respectively, the B.Ed. (H.I) training programme was started at SRC & ERC of AYJNIHH, in addition to already running programme at Mumbai since 1897. This enabled several schools to upgrade their D.Ed. training levels.

Further the Bombay University provided affiliation to conduct M.Ed. (H.I) training from 1995-96 at AYJNIHH, Mumbai. This provides better qualified Lecturers for B.Ed., course and equips teachers for higher education, using curricular approved by RCI.

RCI has also recognized Madhya Pradesh Bhoj (Open) University (MPBOU) for conducting the B.Ed. Special Education Programme through distance mode and it provides technical expertise to the MPBOU and the study centers.

Some Universities are also getting interested in running similar programmes. (Nikam, 2003).

Human Resource Development for Locomotor Disability

The present situation of human resource development for locomotor disabled is being analysed on number of locomotor specific manpower, number on distribution of their training centers, number of standardized courses / syllabus, activities of different councils or standard enforcement authorities, available funding resources etc.

Medical Council of India has registered 575,600 doctors as on 31.12.2001 of which some graduate doctors, some pediatricians, some orthopaedic surgeons and all physiatrists (specialists in PMR) are looking after the medical rehabilitation services of locomotor disabled. Indian Association of Physical Medicine & Rehabilitation (IAPMR) which register practicing doctors of medical rehabilitation with postgraduate qualification both in PMR as well as any other speciality with actual work in medical rehabilitation, has registered 300 doctors of which 175 possess postgraduate degrees who were registered on the basis of their work experience in rehabilitation. There are 22 departments of physical medicine & rehabilitation in 181 MCI recognized medical colleges of the country. The departments are in Medical colleges. About 50 percent of these departments have

got post-graduate degree course in PMR. In addition, there are Departments of Physical Medicine & Rehabilitation in some tertiary level hospitals, which also undertake training in Physical Medicine & Rehabilitation of undergraduate and postgraduate level.

The cumulative number of training centers for post-graduation in PMR is 27, which includes MCI centers as well as NBE centers. Of these 27 training centers in PMR, 3 belong to Ministry of Social Justice & Empowerment while 24 belong to Ministry of Health & Family Welfare.

The training programme for post graduate diploma and degree in physical medicine & rehabilitation has been standardized by MCI. The revised undergraduate medical curricula, as approved by MCI in 199, has included teaching and training in physical medicine & rehabilitation, but the same is kept as optional. Indian Association of Orthopaedics has 4,000 doctors registered with it. They are relevant to the locomotor handicaps as most of them performed corrective surgery. There are department of orthopaedics for postgraduate training in 100 medical colleges and 50 percent of district hospitals have service dept. of Orthopaedics.

Indian Association Physiotherapists has about 10,000 physiotherapists registered with it. There are about 80 colleges and schools of physiotherapy in the country. As there is no council for regulation of physiotherapists, there is a mushroom growth of training colleges in the country particularly in South India. Voluntary exercise is being done by IAP without any statutory authority for regulation of the physiotherapy profession. IAP register the training colleges after inspection and awards recognition to their training programme. However, this voluntary exercise of IAP has not yielded desired results in regulating the profession of physiotherapy. Of these 8 colleges about 42 are registered while 38 are conducting training without any registration. RCI has developed course curricular of two and a half years for diploma course and three and a half years course for degree in physiotherapy. IAP has recommended four and a half years degree course. A mixed picture of duration of training is seen in the country at present. The training programme for postgraduate degree is also standardized and presently is being run at few colleges. On an average, there had been 50 percent exports of this group of professionals, which has become less in recent past on account of stoppage by USA for hiring physiotherapists.

Indian Association of Occupational Therapists is the body, which register qualified occupational therapists. As per IAOT there are approximately 2,500 occupational therapists registered with it. There are about 20 colleges / schools of occupational therapy in the country. The duration of the training and the mushroom growth of training centers is almost the same as in physiotherapy, on account of lack of any council. The IAOT has voluntarily taken up the function of regulating the profession by registering the colleges / schools of training of occupational therapy and recognizing / derecognising their training programmes. However, this voluntary exercise of IAOT has not yielded desired results in regulating the profession of occupational therapist. Hardly 12 training colleges are recognized by IAOT. The Training curricula for diploma and degree is standardized by RCI and IAOT both. At some places postgraduate training in occupational therapy is also undertaken.

Training of the medical officer of PHC was meant for transferring the knowledge of disability management to PHC doctors and according to by Status of Implementation 2001 on National Programme on Orientation of Medical Officers working in Primary Health Centres to Disability Management, 293 Master Trainers and 3,581 Medical Officers are trained against the target of 30,000 Medical Officers are trained against the target of 30,000 Medical Officers. Out of 36 states and Uts only 20 could be covered.

RCI has recognized 160 institutions both in government and in non-government sectors, where Rehabilitation Council of India training courses are operated. Of these institutions only 21 are running training courses for locomotor disabled. These 21 training institutions are spread over 18 States / UTs. It has also registered Prosthetic and Orthotic Manpower as professionals / personnel. They are working in aids and appliance workshops. They are certificate / diploma and degree holder in Prosthetic and Orthotic science. Diploma course and degree course in Prosthetic and Orthotic science has already been standardized by RCI. There are about 250 registered professionals / personnel in the category of prosthetic and orthotic manpower. In the country there are seven training colleges, which are imparting training of degree level in Prosthetics and Orthotics.

RCI also registers multi-rehabilitation workers under the category of Multi-purpose Rehabilitation workers and technicians. RCI has recognized two years training programme for multi-rehabilitation workers, who is supposed to be key person for rehabilitation at block level. The programme was started with high hopes for producing skilful functionaries, who can act as worker, facilitator, coordinator of rehabilitation programme of disabled of a block, but it has not pick-up the required momentum due to manifold reasons. Initially, the manpower was being produced by seven training centers, which have been reduced to three in 2000. There are approximately 500 MRW in the country. There is a need to review this key training programme from all the angles, fine tune it from the point of view of the needs of all stake holders and refloat it in modified form.

It is a fact that the focus of the programme of rehabilitation of a locomotor disabled person is the patient himself. It is also a fact that the awareness about his disease and disability can bring about a lot of changes in success or failure of the programme. However, it is a pity that the general awareness programme about disease, accident and disability are only confined to some slogans, posters and T.V. films, which neither equip the disabled person with proper knowledge and skill nor facilitate the process of rehabilitation. The same is the case with the parents and family members of a locomotor disabled. However, a ray of hope was generated when RCI started structured bridge course, which was taken up 21 training centers and trained 8,841 such parents and family members, but the same is meant to clear the backlog only.

On the basis of the situation analysis of manpower, training facilities, regulatory mechanism and funding sources and manpower projections as given in the report on Manpower Development by RCI, it is clear that the issue of manpower development requires re-examination and in depth analysis. As locomotor disabled is primarily the concern of Ministry of Health & Family Welfare, it is the suitable ministry for doing this job. There is a set strategy of development

of manpower in different national programmes, which consists of national trainer, regional trainer, district trainer and PHC trainers. They are known by different names at different programmes. It is necessary that while planning and phasing the training, the same strategy should be followed and efforts should be made to converge all training facilities at one focus. The training should cover the manpower to be produced in future by introduction of rehabilitative component in their training curriculum, the manpower already available for the locomotor disabled persons by orienting them to the needs of locomotor disability and by producing required number of qualified teachers for them. This is the only method by which rehabilitation of locomotor disabled can become a part of regular service delivery system. (Srivastav, 2003)

Human Resource Development for the Mentally Retarded

One important area which is to be attended on priority is the development of manpower and training facilities in various areas of manpower, more particularly the teacher training programmes in the field of rehabilitation of mentally retarded, which was individualistic, haphazard, characterized by diversity, incompleteness and largely by irrelevance. There was no restriction imposed or condition to follow, nor bodies to process. Even if RCI came into existence as a society in 1986 to regulate the broad parameters of manpower development and the various programmes related to it. The recommendations and suggestions were hardly implemented wherever any special education training programme was being conducted.

Based on the recommendations on the National Education Policy, the Rehabilitation Council of India was formed as a statutory body under the RCI Act 1992 (w.e.f. 1993) passed in the Parliament after which manpower development and training programmes came straightway to the grip of RCI.

For human resource development programme, RCI is conscious of its role in maintaining and providing well qualified professionals, and high quality standards of services. For this purpose, RCI has formulated norms for recognition of institutions, and programmes. These are (i) only agencies, institutions receiving grant either from the Central Govt. or the State Govt. are considered, and (ii) the required infrastructure and professional standards have been clearly prescribed for each category qualify to recognition by RCI. After fulfilling the above criteria., inspection teams of highly qualified professionals are sent to study the capabilities of institutions for giving recognition by RCI. Under section 11 of the RCI Act, it is a mandatory legal requirement for all universities and institutions offering or intending to offer training courses in the field of disability rehabilitation to seek RCI recognition before the commencement of the course. Accordingly, all the institutions are inspected by the visiting experts to assess infrastructural facilities, faculty, etc. before granting recognition to start the programme. So far 160 institutions have been granted recognition to run courses recognized by the Council.

The manpower report (1996) prepared by RCI has projected that about 0.36 million persons would have to be trained during the 9th Plan period.

Various National Institutes as well as the Ministry of Social Justice and Empowerment are implementing the Manpower Development Programmes. Currently such centers run the Diploma in Special Education (Mental Retardation) and D.S.E. (M.R) course producing about 800 special teachers every year. The Universities offering B.Ed. and M.Ed. in special education have also increased considerations.

Manpower Requirements

RCI has developed in the manpower development document the type of professionals who would work in the field of disability and in mental retardation with an estimate (Projected)

For all disabilities RCI has developed 59 courses for different levels and different professionals by now, besides the short term courses, i.e., Bridge courses, PHC doctors training curriculum, and 45 days programme for primary teachers working under DPEP system.

A projection of Human Resource requirement for the ninth and tenth plans phase by RCI reveals a great gap between availability of trained teachers and the number of children to be catered to. It has also recognized as many as 41 training institutions in the country where the programmes are located.

Human Resource Development Programme

The various programmes in manpower development which are running can be looked in terms of long duration courses, short programmes, and workshop / orientation programmes contributing to professional inoculation of different personnel. The special teacher training / and master trainers are most essential. RCI has standardized the teacher training curriculum at certificate to M.Phil levels. During the year 2000-2003, NIMH has trained special teachers to work in special schools. Diploma course in special education was conducted at centers supported by or affiliated to NIMH are spread across the country. This is the largest network of teacher training centers in the field of mental retardation in the country. Diploma in special education holders are now available.

The Institute has been conducting a year degree course in rehabilitation studies (MR). The course is designed to impart skills from multi-disciplinary aspects so that comprehensive services can be provided for persons with mental retardation in non-school educational settings. The Bachelor of Rehabilitation service programme in MR is also being conducted in Chennai at the Holy Cross College with built in rehabilitation practice programme. State-wise qualified candidates in BRS course upto 2001 indicate that out of all state AP, Bihar, Uttar Pradesh, Tamilnadu have taken a major chunk. The States, Union territories like Assam, Goa, Chandigarh, Haryana, Himanchal Pradesh, Karnataka, Nagaland, Punjab are the least recipient of the programme.

A one year academic course preparing professionals as vocational instructors DVTE (MR) for the purpose of training-cum-employment in the field of mental retardation has been started from the year 1995-96. This course presently is being offered at NIMH, Secunderabad and Navjyothi Trust, Chennai which is financially supported by NIMH.

This course has inputs from industrial engineering, psychology, social work, management and special emphasis of training persons with mental retardation. Eligibility for admissions is 10+2 or intermediate or its equivalent examination in general education or vocational education.

Distance Learning for HRD in Disability

Distance learning is emerging as a possible solution to meet the shortfall of rehabilitation professionals. In a break-through development, rehabilitation education programmes are now available through the distance learning mode. Under an agreement with Rehabilitation Council of India, Madhya Pradesh Bhoj (open) University has launched B.Ed. (Special Education) through distance mode for training of special teachers.

The programme has been launched throughout the country through 51 Study Centres. Of these 21 Centres are recognized to run the Mentally Retarded programme.

On an average about 600 to 700 teachers receive the B.Ed., SE-DE (MR) during 2001-2002 (14 months) and during 2002-2004 another 500 are enrolled. The course duration has been change now to 18 months. As per another MOU signed with Indira Gandhi National Open University (IGNOU), certificate course for CBR workers through distance mode will be launched shortly. Another programme for sensitization of parents through use of audio-visual/multi-media technology is also be launched shortly.

The NIMH at Secunderabad has been running a post-graduate diploma in early intervention in Mental Retardation.

It has also developed a Diploma level course for training teachers for pre-school in the area of mental retardation. These programmes will eventually contribute to meeting the needs of rehabilitation of mentally retarded or intellectually challenged in India in the foreseeable future and should be run in different institutions to meet the target.

At present the following programmes are also being run which prepares manpower related to the rehabilitation of the MR. Master of Rehabilitation Services, Holycross College, Tiruchinapalli, Chennai Multi Rehabilitation Workers Safdarjung Hospital, New Delhi, Mercy Home, Chethipuzha Madras Institute of Rehabilitation Service, Vikalanga Kendra Allahabad, Master in psycho-social Rehabilitation. The Richmond Fellowship Society, Bangalore, M.Ed. (Multicategory), Ramakrishna Mission, College of Education, Coimbatore, Chennai, M.Ed. Special Education

S.N.D.T. Women's University, Mumbai, Post-Graduate Diploma in Developmental Rehabilitation (PGDDR), THPI, Hyderabad, Post Graduate Diploma in Rehabilitation Psychology (PGDRP), Aligarh Muslim University, Aligarh, Calcutta Univ., Psychology Dept. Calcutta, P.G.D.S.E. (M.R.), Society for Mental Health Care, Burdwan, M.Phil (Clinical Psychology). Manipal Academy of Higher Education, Manipal. However, NIMHANS, Bangalore and CIP, Kanke, Ranchi also offer such programmes. M.Phil in Rehabilitation Psychology, NIMH has also stated in 2003-2004 with an intake of

10. Besides PT/OT, courses, Speech Therapy Courses are being run in a number of institutes in the country including NIRTAR, All India Inst. Of Speech & Hearing, NIOH, ANJNIHH. (Panda - 2003).

Innovations in Human Resources Development for persons with Disabilities

The RCI Act provides that every person delivering services to persons with disability must possess a qualification recognized by RCI and be registered with the Council as a mandatory requirement.

The scheme of offering a Bridge Course was devised as a means to overcome the back log of untrained manpower and was launched as a National programme on 2nd October 1998. It was an one time measure designed to assist those professionals who were working prior to 1993 in the field of rehabilitation, but did not have a qualification recognized by the Council, to get registered with it.

Teachers, Instructors, counselors, placement officers, CBR workers or any other categories of professional/personnel, dealing with disabled persons without any recognized qualification, prior to 1993, shall be eligible for joining the Bridge Course.

The scheme covers the major areas of disabilities including cerebral palsy, learning disability, autism and attention disorder is one area.

There are two broad objectives of the course :

1. To train those who have had wide experience but no recognized qualification.
2. To spread awareness about the problems and potential of people with disabilities particularly in rural areas.

While most of the trainees have acquired considered experience in teaching, they feel that the Bridge Course has exposed them to various professional and management aspects of rehabilitation. Not only has it helped them in a pure academic sense, it has also made them more professional in outlook and appreciate the kind of linkages that need to be worked out in the community and society. The Bridge Course has further helped them to update their skills and create a more functional environment in their respective institutions. This has been a forwarding looking step in HRD preparation.

It may be one of the solutions for meeting the need of large manpower in the field of disability significantly different from a zero base.

***Forty Five Days Foundation Course on Disability :
A step towards inclusion***

RCI has developed 45 days training programme which includes five areas of disability : MR, HI, VI, LD, LI. The purpose of the programme was to orient the teachers of primary schools through DPEP and state Govts and give the knowledge, skills, attitudes and instructional teaching techniques to handle the disabled children in the regular schools. Such training will not only contribute to care of disabled in the classroom but will contribute to the enhancement of schooling and eventually to UEE in an inclusive setting being a cost effective programme.

The Ministry of HRD, Government of India is also making efforts to incorporate special education in the curriculum of regular school teacher training programme. Both pre-service and in-service training programmes are being modified to incorporate special education component into the curriculum. Many pre school teacher-training programmes have also included "Education of exceptional children" in their curriculum. Considering the paucity of trained teachers and the large number of children with disabilities to be reached, the nation is gearing up to clear the backlog of untrained teachers in special schools and in regular schools.

National Programmes on orientation of Medical Officers

National programme on Orientation of Medical Officers working in Primary Health Centres to Disability Management has also been launched the RCI plans to train about 30,000 Medical Officers through selected agencies located all over the country; i.e. medical colleges, NGOs, Rehabilitation centres.

***Short duration Programmes for professionals and
Growth of Functionaries Including parents***

Both the Government and Voluntary Organisations are involved in extension services of training the trainers of children with severe disabilities. Crash orientation seminars. Workshops are organized for teachers of ordinary schools on different aspects of special education. A number of programmes that the National Institute of Mentally Handicapped and its Regional Centres, NGOs, leading NGOs like THPI, Amarjyoti, MRIH, CHETNA, DEEPSEKHA, and SNTD Women's University, an MIND'S College of Education, are running. These simply demonstrate coverage, and continuous awareness and professional development through exchange participation, deliberation contributing to the holistic development and rehabilitation of mentally retarded. The CRE programme have now been standardized to quality standards.

Parent Training Programme

NIMH is has initiated wide ranging family oriented services. It is one of the models of services where the intention is to empower the parents and family members to look after their children with mental retardation as against providing

institutional support or residential programmes which are expensive and lead to de-socialization of persons with mental retardation. This is a unique programme now being followed by many NGOs.

Professional Enculturation through workshops

NIMH organizes national level programmes : one for professionals, one for parents, and one for persons with mental retardation on different themes to build latest awareness and thinking in the area of intellectual disability.

In human resource development one of the major activities is to conduct refresher courses, training workshops and continuing education programmes for professionals. Short-term courses are being conducted by Govt. University & NGOs and also other schemes of disabilities providing opportunities to professionals to upgrade their knowledge and skills and render services to persons with mental retardation. It is estimated that there are 832 institutions in the country having an estimated 8,320 professionals at an average of 10 professionals per institution, who need continued exposure(Panda 2003).

Human Resource Development for persons with Multiple Disabilities

A. Human Resource Development is the key to initiate and maintain quality services for deaf blind children. Since the field is a new one in the country there is an obvious need for training and expertise in order to sustain the different services to deaf blind persons.

- RCI recognised courses for teacher training in single category disability has helped in pooling in resources for the deaf blind field till date.
- RCI recognised first teacher training course in Deaf blindness in Asia and the National Institute for the Visually Handicapped certified the same course which is running at the Helen Keller Institute, Mumbai with support from Sense International (India)
- Component on Deaf blindness has been included in the training of Primary and Secondary teachers.

Short Term Programme

Besides the above recognised and certified courses, there are a number of informal training activities being undertaken in the field of deaf blindness in the country. Some of the significant ones are :

- Awareness training programmes for in-service single category teachers, itinerant /resource teachers, medical professionals, community workers and so on.
- Orientation programme on needs of deaf blind children for teachers working for children with deaf / blind / multi handicapped / Cerebral palsy / Mental retardation.

- Specific need based topics such as Early Identification and Assessment, Communication and so on for teachers working with deaf blind children.
- Leadership training for personnel organising and managing different kinds of services of deaf blind children.
- Intensive training on working strategies for and hands on workers at the programme sites.

The first Deaf blind Asian Conference, 2000, held in India set the pace for many professionals to come together and brainstorm on the various issues concerning human resources development specific to the field of deaf blindness. Similarly the National Experts Meetings, organised by Sense international (India) have been instrumental in getting people together to identify their staff development needs and match it with appropriate existing training opportunities or create new training activities.

As the field is emerging there has been a repeated concern for the need for developing more and more formal training programmes for different target groups. (Paul - 2003).

B. A large number of innovative and well-planned programmes have been initiated across the country for this category of children with multiple disabilities with visual disability.

The Hilton Perkins International Program, USA took the lead in providing training to professional workers and Master Trainers of the children with multiple disabilities. Due to initiatives of Sense International some innovative programme have been undertaken.

- (a) New Campus of the Helen Keller Institute for the Deaf and Deaf blind, Thane-Belapur Road, Navi Mumbai was inaugurated on 3rd March, 2001. The new and spacious premises also houses Vocational Training Unit for Deaf blind Adults and the Teacher Training Programme.
- (b) Satellite Centres : BPA has established six Hilton Perkins International sponsored Satellite Centres for providing comprehensive services to children with multiple disabilities in remote areas. Out of 78 such children, 17 of them are those with deaf blindness. The HPI has also extended technical support to a large number of organisations in India including Education Leadership Programme, teacher training, early intervention and material development.
- (c) Nation-wide programme : The SII has extended technical support to a number of organizations including training through Professional Development Programme. Home Based Services to Deaf blind Children in seven states of India.

Human Resource Development for Cerebral palsy

All the major NGOs in the cerebral palsy sector have taken a leading role in providing training at community, secondary and tertiary levels. They have worked closely with RCI in developing and augmenting training programmes. In fact the first university that came forward to recognise a disability course was

Jadavpur University in West Bengal. Since cerebral palsy does not fall under the purview of any of the existing National Institutes, NGOs have taken a lead in supporting and designing training initiatives. Specialised training programmes in this category have recently been developed on self-advocacy, developmental therapy and augmentative and alternative communication (AAC). Besides professionals training programmes the emphasis of all the NGOs working in the field of cerebral palsy is one working with the families by providing opportunities for empowerment and training. People with cerebral palsy need to be provided with more opportunities to take a leading role in taking policy decisions about their own future, as they are interested and potential leaders in this field.

Name of the institution	Courses offered
The institutions such as The Spastics Society of Tamil Nadu; Chennai;	P.G. Diploma in Special Education Diploma in Basic Developmental Therapy for Cerebral palsy and other Neurological Disorders
Indian Institute of Cerebral palsy, Kolkata	Post Graduate Diploma in Special Education
The Spastics Society of India, Mumbai	Post Graduate Diploma in Education of the physically Handicapped (Dip. Ph. H.)
Vidya Sagar (Formerly Spastics Society of India, Chennai)	Post Graduate Diploma in Special Education

Short Term Courses

Community initiatives in Inclusive Education course for trainees and planners of Community Disability services; Orientation course on Disability management for Nursing students. Orientation of both under-graduate and Post-graduate Medical students.

Senior trainers course ; Zonal Affiliate trainers course ; Community Based Rehabilitation physical and Functional Management of Multiple Disabilities in the Community; Basic Management of Cerebral palsy for Medical Practitioners and Basic Management of Multiple Disabilities in the Community are being conducted to update and / or develop manpower in the area of CP.

Training of Care Givers

The National Trust for the Welfare of persons with Autism, Cerebral palsy, Mental Retardation and Multiple Disabilities has formulated a scheme for providing a three-month training programme for care givers with the objective of empowering families to retain their disabled members within the family and the community. The above training programmes are presently being conducted by Indian Institute of Cerebral Palsy, the Spastics Society of Tamil Nadu and other training NGOs in India. (Kaul 2003)

Courses conducted by RCI recognized Institutions

- P.G. Diploma in Developmental Therapy.
- P.G. Diploma in CBR.
- B.Ed. (Special Education)- MR-HI/VI
- Bachelor in Mobility Science.
- B.Ed. Special Education - Distance Mode)
- Bachelor in Audiology and Speech Language pathology (BASLP).
- Bachelor in Rehabilitation Science.
- B.Sc. (Special Education and Rehabilitation).
- Bachelor in prosthetics and Orthotics.
- Bachelor in Rehabilitation Therapy.
- B.A., B.Ed. 9VI)
- M.Ed. (Special Education) – MR/HI/VI
- Master in Audiology and Speech Language – Pathology.
- Master in Rehabilitation Science.
- M.Sc. (Psycho-Social Rehabilitation)
- M.Phil. (Clinical psychology)
- M.Phil. in Rehabilitation Psychology.

Recent Initiatives taken by RCI

- i) The Council is working to establish a College of Rehabilitation Sciences to impart advanced training to professionals covered under the RCI Act and the Persons with Disability Act. The objective is to advance the frontiers of knowledge underlying the practice of rehabilitation disciplines and professions through research, teaching and professional development, besides standardization of education and rehabilitation of persons with disabilities. The College would aim to secure the advancement, diffusion and extension of knowledge in all disciplines of learning for persons with disabilities.
- ii) The RCI regularly maintains linkages with various National and International agencies. This is important to share the new programme developments and latest technologies emerging day by day. It also helps in collaboration, updating knowledge concerning disability and exchange of literature, which concerns to human resource development.
- iii) In order to utilize the latest information technology and enhance the efficiency, the process of computerization of the activities of RCI is being undertaken by the National Informatics Center (NIC), Govt. of India. Under the programme, LAN system has already been installed and the officials have been trained by NIC in computer applications. RCI website is being updated to give it a more professional look. In addition to information on activities of RCI, it is also proposed to have comprehensive information on all areas of

disabilities for the benefit of persons with disability, parents, professionals, researchers, administrators and others. The website is being made bilingual, i.e., English and Hindi.

Teleconferencing/video conferencing facilities are also being created at RCI with the assistance of NIC which will have linking with NIC centres all over the country. Once functional, it will help in dissemination information more quickly, particularly in rural and remote areas.

Rehabilitation Council of India launched its website (www.rehabcouncil.nic.in) in pursuit of automation and excellence for improving the quality of life of persons with disabilities. The website is a step forward in pursuit of the goal of improving the quality of the disabled people as it would enable the society to have access to the latest development in the relevant fields. (Singh, 2003)

Review of the Manpower Development report of the RCI for Ninth & Tenth Plan has indicated some specific requirements and accordingly.

The following Human Resource Development Courses have been suggested

1. Diploma in Prosthesis and orthosis
2. Bachelor course in Rehabilitation Therapy
3. Postgraduate Diploma in CBR
4. PG Diploma in Rehabilitation
5. PG Diploma in Disability Rehabilitation
6. M.Sc. in Prosthetics and Orthotics
7. Credit based courses
8. Diploma in special education (Autism spectrum Disorders)
9. M.Sc. in Audiology
10. M.Sc. in speech pathology
11. M.Phil in Rehabilitation Psychology
12. Diploma in special Education - Deaf blind
13. PG Diploma in Cerebral palsy
14. M.Ed. Multiple disability
15. Modular course on Research Methodology

These course in addition to the existing one's would contribute to comprehensive human resource development provided that the programme delivery, built in practical internship (on the job training). Proper monitoring and evaluation, courses being taught by trained professionals are taken up quite seriously be it any mode, Any attempt to make HRD programmes populist will not contribute to disability rehabilitation management.

Humanistic element in Human Resource Development Programme

As is obviously the case, human resource development programmes are basically knowledge, skill and rarely attitude oriented. In case of disability rehabilitation what is equally important is a humanistic orientation to the various problems disabled people face, organisations of disability encounter and such an emphasis would automatically strengthen resource components in training.

This means more particularly the various categories of professionals undertaking training preservice particularly an effective orientation to a few specific areas of concerns for rehabilitation purposes. These are

- Service and human values
- Understanding the needs and rights of the disabled
- Paying individual attention
- Developing and using resources
- Resource Management
- Collaborative working

which could contribute to effectiveness of rehabilitation activities in any organization dealing with disability. Hence, any curricular development and for renewal shall take into consideration the above elements across disabilities and across professional groups, (Rao, 2002) to strengthen the HRD programmes and the products coming out of such programmes.

The future perspective in Human Resources Development for Disability Rehabilitation

Persons with disabilities have problems in undertaking education, work and participation in community activities expected of individual of the same age and socio-economic status. Therefore, the purpose of rehabilitation will be to enhance the capacity of a person with disability to receive better education, vocational training and social skills so that he / she can be mainstreamed.

Mass awareness is very vital for providing rehabilitation services to the unreached, Awareness can be generated through all kinds of means and mass media. In this regard we have to train professionals for providing timely intervention for those who acquire disability early in childhood as a result of infections, trauma or genetic causes. This will also include early detection. Developing simple mechanisms and tools for early identification by primary school teachers and training professionals for providing early childhood education to children with various special needs is also the need of the hour.

We need to train professionals to provide education through multi-option system covering inclusive education, integrated education, special school, distance learning, home based education part time education and alternative schooling or any combination of these that suits the need of the child and also to train paramedical teachers for providing non-formal education.

There is a need to train manpower to promote fundamental as well as applied research in the area of Rehabilitation and Special education. Stress should be laid on empirical action research so that benefit could reach disabled people in the shortest possible time.

The RCI shall undertake a thorough on-going review of the curricula already prepared by it with a view to laying better stress on emerging technology in imparting education and providing rehabilitation services both in urban and rural areas. Further curricula will be developed for the training of professionals to provide entire continuum of rehabilitation services already indicated and to include a component in all training programmes and at bringing positive changes in social attitudes towards disability. The objective will be to promote better appreciation of the potential of all persons with disability. Short term courses will have to be developed for this purpose.

Several foundation courses should be launched through the conventional or distance mode to promote the development of appropriate human resources on an urgent basis without sacrificing quality.

Professional development calls for developing considerable and competent teaching facilities as well as properly monitored and regulated research.

There is a need to consolidate and expand manpower development through upgraded curriculum and teaching learning material at post-graduate and diploma levels in all areas of disabilities. For this, master training programmes should be encouraged by involving experts throughout the country and from abroad. Since a larger number of institutions in the voluntary sector are going to depend on professionals with diploma and certificate holders, focus should be on development and expansion of professional courses at these levels. Priority should be given for expansion of programme of diploma and certificate level. Special emphasis should be given on the psychological rehabilitation of the disabled. Since different Ministries such as Ministry of Health & Family Welfare, Ministry of Human Resource Development, Ministry of labour, Ministry of Rural Development & Employment are contributing for the welfare of disabled persons besides the Ministry of Social Justice & Empowerment, inter-ministerial collaboration and co-ordination is needed for the overall development of persons with disability.

The main purpose of RCI is to accelerate and diversify human resource development in such a way that rehabilitation and education reaches every child or adult with a disability in the country. NGOs have been pioneers in the field of rehabilitation and special education in this country and in almost every country of the world. But the disability scenario is changing the needs of people with disability rapidly. NGOs have to enter into a constructive partnership with the state. But before they can do so, NGOs have to dialogue among themselves to evolve strategies for the promotion of a creative partnership with the State for the purpose of reaching everyone who is unreached today and contribute to HRD activities.

The persons with disabilities formed a substantial amount of the population, rehab services are to be planned and developed. This can be done through HRD programme & institution building. If the promise of the 86th constitutional amendment and such as 26 of PWD Act is to be a reality the States need to plan for early intervention & general orientation for persons with disability and their family. The data clearly indicates disability affects a large portion of older persons with the life expectancy rising and also the years of survival beyond 60. Bearing the needs of elderly persons well need special care & issues of accessibility in view their physical capacity will require attention.

The demand for rehabilitation professionals is very great keeping in view the enormous need of rehabilitation services of nearly 18.5 million people with disabilities in the country. In the 10th plan it is envisaged to reach a respectable figure of between 25 to 30% for which various models are being worked.

The GOI has taken initiative in generating manpower through the network of NIS at the apex level institutes only AYJNHH, NIMH, NIVH, NIOH, NIRTAR, IPH, & in total 144 institutes including apex level institutes. RCI has been set up as a statutory body to formulate & standardize the rehabilitation courses. Many voluntary agencies not only provide services but also act as potential pressure groups.

Conclusion

Organised programmes and packages in the field of human resources development are required to be evolved to effectively manage Rehabilitation activities being undertaken by the NGOs. Ministry of Social Justice and Empowerment is working on a massive some of e-rehabilitation to be launched through out the country for trained tour is everywhere. The strength of community groups / NGO is more in terms mobilizing non-financial resources, inspiring high levels of performance for it and is being able to innovate experiment, & in general carry out activities in a more flexible institutional environmental than that usually allowed in Govt bureaucracies. While NGOs may utilize resources more effectively than government in certain situations they are not realistic in planning for investments in human resources development. HRD involves a range of interrelated activities in order to achieve its goals, Govt. intervention should be sensitive to these interrelationships and use them to their advantage. The determination of priorities should be based on understanding of the cumulative effects of alternative intervention, interdepartmental co-ordination even inter agencies coordination and collaborative team work are valuable solutions to the need and the problem. This needs integration of policy making, planning and implementation at all levels.

HRD has been viewed in terms of capacity building of professionals, technicians, service providers, parents and community members and the disabled child. It is considered that the disabled child himself is a resource and that resource has to be nurtured and developed. In order to conceptualise HRD in this integrated fashion the public policy and manpower requirement have to lead capacity building of different target groups interacting personnel for social security, leadership groups, family and community for advocacy and awareness building and finally research and development professionals for contributing to indigenous practices in rehabilitation. The state of art in HRD in the area of visual impairment, multi disabled visual impairment, hearing impairment, locomotor disabled, mentally retarded, deaf and blind, cerebral palsied, have been described in relation to pre-service training continuing rehabilitation programmes, distance mode of education, short term courses and training of Intervention Specialists including medical officers at the primary health centres and training of Master Trainers. For professional enculturation in the field of HRD, workshops organized by various national Institutes have been focussed and the contribution of Rehabilitation Council of India in the development and standardisation of the curriculum for different categories of rehabilitation professionals have been spelt out including covering linkage with various professional agencies as well as application of Information Technology in HRD. An attempt has been made to make a plea for including humanistic elements in human resource development programme in the field of disability rehabilitation for improving service delivery as well as organizational effectiveness. The future perspective in disability rehabilitation concerning HRD runs across the model which was developed in the beginning portion of the chapter involving professionals, the disabled and the community leading to an integrated model of HRD.

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Chapter 6

Inclusive Education and the Common School in India

Madan Mohan Jha

The purpose of this paper is to examine education for persons with disabilities, of the children at the school level in particular, not in isolation but as a part of the school system. It is the case of the author that giving equal opportunity of education to all children, the disabled included, is not a question of a programme or a project. It is a systemic issue. In that context the paper analyses the policy of the common school system and policies relating to education of children with disabilities, and argues that educating the disabled could become a reality in the foreseeable future if concerns are expressed in regard to the systemic reforms, which benefit all children and the disabled remain an integral part of the reform process.

Introduction

The history of education of persons with disabilities is a progression from segregation to integration, and now to inclusion. It may be important to look at the development in the West, in England in particular since a general perception persists in this country that our system has been influenced by the British (or the colonial) education system. In England, while mass education became the responsibility of the state with the enactment of the Education Act of 1870, a separate Act after 13 years laid a duty on the Local Education Authority (LEA) to provide education for the blind and deaf children, thus laying the foundation of the special education. Subsequent education acts in that country expanded the scope of education for children with other types of disabilities, with the Education (Handicapped Children) Act of 1970 bringing the last group of children- those with severe disabilities- into education. The first attempt to divide the bridge between the general and special education was made with the Education Act of 1976, which laid down a duty on LEAs to provide education of the disabled in normal schools when it was practicable. It is said that this section was never implemented (Jha, 2001).

The most landmark development in education for the persons with disabilities in England could be traced to the Warnock Report of 1978 that introduced the concept of 'special educational needs'. The term has become synonymous with

education of the disabled across the world, and is being used in India by all those involved in it, though it does not have a legal meaning or an agreed definition unlike in England where the 1981 Education Act defines the term, and the Code of Practice issued following the Act, and revised from time to time, lays down a very detailed guidelines on how to identify children with special educational needs and seek additional resources and support from the government.

In India, we do not have such parallel legislations, though we have policy statements from time to time including the Persons with Disabilities Act of 1995, which encourages for 'integrated' education. However, we have not been able to provide the constitutionally guaranteed elementary education for eight years to *all* children, despite the repeated promises, programmes and projects. The proportion of children with disabilities missing the education being offered under the existing system would be very high. The gaps between educational opportunities in India are not confined only to the disabled and the non-disabled, it may be seen across the country among its diverse population as well as the geographical spread. The disparities have been commented upon by Alexander (2000,p.82) cited by Day (2003), India's many disparities include massive differences between rich and poor, exacerbated by geography, class and caste, between world-beating high tech cities...and low tech subsistence farming; between world class universities and training institutes, and rural primary schools, some of which exist in name only, having neither buildings nor teachers. (Emphasis added)

The country has been struggling to achieve the goals of *education for all* through a series of policy announcements and the programme launch, the latest being the 86th Constitutional amendment guaranteeing 'free and compulsory education' to children for age 6-14, the *Sarva Siksha Abhiyan* and the education bill intended to convert the Fundamental Right to elementary education into a reality. When it comes to education of the persons with disabilities the immediate hunch of the policy makers and 'special' educationists is to launch some new schemes for the disabled children, or rehash the old one and refer to 3% reservations. The paper becomes relevant for the policy makers, special educationists and social activists as it presents a different paradigm to approach the issue of education for children with disabilities.

Policy progress for educating the disabled

There has been four major policy initiatives aimed at bringing children with disabilities into the school system. Notably, the first initiative had been taken before the country became independent, in 1944, when the Central Advisory Board of Education (CABE) submitted a report to the government on the post-War educational development in India. John Sargent, the British chief, had largely authored the report, and might have been influenced by developments in England with the 1944 Education Act that made it *mandatory* for the local education authority to provide 'special education treatment' to those with a 'disability of mind and body' in special schools or elsewhere (Jha, 2001).

The Sargent report made three important recommendations, which remain relevant even today. First, it recommended that 'provision for the mentally and physically handicapped should form an essential part of a national system of

education and should be administered by the education department.' Second, '*wherever possible, handicapped children should not be segregated from normal children*'. Third, the report set aside 10 percent of total budget for the basic high schools for the provisions for the disabled on '*really comprehensive lines*' (CABE, 1944, p.11, emphasis added)

The first education commission or the Kothari commission in 1968 recommended the '*integrated education*' for the disabled, but made a judgmental observation, contrary to the spirit of the integrated education, when it said, '*many handicapped children find it psychologically disturbing to be placed in an ordinary school*'. The second contradiction in the commission's report could be seen in its assertion that '*the Constitutional Directive (Article 45) on compulsory education includes handicapped children as well*', but in its '*plan of action*' it recommended facilities only for '*ten percent of the total number of the handicapped children*' by 1986, thus leaving 90 percent outside any intervention by the government (Education Commission, 1966). The 1968 National Education Policy followed the commission's recommendations and suggested the expansion of education facilities for the disabled children and also the development of '*integrated programmes*.' This led to the formulation of the Integrated Education of Disabled Children (IEDC) in the then welfare ministry in 1974.

The National Policy on Education, 1986 (as modified in 1992) called for the education of the disabled with the others '*wherever it is feasible*' (MHRD, 1998). Three years later, the Persons with Disabilities Act, 1995 required the appropriate governments to '*endeavor to promote the integration of students with disabilities in normal schools*' (emphasis added). It may be seen that since 1944, in all the three policy statements there have been mere changes in the phraseology - wherever possible (CABE 1944), wherever it is feasible (NPE 1986/1992) and endeavor to promote (PWD Act 1995) without making any significant departure aimed at the system as whole that would '*include all children with disabilities*'.

The progress at the international level and the UN fora had been on different line in 1980's and 1990's to which India has been consistently committed. The UN World Programme of Action Concerning Disabled Persons (1983) called upon the member states to '*recognize the rights of the disabled persons to equal educational opportunities*' (Article 120). The World Declaration on Education for All (1990) recommended for the steps '*to be taken to provide equal access to education to every category of disabled persons as an integral part of the education system*' (Article 3.5). This was again emphasized under the UN Standard Rules (1993), which insist that the education of persons with disabilities should be '*an integral part of the education system*' (Rule 6). The most landmark development in education for persons with disabilities has been the World Conference on Special Needs Education: Access and Quality (Salamanca Statement, UNESCO, 1994), which proclaimed that '*Regular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all; moreover they provide an effective education to the majority of children and improve the efficiency and ultimately the cost-effectiveness of the entire education system*' (UNESCO, 1994).'

In the same spirit the conference called upon all governments and urged them to 'give the highest policy and budgetary priority to improve their education systems to enable them to include all children regardless of individual differences or difficulties', and 'adopt as a matter of law or policy, the principle of inclusive education, enrolling all children in regular schools, unless there are compelling reasons for doing otherwise'.

While the emphasis at the world level has been on equal opportunity and change in system so as to *include* persons with disabilities into the educational fold, the Indian policy has largely remained unchanged since 1944, and the state interventions have remained piece meal and targeted only at a small percentage of the disabled. While reviewing the national policy, the Committee headed by Acharya Ramamurty observed that the education of the disabled is viewed as a 'social welfare' activity and 'the IEDC scheme was being implemented in terms of running 'Mini Special Schools' within general schools. The committee further commented, 'NPE has not stressed the mobilization of the total general education system for the education of the disabled. Special schools have been treated in isolation from other educational institutions from the point of view of providing the educational supervisory infrastructure, leaving it to the ministries of welfare and HRD to co-operatively develop the same (MHRD 1990).' While critiquing the National Policy on Education, 1986 (as modified in 1992) Jangira (1997) observes, 'Though endorsing integration, the NPE seemed hesitant in full commitment to universalization of elementary education for this group of children (disabled) just like other children. It remained silent on the department of education assuming full responsibility for education of children with disability (p.496).'

As per a UNESCO report of 1995 over ninety five percent of the countries surveyed had transferred responsibility of special education to the mainstream ministry of education (UNESCO, 1995). The policies in regard to the education of children with disabilities have remained fragmented, and vague in regard to ascertainment of the 'feasibility' and 'possibility' of admission of these children into regular schools. Who decides the 'feasibility' and 'possibility' on their behalf? Do they get the same power to exercise choice of schools as available to the non-disabled children and their parents? It may be worthwhile to examine the development of policies on the general school system in the country since independence if children with disabilities are expected to enter general schools as a part of the integration and inclusion into the society through the school as a vehicle.

Common School System

On the eve of India's independence the country had a road map, in the shape of Gandhi's Basic Education to 'alter the symbolic meanings of education and thereby to change the established structure of opportunities for education' (Krishna Kumar, 1994). Launched in the National Education Conference in Wardha in 1937 the Basic Education or *Buniyadi Siksha* had been under operation for ten years, which aimed at 'a proper and harmonious combination of body, heart and soul' by conceptually and pedagogically integrating the 'world of work' with the 'world of knowledge' (Fagg, 2002). The author has tried to understand the *inclusive*

education, the buzz word for bringing children with disabilities into regular schools, including in India, in the context of Fagg's 'Back to the Sources: A Study of Gandhi's Basic Education' (2002, National Book Trust) and found certain similarities in both the concept as expressed by him in the Foreword (Fagg, 2002), 'I have found in both discourses competition giving way to cooperation, individual excellence to group achievement and rote learning to activity and experimental learning. I am thus tempted to draw a parallel, in a pedagogical sense, between the internationally recognized paradigm of inclusive schooling to achieve 'education for all' and Gandhi's (basic) education system as presented by the Report of the Zakir Hussain Committee' (p. xiv)

The question of education of the disabled in inclusive settings is largely related to the notion of the right to equality and to protection of life and personal liberty enshrined in the Indian Constitution (Article 14, 21) read with the Directive Principles under the Article 38 (social order with justice and elimination of inequalities in status, facilities and opportunities), Article 39 (tender of age children not to be abused) and Article 46 (promotion of educational interests of the weaker section). While the first Education Commission during 1966-68 formally recommended work experience as an additional subject as a 'substitute' for the Basic Education, it was finally 'butchered' by the Ishwarbhai Patel Committee (1978) by the SUPW (Socially Useful Productive Work) included in the curriculum as a separate subject. Such policy stance created an artificial division between the skill based education or vocational education, largely relevant to the mentally challenged children and the academic stream focused upon literacy and numeracy. Though the commission could not see through the essence of the Basic Education as an epistemological innovation, it suggested restructuring of the school system so as to create a 'common school system of public education'. The recommendations called upon the government to end the 'caste' system in the school management, for the common admission policies that will prevent segregation of classes, involvement with local communities, and freedom for experimentation and creativity. The common school system was intended to lead to the *neighbourhood school* within twenty years that would prevent segregation between different groups of children. It needs no overemphasizing that the neighbourhood school system offering education of a comparable quality, and accessible to all would serve the interest of the disabled, in particular. The 1968 national education policy accepted the Commission's recommendations on the common school system 'to promote social cohesion and national integration.'

There does not seem to be any analysis done as to why the common school system could not be built up, and how education of comparable quality could be made available to all children, the disabled and the disadvantaged in particular, while making National Education Policy of 1986. Nevertheless, the NPE 1986 reiterated the implantation of the common school system and laid the following statement

The Constitution embodies the principles on which the National System of Education is conceived of. The concept of a National System of Education implies that, up to a given level, all students, irrespective of caste, creed, location or sex, have access to education of a comparable quality. To achieve this government

will initiate appropriately funded programme. Effective measures will be taken in the direction of the Common School System recommended in the 1968 policy (MHRD, 1998,p.5).

No measures were taken to give effect to the common school system policy either in the POA (programme of action) of 1986 or in the POA 1992 brought out following modification of the 1986 policy in 1992. Besides, a system of non-formal education was introduced for the 'drop-outs' and other disadvantaged children, thus sowing the seeds of a dual-system of education in the Indian school. The policy encouraged NGOs running Non Formal Education (NFE) in the name of innovation and creativity, thereby creating a powerful group of 'vested interests' to lobby for the second track education system for the 'poor', romanticize and glamorizing 'their education' and show utter contempt for the formal system, and thereby the teachers and the text books, which were created and prescribed at the instance of the same policy makers. It was claimed that the NFE could be designed to make it 'socio-culturally and physically accessible, curriculum flexible and relevant and recruiting 'instructors' (not teachers) who would have empathy for the children from the disadvantaged section. Sadgopal (2004) finds it intriguing that while all these desirable features were recommended for the non-formal system, the policy makers allowed the formal system serving them directly to 'continue to be inflicted with all the undesirable features!' For instance, while the NFE would have 'relevant' curriculum, the formal system would continue to have 'irrelevant' curriculum; while the NFE would have 'joyful' learning, the education in formal system would remain joyless to make sure that the poor, the 'non-achievers' and the challenged drop out; and finally the NFE would have flexible time and structure so that children could continue as child labour to suit the employers.

The Ramamurty Committee set up to review the 1986 policy recommended to bring 'private schools into the common school system through a combination of incentives, disincentives and legislation' and to transform Government, local-body and aided schools into genuine *neighbourhood schools*. The Committee also recommended that the instruction for all be in the medium of mother tongue at the primary level, the NFE be phased out and special schools for educating the disabled be made as a part of mainstream education system. The big question is if all these systemic reforms were introduced- would it not facilitate the children with disabilities to get *included* in the school system?

There is not much data on the impact of the non-exclusive and divisive schooling policies on children with disabilities, but there are evidences on the fall out on other sections of the children population. The PROBE Report (1999) has reported forms of social discrimination operating in the Indian school system. A system of 'multiple tracks' has come up providing different forms of schooling opportunities to different sections of population. Some such school systems are: private fee charging schools for middle, upper middle and elite classes; government and municipal schools for low middle and poor classes; NFE, EGS, AE centres for the poor and the under-privileged; schools for child labour; kendriya vidyalayas for salaried central employees; schools for 'talented' rural children etc. There is no exact count of growing private schools in India though Panchmukhi

(1983) estimated twenty percent way back in 1983 observed its tendency to 'perpetuate social inequalities and divisions', and Kingdon (1996) has agreed to its serious impact on issues of equity in the Indian school system. The impact of private schools on the disabilities would get a reference in the next section of this paper. The impact of the existing policies on the scheduled castes and scheduled tribes could be seen from the following table.

Table 6.1 Drop Out Rates

Age	Non-SC/ST (%)	SC (%)	ST (%)
Year 11 boys	37	43	56
Year 11 girls	42	47	59
Year 14 boys	50	61	71
Year 14 girls	57	67	76

Source: Compiled from Selected Educational Statistics, 2001, MHRD, New Delhi

Gaps indicate that the formal system is designed to make it unsuitable for the large sections of population, which are disadvantaged. How far it would be able to respond to the disabled unless there is design change? There is not much research evidence on the impact of mixing children from different socio-economic backgrounds on their overall performance in the Indian context (Jha, 2001). However, a US studies shows, if poor students are missed in middle class schools, the over all performance of all children improves (Kahelnberg, 2001). In the UK also, it has been observed since 1950's that 'the way to raise the achievements of all children is to have schools, which incorporate a socially-mixed intake with a range of abilities' (Tomlinson, 2004). Since early 1960's Britain began dispensing with the selection system for getting children into grammar schools, and switched over to the 'comprehensive education', and standards, as measured by those entered for and passing public examinations have been steadily rising' (Tomlinson, 2004). During the same decade the first education commission had recommended the 'common school system' in India, which remained and continues to remain in the domain the policy rhetoric.

Reporting from statistics on educating the disabled

Without going into the merits of the existing policies towards education of children with disabilities, one may be interested in what has been happening to their education in actuality. There is no comprehensive data to suggest the extent of the literacy and schooling among the disabled. While anecdotal references suggest a very low figure of 2-5 percent of the disabled into schools in India, the same is not corroborated by the NSSO (1994) survey made in 1991, which reported that in rural India 70 percent of the physically disabled were not literate as against 46 percent in urban India. It is likely that such a 'high' percentage in comparison to the general perception might be due to the definition of the physical disability in the NSSO survey that included only visual, hearing, speech and locomotors disabilities. However, one can't ignore the observation by Miles (1997) that the number of children with disabilities 'casually integrated' in ordinary schools must

be exceeding those in special schools. It would be interesting to watch the census 2001 report on literacy percentages and educational levels of the disabled persons in different States.

The author has recently conducted a survey of the CBSE affiliated schools-government, aided and unaided (private) in Delhi and neighbouring districts of UP and Haryana by sending questionnaires to 205 school principals selected on the basis of stratified random sampling. A preliminary analysis of 82 returns received reveal two factors. First, though almost all schools claimed admitting children with disabilities the average number of students in each school is five only. Besides, the proportion of children with locomotor disabilities is very high in government schools (100 out of 108) with no one reporting the admission of children with 'learning disabilities'. On the other hand aided and private schools reported less number of locomotor disabled children and increasing number of children with learning disabilities. While aided schools had 24 locomotor disabled and 33 children with learning disability (total 67 in 17 schools), the unaided schools report to have admitted 71 locomotor disabled and 134 children with learning disability (total 260 in 45 schools).

Second, revelations about principals' perceptions on disabilities and their information on integration/inclusion are also pointers to policy makers. Of the 82 principals, whose returns have been analyzed, 45 think that disability is God given, while 30 disagree to this theory. Again according to 53 principals disability is a type of disease, but for 21 it is not. There is not much difference in perceptions among principals in government, aided and private schools. Higher proportions of the respondents in all the three types of schools consider disability a disease.

As stated in the earlier section of the paper, a scheme to 'integrate' children with disabilities was launched by the central government way back in 1974 in the then welfare ministry. The integrated education of the disabled children or the IEDC was revised in 1992 and transferred to the Ministry of Education. The Persons with Disabilities Act of 1995 calls upon to 'promote the integration of students with disabilities in the normal schools'. The 1995 Salamanca Statement issued following the world conference on children with special needs, to which the country is a signatory, has committed us to the principals of inclusive education. Despite all such policy rhetoric, the scenario in the ground is entirely different. While nearly all the principals reported that they had heard about the special schools, only 49 said that they knew about 'integrated schools' and still lesser only 37 have heard about inclusive schools. Again, there does not seem to be much difference between government, aided and private schools on this account.

Perspectives and Discourses on Disability

Traditionally perspectives on disability have been influenced by medical factors. People believed, and many still do as reflected from the principals' responses referred to in the previous section, that disability is some sort of a disease. It could be diagnosed and cured or rectified. Such lay perceptions arising mostly from the medical explanation of disability lead to 'fear, prejudice, pity, ignorance, misplaced patronage and resentment resulting in social practices which are blatantly discriminatory' (Fulcher, 1999). It also brings in sympathy, charity and

human approach towards the disabled leading to the justification for segregating the disabled and organizing special schools in the form of special schools (Jha, 2001). Tomlinson (1982) contested medical model of the disability and charity and humanitarian considerations for establishing special schools in Britain, and finds 'the economic and commercial interests of a developing industrial society' as the factor behind the promotion of special education. Besides she argues, the 'vested interests of professional groups, particularly medical men' encouraged special education of the of the disabled before the state began the large scale interventions.

The psycho model has generally followed the discourse on medical model of the disability, wherein as Tomlinson (1982) points out 'other professional interests became more important'. In Britain, following the rejection of the medical model by the Warnock Report in 1978, the concept of special needs was introduced and an army of psychologist began rising to offer their services and for giving 'special education treatment' to the children identified as having 'special needs'. Under this model while the children are not referred to be as 'defective' or 'impaired', but deficits or deficiencies are pointed out within the child and the same are required to be compensated with additional resources. This model has given birth to the 'integration' theory, under which though a child may be allowed to get into the regular school, but he/she would be expected to fit-in into the system without the school bringing in any substantial changes in its culture, ethos and practices. This approach more than often leads segregation of a child within the school or at times within the classrooms. Some schools create special sections or learning centres for educating 'these children' and for occasional social and extra-curricular integrations, which are seen more as rituals than the natural integrated peers integration. Most of the schools in India, particularly under the private sector, are emerging under this model.

The recent discourse on disability may be called the 'diversity discourse' emerging from the sociological perspectives. Extensive work has been going on across the schools in the world whereby disability is seen more as a 'societal and legal construct' (Sleeter, 1987; Fulcher, 1999) than as a 'defect in' or a 'deficit within' a child. Under this discourse, the solutions are attempted not be curing or compensating a child but by accepting, valuing and 'celebrating' a child and its ability. It initiates a mode of dialogue based on the principles of equality and equity, unlike the medical model, which is prescriptive indicating a sense of hierarchy and control, or the psycho model, which is a no-change situation emerging from a sense of superiority in the existing school system. The equality advocated under this discourse is not the sameness. It does not mean a forced equal treatment but refers to giving an equal opportunity and removing the barriers and impediments so that children with disabilities are able to participate and feel involved in the educational process. Under the diversity discourse or the sociological perspectives, the system looks inward, it becomes reflective, and a reform process begins. This leads to true inclusion not only of the disabled but also of all other children. Sociological perspectives on the disabled and their education have got a boost since the Salamanca Statement (UNESCO, 1995). The following table could depict all the three discourses on disability, which also explains distinctions between special, integrated and inclusive schools.

Table 6.2 Disability- diversity discourse: A sociological perspective

Defect/medico	Correct/ Rectify	Special/ segregate	Control/ prescriptive
Deficit/psycho	Compensate/ Resource	Integrate/ fit-in	Superiority/ no-change
Diversity/socio	Accept/vale	Inclusive/ reformative	Equity/ not sameness

Adapted from Jha (2001)

Systemic issues at two levels

What has been argued is the system change at two levels: structure and perspectives. While at the structure level a case has been made for the common school system, at the level of perspective it seems important for the Indian school system to join the international discourse and look at the disabilities not just a problem of, or within a child but those of the society at large, and the school system in particular. Supported by the RCI (Rehabilitation Council of India) the author in collaboration with colleagues has launched a project for workshops with school principals from Delhi and neighbouring districts. Guided by the later aspect of the system issue, which is a sociological perspective, the project is informed by the following philosophies, meanings and framework.

- Disability is a societal and legal construct. Therefore, deconstruct disability.
- All children enjoy learning, which is a multi-dimensional phenomenon, beyond literacy and numeracy.
- Children differ in the ways they learn.
- Teaching children with disabilities is not essentially different from teaching the non-disabled
- Diversity is a part of the Indian classroom.

Meanings

- Education and schooling is beyond literacy and numeracy.
- Intelligence is not static; there is well-developed theory of multiple-intelligence (Gardner, 1993).
- Inclusion is not confined only to the disabled. It also means non-exclusion. A true inclusive school must not be selective. Selection in any form or with any explanation is against the spirit of inclusion. (Here the concept of the common school system and the principle of inclusive education confluence.)
- Inclusion benefits all children. It brings in an engaging pedagogy, a caring and loving school culture and a differential approach to the same classroom.

Under such a vision of inclusive education the project has the following framework in view, which becomes important from policy angle.

- Identification and assessment are not required before children are admitted into schools. This has been dispensed with in most developed countries.
- Some children with 'severe' disabilities might need individualized teaching within an inclusive school culture.
- All children need to be responded to with required support and services. Hence the 40% criterion for declaring a child with disability as beneficiary of educational subsidies becomes meaningless.
- 3% reservation for admissions into schools is less relevant for the children, particularly in the age group of 6-14, in view of the Constitutional guarantee of equality before law (Article 14), protection of life and personal liberty (Article 21) and right to education (Article 21A), all as Fundamental Rights. Implementation of these constitutional provisions would enhance the presence of children with disabilities in regular schools by more than three percent.

Conclusion

The paper examines policies regarding education for children with disabilities in inclusive settings and on the common school system for all children, and tries to establish linkages between the two. It is argued that it's not only a question of structural changes in the school system, but also of the perspectives on disabilities and educating children labeled as 'disabled'. What is required is a paradigm shift from psycho-medico model of disability to the socio model, from an approach to detect defect and deficit within children to viewing disability as a form of diversity making their presence in schools a natural thing to happen. The author advocated for securing the Constitutional rights guaranteed under Article 14, 21 and 21A to enhance educational benefits to more than three percent children as provided for under the Persons with Disabilities Act, and irrespective of the percentage of 'impairment'. After launching of programmes or projects, and making of laws that would determine the *education for all*, children with disabilities included. Ultimately it is a question of systemic reforms and perspectives towards disabilities, inclusion and education.

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Chapter 7

Accessibility Issues

Sunita Singh

Accessibility as a generic term include approachability to build an environment as also in terms of access for education, employment. The author delineates various components of accessibility that includes safety, independence, affordability, logicity of layouts etc. The provisions of PWD Act, 1995 as also the guidelines for a barrier free environment have been highlighted by the author who feels that benefits of accessible environment is enjoyed not only by the persons with disabilities, but also other groups of persons such as children, women, elderly, and chronically sick. It is argued that universal design need to be applied to make the environment barrier free. The chapter depicts pictures with description about the minimum designing needs for public facilities such as parking, flooring, counters, switch boards, doors, lifts, pathways and corridors, toilets etc. Allaying the fears of high cost involved in ensuring barrier free environment, the author argues that in many cases, inaccessible facilities/environment can be made accessible by minimum investments and renovation. Besides, ensuring a barrier free construction from the designing stage is also a much cheaper option than modifying a new construction.

Introduction

“Accessibility” as per its dictionary meaning means “approach-ability”. In that sense it could refer to access to many aspects of life i.e. education, employment, information, technology etc. But broadly when we talk about accessibility issues for persons with disabilities, we refer to their access / mobility within the built environment – both internal and external i.e. their movement within the building, in markets, parks, on footpaths and roads etc.

Components of Accessibility

An accessible environment is one, which has the following components namely:

- **Safety:** - A place where people can move around safely.
- **Independence:** - where people are able to use the facilities independently.
- **Affordable:** - where barrier free or accessible environment does not come with premium.

- **Logical layout:** - where people are able to navigate without too much physical exertion i.e. not having to move through the length and breadth of the building to access information or make use of the facilities.

Currently in both cities and villages in India, the conventional constructions and public transport system are inaccessible. Conscious efforts need to be made to incorporate and implement modification in the designs of the built environment including the transport system.

Recently, there have been some efforts to incorporate some accessible features in the buildings, subways but railway stations and insensitivity and lack of understanding about the subject is glaringly apparent. Slopes have been made at any angle, toilets are devoid of grab bar and other essentials.

Statutory Commitments & Guidelines

In the year 1995, India has enacted the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act. Chapter VIII, Sections 44 to 46 deal with non-discrimination in transport, on the roads and in the built environment. Section 46 directs that the appropriate governments and local authorities shall within the limits of their economic capacity and development, provide for ramps in public buildings, barrier free toilets for wheel chair users, Braille symbols and audio signals in elevators and lifts and ramps in hospitals, primary health centres and other medical care and rehabilitation institutions. Under Section 44, establishments in the transport sector are required to design rail compartments, buses, etc. in such a way as to promote easy access to disabled persons. Section 45 provides for installation of signals at traffic lights on public roads, kerb cuts and slopes to be made in pavements, facilitating easy access of wheel chair users, engraving on the edges of railway platforms, designing appropriate symbols of disability and warning signals at appropriate places.

The Central Public Works Department (CPWD) under the Ministry of Urban Affairs and Employment, have developed "Guidelines and Space Standards for Barrier Free Built Environment", which also includes model building bye-laws to facilitate adoption of these by local bodies in the state.

India has also adopted to the Biwako Millennium Framework for Action: towards an Inclusive, Barrier-free and Rights-based Society for Persons with Disabilities in Asia and the Pacific, which encourages and promotes its member countries to focus on seven priority areas; access to built environment and public transport being one of them. Keeping in view the commitments that India has made to itself, we have a long way to go as regards making the environment barrier free and accessible for the persons with disabilities.

Who Benefits from an Accessible Environment?

Obstacles in movement is encountered by so many more people other than people with disability such as those carrying packages, elderly persons, pregnant women, and parents of children with strollers, those who are ill or fatigued, those suffering from temporary disability and those with orientation difficulties. In addition, short people, tall people, large people, left side dominated individuals, children etc. often encounter functional problems because most of the built environment and products are designed for the non-disabled people. For example, a left-handed person faces difficulty in using a two-wheeler scooter because the controls are designed for right-handed majority. Similarly most Indian women find the seat belt of the jabbing into their throats, because the product might have been apparently, designed for males. The visitor in an unfamiliar city or building also might need help of signages to find the places. Hence, one can see that the benefits of a good functional design do not extend just to a handful of people but would be for the benefit of all.

Thus, there is a need to have an integrated/comprehensive approach to the development of environment and products that can be used effectively by all, to the greatest extent possible, without need for adaptation of specialized design. This approach is called **Universal Design** and it aims at enabling all of us to experience the full benefits of the products and environment around us regardless of our age, size or ability.

Seven Principles of Universal Design (Balaram, 2003)

The concept of Universal design is fairly recent in origin and puts forth seven widely accepted principles of practice. These principles may be applied to evaluate existing designs, guide the design process and educate both designers and consumers about the characteristics of more usable products and environment. Each principle is explained with an example as below:

Principle one: Equitable use

The design should be useful and marketable to people with diverse abilities. A simple everyday example is the doorknob.

A simple everyday example is the door knob. A round smooth knob can only be used by young and strong people. Instead, if a design of rubber - gripped, lever type knob is introduced, it will benefit all.

Principle two: Flexibility in use

The design should accommodate a wide range of individual preferences and abilities. Good examples are toilets with grab bars and door frames, wide enough for wheel chairs to pass, Elevator switches located at a low level can be used by non-disabled adults, children as well as wheel chair users.

Principle three: Simple and interactive use

Use of the design should be easy to understand regardless of the users experience, knowledge, language skills or current concentration level. For

example, the text in any message should be replaced with a picture or icon which could be understandable for illiterate as well as literate people. An embossed picture is even better as it can communicate even to a visually impaired person.

Principle four: Perceptible Information

The design should communicate necessary information effectively to the user regardless of ambient conditions or the users abilities. For example, a label on a drug bottle should have text large enough and with enough contrast with the background so that people with low vision, elderly people as well as non-disabled people can read it well. This aspect is vital in critical for right amount of drug dosage, emergency instructions etc.

Principle five: Tolerance for error

The design should minimize hazards and adverse consequences of accidental or unintended actions. For example, the cup should be so designed as not to slip from un-steady hands and should be able to withstand clumsy or erroneous use.

Principle six: Low physical effort

The design should be used efficiently and comfortably and with a minimum of fatigue. For example, replacing heavy lever type handles and controls with feather touch buttons a friendly design for all.

Principle 7: Size and space for approach and use

The design should be appropriate in size and adequate space should be provided for approach, reach, manipulation and use regardless of users body size, posture or mobility is the the principle is very significant in the modern world where all things are getting increasingly miniaturized. Cell phones for example should be designed particularly with this consideration to suite all including people with fat fingers, unsteady hands, fingers with nails etc.

Thrust areas for improving Accessibility

A barrier free environment is a welcome step for all including persons with disabilities . It is a statutory commitment to be fulfilled within the limits of economic capacity and development when it comes to persons with disabilities.

Following are the major areas of attention for improving accessibility:

1. The external environment, which includes footpaths, kerb ramp at walkway, pedestrian crossing, traffic signals, subway and overhead bridge, playgrounds, parks etc.
2. The internal built environment, which includes homes, schools, factories, companies, hotels, movie houses, museums, tourist spots, sports complex, public buildings, etc.
3. Public Transport by road and rail. Also, equal access to water and air transport.
4. Products that affect daily living like safe non-slippery good grasp utensils, safe cooking gas, obstacle climbing wheel chairs etc.

Minimum Accessible Design Needs for a Public Building

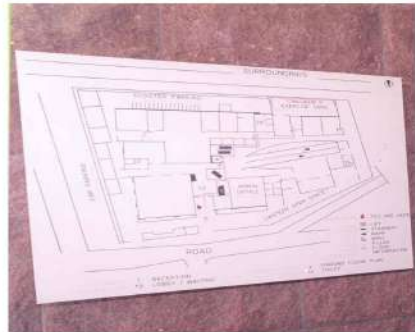
Parking facilities earmarked for persons with disabilities at the entrance so that the person does not have to move a lot from the parking spot to enter into the building.



Ramps at the entrance to enable the wheel chair users to get to any floor easily and independently. The flooring on the ramp should be non -slippery to enable the wheelchair user to ascend safely and smoothly. At regular intervals the ramp should have landings to provide a breather for the wheelchair user during ascent and to control the speed during descent.



Signages in Braille: At the entrance, there should be a route map that has the guidelines to all the departments in the center and the entire plan of the building is in Braille for the benefit of the visually impaired people. At the entrance of each room, there should be a board, which has signboards in Braille indicating to the visually impaired person where he/ she is heading.



Flooring: The major pathways of the entire building should be fitted with tactile tiles (tiles with different surface) of contrasting colour to guide visually impaired people within the building. Anti skid tiles need to be used to prevent slips and falls. Change in the level of flooring like starting or landing of steps can be indicated by different tactile floorings.



Public dealing counter, switchboards and other essential amenities like public telephones, drinking water etc. placed at a lower level for easy access by wheelchair users. The switchboards should be lined in a dark colour (black) to enable the people with low vision to identify the same comfortably.



Railings throughout the building at two levels (for adults and children) as additional support for people using crutches, elderly etc to move freely.



Doorways and corridors: The width of all the doors in the building should be more than 900mm and corridors more than 1500mm for easy and independent maneuverability of wheel chairs. The opening and closing of doors should be easy and door handles should be smooth, end carved in to ensure that clothes do not get caught or cause injury to anyone.



The lift with auditory signals and embossed controls, enables visually impaired people to alight or embark at the right floor. A sensitive sensor prevents the door from closing when the person enters or exits the lift. Hand rail support in the lift is also essential.



The washrooms/toilets need to be spacious enough for movement of wheel chair. There should be grab bars for the wheelchair user and people using crutches. The toilet seats should be placed at an appropriate height for easy transfer from a wheelchair. Special attachments need to be fixed to wash so that hands are free to hold the grab bar.



Washbasin: The area below the washbasin should be kept vacant so that a person using a wheelchair can maneuver himself or herself by wheeling comfortably to reach the tap in the basin. **The taps** should have a lever, that is easy to operate for everybody especially for people without hands or fingers, to use independently. It applies also to people with hand deformities.



Visual information systems for hearing impaired like ticker tape information system particularly in public buildings, airports, railway stations and blinking signals for room bell and intercom services in hotels etc.

Nosing and landings of contrasting bright colours for steps to ease the movements of visually impaired/ low vision persons.

Rooms should have good **lighting & illumination (which is non reflective) and acoustics**. Contrasting colours can also be used to aid identification of various components of buildings.

Underground cabling to ensure no cable runs through the building and people do not trip over wires. Furniture with rounded edges should be used to avoid accidents.



Emergency evacuation path should constitute ramps rather than stairs, which will assist all categories of people for easy and quick evacuation.

Minimum Accessible Design Needs for External Environment

Appropriate signages should be placed to facilitate movement of people. Signs should be clear, simple, visible and easy to read and understand and properly lit at night. Accessible space and facility should be identified by international symbol of accessibility. The colour combinations of red/green and yellow/blue should not be used in order to avoid confusing colour-blind persons. Maps and information panels should be placed between the heights of 0.9m to 1.8m to allow ease in reading by wheel chair users.

Kerb ramps to facilitate movements wherever there is a difference in level on pedestrian paths or cross paths such as street intersection, pedestrian crossing, parking area, building entrance and pathways. Tactile floors of contrasting and bright colours should be placed at vantage points to indicate difference of level and directions.

Parking space at convenient location and the space must be large enough for vehicular doors to fully open and for wheelchairs to be placed perpendicular to the parked vehicle.

Subways for crossing roads should have ramps of at least 1: 15 slope and with landing for resting after every 10m, instead of stairs.

Auditory signals should be provided at busy cross-sections.

Public transport system needs to be accessible with appropriate provisions of space and movement of wheel chairs, audiovisual information systems etc.

Cost Considerations

There is a general misconception that accessible designs cost much more than the conventional design. In fact incorporating principles of accessible design/ universal design in new construction projects is claimed to typically require less than 1% of the total construction cost. Moreover, many of the universal design features may cost nothing or actually save money. Like selecting door handles that are easier to use does not require any additional expenses. Designing of main entry with level access and no change in level inside eliminates stairs/ ramp and saves money. Improved functional design can also save money over the life of the building by lowering the cost of renovation. Even renovation cost of old construction for incorporating accessible design is cost effective when thought in terms of the benefits extended to people.

Current Scenario

In spite of existence of legislative provisions, building codes and byelaws, resource constraints really make accessible environment in cities and rural areas an uphill task. A beginning has been made in some places:

- All airports and 150 railway stations are reported to have provided facilities such as barrier free entry, non-slippery walkway, accessible water taps, wheelchairs at railway stations etc.
- Delhi Metro, which has recently come up, has an exemplary accessible environment.
- Many Municipal Corporations like Bangalore and Kolkata have adopted building bye laws for barrier free environment.
- Collectorate Offices and other such important buildings frequented by the public are being made barrier free.
- Delhi Transport Corporation (DTC) is planning to introduce high capacity buses on certain routes that are disabled friendly.
- The University Grants Commission has allocated separate funds to ensure barrier free accessible universities.
- Research work has been undertaken to develop products and aids useful for persons with disabilities like safe cooking gas for the visually impaired, motorized wheel chair, development of speech card, lifts for small heights etc.

However, all these have not made things very different for persons with disabilities. Even if public buildings are barrier free reaching them often is difficult. More thought has to be given to the needs of visually impaired and hearing impaired while making buildings and roads barrier free. Similarly many of the constructions undertaken (especially ramps and toilets) are often not as per the specifications and hence cannot be used safely or independently by persons with disabilities or other such user groups. Commercial production of aids developed through research in many cases is yet to take place. Resultantly, it has not been possible to make the benefits available to the user group.

Future Needs and Challenges

There is a need for architects, engineers and urban planners to realize that the problem of accessibility cannot be tackled piecemeal but requires a holistic approach as has been taken in many parts of the world. It is further being realized that slow implementation of such provisions, has been due to lack of awareness as well as conviction regarding the need for such facilities. Hence there is a great need to create awareness among the policy makers, engineers, architects, local bodies etc. to make them understand the needs and requirements of an accessible environment. In addition, the following actions need to be taken:

- Adoption of building bye-laws by all the States.
- Include the idea, concept, basics and standards for planning an accessible environment in the curricula for training the architects and civil engineers.
- Education and training of professionals to ensure that the structures designed/constructed have all the barrier free features.
- Modify the building byelaws to keep up with the latest ideas of universal design in consultation with persons with disabilities.

- Development of guidelines for barrier free transportation.
- Developing standards for products like tactile flooring, grab bar etc.
- Publicizing the places from where such products can be purchased.
- Research & development for accessible designs of various products like public transport systems, daily living aids etc.
- Commercialization of products developed through research projects by bridging the gap between researchers and manufacturers.
- Appropriate Governments should develop awareness about common standards and bye-laws for adopting the same in an uniform manner across the country.

Conclusion

It is one of the basic responsibilities of an architect to enable the physically challenged citizens for accessing, using and participating in the built environment, thereby ensuring equal opportunities and their full participation in social life. When the built environment is designed to enable the disabled and elderly, the able bodied users will find it even more friendly and easy to use. Thus, every built environment should be designed for its easy usage by persons with diverse bodily capabilities through a successful implementation of standards. However a cursory approach towards this will not be effective. There is a great need to create awareness among the policy makers, engineers, architects local bodies and to make them understand the needs and analyze why we do not come across people with disabilities in our schools, colleges, work environments or in social gatherings. There is also a need to consult persons with disabilities at all levels while planning and building external and internal environments. Education and training of professionals on this issue plays a significant role in promoting a barrier-free world.

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Chapter 8

Information, Communication and Technology : A Tool for Empowerment of Persons with Disabilities

Dharmendra Kumar
Dipendra Manocha

In this chapter, the authors deal with the recent advancements that have positively affected the lives of each category of persons with disabilities with the advent of information and communication technology and the constraints that the people of developing societies face in its application. The authors feel that a sincere effort in making the benefits of ICT reach the disabled population will not only improve their quality of lives, but also their contribution towards the society.

Introduction

Information technology has revolutionized the life of common man. It has not only increased their accessibility to information globally but has also enhanced interpersonal communication. Basic functional units used in information and communication technology such as 'microchips' and 'softwares packages' have made such things possible in the life which, were thought to be impossible earlier on. The persons with disabilities to some extent, have also got their share of fruits of these developments in the developed world. They are in better control of their lives with the help electronic gadgets, software packages and digital control panels developed on the principles of information technology.

It may sound amazing to those who are not accustomed, to see blind persons using computers and surfing the internet today. The world sees with gaping eyes when it listens to renowned scientists like Stephen Hawking, who has lost the power to speak and has minimal muscle power left in his upper limbs. But such miraculous deeds have been made possible by the ever-developing field of Information and Communication Technology (ICT). Similarly, the persons with disabilities affected by all the four major categories of impairments have been benefited by the innovations and adaptations made with the help of ICT.

Independent access to information has been identified as one of the core and key issues for persons with blindness. Most of the information is disseminated either in the visual or in audio format. Thus making persons with vision and hearing impairment dependent on their non-disabled counter parts for its access. The readings of newspapers, studying text books, writing answer sheets, consulting dictionary, writing application, filing of forms etc. are the functions which need to be performed every day by any educated person. Even if a person is a home bound he or she could need to refer to calendars, read bills, telephone books etc. to be able to live an independent life. Reaching a place is impossible without reading sign boards, bus numbers etc. Thus access to information is essential for performing educational, vocational, recreational and daily living activities. Considering the importance of this UNESCAP has identified the access to information and communication technology by persons with disability as one of the key areas in Biwako Millennium Framework Document, which identified the target action areas for the decade of persons with disability 2003-2012.

ICT and Locomotor Disability

Major challenges which confront a person with locomotor disability include their mobility, transfers from one place to another and accessibilities to various public and private premises. Sometimes they have to be dependent on others even for their activities of daily living which not only affects the privacy of the persons but also their morale adversely. The adoption and information and application of communication technology have greatly helped the persons in becoming independent.

Aids and Appliances

Technologically well-developed appropriate aids and appliances are an integral part of rehabilitation process of a person with locomotor disability. They not only improve the mobility of persons, their access to different places but also the quality of life. It gives a lot of confidence and immense pleasure in using it if it is a well fitting, cosmetically good looking, aesthetically designed, light and comfortable to use. No one, for that matter, would like to use an ugly looking or ill fitting body wear. It is, therefore, within the rights of the persons with disabilities to ask for aids and appliances, which are not only easy to use but also affordable and available in different variables. A lot of research and development activities are taking place worldwide in the field of assistive devices. The information about them is available on the internet. On the click of a mouse, one can surf the websites and enrich knowledge. As per requirements, one is in a position to choose the best suitable device. The disabled person can also interact with the manufactures, rehabilitation scientists and professionals in the field via e-mails to help them in their efforts of selecting the most appropriate device.

Computer Aided Designing and Computer Aided Manufacturing (AD and CAM) of Prosthesis

Computer aided designing and manufacturing of components of prosthesis are available now a days in different rehabilitation centres. One of the most

troublesome part of a prosthesis is its socket which comes directly in touch with the stump of the amputated limb. An ideal socket should be properly fitting, flexible, comfortable and free of rough edges. It requires frequent changes if it is ill fitting, loose or injures the stump due to friction or if it projects irregular margins. Computer designed prosthesis basically helps in taking the mould of the stump. In normal practice the mould is taken with the help of plaster of paris bandages, which are wrapped around the stump. In this, there are chances that some discrepancies still remain between the actual shape of the stumps and the mould. Because the patient is not available at the time of shaping of mould, the plastic socket made on this mould some time remains ill fitted, either loose or tight over the stump. This process also requires longer time and by the time prosthesis is ready, the stump is shrunken and the prosthesis renders loose in fitting. The computer aided designing and manufacturing makes the mould same day and conforms to the shape of stump. Moreover a large number of patients can be fitted prosthesis the same day without waiting with the help of CAD and CAM.

Gait Analyzers

Various gait analyzers are available which can give comprehensive data about the walking pattern of a person. It can pinpoint about the deficiencies and inadequacies which require correction while the earlier versions of commonly used gait analyzers work on the principles of range of motion analysis of the pictures received on the three view cameras. The latest versions work on the principle of pressure transducers and positional electrodes. These are useful not only in improving neurological conditions like hemiplegia, poliomyelitis etc. but also in pointing out appropriateness/inadequacies in prosthetic devices. The defects in a prosthesis can be corrected and gait can be improved with the help of computer trynograms.

Electronic Wheel Chairs

While a standard wheel chair can be comfortable for paraplegia with stronger arms, it may not be very helpful for a person with weaker upper limbs. A quadraparesis person with weak upper limb will always be dependant on others for his mobility from one place to another. High technology electronic wheel chairs offer excellent mobility to such persons. These are compact manoeverable and battery operated. Some of the models available are also foldable. The control unit consist of a light touch on-off switch and a multi-directional controlling joy stick. The technology is simple and efforts of developing an indigenious and affordable model are likely to become successful in near future. For the persons who do not have any power in their upper limbs including hands, trials are on to develop slow operated wheel chairs in which the central panels are designed in such a manner that even of muscle or blow from the mouth can control the direction and speed of wheel chair. In cases of quadriplegia the control unit is operated by the chin or finger of the persons with disability. The multifunction chin control, finger control, foot control systems can be adapted according to the needs of the patient varying from a single hand operated joystick control system to multiple control where more than one system is operable.

Computer Assisted Instruction (CAI) for Students with Mental Retardation

Given an opportunity, persons with mental retardation can also learn using computers. The Department of Special Education at NIMH has developed softwares for teaching literacy and numeracy skills to persons with mental retardation. Literacy software covers functional words in English and the second package covers forming sentences using the functional words. Numeracy software covers numbers upto 10 in the first package and numbers beyond 10, addition, subtraction and application in second package (Jayanti Narayan and Vijayalakshmi Myreddy,2003)

Computer Assisted Instructions

Computer assisted Instruction has several types of instructional programmes namely, drill and practice, tutorial, educational games, demonstration, simulation, problem solving and discovery learning for helping the children with mental retardation to develop their potential.

- Drill and Practice- Those softwares are developed to help the students practice the previously learnt materials on computer, thus enhancing automatic level of responding. Though it provides over learning, repetition and immediate feedback it may end up to be monotonous and have limited cognitive demands.
- Instructional games - These are highly motivating as learning occurs through games. It increases concentration, coordination and dexterity, but it has the threat of children wanting to play the games and not actually meeting the educational objectives.
- Simulation - Experiences provided in simulations are analogous to real life situations, demanding active involvement of the student in problem solving. However, it may be difficult to integrate this component in academic curriculum, which is structured and rigid.
- Tutorial - This assists the child to work independently and provides for review of learnt materials. It has the facility to present instruction in sequential, step-by-step manner. Child's own motivations are a prerequisite for use of this software.
- Demonstration - This allows the students and teachers to manipulate relationship among variables by pressing the keys and has presentations with colour, graphics and sounds that sustain interest.
- Problem solving - Computer as a tool to solve problems is used in many areas, especially, in calculations, where the student analyses the problem and writes executable programme to get desired results.
- Discovery learning - This can be integrated in games and simulations and it allows a child to learn by exploration and experience.

Access and Current Trends

The technology advance in general education as well as special education is of recent origin. A pilot project on computer literacy was launched in 1985 by Department of Education in a number of regular schools. Presently in a number of states, regular school education includes computer literacy as a part of curriculum. Word processor programmes in Indian languages have been developed for wider reach. Production of adapted peripherals and add-on devices with indigenous softwares are rapidly increasing to suit the need of the disabled individuals. The biomedical engineering departments of colleges of technology collaborate with special education programmes for development of suitable materials for the disabled persons in India. Following are some of the devices developed in India. (i) Writing aid for persons with motor disabilities was developed by Indian Institute of Research and Information Services, New Delhi (ii) Communication aid to children with cerebral palsy called 'Swarlipi', where an electronic interface provides access to computer using, touch, movement of head, eye ball, blow energy or tongue. (iii) The Indian Institute of Science (IIS), Bangalore has developed three gadgets for the visually impaired individuals to manipulate a computer. In addition, speech synthesizer, electronic Braille shorthand machine have also been developed. The National Institutes for the disabled person in our country are also experimenting with technology for the disabled individuals.

Advantages and Limitations

As we all know, computers have changed the entire lifestyle of people. Those with disabilities are no exception. In the area of mental retardation, where individualized instruction is essential, the computer is a boon. It provides the individual learning time to student. After training, the teacher may allow the child to use the computer on his own, and she can attend to other children. The interactive programmes play the role of the teacher too. The disabled person's self esteem is boosted when he proudly say he uses computers. Going with the principle of normalization it provides access to retarded children. The suitably selected softwares help as drill and practice for the content already taught by the teacher. The studies done at NIMH through multicentred data collection on use of CAI revealed that even severely retarded children benefit from the programme, the students attention span increases and distractibility reduces, the students do their routine duties well if promised of computer time thus serving as a good reinforcement.

Limitations

When we look at limitations, affordability stands out as a major problem. CAI seems out of reach for majority students. Indian softwares are minimum thus having limited access, especially so, for education of those with mental retardation. The NIMH has developed a few exclusive softwares and is in the process of developing more of mentally retarded persons. Multilingual characteristic of our country in another problem in quick reproduction and use

of softwares. Transfer of training from computer to daily living activities is difficult in mental retardation unless the teacher takes extra efforts. Moreover the teachers herself needs to be trained in the use of computers.

Information Technology Based Communication / Education

This technology is particularly useful in the cases where speech is also involved and the persons find it difficult to communicate. The conditions like cerebral palsy and brain injuries and multiple sclerosis in adult some times affects the muscles involved in speech mechanism. To help such cases voice out put communication aid (VOCA) device has been developed in different languages. The indigenous software and hardware equipment are under field trial in our country also. The advantage with this package is that it can be developed into local languages and can be operated without a mouse with the help of a special switch.

ICT for Persons with Visual Impairment

The information technology has not only opened the door of direct use of PC by persons with blindness or low vision but also has revolutionized the way the text books and reading materials can be produced in accessible format such as Braille, talking books, large print etc. for them. This technology of direct access by persons with blindness has been in use in the developed countries for the past two decades but in the developing country like India the doors of this technology were opened only for the persons who could read and write in English medium. Presented below are results of two projects, which attempts to break this barrier of language with ICT solutions for persons with blindness.

The DAISY Standards and the DFA Project

This technology offers a possibility to make information available in text, audio, video or picture format that is accessible for persons with visual impairment, dyslexic, slow learner etc. The digital technology also has the possibility of presentation and dissemination in many different formats. For example, an audio stream can be stored and compressed in innumerable proprietary or non-proprietary systems. Each system would require an encoder and decoder for this audio stream. To ensure that the information produced in one part of the world is accessible for persons with blindness everywhere, a Consortium was established in the year 1996 to formulate standards for storage and playback of digital information. This Consortium is known as the DAISY Consortium. This consortium has members from more than 40 countries from all round the world. Various organizations producing materials in accessible format such as talking books, Braille books etc. are members of this organization. Initially this Consortium was formed only to set standards for new generation of talking books using digital instead of analogue technology, but, considering the use of the digital technology in production of all the other alternative formats, the objective of the DAISY Consortium was expanded which has resulted in convergence of many technologies.

The DAISY Digital Books

Traditionally the talking books were recorded using the analogue technology and stored on audiocassettes. The following reasons made it compulsory to shift the recording processes of the recording books to a digital format:

- Technology for general audio recording changed from analogue to digital. Digital recording offers variety of advantages like enhanced editing and mixing features.
- New mediums like CD and mini digital disks have become popular and replacing gramophone records and audiocassettes.
- The production of audiocassettes for the general audio industry is reducing. Thus there is a possibility, that in near future, availability of audiocassettes will reduce which would also result in an increase in its cost.

Apart from the reasons mentioned above, talking books that are recorded using digital technologies have the following advantages over the talking book recorded on audiocassettes:

- i) A single book is recorded on many cassettes, where as only one compact disc (CD) is enough to record one full book.
- ii) Due to the serial access, it is difficult to reach a desired location in a book using the audiocassette. CD has a random access and if proper marks are placed then desired location can be reached very easily. It could be reaching a desired page in a book or reaching a chapter or a topic inside a chapter.
- iii) A cassette is much more vulnerable to damage than the CD. Moreover, once the recording is available in digital format, many masters can be stored on different mediums to minimize the chances of loss of recording
- iv) A CD takes very less space in comparison to an audiocassette. This means the maintenance and storage of CD is much easier than that of an audiocassette.
- v) A book on audiocassette takes 20 times more space than its print version whereas, talking book recorded on CD would occupy at least 15 times less space than its print version.
- vi) On a CD, quality of duplicates is as good as the master. On audiocassettes, the quality of the duplicate is inferior to the master. Even the quality of the master deteriorates due to the warning out process.
- vii) Digitally recorded material can be recorded on many different mediums and also transferred in many different ways including on the Internet.

Digital Talking Books recorded in accordance to the DAISY standards would add many enhancements to the talking books. Following types of talking books can be produced:

- Complete audio with table of contents structure – These books provide random access to any chapter, subsection or page of the audio recording of the book.
- Full audio with full text – In this book, while the audio of the book is being played, the text of that recording gets displayed on the computer screen.

This feature specially helps persons with dyslexic, slow learners or persons with low vision. This also allows searching of any word or phrase in the book.

- Full text with no audio – This is a fully structured book that can be read on the computer with the help of a screen reading software.

DAISY Book in Braille Format

The tools available for Braille transcription are now being adopted to convert text files included in a DAISY book into a Braille format. The software DAISY book player support refreshable Braille display, thus providing access to material in Braille to the users. The software DAISY book reader also has enhancements to produce the text of the DAISY books in large print to cater to the needs of persons with low vision. Thus, the most important feature of the DAISY standards has evolved in a way in which by creating one source document in html e-text format, the material can be produced as audio, Braille, large print or as e-text book with in a matter of few minutes. A DAISY book can be explained as a set of digital files that includes one or more digital audio files containing a human narration of part or all of the source text; A marked-up file containing some or all of the text (strictly speaking, this marked-up text file is optional); A synchronization file to relate markings in the text file with time points in the audio file; and A navigation control file, which enables the user to move smoothly between files while synchronization between text and audio, is maintained. Efforts are being made for acceptance of DAISY standards in the mainstream electronic book publishing industry as Industry Standard. This would result in accessibility for persons with blindness or low vision to any book, which is published electronically without the need for any translation, transcription or reproduction.

The DAISY For All Project (DFA)

The implementation of the DAISY technology was restricted to the developed countries till the year 2001. Since 80% of the population of persons with blindness live in developing countries, it was essential to introduce and implement DAISY standards in these countries to reach out the maximum number of end users. With the initiatives of organizations such as National Association for the Blind, New Delhi, India, Japanese Society for Rehabilitation of Persons with Disability (JSRPD), Tokyo, Japan and the Thai Association of the Blind, Bangkok, Thailand, an initiative with the name of DAISY For All was taken by the DAISY Consortium in the year 2003. The DAISY For All Project was conceived by the standing committee of the DAISY Consortium of the developing countries. This Project is funded by NIPPON Foundation. The main objectives of the project is to encourage production and dissemination of Digital Talking Books in the developing countries and to provide information in accessible format to the persons with blindness in their local languages. This would be done through creation of content in the local language and developing playback and talking book authoring tools that support local language content. The achievements and major streams of action to be taken under the project are given in Appendix

Screen Access for All (SAFA)

Appropriate speech output from a computer is the most commonly used access technology, which enables persons with blindness to use a computer. This speech output comprises of two components: i.e. (a) Screen Reading Software and (b) Text to Speech Engine.

The screen reading software is a computer programme that picks up the relevant information from the screen and sends this information to text-to-speech engine or speech synthesizer or a Refreshable Braille Display. This software determines what would be spoken by the computer. There are innumerable screen layouts and user interfaces of computer applications. To be able to determine what would be the appropriate text to be spoken in each of those screens is an unending task. Screen readers need regular up-gradation as the new programmes and applications are being introduced in the market. A single key of the keyboard does different things in different softwares on a computer. For example, in a word processing environment right arrow goes to next character whereas in the menu bar right arrow takes the focus to the next menu item. The speech output required in these two situations differs entirely. In the first situation only one character needs to be spoken whereas in the second situation complete item of focus needs to be spoken. Therefore, the screen reader sends the text to be spoken to the TTS in relevance to the key pressed and also considering the situation where the key is pressed.

A text-to-speech engine on the other hand is the software which converts any text string into a spoken word form. A screen reading software determines what will be spoken and the text-to-speech engine determines how that text would be pronounced. The quality of speech output and the various voices depend entirely on the text-to-speech engine. Apart from being used as a speaking device for the screen reading software the TTS is used in various other applications such as computerized telephonic inquiry systems, computerized announcement systems, etc. To be able to design a speech output system for any particular language it is essential to have a text-to-speech engine for that particular language. Screen reading software can then be designed or adapted to give appropriate speech output to blind persons in that particular language. Screen reading software and a text-to-speech engine are two entirely different application programmes which work in tandem providing accessibility to computers for persons with blindness.

Till date, the screen reading softwares which could support Indian languages were not available. This meant that the world of information was not available to persons with blindness who wished to read and write in their own language. SAFA Project was undertaken by NAB to provide solutions to this problem. The Hindi language text-to-speech engine was obtained from IIT-Hyderabad for the development of the SAFA screen reading software. Subsequently, the support for Hindi language text-to-speech engine vaachak has been added to the screen reader. The vaachak has been produced by the Prologix Company situated in Lucknow. The SAFA screen reading software provides facilities of reading and writing independently in MS-Word, WordPad and Notepad. It enables reading of Hindi text from the websites using internet explorer and also has the facility to read and

write e-mails using outlook express in Hindi language to the blind persons. The SAFA is a bilingual screen reading software. It can automatically detect whether text is written in the English or Hindi language and provides speech output in the appropriate text-to-speech output. The software is in its beta test stage and is due for release. This software is being prepared by a team of computer programmers who are themselves blind persons.

Use of ICT for Employment Opportunities

Information Technology has provided various tools such as personal computers, note-takers etc. to persons with blindness. The computers, which are used by the blind persons, are not different from those used in the work environment for performing various job processes. This essentially means that persons with blindness can work on various jobs where extensive reading and writing is involved and where there is a scope of using the computer for such reading and writing. Many of such jobs traditionally were considered unsuitable for them. Although, in principle it is known that IT has empowered persons with blindness to work productively at many job situations, clear identification of such jobs was not available. Knowledge about new IT tools for persons with blindness, their capabilities and their potential to enable persons with blindness to perform any specific job was very limited. As a result of this, very few of such jobs are actually available to the persons with blindness. Many of the jobs, where persons with blindness can work productively with the help of IT tools, require professional qualifications and special training. Until such jobs are clearly identified, educational and rehabilitation institutions will be unable to design appropriate training modules to make persons with blindness eligible for new job opportunities.

Information Technology has increased productivity and efficiency in almost every profession. IT tools are redefining the job profiles in the work environment. Many of such Job profiles provide job opportunities for persons with blindness or low vision especially in the fields of Business Process Outsourcing, IT profession, tourism and as editors, Labor Welfare Officers, teachers, Law officers, Personnel Managers, Bankers, Librarian, Office Assistants etc. In these sectors, 31 new jobs were found where Persons with blindness could work productively. It has also been found that due to the re-definition of job profile amongst the 395 already identified jobs in A, B and C categories under Government of India where persons with blindness or low vision are being employed, 80 jobs require efficiency in IT tools to maintain the productivity levels expected in these professions. This list should not be treated as an exhaustive list. IT Tools remove the basic barrier of dependency on reading and writing and therefore, the jobs that is doable by persons with blindness becomes unlimited. The line which divides what job processes IT tools can make accessible or not, is still shifting, thereby expanding opportunities for visually disabled.

Current Status of Adaptive Technology and its Application in India:

Job in the office environment is done either in English or Local language. The Indian language versions of general-purpose Computer software for Word Processing, Spreadsheet etc. are being used widely but the screen reading softwares to support the Indian languages is not available. Therefore, the application of IT tools for persons with blindness in India is limited to the job processes being done in English language. The use of this tool in education too is therefore limited to select population of persons with blindness that uses English as the medium of their study. The percentage of persons with blindness who receive basic education is also not more than 10% and therefore the use of IT tools for increasing employability gets limited. India has 22 official languages and the screen reader would be required to support these languages to be able to provide solutions to the persons with blindness.

Some of the job processes found doable by persons with blindness or low vision require customization of screen reading software or adaptability in the tools used for those professions. A detailed research in each of these professions needs to be undertaken to translate the identification of jobs into employment generation. Efforts also need to be made in the direction of adaptability of courseware to enable persons with blindness to acquire qualifications required for the identified jobs.

Conclusion

As access to the built environment is the key issue for persons with mobility impairment, access to Information is the key issue for the persons with vision impairment. Similarly the inaccessibility of the communication technology is the key issue for persons with Hearing impairment. The technology presents unlimited scope of solving these problems. For example an infrastructure with proper use of video phone can provide a very effective solution to telephony for persons with hearing impairment. This would involve installation of video phone for the user with hearing impairment and at a central location where sign language interpreter acts an operator. This facility is successfully being used in some European countries. Similarly, computer assisted instructional programmes for mentally retarded students that includes drill and practice, tutorial, educational games, demonstration, simulation, problem solving and discovery learning for can open a new world for them. By operating his/her personal computer, a wheel chair user can control many activities in the house such as operating fans, air-conditioned, television and other gadgets, closing/ opening doors etc. Such examples are innumerable but their local adaptations are very few which need to be replicated and many new examples to be created in our own conditions. The essence of the matter is to identify the requirements of people with various disabilities in India and try to solve them with readily available technological advancements. These efforts, if done with utmost sincerity will not only make living qualitatively independent for disabled persons but also motivate them to perform better in terms of activities of daily living. It is an old dictum world over that if a person's dignity is safeguarded he always strives to perform better in life.

So is true with persons with disabilities. If the society takes care of their disabled brethren, give them their due advantage and opportunity of ICT to use it productively, it will allow them to participate and lead a dignified life and participate in the mainstream activity of the society.

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Achievement and Major Streams of Action to be taken under the project

A. Achievements

- 10 persons from 4 developing countries have been trained as co-trainers for the Focal Point Trainings for DAISY Production.
- An extremely talented team of programmers consisting at least 50% of programmers with vision impairment is now working on localization of DAISY Playback Tool for Thai and Indian languages. The work on the Hindi language version of AMIS DAISY books player software has already been completed and the software has been uploaded on the project website for free download. These programmers have also started their work on next generation of the DAISY Playback Tool called AMIS-Next.
- 25 persons representing 17 organizations from Thailand, India, Srilanka and Nepal attended the Focal Point Trainings at Bangkok and New Delhi. These organizations were given the DAISY Production software's and the skills to undertake the DAISY Talking Book Production.

B. Major streams of action to be taken under the project.

- 1) Establishing Focal Points and Resource Centres: Over the period of 5 years, the project aims to establish Focal Points in 36 developing countries. 2 to 10 resource centres will also be established. These centres will work as contact points for DAISY Consortium for their respective countries. These centres would be equipped to undertake training and production of DAISY Books.
 - 2) Software development: Team of programmers is appointed to develop open source software for development of DAISY Books Playback Tool which could be adopted for various languages. The team would also work on developing the software for creation of DAISY Books. The second part of this activity would be to conduct workshops for the development of human resources within the developing countries to work on open source software projects of DAISY related tools.
 - 3) Implementation in the first year of the work: Within the first year of implementation which is from April 1, 2003 to March 31, 2004, 2 resource centres have been established in Bangkok, Thailand and New Delhi, India.
- Focal Point Training: Training for the production of Digital Talking Books would be conducted at every focal point. The training would also have content for the management of talking production and dissemination. For the current

year, Focal Point Training has already being conducted in Bangkok in August, 2003 and in New Delhi from November 8-13, 2003.

- International Trainers Training Programme: In August 2003, a training programme was conducted in Bangkok to train trainers from developing countries. These trainers have been empowered to become the co-trainers at the Focal Point Training Programmes. 4 persons from India attended this training and 3 out of these were co-trainers in the Focal Point Training held at New Delhi.
 - Open source software development workshop: Two workshops were conducted in October, 2003 in Bangkok and in December, 2003 in Geneva respectively. 6 talented programmers from India attended the training in October, 2003 at Bangkok. 8 persons from India attended the second workshop in Geneva from 15th – 19th December, 2003. 4 out of these 8 persons were the trainees from the first workshop. These programmers participated in the advanced working group session to work on the next generation open source DAISY Playback Tool.
- 4) The DEA project is working on the acceptance of the DAISY standards by participating and showcasing the technology at International Seminars such as World Summit of Information Society, etc.

Chapter 9

Social Security for Persons with Disabilities in India

P Madhava Rao

While the programmes of Social Security are to guarantee income maintenance or income support, the condition of the disabled persons is somewhat different. Some might have become disabled due to work injury or accident or due to some other contingency during their work life. Such persons have employment related social security schemes in operation in India. However, there are majority of the disabled persons in the country who are not employed but require social protection. This chapter seeks to address the problems of those along with their social security needs and attempts to design a policy of social security for them.

Introduction

The International Labour Organization (ILO) defines Social Security as “the security that society furnishes through appropriate organization against certain risks to which its members are perennially exposed. These risks are essentially contingencies against which an individual of small means cannot effectively provide by his own ability or foresight alone or even in private combination with his fellows. The mechanics of social security therefore consists in counteracting the blind injustice of nature and economic activities by rational planned justice with a touch of benevolence to temper it.” This definition of ILO clears and centers on provision of support to an individual or to his /her family to protecting them falling into contingent poverty which is that the individual is not otherwise poor but for the contingency. These contingencies as per ILO are sickness, medical care for the worker, maternity, unemployment, work injury, death of worker, invalidity and widowhood. The contingencies however are the work related contingencies and the individual and his family will be protected only in the case the individual is working before becoming a subject of the contingency. Thus being employed is a precondition for becoming eligible for social security benefits. Ironically, this definition does not cover the protection that has to be provided for the people who are already poor and therefore the Social Assistance programmes cover them.

Evolution of Social Security

The concept of social security is as old as the history of man. Stories of Bible tell us how, during the years of famine, Joseph tried to tide over the situation by making use of surplus stocks of grain which he had stocked during the earlier years of plenty. The oldest institution of social security is family that includes the extended family. Industrial revolution in the Europe has seen the growth of urban and industrial centers that affected the rural joint families thereby disturbing the institution of social security in the joint family system. When individual was unable to take care of his own needs, the society realized the importance of protecting the individual and his family. In Great Britain the poor laws were enacted to provide minimal food and shelter in a workhouse to the poor. Private savings, compensation by employers, medieval guilds, mutual aid or mutual benefit societies, private insurance and life insurance are some of the evolutionary forms of social security efforts.

Need for Social Security

Modernization and urbanization have resulted in radical socio-economic changes and given rise to new conflicts and tensions consequent upon the erosion of age old family and fraternal security. The transition from agricultural economy to an industrial economy brought in special accompanied problems that called for social security.

Purpose and contingencies of social security

The purpose of any social security measure is to give individuals and families the confidence that their level of living and quality of life will not erode by social or economic eventuality; provide medical care and income security against the consequences of defined contingencies; facilitate the victims physical and vocational rehabilitation; prevent or reduce ill health and accidents in the occupations; protect against unemployment by maintenance and promotion of job creation and provide benefit for the maintenance of any children. The contingencies of social security as delineated by ILO are medical care, sickness benefit, unemployment benefit, old age benefit, employment injury benefit, family benefit, maternity benefit, invalidity benefit and survivors benefit.

Social Security Strategy in India

The social security strategies include the following:

- Social insurance with the participation of the beneficiary pooling risks and resources
- Social assistance financed from general revenues and granting benefits on the basis of means test
- Employers liability schemes where there is an identifiable employer and within the economic capacity of the employer
- National Provident Funds
- Universal schemes for social security.

Social security in India

Article 43 of the Constitution speaks of state's responsibility to provide social security to the citizens of this country. In India, we find all the above strategies in practice. For the purpose of discussion, we may categorize the social security schemes available in India as Preventive Schemes, Promotional Schemes, and Protective schemes.

A. Preventive Schemes

Preventive Schemes are the Schemes aimed at risk prevention. In the strategy of social management of risks, preventive approach tries to prevent poverty and helps people under below poverty line to come above poverty line. Preventive health care, vaccinations against diseases forms part of the preventive strategies. Majority of the schemes are of social assistance in nature.

B. Promotional Schemes

Promotional social security schemes are mainly of Means tested Social Assistance type, where to guarantee minimum standards of living to vulnerable groups of population, the Governments at the State and Center draft schemes financed from the general revenues of the Government. These are the strategies of risk mitigation. These guarantee:

- **Food and Nutritional Security** by ensuring per capita availability of food grains, access to food, developing agriculture sector, targeted Public Distribution system etc.
- **Employment security** by ensuring employment by generating employment, redeploying the surplus manpower in any sector, creating rural employment opportunities, encouraging technological up gradation.
- **Health Security** by ensuring availability of medical facilities, maintaining standards of sanitation and drinking water, eradication and control of communicable diseases, timely vaccination of children and child bearing women, health insurance, old age homes and social insurance for the elderly.
- **Education Security** by ensuring opening of schools, Encouraging children to attend classes, Making education compulsory upto certain age, opening adult learning centers or formulating schemes like Sakshara, running schemes like mid day meals etc.
- **Women Security:** by empowering women, encouraging women literacy, banning dowry, designing widow pension schemes.
- **Assistance to the Disabled** by undertaking programmes to promote health and education among the disabled persons, providing rehabilitation services and reservations in services so as to enable them to participate in social and economic activity.

All the above form part of promotional social security schemes where State Governments are more involved than the Central Government. Examples of schemes in the promotional social security area include: Food for Work, Jawahar Rojgar Yojana, Antyodaya, Rural Landless Labourers Employment Guarantee Schemes, Programmes of Integrated Rural Development Project, Drought prone area Programmes, Sakshara, Integrated Child Development Scheme (ICDS), Public Distribution System, reservations for the disabled in services, special educational institutions for the disabled persons etc.

C. Protective Social Security Programmes

The protective social security programmes help the poor in removing / reducing contingent poverty. In India, the protective social security programmes have been designed to address the contingent poverty or the contingencies as defined by the ILO. These programmes take care of: old-age income needs (Old age pension), survival benefits (Provident Funds), medical need of insured families (Medical Insurance), widow and children/ dependant economic needs (Widow/ Children/ orphan, and dependent pension), maternity benefits, compensation for loss of employment and work injury benefits.

The benefits are extended only to working population majority of whom are in the organized sector through legislations like:

- Employees State Insurance Act 1948
- Workmen's Compensation Act 1923
- Employees Provident Fund and Miscellaneous provisions Act 1952
- Payment of Gratuity Act 1972
- Maternity Benefits Act 1976

Social Security for Disabled Persons in India

Having discussed the social security concepts and strategies and programmes available for the vulnerable groups, the need for the Social Security Programmes for the persons with disabilities can hardly be overemphasized. However, we need to understand that the family has been the primary producer of welfare even before the birth of a welfare state on the lines of modern welfare approach. Later community, membership institutions, markets, and finally States provided welfare facilities. Particularly in democratic states, it has been the political necessity to produce and distribute welfare for the vulnerable groups in the society. The magnitude of the woes of the persons with disabilities is vast and its impact on the individual, family and community is severe. The most vulnerable groups among the persons with disabilities include very young children, women and the aged with disabilities. Their existence and lively hood requirements have to be taken care of by some agency in the society- that agency could be the state in the absence of benevolent markets and communities and more so when the families of the persons with disabilities cannot do so. Further it is apart of social justice that a State may assure to its subjects.

In the United States the Social Security Administration, United States (SSA) considers one as disabled under Social Security Rules, if one cannot do work that he did before and SSA decides that he cannot adjust to other work because of his medical condition(s). A person's disability must also last or be expected to last for at least one year or to result in death. Social Security program rules assume that working families have access to other resources to provide support during periods of short-term disabilities, including workers' compensation, insurance, savings and investments. "The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995, inter-alia and strives to promote empowerment of persons with disabilities. The right to receive support and assistance, although essential to improving the quality of life of people with disabilities, is not enough. Guaranteeing access to equal political, social, economic and cultural rights should be the

Data:

NSSO 58th Round, undertaken in 2002, estimates that about 1.85 percent of population suffer from some kind of disability or other. However, detail data are available now for designing a comprehensive social security system for persons with disabilities. In contrast, detailed statistics on the disabled population in Europe is available on the basis of which social security is planned & implemented. Some of the fundamental rights contained in the European Convention on Human Rights and its Protocols, and the Revised European Social Charter include the right to education; the right to work; the right to private and family life; the right to protection of health and social security; the right to protection against poverty and social exclusion; the right to adequate housing, etc. Based on these statistics the European countries are working hard to make their disabled people enjoy the fruit of the policies. Therefore, availability of detailed data on the disabled population in India is a pre-requisite for better planning and implementation of social security schemes. Data on the following aspects as regards the disabled population in the country will be useful in this regard:

- **Parents with disabled children below poverty line:** This is required to design some additional social assistance schemes.
- **Unemployed disabled persons who can be gainfully employed:** This is required to design special employment schemes and employment drives and to evolve income generation strategies for the disabled persons and ultimately make them eligible for protective type of Social Security Schemes.
- **Non-employable disabled persons who always require support of the Family /Community or the State:** This is required to design State assisted / funded schemes as well as to rehabilitate them in the homes for disabled persons.
- **Disabled persons above 60 years of Age:** This is required to help mitigate the hardships of the disabled senior citizens through Old Age Pension Schemes in the form of Social Assistance and State assisted health care.

- **Disabled women:** This is required to understand whether the disabled women are dependent on their parents or on their husbands and the poverty status of their family/parents and to design schemes of Assistance or Insurance accordingly. This will also help us to understand the requirements of the disabled women in the child bearing age and making provisions for their maternity care.
- **Disabled widows:** This will help planners to understand the dependency levels of the widows, if they are pensioners, their economic status etc.
- **Disabled persons engaged in agriculture and informal sector:** This data will enable the Government to design programmes of skill up gradation for the workers in the informal employment and self employment and create backward and forward linkages for their economic activities. It is also possible to specially brand the products produced by the disabled and grant export concessions and subsidies.
- **Disabled persons retired from armed forces and capable of being re employed:** This data will enable planners to assess the assistance required for this category of people.

Required Social Security programmes for the Disabled Persons in India

Assistance and benefits both in the form of cash and kind will help ameliorate the condition of the disabled persons who have to bear additional economic and social cost due to their disability. Granting benefits for the persons with disabilities is a necessary condition but not a sufficient one for their empowerment & overall development. People with disabilities, like all people, require love and affection that is most often best provided by their families. Specific measures and assistance are therefore essential to help these families overcome the threat of many possible sources of deprivation and provide a caring home as a much better and more natural alternative to life in large institutions/ homes for disabled for disabled. If the family itself is poor, it may not be able to extend any kind of support to the disabled members but rather treat him as an extra burden. Before designing the programmes suggested hereunder, this fundamental social understanding should not be overlooked.

The cash benefits by way of assistance could be in the form of the following:

- Scholarships to the disabled children
- Old age pension to the aged and widows
- Unemployment assistance to the educated disabled
- Cash subsidies for self employed
- Disablement pension
- Retirement pension

The benefits in the form of kind could be in the form of:

- Concessions and support in various activities and concessions in transport
- Medical assistance
- Medical insurance where employer liability schemes are possible
- Compensation in the case of work injury resulting in disability
- Maternity care for the disabled mothers
- Compulsory provision of crèches in all the work places for the children of disabled mothers
- Reservations and Concessions in services
- Special skill up gradation programmes
- Special Schools and Teacher Training centers
- Tax rebates for the disabled persons as well as the parents of the disabled children

Available programmes for the disabled

Currently reservations in services, concessions in employment, disability pension under the Employees Provident Funds and miscellaneous provisions Act 1952, medical and maternity benefits under Employees State insurance Act 1948, benefits under the Workmen's compensation Act 1923, special schools for the disabled children, disability specific assistance programmes are available in the country, though the coverage is not comprehensive. Ironically three major Social Security Acts listed above are the employer liability and employment related benefit schemes. They are operative only in the case of disability during the course of employment. There are no programmes for old age and survivor benefits in the case of the disabled who cannot be employed or the disabled person who are not employed even after crossing the employable age. There are no programmes for the disabled, dependent and aged widows excepting some very meager assistance given by some State Governments such as old age pension of Rs.75 per month. In addition we find that multiplicity of agencies and duplicity of benefits are very common to all the social security programmes available in India, and the plight of the persons with disabilities has no exception to this rule.

Annexure II gives the status of pension/ unemployment allowance for the persons with disabilities, State /Union Territory wise- source: Chief Commissioner Disabilities

Programmes/ Schemes required to be designed for the Disabled Persons

Currently available schemes or programmes do not comprehensively address the problems of the disabled persons. The major Social Security Acts available in India aim only at employment related disability. In fact a large number of the disabled persons are outside employment or in informal economic activities or simply dependent on their parents, children and/ or spouses. In some of the

Rural Development and other programmes there are some disabled beneficiaries. However, keeping in view the statutory provision of 3% reservation for persons with disabilities in all poverty alleviation schemes, the coverage is negligible. This provision needs to be effectively implemented.

In the United States the Social Security and Supplemental Security Income disability programmes are the largest of several Federal programmes that provide assistance to people with disabilities. While these two programmes are different in many ways, both are administered by the Social Security Administration and only individuals who have a disability and meet medical criteria may qualify for benefits under either program. Supplemental Security Income (SSI) is a Federal income supplement program funded by general tax revenues (not Social Security taxes) It is designed to help aged, blind, and disabled people, who have little or no income; and it provides cash to meet basic needs for food, clothing, and shelter. Based on the international best practices and the India specific requirements the urgent need is to formulate the following types of benefits and programmes:

- i) Universal old age defined benefit Pension Schemes for the disabled without any means test (As Social Assistance) should be thought of based on national average wage that guarantees poverty alleviation among the persons with disabilities;
- ii) Universal Medical benefits (possibility of establishing opening separate out patient windows for the disabled should be seen to lessen the hardships of the disabled patients who stand in the general queues in the public hospitals), free treatment to the disabled persons by corporate hospitals could be thought of a precondition for grant of license to the corporate hospitals;
- iii) Universal Unemployment Assistance to the disabled persons with means test will definitely alleviate poverty among the persons with disabilities and employable. However, a scheme of discontinuance of the benefit in the event of non-acceptance of employment may be thought of to protect them from falling into unemployment trap;
- iv) Tying up with corporate hospitals to extend medical care at a concessional rate to the disabled, where the disabled have a capacity to pay, and subsidizing cost of surgical treatments in the hospitals;
- v) Social Assistance to the disabled children and scholarship schemes for them if they re school going. Pre-examination training to enable them to sit for competitive examinations along with other candidates;
- vi) Special Employment and Skill up gradation programmes
- vii) Bank credit at subsidized rate of interest for the self-employment projects taken up by the disabled persons (NHFDC activities needs to be expanded)
- viii) Reservations in services and other concessions provided needs to be effectively implemented
- ix) Incentives to be given to employers encouraging employment of the disabled persons in consonance the provisions in the PWD Act, 1995.

Financing of the Schemes

The approach to financing the schemes designed for the disabled persons as also launching of new social security schemes for persons with disabilities should be broadened and the following options including the traditional budget allocations out of the Government funds need to be explored:

- Finance from the general revenues or tax financed as a major source;
- Collection of cess from the industries, employment in which leads to occupational diseases and work hazards;
- Special tax on luxury items and those items consumption of which are injurious to health
- Contribution from employed parents of the disabled to establish a separate fund for Disability welfare;
- Donations from charitable organizations;
- Donations from international donors and agencies;
- Employer share of contribution at enhanced rates for the programmes designed to address contingent poverty;

Administrative Arrangements

The current Administrative arrangements for delivery of support and benefits to the persons with disabilities are scattered. There is neither a uniform benefit formula nor is there any single agency that administers or guides the program. It is suggested that multiplicity of agencies or departments currently looking after disability benefits need to be integrated together to have a comprehensive program design and implementation policy under one umbrella with a Chief Executive Officer. However disability specific branches under that agency may be designed to continue the professional approach.

As per the Act, one of the jobs of the office of Chief Commissioner for persons with disabilities is to monitor utilization of funds disbursed by Central Government. This needs to be ensured. A National Commission has also been set up recently to aid & advice the Government regarding disability and rehabilitation matters and to recommend action. Data may be collected through census as also NSSO surveys at regular intervals. A National Unique Identification Number on the lines of National Social Security Number may be thought of to avoid duplicity in benefit delivery. The State Governments may start, in right earnest issue of identify cards, preferably, SMART cards with assigning such numbers. All the States may appoint independent State Commissioners, who, as per the Act., may perform their quasi-judicial function in supervising and implementation of various provisions of the Act., and redressing grievances. Administration arrangements may be made for collection and recording of contributions and donations for developing a fund for social security programmes for disabled.

The current system of collection of contributions under protective Social Security schemes need not be disturbed; investment of funds and budgetary

allocations made for the purpose need to be enhanced and designing effective income generating schemes may be given attention. Suitable schemes along with administrative arrangements may be made for delivery of benefits including medical benefits, old age pension and benefits in cash or kind.

Conclusion

The current Social Security programmes are employment related and do not appear to have any special attention to the disabled persons. To be eligible for the benefits one has to become disabled after getting into employment. This approach does not address the disability ab-intio and major problems of non-employment and poverty among the disabled persons. Disabled persons in India are the most vulnerable group. Unfortunately, disabled persons irrespective of their economic status are subjected to social exclusion in the society. Economic, psychological and social confidence building is therefore immediately necessary. Social Security programmes for the disabled, to some extent will relieve the pain of being dependent. Comprehensive administrative arrangements, pooling up funds from various sources and delivering the benefit under professional supervision and control are the other immediate requirements. Lack of information and dissemination & absence of a single window approach makes persons with disabilities often unaware of what benefits and schemes are available to them. Besides ensuring that available benefits reach them, more resources from local, state, national and international agencies, Government and Non Government Organisations need to be mobilized. For example, resources available under various Departments/ Ministries and schemes such as Rural Development, HRD Ministry, Labour Ministry, DRDA Programmes, grant in aid schemes for special schools, pension schemes, LNDP programmes, CAPART, NHFDC, and international funding organizations such as NORAD, Action Aid, SIDA, DANIDA and others need to be harnessed.

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Facilities & Benefits Available for Persons with Disabilities

Several ministries/departments of the Government of India provide various concessions and facilities that include:

Concessions on Railways Railways allow disabled persons to travel at concession fares up to 75% in the first and second classes. Escorts accompanying blind, orthopedic ally and mentally handicapped persons are also eligible to 75% concession in the basic fare.

Air Travel Concessions Indian Airlines allow 50% concession fares to blind persons on single journeys.

Postage Payment of postage, both inland and foreign, for transmission by post of 'Blind Literature' packets is exempted if sent by surface route.

Customs/Excise Braille paper has been exempted from excise and customs duty provided the paper is supplied direct to a school for the blind or to a Braille press against an indent placed by the National Institute for the Visually Handicapped, Dehradun. All audiocassettes recorded with material from books, newspapers or magazines for the blind are exempt from custom duty. Several other items have also been exempted from customs duty if imported for the use of a disabled person.

Conveyance Allowance All central government employees who are blind or orthopedic ally handicapped are granted conveyance at 5 per cent of basic pay subject to a maximum of Rs. 100 per month.

Educational Allowance Reimbursement of tuition fee of physically and mentally handicapped children of the Central government employees has been enhanced to Rs. 50/-.

Income Tax Concession: The amount of deduction from total income of a person with blindness, mental retardation or permanent physical disability has been increased to Rs. 40,000/-.

Award of Dealership by Oil Companies: The Ministry of Petroleum and Natural Gas has reserved 7.5 per cent of all types of dealership agencies of the public sector companies for the orthopaedically handicapped and blind persons. However, persons with visual handicap are not eligible for LPG distribution. Similarly, the Ministry has also reserved 7.5 per cent of such dealership/agencies

for defence personnel, and those severely disabled either in war or while on duty in peacetime.

Posting : Candidates with Physical handicaps, appointed on a regional basis be given as far as possible, appointments as close to their native place.

Economic Assistance by Public Sector Banks : All orphanages, homes for women and persons with physical handicaps as well as institutions working for the welfare of the handicapped, are given loans and advances at very low rates of interest (4% under DRI) and a subsidy of 50% up to a maximum of Rs. 5,000/- is also admissible. State Governments/Union Territories also give concessions/facilities such as reservation in jobs, scholarships, old age pension, free travel in buses, etc.

Funding scheme for special schools: A grant-in-aid scheme for voluntary organisations to develop institutes that serve to provide educational and social opportunities for persons with disability. To know more about scheme and to download the application form

Appendix II

Status of Pension/Unemployment Allowance for Persons with Disabilities

	States/UTs	Disability Pension/Maintenance Allowance	Unemployment Allowance	Remarks
1.	Andhra Pradesh	Disability Pension of Rs. 75/- per month is given to all categories of disabled who are between the age group of 18 – 65 years with minimum 40% disability.	Rs. 75/- per month is given to unemployed disabled persons who are on the live registers of District Employment Exchange and who are in the age group of 18-65 years, provided parents'/guardian's annual income does not exceed Rs. 12,000/-	
2.	Bihar	Disability Pension is provided to disabled persons by Labour Department of the State.	-	
3.	Chattisgarh	Social Security Allowance of Rs. 150/- per month.		
4.	Delhi	A scheme under which a one-time financial assistance of Rs. 1000/- is provided to those persons who have 40% or more disability and whose per annum income is not more than Rs. 22,000/-.		Proposal regarding scheme for payment of an unemployment allowance to persons with disabilities, registered with the special employment exchange for more than two

				years and who could not be placed in any gainful occupation has been made and is under process.
5.	Goa			Grant of Unemployment Allowance is approved by the Govt. Details are not yet available
6.	Gujarat	Disability Pension of Rs. 200/- p.m. is given to disabled persons who have more than 75% disability, are above 18 years of age and whose family is below poverty line.		
7.	Jammu & Kashmir	Rs. 300/- per month provided as Disability Pension.	-	
8.	Jharkhand	Pension Scheme for disabled exists. Details not given.		
9.	Haryana	Scheme for pension for persons with disabilities has been notified. Notified.	Scheme is in force in the State.	
10.	Himachal Pradesh	Disability Relief Allowance of Rs. 150/- p.m. is provided to those disabled persons who are having at least 40% disability and whose annual income does not exceed Rs. 6000/- per annum and the income of earning sons should not exceed Rs. 11,000/- per annum.	-	

11.	Kerala	Special pension scheme for PWDs having an annual family income of Rs. 12,000/- or less exists in the State.	Unemployment Allowance to all educated youths, including persons with disabilities, subject to certain eligibility conditions, is sanctioned.	
12.	Maharashtra		Government of Maharashtra has a Scheme for Educated Unemployed and this includes persons with disabilities also. This scheme is implemented through Employment Exchanges.	
13.	Manipuri	Disability pension of Rs. 100/- p.m.	-	
14.	Mizoram	Disability pension given to totally blind and bed-ridden persons who are totally dependent on their families @ Rs. 100/- p.m.	Unemployment allowance of Rs. 100/- p.m. given	
15.	Nagaland	Disability pension of Rs. 100/- p.m. is given to blind people.		
16.	Punjab		Unemployment Allowance of Rs. 400/- p.m. and Rs. 300 p.m. is given to blind/deaf unemployed graduates/post graduates and under graduate respectively, for Ortho. Handicapped Rs. 200/- and Rs. 150/- p.m. respectively.	

17.	Meghalaya		Implementing the scheme of unemployment allowance @ Rs. 50/- per month for PWDs	
18.	Orissa	Orth. Handicapped, totally blind, mentally retarded and persons affected by Cerebral Palsy over five years of age are given pension @ Rs. 100/- p.m. (70,000 beneficiaries are being provided such pension each year.)		
19.	Sikkim	Pension provided. (16.80 lacs allocated during 2002-3 - 700 beneficiaries.)	Subsistence Allowance is being given.	
20.	Tamilnadu	Those who are not placed in any gainful employment due to severe disability are given maintenance allowance of Rs. 150/- per month.	For Visually impaired, allowance is given ranging from Rs. 200/- to Rs. 300/- per month till they get employment or they reach 40 years (45 years in the case of SC, ST) whichever is earlier.	
21.	Tripura	State Government is giving pension to the disabled persons of destitute families @ Rs. 125/- per month.	-	
22.	West Bengal	Pension is provided. (6887 beneficiaries - Rs. 42,00,000 allocated for 02-03).	-	
23.	Uttar Pradesh	<i>Viklang</i> Pension of Rs. 125/- pm is given to destitute handicapped persons having monthly income below Rs. 1000/- per month.		

24.	Uttaranchal	Disability Pension of Rs. 125/- pm is given to destitute handicapped persons having monthly income below Rs. 1000/- per month.		
25.	A & N Islands	-	Rs. 100/- p.m. as unemployment Allowance is given.	
26.	Chandigarh	-	Unemployment allowance of Rs. 400/- pm for Graduate/PG VH and HI persons. Rs. 300/- pm for Matriculate and under graduate VH and HI persons is given.	
27.	Dadra & Nagar Haveli	Financial Assistance to Destitute Disabled is @ Rs. 60/- p.m.		
28.	Laksha dweep	Pension for Old Age, destitute disable is being given.		
29.	Daman & Diu	Disability Pension of Rs. 60/- p.m. is available for persons with disability with the age of 55 and above	Scheme for unemployment allowance has been formulated.	
30.	Pondicherry		Rs. 200/-/Rs.300/-/ Rs. 500/- per month to unemployed educated persons is being given.	

Source: Office of Chief Commissioner for Persons with Disabilities

Part Four
SUSTAINABLE
STRATEGIES

Chapter 10

Evolving Sustainable Strategies for Disability Management : Locomotor Disability

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A K Mukherjee

Locomotor disability is the most dominant category amongst all disabilities. This Chapter gives the broad definition and terms related to locomotor disability and discusses causes of acquiring such disabilities. Author analyse the data on locomotor disability to show the increase in percentage of locomotor disability during the last two decades. After briefly mentioning the schemes and programmes for rehabilitation of persons with locomotor disability, the authors suggest a number of sustainable strategies for prevention and management of locomotor disability and calls for an integrated multi-sectoral and multidisciplinary approach by the role players.

Introduction

Persons with disabilities are amongst the most marginalized and disadvantaged sections of the society. In the last quarter of century there were several significant landmarks and growth and awareness in the sector of disability both at the national & international level. The year 1981 was declared as the International Year of Disabled Persons. Subsequently, the year 1983-92 was proclaimed by the General Assembly as the UN Decade of Disabled Persons when a global movement emerged for integration of disabled people into the society through a World Programme of Action. The ESCAP proclaimed 1993-2002 as the Asia and Pacific Decade of Disabled Persons. India is also a signatory to the UNESCAP decade and needless to mention that our country intensified efforts to address the causes of disability at national level and with international stakeholders through programmes like Pulse Polio Campaign, National Programme for the Control of Blindness, Leprosy Eradication etc. Introduction of Acts (PWD Act of 1995, RCI Act of 1992 and National Trust Act of 1999) also played an important role for empowering the disabled persons. UN-ESCAP proclaimed extension of Asian Pacific Decade of Disabled Persons (1993-2002) for another Decade (2003-

2012) and adopted Biwako Millenium Framework for Action to promote an inclusive, barrier free and right based society.

India is a developing nation having a social fabric with socio-cultural, religious, geographic, climatic and demographic variations. This is of more significant while subjects related to a marginalized and under-privileged group are considered. Despite economic constraints, India has a vision for all round growth and intends to enter into the group of developed nations by the year 2020. Tenth Five Year plan targets more rapid growth and intends to double per capita income by the year 2010. To achieve ambitious targets, all sections of society including persons with disabilities have to be taken together.

Development through industrialization and urbanization has put more pressures and challenges for the social sector. During the last two decades, the Government of India has become increasingly concerned about the needs/welfare of Persons with Disabilities through convergence, empowerment and giving them due opportunities and rights. The issues concerning their participation and mainstreaming in society are being addressed. The qualitative changes and wider coverage are being attempted through convergence, intersectorial, inter and intra-ministerial coordination at central, state and district level.

Locomotor Disability

The rehabilitation services for the locomotor disability is known to us since long in term of homes for crippled. In organized sector, it got recognition due to the compensation claims and a 'Workmen Compensation Act' came in force as early as in 1923. Manual for Doctors to assess locomotor disability was published by ALIMCO in 1974. It was based on guidelines published by American Academy of Orthopaedic Surgeons and became popular amongst orthopaedic surgeons. Based on the recommendation of expert group meeting organized by WHO and AIIMS & Ministry of Health in 1984, the uniform definition of disabilities and guidelines to assess disability were notified by Ministry of welfare (presently Ministry of Social Justice & Empowerment) Government of India in 1986.

Rapid industrialization, high speed vehicular traffic and diseases like polio were major contributory factors for locomotor disability during last quarter of the century. Improved health conditions, control of communicable diseases, use of modern medical equipment & technology that have helped in saving lives, has increased life expectancy and reduced mortality rates. This has resulted in survival after a disease or accident with the burden of disability. The increasing geriatric population due to increased life expectancy has posed new challenges of geriatric disabilities. The improved natal and pre-natal, Maternity and Child Health (MCH) services has increased chances of survival of new-borns but thereby, also increased the incidences of survival with premature birth defects, cerebral palsy etc .

Locomotor disability is defined as a person's inability to execute distinctive activities associated with moving both himself and objects, from place to place and such inability resulting from affliction of musculo-skeletal and/or nervous system. The common terms which are referred while discussing locomotor disability are explained as under:-

- **Impairment:** An impairment is any loss or abnormality of psychological, physiological or anatomical structure or function in a human being.
- **Functional Limitations :** Impairment may cause functional limitations which are partial or total inability to perform those activities necessary for motor, sensory or mental function within the range or manner of which a human being is normally capable.
- **Disability:** A disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.
- **Handicap-** Irreversible disability leading to limits in day to day functions of individual's life.
- **PPI-** Permanent Physical Impairment(PPI) in functions of specific body part due to impaired anatomical structure. The functional loss is correlated with anatomical part and the individual.

In the prevailing system of disability assessment under guidelines notified by the Government of India, it is assessment of PPI that is commonly interpreted as disability. In contrary, under the International Classification of Functioning Disability and Health (ICF), the functional loss in relation to individual is assessed.

Data on Locomotor Disability

Recent National Sample Survey Organization's Survey of 2002 estimated that 18.5 million persons are having disability in the country and the number is high in the rural areas. Amongst locomotor disabled, probable causes of disability include Polio, injuries (other than burn injuries) and old age. Statistics shows that number of polio is highest followed by injuries and old age. It is to be mentioned that causes like stroke, arthritis, cardio- respiratory diseases are generally higher in older age. Massive programmes for prevention of Polio have already been undertaken across the country and the incidence has reduced drastically. 1934 cases of acute Polio reported in 1998 have reduced to 268 during 2001. This is possible due to all round efforts both national and international, to eradicate Polio. NSSO(2002) estimates show that 10.66 million (58% of all disabled) persons are having locomotor disability in India. Out of them 8 million live in rural and 2.66 million in urban areas. Four percent of locomotor disabled have multiple problems which complicate the situation further. Like earlier NSSO surveys, the prevalence of locomotor disability was found higher in rural areas i.e. 1046 & 901 per 100,000 in rural and urban population respectively. Affected males are more in number as compared to females i.e.,1217 males against 785 females both in rural and urban areas.

Table No.10.1 Prevalence Rate of Locomotor Disabilities (per 100,000 population)

Year	1981	1991	2002
Rural	828	1074	1046
Urban	679	962	901

(Source- NSSO Survey,2002)

Industrialization and introduction of high speed vehicular traffic and mechanization of agriculture sector had direct impact on increased incidence of locomotor disability. It is evident also as the prevalence was found to be highest in Punjab (1484) in rural and in Kerala (1195) in the urban sector.

Though there is significant decline in incidence of poliomyelitis during last few years, the impact of Polio in the past is still seen today. The deformity of limbs mostly because of residual paralysis of polio was found to be maximum i.e. 466 in rural and 455 in urban areas. While dysfunction of joints was found in 23 % cases and paralysis in 15% cases amongst persons with locomotor disabilities, polio and injuries (other than burn) were found to be prominent in being responsible for causing locomotor disability each in 27%-28% cases. With the increase of geriatric population, the prevalence of old age locomotor disability are increasing and is almost equal to leprosy related locomotor disability cases(3%-4%) as reported by NSSO (2002).

It is found that over the periods 1981 to 2002, while there was an increasing trend in the prevalence rate between 1981 and 1991, it remained steady during 1991 to 2002 in rural areas and had a very marginal dip in case of urban areas. Further, the incidence rates have also dropped marginally during the period.

Table No.10.2 Prevalence of Disability

	All disabilities*		Locomotor Disability**	
2202(58 th round)	18.53	(1.8)	10.66	(57.5)
1991(47 th round)	16.36	(1.9)	8.04	(49.2)
1981 (36 th round)	13.67	(1.8)	5.43	(39.7)

* Brackets show percentage of total population

** Brackets show percentage of total disabled population

The number of geriatric population increased form 42.5 million in 1981 to 55 million in 1991 which have further swollen to 70.6 million.

Programmemes for Locomotor Disabled Persons

Various policies, programmemes & schemes for welfare and empowerment of disabled were taken in five year plans since 1951. During the Fifth Plan, the National Institute for Orthopaedically Handicapped was set up at Kolkata. In 1975, prevention of disability got some impetus by launching of the Integrated Child Development Scheme (ICDS). The need of rehabilitation services for locomotor disability was further realized and IPH & NIRTAR were established during Sixth & Seventh Plan. The services for disabled persons were expanded through the District Rehabilitation Centre (DRC) scheme.

Subsequently in Ninth plan, the states responsibility to empower the disabled with equal opportunities, protection of rights and full participation in the nations development process gained importance & Persons with Disabilities Act (Equal opportunities, Full Participation & Protection of Right),1995 came in force. RCI

was set up in 1992. The National Trust was set up in 1999 for the group of disability not covered under Disabilities Act, 1995. The National programme for Rehabilitation of Persons with Disabilities (NRPD) was launched in 1999-2000 as a State Sector programme. To meet the increased demand of trained manpower and rehabilitation services, five Composite Regional Centres at Srinagar, Bhopal, Lucknow, Sundernagar (HP) & Guwahati were established in 2000-01. Through CRCs, a composite approach in manpower training and single window approach for all categories of disability in terms of providing rehabilitation services has been adopted for first time. The concept of disability specific training has now shifted to a multi purpose & composite approach adopted by these CRCs. Four Regional Rehabilitation Centres (RRCs) at Mohali, Jabalpur, Bareilly & Cuttack, were established in 2000-01 through networking with Indian Spinal Injury Centre (ISIC) at New Delhi to provide specialized rehabilitation services to the persons with spinal injuries. Setting up District Disability Rehabilitation Centres (DDRCs), 90 of which are already functional, is a step in right direction towards decentralized delivery of services.

Prevention

In prevention of disability, Ministry of Health plays a key role. The Ministry of Social Justice & Empowerment, which is a nodal ministry in disability rehabilitation along with Department of Women & Child Development (through ICDS) and Ministry of Human Resources Development (through schemes like DPEP, IED and SSA) also contributes significantly. Following National programmes by Ministry of Health helps in disability prevention:

- Universal Immunization Programme (UIP)
- National Polio Eradication Programme- Pulse Polio.
- National Leprosy Control Programme
- National Iodine Deficiency Disorder Control Programme & pilot project on micro-nutrient.

The National Programme of Rehabilitation for Persons with Disability (NRPD) also focus on disability prevention through generating by awareness and community participation.

Early medical & rehabilitation intervention facilities are supposed to be available at PHC level. A national programme of PHC doctors on disability management launched by RCI in 1999. The knowledge on prevention and early intervention in disability management is also being imparted to MBBS students in existing medical course. To reduce the incidence of locomotor disability, RCI programme emphasizes upon pre-natal health check up of mothers. Early identification, intervention and prevention of locomotor disability in the age group of 0-6 years and in pregnant mothers are undertaken by ICDS. 54.3 million children (0-6 years) and 10.9 million mothers have been benefited under the scheme. While vaccination is the focus under Universal Immunization Programme (UIP) & Pulse Polio programmes, supplementation of iodized salt and micronutrients is targetted in National Iodine Deficiency Disorder Control Programme. Awareness and early detection are focus areas under the Leprosy control programme &

NPRPD. The national programmes are being implemented through primary health care delivery system. About 90 DDRCs established recently in different parts of the Country under Ministry of S.J&E also play an important role in prevention of locomotor disability.

Prevention of disabilities related to Injuries

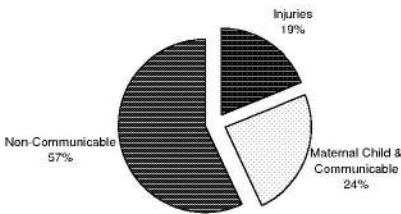
Disabling injuries resulting from vehicular & industrial accident are second commonest cause of disability. With the increasing incidence of injuries but better emergency management to save lives, the incidence of disability is likely to increase. Increasing mechanization in agriculture & industry, induction of semi and un-skilled workers in various operations and rapid increase in vehicular traffic have resulted in increased morbidity/disability due to accident and trauma. Overcrowding, lack of awareness and poor implementation of essential safety precautions are responsible for disability. The disease burden estimates for India in 1990 and the projections for 2020 shows that there is going to be an increase in injury related diseases from 15% to 19% indicating higher incidence of disability due to injuries .

Disease Burden Projections

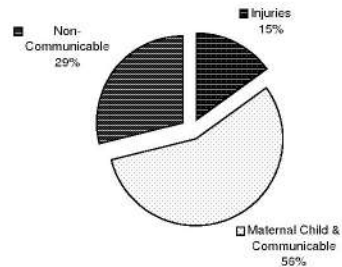
Fig.10.1(a)

Fig.10.1(b)

Disease Burden Projections-India 2020

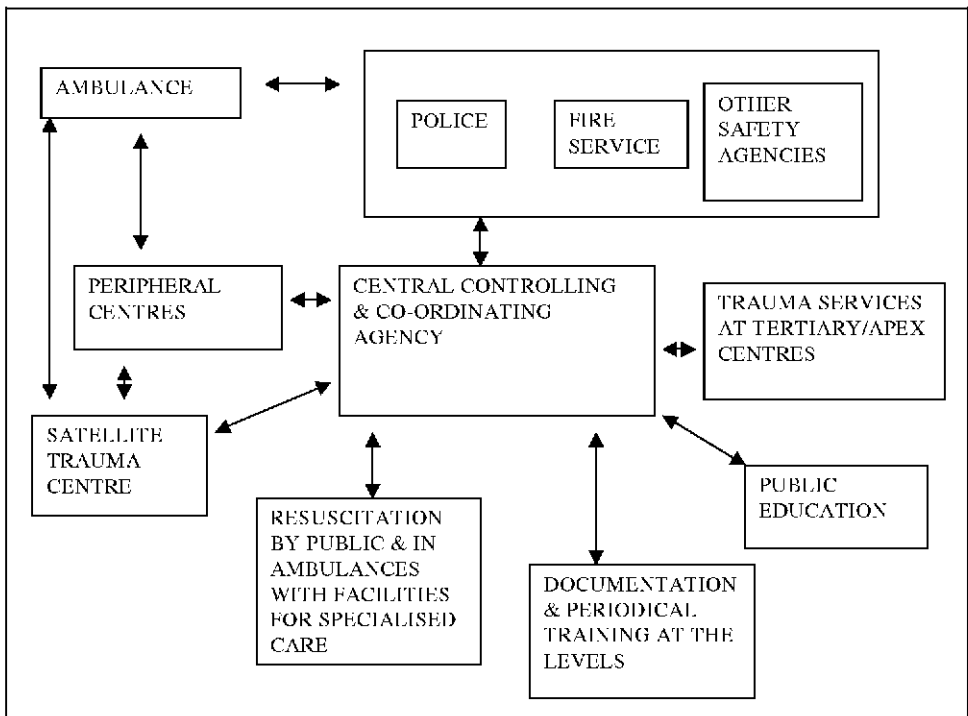


Disease Burden Estimates-India 1990



At present there is no organized comprehensive trauma care service either at the Centre or in the State. To reduce injury related disability, adequate training to medical and paramedical personnel, quick and safe transport facilities of patients, strengthening of existing emergency & casualty services are required. A module of trauma services have been proposed below for a city like Delhi.

Figure 10.2 Proposed Module of Trauma Service



Assistive aids/ appliances for Locomotor Disabled Persons

The rehabilitative assistive devices play an important role in improving the function of affected part of body. These may be mobility aid in the form of wheel chair (manual or motorized), artificial limbs or orthotic aid as per individual's need. To manufacture components of assistive aids for the persons with locomotor disabilities, ALIMCO was established in Kanpur in the 70s. It has expanded its activities by setting up four auxillary production centres at Bhubaneswar, Jabalpur, Rajpura & Bangalore. New prosthetic devices and improved mobility aids at reasonable cost have been developed at ALIMCO through its modernization efforts.

Keeping in view the increased demand for assistive devices, many private manufacturers have entered into the market and are producing quality products. Following strategy may be adopted in providing quality aids/appliances.

- The standards for all types of different aids/appliances need to be developed & monitored and also competitiveness between Government and private manufacturers need to be encouraged.
- The private manufacturers using appropriate technology at reasonable cost need to be encouraged.
- The need oriented low cost and standard quality aids should be encouraged.

- Insurance companies and corporate sectors should be encouraged to share the burden.
- Simple and appropriate technology needs to be adopted in designing new aids and appliances.
- The aids /appliances should be affordable and available. It is better if it can be fabricated/repaired locally.

Economic Rehabilitation

Comprehensive rehabilitation aims finally at ensuring dignity and economic independence to the disabled persons. In the Government sector, empowerment through reservation in jobs under group A,B,C&D against identified posts have been made. The list of such jobs have been expanded and efforts are being made to fully implement the reservation policy in all Ministries and Departments of central, state governments and UTs. The work places have to be made barrier free to facilitate this.

With the objective of economic empowerment through self employment as a part of comprehensive rehabilitation process, NHFDC was established in 1997. Besides entrepreneurship & self employment through NHFDC & public sector financial institutions, 40 special employment exchanges, 41 special cells are functioning which have extended placement services. This effort is also supported by 17 VRCs under Ministry of Labour located all over country. These are in addition to the facilities available with institutes & NGOs supported under Ministry of SJ&E and the polytechnics working under Ministry of HRD.

To sustain this endeavor of economic empowerment of persons with locomotor disability following measures need to be taken,

- Barrier free access to work place.
- Ergonomics modification at work stations
- Appropriate aids & appliances
- Participatory approach in formulation of employment policies.
- Since Government jobs are shrinking and more avenues in private and service sectors are coming up, the mind-set of employers and disabled persons need to be changed towards private sector jobs and self-employment ventures
- More emphasis should be given in vocational training, self employment and entrepreneurship development by participatory approach.

Educational Rehabilitation

The educational integration of children with locomotor disability was launched through IED under DPEP which has been strengthened further through SSA. The children with disabilities are identified, assisted in getting aid/appliances and integrated in education through inclusive approach. The school are made barrier free and resource room for disability are improvised. The children with locomotor disability do not require special teaching material for teachers, but a changed positive mind-set amongst parents, teachers, students and the society as

a whole. Sometimes, minor provisions and changes in the physical environment is enough to make the premises accessible to the children with locomotor disability. The inputs on disability in the teachers training curriculum and inclusive & integrated approach in education system under SSA is likely to change the picture in coming years. The reports of UNDP project on integration of children with disability and the SSA scheme have shown encouraging results.

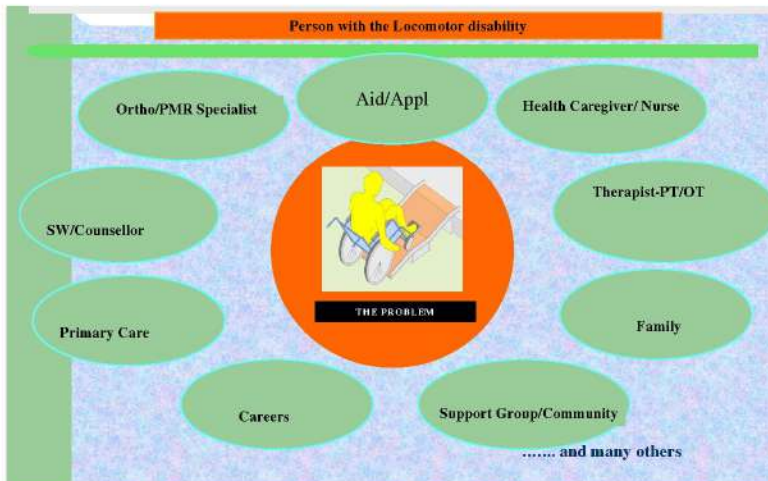
Educational facilities to the children with locomotor disability are also extended through support to NGOs under the umbrella scheme of Ministry of Social Justice and Empowerment, SSA aim to cover all children aged 6-14 years by 2010. DPEP, IED and IEDC schemes running in 28 States/UTs have covered around one lakh disabled students in 2200 schools. The National Scholarship for disabled students undergoing post matric and higher studies has been introduced recently by Ministry of SJ&E which need to cover more and more students in future. Development of barrier free access to school, change of attitude of teachers and parents, promoting an inclusive approach and vocationalization of education are the thrust areas for future approach to sustainable educational rehabilitation for locomotor disabled.

Sustainable Strategies

- (i) The concept of rehabilitation has changed from institution based to community oriented, from segregation to inclusion to the society, disability specific friendly designs to universal design concept. But to reach all the disabled persons and for realization of the dream of inclusive society for the persons with disabilities, it is imperative that sustainable strategies need to be evolved with emphasis on following areas
- Disability to be made a priority issue in the developmental process
 - Convergence and coordination with developmental sectors.
 - Decentralization & networking of existing services.
 - Environmental Care.
 - Accountability and transparency in management & decision making.
 - Human Resource Development & Capacity building.
 - Realistic planning & increased budget allocation
 - Development of Modules for self sustainable projects.
 - Promotion of Research & Development.
 - Tele-rehabilitation
 - Participation of NGOs having professional background to reach the un-reached
 - Documentation, Information Dissemination and use of media.
 - Improvement in primary health system.
 - Convergence of available rehabilitation services
 - Optimum utilization of resources - both material and manpower.
 - Vigilant supervision and monitoring of schemes and programmes.

- (ii) The key to solving the disability management issues lies in participatory management with developmental organizations and involvement of persons with disabilities, Government's networking with various State Institutions/NGOs, training Institutions, autonomous organizations and Universities to organize training programmes, seminars, workshops and research activities related to disability prevention & rehabilitation management will improve coordination and bring the desired synergy in implementation.
- (iii) Mass immunization to prevent deformity due to preventable diseases, intensive education programme for the prevention of accidents as well as services for medical personnel and paramedicals need to be promoted. Capacity building programmes are required on continuous basis covering as many as possible from as many as organisations responsible for such work. Information dissemination through electronic, print and internet media to create informed public opinion relevant for people's participation is necessary.
- (iv) Disability and poverty have close interlinks. As most of the persons with disabilities live in abject poverty struggling for survival, they can not take any special care due to the cost involved in disability prevention. Hence, community oriented disability prevention programme and comprehensive primary health care need to be stressed and made available to the persons below poverty line free of cost.
- (v) In management of locomotor disability a team of professionals consisting of doctors, therapists, Prosthetist-cum-Orthotists, counselors and social workers are needed. In view of scattered distribution, varied clinical presentation and different needs of the disabled population majority of whom reside in rural and remote areas, such team is neither available nor affordable. An integrated and multidisciplinary approach to locomotor disability is depicted in the figure below.

Figure 10.3 Integrated Multidisciplinary Approach to Prevention and Rehabilitation



- (vi) A sustainable strategy of three tier system of service delivery at village, district and state level need to be developed. The trained manpower should be multipurpose workers at village and district level. More emphasis on the training of this category of service providers in the form of certificate and diploma courses need to be given. A large no of CBR and Multi purpose workers need to be trained.
- (vii) Presently, the locomotor disabled persons are dependent on the existing PHC system which itself is overburdened with emergency management, health care and MCH services. In such a situation, it is difficult to give special attention towards disabled persons. The medical and paramedical staff at PHC level need to be given additional inputs on disability and rehabilitation. Recent introduction of training of PHC doctors by RCI under a national programmeme need to be expanded and continue on an ongoing basis. Such training programmes should have quality with more medical inputs and be organized jointly with Health Department.
- (viii) Persons with deformed joints are highest in number amongst locomotor disabled. They need surgical correction on priority. Therefore the existing provision of surgical correction under the ADIP scheme need to be encouraged. The medical and surgical services for disability correction at tertiary health care system need to be strengthened. The private practitioners of modern medicine, homeopathy and indogenous systems and their professional bodies may also be involved. The support of corporate sector hospitals should also be taken. The rehabilitation facilities of spinal injured need to be developed at district level. The training of handling and transfer of spinal injury cases should be imparted to all members of team dealing with trauma cases. Community awareness on spinal injury should be made through use of mass media.
- (ix) Governmental efforts through limited number of Institutions are strengthened by assisting large number of NGOs spread all over country through providing Grant in Aid assistance. Considering the diverse demographic, socio-cultural practices and geographic locations, community participation and involvement of NGOs with Government support need to be further strengthened. This will be helpful in reaching the un-reached population. NGOs with professional background and working in multi-sectorial areas need to be involved to keep the programme cost effective and sustainable.
- (x) Information technology is now one of major components of technological infrastructure for providing services to un-reached areas and special target groups. IT infrastruture can be directed to promote community awareness, identification, prevention and intervention measures of disability. Even for fabrication of aids and appliances, IT can be put to use.

The nationwide network of NICNET provides rapid reporting mechanism for health information and MEDLARS. Biomedical Informatics Programmes provide ready access to medical database to researchers & practicing professionals. NICNET and MEDLARS may be coordinated in better delivery of rehabilitation services. The use of computer at panchayat level is likely to improve coordination

in making rehabilitation services possible in remote and inaccessible areas. Online telemedicine/rehabilitation advices need to be developed by way of bringing experts together to assist local professional in management of disability. In view of scattered distribution, wide variation in problems and needs, development of vertical infrastructure of rehabilitation will not be cost effective. Existing cyber café and helpline approach need to be developed. The infrastructure available in health, rural development, education, social welfare etc. need to be better coordinated and utilized. Horizontal integration of existing programmes needs to be done.

- (xi) To fill the prevailing gaps and to reach the un-reached, a mass awareness as well as participative approach is needed. In this regard, the following areas need immediate attention.
- Easy access & availability of aids & appliances.
 - Medical / surgical inputs need to be emphasized more to reduce and prevent disability.
 - Measures to be taken for disability prevention with trauma management.
 - Disability due to violence, terrorism and disasters need to be taken care of at an early stage.
 - Care and measures of geriatric population.
 - Vulnerable groups like chronically poor, girl child, women and street children with disability deserve special attention.
 - Convergence of services with multidisciplinary approach is needed.

Conclusion

Disability is a part of dynamic human life process which can be prevented in about half of the cases and reduced significantly by taking appropriate and timely measures. How much we can reduce disability and are able to bring the disabled persons into main stream to use their potential is in fact a question of attitude, prioritization and investment in the sector. Disability management is a multisectoral and multidisciplinary subject, which involves many role players. Therefore, it is proposed that all the major role players i.e, Government, NGOs and the Community should all work together for a common goal. With the adoption of the sustainable strategy and suggestions given in this chapter, the impact and incidence of locomotor disability can be reduced and the society can move towards an inclusive, barrier-free, and right-based society for the persons with disabilities.

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Chapter 11

Evolving Sustainable Strategies for Disability Management : Visual Disability

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A K Mittal

This chapter briefly overviews the characteristic features of the development of rehabilitation services for the visually disabled, in the country, the present status and future challenges and priorities. Some of the specific approaches and procedures, which could be of an enduring and ongoing nature, and also contribute towards the achievement of our goals for sustainable rehabilitation of the visually impaired children and adults, are also dwelt upon such strategies include, the authors feel, attitudinal change, strengthening voluntarization, early intervention, integrated/inclusive education and in some cases residential schools, production and distribution of material, research application and community based rehabilitation.

Introduction

The phenomenon of blindness has been with us in the country almost from the time of the dawn of our civilization. In India blind persons have been reported to be the composers of a number of Shlokas (Richas) included in the Rig Veda during the Vedic times. Such blind persons were designated as 'Rishis' or 'Manishis'. During the Mahabharata era, we have the instance of the blind king, Dhritrashtra. It is also recorded that when Emperor Ashoka embraced Buddhism after the Kalinga war, he began to provide homes for the disabled and there is reason to believe that the blind persons were included among those who were provided food, clothing and shelter. It is, thus, clear that in ancient times India respected and utilized the talents of the blind persons, unlike other civilizations.

The situation apparently worsened for the disabled persons during medieval times. Yet, even in those years, works of the poet Surdas have entitled him to an immortal place in Indian literature and culture comparable to that of Homer in the West. With the growth of the Renaissance phase in India, the plight of the

blind and other disabled persons once again attracted attention. The first school for the deaf and that for the blind came into existence in India around 1885 and 1887 respectively; the process of development has since then gone through several remarkable stages and phases.

Magnitude

The prevalence and incidence of blindness has varied from time to time depending upon the pattern of diseases that have affected a given society. To illustrate, in earlier times, with poor nutritional and infant care, the incidence of child-blindness was higher resulting in the problem of Xerophthalmia. However, with increased/improved medical facilities, the incidence of child-blindness due to Xerophthalmia or other severe forms of Corneal Opacity have shown a welcome downward trend.

Persons with disability were enumerated at Decennial Census until 1931. The 1931 Census estimated the number of blind persons to be 2, 30,000 in undivided India. No information is available in the concerned Census Document regarding the specific definition adopted for the enumeration, though it is believed that totally or nearly totally blind persons were enumerated. The famous 'Report on Blindness' (1944) submitted by a Joint Committee constituted in 1942 by the Central Advisory Boards of Education and Health estimated the number of blind persons in undivided India as about 2 million – about 0.5% of the total population. The Report suggested the following definition: "A person is blind if he cannot count the fingers of an outstretched hand at a yard's distance".

A longitudinal study was undertaken by the Indian Council for Medical Research during 1971-74. Their definition included: Total absence of sight; Visual acuity of 20/200 or less (Snellen) in the better eye with correcting lenses; and field of vision subtending an angle of 20 degrees or worse. The study estimated that India had about 9 million blind persons i.e. about 1.4% of the total population.

In 1881, the Census authorities took up the enumeration of totally blind persons and came out with an estimate of only half a million blind persons. The National Sample Survey Organization (NSSO) of India has undertaken the task of estimating the number of blind persons through its 36th, 47th and 58th rounds. The following graphic presentations bring forth an interesting comparison of prevalence and incidence rates of blindness as shown by the three Rounds of National Sample Survey Organization:

Figure 11.1

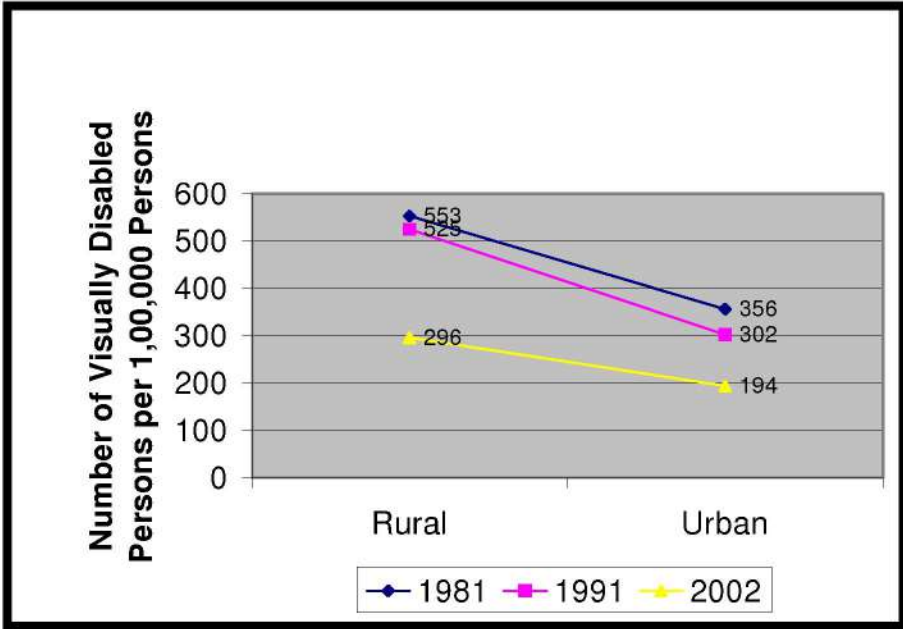
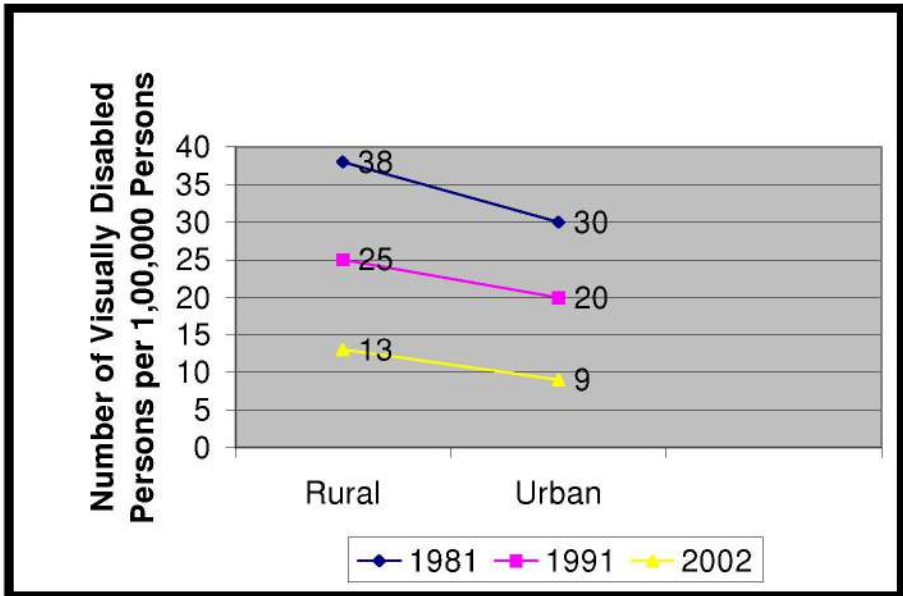


Figure 11.2



There has been a significant drop in the projected number of blind persons as per the 1991 and 2002 figures from 414 blind persons in a population of 100,000 persons and the latter 269 only, representing a decline of about 35 percent. The prevalence rates of blind persons residing in rural and urban areas have been estimated to have come down by about 43.6 percent and 35.77 percent respectively during the period. 2002 estimates assert that over 71 percent of the visually disabled population were blind and the remaining had low vision within the parameters of the definition adopted for the purpose. This is at sharp variance with the oft-quoted statement that 'there are four persons with residual vision in a group of every five visually disabled persons.' Blindness continues, primarily, to be an old age problem; about 1-2 percent were visually disabled by birth.

Some other studies also merit mention here. (i) A study concluded in 1989 by National Programme for Prevention of Blindness in conjunction with WHO estimates the number of blind people to be about 11.92 million – 1.49% of the total population. (ii) A Project which made a door-to-door survey of disabled children in the whole of Block was the Project Integrated Education for the Disabled (PIED) supported by UNICEF through NCERT from 1987-1993. The Project was implemented in the whole of one representative Block in each of the 10 States. Out of the 5306 children with disabilities identified in the 10 Blocks, 775 were children with visual impairment. (iii) The WHO-PBD Data Bank (1997) estimated that there are 8.9 million blind people India. As per the Global Statistics on Blindness 1998, India has approximately 10 million blind persons requiring services. There is, thus, considerable divergence about the total size of the blind population in India. In this enigmatic situation, planners have no alternative but to plan services on a pragmatic basis, using the rule-of-thumb approach of depending on how much demand a given service generates.

Rehabilitation Services for persons with Disability

(i) The Pre-Independence Period

While the first institution for the blind was set up at Amritsar in Punjab, in 1887, the pace of development remained extremely chequered and sluggish during the subsequent 60 years till independence. There were only 32 institutions for the blind in India in 1947. There were very limited arrangements for vocational training or other forms of economic rehabilitation. Traditional crafts like re-caning, weaving, doormat making etc., formed the subject matter of any kind of vocational services those days.

The State Governments were either not giving or giving very small financial assistance to schools for the blind. As a result, these schools had to depend to a very large extent on voluntary contributions. There existed small State/Local level organizations of or for the blind only. The main focus was to provide education: Music was about the only open occupation for the blind as it was generally believed that most blind people were gifted with musical ability. There was virtual absence of a common Braille Code for Indian languages and no Braille printing facility and no unit for the production of basic assistive devices. About ten different codes were being used by schools in different parts of the country.

(ii) Post Independence Scenario

There has been a continuing and rapid expansion of facilities and services for the blind during the 57 years after Independence. The Ministry of Education, Government of India, established in Delhi, a unit for the welfare of the handicapped in April 1947, just prior to the advent of Independence in accordance with the recommendation contained in the 'Report on Blindness' of 1944. Ministry of Education offered scholarships to blind students at secondary and college stages. It took over the St. Dunstan's Hostel for the War-Blinded in Dehradun, on January 1, 1950 and renamed it as the Training Centre for the Adult Blind, which formed the nucleus of the present-day National Institute for Visually Handicapped. In 1951, Bharati Braille came to be accepted as the National Code for the country. The Central Braille Press and the Workshop for the Manufacture of Braille Appliances was established in Dehradun during the 1950s. In 1954, the Government of India established the Central Social Welfare Board, which provided small grants to certain Institutions and handicapped persons including the blind.

In 1961, the Government of India initiated its Scheme of Assistance to Voluntary Organizations for the Handicapped followed by Scheme of Assistance for Integrated Education (1974), Scheme of Assistance to Disabled Persons for Purchase/Fitting of Aids and Appliances (1981), Special Employment Exchanges (1954), Vocational Rehabilitation Centres for the Handicapped (1964), Scheme of National Awards (1970), the Schemes for the establishment of Composite Regional Centres and District Disability Rehabilitation Centres (2002) for benefiting the disabled population including visually disabled persons and finally the Scheme of National Scholarships (2002).

As against the paltry figure of just 32 institutions for the blind in the country before independence, the number is now about 350. A number of institutions working for the blind were assisted by the Ministry of Social Justice & Empowerment.

The number of Braille printing presses has been going up steadily in the country. Many of these printing houses are now producing books in Braille with the help of very high-speed computerized Braille embossers. Similarly, a number of voluntary organisations have also come forward along with Manufacturing of Braille Appliances Workshop in Dehradun to produce basic assistive devices. Equipment like Perkins Braille Writers are also available in the country at substantially reduced costs. Education of blind children receives special attention in the Scheme of Integrated Education as also in Sarva Shiksha Abhiyan (SSA). A large number of NGOs are, today conducting outreach and community-based rehabilitation services to address the needs of blind and other disabled individuals at their own doorsteps in rural areas. The National Handicapped Finance Development Corporation (NHFDC) seeks to promote self-employment through concessional finance.

The Government initiatives for promoting employment of the disabled including the blind have also been making some useful headway. There are, today, 23 Special Employment Exchanges, 55 Special Cells in Regular Employment Exchanges and 17 Vocational Rehabilitation Centres for the Handicapped. The

identified lists of posts have been revised in 2001 to include a large number of jobs suitable for the visually impaired. Research has also been undertaken to open up vistas of opportunities for the blind in small-scale income-generating activities. The Regional Centre of NIVH, through a systematic research study, has identified 106 such activities for blind and low vision persons in the four Southern States and UT of Pondicherry.

Progress has also been witnessed in the field of vocational training. Today, a wide range of vocational courses are available for the blind, some striking examples being courses in light engineering, computer-aided services, stenography, physiotherapy, middle-managerial skills etc. along with a range of conventional occupations.

Technological research undertaken in the field ranges from development of an Optical Character Recognition (OCR) facility and Braille translation softwares for Indian languages to simple micrometers and other measuring instruments. India is, today, a leading manufacturer of a wide variety of educational, mobility and recreational devices for the blind, among developing countries of the world.

Issues of Concern

Despite concerted endeavours being made by the Government and the voluntary sector for the empowerment of visually impaired, the magnitude of the remaining task is equally imposing. It is estimated that no more than 20% of our school-age blind children are receiving education of one kind or the other. This is despite the fact that the Persons with Disabilities Act stipulates that the appropriate Governments and the local authorities must "ensure that every child with a disability has access to free education in an appropriate environment till he attains the age of 18 years." The goal of promotion of integration of blind and visually impaired students in regular schools, leaves a great deal to be desired in many parts of the country. Research evidence also tends to suggest that blind children receive very limited training in such basic compensatory skills as Braille, daily living skills, personal management, mobility etc., in many programmes of integrated education (Punani, 1997). Very few and sporadic services are, currently available for early detection and early intervention to help blind children (0-4 years) and their parents/families.

Though progress has taken place in areas of vocational training and employment, yet, a great deal still needs to be done, especially in view of the challenges being posed by increasing globalization and automation. There are also marked regional disparities and imbalances in respect of programme-implementation and service-delivery for blind children and adults. Two special groups i.e. the multiply disabled children and youth with visual disability and the forsaken geriatric population call for urgent attention. While the National Trust Act of 1999 does seek to address problems of multiply disabled children to some extent, there is still a yawning gap between programmes and implementation, with particular reference to the multiply handicapped child with visual impairment.

There is lack of coordination in activities carried out by different NGOs. We come across a number of instances of avoidable overlap and duplication. Suitable social audit can help to provide better quality services both by the NGOs and Government organizations. Many schools and vocational training centres still have untrained/ under-trained teachers and instructors resulting in the general lack of professionalism and management standards in those institutions.

Lack of resources with the NGO sector that results in low salaries paid to the staff limits motivation and causes frequent migration of faculty members which is a cause for concern. There is also the pressing problem of shortage of reading material and assistive devices as well as trained staff for educational and vocational programmes for blind children and youth. The multiplicity of languages, divergence in textbooks prescribed in States and frequent changes in these books, further complicate the task of expeditious provision of reading material in Braille. While every effort is made by the NIVH to produce an increasing number of the required basic assistive devices, there is an inevitable gap between demand and supply.

The curriculum followed in most schools and training centres continues to be mundane providing little scope for full flowering of the individual's personality. Limited opportunities are provided to blind children and youth for effective and boisterous physical exercises and out-door sports. Many of our schools and centres are not yet successful in integrating their students/ trainees in mainstream activities and interaction in society. The highly institutionalized character of many organisations tends to give rise to maladjusted behavior resulting in either overt aggression or complete withdrawal or introversion among beneficiaries.

11.5 Sustainable Strategy

The challenges, as discussed in previous paragraphs call for continuing imaginative approaches based on meaningful and workable strategies. Our efforts have to be directed at consolidating the gains already achieved through suitable quality-upgradation and adding new dimensions, wherever required. The following paragraphs seek to address some urgent issues and priorities and also suggest a few practical corrective measures.

Attitudinal Change

The world in which the blind man finds himself creates the tragedy for him and in him. Here, Cheigny the author of these words, is giving vent to the feelings not only of his fellow blind peers, but also of many wise, understanding and reality-loving sighted friends. Most of the problems and obstacles confronting the blind children and adults could be overcome, if we are able to bring about a paradigm shift in attitudes of parents, siblings, neighbours and the community at large to visual disability. Blindness has, through the ages, given rise to a number of myths, misconceptions and prejudices, which tend to alienate and segregate those faced with the disability.

A vigorous campaign of attitude-modification needs, therefore, to be mounted. Electronic media have to be closely involved in all such endeavors. We need to develop video materials which contain profiles of successful blind persons functioning in a wide variety of settings giving a realistic portrayal of successful visually impaired persons representing a cross-section of population. NIVH is engaged in producing two such films and several video spots concentrating on the capabilities of blind persons and disability-prevention. The spots would focus on various aspects of rehabilitation and disability-reduction. A documentary film 'Andhere Se Prakash Ki Ore' produced by Door Darshan Kendra Delhi on NIVH programmes and activities was awarded Gandhian Philosophy and Public Service Broadcasting Award for 2003.

Films Divisions in different States as well as different audio-visual publicity channels in the Union Ministry of Information and Broadcasting may be persuaded to take up such work. Incentives may be offered to prominent producers of short films/documentaries for conveying the desired messages. Short modules may be prepared in collaboration with leading NGOs about education and rehabilitation possibilities that can be broadcast. What is essential is that audiences in rural areas, urban slums and remote places are addressed through suitable capsules in their languages. There could, perhaps, also be a annual National Award for the most outstanding documentary.

Closely related to the need for community sensitization is the pressing requirement of disseminating information about existing Government Schemes, benefits and concessions for the blind and other disabled groups to every nook and corner of the country. A Research Study (2002) recently concluded by NIVH in the four Southern States brings out the disconcerting fact that the number of respondents who were aware of the concessions provided by the Government of India was 48.23% in a sample of 400 persons. The awareness among urban respondents was higher (57.20%) than rural respondents (39.25%). The situation regarding the level of awareness of the provisions of the Persons with Disabilities Act was even more distressing. Among the total respondents, 79% (urban – 34%, rural – 44%) were not aware of any of the provisions of the Act. Even among those who showed awareness (21%), the majority had only moderate information. To counter this lack of awareness about Government Schemes, we have also to undertake intensive efforts to sensitize officials at the District levels. Sensitization programmes could be formulated and conducted from time to time by National Institutes (NIs) and the Rehabilitation Council of India (RCI) for the benefit of these officials concerned.

Strengthening Voluntary Action

Majority of programmes and services for the blind continue to be administered by voluntary organizations. It is, therefore, imperative that these organizations are provided the necessary support for undertaking their tasks with increased efficiency, earnestness and success. These organizations can be categorized, largely, into two groups; (i) Self-help organizations of the blind taking up, mainly, lobbying and advocacy activities and (ii) other agencies engaged in the conduct of programmes and services. At both levels, capacity-building support

is urgently required. Their members and office-bearers could receive training in leadership and management skills, so that they could not only function as mere pressure groups but also help to ensure proper quality control in respect of programmes throughout the country. For this purpose, these organizations could also substantially widen their base of membership and provide equitable representation on their leadership and executive positions to more vulnerable segments of the blind population - women and those living in rural areas. Suitable empowerment of blind women could be an essential pre-requisite for support to these self-help bodies.

At the international and regional levels, great emphasis is now being laid on ensuring proper development of self-help associations. In fact, women with disabilities and self-help organizations constitute two of the seven priority areas identified for intensive support during the extended ESCAP Decade of Persons with Disabilities (2003-2012) as per the related BIWAKO Millennium Framework for Action Document. Globally support is now far more easily forthcoming than ever before, for strengthening these associations and empowering women with visual impairment. A recent example is the Capacity-Building Project undertaken by the World Blind Union with funding from DANIDA, through the Danish Association of the Blind. The Project worked for strengthening fledgling organizations of the blind in six Middle-East and Central Asian countries. Similar funding may be mobilized for related organizations in India.

Voluntary organisations engaged in programme-administration and service-delivery for the blind carry a special responsibility of inducting necessary professionalism into their functioning. The need for capacity-building for such organizations is paramount in terms of human resource development and material resource mobilization. There are certainly, limits to the extent of financial assistance they could get from Central and State Governments. Therefore, these organizations may be helped to take up more progressive methods of fund-raising from the community. The experiment of running income-generating projects so successfully implemented in several East Asian countries might be tried out here also to fetch dependable revenue for the concerned organizations.

It might also be of help to further develop and elaborate guidelines for effective management of services by NGOs. Sensitive monitoring and evaluation by panels of professionals could also contribute towards ensuring improved quality and standards of services rendered. A regular and continuing system of social audit could also be introduced on a larger scale. Necessary norms and standards could be reviewed in regular intervals consultation with NGOs, rehabilitation professionals and social scientists.

The strategy, here, is to consolidate and reinforce the real base and anchor of our service-delivery systems, viz., voluntary organizations. A clear delineation of roles for NGOs and the State would be an essential component of this strategy. To begin with, the approach could be tried out with selected NGOs on a pilot basis as a part of a research project to be undertaken by the Government or through the National Institutes.

Early Intervention Strategies

Rightly does the BIWAKO Millennium Framework for Action Document (2002) observe: "Infants and young children with disabilities require access to early intervention services, including early detection and identification (birth to 4 years old), with support and training to parents and families to facilitate the maximum development of the full potential of their disabled children." This is of vital significance for children with visual impairment and their parents. For, visual disability gives rise to a severe trauma among the parents, which jeopardizes positive parent-child relationship. Negative attitudes and mis-conceptions among parents or care-providers further vitiate the environment for the blind infant. The strategy required here has to commence from the grass-roots level. There has to be much greater interaction and interface between workers available in the villages, families of blind children and rehabilitation specialists/teachers available in the district. The introduction of nurseries for pre-school children as a part of the ICDS programmes, holds out considerable potential for young blind children as well. There have already been several attempts to sensitize and orient ICDS workers towards the special needs of blind infants and the components of parent-support and counseling. A review of such endeavors may be done through the joint efforts of special school teachers and institutions of training in professional social work and a standardized capsule could be worked out for more intensive orientation of ICDS workers and those working in emerging nursery schools.

Health workers available in villages could also similarly be involved with regard to early detection and identification of visual impairment among infants. In fact, the Village Panchayat Institutions could also be motivated to play a more dominant role in effective disability-prevention and management programmes in rural areas. Thus, our strategy here is to bring about sustained and continuing coordinated action on the part of the functionaries deployed in rural areas. An institution/training centre for the blind functioning at the District Headquarters could function as a nodal and coordinating agency with necessary support from social work professionals and other responsible citizens. The State Departments of Women and Child-Development and Rural Development could function in close convergence to produce the required synergy of effort and action. The recently established District Disability Rehabilitation Centres in about 90 districts could be a useful resource to help in this direction.

Integrated / Inclusive Education and Residential Schools - the Complementarity:

The Government has been implementing schemes of integrated education for the handicapped regularly for the last about 30 years. The impact of the Scheme has, however, not been evenly distributed. It is a matter of growing concern that the number of children with visual impairment attending regular schools has been far less in proportion to some other disabilities in many States. Some initial research as also observation by professionals testifies to the fact that the quality of services offered to blind children under these programmes also leaves a great deal to be desired in many States. Indeed, as the Salamanca Statement and

Framework for Action on Special Needs Education puts it: "Regular schools with inclusive orientation are the most effective means of combating discriminatory attitudes creating welcoming communities, building an inclusive society and achieving education for all. Moreover, they provide an effective education to the majority of children and improve the efficiency and ultimately the cost-effectiveness of the entire education system".

The idea of integration and inclusion sometimes tends to get seized rather too eagerly, even though the outcome turns out to be mere proximity of blind children with sighted ones in regular classrooms. This is, by no means, to discard or undermine the importance of the concept of integration and inclusion for blind children. What is being submitted, here, is that we cannot follow a one-track strategy. A Paper entitled 'Education of the Visually Handicapped – There is more to it than the Salamanca Statement' prepared by blindness organizations of Nordic countries states: 'Grandiose statements about integrated education for blind and partially sighted children, young people and adults, are not enough. The basis of true integration is that visually handicapped persons are given the skills necessary to ensure full participation as opposed to their mere presence in the regular educational system.' It is, perhaps, for this reason that Chapter V of Persons with Disabilities Act lays special stress on promoting 'the integration of students with disabilities in the normal schools' and suggesting 'setting up of special schools in Government and private sector for those in need of special education'.

A Joint Policy Statement on the Education of Children and Youth With Visual Impairment issued by the International Council for Education of People with Visual Impairment (ICEVI) and the World Blind Union (WBU) contends "Inclusive education as one of the alternative models of service delivery, on condition that all necessary steps are taken to first put in place the required number of teachers trained in the special needs of blind and low vision children and the essential support systems – necessary equipment, Braille text books, low vision devices – to guarantee true inclusion." Integrated/inclusive education requires a great deal of pre-launch preparation and putting in place the required inputs for making it really meaningful for children with visual impairment.

Integration/inclusion thus is a must for achieving the goal of 'Education for All' children with visual impairment. The special schools, which are available in many districts, could be used as Resource Centres for providing necessary support services and blindness-compensating skills for the concerned children to promote inclusive education. The specific strategy being suggested, here, is that at least one especially trained teacher of blind children, may be designated the task of organizing and coordinating action for facilitating meaningful educational integration for children with visual impairment. This would call for no more than 600-700 special teachers for the entire country and one teacher would have a work load of not more than 20-25 children, in view of the fact that the number of visually impaired children of the school-age is not very large in the country. To effect further economy, a retired trained teacher from a school for the blind could be engaged for the purpose with a suitable honorarium.

Thus, residential schools and inclusive schools have to be viewed as complementing and supplementing each other and not for supplanting or replacing each other. The strategy indicated here, would not only be sustainable but could also usher in an era of true integration for all visually impaired children within the specified time-frame.

Production and Distribution of Material for the Visually Impaired

Section 27 (f) of the Persons with Disabilities Act stipulates 'providing every child with disability free of cost special books and equipments needed for his education.' It is essential as a meaningful strategy endeavor, to go in for decentralization and devolution with regard to meeting the above goal for blind children and youth. It may be worthwhile if the country has Braille printing presses on the basis of language. Most States already have such an arrangement, albeit on varying levels of efficiency. These may be suitably upgraded with the acquisition of fast-printing Braille embossers and that there is no overlap or duplicity of effort.

As regards production of equipment, NIVH continues to be the largest single manufacturer. The facility at the Institute is being updated and manufacturing procedures have been streamlined. Equipment is also being distributed through the Institute's regional outlets at Chennai, Kolkata, Secundrabad, etc. These distributing units would be further enriched with regular replenishments so that the user could get the required device nearer to his home/place of work within a greatly reduced span of time. The strategy may envisage endeavors to meet local requirements through regional outlets and with the help of language-specific Braille printing facilities. Considerable support is, now, available through international agencies for strengthening and upgrading related production and manufacturing facilities. The World Blind Union and ICEVI have proposed to work together to provide easy access to the required technologies to users in developing countries. This is, indeed, a welcome initiative.

A Research and Technology-Application

Meaningful research and development activity holds the key to effective educational and vocational rehabilitation and mainstreaming for visually impaired children and adults. Functional research that addresses the perceived realities and seek to bring forth practical solutions need to be promoted. Research of a technological nature may eventually result in large-scale production of the new devices and not remain confined to prototype-development or laboratory tests alone. It would be advisable if research activity is directed, largely, to the areas identified under Section 48 of The Persons with Disabilities Act. Research may be carried out in areas such as prevention of blindness, early intervention services, design & development of assistive devices, psycho-educational assessment, rehabilitation, including CBR and job-identification.

It is also proposed that a suitable compendium of abstracts of research projects undertaken for the blind during the last ten years in the country might be prepared by NIVH in collaboration with other related research bodies/

committees. This would facilitate easy information-dissemination and give necessary impetus to prospective researchers. We are also to work in close coordination with Institutes of excellence in the fields of engineering, science and technology.

Considerable resources could be located through UN agencies like UNESCO, UNICEF and ILO for supporting useful and practical research. Incentives are also available through various organizations like the World Blind Union, the Canadian National Institute for the Blind etc., for encouraging innovative work that might be undertaken in developing countries.

Community-Based Rehabilitation (CBR)

The blindness sector was the first to take the lead in India to provide rehabilitation services to blind clients at their own doorsteps in rural areas. Thus, the first such project was undertaken in and around Madurai in Tamil Nadu, during mid 70's. Since then, a great deal has been said and written about CBR approaches for the benefit of visually impaired persons. An increasing number of NGOs have been coming forward to take up CBR activities. However, there are two important aspects which our attention has to be directed to, here.

CBR tends, at times to be viewed and used as a soft intervention model. As a result, we encounter, several times, programmes and projects, which seem to go astray and deviate from the accepted goals and objectives. Therefore, it is now being increasingly emphasized that CBR activities must be regarded as full-fledged professional endeavors, which must adhere closely to and address specific needs and interests of blind clients at different levels. There should also be regular reviews and evaluation of the effectiveness of the intervention strategies, at periodic intervals. A case in point is an evaluation undertaken in 2001-02 by the Institute's Regional Centre of the CBR Projects implemented by them in 10 block areas in Tamil Nadu and Andhra Pradesh, serving 1116 blind clients during the period 1990-91 – 1999-2000. The sample consisted of 100 respondent-clients. The evaluation finding revealed that 90.23% of the clients found the services as being useful and close relatives (primary caregivers) of 88% of the clients opined that the clients had moderate to good progress through these projects.

There is considerable divergence of opinion among rehabilitation professionals and programme-administrators about whether CBR should be based on a single-disability approach or whether it should address groups of different disabilities, i.e. 'cross-disability approach'. It is strongly contended that persons with sensory impairment – the blind and the deaf – need highly specialized and individualized attention and services. Therefore, their legitimate needs and interests tend to get drowned in interventions intended for varying disabilities. This does not allow the blind individuals to acquire necessary compensatory skills or receive intensive individual help for vocational training. On the other hand it is contended that a single-disability intervention approach is neither feasible nor economical in a vast country like ours. It is argued that an exorbitantly high number of field workers with resultant heightened expenditure, would be involved in following such an approach.

At the international level however, the World Blind Union and the World Federation of the Deaf have been forcefully voicing their concern and anxiety over the depleted attention blind and hearing handicapped persons tend to get in multi-disability approaches. The Presidents of both these organisations expressed their complete disenchantment with the cross-disability CBR methodology at the International Consultation on CBR Review organized by WHO in Helsinki towards the end of May, 2003. A World Blind Union Position Paper on Rehabilitation of Blind and Partially Sighted Persons gives a clarion call for abandoning the cross-disability approach, since according to them, "Experience shows that people with sensory disabilities such as the visually impaired are very rarely targeted through such programmes."

There is a pressing need to find a *via media*. Perhaps, specific guidelines could be worked out to ensure that the interests and concerns of visually impaired are adequately and comprehensively addressed even while following a cross-disability approach. Perhaps, certain standards and benchmarks relating to the expected outcomes of such interventions for the benefit of such clients, could be clearly worked out ahead of the launch of a project based on the cross-disability approach. The funding agencies may also take due cognizance of these norms while assessing projects for extension of support from year to year.

CBR interventions may provide due support to the usually marginalized groups of clients in rural areas/urban slums – the elderly and girls/women with visual impairment. Women constitute over 54% of the projected blind population in the country as per the figures of the 58th Round of NSSO. About 68-72% are reported to have acquired visual disability at the age of 60 years and above, as per the figures of this survey. Obviously, no intervention strategy could afford to leave out such a large segment of a given population. The needs of medical care, recreation and social communication must be addressed through our interventions with particular reference to the geriatric group. In fact, the performance of the field staff may be assessed primarily on the extent to which they have been able to address issues concerning these two groups.

Finally, our interventions in this sector need to shift more and more from being 'community-based' to 'community-participatory.' Ownership of the project by the community has to be an essential outcome of each intervention and that could be possible only when community resources are involved from the very beginning in planning and executing various services for the identified clients. In the absence of such a participatory approach, our programmes only tend to shift the focus to whatever the field staff can or cannot do, resulting in the ownership being passed on more and more to the implementing organization rather than the concerned village community.

Conclusion

We, thus, find that convergence of resources, close coordination, suitable follow-up, monitoring and evaluation as well as greatly increased emphasis on attitude-modification, acquisition of compensatory skills and meaningful inclusive education and CBR interventions form the major plank of our sustainable strategies. The Government, the community, blind persons themselves and their

organizations as also international agencies have all to play their respective roles and play them well.

The World Blind Union at their General Assemblies held in Toronto (1996) and in Melbourne (2000) had the challenging theme of 'changing what it means to be blind' for their deliberations. In our case, this refers to wide ranging changes in the socio-economic conditions of the blind population – from seclusion to mainstreaming, from deprivation to development, from neglect to opportunity. Our foregoing discussion of the strategies for disability-reduction/rehabilitation could make vital contributions in this direction.

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Chapter 12

Evolving Sustainable Strategies for Disability Management : Hearing Disability

R Rangasayee

This chapter deals with the problems of persons with hearing handicapped, giving a whole life perspective. The issues addressed includes all age groups with pre-lingual or acquired hearing impairment. Attempt has been made to seek solutions within the systems that exist in the country with a futuristic approach. The author has given, wherever efforts have been initiated to circumvent the economic problems with suitable human efforts.

Introduction

The visuo - spatial human race continues to rely on the sense of hearing or audition for its survival. Therefore, loss of hearing leads to a devastating effect, no matter when it affects a person. The impact is pronounced when a person is unable to hear from birth or early childhood. The seven ages at which deafness is known to affect or emerge are prenatal (genetic or viral), birth (complicated delivery, Rh-ve) early childhood (diseases like Typhoid), puberty (otosclerosis-genetic), 20s(industrial deafness), 40s (systemic diseases), and 60s (aging or presbycusis).

Type, degree, and age of onset of hearing loss are primary factors that determine the extent of its impact on the person affected. However, where equitable services are not accessible, secondary factors such as gender, rural - urban divide, quality of service, use of suitable technology, transport, knowledge of service facilities and their outcomes tend to alter the life of a person with hearing handicap. Therefore, sustainable strategies should address both primary as well as secondary factors that contribute to the actual impact of hearing handicap on one's life.

Operational Needs

The operational needs for sustainable disability rehabilitation and prevention of hearing handicapped are as follows:

- i) Creating awareness to empower the household with the knowledge of hearing, hearing loss, its intervention, and proactive attitude as need of the hour.
- ii) Early Identification, referrals and diagnosis
- iii) Early Intervention
- iv) Provision of suitable aids and/or appliances such as hearing aid, earmoulds, group hearing aid, solar charger, etc.
- v) Education
- vi) Employment
- vii) Social Practices
- viii) Prevention

Creating Awareness

Creating awareness is the larger responsibility of the media and that of certain infrastructure that exist in schemes like ICDS in Ministry of WCD, and IEC in the Ministry of Health and Family Welfare. The key message that ought to reach is importance of early detection, early intervention and deafness prevention measures such as immunizing against rubella, avoiding exposure to excessive noise, etc. The Cable TV has reached 50% and 16% penetration in urban and rural households respectively. This needs to be fully utilized for the advantage of the disability sector. The IEC of health department is becoming increasingly sensitive to disability issues, thanks to the District Collectors heading the District Management Team (DMT) of District Disability Rehabilitation Centre (DDRCs), a Scheme of Ministry of Social Justice & Empowerment, Government of India.

Early identification, referrals and diagnosis

Early identification, referrals and diagnosis have to be essentially linked to ICDS, PHCs and DDRCs. The 72 days of job training course of Anganwadi workers devotes two days towards identification and referral of children with disabilities. However, the Scheme should introduce a monitoring format and also ensure that inclusion of children and women with disabilities get reflected in all its activities.

The diagnostic facilities are available almost in 70 percent of the 578 districts in India for persons with hearing impairment 6 years of age and above. It is not true for diagnosing hearing loss in children below 6 years of age, particularly below 3 years age group who would find it difficult to participate in behavioural hearing testing procedures. The children below 6 years of age and those above 6 years but have severe motor or communication handicap will need sophisticated gadgets such as Auditory Brainstem Response (ABR) audiometer, Oto Acoustic Emission (OAE), Immittance Audiometer, etc. These instruments are essentially required as screening tool, as well as diagnostic tool, particularly to test difficult children and adults. This range of instruments cost about rupees 20 lakhs. Indigenous market is yet venture into design, development and marketing of these products. However, the Recorders & Medicare Systems, Chandigarh has produced

ABR audiometer at almost half the cost of such products made in developed economies. Design and development initiatives with an eye on global market has to be seen as a thrust area not only to meet the emerging needs but also to catch up with developments elsewhere.

It is pertinent that screening techniques with high probability index such as high risk register behavioural testing methods etc., need to be used and popularized extensively through the DDRCs, Medical College Hospitals, CRCs and National Institutes.

The World Health Organization has gone a step ahead in suggesting genetic screening of new born babies as routine check up . Certain mutations such as Connexin 26 or Myosin 15 are so commonly prevalent accounting to about 30% of congenital genetic deafness . This gene mapping procedure, though is in emerging stage in most of the countries, India has both 'know how' and 'do how', thanks to the project funded by DBT, New Delhi which is being jointly implemented by JNCASR, Bangalore, AYJNIHH, Mumbai , ENT Dept of Maulana Azad Medical College, New Delhi and PGIBMS, Chennai. The project to create an atlas of genetic deafness in India will ultimately lead to genetic diagnosis and counseling services in the near future. The AYJNIHH , Mumbai has a Task Force on Genetics of Deafness to augment development in this area.

The process of early intervention always faced hitches essentially linked to lack of awareness, and shortage of facilities for early identification, and diagnosis. Research has shown that early intervention leads to renetworking of the auditory pathway in congenital deafness. This is a key result area. The National Workshop on Early Intervention conducted by AYJNIHH in 2002 revealed that 30 to 90 per cent of children enrolled in 8 different programs that were reviewed , went to mainstream education in a period of 3 years. The AYJNIHH and Bala Vidyalaya School for Very Young Children with Hearing Impairment, Chennai. have jointly launched a Scheme to promote early intervention of children with HI below the age of 2 years. It is being implemented through 5 AYJNIHH's centres, NISH, Trivandrum and Bala Vidyalaya, Chennai. Special Educators and audiologists are being given one month training to work with HI children below 2 years of age.

Bala Vidyalaya , Chennai is well known for its success in inclusive education leading to higher education and high end jobs for over 3 decades and is being managed by a group of parents of children with hearing impairment. Based on this successful experience using the locally available technology, involving parents intensively, this human resource based approach is as effective as high tech high cost measures being followed elsewhere. More information about the Institution is available on the website balavidyalaya.com. The project at AYJNIHH on early Identification and Intervention has produced audio visual and printed material for use by professionals and parents which are available at nominal price.

Provision of suitable Aids and Appliances

In the context of aids and appliances, the country is totally dependent on analog pocket model body worn hearing aids to meet the needs of economically

weaker sections of the society. However, the market offers widest choice of hearing aids that are otherwise available in developed economies. Those who can afford, avail these products from open market cost which ranges from Rs.3000/- to as high as Rs.80,000/- per hearing aid. Miniaturization and improved signal to noise ratio coupled with reduced distortion through the use of digital technology substantiate the price hike.

The country has to move towards providing digital technology based hearing aids under its scheme of Assistance to Disabled Persons (ADIP). The technologists have to work to bring down the cost. While there are 3.8 million persons with hearing impairment (NSSO 2002) in India, of whom at least 1/3 (1.3 million) are below poverty line, the hearing aids being distributed/sold in Indian market does not cross 1.25 lakh per year. Even provision to supply of BTE (analog) hearing aids is kept in abeyance as the cost of BTE is 3-5 times greater than that's of cost of pocket model hearing aids that are currently being distributed free of cost under ADIP Scheme of GOI.

The leading manufacture such as Alps, Elkon, Novax and Arphi and a couple of others assemble Behind the Ear, In the Ear, In the Canal aids and are marketing them under their banner. Further, with the liberalization of import policies of India, the whole world market has been thrown open to Indian consumers. As a result, in the last couple of years, several hearing aids of international brand including the digital CIC hearing aids are available. Thus, over 20 brands of hearing aids with their several hundred models are in the market today. However, it is worth noting that they are available only to the urban elite and not for the majority of the population living in villages in the country.

In this context, the initiatives of C-DAC and DIT Trivandrum in the development of digital programmable hearing aid at affordable socially equitable price needs to be commended and encouraged. IS:10776 (1984) of Bureau of Indian Standards (BIS) for hearing aids is under review for up gradation, and expansion of list of items related to Hearing Instruments is also under consideration. BIS norms for items such as Induction Loop System, Group Hearing Aids, Solar Charger for charging AA Cells for use in Body Level Hearing Aids, Standards for hearing aid cords, will have to be worked out. The work is under progress.

Sustainable developments, repair, and maintenance of hearing instruments can happen if following measures can be dovetailed in the existing service/HRD Systems.

- a) Engineering subjects should focus on Rehab engineering. Each branch of engineering has its role and relevance that need to be incorporated in the curriculum.
- b) The radio mechanics and their training programmes should also include care and maintenance of hearing aids.
- c) The Community Politechniques of MHRD can incorporate this in suitable module(s).
- d) The large bodies of S & T development in the country such as CSIR & DST should give preferential funding to technology projects that address the needs of persons with hearing impairment and other disabilities, so that Virtual

Reality Technology within the reach of common Indian can be augmented. The S & T Mission Mode of MSJ&E is doing a commendable job in this direction.

Production of ear mould to meet the need of the user is a greater challenge. Because, it is custom made. The hard acrylic heat cure earmould costs Rs.67 and takes two days to make. However, if you have light curing technique is used it costs Rs.108/ approximately (all costs excluding labour charges) and can be delivered in 2 hours, if needed. The thermosoft mold costs approx. Rs.160/- and the proper instant mold costs Rs.340/- (approximately). It has been found economic to procure the soft mold /impression (non Shrinkable) material from the open market and than to venture into indigenous research and development in this area. However, concepts like central ear mould lab, use of ultrasound imaging techniques to scan the ear canal to enable automatic production of large scale customized earmolds need to be explored in Indian context on priority basis.

AYJNIHH has been giving training to professionals and technicians to make ear molds. AIISH, Mysore is offering one year course. The AYJNIHH, Mumbai will also be offering TOT in ear mold making so that more centres in the country can disseminate skills of making quality earmold taking suitable assistance under ADIP scheme/DDUS for District Rehab of MSJE.

Education

In the context of educating the hearing impaired, the issues that need consideration are:

Early Detection and Intervention

As estimated by ICMR (1985), one in every thousand babies are born deaf. It is also estimated that over 25000 children with hearing impairment are born every year across the expanse of 3.28 million sq. kilometers of India. In order to bring them at par with other children of their age for formal schooling, it is very essential to 'catch them young'. 0 to 5 years is said to be the critical age for all developments especially for language skills when the brain is neurologically ready for the language acquisition, (Lenneberg, 1967). Hence early detection, coupled with quality intervention, is essential. Ignorance, lack of awareness, suitable amplification devices, and availability of appropriate intervention programmes are some of the critical issues that needs to be addressed. Screening the high risk babies, and check list for parents of young babies for auditory behaviour are some of the solutions which can be easily taken up for early detection.

Mass media can be extensively used for awareness about early detection and intervention so also for late entrants for enrollment in educational programmes. Maintenance rather than procurement of hearing aids, sometimes becomes a critical issue for parents. Training the available staff at village level such as ICDS and Primary Health Centres for the maintenance and counseling parents for its care, especially during feeding, playing etc., can ensure that the child is not devoid of amplification. Most of the intervention programmes are available only in the urban areas and professionals are hesitant to set up centres

in rural areas. Enrolling the local manpower for training programmes, conducting correspondence and contact programmes in regional languages, training Anganwadi workers and regular school teachers are some of steps to ensure interventional services in the rural areas.

While focusing our attention on early intervention, the late intervened and late entrants cannot be overlooked. Late intervention is also an equally important educational issue. The point that needs to be emphasized to parents is 'better late than never'. Absence of age appropriate curriculum to suit the specific needs of late intervened children are the difficulties encountered by the teachers instructing them which needs to be addressed.

Modes and methods of communication

Degree and nature of hearing loss affects the acquisition and production of spoken language, hence many children with severe and profound hearing impairment, may primarily use manual mode of communication. However, with the advent of sophisticated digital, programmable hearing aids and more recently the cochlear implants, some children with hearing impairment are blessed with good acoustic inputs. This results in better chances of development in use of oral mode of communication. The battle of modes and methods of communication though not very strong in India, as compared to the western countries, still needs to be addressed. A study conducted by Pais (2002) on 30 children studying in 'oral aural' and 30 children studying in other methods of communication' brought out the fact that consistency in the use of methods of communication is very important for acquisition of desirable language levels and provides fruitful results.

This issue also has another dimension because children from different backgrounds of methods of communication are being included in regular school system. Children who are intervened using 'oral method' of communication may not encounter much difficulty when 'integrated or included' in the regular school, however for children using 'total communication' or 'manual method', interpreter services may have to be provided in the regular school system.

Teacher child ratio

Children with lesser amount of residual hearing and those not benefiting much with hearing aids, learn and acquire language mostly through vision. They speech-read (lip-read) their teachers and hence need to be seated closer to their teachers. This proximity to the teachers is also essential for other group of children with hearing impairment considering the fact that intensity of sound decreases with increase in the distance. Secondly, linguistic barriers severely affect the concept and skill development. Hence teachers need to pay extra attention and devote extra time to these children. Teacher-child ratio either in segregated special schools or inclusive regular schools is thus an important concern taking into account the size of population in schools. Services of the resource teachers, assistant teachers, craft teachers, social workers who have comparatively lesser instructional hours could be utilized and children could be grouped for instructions.

Literacy issues

Reading which encompasses understanding the printed matter is a linguistic activity. Needless to say, limitations of language creates problems of reading comprehension, which may lead to inadequacy in the written expression. As stated by Wray and Robertson (2003), "being unable to hear can be an unpleasant hindrance but being unable to read and write in a world where literacy provides entrance into virtually every adult activity is bound to be devastating".

Literacy problems of children with hearing impairment are thus an important educational issue calling attention. The textbooks, which are an important source of information for enhancing knowledge and fostering reading habits, needs to be seriously paid attention to. Some children with hearing impairment may not be able to make sense of the regular text series followed in schools because textbooks are written for normal hearing children.

A study conducted by Gathoo, More and Wadekar (2004) brings out the fact that an adapted textbook using various strategies of adaptation such as language, presentation, illustration, tabulation, bullet forms and day to day examples, help the children in better understanding of the content and fosters self study. It needs to be mentioned here that all children with hearing impairment, may not require adapted version of textbooks, so a choice as given in the western countries may be given to the children in our country for selection of textbooks for instructions in schools.

Language exemption

Taking cognizance of the problems encountered by the children with hearing impairment for the acquisition of one language itself, the Persons With Disability Act (1995) has rightly given educational provision of exemption of second and third language from the curriculum of these children. This is both a blessing and a curse. A blessing because the children are saved from a difficult ordeal of accomplishing the task of learning a second language but it is a curse because most of teachers and parents opt for native vernacular language which they find it easier for their children. This results in exemption from learning English by almost 80% to 90% of children in our country leading to difficulty in higher education and in finding jobs in later years.

Also, keeping the child devoid of English language puts restrictions when it comes to the use of technology. Information Communication and Technology (ICT) which may, in fact bring the world closer to the child with the click of a mouse, remains a dream for the children with hearing impairment. Linguistic insufficiency creates barriers of accessibility to the available drill and practice training for the special children with hearing impairment. Emerging web resources in local languages may address this issue, but exposure to English (with exemption of exams) may still be considered for children with hearing impairment for the primary school.

Avenues for higher education

Most of the special schools for children with hearing impairment in India are being recognised to impart education till 4th grade level only. A few selected special schools, approximately 175 offer education till the secondary level, and a still very few approximately 30 offer higher secondary education. There is only 1 special college imparting higher education to the hearing impaired. A strong foundation of the primary school resulting into integrated education in the regular school and achieving higher education is a desirable state. It is estimated that less than 0.1% of school children with hearing impairment enroll and attend college education. The reasons cited are difficulty in following instructions in regular classrooms of colleges and to cope with the pace of learning.

The non-formal system of education is a viable solution. Study material to suit the needs of special children, flexibility in the choice of subjects, so also accumulation of credits can help children with disabilities to learn at their own pace and sometimes earn and learn together. The formal higher education system also needs to be disabled friendly. Orientation course for faculty and staff may create a disabled friendly atmosphere in colleges and facilitate higher education.

Manpower development

Insufficiency of manpower is an important issue reflected in the proceedings of the National Workshop of Rehabilitation Scientist(2003). It is estimated by RCI that a total of 15000 teachers of hearing impaired in the 9th plan and 30000 teachers in the 10th plan would be trained. However, this would be sufficient to teach only 20% children with hearing impairment. apart from these, a rural urban imbalance, so also state wise disparities are the key issues in the manpower required for the education of the children with hearing impairment. Educational rehabilitation also requires a team approach of professionals, which includes special educators, audiologists, speech therapist and social workers. Due to saturation of jobs in urban areas and contract job system, the field of special education of hearing impaired fails to attract talented professionals for teaching children with hearing impairment. These issues could be addressed by creating awareness about the professional course, holding entrance exams, giving incentives to the teachers working in the special field so also creating avenues for higher education for the teachers.

Assessment in Education

In the education of the children with hearing impairment, the objectives and the activities to achieve them are two fold i.e., Language-based and knowledge-based. The evaluation (summative or formative) also therefore, has to be two fold. Routine schools examinations mostly carry the load of assessment of knowledge. Uniformity in strategies and the formatting needs to be brought about immaterial of type of schooling, (residential v/s day) method of communication (from only oral to only manual) or amount of specialized input (from fully segregated to fully inclusive)

Language-based assessment has been an extremely neglected area and has much scope for improvement. Some of the areas where efforts could concentrate are: consolidating and streamlining informal language assessment strategies in special as well as regular schools, development/adaptation of standardized language assessment test tools, establishing state wise boards for language examinations, training of the teachers and involving parents and families towards the goal of functional assessment of the students and the environment in which it is placed, Huddar (2004).

Research and documentation

Phenomenal amount of work and experimentation is happening within the teaching community. Documenting the innovations and findings, so also undertaking research activities need to be encouraged amongst the teachers. Many teacher-training programmes did not have the input to the teacher trainees about research and documentation. Hence orientation for research and refresher courses would bring out fruitful researches and documentation, which would help fellow professional to reduplicate the success of others and find solutions to their failures.

Networking among the professionals

Networking brings the world closer. Networking amongst the professional brings betterment of educational practices for children with hearing impairment. It would help professionals to reach and teach better. Dissemination of information through networking would ensure that they are adding to the combined process of learning. Hence, it needs to be facilitated. Conferences, conventions and the organisations of teachers could offer such networking. These need to be promoted and supported in the larger interest of education of children with hearing impairment.

Suggestions for Action Plan

The suggestion for Action Plan for ensuring education of hearing impaired are as follows:

- 'Catch them young', and provide quality intervention
- 'Better late than never', with support of restructured curricula
- Assistance from mass media and linkages with grass root level bodies and professionals.
- Working towards the desired balance between need based variations and consistency in educational practices (including methods of communication), rather than involving in battles of methods.
- Availability of interpreter services, resource teachers in regular school
- Seating arrangements, grouping for instructions and optimum utilisation of available manpower to counter the increasing teacher-child ratio.
- Availability of adapted textbooks for those who struggle to develop literacy skills through regular text books

- Introduction of English to facilitate access to the use of technology
- Creation of avenues for higher education
- Creation of language evaluation board to systemize and consolidating informal language assessment strategies and adaption/development of standardized language assessment tools
- Entrance examinations for professional teacher-education course and incentives to teachers to pursue higher education
- Encourage research, documentation and networking amongst professionals.

Employment

Population of the Hearing Impaired in the Employment age group 2.04 million as per the Annual Report of Ministry of Social Justice & Empowerment, 1999-2000. Total number of persons with disabilities employed through Employment Exchanges is only 102845 which is about 0.54% only.

<i>Out of 102845 placement :</i>	
No. of Hearing Handicapped employed	12191 (11.85%)
No. of Orthopaedically Handicapped employed	79139 (76.94%)
No. of Visually Handicapped employed	9617 (9.35%)
No. of Leprosy Cured persons employed	987 (0.95%)
No. of Mild Mentally Retarded persons employed	911 (0.85%)

Source: Annual Report 1999-2000, Ministry of Social Justice & Empowerment, Govt. of India.

Factors influencing employment of the hearing impaired

- Staggering population and unemployment.
- Location of places of employment
- Lack of educational facilities
- Lack of tools for vocational assessment
- Non-existence of technical colleges.
- Lack of mainstream vocational training opportunities.
- Non-viable trades for training.
- Lack of instructors trained in the use of sign language.
- Apprehension on the part of the employers with reference to Communication skills
- Safety hazards

Types of Employment

- Employment opportunities through open competitions.
- Employment in government sector through reservation
- Employment opportunities through special drives against identified posts.
- Employment exchange guided employment
- Employment through other Govt. agencies like V.R.C.s, DDRC.
- Employment through placement services.
- Employment through poverty alleviation schemes of the Government.
- Employment through special industries for the disabled.
- Employment in Training-cum-production centres.
- Family supported employment.
- Self-employment

Jobs for Deaf on Web: An unique initiative

The website "jobsfordeaf.com" is launched by AYJNIHH. The prime objective of the site is to enable the hearing impaired to get registered for employment and employers to notify their vacancies through this site. This site will be administered by AYJNIHH. The site also provides opportunity for the professionals intend to work for the hearing impaired.

Salient features of the website:

- Facility to create and upload resume for the job seekers.
- Facility to notify jobs / vacancies by the employers.
- Facility to search jobs.
- Assistance and guidance for the jobseekers and employers regarding employment and vocational training for the hearing impaired.
- Facility to chat-discussion forum.
- Link to related website.viz.ayjnihh.org.
- News desk. The latest event related to the hearing impaired.
- You are welcome to visit this site and get back to us with your suggestions and comments. Your suggestions will take us a long way in providing meaningful rehabilitation services to the Hearing Impaired.

Suggestions for promoting employment

- i. Creation of awareness on "Abilities" of the Persons with Disability through Print and Electronic media. Media & Communication Deptt. can play an effective role in it.

Barrier-free environment for the Persons with Disability should be made pre-requisite for educational and training institutes. Deptt. of Education & Training, Rural Development Deptt., Urban Development Deptt. and Public Works Deptt. are required to take lead role in the matter.

- ii. The range of Vocational training be widened and linked to requirement of the employment market. Most of the Vocational Training Centres are stuck with the obsolete trades. It is necessary to introduce new/modern trades having high employment prospects. While doing so, the industries should be consulted in conducting the market research and developing the course curriculum. The vocational training courses should also be aimed at widening self-employment prospects. In this case, Directorate of Technical Education, Directorate of Employment & Training, Corporate Sectors and Ministry of Labour and Industries need to work in close collaboration.
- iii. AICTE, NCVT and SCVT should develop suitable course curriculum for technical training for the Persons with Disabilities. National Institutes may provide technical input in developing such programmes.
- iv. State Govt. should encourage the NGOs to start vocational training programmes for the Persons with Disabilities. Necessary support in terms of Workshop shed, Electricity, Water be provided on priority for such projects.
- v. The Technical Education Department should have a special cell to monitor and guide the technical training activities for the Persons with Disabilities conducted by the NGOs.
- vi. The Community Polytechnic should be popularized. All Govt. I.T.I.s should have extension wing as Community Polytechnic.
- vii. All Instructors of Govt. I.T.I.s should be trained to communicate with the deaf. NIHH will impart necessary training in this regard.
- viii. The Vocational training programmes for the Persons with Disabilities conducted by the NGOs should be recognized by the Technical Education Department for the purposes of employment in the organised / Govt. Sector and financial assistance by the Nationalised Banks.
- ix. State Govt. need to evaluate the viability of the trades run by the I.T.I.s keeping the changing trends in the job market. Technical Education Department may form an expert committee to look into such issues and suitability of the Persons with Disabilities in undergoing the training programme may be examined. If necessary, the training curriculum be modified.
- x. It is necessary that a linkage is established between the training institute and local Industries. The Training Institute and the Industries need to assess the type of manpower required in the employment market. Tailor-made training programmes be initiated for the Persons with Disabilities.
- xi. To enhance Vocational Training opportunities for the Persons with Disability, the NGOs need to establish Vocational Training Centers for the Persons with Disability, preferably one in each Block or at least one each in every district.
- xii. The Ministry of Social Justice and Empowerment may provide financial assistance to the NGO under its Scheme of assistance to NGOs. The National

Institutes for Disabilities can offer consultancy services to the NGOs in developing project proposals and provide technical guidance in conducting the training courses.

- xiii. The property, land, building of the beneficiary or of his/her guarantor be considered as collateral security for the purpose of sanctioning loan to Persons with Disabilities under the schemes of NHFDC. As envisaged in the Persons with Disabilities Act, 1995, the State Govt. should take necessary measures to earmark 3% of the allocation made under Poverty Alleviation Scheme for the Persons with Disabilities.
- xiv. The organisations like FICCI, CII and PHDCCI etc. should take a lead role in creating awareness on "Abilities" of the Persons with Disabilities. The Private Sector should come forward to employ Persons with Disabilities by way of matching the "abilities" of the Persons with Disabilities and Job requirement. Govt. may think of giving Tax Holidays to the prospective employers who have employed Persons with Disabilities not less than 5% of their total workforce.
- xv. The DOPT need to revise the definition of Hearing Handicapped in accordance with the section 2 (l) of the Persons with Disabilities Act, 1995. Due to non-revision, majority of hearing impaired persons are not able to get employment in spite of fulfilling other conditions. Till date the Banking Sector, Railways and Public Sector Undertakings are insisting that the person should have 90 dB (in some cases 70 dB) hearing loss in the better ear to be eligible for the posts reserved for the hearing handicapped. Whereas, u/s 2 (l) of Persons with Disability Act, 1995, it is defined that 'Hearing impaired' means loss of 60 dB in the better ear. This discrepancy needs to be corrected immediately. Necessary circular be issued by DOPT and Finance Ministry to all PSUs, Nationalised Banks respectively. Railway Board should issue similar circulars to its Divisional Offices.
- xvi. Development of Entrepreneurship Skills should be an integral part of the Vocational Training Programmes to enhance self-employment prospects. The expertise available with Small Industries Service Institutes (SISI) and District Industries Centers (DIC) can be utilized in this regard.
- xvii. The Rural Employment programmes under SJSY Schemes envisaged by the Ministry of Rural Development should be disabled friendly and be made accessible to the Persons with Disability. Necessary relaxations and modifications both in the eligibility criteria and infrastructure be made to suit to the needs of the Persons with Disability. The Ministry of Rural Development need to initiate necessary action in this regard.
- xviii. The Employment Exchanges be empowered to verify the records of recruitment of Govt. Offices and Public Sector Undertakings in relation to the observance of the policy of reservation of jobs for Persons with Disability. This will open up the employment prospects for the Persons with Disability. The Department of Personnel & Training in consultation with the Ministry of Labour and other ministries need to make necessary reference in this regard. The NGOs receiving grants from Govt. should come under this purview.

- xix. To enhance the employment prospects for the Persons with Disability in Private Sectors, The Persons with Disabilities Act, 1995 made the provisions of Incentives to be given to the employers for employing at least 5% of the employees with disabilities. The incentives like Tax rebates, Excise Concession, Tax Holidays, preferential allotment of land, Soft loans, Easy payment terms etc. could be thought of. The State Commissionerate for the Persons with Disabilities may take up the matter with Department of Finance and Department of Commerce and Industries.

The enhance self-employment opportunities for Persons with Disability in Rural Areas, the NHFDC may establish linkage with Nationalized Banks.

- xx. The NGOs should come forward to implement the Micro Finance Scheme of NHFDC.

The loan amount under D.R.I. scheme be increased and implemented in its real spirit by the Nationalized Banks.

- xxi. NGOs and the parents of the Persons with Disability be encouraged to set up Sheltered workshops, Cottage Industries (Home Bound) for the severely disabled persons.

- xxii. The Municipal Corporations should give preference to the Persons with Disability in allotment of Shops, Kiosks and Space for Self-Employment.

Social Practices

Marriage counselling is a need felt service. Also, legal aid cells will have to be sensitized to take up with the issues pertaining to the persons with hearing impairment. Sign language interpreter services are gradually picking up through the organised efforts of RCI, Ramakrishna Mission (Coimbatore) and AYJNIHH. AYJNIHH offers courses in sign language on part time and full time basis. The self instructional Compact Discs are available on sale.

Barrier free environment for the hearing handicapped person is to have less of noise in the work place so that he can use his hearing aid effectively, have good visibility in the work place/study centre/school so that speech reading is possible observing the face of the speaker, and to have increased signal to signal ratio either through FM system which is out of reach for most people or use of induction loop system which cost less than Rs.8,000/- per set. AYJNIHH has been installing this at public places, on request. It is located in the railway stations at New Delhi, Chennai, Secunderabad and in the hospital at Badlapur Town Panchayat in Thane District.

Prevention

Cause of sensorial deafness that lead to conditions warranting exclusive services set routinely available in the vicinity are as follows:

- i. Material Rubella
- ii. Genetic disorders
- iii. Continuous exposure to high intensity noise

iv. Infections diseases and

v. Aging.

Ear diseases, wax in the ear, etc can further complicate the issue, if co exist with condition earlier mentioned. The ear disease is curable through medical / surgical intervention.

The PHC medical officers need to be oriented to manage ear discharge and the facility at Dist, H.Q Hospitals need to be further strengthened.

Maternal Rubella and Genetic defects lead to 80% of congenital deafness in India. WHO Bulletin (1997) reports the study of Roberson et al to show that Rubella sweeps India ones in 3-4 years and that strain remains for 6-8 years.

It costs Rs.25/- to immunize a person for life time. This should get priority.

Genetic counselling services are increasingly being made available in India. It is important that in families with history of childhood deafness, consanguinous marriage should be avoided. The media should be proactive in spreading this message.

However, a roadmap has been well drawn towards creating best of Genetic services in the country through indigenous technology keeping the cost in mind.

Ensuring sustainable outcomes

Sustainable outcome with equity calls for following actions.

- i) The Panchayats should take up the issue of disability prevention and management. The Badlapur Town Panchayat in Thane District has done this through passing a resolution that Rs.10/- will be collected per property per year towards disability rehabilitation. The 22500 properties generate amount Rs.2,25,000 per year. This CBR activity started in the year 2001, received the best Barrier Free Town Panchayat Award in 2002 from the Hon'ble President of India. The Town Panchayat has now started a special school each for children with MR and hearing impairment. Both are early intervention centres. The Town Panchayat has only 1,25,000 population.
- ii) No country in the world can afford to meet all the expenses to rehabilitate the Persons with Disabilities. Even the developed economies bank on Insurance Scheme. India should take this approach at the earliest. As Karl Marx has said, " Law can never be above economic order". Conventions can happen, Acts can be passed. But outcome can be sustained only through Insurance which is one of the best known community funded activity of the modern era. New India Assurance has a scheme called 'Birth Right Scheme', which needs to be popularized.
- iii) The delivery of services should be based on the need of the client and not on the convenience of the service providing agency be it Non Government Organization or Government Organization. The third option of Private Voluntary Agencies (PVAs) has to be explored.
- iv) Application of technology particularly tele-technology towards reaching the unreached, creation of Help-line etc will have to be seen as thrust area, if one needs to survive in the globalised economy.

Conclusion

While evolving sustainable strategies for disability rehabilitation and prevention of hearing handicap in the Indian context the issues such as creation of awareness, early identification, referrals and diagnosis, early intervention, prevention, provision of suitable aids and appliances, education and employment for the hearing impaired need to be addressed. It is also important to involve the panchayats, develop a suitable insurance scheme depending on real client needs and use of Information Technology for ensuring sustainable outcomes. The Biwako Millennium Framework calls for a barrier free rights based inclusive society. There is need to focus on the seven target areas with reference to each disability. AYJNIHH has formed working group to address issues in each target area relating to hearing impairment and proposes to undertake research in relevant areas which will help to achieve the objectives of empowerment of persons with hearing impairment.

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Chapter 13

Evolving Sustainable Strategies for Disability Management: Mental Retardation

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T C Sivakumar

The persons with mental retardation by virtue of their condition are dependent in their activities of daily living. Supporting them to access their rights, assisting them to enhance quality of life and creating a congenial environment for them to survive like any other human being depends upon creating user friendly service models. These service models require human resources. Identification of the service models and utilization of the human resource require proper planning and research. The sustainable strategies for the rehabilitation of persons with mental retardation require concentrated effort from resources and programmes in a convergent mode from multiple agencies including the community. This paper deals with analysis of the current status in terms of the services and human resources available with suggestions to develop programmes create sustainable enabling environment.

Introduction

Mental Retardation is a condition wherein the development of the brain is delayed in contrast with the physical development. The individual will not be able to cope up with the demands to negotiate with the day to day life requirement. The profile of persons with mental retardation has deficits in the areas of intellectual functions, motor - both gross and fine - functions, communication and socialization. However, the intensity of the inability in dealing with the environment is different in each individual. In the International Classification of Diseases and Related Health Problems, mental retardation has been defined as a condition of arrested or incomplete development of the mind which is especially characterized by impairment of skills manifested during the developmental period which contributes to the overall level of intelligence, that is cognitive, motor and social abilities (ICD -10, 1992). According to the American Association of Mental Retardation (AAMR), it is a disability characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual,

social and practical adaptive skills originating before 18 years of age. AAMR emphasizes five assumptions essential to the application of this definition.

- i. The limitations in present functioning are explained within the context of community environments typically of the individual's age, peer and culture.
- ii. A valid assessment considering cultural and linguistic diversity as well as differences in communication, sensory, motor, and behavioural factors,
- iii. Coexistence of limitations and strength within the individual,
- iv. Description of limitations to develop profile on needed supports,
- v. Expectation of improvement in the life functioning of the person with mental retardation as a result of sustained period of personalized support (AAMR, 2002).

Persons with Disability (Equal Opportunity, Protection of Rights) Act 1995

Prevalence of mental retardation is considered to be 94 per 1,000,00. Incidence of mental retardation cut across the socio-cultural and gender differences, though the prevalence rate is seen higher for males in both rural and urban areas (NSSO, 2003). Various causes have been identified for mental retardation (Persha, A.J, et al, 2003). However, many reasons for the causes are yet to be established. A broad understanding of the causative factors is listed below:

- a. Pre-conceptual reasons - It is possible that an individual with chromosomal/genetic disorder can carry the aberration to the offsprings. In case the both spouses have similar predisposition, the chances of having a child with disability may double. Couple having consanguinity with family history of genetic disorder stands for high-risk offspring with disabilities. In addition to hereditary factors mentioned above, the Rh incompatibility in the blood of the couples forms a major cause for a child having disability. The latest report from NSSO found out that more than 70% of the reasons for the disability occurs before the birth of the child.
- b. Pre-natal causes - The prenatal period from the conception till the delivery is a sensitive phase. Any physical strain to the mother has a direct impact on the fast developing fetus. Infectious diseases, exposure to radiation, consumption of chemicals, illegal attempt on abortion, imbalanced or mal-nutritious condition of the mother are some of the commonly reported reasons for the developmental anomalies in the central nervous system which in turn can present as mental retardation.
- c. Natal - Prematurity is one of the major reasons for developmental delay. However, the support of the medical technology has reduced this risk. Other common reasons are prolonged labour, abnormal fetal positions and prolapsed umbilical cord. Delayed birth cry due to anoxia, hypoxia, birth trauma and asphyxia may cause considerable damage to the fast developing brain.
- d. Post - natal - Frequent illness, imbalanced and mal-nutritious conditions, injury to the brain etc., can mark irreparable damage to the developing central nervous system that may manifest as developmental disabilities.

Since mental retardation is a condition of the brain and not a disease, cure in terms of medical treatment is not feasible and therefore not recommended. Instead, preventive aspects are emphasized which can be planned in the same order of the causative factors.

Pre-conceptual level - The preventive measures like genetic testing and Rh matching are recommended for the prospective parents. Physiologically and psychologically the safe age of a mother for the first child bearing is between 20 and 35 years.

Pre-natal - regular medical checkups, intake of prescribed drugs, avoidance toxicants and injuries, avoidance of physical and mental trauma is some of the precautions to be taken during prenatal period.

Natal period - it is always considered that the delivery be conducted by trained and experienced persons, so that any eventuality during the delivery process can be effectively dealt with. As far as possible the delivery has to be conducted in a hospital setup.

Post-natal period - this is also a significant stage in terms of the longitudinal period in which the developing human brain is susceptible for regression due to physical and mental trauma. Extreme care has to be taken to protect the fast developing child from being becoming the victim of mental retardation.

Appropriate means of awareness is the answer to prevent mental retardation. Government of India has various schemes and programmes for the grass root level workers aiming at reducing the incidence of mental retardation. Orienting the school, college children on the causative factors on mental retardation is another method for the prevention of children with disability.

Due to the degenerative status of the brain cells, it is impossible to bring out changes once the damage occurs. Hence, the prognosis of the child with mental retardations is always very poor. The management option available is stimulating the residual abilities with the support of a multi-disciplinary professional team, which may include medical professionals - pediatrician, psychiatrist, psychologist, special educator, speech therapist, physiotherapist, occupational therapist etc. Assessment in a child with mental retardation involves a multidisciplinary approach. Various professionals have different roles and responsibilities in gathering information for delivering of services. Early identification and intervention can mark considerable positive changes in the developmental pattern during the post-natal stage. The role of a psychologist, special educator for the children with mental retardation, social worker, is crucial in educating a child with mental retardation.

Current Status

The rehabilitation of persons with mental retardation can be explained in a life cycle approach. Zero to three years is the critical area where early intervention can make long lasting changes in the life of a child. The basic aim and objective of early intervention are:

- early detection and prevention of disabilities and handicaps,
- acceleration of rate of development in the child,

- acquisition of new behaviour/ skills by the child increase independent functioning of the child,
- minimize the effects of the handicapping condition,
- prevent secondary handicaps,
- render support to the families of ,these children to cope with the challenges (Persha, 2003)

There are many models available on early intervention as well as established and standardized assessments system leading to intensive stimulatory therapy by a team of rehabilitation professionals. However, to optimize the human resource value, the rehabilitation council of India has planned the development of human resources based on the single window delivery service system. The one year Post Graduate Diploma in Early Intervention (PGDEI) course prepares candidates from the medical, developmental psychology, speech and language therapy, occupational and physiotherapy back ground to extend the required services.

The next stage in the life cycle approach is the preschool education period. This is the crucial time where the parents are at a lost when they are faced with no option to educate their child with mental retardation. In the preschool stage also intensive stimulation is given in the areas of cognition, motor functions, communication and socialization. Professionally trained people are very helpful for continued development of the child and Diploma in Early Childhood Education (DECSE-MR) prepare these professionals to work with children with disabled in their preschool stage, single handedly.

The preschool education is followed by special education programme, which is extended through group teaching as well as individualized training programmes. The total number of special schools for the children with mental retardation in India is identified as 730 in which 26% has residential facilities. An analysis of the growth of special schools for children with mental retardation over the years shows that there were about 250 before 1985. There is a 35% growth in the in the last 20 years and more than 40% growth in the last 10 years. Out of 730 special schools identified, 51.5% are from the Southern States, 21.9% is from the Western part of the country, 14.5% is of the East, and 10.5% is from Northern part. The share of seven states from the North East is 1.4% of the total special schools in the country (Rao, 2003).

It is estimated that about 7000 special educators are available in the country either working as full time or part time teachers. Apart from this, medical professionals, psychologists, speech therapists, occupational therapists, physiotherapists, art and craft teachers are also engaged in extending the services to the children with mental retardation who are in the special schools. The Ministry of Social Justice & Empowerment, Government of India has schemes to extend financial support for initiating and maintaining the activities of the special schools.

The human resource development programmes in imparting special education services are Diploma in Special Education (Mental Retardation), B.Ed.in Special Education (Mental Retardation), M.Ed. in Special Education (Mental Retardation). These programmes are currently available in various parts of the country.

The vocational training for the persons with mental retardation has always been associated with sheltered workshops. Sheltered workshops are usually attached with the special education centers that provide job skill training to adult persons with mental retardation. In our country, 60% of the 730 schools for the mentally retarded have reported of vocational training centers (Rao & Sivakumar - 2003).

The other methods offered as vocational training are home based training, competitive employment and extended sheltered workshops as part of self-help groups. It is observed that 97% of the vocational training and placement of children with mental retardation is accessed by the mild, moderate category. The services in vocational training centers are predominantly paper based, cloth based, chemical based, preparation of food items, novelty items, engineering, agro-based services and open employment. Initially, the services in vocational training was seen from traditional point of view with an attribution of charity and a leisure time activities for the disabled. The traditional model also considers vocational training as a medium of stimulating the cognitive and adaptive skills of an individual and as a means of complacency and training in generic skills. Presently, non-traditional approach is also under practice where vocational training is given on the basis of ability of an individual. It is more of a right-based activity and the major goals are empowerment and development. This will lead to enrichment of the existing skills in the adult person with mental retardation with focus on enhancing the competitive spirit so that he/she can enter into a competitive market.

Diploma in Vocational Training and Employment (Mental Retardation) is designed for creating the required human resources. This programme at present is available at five centres in different parts of the country. However, inadequate number of vocational training centers and the obsession for traditional models are the constraints in the growth of gainful employment of the persons with mental retardation.

Other long term training programmes such as Bachelors Degree in Rehabilitation Therapy, Masters in Rehabilitation Sciences, M.Phil in Rehabilitation Psychology are vital for effective rehabilitation services in the area. The efforts in creating trained professional will become successful, if human resources at faculty/master level are developed.

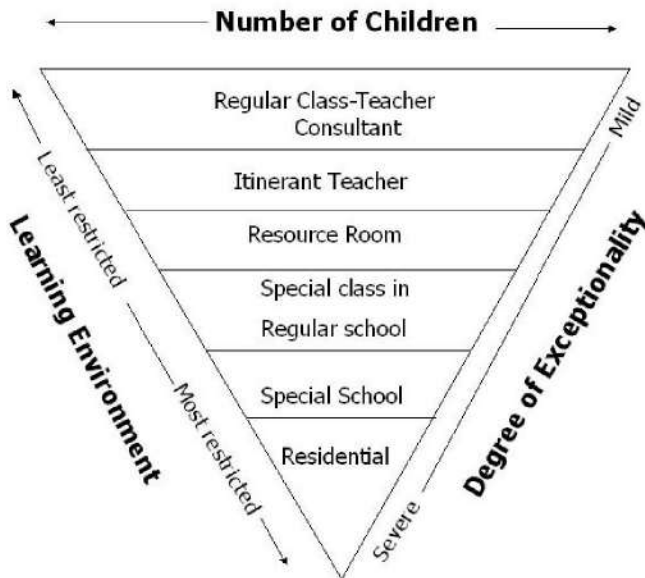
Sustainable Strategies in Disability Management - Suggested Initiatives

Taking into consideration the current programmes and the strengths of the infrastructure in various developmental agencies of Central and State Governments, programmes embedded with convergence mode are the need of the hour

- Convergence with various ministries relating to education, social welfare, commerce etc. for better understanding and contribution in the rehabilitation of persons with mental retardation by pooling the human and financial resources.

- Developing rural models: Though special schools are available in the rural sector, comprehensive rehabilitation for persons with mental retardation is yet to be implemented. Apart from the special schools for educating the persons with mental retardation, inclusive approach in the regular schools is required for rehabilitating persons with mental retardation.

It is observed that 85% of the children with mental retardations falls into the category of mild and moderate who can be benefited by inclusive educational approach. This may also include admitting them into regular classes with class teacher as a consultant with adequate orientation of mental retardation. Other options are engaging an itinerant teacher, creating resource rooms in regular schools, and arranging in special classes in regular schools for the children with mental retardation. However, the remaining 15% of the children with mental retardation, falling under the category of severe to profound level would benefit only through special schools and residential set up. The figure below explains this process.



As it may be observed from the figure that more number of children with mental retardation benefit from least restricted learning environment which is directly proportionate to the less severity of retardation. The most restricted learning environment supports the more severely disabled groups in terms of the degree of expression.

- Measures of sustainable rehabilitation programmes - reengineering the vocational training on completion lines with full complement of the four essential stages viz., , the vocational training of persons with mental retardation require a complete change in its present form. The vocational training has to be supported with appropriate pre-vocational components from the special schools.

- Model on transition programmes from school to work need to be developed. The vocational training should lead to the vocational placement based on the community from which the person with mental retardation belongs. All special schools need to expand into the state of the art vocational training. Existing industrial training institutes can be equipped to train the persons with mental retardation. This may require moderate changes in the apprenticeship act as well as in the training methodologies to suit special needs of the persons with mental retardation. The vocational training needs to focus on the job placements. The apprenticeship act may be amended to include on the job training of persons with mental retardation. Even though, all the districts have the provisions to open special cell as the Special Employment Exchange to facilitate employment prospects of persons with disability, specific actions are required to include persons with mental retardation in this scheme. In addition, some competent special schools can be identified as special employment exchanges. The better vocational climate exists in the centers which have provisions for pre-vocational training, vocational training, on the job training and job placements (Rao et al).

Along with the vocational training, measures are also to be taken to orient the public on the vocational potential of persons with mental retardation so that the trained persons can easily be accommodated in the community (Rao and Sivakumar, 2004).

Future actions

A. Services

Early Detection and Early Intervention

- Training of grass root level and community level workers.
- Training the nursing staff and para-medical staff.
- Equip the PHCs and primary sub-centres to provide early intervention services atleast on weekly or fortnightly basis.
- Initiation of early intervention services for 0-4 years of children at all District hospitals.
- Orienting the media

B. Special Education

Early Childhood Special Education

- Promoting admission of the children with developmental delays in pre-schools.
- Training of pre-school teachers.
- Encouraging and promoting admission of children with mild and moderate high functioning mentally retarded children in the regular schools.
- Training the regular school teachers.

- Training to DIET instructors on special education aspects.

C. Vocational Training

- Trained human resources
- Increase in non-traditional occupations
- Training through existing network of 4000 it is
- Standardization of curricula and certification by NIOS & NCVT.
- Competitive and supported employment
- Linkage with industry and commerce.
- Preparing the society.
- Training the special teachers in therapies.
- Promoting itinerant teaching in the regular schools, who can visit the schools and provide itinerant services.
- Creating barrier free environment.
- Promoting music and dance.
- Promoting parent associations and self-held groups.
- Research and Development.
- Convergence mode of the developmental agencies.

D. Human Resource Development and Project Management

- Inclusion of a subject on early intervention in the syllabus of para-medical course and MBBS.
- Increase in the centres offering training programmes.
- Orienting the regular school teachers.
- Capacity Building.
- Leadership programme.
- Technology management.

Conclusion

The spectrum of the services for the persons with mental retardation needs to be effectively dovetailed in all the programmes not as a special service but as regular ones for general population in a convergence manner right from the village level through district, State and Central levels. Active involvement of Non-Governmental Organizations is very vital for successful implementation.

Success of the sustainable programme is determined by the quality of life of persons with mental retardation and their families for which in built mechanism of monitoring and evaluating these programmes on a continual basis is crucial. Such a mechanism needs to guide for improvement to achieve the ultimate goal of programme sustainability

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Chapter 14

Evolving Sustainable Strategies for Disability Management : Cerebral Palsy, Autism, Mental Retardation and Multiple Disabilities

Aloka Guha

While painting on the common threads between the four categories of disabilities, the Chapter discusses service delivery systems in a 13 point Management Continuum, NGO & Government of India models, the Rehabilitation team, core & support services & the challenges faced by this group. The new Social Model vis-a-vis the old Medical Model is discussed. The role of the existing schemes & programmes, NGOs as also parents that are central to the positive outcomes of disabled children is also discussed in the chapter. The author feels that the stronger the partnership between the parents & the professionals, the clearer the roles & responsibilities between them, the better will be future of the disabled child.

Introduction

Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities are the most marginalized groups within the Disability Sector. There are 9.94 lakh persons with Mental Retardation, 2.74 lakh persons with Cerebral Palsy and 19.67 lakh persons with Multiple Disabilities in India as per the latest NSSO 2002 Data. No data on Autism in India is currently available. This group needs, firstly, to access the same benefits & concessions that are available to persons with other disabilities. Along with this homogenization with the larger disability sector, there should follow a seamless integration into mainstream society. The National Trust Act 1999 has provided discrete legal status to this group while the Constitution guarantees civil, political, economic, cultural & social rights.

Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities have three common threads, that they are all Spectrum Disorders the co-morbidity is

reasonably high as shown below:

Table 14.1 Co-Morbidity in Developmental Disorders	
Developmental Disorders	Co-Morbidity
Severe Mental Retardation	
Cerebral Palsy	-20%
Seizure Disorder	-20%
Sensory Deficit	-55%
Psychiatric and Behaviour Disorders	-55%
Mild Mental Retardation	
Cerebral Palsy	-5%
Seizure Disorder	-10%
Sensory Deficit	-25%
Psychiatric and Behaviour Disorders	-40%
Cerebral Palsy	
Seizure Disorder	-20-60%
Refractive Error	-35%
Hearing Loss	-10%
Psychiatric and Behaviour Disorders	-30%

(Source material: Dr. A M Fox's lecture notes at Spastics Society of Tamil Nadu)

The core areas of concern integral to management are the same i.e., communication, cognition, mobility and socialization. The other common factor among these four disabilities, however is that they are without doubt, the most marginalized and neglected groups even within the disability sector.

Data on Mental Retardation, Cerebral Palsy, Multiple Disability and Autism

Out of the estimated 18.5 million disabled persons, the percentage of disabled population having from Mental Retardation, Cerebral Palsy, and Multiple Disability as per NSSO Survey is given in Table 1.2. No data on Autism in India is currently available. The epidemiological surveys to findout the prevalance of Autism Spectrum Disorders are yet to be initiated.

**Table 14.2 Persons with from Mental Retardation,
Cerebral Palsy, Multiple Disability**

	Mental Retardation	Cerebral Palsy	Multiple Disabilities
Population	9.94 lakhs	2.74 lakhs	19.67 lakhs
Percentage age of total population	0.09%	0.03%	0.20%
Percentage of disabled population	5.37%	1.48%	10.63%

Legal Status

With the enactment of the National Trust Act of 1999, the conditions namely Autism, Cerebral Palsy, and Multiple Disabilities have found separate and individual legal status. Although the National Trust Act does not guarantee the 3rd Generation rights or developmental rights per se, there are specific rights and benefits flowing from its approved programmes under Section 10 of the National Trust Act. The recent nature of legislation is indicative of the recognition of these disabilities as being disabilities discrete from mental retardation.

Rights

All Civil and Political Rights are guaranteed to this group under the Constitution of India, Articles 12-32 of Chapter 3 on Fundamental Rights. Under Section 16 of the Representation of People's Act, they may be enlisted in the electoral rolls.

Guidelines to States for developing criteria for the realization of Economic, Social and Cultural Rights are enshrined in Chapter 4 of Directive Principles of State Policy.

Service Delivery Systems

A whole range of service delivery systems are available today and none of them are mutually exclusive. In fact, most families choose the eclectic or combination models of service delivery which provides the maximum flexibility and is best suited to individual needs. The service delivery system for the persons suffering from Mental Retardation, Cerebral Palsy, Multiple Disability and Autism may include the following:

- Hospital Based Rehabilitation
- Institution Based Rehabilitation
- Extension/Mobile Services
- Community Based Rehabilitation

- Home Based Services
- Eclectic/Combination Models
- E-based Rehabilitation
- Transitions between delivery models
- Integrated settings in regular schools
- Inclusive settings in regular schools
- Short Term Respite Care Centres
- Fully Residential Centres/Permanent Homes
- Hostel facilities for weekdays

Sustainable Strategy

National Trust

The National Trust for welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 came into force w.e.f. 30th December, 1999. The Trust supports programmes which promote independence, facilitate guardianship where necessary and address the concerns of those special persons who do not have their family support. The Trust also seeks to strengthen families and protect the interest of persons with autism, cerebral palsy, mental retardation and multiple disabilities after the death of their parents.

Objectives of the Trust as per the Act includes:

- (a) to enable and empower persons with disability to live as independently and as fully as possible within and as close to the community to which they belong;
- (b) to strengthen facilities to provide support to persons with disability to live within their own families;
- (c) to extend support to registered organizations to provide need based services during the period of crisis in the family of persons with disability;
- (d) to deal with problems of persons with disability who do not have family support;
- (e) to promote measures for the care and protection of persons with disability in the event of death of their parent or guardian;
- (f) to evolve procedure for the appointment of guardians and trustees for persons with disability requiring such protection; and
- (g) to facilitate the realization of equal opportunities, protection of rights and full participation of persons with disability

The National Trust is empowered to undertake the following categories of programmes:-

- (a) any programme which promotes independent living in the community for persons with disability by –
 - (i) Creating a conducive environment in the community;
 - (ii) Counseling and training of family members of persons with disability;
 - (iii) Setting up of adult training units, individual and group homes;
- (b) any programme which promotes respite care, foster family care or day care service for persons with disability;
- (c) setting up of residential hostels and residential homes for persons with disability;
- (d) development of self-help groups of persons with disability to pursue the realization of their rights;
- (e) setting up of local level committee to grant approval for guardianship;
- (f) Such other programmes which promote the objectives of the Trust.

The Trust is empowered under the Act to provide for the guidelines for monitoring and evaluating the activities of the registered organizations who are receiving financial assistance from the Trust.

The Trust constitutes local level committees at district level to undertake specific activities in pursuit of its objectives.

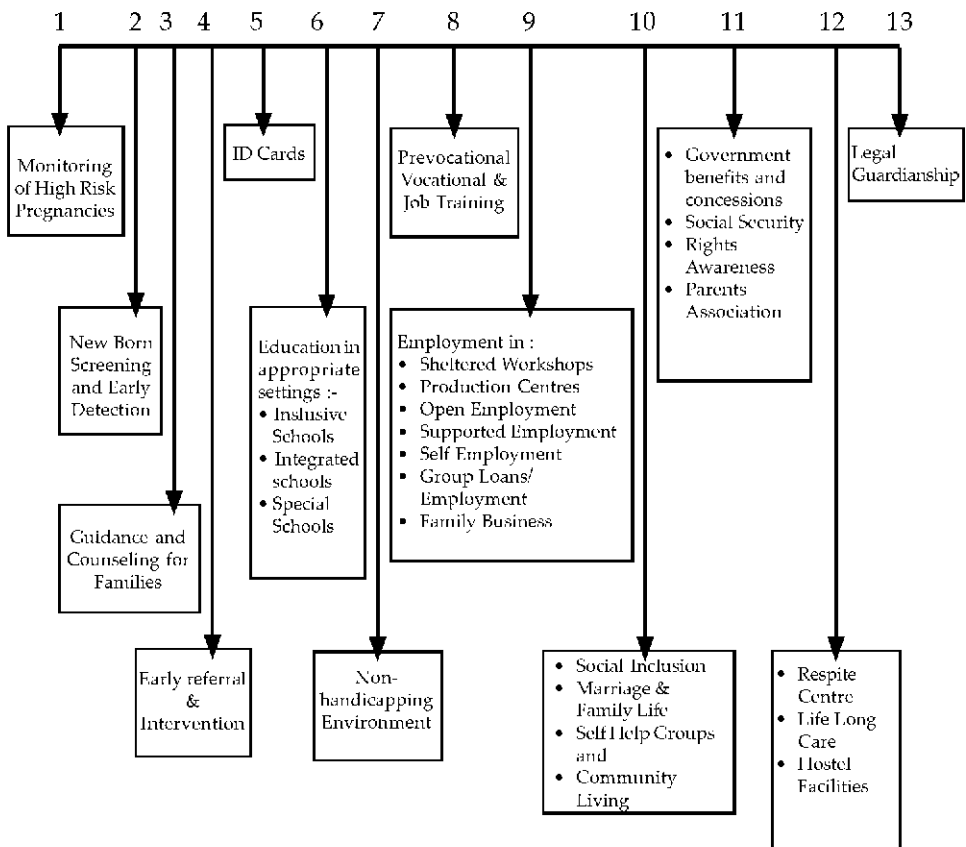
As regards guardianship, parent of a person with disability or his relative may make an application to the local level committee for appointment of any person of his choice to act as a guardian of the persons with disability. The local level committee shall receive process and decide on such applications received. Duties of guardian include taking care of such person of disability and his property and for being responsible for the maintenance of the person with disability. Every person appointed as a guardian under Section 14 of the Act are required to deliver to the authority which appointed him, an inventory of immovable property belonging to the person with disability and all assets and other movable property received on behalf of the person with disability, together with a statement of all claims due to and all debts and liabilities due by such person with disability. Abusing or neglecting a person with disability or misappropriating or neglecting the property will cause removal of the guardians.

Management Continuum

A thirteen point management continuum covering various aspects of sustainable rehabilitation management of the persons with Mental Retardation, Cerebral Palsy, Multiple Disability and Autism has been developed and presented in Table 14.3. It may be kept in view that the needs of persons with these four disabilities are uniquely different from the needs of persons with other disabilities. Such special needs are in:-

- Importance of behaviour Modification for enhancing desirable behaviour
- Training in management of sexual needs and menstrual hygiene
- Training in self care
- Training in socialization and adaptive skills
- Need for respite and permanent care for those with profound disabilities
- Need for Legal Guardianship

Figure 14.1 The 13 Point Management Continuum



NGO

Over the last hundred years, a variety of NGO models have evolved. Some of them are :-

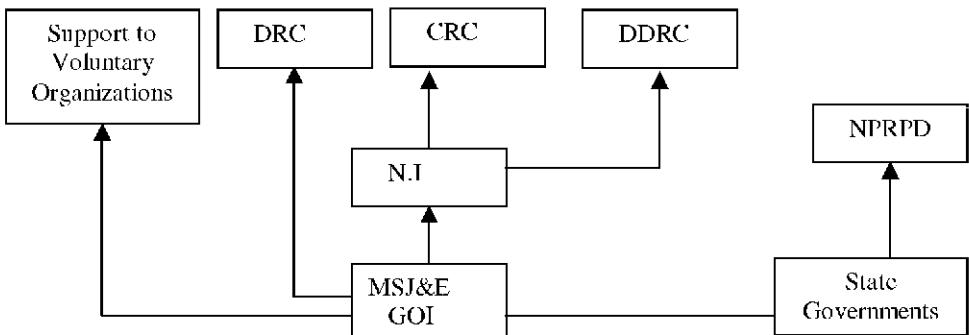
- Child to Child Model - M.S University, Baroda
- Parents as Co-Therapists Model - Maduram Narayan Centre, Chennai.
- Disabled Persons as professionals - Spastics Societies
- One to One Model - Helen Keller Society for the Deaf Blind, Mumbai
- Parents as Professionals Model - Mithram, Kerala
- Professional – Volunteer Model - Most Centres
- Fully Professional Teams - Thakur Hari Prasad Centre, Manovikas Kendra
- Management – Technical-Combination - Blind People’s Association, Gujarat
- Independent Living Model - Swayamkrushi, Hyderabad
- Disabled Persons as Employees - Worth Trust, Tamil Nadu

It may be noted that these are only some good examples, many variations are equally effective. Many programmes in the area of Autism, Cerebral Palsy and Mental Retardation are parent initiated as in Action for Autism in Delhi or parent directed programmes as in U.P Parents Associations in Lucknow or parent-participated as in Bodhayan in Kolkata. In these four disabilities, perhaps, more than in any others, the parent-professional partnership is the key to the success of the programme and the single biggest indicator for holistic development of their children.

Government module

The Government schemes and Programmes for persons with disabilities are implemented as represented in the module below:

Figure 14.2 Government module



Human Resource Development

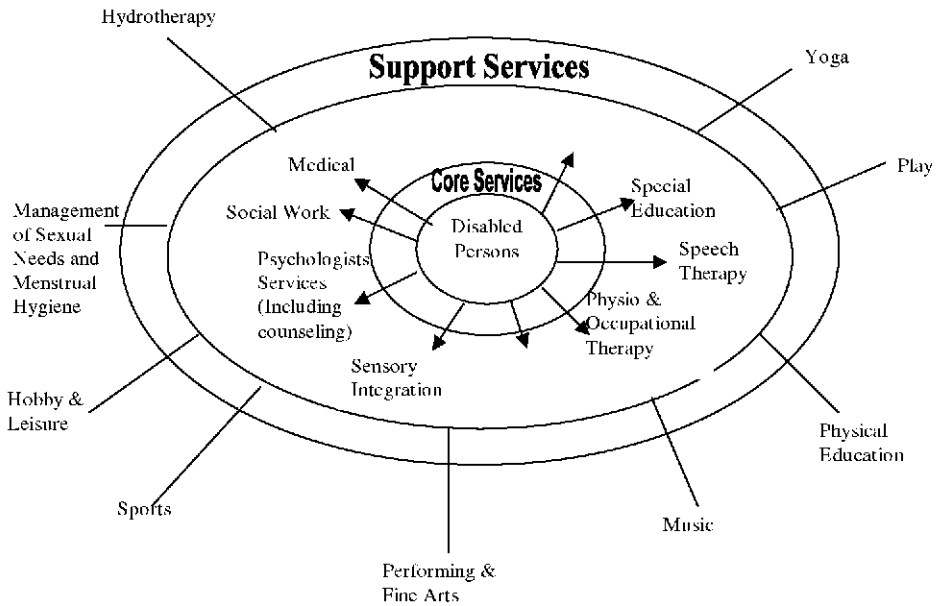
New research findings are continually expanding our understanding of the complexities of human development, especially in the early development period. New intervention approaches, particularly in Autism, most often demanding close interactions between parents and professionals, and across professionals are being explored and reviewed. To become, and to remain, competent professionals/ personnel, we need up-to-date pre-service preparation, focused in-service training, and specialized continuing education opportunities.

Effective Rehabilitation Team

As our understanding of disability and rehabilitation progresses dramatically, our concept of the ideal professional team has also evolved over the years. The team may be an Inter-disciplinary one where different disciplines work with the same client but in isolation or a multi-disciplinary team where team members work individually on each client but share vital information and plan IEPs in joint sessions. In case of the third category i.e. trans-disciplinary team, however, one case worker takes inputs on the client from all other departments and then trains him/her alone. In view of CBR gaining popularity as a viable strategy for developing countries, and in view of the stress of moving from one professional to another, the third option, that is the Trans-disciplinary Team, is the most preferred option in today's context.

Services Needed for persons with Autism, CP, MR & MD

Persons with Mental Retardation, Cerebral Palsy, Multiple Disability and Autism in general not only need medical attention and assistive devices, but a plethora of inputs to make their lives bloom and make them functionally as independent as possible. The following Model depicts the wide range of services ideally needed for persons with such disabilities. Some core services are essential and non negotiable, and some are meant for supporting accelerated development.

Figure 14.3 Support Services

It is worth mentioning that Special Olympics (for sports) Abilympics (for Vocational) and Very Special Arts (for Fine Arts) have made a huge impact, both nationally and internationally on the lives of persons with these four disabilities.

Role of Nutrition

There is growing recognition of the interface between nutrition and neuro-developmental disorders. Undoubtedly, access to good nutrition will greatly improve the functional outcomes of children with these disabilities, just as the outcome of pregnancy is much improved if proper attention is paid to the nutritional status of the mother, before, during and after the pregnancy.

Challenges Ahead

The disability sector has reached significant cross-roads. The future outcome will depend on how we face the following challenges :-

- Developing horizontal models of rehabilitation through convergence
- Enhancing national capacities in prevention and in neonatal screening
- Mobilizing information and communication channels
- Building partnerships and multisectoral linkages
- Mobilizing resources
- Enhancing managerial, analytical and technological capacities

- Increasing research and development activities.
- Developing code of ethics for caregivers and institutions
- Ensuring more community-specific curricula, ecological in approach
- Emphasizing more innovative teaching strategies
- Bringing about Systemic changes
- Concentrating on Pre-integration readiness of regular schools and work places
- Maintaining geographical equity in services and in funding
- Developing National policies which reflect the enormity of the neglect traditionally faced by this group
- Ensuring smooth transitions from school to work
- Promoting a Lead Free Environment (campaign against lead poisoning)
- Arranging for accessible transportation & public places

Future focus for Disabled Persons

Persons with disabilities & their families have the following specific needs that to be provided with a focused approach:

- Training in Rights and in leadership skills
- Forming Parents Associations in every district
- Understanding the principle of Autonomy and self determination
- Learning to live independently

Figure 14.4 The Medical Model of Disability

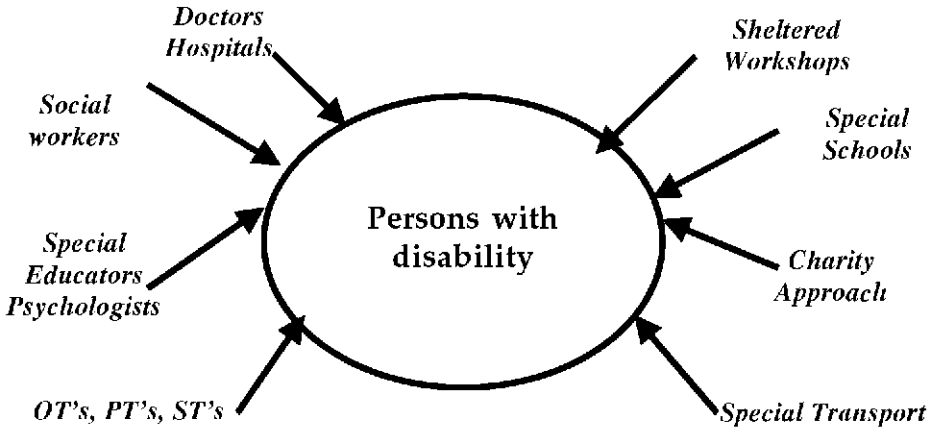


Figure 14.5 The Social Model of Disability

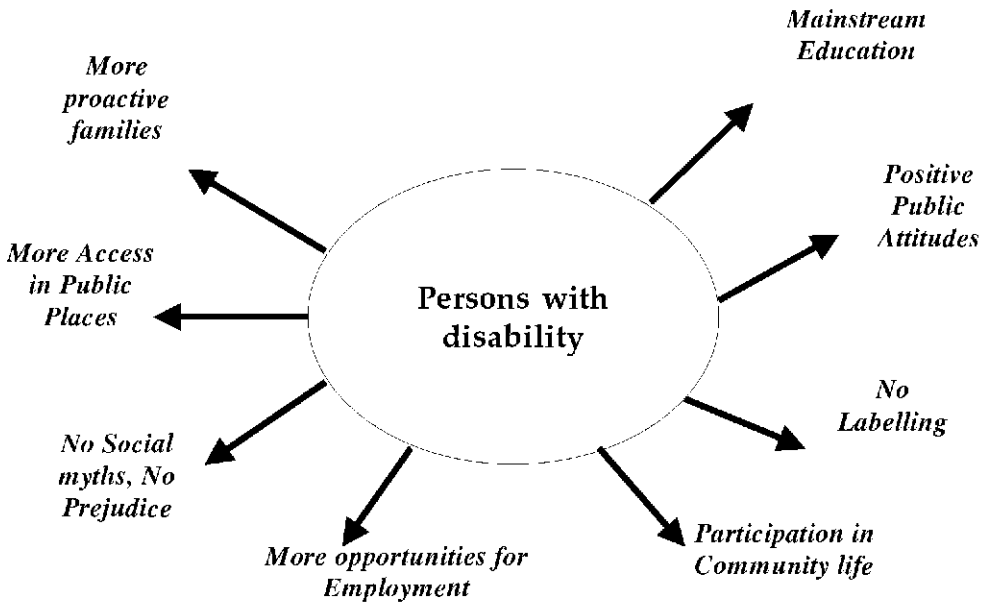


Table: 14.3 Differences between the medical and social models

THE MEDICAL MODEL	THE SOCIAL MODEL
<p>Child is faulty</p> <p>↓</p> <p>diagnosis</p> <p>↓</p> <p>labelling</p> <p>↓</p> <p>impairment becomes focus of attention</p> <p>↓</p> <p>assessment, monitoring, programmes of therapy imposed</p> <p>↓</p> <p>segregation and alternative services</p> <p>↓</p> <p>'ordinary' needs put on hold</p> <p>↙ ↘</p> <p>re-entry if 'normal' enough exclusion</p>	<p>Child is valued</p> <p>↓</p> <p>strengths and needs defined by self and others</p> <p>↓</p> <p>OUTCOME based programme designed</p> <p>↓</p> <p>resources made available to 'ordinary services'</p> <p>↓</p> <p>training for parents and professionals</p> <p>↓</p> <p>relationship nurtured</p> <p>↓</p> <p>DIVERSITY WELCOMED</p> <p>↓</p> <p>Society evolves</p>

Table: 14.4 Empowerment of the family & Responsibilities of Rehabilitation workers :

Expectations of family:	Responsibilities of Rehabilitation Workers
<p>To be the ultimate decision makers</p> <p>To utilize their own resources</p> <p>To receive information which will enable them to make the best decisions about effective care</p> <p>To define the priorities of intervention</p> <p>To choose the level and type of involvement and the level of support they require</p> <p>To receive services in a trouble free and timely manner ["No hassle"]</p> <p>To have access to information</p> <p>To maintain their dignity and integrity through the care-giving process</p> <p>To be supported in the decisions they make.</p> <p>To have their opinions asked for and listened to</p> <p>To receive individualized services</p>	<p>To encourage client decision making in partnership with other team members</p> <p>To assist families in identifying their strengths and building their own resources</p> <p>To inform, answer and advise families and to encourage informed choices.</p> <p>To work in partnership with families to identifying and prioritizing their own needs</p> <p>To collaborate with parents at all levels of care (individual child, program development, implementation and evaluation, policy formation)</p> <p>To share complete information in a continuous and accessible manner</p> <p>To respect values, wishes and priorities of the family</p> <p>To accept and support the decisions made by the families</p> <p>To listen</p> <p>To provide flexible and individualized care and services which can respond to changing needs</p> <p>To accept diversity among families : racial, linguistic, religious, cultural and socio-economical</p> <p>To believe and trust parents</p> <p>To communicate in a language understood by parents</p>

Facilitative Programmes

Some highlights of facilitative programmes for people with Mental Retardation, Cerebral Palsy, Multiple Disability and Autism are given below:

- The contribution of National Institute for the Mentally Handicapped, particularly in the area of HRD, Material Development, Parent Training, Development of models is quite significant.
- District Primary Education Programme – Integrated Education of the Disabled (DPEP-IED): Under this one programme alone 80,926 persons with mental retardation and 53,213 persons with Cerebral Palsy, Learning Disability and Multiple Disabilities have been enrolled in mainstream schools.
- Sarv Shikha Abhiyaan (SSA): In Gujarat alone, 10,000 persons with mental retardation are in regular schools.
- National Open School: Provides excellent opportunities for completing high school at the students' own pace.
- Indira Gandhi National Open University (IGNOU): Distance Learning is now helping those who wish to pursue short courses after schooling.
- The National Trust : Especially useful in developing rural institutions, & in local initiatives through Local Level Committees; some 3 lakh persons with these disabilities have benefited through convergence into SGSY, SGRY, IAY, Pradhanmantri's Antyojana, NOAPS, School and Balwadi inclusion, etc at the District Level. Legislation creates its own impact across the country. Through training of Caregivers scheme, Legal Guardianship, advocacy issues, and awareness generation at the district level, the very profile of these four disabilities has been raised significantly at various levels of civil society.
- United Nations Development Programme (UNDP) – UNDP funded Zero Rejection Project in UP and Karnataka for Support to Children with Disabilities. The objective of the project is to sensitize, mobilize and empower the community to participate in the local school management and ensure that every child with disability in the project area has access to education in an appropriate environment.
- National Handicapped Finance & Development Corporation (NHFDC) – Scheme for Parents and Legal Guardians of persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities, when fully utilized, will help several thousand persons

Voluntarism

India has a large potential for fostering genuine voluntarism especially in rural and remote areas where services and facilities are few and far between. With some baseline training, perhaps by distance mode, volunteers could fill the vacuum for neighbourhood caregiving.

Conclusion

Persons with Autism, cerebral Palsy, Mental Retardation and Multiple Disabilities should not become victims of our low expectations; at the same time, over expectations tend to cause frustration resulting from repeated failure – this may in turn lead to a permanent sense of inadequacy. The key therefore, is in making the most realistic assessments possible and pitching the goals one or two notches higher. But most of all, the challenge lies in creating pervasive attitudinal change in civil society so that the public's negative attitude does not become the disabled person's real handicap.

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Part Five
PUBLIC PRIVATE
PARTNERSHIP
AND RIGHTS
BASED PARADIGM

Chapter 15

Human Rights for persons with Disabilities

Anuradha Mohit

This paper attempts to discuss human rights of persons with disabilities who, temporarily or permanently, experience physical, intellectual or psychological impairment of varying degrees. Most often, their lives are handicapped by social, cultural and attitudinal barriers which hamper their full participation and enjoyment of equal rights and opportunities. Persons with disabilities have been viewed, as deserving pity and care, not as holders of rights, equal in dignity and freedom.

Introduction

It is estimated that there are about 600 million people in the world who have disability of one form or another. Over 2/3rds of them live in developing countries with high density of their population in Sub-Saharan Africa and in South and South-East Asia. There is wide variation in the estimated disability rates reported by the developed and developing countries. The variation depends, to a large extent, on the definitions of disability used, which either expand or limit the disability groups covered in the survey (Asia and the Pacific into the Twenty First Century, 2002). For example, the New Zealand's 1997 household survey yielded the average of 19.1 percent. In contrast, the 1991 National Sample Survey of India, covering four disabilities (visual, hearing, speech and locomotor), yielded a prevalence rate of 1.9 percent. In the same year, a separate sample survey brought forth 3 percent average of population with delayed mental development in the age group of 0 to 14 years. This brought the average population of persons with disabilities in India, China and Pakistan close to 5 percent in comparison to 19.1 percent in New Zealand and 18 percent in Australia (United Nations Statistics Division, 1996).

In a country like India, underreporting is also due to stigma attached to disability and the tendency to conceal it. Mild to moderate disabilities are not perceived disabling by the rural Indians, and hence are not reported. There are other problems, which contribute to poor reporting such as inadequately designed questionnaire and training imparted to enumerators.

Moreover disability is a relative term because different cultures define their norms of disability differently. The title "disability" conceals behind it a loosely connected heterogeneous group of many disabilities. For instance, being a woman, low caste, poor and ethnic minority are some commonly perceived disabilities and across the cultures, persons having physical or intellectual challenges are also considered disabled, though are rarely counted amongst those requiring protection against discrimination for equal enjoyment of rights and citizenship. Social values, norms and attitudes are not static and are liable to change, depending on a wide range of factors and forces that operate at macro and micro level. Consequently, the formal notion of disability undergoes revision to accommodate the change.

Evolution of Disability Policy in India

Ancient period

It is believed that in the prehistoric period the sick, aged and disabled were left to nature's mercy since survival of the fittest was the law practically in operation. There are references in ancient Tamil literature that children born with congenital defects and stillborn children were cut vertically into two with a sword and then buried (Ramanujam, 2000). With the exception of this Tamil tradition, we do not find any tangible instances of the inhuman practice of elimination of the disabled in India. It has been a part of India's cultural heritage to help the poor and the needy even at a great personal sacrifice. In keeping with this tradition, every possible protection was extended to the disabled by the family and the community to ensure survival atleast at a subsistence level. However, welfare measures provided in the ancient period did not guarantee same rights to the disabled members as were granted to others. For instance, about the right to property Manu says, "Eunuchs and outcastes, person born blind or deaf, the insane, idiots and the dumb, as well as those deficient in any organ (of action or sensation) shall receive no share." Similarly, the civil and criminal code laid down by Manu, *inter alia*, regards those deficient of organs and sense as not worthy of being held as witness. Such practices indicate that although the disabled were treated with pity and compassion in ancient India, their rights to social equality were not recognized (Murickan and Kutty, 1995).

Mahabharata

Dhritrashtra, the blind Kaurav king was not found worthy of throne due to his blindness. However, during his period the concept of welfare of the disadvantaged and vulnerable by the State had evolved to a certain extent. For instance, in the Mahabharata, Narad while interrogating Yuddhishtira, the eldest Pandav prince asks, "Do you treat as father, your subjects who are afflicted with, blindness, dumbness, lameness, deformity, friendlessness and those who have renounced the world?" The State was also expected to provide for the war-disabled and their dependents for Narad extends his dialogue with Yuddhishtira and further enquires, "Do you maintain the women of those who died for you or who have come to a sad plight while fighting for you in the battlefield?" (21) The epic

of Mahabharata reflects the State response to problems, which are now perceived individual issues requiring family support.

Maurya Period

The Maurya period marks a turning point in the perception of disabilities and the approach to deal with it. "This period, particularly the reign of Chandragupta, stands out unique in establishing workshops for the vocational rehabilitation of the physically disabled as well as other socially and economically handicapped members." Kautilya, the renowned political economist of the Maurya period lays down in Arthashastra "the king shall provide the orphans, the aged, the infirm, the afflicted and the helpless with maintenance." For their self reliance and economic independence Kautilya suggests awarding work on priority to women who are widowed, single, crippled and abandoned, retired for their subsistence. He also recommends earmarking certain jobs exclusively such as spinning, weaving, cutting of wool, cotton, fibre, hemp and flax for the disadvantage and vulnerable from a social and economic standpoint.

Emperor Ashoka had developed an elaborate public health system. It is recorded on its edicts that 'the king erected hospitals along all the highways and deputed physicians and made arrangements for medicines, food and drinking water. Gopas, the village animators were instituted to maintain record of birth, death, caste and also to provide for the ill, infirm and those in need of help. Actions of Emperor Ashoka were also inspired by Buddhist interpretation of state and society. The doctrine of Ahimsa manifested in higher acceptance of variation and the state became more tolerant to differences, which could be seen in the organization of social arrangement provided for the vulnerable and disadvantaged in that period.

Mughal Period

During the Mughal times, the institutions established for the welfare continued to thrive since Zakat (a system of charity) was strictly adhered to. In fact, the Mughals instituted a special department with a head (Sadr) to supervise charities and endowments. The public facilities in this period were open to all citizens regardless of caste and class. The Mughal Emperor Akbar took special care for maintaining social harmony and order.

Colonial Period

The safeguards, which existed in the old order, ceased to be effective during the British colonial rule, as the Government then had little regard for the well being of members of the annexed territories. In the absence of necessary social arrangements the problems of destitution, beggary, crime, and delinquency grew out of proportion. The theory of karma and fate further compounded the situation as disabilities were regarded as an outcome of one's sins and evil deeds of past lives. The indifference of the state and emergence of antiquated values defined new norms of disabilities causing stigmatization and acute isolation. The crumbling

of the old order and in the absence of new healthy substitutes, family became the primary social institution as an alternative to public arrangements for dealing with problems of disability.

The institutions, which the Imperial Government established for the care of the destitutes, beggars, and particularly the mentally ill persons offered asylum-like environment. Such an arrangement was enough to further alienate persons with disabilities. Asylum-like character of the new institutions unleashed in its wake the process of dehumanization of the PWDs. The Indian Lunacy Act of 1912 was established for the mentally retarded and mentally ill people. The Act allowed that any wandering or destitute person deemed of unsound mind could be relegated to an asylum by a magistrate, as could a convict who had become violent in prison (Culshaw, 1983).

Charity

The next phase of change came about with the introduction of special schools by Christian missionaries. The first school for hearing impaired persons was established in 1884 by the Roman Catholic missionaries at Mumbai. Likewise, Miss Annie Sharp started the first school for the blind in 1887 at Amritsar, Punjab. The school functioned in the premises belonging to the Church of England Missionary Society. Though sporadic yet a more rational approach to the education and rehabilitation of persons with disabilities once again surfaced on the socio-cultural map of India. Inspired by the missionaries, many philanthropic Indians too came forward to ameliorate the lot of neglected and destitute people including those with disabilities. The freedom struggle and parallel movements for social reforms led to conditions conducive to the multiplication of voluntary sector. As a result, nearly hundred special residential schools and training centres for PWDs came into existence which the post-independence State either took over or registered them under The Societies Registration Act, 1860.

Independent India

Preamble to Indian Constitution while giving a structure and philosophy of governance clearly lays down ".....secure to all its citizen; Justice, Social, economic and political; Liberty of thought, expression, belief, faith and worship; Equality of status and of opportunity; and to promote among them all Fraternity assuring the dignity of the individual and the unity and integrity of the Nation....."

Equality

Under right to equality, Constitution of India guarantees equality for all its citizens before law and equal protection of law (Article 14) and similarly, to afford real equality, prohibits discrimination on the grounds of "religion, race, caste, sex, place of birth or any of them"(Article 15 and 16). Further, to ensure equality in the outcome, the Constitution of India in Article 16(3 & 4) encourages the State ...to frame any law, make provision for the reservation of appointments or posts in favour of any backward class of citizens which, in the opinion of the State, is not adequately represented in the services...

There has been a mixed response to the concept of reservation in appointment to any public office. The judiciary had the occasion to examine not only the legality of such a concept but also its consistency with the right of equality. The most important judgment, which has set at rest, this controversy is the case titled *Indra Sawhney v. Union of India* 1992 Supp (3) SCC. This case is of particular relevance even from a disability stand point since the apex court also examined the legality of reservation in favour of the disabled who are not explicitly covered under Article 16 of the Constitution. The Court is of the view that "... mere formal declaration of the right would not make unequals equal. To enable all to compete with each other on equal plane, it is necessary to take positive measures to equip the disadvantaged and the handicapped to bring them to the level of the fortunate advantaged. Articles 14 and Article 16(1) no doubt would by themselves permit such positive measures in favour of the disadvantaged to make real the equality guaranteed by them.

Legislature as well as Indian judiciary has justified introduction of special measures to guarantee de facto equality. In *Dr. Jagdish Saran & Ors. Vs. Union of India*, Supreme Court cases 1980, 2 SCC 768, Justice Krishna Iyer held, that even apart from Article 15(3) and (4), equality is not degraded or neglected where special provisions are geared to the larger goal of the disabled getting over their disablement consistently with the general good and individual merit.

Discrimination

The formal recognition to discrimination on grounds of disability is a recent phenomenon and the laws enacted 20 years ago generally did not include disability in the list of prohibited heads of discrimination. For instance, the Indian Constitution in Article 15 and 16 prohibits discrimination in the matter of employment and access to public facilities on grounds of religion, race, caste, sex and place of birth, but is silent on disability. In fact the service rules until 1995 prevented entry of persons with disabilities in higher grades of service. The rule gave the employer authority to force premature retirement in public interest and often employees who acquire disability during service were either forced out of job or reduced in rank and their opportunity for career enhancement could be suspended forever.

It is worth noting that even in the absence of formal recognition of disability based discrimination, the Indian judiciary has been very forthright in setting aside discriminatory rules. For instance the rule prescribing physical fitness criteria for entry in the government service disqualified candidates on account of their disability. In the case of *Nandakumar Narayanarao Ghodmare vs. State of Maharashtra and Ors.* (1995 Vol.6, Supreme Court Cases 720), the candidate was rejected because of colour blindness. When it was pointed out to the Court that only 5 posts out of 35 posts required perfect vision, the Supreme Court directed the Government to consider the case of the appellant and to appoint him to any of the posts of the Agricultural Class II Service post, other than the posts which required perfect vision.

With the increased awareness regarding disability-based discrimination extra legal safeguards have now been provided in several jurisdictions. The Persons

with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 of India has an exclusive Chapter titled Non Discrimination. The provisions related to non discrimination in the Act actually builds on Article 15 and 16 of the Constitution. Section 45, 46 and 47 are so clearly stipulated leaving little room for ambiguity. As a result quasi judicial and judicial bodies have been able to very expeditiously dispose cases of discrimination. For instance the High Court of Delhi in *Rajbhir Singh vs. DTC*, 97 2002 DLT 19 Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 , Section 47 writ of certiorari, reinstated with full back wages and consequential benefits. The Court directed the respondent "to take petitioner back into service and pay salary from the date when the respondent stopped paying salary of termination of his service.

State Obligations

The Preamble, the Directive Principles of State Policy and the Fundamental Rights enshrined in the Constitution of India, envisage a very positive role for the State towards its disadvantaged citizens. Article 41 enjoins, "The State shall, within the limits of its economic capacity and development make effective provision for securing the right to work, to education and to public assistance in cases of unemployment, old age, sickness and disablement".

Despite such a progressive Constitution and judiciary the approach to disability has been motivated by charity. The Indian society view disability as an individual issue and treats it within the means available to a family. At the same time, a large section of Indian society living below the poverty line and the families in crisis has historically used the services of philanthropic and charitable institutions. Likewise, the Governments of independent India rely heavily on charitable NGOs for securing basic rights such as education, work, shelter, health and nutrition for persons with disabilities. As a consequence, the entire process of development surpassed people with disabilities.

A distinct Self advocacy movement of people with disabilities gained momentum during 1970's which started a sustained campaign demanding protection and recognition of their human rights. Towards this end, enactment of a comprehensive legislation having a rights based approach with special emphasis on social and economic rights was being advocated. Though the government recognized the need for such a legislation as early as in the year 1980 but, such a legislation could be enacted only in 1995. The delay could be attributed to the fact that the Indian Constitution while distributing legislative power between the centre and the State kept the disability issue in the State list at Entry 9 of Schedule 7. The Parliament of India gained competence to legislate on disability issues with the signing of the proclamation of equality and full participation of people with disabilities in Asian and Pacific region. Article 249 of the Constitution empowers the Parliament to legislate on any subject falling in any of the list in order to fulfill its international obligations.

15.2.11 National Trust Act, 1999

As certain groups among the disabled are more vulnerable than others therefore, an enactment for the protection of such persons, their property and well-being was felt necessary. The enactment of the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999, aims to fulfill a common demand of families seeking reliable arrangement for their severely disabled wards. The specific objectives of the Act are: -

- To enable and empower persons with disability to live as independently and as fully as possible within and as close to the community to which they belong.
- To promote measures for the care and protection of persons with disabilities in the event of death of their parent or guardian.
- To extend support to registered organizations to provide need based services during the period of crisis in the family of disabled covered under this Act.

The Trust Act mandates the creation of a Local Level Committee comprising District Magistrate along with one representative from a registered organization and one person with a disability. The Local Level Committee is vested with the authority to decide upon the applications of legal guardianship. The Act provides for the manner in which legal guardians are to be appointed. The conditions of eligibility, the order of eligible applicants, the disqualifications of applicants are contained in Regulations 11 to 14. The Act also lays down the duties of the guardian who has to furnish periodic returns to the LLC about the assets of the ward and their disposal in his hands. Similarly, the Committee too is required to maintain inventory and annual accounts of the property and assets, claims and liabilities submitted by the legal guardians to it.

The overall supervision of this Act is vested with a national trust board appointed through a democratic process by the registered organizations of the parents and others providing services to this segment of the disabled population. The Government has contributed Rs. 1 billion to the trust fund. The interest earned is used in supporting the mandated activities.

Mental Health Act, 1987

No doubt legislative action in the field of disability gained momentum in mid nineties, however, the enactment of the Mental Health Act of India, 1987 could be possible as the subject of health falls under the concurrent list in the Constitution; empowering both the Centre and the State to introduce any measures including the authority to legislate. The Mental Health Act can be described as a civil rights legislation with its focus at regulating standards in mental health institutions. There are serious question marks to the effectiveness of this Act in ensuring protection to his person, property and its management of persons covered. For instance until recently many mentally ill persons were consigned to jails and those living in mental health institutions were no better as the conditions

both in prisons and in mental institutions were far below the stipulated standards. In *Sheela Barse Vs. Union of India & Anr.* 1993 4 SC 204 a case of detention of non-criminal mentally ill persons in the jails of West Bengal. Their appalling conditions were noted by the Supreme Court, which observed that admission of non-criminal mentally ill persons to jails is illegal and unconstitutional.

Similarly, in *Chandan Kumar Banik - Vs - State of West Bengal*, 1995 Supp. [4] SC 505, the Supreme Court went into the inhuman conditions of the mentally ill persons in a Mental Hospital at Mankundu in the District of Hooghli. The Supreme Court deprecated and discontinued the practice of tying up with iron chains of patients who were unruly or not physically controllable and ordered drug treatment for these patients. The indifference of State and private authorities once again caused the tragic death of 26 inmates at Erwadi as they were tied to their beds on the night the fire broke out in August 2001. Following this tragedy the National Human Rights Commission of India advised all the Chief Ministers to submit a certificate stating "no persons with mental illness are kept chained in either Government or private institutions".

The Commission is mandated under section 12 of the Protection of Human Rights Act 1993 to visit the Government run Mental Hospitals to "study the living conditions of the inmates and make recommendations thereon". In 1997 Project Quality Assurance in Mental Health institutions was initiated to analyze the conditions generally prevailing in 37 Government run mental hospitals and departments. The findings of this study (1999) confirm that Mental Hospitals in India are still being managed and administered on the custodial model of care characterized by the prison like structures with high walls, watchtowers fenced wards and locked cells. Mental hospitals are like detention centres where persons with mental illness are kept caged in order to protect the society from the danger their existence poses.

The study further points out although the Mental Health Act has come into effect since 1987, admissions and discharges are still being governed by the Archaic and Inhuman provisions of the Indian Lunacy Act 1912. The project report says that in NIMHANS (Karnataka) "some referrals from the magistracy still come under the Indian Lunacy Act". Percentage of involuntary admissions is found to be very high and the provisions of section 19 permitting admission under certain special circumstances by a relative or a friend are being widely abused. The comprehensive findings of this study along with a set of detailed guidelines for quality assurance in mental health institutions are compiled in a report which has been circulated to all the Health Secretaries in the States. The NHRC right from its inception has proactively initiated several measures and has been appointed by the Supreme Court to supervise the functioning of a few mental health institutions.

Persons with Disabilities Act, 1995

The enactment of Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 is a signal achievement of the Indian disability movement. Preamble to this Act clearly delineates its objective of promoting and ensuring equality and full participation of persons with disabilities.

The Act aims to protect and promote economic and social rights of people with disabilities. The Act covers 7 disabilities. The criteria for classification of each category of disability embodied in the respective definitions of concerned disability group are medical and not based on social perception of disability.

The Act spells out the responsibilities of the various organs of the State and also provides policy guidelines. The Act lays down specific provisions for the development of services and programmes for equalizing the opportunity for the enjoyment of right to education, work, housing, mobility and public assistance in case of severe disability and unemployment. To execute the mandated responsibilities Central Coordination Committee and State Coordination Committees have been envisaged in a multi-sectoral mode representing major developmental ministries, members of parliament, disability NGOs and a woman with disability. To redress individual grievances and to provide safe guards to the rights of persons with disabilities, to monitor implementation of disabilities related laws, rules, regulations and to oversee utilization of budget allocated on disability the institution of Chief Commissioner in the Centre and Commissioner for persons with disabilities in the States have been provided. These quasi-judicial bodies are vested with the powers of a civil court. The wide-ranging provisions of this Act are compiled under 14 different chapters.

This historic legislation has been a corner stone of evolution of jurisprudence on the rights of persons with disabilities. As a result disability concerns have come into sharp focus. Within a period of 7 years of enforcement of this enactment its weaknesses have also surfaced in the absence of powerful implementing instrumentality. Unlike usual indifference the government soon realized these weaknesses and exceeded to the demand of disability movement for overall review of the Act. Towards this end a Committee was constituted which harmonized views of the disability sector and relevant bodies in its comprehensive report. Unfortunately, no concrete proposal has been moved to the Indian parliament for carrying out such amendments that have been felt necessary to plug the loop holes in the present Act.

RCI Act, 1992

The Rehabilitation Council of India was set up by the Government of India in 1986 initially as a society to regulate and standardize training policies and programmes in the field of rehabilitation of persons with disabilities. The need of minimum standards was felt urgent as majority of persons engaged in education, vocational training and counseling of persons with disabilities were not professionally qualified. Poor academic and training standards adversely affect the chance of disabled in the world of work. Therefore, an Act of Parliament in 1992 enhanced the status of the Council to a statutory body with an aim:

- 1) To standardize training courses for professionals dealing with people with disabilities.
- 2) To prescribe minimum standards of education and training of various categories of professionals dealing with people with disabilities
- 3) To regulate these standards in all training institutions uniformly throughout

the country.

- 4) To promote research in rehabilitation and special education.
- 5) To maintain Central Rehabilitation Register for registration of professionals.

The RCI regulates training standards for sixteen categories of rehab workers. The Council is proactively promoting training and research initiatives utilizing experience of specialized as well as mainstream academic institutions.

International Norms and Standards on Disability

In the 1970s, the evolution in thinking of disability issues at the United Nations manifested itself in a number of UN initiatives, which embraced the growing international concept of human rights of persons with disabilities and equalization of opportunities for them. For instance, in resolution 2856 (XXVI) of 20 December 1971, the General Assembly proclaimed the Declaration on the Rights of Mentally Retarded Persons. According to the declaration "the mentally retarded person should enjoy the same rights as other human beings, including the right to proper medical care, economic security, the right to training and rehabilitation, and the right to live with his own family or with foster parents. Furthermore, the Assembly declared that there should be proper legal safeguards to protect the mentally retarded person against every form of abuse if it should become necessary to restrict or deny his or her rights".

UN Declaration of 1975

In 1975, the General Assembly of the UN adopted the Declaration on the Rights of Disabled Persons, which proclaimed that "disabled persons have the same civil and political rights as other human beings." The Declaration states, "Disabled persons should receive equal treatment and services, which will enable them to develop their capabilities and skills to the maximum and will hasten the process of their social integration or reintegration". This Declaration is a comprehensive instrument with a clear focus on the rights of persons with disabilities. These Declarations have not been used enthusiastically by the disability movement in furthering their agenda perhaps due to non-binding character and inadequacies of content. For instance, Article 7 (Right to work) of the Declaration on the Rights of Disabled Persons imposes a limitation in the enjoyment of right by persons with disabilities by mentioning "according to their capabilities, to secure and retain employment or to engage in a useful, productive and remunerative occupation."

World Programme of Action, 1981

The world community observed 1981 as the International Year of the Disabled Persons. Its central theme was – "Full participation and equality". It set the trend of human rights in the disability arena, as the State was held responsible to guarantee enjoyment of full citizenship and fundamental rights by persons with disabilities. Subsequently, the UN General Assembly adopted the World Programme of Action, the most comprehensive global strategy which placed

'equalization of opportunities' as a central theme and as its guiding principle for the achievement of full participation of persons with disabilities in all aspects of social and economic life. To give recognition to economic, social and cultural rights of persons with disabilities the period 1983 –1993 was observed as the UN Decade of Disabled Persons. The Decade intensified debate on equal opportunities and non-discrimination. Recognition of the inherent equality of all human beings as well as the entitlement of each individual to all human rights forms the core of human rights law. In international human rights law, equality is founded upon two complementary principles: non-discrimination and reasonable differentiation. The principle of non-discrimination seeks to ensure that all persons can equally enjoy and exercise all their rights and freedoms. Discrimination occurs due to arbitrary denial of opportunities for equal participation. For example, when public facilities and services are set on standards out of the reach of persons with disabilities, it leads to exclusion and denial of rights. Equality not only implies preventing discrimination (example, the protection of individuals against unfavorable treatment by introducing anti-discrimination laws), but goes much beyond in remedying discrimination against groups suffering systematic discrimination in society. In concrete terms, it means embracing the notion of positive rights, affirmative action and reasonable accommodation.

UN Standard Rules, 1993

The UN Standard Rules on the Equalization of Opportunities for People with Disabilities, 1993 is an instrument based on the principle of material equality. The principle of 'equal rights' in the Standard Rules is described as implying "that the needs of each and every individual are of equal importance, that those needs must be made the basis for the planning of societies and that all resources must be employed in such a way as to ensure that every individual has equal opportunities for participation."

The UN Standard Rules, for their very nature, have been recognized as a human rights instrument. In the first operative paragraph of resolution 2000/51, the Human Rights Commission recognizes the UN Standard Rules as an evaluative instrument to be used to assess the degree of compliance with human rights standards concerning disabled people. The Commission recognizes that "any violation of the fundamental principle of equality or any discrimination or other negative differential treatment of persons with disabilities inconsistent with United Nations Standard Rules on the Equalization of Opportunities for Persons with Disabilities is an infringement of the human rights of persons with disabilities

The Standard Rules are classified into four parts. Part one - "Preconditions for equal participation" - consist of four rules. They state basic areas like the awareness-raising, medical care and treatment, rehabilitation and support services.

Part two - "Target areas for equal participation" - describes the responsibility of the society in eight main areas like accessibility, education, employment, income maintenance and social security.

Part three consists of ten comprehensive rules. Among those are information and research, policy-making and planning, legislation, co-ordination of work, the role of the disability organisations and personnel training.

Part four of the Standard Rules, lays down a mechanism for the monitoring. This is the unique feature in a non-binding instrument in the category of 'soft' law. The purpose of monitoring is to enhance the awareness and application of the Rules. The Special Rapporteur appointed by the UN is charged with the responsibility of monitoring the implementation by the States and to suggest measures for better implementation of the Rules.

Even if ten years have passed since the adoption of these Standard Rules by the UN General Assembly, their application in countries remains very different and uneven. In 1999, WHO (WHO/DAR) in consultation with UN Special Rapporteur on Disability and his panel of experts, developed a questionnaire based on which a study was carried out to assess application of Standard Rules particularly Rule 2 on medical care; Rule 3 on rehabilitation; Rule 4 on support services; and Rule 19 on Personnel training. According to the report on the analysis of the answers received from 104 countries "the application of Standard Rules requires strengthening in all the four areas of investigation."

Despouy Report, 1984

In August 1984, the Sub-Commission on Prevention of Discrimination and Protection of Minorities appointed a Special Rapporteur, Mr. Leandro Despouy, to conduct a comprehensive study on the relationship between human rights and disability. In his report (1993), Mr. Despouy made it clear that disability is a human rights concern, with which the UN monitoring bodies should be involved.

International Covenant on Economic, Social & Cultural Rights (ICESCR) 1994

The Committee on Economic, Social and Cultural Rights under International Covenant on Economic Social and Cultural Rights (ICESCR) in 1994 assumed the responsibility for disability rights by issuing a General Comment No 5, in which the Committee makes an analysis of disability as a human rights issue. The General Comment states: "The Covenant does not refer explicitly to persons with disabilities. Nevertheless, the Universal Declaration of Human Rights recognizes that all human beings are born free and equal in dignity and rights and, since the Covenant's provisions apply fully to all members of society, persons with disabilities are clearly entitled to the full range of rights recognized in the Covenant. Moreover, the requirement contained in Article 2 of the Covenant that the rights enunciated will be exercised without discrimination of any kind based on certain specified grounds or other status clearly applies to cover persons with disabilities".

International Covenant on Civil & Political Rights

The Quinn and Degener study on the use of human rights instruments in the context of International Covenant on Civil and Political Rights, suggests that out of 114 States party reports reviewed, 76 (67%) made some reference to disability. Other than addressing social welfare measures and equality laws, States party reports tend to refer to disabled persons in connection with civil commitment and the compulsory treatment of mentally ill or intellectually impaired persons.

The States parties with reference to disabled persons do not extensively cover treatment of disabled defendants and prisoners, voting rights, marriage and divorce laws, and immigration laws and bioethics issues. With the exception of the initial report of the Czech and the second periodic report of Ireland, which frankly acknowledge that State prisons are unable to accommodate disabled prisoners. Denmark reports that the state has established a training programme for police officers on how to deal with disabled prisoners. UK reports that a common standard of conduct has been laid down for all the staff working in prisons, which also refers to disabled inmates. These trends reflect greater respect for civil and political rights of persons with disabilities in a much broader context.

The various civil and political rights contained in the ICCPR can be classified under four broad categories: a) rights that refer to human existence b) liberty rights c) associational rights and d) political rights. All rights enshrined in this Covenant are of equal importance to PWDs. For instance, Article 14 and 15 recognize important rights in the context of criminal proceedings such as the right to a free hearing, including "to have a free assistance of an interpreter if he cannot understand or speak the language used in court." (Theresia, 2002). Freedom from slavery and servitude (Article 8) is an important right for disabled persons both within the special and the mainstream institutions. In many countries children and women are abducted, maimed and disabled to be used for beggary and as domestic and bonded labour. Violations of this nature are clearly covered by this Article. General Comment No 8 stresses that Article 9, paragraph 1 (the right to liberty and security of person): is applicable to all deprived of liberty, whether in criminal cases or in other cases such as, mental illness, vagrancy, drug addiction, immigration control etc. Article 25 of the aforesaid Covenant "establishes the right of everyone to take part in the conduct of public affairs, directly or through freely chosen representatives; to vote and be elected at periodic elections by universal suffrage; and to have access, on general terms of equality, to public service in his country". The norms laid down in the International Standards are predominantly protective in nature and do not exclude any individual or class of individuals. In General Comment No 8, the Committee on Human Rights establishes that physical disability can never be a legitimate ground for restricting the right to vote. Neither may any intellectual disability be considered a reason for denying a person the right to vote or to hold office. The Comment further states that persons assisting disabled voters must be neutral, their only task being to preserve the independence of the voter. The Comment highlights the importance of participation in the political process by persons with disabilities who constitute a sizeable minority but have been an insignificant political constituency due to unfavorable circumstances. From the approach adopted by the Treaty Monitoring body, it is evident that people may be different from a physical and intellectual standpoint but so far as their civil and political rights are concerned, all people are the same.

Convention on Rights of the Child

There's yet another important international instrument viz. Convention on Rights of the Child which establishes the rights of a disabled child to effective

access and reception of education, training, health care services, rehabilitation services, preparation for employment and recreation opportunities in a manner conducive to the child's achieving the fullest possible social integration and individual development, including his or her cultural and spiritual development (Article 23). In fact, this is the only instrument, which has comprehensive and exclusive provisions regarding rights of the disabled children although Article 2 of this Convention prohibits any discrimination in respect of the enjoyment of Convention rights on the ground of disability. In paragraph 2 of Article 23, States parties are encouraged and required to ensure assistance to children with disabilities who are eligible and who apply for such services. The Committee on the Rights of the Child has identified four general principles that should guide the implementation of all Convention rights: a) non-discrimination b) best interests of the child c) right to survival and development d) right to be heard and to participate. "The Committee on the Rights of the Child considers the self representation and full participation of children with disabilities as central to the fulfillment of their rights under the Convention. Article 12 may thus be viewed as the Convention's backbone. It encourages States parties to give a face to the invisible and a voice to the unheard, thereby enabling children with disabilities to enjoy a full and decent life in accordance with Article 23. Furthermore, the Committee has expressed its determination to do all it can to encourage governments to prioritize the rights of children with disabilities, and in line with Article 12 to ensure that disabled children participate in devising solutions to their problems." (Kilkelly, 2002) The CRC is unique in explicitly addressing the issue of disability, and it therefore has a great potential in advancing the rights of children with disabilities.

Convention against torture

The Convention (The Convention Against Torture and Other Cruel, Inhuman or Degrading Treatment or Punishment) is of particular relevance to millions of people with disabilities who are subjected to inhuman and degrading treatment in the institutions meant for their care and development. The imbalance of power is the root cause of such violations which happen due to poor supervision and arbitrary standards in the special institutions for persons with disabilities. Mental health institutions, homes for severely and multiply disabled are the breeding grounds of such unlawful practices. Torture has aroused profound concern in all quarters. Article 5 of the overarching Universal Declaration on Human Rights and Article 7 of ICCPR prevent inhuman and degrading treatment including medical treatment without the consent of the individual in question. The fact that the Convention only covers torture committed by or with the consent of public officials may be thought to limit its significance in the context of disability. Since increasingly, countries in the developing world and some in the developed are routing services through private voluntary organizations it becomes all the more necessary for the States to regulate standards and working of these institutions to check instances of abuse as States parties are under an obligation to prevent torture (Article 2). Persons with disabilities who are institutionalized rarely take recourse to legal remedies. It is mainly due to their total dependence

for survival on these institutions and State sponsored care providers. In this respect, the disability related discrimination is an outcome of inadequate regulations and indifference to the problems faced by the disabled. Article 4 of the Convention requires each State party to ensure that all acts of torture and criminal offences are covered under the domestic law and their record is maintained category wise. Reports should, therefore, provide detailed information on criminal laws that prohibit torture. Emphasis should be placed on their applicability to persons with disabilities.

Convention on the Elimination of all Forms of Discrimination against women

Convention on the Elimination of all Forms of Discrimination against Women (CEDAW) is a human rights treaty with the focus on women in general and marginalized and vulnerable women in particular. Recognizing that disability combined with gender stereotype cause multiple disadvantages, the Treaty Monitoring Body under this Convention adopted General Recommendation No 18, which urges State parties to include information on women with disabilities in their periodic reports with respect to their exercise of several rights contained in the Convention. This makes it amply clear that all provisions contained in this Convention are very much applicable to women with disabilities as they are for other women. The purpose of adopting a General Comment is to assist State parties in fulfilling their reporting obligations. The attention of the State parties through a General Comment is drawn to the insufficiencies and to the neglected areas. The Treaty Monitoring Body not only analyses the shortcomings in the report but also provides useful suggestions to stimulate appropriate response from the State parties. Most importantly, the General Comments offer authoritative interpretation of the Covenant and its application in domestic law.

ILO Discrimination (Employment & Occupation) Convention 1958

In addition to the UN human rights instruments, the International Labour Organization has developed a number of international instruments relevant to disability – including ILO Convention No. 159 concerning Vocational Rehabilitation and Employment of Disabled Persons, Convention No. 142 concerning Vocational Guidance and Vocational Training in the Development of Human Resources, Convention No. 168 concerning Employment Promotion and Protection against Unemployment, Convention No. 102 concerning Minimum Standards of Social Security, Convention No. 121 concerning Benefits in the Case of Employment Injury and related ILO instruments, such as the ILO Code of Practice on Managing Disability at the Workplace. Of particular note is the **Discrimination (Employment and Occupation) Convention 1958** (International Labour Organization Convention no.111) which defines “discrimination” as: *any distinction, exclusion or preference” Imade on any of the grounds specified in the Convention itself or specified by the State concerned” which has the effect of nullifying or impairing equality of opportunity or treatment in employment or occupation.* Distinctions in respect of any particular job, based on the inherent requirements of the job, do not constitute discrimination.³ The Convention also specifies, in Article 5, that special measures, including

affirmative action, for people with disabilities may be introduced without being prohibited as discrimination against other workers:

- Special measures of protection or assistance provided for in other Conventions or Recommendations adopted by the International Labour Conference shall not be deemed to be discrimination.
- Any Member may, after consultation with representative employers' and workers' organisations, where such exist, determine that other special measures designed to meet the particular requirements of persons who, for reasons such as sex, age, disablement, family responsibilities or social or cultural status, are generally recognized to require special protection or assistance, shall not be deemed to be discrimination.

Disability Convention

The UN General Assembly in its Resolution 56/168, 2001 recognizes that Governments, UN bodies and NGOs have not been successful in promoting full and effective participation and opportunities for persons with disabilities in economic, social, cultural and political life. Expressing deep concern "about the disadvantages faced by 600 million disabled around the world" the General Assembly passed a resolution to establish an Ad-hoc Committee to consider proposal for a comprehensive and integral international Convention taking into account the recommendations of the Commission for Human Rights and the Commission for Social Development.

While arguing for the Disability Convention, the Asian and Pacific forum of Human Rights institutions emphasizes that "a coherent and integrated human rights approach to disability cannot be developed under the present treaty system" and an exclusive Convention would give "status, authority and visibility" to disability in the human rights area which cannot be achieved through the process of reform of existing instruments and monitoring mechanisms. Adding a new treaty would also complement existing international standards for the rights of the disadvantaged. Favoring thematic treaty on disability rights Gerard Quinn states "It would make much more sense to encapsulate the relevant human rights standards in a single legal instrument. It would clarify State parties obligations and it would give disability NGOs a clear target – one that is dedicated to disability rights in a holistic sense. This, in turn, could potentially enable international law to accelerate positive developments within states."

In conclusion, international and domestic laws are a reliable vehicle that can aid transformation in material conditions and mental attitudes towards disabilities. The contemporary international law recognizes that all States have a duty under article 56 of the charter of the United Nations to ensure respect for and to observe human rights, including the incorporation of human rights standards in their

national legislation. The Constitution of India empowers the government to take measures necessary to honour India's commitment to any international treaty or agreement. In the last 10 years government has adopted special laws, policies and schemes which are briefly analyzed here.

International instruments, such as declarations, resolutions, principles, guidelines and rules, are not technically legally binding. They express generally-accepted principles and represent a moral and political commitment by States. They also can be used as guidelines for States in enacting legislation and formulating policies concerning persons with disabilities. General policy instruments, such as the outcome documents of world summits and conferences, are applicable to persons with disabilities. These instruments include, for example, the Copenhagen Declaration and Programme of Action adopted at the World Summit for Social Development (6-12 March 1995), and the Millennium Declaration and the Millennium Development Goals adopted at the United Nations Millennium Summit in September 2000.

Disability Specific non-binding International Instruments

Several disability-specific non-binding international instruments have been adopted at the international level. The instruments include:

- Declaration of the Rights of Mentally-Retarded Persons,
- Declaration on the Rights of Disabled Persons,
- World Programme of Action concerning Disabled Persons,
- Tallinn Guidelines for Action on Human Resources Development in the Field of Disability,
- Principles for the Protection of Persons with Mental Illness and the Improvement of Mental Health Care,
- Standard Rules on the Equalization of Opportunities for Persons with Disabilities,
- ILO Recommendation concerning Vocational Rehabilitation of the Disabled,
- ILO Recommendation concerning Vocational Rehabilitation and Employment (Disabled Persons),
- Sundberg Declaration on Actions and Strategies for Education, Prevention and Integration, adopted by the UNESCO World Conference on Actions and Strategies for Education, Prevention and Integration, Malaga (Spain), 2 - 7 November 1981,
- Salamanca Statement and Framework for Action on Special Needs Education, adopted by the UNESCO World Conference on Special Needs Education: Access and Quality, Salamanca (Spain), 7 - 10 June 1994 .

Asian and Pacific Decade 1993-2002

The Governments of the ESCAP region, proclaimed, the Asian and Pacific Decade of Disabled Persons, 1993-2002, by resolution 48/3 of 23 April 1992, at Beijing. The resolution was intended to strengthen regional cooperation in resolving issues affecting the achievement of the goals of the World Programme of Action concerning Disabled Persons, especially those concerning the full participation and equality of persons with disabilities. The Meeting held at Bangkok in June 1995 examined the progress made since the introduction of the Decade and adopted 73 targets and 78 recommendations concerning the implementation of the Agenda for Action, including the gender dimensions of implementation. Of the 12 policy areas under the Agenda for Action, ESCAP has focused its efforts on areas that were not covered by the mandates of other United Nations instruments and bodies. The policy areas include national coordination, legislation, information (in particular, disability statistics), accessibility, assistive devices and self-help organizations of disabled persons. A comparative advantage of the ESCAP disability programme was the development of active inter-divisional collaboration, including the ESCAP Human Settlements Section, in the promotion of non-handicapping environments; the Rural Development Section, in poverty alleviation among rural disabled persons; the General Transport, Coordination and Communications Section and the Tourism Unit, in the promotion of accessible public transport and the promotion of barrier-free tourism. However, despite the achievements of the Decade, persons with disabilities remain the single largest sector of those least-served and most discriminated against in almost all States in the region. Much remains to be done to ensure the full participation and equality of status for persons with disabilities. Therefore, the countries in the region have decided to launch a follow up decade 2002-2012, with an aim to create barrier-free rights based society. It is hoped that the extension of the Asian and Pacific Decade of Disabled Persons for another 10 years will complete the achievement of the Decade goal of full participation and equality of people with disabilities.

Biwako Millennium Framework 2003-2012

In May 2002, ESCAP adopted the resolution "Promoting an inclusive, barrier-free and rights-based society for people with disabilities in the Asian and Pacific region in the twenty-first century". The resolution also proclaimed the extension of the Asian and Pacific Decade of Disabled Persons, 1993-2002, for another decade, 2003-2012.

The "Biwako Millennium Framework" outlines issues, action plans and strategies. To achieve the goal, the framework identifies seven priority areas for action, in each of which critical issues and targets with specific time frames and actions follow. The seven priority areas include:

- (1) Self-help organizations of persons with disabilities
- (2) Women with disabilities
- (3) Early intervention and education
- (4) Training and employment, including self-employment

- (5) Access to built environment and public transport
- (6) Access to information and communication including ICT
- (7) Poverty alleviation through capacity building, social security and sustainable livelihood programme

The next decade will ensure the paradigm shift from a welfare approach to a rights-based approach to protect the civil, cultural, economic, political, and social rights of persons with disabilities.

Conclusion

To conclude, legislative initiatives in India gained momentum during last decade and the thrust of all these initiatives is on achieving equality of people with disabilities both by granting them basic socio economic rights as well as by taking various affirmative and special measures to achieve real equality. National Human Rights Commission has also started focusing on human rights issues of PWD by integrating their concerns into all aspects of its work. The Commission has outlined a broad policy approach and as prioritize 14 areas for intervention with the aim to remove structural inadequacies by encouraging disability inclusive laws, policies and programmes at all levels. Thus, India is now poised towards a legal framework which would provide adequate safeguards both procedural and substantive for the protection of full range of their human rights. International initiatives have a positive bearing on the legal protection India has afforded to its disabled citizen, vice versa it has a potential to contribute to the proposed binding convention on the theme of disability.

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The UN Standard Rules on the Equalization of Opportunities for People with Disabilities,
1993

Chapter 16

Public-Private Partnership

Nandini S Rawal

Cooperation and participation of civil society is one of the key elements for successful intervention in any social sector development programme. When it comes to ameliorating the conditions of the disadvantaged sections of the society such as persons with disabilities and more so when major number of such population live in rural areas it is almost not possible for any government agency to ensure optimum intervention without involvement of civil society. The author discusses the increasing importance of public-private partnership in this fast emerging right based approach, and increased Government commitments. Emphatic mantra of success today is that of colloboration, corporation network and partnership. Highlighting fruits of successful partnership between State Government and the NGO, she is involved in, the author gives a clarion call to both the governmental and non-governmental organisations to break walls and move collaborative efforts, an effective partnership for ensuring speedy empowerment of PWD.

Introduction

With the advent of the twenty-first century, walls have been broken, barriers between countries have crashed, markets have metamorphosed and technology has enabled information to be disseminated across the world within the blink of an eye. Traditional enemies are allies, competitors have merged and are happily working amicably together. The world has become smaller, thanks to an excellently planned and orchestrated technological network. This amazing network has enabled the free and unfettered flow of information.

If all these changes are taking place in the world, can the field of rehabilitation remain unaffected, untouched? From a veiled mystified, rigid rehabilitation field, we NGOs are today an open, vociferous, 'visible' animated and 'empowered' agent of development. The last decade has seen a revolutionary change in the field of disability in India

Deterrants in Public-Private Partnership

Traditionally, Indian society have developed different attributes for both private and public sectors while, private sectors are viewed as being flexible, open and lucrative. Public enterprises are seen as rigid, powerful, all encompassing

but not very effective. The debate of the pros and cons of each sector are many and varied. Basically, both sectors are different and in these differences lie their strengths. It is these differences that will help to complement one another and bring in synergistic returns in the event of an effective public-private partnership.

However, when there is talk of collaboration with someone or some organization that is different in terms of practice from one's own, there is an immediate resistance. Suddenly all our guards are up. Why then as rehabilitation organizations stand alone?

(i) Traditionally the field of rehabilitation has been dominated by NGOs. There are a large number of government organizations also which have emerged as large players. If one sees the dynamics, one will observe that organizations whether government or NGO, they rarely collaborate with one another. Organisations in the same city do not meet one another for any consultative inputs. Heads of organizations from the same organization, meet each other at national workshops or international consultations. Organisations generally feel very insecure about meeting and sharing with one another due to the spirit of competitiveness and existence.

The field of disability has become very sophisticated and technical over the past 30 years. Experience and expertise has been honed and perfected and many spheres of expertise have become the sole preserve of certain agencies whether government or NGOs. The areas of expertise are guarded jealously and zealously as if their monopoly will be shattered if they share their knowledge. The other logic is that we are not open minded enough to share. For e.g. certain agencies have developed check lists for intervention and assessment in duplication of efforts and reinventing of the wheel.

Certain fields of expertise become the Unique Selling Proposition (USP) of the agency i.e. the agency has a competitive advantage because of one of its unique characteristics. For e.g. a certain agency may have expertise in the assessment of persons with multiple disabilities. This assessment team becomes a USP of the organization. This makes some organizations reluctant to share their knowledge for fear of losing its rank if other people get the knowledge and the skills.

(iii) Apparently it is, sometimes lack of inter-agency faith that stops partnership efforts. Agencies are not sure or are wary of the outcomes of collaboration.

Partnership: Essence of Success

In this fast emerging scenario of rights based approach to rehabilitation and increased Government commitments coupled with IT revolution, today's mantra of success is that of collaboration, cooperation, networking and partnerships

Since the world came into being, partnerships have come into existence, starting with Adam and Eve- which resulted into the social custom of marriage – probably the longest surviving Partnership today.

This is a Partnership of sharing, love, and convenience but are professional partnerships different? Webster's Ninth New Collegiate Dictionary defines Partnerships as:

- a. Legal relationship between two or more persons contractually associated as Joint Principals in a business
- b. A relationship resembling a legal partnership and usually involving close cooperation between parties having specified and joints rights and responsibility.

The public and the private sectors by their very name are totally different in form, structure, operating style, resources and reach. A true marriage between these sectors would yield good results in the benefit of the disabled persons.

The resultant benefits include the following:

- duplication of resources would be avoided
- cost-effectiveness
- foster excellence
- help build capacities
- promote equality and access

Partnership Statement

Partnership is a relationship of substance between two or more organisations involving shared responsibilities in undertaking activities as mutually agreed upon. The Principles of Good Partnership Practice state:

- All partners should know what is involved
- All partners should be informed and continually updated
- Transparency in practice
- Openness of heart and mind
- Adherence to principles

Effective public private partnership support alone do not stand for funding. It stands for sharing of resources (Human & Material), sharing of expertise, empowerment of personnel, sharing of goodwill and mutual assistance in problem solving

Keys to successful partnership

- Identify & Quantify your needs: The best of partnerships can work if partners are aware of their needs properly. They need to be sure of the exact quantity and quality of the collaboration.
- Prepare your records: The partnership statement needs to have proper records in terms of expectations of both parties and responsibilities of each.
- Present your need with substantive data: The partners need to meet each other with substantive data about the extent of cooperation, involvement of personnel, risks foreseen, sharing of benefits etc.
- Acknowledge your partners: Partners need to acknowledge each others expertise, contribution and collaboration. This will lead to a healthy and open relationship.

- Maintain accountability & transparency: Partnerships will stand the test of time if partners are frank, open and transparent in their dealings. Any opaqueness in dealing will lead to mistrust and suspicion.
- Be courteous and prompt in reports: Partners need to follow etiquette and decorum in dealing with one another. They should try to see that no feathers are ruffled in the partnership.
- Publicize the cause: When both partners get together and publicize the benefits of their partnership, the field of rehabilitation will be benefited.

Public Private-Partnership strategies

Like the Global Programme for sight-the Vision 2020 Programme, the Indian Scenario should see the emergence of a well developed and well enunciated policy called "Partnership Pact for Progress". For this, we need to identify "Sensitive Companies & Training Institutes" which have a good business model, have strong performance cultures and aim for technology advantage. The organizations must address the future of rehabilitation in a pro-active manner and believe in the need for convergence and building up synergy through cooperation. The possible areas of collaboration between the Private and Public could be the following

- Human Resource Development
- Technology
- Manufacture of Rehabilitation Aids and Assistive Devices
- Prevention and Cure of preventable and curable disabilities
- Consumable materials for rehabilitation

The Key Players and Stakeholders in the Partnership

- Persons with Disability
- Rehabilitation Council of India, National Trust, Ministries
- Training & Educational Institutions
- Universities
- Rehab Professionals
- Corporates
- Government
- Other Partnering Organisations
- NGOs

Some examples of corporate sector partnerships may be funding HRD programmes recognized by RCI, financing research in the development of technology and dissemination of the same for the benefit of disabled, manufacture and distribute assistive devices at highly subsidized rates, through NGOs etc. Funding of preventive efforts through free supply of drugs by the pharmaceutical companies can be done. Consumable materials like Braille paper, tubes, pipes for wheelchairs could be organized by the industries.

Partnerships: An example

The Blind People's Association (BPA), the organization to which the author belongs has blazed a trail in forging partnerships with the Corporates on one hand and the Government Sector on the other, in areas such as, policy making, programme development, advocacy, awareness creation, service delivery and creation of equal opportunities for persons with disabilities.

- (i) **Spread of Integrated Education:** The Government of Gujarat funded a total of 2000 disabled children at a cost of Rs. 1.2 Crores. The BPA and the Governmental sat together and developed a plan for reaching out to 30,000 additional children, including teacher training, development of teaching learning material. The budget today stands at Rs. 12.5 Crore.
- **Ashtavakra Scheme of Community Based Rehabilitation:** The scheme of BPA for covering the 225 tehsils of Gujarat was approved by the Government at a total cost of Rs. 76 crore. The BPA is the nodal agency while the project is implemented by different local NGOs.
 - **Give Vision Everyday (GIVE) Initiative with Torrent Pharmaceuticals:** It is a joint initiative that BPA has with Torrent. Torrent has prepared publicity material on eye care and rehabilitation of the blind and donates 50 paise on every strip of "One-Up" tablets.
 - **ONGC's Employment Initiative:** ONGC was requested to help fund self employment ventures for the disabled. The BPA approached the Ahmedabad Municipal Corporation and requested it to reserve 100 spaces for the disabled. The ONGC has funded setting up of sales kiosks and telephone booths.
 - **Voice & Vision with NIMH and Hilton Perkins International Program:** The best experts in this field from the government and NGO sector got together with the financial patronage of the Hilton Perkins Program and the administrative backing of the NIMH. A wonderful source book for parents and practitioners has been published.
 - **Other initiatives:** It has coordinated with a number of agencies for employment of blind persons, meditation, free land, medicines, diagnostic services, computerized Braille press etc. It has effectively fostered partnership with a number of organizations including Handicap International, Sight Savers International, Christoffel Blindenmission, Die Johanniter, Helpage International, Healthlink Worldwide and International Council for Education of People with Visual Impairment(ICEVI) for promoting welfare of visually impaired.

Conclusion

In a nutshell, the prescription for Partnership for today is to assess requirements, identify players, put processes in place, move towards collaborative efforts, meet partners regularly, evaluate the partnerships for further strengthening and modify the same for mutual benefit. Successful partnership between the NGOs and corporate sector will not only help sensitize that segment of society towards the cause, but also attract material help for the welfare of persons with disabilities. Partnership with the Government is becoming an essential conditions for both parties to succeed. Neither the Government can succeed on a stand alone basis with its limited institutional infrastructure in achieving the objective of effective empowerment of persons with disabilities nor the NGOs can work to their fullest potential and build capacities and achieve new heights of success without partnership. With the Government agencies and Departments.

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Chapter 17

Future Challenges in Rehabilitation of Persons with Disabilities

H P S Ahluwalia

The author, in this chapter submits his own experience after getting injured in the war of 1965 and presents his view point. As regards the major challenges faced by the persons with disabilities and also the agencies involved in social economic rehabilitation efforts, the author contents education, vocational rehabilitation and employment accessibility and public awareness as the four major challenges that needs to be made for empowerment of persons with disabilities. It is stressed that accessibility of not only physical nature but also in terms of information and communication is required and there is a need to policy makers, planners, educationists, health professionals, medial professionals etc for removing the mental block and bringing in innovative measures for the benefit of disadvantaged sections of the society.

Introduction

In 1965 after climbing Mount Everest I was wounded in the Indo-Pak war in the month of September during the same year. My injury left me confined to a wheelchair. Nobody had any inkling about rehabilitation or treatment. It was a pathetic scenario. I was thus shunted from one hospital to other. This carried on for almost three years till I went to Stoke Mandeville Hospital, UK for my rehabilitation. It was the only institute meant for rehabilitation of the individuals union spinal injuries. It was at Stoke Mandeville that I learnt about the disability, its rehabilitation and challenges that one would have to face in the course of life. We have now come a long way and have certainly made good progress in the field of disability.

Disability has been in existence ever since the evolution of mankind. India having a large population of over one billion certainly has a large population of persons with disabilities. If we take a global perspective there are approximately 600 million persons having some disability or the other. 2/3rd of the population

with disabilities live in the developing countries and India has almost 8-10 percent of this global population with disabilities. Estimates of disabled population in India as a proportion to the total population varies from the latest official estimate of 2 percent to 10 percent. Government of India has several Acts, namely, Persons with Disabilities Act, (1995), Rehabilitation Council of India Act (1992), National Trust Act for Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities (1999) to safeguard the rights of persons with disabilities in the Country. In the last decade there has been a sea change in the policy approach of the government towards the cause of persons with disabilities.

During the last 50 years, the phenomenal developmental change is sweeping all nations extending from North to South and East to West. With these changes the very definition of the societal norms are in constant scrutiny and the concept of civil society is growing very strongly specifically among democratic countries. Civil Society and many non-profit groups are coming closer to be active partners in societal changes.

In the beginning of new millennium, United Nations made a developmental Millennium Declaration and stressed "The collective responsibility to offer the principles of human dignity, equality and equity at global level". In the South Asian region, the Biwako Declaration of 2003 endorses the same principle and philosophy wherein it envisages action points to have "an inclusive; barrier free and right based society". This is a clear expression of integrating all people including the disabled persons in the main stream of society.

The people with disability play an equal partner in the developmental process. In 1995, the Government of India brought out the Persons with Disabilities Act which clearly commits for equality between the non-disabled person and person with disabilities in all spheres of our social system. As India is progressing faster in all fronts leaving out people with disability is not only a moral question but also not an economically a viable concept. The people with disabilities have to get the participation necessary support and require to be fully integrated in the main stream of society/NGO. In any socio-economic with development, there are three partners – Government, Semi Government and Voluntary Organization. The word voluntary, a Latin word is derived from 'Voluntas' meaning there by, 'Will'. Therefore, the voluntary organizations are supposed to function with the support of their moral code. The role of NGOs has been well recognized by the United Nation and the Government of India.

The 20th century has witnessed a phenomenal growth in development of NGO sector especially in developing countries. India has the 2nd largest voluntary agencies after Brazil. Of the total NGOs working in India, 78.5% work in the social sector. In any developing country there has been always a shortage of resources. In that situation, it is the voluntary agency that can provide a great relief to the community. Besides, being non-profit organization and based on moralistic tradition, NGOs are working in many remote corners and sometimes, without any expectation for helping the disabled people. The 10th Plan document has emphasized that NGOs must be treated as equal partner with the Government. They play a complementary role and the Government should continuously interact so as to get the continuous feedback from grass root level. Role of NGOs for the

disabled is well established. Their service need to be respected and nurtured for promoting empowerment people with disabilities.

Socio-Economic Rehabilitation

In the final phase of rehabilitation, it is the economic rehabilitation, which is very vital for persons with disabilities to stand up as equal partner in the community. Despite much international and national legislation, policies and practices, situation in India is not satisfactory. One of the studies by an NGO has shown that less than 2% persons with disabilities are economically productive. This problem can be addressed in two ways – firstly, they must be provided with the necessary vocational skill through training and secondly, either they can be assisted for getting an employment in Government or Private sector or they have to be helped for self-employment generation. Decent vocation is the fundamental right of any human being, which guarantees equity, security and above all human dignity. Although Government of India has some programmes for vocational training and employment, more intensive effort is necessary to improve the scenario in the country.

When an individual is disabled due to certain diseases or accident, it is just not that the individual suffers but it is also the family members and friends who undergo serious disturbances. Unless we give a holistic look on the quantum of sufferings, we fail to recognize the need for rehabilitation for people with disability.

In designing any programme, related to welfare of persons with disabilities service delivery namely education, vocational training or vocational placement, family plays a central role. Thus inclusion of family members in any programme for the handicapped people will be a rewarding experience. This is all the more true in Indian society where human bondages among family members are deep and ties are strong . In Indian culture, an individual is not that important as the whole family, any major decision taken for an individual in many cases, comes from a collective decision. Therefore, is a need for inclusion of the family members such as parents of person with disability before designing any programme for person with disabilities.

Challenges

Education,

Vocational Rehabilitation & Employment,

Accessibility, and

Public awareness are the four major challenges face by a disabled person which are discussed below :

Education

As we all are aware, illiteracy even for non-disabled persons, poses a great challenge before the individual and the society. Literacy among persons with

disabilities is below the natural, average. Very few disabled persons have access to education through special schools, inclusive schools, open schools or any other alternate mode of education. As per our estimates, not more than 3,500 service centres are available for catering to the needs of persons with disabilities. Sarva Shiksha Abhiyan (SSA) launched by the Government, provides for education of children with disabilities in regular schools. The Free and Compulsory Education Bill is another attempt in this direction.

However, we have a long way to go before achieving the long cherished goal of Universalization of Education covering disadvantaged sections including persons with disabilities as trained teachers, resource persons and support services are lacking in regular schools. Therefore, there is a need to introduce pre-service and in-service training programmes on a massive scale. Preventive measures, early identification and pre-school education are other areas of concern which needs to be addressed on priority basis.

Some efforts have already been made in this direction by the Government. A number of schemes have been brought out which would provide direct benefit to children with disabilities like SSA and DPEP etc. But if we look closely at the ground realities, some children with disabilities are still reluctant to go to school inspite of all benefits and concessions given by the Government. Here we need to educate the parents about the importance of taking their child to school. Also, teachers are required to be sensitized to disability issues. A sensitization programme for in-house teachers working at all levels in Government, Private and Public schools was launched last year by the Government called the foundation course through Madhya Pradesh Bhoj Open University (MPBOU). This is a three months course started through distance cum face-to-face mode. Similarly, a course has been developed by RCI to sensitize the parents of the disabled children through Indira Gandhi National Open University (IGNOU). The Government has started B.Ed special education through Madhya Pradesh Bhoj (Open) University in 2000-01.

Vocational Rehabilitation and Employment

Self reliance comes through economic independence for which vocational and skill based education and training is a must. The Government of India through the Ministry of Labour has set up 17 Vocational Rehabilitation Centres (VRCs) for the persons with disabilities imparting training in various trades leading to gainful employment. The number of VRCs is too few considering the population of persons with disabilities. There is also a need to identify new trades and occupations for persons with different types of disabilities and the training thereof. The Persons with Disabilities Act provides three per cent reservation in against identified posts Government jobs for persons with disabilities. The Supreme Court of India has recently taken suo moto cognizance of media reports denying placement of persons with disabilities in Indian Administrative Services due to their disability, despite successfully passing the examination.

There is a need to create employment opportunities for the disabled in the private sector through some form of commitment. The rural artisans and craftsmen could also be trained to train, the persons with disabilities in the villages in respective skills for self employment. The National Handicapped Finance

Development Corporation (NHFDC) has several loan schemes for setting up of own businesses and small scale industries.

Accessibility

Access is a very wide concept. The term Access is not an act or state, but a liberty to enter, to approach, to communicate with and to participate or make use of physical, environmental and structural systems, processes etc. regardless of type and degree of disability, gender or age. Right to education, work, freedom of mobility of expression is of no relevance unless the points of entry to success, work place, sports and cultural arenas are made accessible. Accessibility of all these again depends on how the public transport is designed and managed. The same holds for public information which if not made accessible would result in people remaining ignorant despite all round progress in the society. In a nutshell, accessibility is the over riding concern for persons with disabilities all around the world.

For easy accessibility and mobility of persons with disability, barrier free environment is a must. Accessibility not only of physical nature but also in terms of information and communication is desired. The concept of accessibility as per the Biwako Millenium Declaration – information and communication technology plays a vital role. When India has been recognized globally as technology hub where Indians are moving extremely fast, it is vital that the interest of the persons with disabilities be safeguarded. I believe during the next 5 years Internet cafes will be available in the remote corners of the country. The time is right to emphasize that persons with disabilities also share the advantage of both information and communication technology. With the exploding Communication and Information Technology in the country, there is a lot of scope for persons with disabilities to overcome the barriers.

For free mobility and accessibility in buildings and public places, awareness is building up among the planners, policy makers, architects and others who matter. Guidelines have been framed for construction of buildings, public places and public transportation. Latest technology is being applied for the development of aids and appliances.

Public awareness

No matter whatever we do, a great deal of awareness building is required across the society for the fruits to reach the needy. Therefore, mass awareness programmes are required not only for the persons with disabilities and their family members about their rights, schemes, concessions and privileges but also among the general public about the strengths, abilities and potentials of persons with disabilities. There is a need to sensitize the people at the helm of affairs such as policy makers, planners, administrators, health professionals, educationists, architects, media professionals etc.

If we sum up these problems and challenges in the new millennium, we come to the conclusion that it is more of an attitudinal problem. We have to remove the mental block which exists at the level of policy making and laso

implementation level. This will be done by bringing innovative measures. With the concerted efforts of one and all, we may one day achieve the goal of Rehabilitation for all in the country.

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apex institution in the field of disability sector. He has served in reputed hospitals including PGIMER, Chandigarh and Sabdurjung Hospital, New Delhi. Before entering into the field of disability rehabilitation. He has been actively involved in managing indoor and outdoor patients with special interests in management of spinal cord injury, poliomyelitis, congenital anomalies and cerebral palsy patient. Dr. Kumar has experience of teaching postgraduate students in orthopaedics surgery and physical medicine and rehabilitation and students pursuing Bachelor Degree courses in the field of physiotherapy, occupational therapy, prosthetic and orthotic engineering. Address: Director, Pandit Deendayal Institute for the Physically Handicapped, 4, Vishnu Digamber Marg, New Delhi-110 002. Telephone: 011-23232403. email:diriph@reno2.nic.in

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Madan Mohan Jha, a joint secretary (on study leave) in the Ministry of Human Resource Development, Government of India has been researching on inclusive education with fieldwork in India. Mr. Jha was educated in a village school and has seen functioning of the Indian school system closely during his field postings as a member of the Indian Administrative Service, first as Deputy Commissioner/District Magistrate in the districts of Dhanbad, Ranchi and Saharas in Bihar/Jharkhand, then as Director of the UNICEF supported Bihar Education Project. His assignment as the joint secretary in the ministry of HRD, with responsibility for integrated and secondary education, provided him perspectives on policy as well as practice. He also participated in number of national and international workshops and seminars. He is presently pursuing his academic interest in the field of inclusive education in University of Oxford. Address: D-1/118, Satya Marg, Chanakyapuri, New Delhi-110021. Telephone: 00-91-11-24673428. email.

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Ms Anuradha Mohit, M.A., M. Phil., is Special Rapporteur in National Human Rights Commission, India. She has served as Deputy Chief Commissioner in the office of Chief Commissioner for persons with disabilities, Development Officer and Executive Director in the National Association for the Blind and lecturer. Ms Mohit, herself visually impaired since the age of ten, has been involved in advocacy and networking in various capacities as Chairperson, Convenor and member of various committees in the field of disability. Address: Sector-C, 3/3125, Vasant Kunj, New Delhi-110 070. Telephone:91-011-689 7845(Res), 91-011-613 0219(work). e-mail:anuradhamohit@yahoo.com

Dr. A. K. Mukherjee, presently working as the Director General in Indian Spinal Injuries Centre, New Delhi, is a former Director General of Health Services, Government of India; the Secretary General of Red Cross and the Chief of the Medical Council of India. He has been honored by the Indian Medical Association and various other voluntary organizations in the country and abroad. He has a book to his credit titled - Disability : A Continuing Challenge and has published more than 200 articles in various national and international journals. Address: Director General, Indian Spinal Injury Centre, Sector C, Basant Kunj, New Delhi.

Prof. Kailas Chandra Panda, b. May 1935, Cuttack, India was educated at Utkal University and Patna University in Experimental Psychology and obtained his Ph.D in Educational Psychology with Mental Retardation from Indiana University, Bloomington, USA in 1970. Dr. Panda worked as a Faculty in Psychology from 1960 and superannuated in 1995 as Principal of the Regional College of Education (NCERT), Bhubaneshwar. Dr. Panda is a well-known researcher in Educational Psychology, Disadvantaged Children, Education of Children with Special Needs, Teacher Education, Educational Measurements and Evaluation. His publications include over 200 articles in National and International Journals, Trends in Educational Psychology, Educational Research Methods, Mainstreaming-Social Processes; and Quality Control in Educational Research. Books cover - General Psychology, Child Development, Elements of Introduction, Education of Exceptional Children, Educational Psychology. He has been a member of several national bodies, Universities, UGC, NCERT and a standing Technical Expert of Rehabilitation Council of India. His biographies have been published in American Biographical Institute, Men of Advancement, Cambridge, International Directory of Psychologist, Netherlands, International who's who England; Reference Asia, Indian Yearbooks. Being arecephant of ICME, Dr. Panda has successfully guided over 45 candidates for Doctoral and Post Doctoral research in different areas of

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Dr. S. R. Shukla has a first Class Master's Degree in Psychology and has acquired a Doctoral Degree in Psychology. He has received professional training as Master in Education (Special Education) from University of Manchester, U. K. and studied programmes for the blind and the visually impaired in USA and Scandinavian countries. Dr. Shukla joined the field of disability-rehabilitation in the Ministry of Labour and Employment in 1976 and moved to the National Institute for the Visually handicapped as Assistant Director in 1984. He has been the Director of the Institute since 1997. He has a wide and distinguished research and administrative experience and has over hundred articles/papers/documents to his credit. Address: National Institute for the Visually Handicapped, 116, Rajpur Road, Dehradun-248001. Telephone:0135-2735353. email:nivh@sancharnet.in

Mrs. Sunita Singh M.Sc. is a member of Indian Forest Service (1987 Batch). She is the Project Director for District Rehabilitation Centre Scheme under Ministry of Social Justice and Employment, Government of India and is responsible for the implementation of various programmes related to disability and awareness generation. She has held various positions in different forest divisions. She has attended several workshops at national and international level, published a paper and has received the State Gold medal for best Forest Management in the year

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Shri C.S. Mohapatra, M.Sc(Economics), London School of Economics and Political Science, UK and M.A.(Analytical & Applied Economics), Utkal University is a member of Indian Economic Service (IES) of 1986 batch. As Director in Disabilities Division of Ministry of Social Justice and Empowerment, Government of India, he has contributed significantly to the institution building and decentralization efforts of the Government for empowerment of persons with disabilities. He has wide experience in the fields of agricultural price policy, planning & policy formulation with focus on social sector issues including disability concerns and has contributed papers in national and international workshops/ seminars. Shri Mohapatra has exposure to rural lending as an officer in a nationalized bank. He has a flair of writing and is the founder member of Sandhyatara Sahitya Sansad, a two and half decade old literary organization in Orissa. As Chairman of the Expert Committee on Exemptions and Concessions relating to Central Excise and Customs duties available to the persons with disabilities and institutions for their welfare, he has submitted a number of recommendations for additional concessions/ exemptions as also simplifications of procedures to the Government. Shri Mohapatra, as a member of the high level delegation to the UN-ESCAP Inter Governmental Meeting at Otsu, Japan in October 2003 was involved in drafting and finalization of the Biwako Millennium Framework Document for Action 2003-2012. Address: Director, Ministry of Social Justice and Empowerment, Government. of India, Shastri Bhawan, New Delhi-110 001. email:mohapatra_cs@hotmail.com.

Ms. Aasha Kapur Mehta is a Professor of Economics at the Indian Institute of Public Administration and leads the Chronic Poverty Research Centre, UK work in India. She has been a Fulbright scholar and Mc Namara fellow. Her area of research now entirely is focused on poverty reduction and equity related issue.

Workshop Schedule

Workshop on Disability Management in India -
Challenges and Perspectives

(4-5 March 2004)

Venue: IIPA Conference Hall, New Delhi

4th March 2004 (1st session):

9.30 a.m. to 10.00 a.m.	Registration	Dr. R.K. Hora. Officer Incharge
10.00 a.m. to 10.30 a.m.	Welcome Address Inaugural Address	Dr. L. Govinda Rao / Shri C.S. Mohapatra 1) Dr. P. L Sanjeev Reddy, Director, IIPA
10.30 a.m. to 10.45 a.m.	Tea Presentations and discussions	Dr. Uma Tuli Chief Commissioner for Persons with Disabilities- in Chair
10.45 a.m. to 11.15 a.m.	Introduction	Smt. Rajwant Sandhu
11.15 a.m. to 11.45 a.m.	Inclusive Education and the Common School in India	Shri Madan Mohan Jha
11.45 a.m. to 12.15 p.m.	Information and Communication Technology for persons with disabilities	Dipendra Manocha
12.15 p.m. to 1.00 p.m.	Discussion	

4th March 2004 (2nd Session)

	Presentation and discussion	Major H.P.S. Ahluwalia Chairman, Rehabilitation Council of India - in Chair
2.15 p.m. to 3.00 p.m.	BIWAKO Millennium Framework for Action- A Guide for future	Dr. L. Govinda Rao
3.00 p.m. to 3.30 p.m.	Accessibility issues	Smt. Sunita singh
3.30 p.m. to 4.00 p.m.	Discussion	
4.00 p.m. to 4.15 p.m.	Tea Presentation and discussion	Smt. Aloka Guha Chairperson, National Trust
4.15 p.m. to 4.45 p.m.	Management of persons with Cerebral Palsy, Autism, Mental Retardation and Multiple Disabilities	Smt. Aloka Guha
4.45 p.m. to 5.00 p.m.	Social Security for persons with disabilities	Shri P. Madhava Rao*
5.00 p.m. to 5.30 p.m.	Discussion	

* Paper presented by Ms. Jahnvi

5th March 2004 (1st session):

	Presentation and discussion	Smt Rajwant Sandhu, Joint Secretary, Ministry of Social Justice and Empowerment-in Chair
10.00 a.m. to 10.30 a.m.	Public - Private Partnership	Ms. Nandini Rawal
10.30 a.m. to 11.00 a.m.	Poverty and Disability in India	Shri C.S. Mohapatra
11.00 a.m. to 11.30 a.m.	Future challenges in Rehabilitation of person with disabilities	Maj. H.P.S. Ahluwalia *
11.30 a.m. to 11.45 a.m.	Tea	
11.45 a.m. to 12.15 p.m.	Sustainable Strategy for Disability Management - Locomotor Disability	Dr. Ratnesh Kumar and Dr. A.K. Mukherjee
12.15 p.m. to 1.00 p.m.	Discussion	

5th March 2004 (2nd Session) :

	Presentation and discussion	Shri B.S. Baswan, Secretary Ministry of Social Justice and Empowerment - in Chair
1.45 p.m. to 2.15 p.m.	Sustainable Strategy for Disability Management - Visual Disability	Dr. S.R. Shukla and Shri A.K. Mittal
2.15 p.m. to 2.45 p.m.	Sustainable Strategy for Disability Management - Hearing Disability	Shri. R. Rangasayee
2.45 p.m. to 3.15 p.m.	Sustainable Strategy for Disability Management - Mental Retardation	Dr. L. Govinda Rao and Shri T.C. Sivakumar
3.15 p.m. to 3.45 p.m.	Employment of Persons with Disabilities : A Futuristic View	Shri C.S. Mohapatra Shri Bhushan Punani
3.45 p.m. to 4.00 p.m.	Tea	
4.00 p.m. to 4.30 p.m.	Discussion	
4.30 p.m. to 5.30 p.m.	Summing up	Prof. Aasha Kapur Mehta Dr. P. L. Sanjeev Reddy, Director, IIPA - in Chair
	Valedictory Address	Shri B.S. Baswan, Secretary Ministry of Social Justice and Empowerment

*Paper presented by Shri S.K. Mishra

Workshop Summary

Aasha Kapur Mehta

The workshop was flagged off by Dr. P.L. Sanjeev Reddy, Director, Indian Institute of Public Administration with his inspiring, thought proving and insightful inaugural address, after two days of intense discussions on various emergent issues confronting the disability sector on the basis of paper presentations by eminent experts in the field, sustainable strategies for disability management were chalked out during the closing session of the workshop. It attracted active participation from senior bureaucrats, NGOs, experts and academicians. The workshop ended with the useful suggestions given by Shri B.S.Baswan, Secretary, Ministry of Social Justice and Empowerment during his valedictory address. Each paper presented during the two-day workshop had a number of suggestions and commendations in the relevant areas covered. The highlights of the discussions are presented in brief here under:-

1. National Sample Survey has released very valuable data on disability earlier this year and this will serve as a useful base for planning the delivery of services to persons with disability. Data based on National Sample Survey 58th Round estimates show that 1.85 crore persons i.e. 1.8percent of India's population is disabled. The highest incidence is of locomotor disability followed by hearing, speech and visual disability.
2. Spatially, the incidence of disability is highest in Andhra Pradesh, Kerala, Himachal Pradesh, Maharashtra and Haryana. 84 percent of those over 60 and those with mental retardation and 82 percent of those with speech disability were born with it. Most of the other types of disability were acquired later in life. 13 percent of the disabled persons cannot take care of themselves even with aid/appliance. 17percent of disabled can take care of self with aid/appliance. 55 percent of disabled persons are illiterate. 73percent

of the disabled persons were out of the labour force. 67percent of the blind became so after reaching 60 years of age. Analysis of data with regard to what caused the disability, the age of onset, spatial spread and other dimensions that the NSSO data - 2002 reveals, can help in planning of appropriate medical and rehabilitation interventions.

3. There is increased incidence of disability among older persons. This is both due to an increase in longevity and a decrease in incidence of disabilities among younger persons because of access to better health services. For example, there is decrease in demand for calipers in small sizes due to reduced incidence of polio among young children. 49.91 lakh children (0-18 years) are found disabled. Among the many issues raised was the importance of ensuring that all children do attend school. This raises issues of integration based on barrier free access to buildings and need for devices and appropriate transportation. There is also need for training of teachers so that education providers understand the needs of disabled children. Vocational training should be linked to jobs available in industry and business. The importance of community support and of universal design for buildings are among the many issues that have been highlighted in the papers.
4. In the context of education, inclusive education and common schools for all children were stressed. We have massive growth of private schools as against many government schools of low quality and this is leading to the creation of educational haves and have-nots. Instead of considering the child as the problem and identifying attributes such as dyslexic, slow learner, in a wheel chair, unable to read/write etc., we need to change our perspective and use of language and treat the environment/school/lack of access as the problem and see the value in the child as is. So, if the child is impaired, the teacher and the classmates need to know how to reach out to this child to 'include' him or her. Hence, there is need to provide training to pre-school and school staff.
5. It was pointed out that
 - All Public Health Centers (PHCs) and sub-centers need to be strengthened with early intervention services as maximum help can be provided at the earliest.
 - Include special education as a compulsory subject in both theory and practical courses in teacher training programmes.
 - Engineer a shift from traditional items like candle making to demand based non-traditional items for vocational training.
 - Introduce vocational training to adults with disabilities in all technical institutes in India.
 - Provide access to built environments and public transport - not just in railways but also buses, roads all places of public utilities including Cinema Halls and Hotels.

- Safe mobility, uncluttered spaces and underground cables, allow independent movement at affordable prices. Universal designs need a little thought and add not more than 0.5percent to 1percent to the aggregate expense. For example round door-knobs rather than levers provide better grip. If a person has hearing impairment then blinking signals for room bell are helpful. Other examples are visual systems, appropriate signage and kerb ramps. Currently, in Delhi, airports and the metro are accessible but most other places are not. Progress is slow and construction is faulty.
 - Creation of awareness among policy makers, engineers, architects and local bodies is important and building bye-laws need to be modified to include universal access and barrier free environment.
 - Research and Development for cost effective solutions is required as is commercial linkage for products developed through R and D. Gaps between research and manufacture require bridging.
 - Government should develop common standards for all cities and ensure that these are followed.
 - Infrastructure that is created must be maintained.
 - Skill impartation is important in regaining livelihood.
6. In the context of providing access to information to the disabled persons, it was pointed out that today the prime medium for storage and distribution of text, audio, video or picture is through use of digital technologies. DAISY standards or digitally accessible information system create one source document in html e-text format and based on this, the material can be provided as audio, Braille, large print or e-textbook in minutes.
 7. It is important that a repository library be created from which materials can be accessed on demand. Information failure needs to be corrected. IT can help with development of speech synthesizers. India lags behind in development of mobility enhancing battery operated wheel chairs and joy sticks.
 8. It was pointed out that a management continuum comprising all the following is needed in the context of disability.
 - i) Monitoring of high risk pregnancies
 - ii) New born screening for early detection
 - iii) Guidance for families
 - iv) Early referral
 - v) Issue of ID cards
 - vi) Education in inclusive schools, integrated schools, special schools
 - vii) Non-handicapping environments
 - viii) Vocational and job training

- ix) Suitable employment - sheltered workshop, open employment, self employment
 - x) Social inclusion - community living, family life, self help group
 - xi) Provision of access to government benefits, social security, its awareness
 - xii) Hostel facilities
9. Both core services such as special education, speech therapy, medical intervention and support services such as yoga, sports, music, hobbies, hydrotherapy, etc. need to be provided.
 10. There has been evolution in our understanding of rehabilitation as we move from inter disciplinary teams to multi disciplinary, to trans disciplinary methods. Trans disciplinary methods require that one case worker takes input on the client from all departments and then trains the person.
 11. It needs to be noted that through rehabilitation, 81,000 persons with Mental Retardation are in mainstream schools. The National Open School provides opportunities for completing high school at a person's own pace.
 12. We need to build on the attributes of the government, PSUs, corporate sector, NGOs, international agencies and communities and collaborate, cooperate, network and partner with all key stakeholders. This includes persons with disability, RCI, National Trust, Ministries, Training and educational institutions and universities, rehabilitation professionals, corporates, NGOs and communities. For example, BPA has forged partnerships in Gujarat. Government of Gujarat funded 2000 disabled children at a cost of Rs.1.2 crores. BPA and government together reached out to 30,000 additional children and provided teacher training and learning material and the budget is now 12.5 crores. It approached ONGC and Ahmedabad Municipal Corporation for funding the setting up of spaces for kiosks and phone booths that would provide self-employment for 100 disabled people. The potential from networking is enormous and none of us can get very far by walking alone.
 13. Study showed that 52 percent of those who accessed the Government Institutions/ centers were poor, 55percent were rural based, and their average family size was 6. Locomotor disability is the highest among the different types of disability. Males dominated among those using the centers. 71 percent of those using rehabilitation services were males. Among older persons, only males were accessing services. NSS data shows literacy for disabled persons in India was 60percent in urban and 41percent in rural areas. 81.5percent of those accessing rehabilitation centers were literate, because illiteracy decreases access or literacy is one of the factors for gaining access to rehabilitation centers. This is an important issue and needs to be flagged.
 14. 50 percent of those accessing services were disabled since birth. Accidents and lack of treatment or timely detection were the most often cited reasons for acquiring the disability especially by the poor. 72percent of respondents felt that timely treatment would have decreased the extent of disability. 22per-

cent cited malnutrition as a reason for disability. There are close linkages between poverty and disability. Costs have been estimated and it is only logical that any impairment leads to additional costs. So if a person is poor and is disabled he or she is much worse off as compared with a person who is only poor. Expenses are incurred on purchase of aids and appliances, travel, fitting cost, preparation of documents, recurring cost of repair of aids/appliances, etc. It is important to note that social sectors schemes are the first to be hit when there is a fiscal crunch.

15. Other issues that were highlighted in the workshop include the need for improved coverage of women and the need for Ministry of Rural Development/ Planning Commission to have a higher poverty line for the disabled persons. In view of the linkages between poverty and disability and the increased disparities in access to resources, voice, information and networks faced by the poor, and even more so the disabled poor, policy for the impaired needs to be evaluated from a poverty sensitive lens and in 'reach out' mode. Instead of an 'we are here to serve you if you choose to come to us', our mindset should be, 'to be able to look ourselves in the eye without feeling guilty for having created such unequal and inaccessible systems', and we need to reach out to those who have equal rights on public resources as we do and rather more urgently than we do.

Names and Addresses of Workshop Participants

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<i>Shri B.S. Baswan</i>	<i>Secretary, Ministry of Social Justice and Empowerment, Shastri Bhawan, New Delhi</i>

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About the book : There has been a phenomenal rise in institutional infrastructure and reaffirmation of the commitment to the cause of promoting empowerment of persons with disabilities since the early nineties. This has raised the expectations of persons with disabilities from Government and society. The Biwako Millennium Framework for Action (2003-2012) coupled with the NSSO (2002) data that shows the magnitude and dimensions of disability status in India, have generated a surging need to deliberate on major emergent issues confronting the sector under the changed paradigm. This book contains a rich collection of papers contributed by eminent experts in the field of disability. It gives a comprehensive overview of the challenges faced in disability rehabilitation and management in case of each major area of disability and delineates sustainable strategies for facing those. Written and presented in a coherent and lucid style, the book engages the reader to the issues, policy implications and strategic interventions needed for effective and speedy empowerment of the persons with disabilities. This book educates and sensitizes the reader towards the cause and the rights of the disabled persons and will be valuable for students of rehabilitation, NGOs, bureaucrats and concerned citizens. The professionals and planners may find it interesting to look at the policy suggestions given against emergent issues confronting lives of this disadvantaged section of society.

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