

# Health for Persons with Disabilities in India

**Base Line Report**  
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# Contents

<b>ABOUT THE BASE LINE STUDY .....</b>	<b>2</b>
<b>INTRODUCTION .....</b>	<b>4</b>
<b>1. GOVERNMENT MACHINERY, STRUCTURE AND ROLE .....</b>	<b>5</b>
<b>2. CURRENT SCENARIO .....</b>	<b>7</b>
2.1. PREVENTION OF IMPAIRMENTS .....	7
2.2. MENTAL HEALTH .....	10
2.3. REHABILITATION .....	14
2.4. DISABILITY CERTIFICATES .....	17
2.5. AIDS AND APPLIANCES .....	19
2.6. HEALTH INSURANCE .....	20
2.7. ACCESS TO HEALTH .....	21
2.8. PERSONAL ASSISTANCE/CARE GIVER SERVICE .....	24
2.9. WOMEN WITH DISABILITY .....	24
2.10.HIV/AIDS .....	25
<b>3. BUDGET ANALYSIS .....</b>	<b>27</b>
<b>4. RECOMMENDATIONS .....</b>	<b>29</b>
<b>REFERENCES .....</b>	<b>29</b>
<b>LIST OF ABBREVIATIONS .....</b>	<b>33</b>
<b>ANNEXURE .....</b>	<b>34</b>

# About the Base Line Study

**The aim of the Study was to understand the current scenario vis-à-vis 'Health for People with Disabilities in India'.**

## **Specific Objectives of the Study**

- To study the existing Health Policies/Programmes/Schemes which could and should effect the lives of people with disabilities.
- To study the reach of these Schemes and to analyse their impact with respect to the actual needs of people with disabilities.
- To study the relevant budget allocations and their utilisation especially in relation to people with disabilities.
- To list out emerging concerns and basic recommendations for further discussion/analysis by the subject experts and policy makers.

## **Methodology**

In order to understand the current status and prepare a base line report, the following methodology was followed:

- Listing of all concerned Ministries and then narrowing it down to a few most relevant Ministries.
- Studying the Programmes and Schemes of the short-listed Ministries from their Annual Reports (2007-2008), websites, advertisements in newspapers.
- Studying any other relevant document/ report/ paper prepared by Government/NGO/Individual.
- Extracting the relevant portions from the Eleventh Five Year Plan, Persons with Disabilities Act, 1995 and the UN Convention on the Rights of Persons with Disabilities.
- Taking relevant information from newspaper articles/websites that highlight the needs and concerns of disabled people vis-à-vis health.
- Taking into account the views of some people working in the field of 'Health' through telephonic discussion or e-mail to get a better understanding of the ground realities.

## **Scope and Limitations of the Study**

The Report attempts to provide basic information on the status of health services for disabled people in the country as per the efforts of the Central Government, based mainly on the information available in the Annual Report of Ministry of Health & Family Welfare (2007-2008). Some relevant portions have been taken from Ministry of Social Justice & Empowerment, Ministry of Women & Child Welfare and the National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disability. The Annual Report of the Office of Chief Commissioner for People with Disabilities was not available at the time of writing this Report (January 2009). Hence, we could not study the initiatives undertaken by them. Health is a vast issue and a neglected issue in our country. Each of the health aspect mentioned in the report requires a detailed study. Due to limitation of time and resources, we have restricted the scope of the Report to just flag the various issues/concerns, which can form the basis for any further study. The Report is focused on Central Government initiatives. Studying State level initiatives/issues were out of the scope of this Report.

### **The Research Team**

The Research Team for the project comprised of Rama Chari, Sakshi Broota, Shilpaa Anand and Priya Varadan.

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# Introduction

Health of people with disability is a neglected issue in our country.

It is an established fact that people with disabilities use public health services more than people without disabilities. Right from the time of the birth of a disabled child or from the day a person suspects impairment, she/he visits hospitals and clinics numerous times for diagnosis, treatment, rehabilitation, second opinion, etc. Moreover, many people with disability need to take care of secondary conditions, like pressure sores, fatigue, pain, etc. for which they need medical help.

Persons with disabilities make up nearly 15-20%<sup>1</sup> of poor in developing countries. Disability, poverty and poor health are inter-related. Poverty leads to poor nutrition, lack of access to health, unhealthy and unsafe living and working conditions, which can lead to impairments and disease. After the onset of a disability, barriers to health facilities, education, employment, and other aspects can trap people in a cycle of poverty. Many a times, the health of caretaker in the family too becomes an added concern, but is often neglected. Family resources get depleted as parents move from one hospital / doctor / 'tantrik' to another, in search of a cure, treatment or rehabilitation for their disabled child.

There is a huge gap in terms of health services available for disabled and non-disabled people in the country. Issues vary from inaccessible buildings and diagnostic equipments, negative/stereotypical attitude of health professionals or their ignorance, lack of training to communicate with people with hearing/speech impairment or intellectual disability, inaccessible transport to reach the health centre, or sheer expense of treatment/rehabilitation. Health services need to cater to all, including people with disabilities. Services are required for people with various disabilities, including those with deteriorating conditions, leprosy, multiple disabilities, deaf-blindness, haemophilia, spinal injuries, intellectual disabilities, hydrocephalus, range of syndromes, and many more.

Article 25 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) states that "persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability". The Eleventh Five Year Plan also has mandates related to Disability Certificate, aids & appliances, mental health, rehabilitation, etc. In order to fulfil these commitments, a concerted effort is required from all concerned Ministries and stakeholders.

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<sup>1</sup> Dr Sunanda Reddy, Major Issues Concerning Disabled People, E-Mail to Rama Chari on 9th February 2009

# 1. Government Machinery, Structure and Role

The concerned Ministries for health related issues for people with disability are:

- Ministry of Health and Family Welfare
- Ministry of Social Justice and Empowerment
- Ministry of Women and Child Development

The National Trust too plays its role in providing health and rehabilitation services to people with Autism, Cerebral Palsy, Mental Retardation & Multiple Disabilities.

## **Ministry of Health and Family Welfare (MHFW)**

Ministry of Health and Family Welfare is instrumental and responsible for implementation of various programmes on a national scale in the area of Health & Family Welfare, prevention and control of major communicable diseases and promotion of traditional and indigenous systems of medicine.

The Ministry comprises of the following Departments:

- Department of Health & Family Welfare
- Department of AYUSH (Ayurveda, Yoga & Naturopathy, Unani, Siddha and Homoeopathy)
- Department of Health Research

The two main Flagship programmes of the Ministry to not only strengthen the health systems in the country but also to ensure accessibility and affordability of health services are:

**(1) National Rural Health Mission (NRHM) 2005-2012:** Government of India launched NHRM to carry out architectural correction in the basic health care delivery system. It aims to provide effective health care to rural population, especially the disadvantaged groups including women and children, by improving access, enabling community ownership and demand for services, strengthening public health systems for efficient service delivery, enhancing equity and accountability and promoting decentralisation. It covers the entire country, with special focus on 18 States where the challenge of strengthening poor public health systems and thereby improve key health indicators is the greatest. These are Uttar Pradesh, Uttaranchal, Madhya Pradesh, Chhattisgarh, Bihar, Jharkhand, Orissa, Rajasthan, Himachal Pradesh, Jammu and Kashmir, Assam, Arunachal Pradesh, Manipur, Meghalaya, Nagaland, Mizoram, Sikkim and Tripura.

**(2) National Urban Health Mission (NUHM):** The Ministry is planning to launch NUHM to address the health needs of the urban poor. NUHM will aim to address primary health needs of marginalised urban poor in 429 cities with a population of 1 lakh and above. This includes six capital cities with less than 1 lakh population. Photo family cards will be issued to urban poor families, slum dwellers, migrant workers and extremely vulnerable population who would be identified by the Urban Local Body (ULB) concerned or any other State specific mechanism. Though no person would be denied service in the public health facilities, the marginalised urban families identified under the scheme would receive services on special terms of concession under NUHM.

The **primary role of the MHFW with regard to persons with disabilities is mainly in the area of prevention.** Under the National Rural Health Mission, the Ministry conducts the National Leprosy Eradication Programme (NLEP), the National Programme for Control of Blindness and the National Iodine Deficiency Disorders Control Programme and National Programme for the Prevention and Control of Deafness directly relate to disabled persons as defined by The Disability Act (1995). **The**

**National Mental Health Programme, which is part of the National Health Programme addresses issues of persons with mental illness.**

### **Ministry of Social Justice and Empowerment (MSJE)**

The Ministry of Social Justice and Empowerment ensures the welfare, social justice and empowerment of disadvantaged and marginalised sections of the Indian population such as SC/ST groups, Minorities, Backward Classes and disabled persons. The Ministry has schemes and programmes that address the welfare of persons with disabilities.

The infrastructure network that implements the schemes and programmes related to the health and rehabilitation of disabled persons consists of:

1. Statutory bodies
  - a. Rehabilitation Council of India (RCI)
  - b. Officer of the Chief Commissioner of Persons with Disabilities
  - c. National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities
2. National Institutes
  - a. Ali Yavar Jung National Institute for the Hearing Handicapped (AYJNIHH), Mumbai
  - b. Pandit Deen Dayal Upadhyaya Institute for the Physically Handicapped (IPH), New Delhi
  - c. National Institute of Mentally Handicapped (NIMH), Secundrabad
  - d. National Institute of Visually Handicapped (NIVH), Dehradun
  - e. National Institute for Orthopedically Handicapped (NIOH), Kolkata
  - f. National Institute for Rehabilitation Training and Research (NIRTAR), Cuttack
  - g. National Institute for Empowerment of Persons with Multiple Disabilities (NIEPMD), Chennai.
3. Public Sector Undertaking
  - a. Artificial Limbs Manufacturing Corporation of India (ALIMCO)
  - b. National Handicapped Finance & Development Corporation (NHFDC)
4. Composite Regional Centres for Persons with Disability (CRCs); the District Disability Rehabilitation Centres (DRCs), Regional Rehabilitation Training Centres (RRTC)s
5. Public Private Partnership
  - a. Spinal Injury Centre

### **Ministry of Women & Child Development (MWCD)**

The vision of the Ministry is, “Ensuring overall survival, development and participation of women and child in the country.” For the holistic development of the child, the Ministry has been implementing the world’s largest outreach programme of Integrated Child Development Services (ICDS) providing a package of services comprising supplementary nutrition, immunisation, health check up and referral services, pre-school non-formal education. There are five Bureaus in the Ministry – namely, Child Development (including Food & Nutrition Board); Child Welfare & Protection; Women Welfare & Development; Prevention of Trafficking, Girl Child & Gender Budgeting; Plan, Research Monitoring & Statistics. The Ministry also has four autonomous organisations viz. National Institute of Public Cooperation and Child Development (NIPCCD), Rashtriya Mahila Kosh (RMK), Central Social Welfare Board (CSWB) and Central Adoption Resource Agency.

## 2. Current Scenario

Given below are some of the major issues related to health for people with disabilities that have been analysed based on the Annual Reports (2007-08) of the concerned Ministries and the relevant Sections of the Eleventh Plan. Concerns have also been listed based on our discussions with people working in the sector, including information compiled from newspaper and other reports.

### 2.1. PREVENTION OF IMPAIRMENTS

National Rural Health Mission (NRHM) started functioning in 2005. Many of the prevention programmes conceived by the MHFW are now being implemented by the NRHM, including the blindness control and leprosy eradication programmes.

Following are some of the Health Programmes related to disability prevention under NRHM based on the information given in the Annual Report of MHFW (2007-08):

**Control of Blindness:** In the Annual Report, the goal of the National Programme for Control of Blindness is to reduce the prevalence of blindness from 1.4% to 0.3%. As per the Survey conducted during 2006-07, the estimated prevalence of blindness has come down to 1%. The main objective of the programme is to reduce the backlog of blindness through identification and treatment of blind persons and to develop comprehensive eye care facilities in every District. It also aims to collaborate with voluntary organisations and private practitioners in eye care. Decentralised implementation of the scheme through District Health Societies is identified as the main strategy to achieve the set aims.

Under the Eleventh Plan the primary aim of the National Programme for the Control of Blindness under the NRHM is to consolidate the gains in preventing cataract blindness and also initiate activities to prevent and control blindness due to other causes.

**Leprosy Prevention:** According to the Annual Report 2007-08, the goal of leprosy elimination at national level (i.e. PR of <1 case / 10,000 population) as set by the National Health Policy 2002 has been achieved in the month of December 2005 in 28 States. Remaining seven States and UTs having PR>1 contribute to 27.8% of country's case load. These are Bihar, Jharkhand, West Bengal, Chattisgarh, Delhi, Chandigarh and Dadra and Nagar Haveli. During 2006-07, a total of 1.39 lakhs new leprosy cases were detected. There has been an emphasis on medical rehabilitation of persons infected by leprosy. There are moves to increase the number of institutions providing Re-Construction Surgery (RCS) by including nearly 20 medical colleges PMR (Physical & Medical Rehabilitation) centres. Awareness campaigns were carried out successfully in identified 29 Districts and 433 Blocks in 2006-07.

In the Eleventh Plan, under the list of expected outcomes of NRHM, it is mentioned that Leprosy Prevalence Rate is to be reduced from 1.8 per 10000 in 2005 to less than 1 per 10000 thereafter.

**Iodine Deficiency Disorders Control Programme (IDDs):** According to the Annual Report, 71 million persons are suffering from Goiter and other Iodine Deficiency Disorders (IDDs). These disorders include mental retardation, deafness, and neuromotor defects. Iodine deficiency in the mother's diet has also caused stillbirths and led to abortions in many cases. One of the main objectives of the NIDDCP (National Iodine Deficiency Disorders Control Programme) is to survey and assess the magnitude of IDDIs and also oversee the supply of iodated salt in place of common salt. The strategy



adopted to achieve these aims is primarily the IEC (Information, Education and Communication) programme.

The achievements of NIDDCP are – (1) Issuance of licenses to 824 salt manufacturers out of which over 500 units have commenced production; (2) MHFW has issued a ban on sale of Non-Iodised salt for direct human consumption and (3) establishment of IDD Control Cells in 31 States/UTs. Global IDD prevention day was celebrated with a two-day multi-sectoral workshop on NIDDCP. Representatives of different Ministries, salt manufacturers, iodine importers etc. participated in the workshop.

**Prevention of Deafness:** The National Programme for the Prevention and Control of Deafness is in its nascent stage. It is one of the 'Pilot Projects' of the Eleventh Plan. The Eleventh Plan states, as per WHO estimates, in India, there are 63 million hearing impaired persons, with an estimated prevalence of 6.3%. A larger percentage of our population has milder degrees of hearing impairment, adversely affecting productivity, both physical and economic.

The objectives in the Eleventh Five Year Plan will be to prevent avoidable hearing loss; identify, diagnose, and treat conditions responsible for hearing impairment; and medically rehabilitate all hearing impaired people. It concentrates on training and developing manpower for the early identification, prevention and management of hearing impairment and deafness. Another important component of the programme is capacity building in the hospitals, primary health care and community health centres with respect to ENT/ Audiology infrastructure. Efforts are also focused on screening camps for early detection of hearing impairment and deafness, management of hearing and speech impaired persons and rehabilitation (including provision of hearing aids), at different levels of health care delivery system. Awareness generation and IEC activities are a major aspect of the programme and they consist of information dissemination on early identification of hearing impairment in children and also removing stigma associated with deafness.

**Immunisation Programme:** Pulse Polio Eradication was started in India in 1995 to eradicate Polio from India. There has been significant success in reducing the number of polio cases. The cases declined gradually to only 66 cases in 2005. Out of the 35 States and UTs, 33 States are free from indigenous transmission of polio virus since last three years. It is taking more time in UP & Bihar to achieve zero transmission due to factors like high population density and poor sanitation.

**Nutrition:** Nutrition Cell in MHFW provides technical advice on all matters related to policy-making, Programme implementation and evaluation, training modules for different levels of medical and para-medical workers. The Cell has been working on creating awareness regarding prevention, and control of micronutrient deficiency disorders, diet related chronic disorders and promotion of healthy lifestyle through dissemination of various types of IEC materials. An Expert Group Discussion on Infant & Young Child Nutrition (IYCF) for prevention and control of nutrition and micronutrient deficiency was convened. A National Programme for Prevention & Control of Fluorosis has been formulated and would be launched during the current financial year (2008-09) in five Districts of the country as Phase 1.

**Up-gradation and strengthening of Emergency Facilities of State Hospitals Located on National Highways:** A new Scheme for establishment of Network of Trauma Centers along the National Highways, spread over the Golden Quadrilateral, East West and North South Quadrilateral has been launched. The project would comprise of well-equipped life support Ambulance at every 50 km of National Highways with well equipped staffed trauma centres at every 100 km-200 km of the National Highways.

**Integrated Management of Neonatal and Childhood Illnesses: (IMNCI):** IMNCI encompasses a range of interventions to prevent and manage five major childhood illnesses i.e. acute respiratory infections, diarrhoea, measles, malaria and major causes of neonatal mortality pre-maturity and sepsis.

**Home Based New Born Care (HBNC):** Under this programme, Accredited Social Health Activists (ASHAs) are trained in identified aspects of newborn care.

#### **Provisions in the Eleventh Plan with respect to Children with Disabilities:**

In the Eleventh Plan, 'Towards Women Agency & Child Rights', under the section, 'Providing for Special Needs of Differently-abled Children', it states, "It is critical to see disability as a child protection issue as well. Even today, data related to disability among children varies with source. **It is estimated that hardly 50% disabled children reach adulthood, and no more than 20% survive till the fourth decade of life.** Although there is very little information regarding the nutritional status of children with disabilities, it is recognised that disabled children living in poverty are among the most deprived in the world. Discrimination and often abandonment is a reality for them. Ensuring access to education, health, and nutrition for children with disabilities is a formidable challenge for the Eleventh Plan. The Plan will ensure among other things, provision of ramps in schools, development of disabled friendly curricula, and training and sensitisation of teachers."

#### **Concerns:**

There are many issues related to prevention of impairments. The focus of the Prevention Programmes in our country has been mainly on traditional causes of disability. There isn't any comprehensive programme for prevention, which can cover the whole range of issues. Based on our research and conversations with the experts, we have highlighted the various issues that need attention in order to decrease the prevalence of impairments in our country.

There are issues related to health care for the mother during pregnancy; child-birth related complications (such as lack of oxygen to the brain, haemorrhage or precipitate birth); and care for the new born (infection in early childhood like meningitis, encephalitis, head injuries), which if given adequate attention, the prevalence of impairments can be brought down. The World Bank Report (2007) states, "Access to care during pregnancy and delivery is poor in India. In the three years preceding NFHS-2 (National Family Health Survey 2), 35 percent of pregnant women received no antenatal care: only a marginal improvement on the early 1990s, and with high-risk groups still with less access to care."<sup>2</sup>

A study was conducted by Unnati and Handicap International (published in 2004) in 55 villages and 8 urban slums across four districts in Gujarat. According to their Report, "More than 50 percent of the persons with disabilities in their study were disabled from birth. Often such disability can be related to poor antenatal care, inadequate nutrition and lack of complete immunisation during pregnancy."<sup>3</sup>

According to Dr. Sunanda Reddy, "Much of the childhood morbidity and mortality from disabilities is likely to have roots in micronutrient deficiencies such as severe Iron deficiency, deficiency of Iodine, Folic acid etc."<sup>4</sup>

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<sup>2</sup> *People with Disabilities in India - From Commitments to Outcomes; World Bank, May, 2007*

<sup>3</sup> *Report on Children, Radhika Alkazi*

<sup>4</sup> *Dr Sunanda Reddy, CARENIDHI, Major Issues Concerning Disabled People, E-Mail to Rama Chari on 9th February 2009*

Another study undertaken in Gujarat revealed, “70 percent of the disabled people identified were disabled before school age. This is a surprisingly high figure, and points to the impact of India’s high rates of malnutrition among the under fives, maternal mortality and poor early childhood care. Malnourishment is a major cause of developmental delay and long-term intellectual disability.”<sup>5</sup>

Malnourished children, unlike their well-nourished peers, not only have lifetime disabilities and weakened immune systems, but they also lack the capacity for learning that their well-nourished peers have. In infancy and early childhood, iron deficiency anaemia can delay psychomotor development and impair cognitive development, lowering IQ by about 9 points. Low-birth weight babies have IQs that average 5 points below those of healthy children. And children who were not breastfed have IQs that are 8 points lower than breastfed children.”<sup>6</sup>

There is also increased number of injuries due to road accidents, bomb blasts, natural disasters, etc. There is no data available in the Annual Reports regarding the number of people who have become disabled in the accidents/disasters. “In situations of conflict and disaster, the likelihood of psychosocial trauma and disabilities are also high. Most reports on the aftermath of the natural disaster or situations of conflict underline increased and long-term mental health difficulties amongst children and adults. Often the dramatic changes in a child’s situation is more traumatising than the event itself.”<sup>7</sup>

“The effects of minor impairments can be devastating for child who may find it difficult to perform and yet get no support and protection from the system. The links between hidden hunger, cognitive growth and achievement in education must also be explored<sup>8</sup>.”

There are also social and cultural causes of disabilities. Consanguineous marriages, child marriages, certain superstitions are also reasons for impairments. These can be prevented by awareness and education.

There is also a larger issue related to the way society looks at disability. Many disabled children are starved to death or deliberately not provided treatment, because disabled children are seen as ‘liability’. These cases go unreported. In a newsletter, ‘Health Rights - Work Group for People’s Health and Rights’, December 2005, David Werner writes... “In hands-on workshops I facilitate in Latin America there are always young children with severe cerebral palsy or multiple disability”... On not finding the children in India when he visits three community based rehabilitation projects, he asks and the answer everyone agreed on is that “severely disabled children are often allowed to die.... especially those born disabled and especially girls.”<sup>9</sup>

## 2.2. MENTAL HEALTH

The Annual Report of MHFW states, Mental Health affect nearly 20 per thousand population. Close to 10 million severely mentally ill people are in our country without adequate treatment. With such a large population in our country on one hand, less than one psychiatrist is available for every 3 lakhs population. The psychiatrists/population ratio is rural area that account for 70% of country’s population, could well be 1 in every million. The National Mental Health Programme was started in 1982 to ensure availability and accessibility of basic mental health care to everyone.

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<sup>5</sup> Thomas, P. (2005). *Mainstreaming Disability In Development: India Country Report*. Retrieved 1 January, 2006, from <http://siteresources.worldbank.org/INTSARREGTOPLABSOCPRO/1211714-1144074285477/20873614/IndiaReportDFID.pdf>

<sup>6</sup> Report on Children, Radhika Alkazi, AARTH

<sup>7</sup> Report on Children, Radhika Alkazi, AARTH

<sup>8</sup> Report on Children, Radhika Alkazi, AARTH

<sup>9</sup> Report on Children, Radhika Alkazi, AARTH

A model of delivery of community based mental health care at the District level was evolved and field tested in Bellary District by National Institute of Mental Health & Neuro Sciences (NIMHANS). The model was adapted as the District Mental Health Programme (DMHP) Programme. It now covers 121 Districts in 30 States/UTs, including 11 new DMHP set up during the current year.

Under the Chapter on 'Health and Family Welfare and AYUSH' in the Eleventh Plan, there is specific section on Mental Health. The Plan aims to strengthen District Mental Health Programme (DMHP) and enhance its visibility at grassroots level by promoting greater family and community participation and creating para-professionals equipped to address the mental health needs of the community from within. It will strive to incorporate mental health modules into the existing training of health personnel. It will also harness NGOs' and Civil Society Organisations' help in this endeavour, especially family care of persons with mental illness, and focus on preventive and restorative components of Mental Health. The Eleventh Five Year Plan, recognising the importance of mental health care, will provide counselling, medical services, and establish help lines for people affected by calamities, riots, violence (including domestic), and other traumas.

During the Eleventh Five Year Plan, the Restrategised NMHP will be implemented all over the country with the following objectives:

1. To recognise mental illnesses at par with other illnesses and extending the scope of medical insurance and other benefits to individuals suffering with them
2. To have a user friendly drug policy such that the psychotropic drugs are declared as essential drugs
3. To give greater emphasis to psychotherapeutic and a rights based model of dealing with mental health related issues
4. To include psychiatry and psychology, and psychiatric social work modules in the training of all health care giving professionals
5. To empower the primary care doctor and support staff to be able to offer psychiatric and psychological care to patients at PHCs besides educating family carers on core aspects of the illness
6. To improve public awareness and facilitate family carer participation by empowering members of the family and community in psychological interventions.
7. To provide greater emphasis on public private participation in the delivery of mental health services
8. To upgrade psychiatry departments of all medical colleges to enhance better training opportunities
9. To improve and integrate mental hospitals with the whole of health delivery infrastructure that offer mental health services thus lifting the stigma attached
10. To provide after care and lifelong support to chronic cases.

In the Eleventh Plan, under the section 'Empowering Persons with Disabilities' in the Social Justice Chapter, it states, "Detection of mental disabilities and disorders is critical to addressing mental well-being through both preventive and curative measures. It is vital to recognise that physical disabilities usually coexist with, and lead to, mental disturbance and ill health. The Eleventh Plan will emphasise and adopt a multi-pronged, cross-sectoral approach to identifying, preventing, managing, treating and rehabilitating persons with mental disabilities. There will be a focus on awareness drives, defining the various kinds of disabilities, generating valid census data, inclusion in all areas of development, and community based treatment and rehabilitation approaches. Efforts will be made to strengthen and develop trained human resource to address the growing magnitude of mental disabilities. There will be emphasis on research to generate relevant data and culturally valid rehabilitative measures."

### Concerns:

The objectives of the National Mental Health Programme seem quite impressive. However, implementation at the ground level is extremely dismal.

The poor state of implementation of NMHP is quite evident from the Audit Report of Institute of Mental Health (IMH), conducted by Banyan, an NGO working for fifteen years in Tamil Nadu in the area of Mental Health.

#### **Institute of Mental Health (IMH) - Intention versus Reality?<sup>10</sup>**

Banyan conducted an Audit of IMH on 3<sup>rd</sup> October 2008 to measure specifics like availability of basic amenities to evaluate living conditions of people with mental illness who are residing there.

IMH, the nodal agency for implementation of the District Mental Health Programme (DMHP) is one of the many State run institutions that has been identified for upgradation as a Centre for Excellence in Mental Health. The findings are alarming! The reality stands out in stark contrast to the intentions that are stated by the Government on paper.

**People live in appalling conditions** – wards have inadequate ventilation and are built like prison cells; roofs leak in many wards; toilets lack basic privacy; drinking water available only in open water containers kept under trees and there are not enough mats and blankets.

#### **There is lack of adoption of a basic humane approach**

- Wardens move around with lathis and have been seen to use it to intimidate.
- During the visit, a woman, unclothed, was tied up in her own feces.
- In the visitor's committee meeting held on 31<sup>st</sup> October, a woman was found with pus oozing from her badly injured head. It was revealed that earlier that week she was masked with a cloth and mercilessly beaten on the head by many wardens because she had tried to escape. The incident was brushed aside in the visitor's committee.

In addition to the above incidents, secondary sources tell us more shocking instances of gross violations of human rights.

A senior doctor in the Institute of Mental Health (IMH) has shared with the Banyan that a family has registered a case where a person died due to violence inflicted on him. The same source told us of another family that registered a case because their ward lost both his eyes when they were plucked out in a simulated cock fight that wardens organised between two patients for their entertainment purposes.

A senior doctor in Chennai on the condition of anonymity revealed a gruesome incident where the teeth of a child with mental retardation were broken for oral sex.

Many families complain of intimidation by wardens to harm their wards admitted to IMH for failure to pay bribes. Many vestiges of the custodial system remain. It is unclear if the Institute of Mental Health (IMH) functions under the Mental Health Act of 1987. IMH functions somewhere between a prison and an asylum and not as a hospital.

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<sup>10</sup> Dial 100 Mental Health Helpline - Evolution in Institute of Mental Health (IMH), The Banyan received by E-mail from Disability Law Unit, South On 19th January 2009.

There is a process termed as 'lock up' that occurs on a daily basis, where patients are locked up by evening irrespective of their prognosis – a person, well or unwell, is locked up seemingly as punishment for his/her 'crime of mental illness'. Dinner at IMH is served at 4 p.m. People have to wait until 8 a.m. the next morning for their next meal.

People continue to be committed under the Indian Lunacy Act of 1912. A few months back, close to 100 people from other parts of Tamil Nadu were committed to the institution under the Indian Lunacy Act of 1912.

(Source: Disability Law Unit, Vidya Sagar)

There are several questions that come up here. It has been eight years since the Erwadi incident<sup>11</sup> in Tamil Nadu happened. At that time there was a lot of hue and cry about the treatment of mentally ill people in the institutions, including the intervention of Supreme Court on the issue. What lessons were learnt from Erwadi incident? Why weren't any proactive measures taken to safeguard people living in institutions? What has been the role of the State Mental Health Authorities?

The more relevant questions for this Study are - how can such atrocities be prevented from happening in the future? How can NMHP be implemented better? What support services are required for people with mental illness and their families to not only recover from illness but also for their rehabilitation.

According to a Study conducted by NHRC & NIMHANS<sup>12</sup>, The gap between the resources – human, material and financial needed on account of the growing demand for mental health services and the available resources is our major concern.

According to established norms we need the following resources:-

- psychiatrists 1.0 per 1,00,000 population; one for every 10 inpatients;
- clinical psychologists 1.5 per 1,00,000 population; one for every 25 inpatients;
- psychiatric social workers 2.0 per 1,00,000 population; one for every 25 inpatients;
- psychiatric nurses 1.0 per 3 patients in a teaching hospital and one for every 5 in a non teaching hospital.

Going by the norms as above, we would need:

- Psychiatrists: 9698
- Clinical psychologists: 13,259
- Psychiatric social workers: 19064
- We have 61,521,790 major and minor mental disorders for which we have only 20,893 beds in government sector and 5096 beds in the private sector.

According to D.M. Naidu, Basic Needs<sup>13</sup>, an organisation working in the area of Mental Health, "The reason for the failure of NHMP is that "the how of it" is missing in the programme. There is no clear strategy or mechanism to implement the programme. NMHP is under Central Government and the implementer is the State Government. Monies are not being released on time for the States to implement the programme. There are several initiatives mentioned in NMHP, which have not been implemented. For instance, there is a School Programme mentioned in NMHP which is yet to take off in many States. There is no well established monitoring system, including civil society or affected

<sup>11</sup> In a tragic incident at Erwadi in Tamilnadu during August 2001, 25 people, including 11 women, were charred to death. A devastating fire broke out at 5 a.m. in the thatched hostel housing them. Out of the 46 hostel inmates, 40 were chained to their beds. They kept screaming for help but no one came to their rescue. The 46 hostel inmates were mentally ill. "Seventh Disability" Javed Abidi

<sup>12</sup> Source: Mental Health Care & Human Rights; National Human Rights Commission; and National Institute of Mental Health & Neuro Sciences; Editors: D Nagaraja; Pratima Murthy.

<sup>13</sup> Telephonic Interview with D.M. Naidu by Rama Chari on 8th February 2009

persons. The State Mental Health Authorities, whose job is to monitor implementation, are overburdened with many other responsibilities.”

**Article 16 (3) of UNCRPD states**, “In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.”

**It is also important to note that there is no mention of Mental Health in the Annual Report of Ministry of Social Justice & Empowerment!**

People in the Mental Health Sector are advocating for including Mental Illness under the National Trust Act. The activists in the Mental Health sector feel that the neglect for the issue is because it has become “nobody’s baby”! Though The Disability Act mentions Mental Illness as a disability, there is no work being done by the Ministry of Social Justice and Empowerment to ensure that all the provisions of the Disability Act, 1995 are provided to them. Health Ministry views rehabilitation of people with Mental Illness as the job of MSJE and they focus only on medical aspects and not on the social aspects. There has to be a better coordination between the various Ministries, including Centre and the States and an independent Authority to monitor Mental Health programmes. Civil Society also needs to play a proactive role in terms of ensuring better services for people with mental illness in the country.

### **2.3. REHABILITATION**

Following are the initiatives mentioned in the Annual Report of MSJE with regard to rehabilitation of people with disabilities:

The **Deendayal Disabled Rehabilitation Scheme** provides support to Non-Government Organisations to deliver various rehabilitation services to persons with disabilities. In the financial year 2007-08 (till December 2007), 587 organisations were released grant in aid assistance of Rs. 31.37 crore to benefit 1.30 lakh persons.

**District Disability Rehabilitation Centers:** Since inception (1999-2000), a total number of 199 DDRCs had been sanctioned, out of which 148 had been set up and started functioning. During the year 2006-07, 50 new DDRCs were sanctioned.

The Eleventh Plan states, “To enhance the economic potential of persons with disabilities, 199 DDRCs for comprehensive service in community setting have been sanctioned, but only 128 were made operational by the end of the Tenth Plan. The Eleventh Plan will ensure that the remaining 71 centres are also operationalised. Also, a concerted effort will be made to extend the scheme to another 101 districts so that at least 300 districts are covered by the end of the Plan period. In the selection of the additional 101 districts, special care will be taken to cover backward areas where the prevalence of disability is higher and where services as well as facilities for them are inferior to those in other parts of the country.”

#### **National Institutes 2007-08 (Upto December 2007)**

National Institute for the Visually Handicapped trained 898 special educators and mobility instructors. The institute conducted 19 short term training programmes/workshops covering 738 participants. The Institute conducted 35 composite rehabilitation camps in which 3978 patients were provided services. The National Institute for the Hearing Handicapped conducted 63 long term courses covering 806 beneficiaries and 45 short term courses covering 3012 beneficiaries. Also, the Institute organised 55 camps, which benefited 3315 persons with disabilities and provided aids and appliances to 1708

of them. The Institute also provided socio-economic rehabilitation services to 1358 persons and developed materials and distributed to 63004 copies. National Institute for the Mentally Handicapped, organised 12 long term and 195 short term training programmes, 20 awareness programmes, 60 parent training programmes. A total of 232 assistive devices were distributed to the needy persons with disability under ADIP scheme of the Ministry. National Institute for the Orthopaedically Handicapped provided physiotherapy and occupational therapy to 93822 patients, medical rehabilitation services to 191 patients and organised 28 camps in which 4611 patients including surgical cases were covered. National Institute of Rehabilitation Training & Research organised 6 long term and 4 short term programmes, various seminars/workshop/awareness programmes, provided services in rehabilitation, restorative surgery, aids/appliances etc which benefited 118814 persons including persons with disabilities. Institute for the Physically Handicapped assessed 5431 beneficiaries in the Assessment Clinic, 25889 were provided physical, occupational & speech therapy and 3371 persons with disabilities were benefited by Prosthetics & Orthotics workshop. Also, 35 rehabilitation camps were conducted in which 12237 persons were benefited. National Institute for the Empowerment with Persons with Multiple Disabilities, launched 2 long term diploma courses viz. DSE (Deaf and Blind) and DSE (Cerebral Palsy), and has conducted 5 short term courses. The Institute distributed aids and appliances to 1063 number of persons. The Institute has undertaken 5 R&D projects. It has provided various services like early intervention, physiotherapy, occupational therapy to 2189 persons. Rs. 43 crores were allocated for National Institutes and about Rs. 39 crores has been the expenditure in 2006-07.

The Eleventh Plan under the Section on 'Empowering Persons with Disability' under the Chapter, Social Justice, it states, "Since the National Institutes play a pivotal role in the empowerment of people with disabilities, it is essential that these Institutes be strengthened as Centres of Excellence on par with international standards for undertaking the following tasks: (i) training of professionals, (ii) capacity building and (iii) technology transfer and research".

The Ministry of Health & Family Welfare seems to have done no work in the area of Medical Rehabilitation for people with disabilities in the year 2007-08.

However, in Eleventh Plan, under the chapter, 'Health and Family Welfare and AYUSH', there is a specific commitment made for improving Disability and Medical Rehabilitation. It aims at building capacity in Medical Colleges and District Hospitals to train adequate human resources required for medical rehabilitation programme at all three levels of Health Care Delivery System. Towards this end the following steps are planned:

- To upgrade and develop two Physical Medicine and Rehabilitation (PMR) departments in the country to act as Model Centres
- To set up PMR Departments in 30 Medical Colleges/Teaching Institutions (at least one in each State) and each such department to adopt districts, CHCs, and PHCs for developing medical rehabilitation services
- To train medical and rehabilitation professionals in adequate number for providing secondary and tertiary level rehabilitation services
- To introduce training programme on Disability Prevention, Detection, and Early Intervention at diploma, undergraduate, and postgraduate level
- To provide Rehabilitation Services in Medical Hospitals and evolve strategy of care in the domiciliary and community set up.

**The Ministry of Women & Child Development runs Integrated Child Development Programme (ICDS Scheme)**, which was launched in 1975 with the objective to improve the nutritional and health status of children below the age of six and pregnant & lactating mothers; to lay foundation for the proper psychological, physical and social development of the child; to reduce the incidence of mortality,



malnutrition and school drop outs; to achieve effective coordination of policy & implementation among various departments to promote child development; and to enhance the capability of the mother to look after the health and nutritional needs of the child through proper health and nutrition education. The next phase of the ICDS, i.e. ICDS IV, which is at the planning preparation stage. The ICDS IV will have two major components – Nutrition and Early Childhood Education. The Annual Report (2007-08) of the Ministry states that “Sensitisation Programme for ICDS Functionaries and Trainers on Early Detection and Prevention of Disabilities”.

MWCD also runs Child Guidance Centre (CGC) to provide diagnostic, therapeutic and referral services to children up to 14 years of age with developmental, learning and behavioral problems, including childhood disabilities. During the year (April – Jan 08), 192 cases were registered for assessment, counseling and therapeutic interventions at the Head Quarters and Regional Centres. The dominant problems were learning disability, Attention Deficit Hyperactive Disorder, Autism, Asperger’s syndrome, Minimal Brain Damage, Developmental Delay, Mental Retardation, and Speech & language problems.

The Article 26 of UNCRPD deals with Habilitation & Rehabilitation. (Details of the Article are in Annexure)

**Concerns:**

Majority of disabled people have no access to Rehabilitation Services in the country. Only 15% of the people living in urban areas and 3% of the people living in rural areas can avail rehabilitation services - in India, total coverage is only 5.7%.<sup>14</sup>

According to a study conducted by Unnati and Handicap International (2004) in 55 villages and eight urban slums across four districts in Gujarat, “about 27% of disability was the result of diseases and/or poor medical treatment. This also indicates the low standard of health services and lack of access to primary health care at the village level.”

The health sector is the first point of contact for most families when they suspect impairment. Early detection and intervention are crucial areas for a child with impairment. People with disabilities and their families spend large amounts of money going from one health facility to another in search of information, diagnosis and cure. And, ironically, one of the biggest factors impeding rehabilitation is the medical professionals’ lack of knowledge on disability, due to which, they actively discourage families from seeking health support for children with severe disability. In a study conducted by ASTHA, parents of children with Cerebral Palsy in Delhi reported that they were told by the doctors that nothing could be done for their child. Therefore, rehabilitation measures are not taken and the families give up on their children. Thus starts the devaluation of the child, closely related to neglect and abusive situations.<sup>15</sup>

The medical professionals have little understanding of conditions and give wrong diagnosis. “In Delhi hospitals, children with Autism are routinely labelled as having mental disability”<sup>13</sup>.

The question that we need to ask is whether the systems of maternal and child healthcare in the country have any method of tracking children who are at a risk of disability or of supporting young children who have already become disabled with medical information and referral.<sup>16</sup> Experiences of disability based organisations show that children with disability are not welcome in ICDS centres.

<sup>14</sup> *Rehabilitation Professionals in Public Health Systems - An Initiative to Reduce Vulnerabilities for Disadvantaged Communities by Satish Mishra, Handicap International).*

<sup>15</sup> *Report on Children, Radhika Alkazi, AARTH*

<sup>16</sup> *Report on Children, Radhika Alkazi, AARTH*

According to the Study conducted by Handicap International in Gujarat, “in 95% of the villages where the study was carried out, Anganwadis exist. However, the community is not able to access these services. Much of this has to do with the long term impact of seeing children with disability as special, different and difficult to handle.” It is not that ICDS does not have disability on its agenda. However, one needs to analyse and evaluate the ICDS programme to understand the role they are playing and the services they are offering to disabled children.

It would be also important to analyse the role of MSJE in providing rehabilitation services. They have the National Institutes and District Rehabilitation Centres (DRCs). There is no information about the number of people with disabilities who have received services from DRCs.

MSJE also supports NGOs for providing rehabilitation. Under the NGO Grants Scheme, based on the list of organisations given in the Annual Report, it was noticed that there is no NGO that has been provided support in Himachal Pradesh, Arunachal Pradesh, Sikkim, Andaman & Nicobar Islands, Lakshadweep, Daman & Diu and Dadra & Nagar Haveli. There are regional imbalances in the distribution of the Grants. 58 NGOs in Andhra Pradesh are receiving grants; 56 in Uttar Pradesh, 50 in Karnataka, 50 in Orissa, 15 in Madhya Pradesh, 9 in Punjab; 1 in Jharkhand and 2 in Jammu & Kashmir. Out of the total 459 NGOs that were funded, 196 were from the four major States of South India (38% of the total NGOs). It seems like Grants are being provided on the basis of applications received.

The reach of rehabilitation services is very poor because there seems to be no proactive initiative or strategy on the part of the Ministry to provide services to people with disabilities in the country in a systematic way. There are no specific measures for identification and early intervention for children with disabilities. Early childhood care and education is very important. “Empowering persons with disabilities who lack the basic skills and whose health is failing can be much like building palaces on weak foundations.”<sup>17</sup>

## 2.4. DISABILITY CERTIFICATES

Disability Certificate is the most important document for persons with disability for identity, protection and for availing her/his rights as the citizen of India.

There is no mention of Disability Certificates in the Annual Report of MHFW and in the Health Chapter in the Eleventh Five Year Plan. However, there is very firm provision made in Chapter 6, Social Justice, ‘Empowering Disabled People’ regarding Disability Certificates. It says, “**the Health Ministry will ensure that before the end of the Eleventh Plan, every disabled person possesses a disability certificate. This would help such a person to prove her/his identity as a person with disability for the purpose of availing the benefits for which she/he is eligible. A disabled person should be able to get her/his disability certificate within 30 days of making an application. The responsibility to ensure this will rest with the concerned district magistrate.**”

### Concerns:

At present, there are tremendous difficulties in getting a Disability Certificate. Javed Abidi, Honorary Director, National Centre for Promotion of Employment for Disabled People (NCPEDP), said in a Seminar, “It is easier to get a Passport than a Disability Certificate!” For getting a Passport, one just

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<sup>17</sup> Email from Dr Sunanda Reddy to Rama Chari on 9th February 2009

needs to fill an application form, with certain documents, then it is the duty of the Authorities to do all the necessary checks and that too within a certain period of time, and the Passport reaches you by post! But for a Disability Certificate, one needs to visit the hospital many number of times to get the various tests done, one needs to face harassment of various kinds, and sometimes it take ages to get one Disability Certificate made! The question that is being raised here is, why can't the issuing authority take the responsibility to do all the verifications based on the application, like it is being done in the case of issuing Passport (which is a far more sensitive document than the Disability Certificate)?

Radhika Alkazi<sup>18</sup> had done a research on the issue and found out the following:

- Procedure to get Disability Certificate is not standardised. It varies from hospital to hospital and from State to State.
- There is lack of awareness among persons with disabilities regarding the procedure. There is no place from where a person can get information.
- In some places, it was found that percentage of disability is recorded as “less than 40%” or “more than 40 %” and not the exact percentage. This causes problem in cases where schemes are purely related to exact percentage.
- The requirement of photograph showing disability was found to be another dehumanising factor.
- There was no clear rationale for determining ‘period of validity’.
- Certificates are issued on A4 size paper, which is difficult to carry and is prone to wear and tear.
- For availing some schemes and concessions, Disability Certificate is not enough. The person is made to go through the entire process again.
- Hospitals are not accessible. They are made to go to different places at different level to get assessments done.
- Some doctors are charging exorbitant amounts for issuing the certificate.
- National Trust (NT) recognises Autism, Multiple Disability & Cerebral Palsy as disabilities. One would require Disability Certificate to apply for the Guardianship under the NT Act. NT does not talk about the procedure for availing the Disability Certificate.

The Minister of MSJE had set up a Committee in February 2007 for streamlining and simplification of the procedure for issuing the Disability Certificate. The Committee was chaired by the Additional Secretary of MSJE. The members from the Government included the Chief Commissioner for Disability; Ashish Kumar, Deputy Director General and a representative of Directorate General of Health Services (DGHS). Uma Tuli and S K Rungta represented the NGO sector on the Committee. They have come up with the following recommendations:

Disability Certificates may be classified into two types:

Type 1: For obtaining benefits like – employment, admission to higher educational and professional institutions, and for judicial; determination of compensation claims.

Type II: For benefits like disability pension, unemployment allowance, poverty alleviation schemes, Income Tax exemption, benefits under ADIP Scheme, special school admission, travel concessions in railways, buses, airways, waterways, etc.

The present system of certification for Type 1 may continue and for the Type 2, PHCs may be authorised to issue certificate for “visible disabilities”. They will include locomotor disability - amputation or paralysis of limbs and visual disability – blindness.

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<sup>18</sup> Report on Disability Certificate supplied by AARTH, Radhika Alkazi

We tried to find out the latest with regard to the issue but could not find any information. Probably, there has been no major development that has taken place!

We spoke to Poonam Natarajan<sup>19</sup>, Chairperson of National Trust to take her view regarding streamlining the issuance of Disability Certificate. She said that PHC Doctors could be authorised to issue the Disability Certificate. According to her, it does not require a Psychiatrist/Clinical Psychologist to determine if the person has mental disability. They are unable to do that because MBBS does not have a module on disability.

With the UNCRPD in place it is also important that India modifies the definition of disability to include learning and other disabilities, like Haemophilia, Thalassaemia, etc.

This is a larger issue and requires a lot of discussion and debate. It is already more than a year since UNCRPD was ratified. It is important that disability sector begins its discourse on redefining disability and including some neglected disabilities.

## 2.5. AIDS AND APPLIANCES

The Scheme of ADIP (Assistance to Disabled Persons for Purchase/Fitting of Aids/Appliances) is under MSJE. It was conceived in 1981 to provide “durable, sophisticated, scientifically manufactured, modern, standard aids and appliances” to disabled persons.

The Annual Report of MSJE (2007-08) states that in the financial year 2006-07, Rs. 71.20 crores were allocated for the scheme and an amount of Rs. 49.39 crores has been released to 64 NGOs / implementing agencies upto 31<sup>st</sup> December 2006.

**Artificial Limbs Manufacturing Corporation of India (ALIMCO):** The Annual Report states during the year upto December 2007, ALIMCO organised 983 camps benefiting 1,07,001 disabled people. The product range of ALIMCO includes orthosis, prosthesis for upper and lower extremities, spinal braces, traction kits, wheelchairs, crutches, three wheelers and special tools and equipment required for fitment of prosthetic and orthotic assemblies by limb fitting centres.

The Eleventh Plan, under the Section on ‘Empowering Persons with Disability’ in the Social Justice Chapter, it states “It will endeavour to create awareness about ADIP and other such schemes. This is one scheme which must be universalised. Any disabled person should be able to approach the district magistrate and derive benefit from her/him. The income ceiling for availing assistance will be raised to Rs. 10000/- per month. Moreover, the ceiling for purchase/fitting of aids and appliances should also be enhanced to Rs. 25000/- per month. For manufacturing these aids and appliances, there is need to enhance the production capacity and ALIMCO should not be a monopoly supplier. The approach should be to provide the best possible assistive devices by encouraging multiple manufacturers, and even through imports. The Eleventh Plan shall allocate adequate funds for strengthening ADIP.”

Article 26 of UNCRPD states that “State Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation”.

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<sup>19</sup> Telephonic interview with Poonam Natarajan by Rama Chari on 5th February 2009

### Concerns:

There are several issues related to aids and appliances. The ADIP Scheme has only limited number of equipments, which sometimes do not even cater to the basic needs of people with disability. They are often of low quality and could even have a negative impact on a person's condition, if care is not taken to ensure that right kind of aid is given.

Camps are regularly organised by the Government, Rotary, Lions Club, etc. to distribute wheelchairs and other aids. Many people who have received these donations have reported that they did not find them useful! The reasons ranged from, having no space in the house to keep them; to the fact that they are not taught how to use them or they just do not need them!

According to a study conducted in Gujarat, only 25 percent of the people with disabilities were using aids and appliances. Not only was it difficult to access these provisions, as rehabilitative services tend to be concentrated in urban areas, but the ones who did access these devices found them to be inappropriate, and difficult to repair and maintain in rural areas. Appliances from the Artificial Limbs Manufacturing Corporation of India (ALIMCO), were generally recognised as being poor in quality, and accessing them was time consuming and bureaucratic. This becomes especially problematic for young people, where as a growing individual they are likely to require replacements at regular intervals of some prosthetic device, such as artificial limbs and wheelchairs.<sup>20</sup>

A disability activist who works in rural areas recently mentioned, the "wheelchair produced in Germany is more suitable to our roads than the ones produced in India". Many prototypes get made by Research & Design Institutions but they are not produced or marketed. There are now many improved, sophisticated and hi-tech products available abroad, which can be extremely useful for people with disabilities to work more efficiently and independently. However, the prices of these products are quite steep. Multinational manufacturers do not find it lucrative to set up business here in India, as there are no incentives or subsidies which would help them reduce the cost.

## 2.6. HEALTH INSURANCE

The 60th Round of the NSSO (2004–05), has clearly brought out the fact that in rural government hospitals, an out-of-pocket expenditure of more than Rs. 3000/- is made during every hospitalisation. In rural private hospitals, it is more than Rs.7000/-. The expenditure in the urban areas in private hospitals is more than Rs. 11000/- and about three times higher than the public hospitals. Today, this expenditure would have increased substantially. Therefore, Insurance for poor people is one of the priorities under NRHM and NUHM.

The Annual Report (2007-08) of the Ministry of Health has mentioned, "Under the NRHM, a Task Force has been set up to explore new health financing mechanisms. The terms of reference include review of existing mechanisms to include health financing, human resource implications to manage health financing and risk pooling schemes, extent of subsidies required, ensuring equity and non discrimination, feasibility in various states, suggested design, of pilots and sites to launch community based health insurance models and required modifications of existing structures to introduce health financing schemes".

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<sup>20</sup> Thomas, P. (2005). *Mainstreaming Disability In Development: India Country Report*. Retrieved 1 January, 2006, from <http://siteresources.worldbank.org/INTSARREGTOPLABSOCPRO/1211714-1144074285477/20873614/IndiaReportDFID.pdf>

Recently, a decision has been taken to launch a new scheme for workers in unorganised sector<sup>21</sup> with the objective of improving access to health care and protecting the individual and her family from exorbitant out-of-pocket expenses. Under the scheme, coverage will be given to the beneficiary and her/his family of five members. Providers will be both public and private.

The Ministry had advised States and UTs to prepare Health Insurance Models as per their local needs to be run on pilot basis. Only Andhra Pradesh has started a pilot in their State.

Rashtriya Arogya Nidhi was set up by MHFW in 1997 to provide financial assistance to patients living below poverty line, who are suffering major life threatening diseases. Financial assistance to poor patients is also given from the Health Minister's discretionary Grant.

During the Eleventh Plan, pilots will be undertaken in selected States under NRHM and NUHM. The scheme will empower SHGs, enable households to access micro-credit, and also recover from financial stress during treatment of illness. Local governments are expected to identify population at risk and provide a revolving fund to be managed by a consortium of SHGs. This consortium would also encourage small savings by households and whenever required, give needy households, a cash support of Rs. 5000/- to Rs. 10000/- for hospitalisation, catastrophic illness and death.

The National Trust has recently launched a health insurance scheme called Niramaya. It is for people with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities. The insurance cover is upto Rs.1 lakh for a vast range of health services from OPD to cashless hospitalisation. Under Niramaya, the annual premium is Rs. 250/- and is free for persons with family income up to Rs.15000/- per month.

#### **Concerns:**

Ideally disabled people should be able to access the government and private insurance schemes. But the reality is that many people with disabilities are being denied insurance on the grounds of disability. People with Cerebral Palsy and other severe disabilities are either denied medical insurance or being asked to pay a high premium by private insurance companies<sup>22</sup>. Niramaya was primarily initiated by the National Trust because of this reason.

With increasing costs of health services, Health Insurance has become a must for people in the middle and lower income groups. Disabled people, in general, incur more expenditure on medical and related expenses, such as prescribed medications, care for preventing secondary condition, support services, etc. compared to non disabled people. Recognising this fact, in the US, UK and other countries, they have designed excellent health insurance plans for disabled people and elderly, which is supported by the Government for wide range of expenses including, hospital insurance and medical insurance. Hospital Insurance covers, care in hospitals as an inpatient, critical access hospitals, skilled nursing facilities, hospice care, and some home health care. Medical Insurance covers, Doctors' services, outpatient hospital care, and some other medical services such as the services of physical and occupational therapists, and some home health care.

Article 25 of UNCRPD states, "Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner".

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<sup>21</sup> 93% of this work force is in the unorganised sector.

<sup>22</sup> Telephonic discussion with Neenu Kewlani, ADAPT

According to Dr. Sunanda Reddy, “Insurance Policies for the poor and marginalised should be government–run and carefully expanded with help from the Public Health sector. Rapid expansion of insurance companies without regulation can only serve the commercial interests of the Private Insurance Companies and leave the poor disabled person poorer without necessarily becoming healthier. The Insurance policy of the National Trust with some modifications (Health Insurance Purchasing Cooperatives or Health Alliances can be active) can provide a scope of services beyond simply contracting for health insurance may be offering a partial solution to disabled persons. However, healthcare services may become affordable for all only when the changes in policy take into account all marginalised groups in a Social Security Net. The solution, to my mind is in inclusion.”<sup>23</sup>

## 2.7. ACCESS TO HEALTH

The mission of NRHM is “to provide accessible, affordable and quality health services to the poorest households in the remotest regions”.

Some achievements of NRHM till date (Annual Report of MHFW 2007-08):

- 5.4 lakhs ASHA / link workers have been selected, out of which 4.62 lakhs have been trained.
- 1,77,924 Village Health & Sanitation Committees have been made functional and united grant of Rs. 10,000/- have been given to them.
- Before the launch of NRHM (as on 31<sup>st</sup> March 2005), out of 22,649 PHCs only 1634 were reported 24x7. This number has increased to 8756 PHCs working 24x7. Appointment of 11537 contractual staff nurses, 6232 doctors, 3882 AYUSH practitioners and 4380 Paramedics.
- Contractual appointment of 2282 specialists at CHC. Facility Survey has been completed for 2335 CHC’s and up-gradation work completed in 441 CHCs.
- States have identified 323 District Hospitals for up-gradation and an amount of 20 lakhs have been given to all DHCs for basic services.
- States have set up Rogi Kalyan Samithis (RKS) in 551 DH, 4066 CHCs and 1893 PHCs. Annual corpus grant of Rs. 1 lakh is allotted to the RKS at sub-district level and Rs. 5 lakhs allocated for district level RKS.
- The first integrated District Level Action Plans have been finalised in 509 Districts.
- While the Primary & Secondary Health Care is under the fold of NRHM, the Tertiary Health Care Services are being strengthened by Pradhan Mantri Swasthya Suraksha Yojna (PMSSY). It has two components:
  - Establishment of 6 new AIIMS like Institutions and
  - Up-gradation of 13 medical colleges to the level of AIIMS.

### Concerns:

NRHM is about reforms in the health sector. It aims providing affordable, accessible and accountable services to people. However, there is no mention of needs of people with disability in the NRHM. They have included women and children as part of disadvantaged group but not people with disability. Under NRHM and NUHM, many new hospitals, PHCs, CHCs have been planned. They are also upgrading the existing infrastructure and systems. Focus is also on developing human resources at all levels to strengthen delivery of health services.

People with disabilities find it extremely difficult to access health services in the country for various reasons. A person with Cerebral Palsy had once narrated his experience of trying to find a dentist in his area. He could not find a single dental clinic which was accessible. Some dentists also refused to

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<sup>23</sup> E-mail from Dr. Sunanda Reddy, CARENIDHI to Rama Chari dated 9th February 2009

treat him saying they do not have necessary equipments! It is a fact that most local clinics, health centres and pathological labs are inaccessible to disabled people.

Disabled People's International (DPI), India had conducted an Access Audit of Apollo Hospital, Delhi in 2001. They found several barriers for persons with disability there. Hospitals, in general, would have only a ramp or just a slope at the entrance! They would not have any other necessary facility like accessible washrooms, examining table, suitable weighing machine, etc. to provide services to disabled patients. Hearing impaired people face huge difficulty communicating with doctors because there are no sign language interpreters and doctors do not give time to understand a deaf person. Due to lack of awareness, medical practitioners often misguide parents of disabled children. They do not offer treatments which they would otherwise provide for non disabled people because they falsely assume that quality of life is low for a disabled person.

There are several health related problems of people who have 'invisible' disabilities, whose issues go unnoticed. For instance, people with Thalassaemia run from pillar to post to get their blood requirements from blood banks which many a times have a shortage of the same. People with Haemophilia struggle life-long for injections of anti-haemophilia factor for blood clotting. Since these impairments are not even considered disability in India, they don't even receive any privileges or rights that are available for people with disabilities in the country.

Access to health services is a human right issue. It is important that our health system is made inclusive. The environment, systems and procedures should accommodate disabled people. People with disability should be accorded respect and medical professionals/workers should know how to interact with people with different disabilities. According to Dr. Sunanda Reddy<sup>24</sup>, "Awareness-raising at the care facilities can improve accessing of services by disabled people. For instance, displaying charters of patients' rights and signages to make the facility disabled-friendly can ensure availability of wheelchairs and help from public services. Social work departments of hospitals should be strengthened by enrolling qualified and dedicated personnel."

A lot of people with disabilities are confined to their home and are ignoring their health issues because they cannot travel to clinics/hospitals. They need to be provided home based health service.

Article 25 of UNCRPD dealing with Health, has made the following provisions which are related to Access to Health:

- a) Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
- b) Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimise and prevent further disabilities, including among children and older persons;
- c) Provide these health services as close as possible to people's own communities, including in rural areas.

To fulfil the above commitment, the Government and the disability sector have to devise a strategy to provide accessible, affordable and accountable quality health services to people with disabilities in the country.

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<sup>24</sup> E-mail from Dr. Sunanda Reddy, CARENIDHI to Rama Chari dated 9th February 2009



## 2.8. PERSONAL ASSISTANCE / CARE GIVER SERVICE

The National Trust has initiated a new scheme 'Sahyogi' for training and development of care givers. A fund has been sanctioned to select NGOs to set up Care Giver Cell (CGC). 11 NGOs have been selected across India, where CGC will be set up. They have also worked out training Module for care givers which also provides career progression for people who take up care giving as a profession. They are envisaging the CGC cell to become self sustaining over a period of time. They also have a Scheme for BPL families, where National Trust will provide the salary to caregivers. It is a pilot initiative and based on its success, they will expand the programme.

### Concern:

Care giving services are extremely crucial for people with severe disabilities and elderly. It is a very important initiative that National Trust has taken to set up care giving services across the country. However, the affordability of these services by people with disabilities from lower & middle income groups needs to be addressed.

## 2.9. WOMEN WITH DISABILITY

**Reproductive & Child Health (RCH)** programme was launched by MHFW in October 1997 to bring down maternal mortality and infant mortality ratio.

**Janani Surakshya Yojana** is a safe motherhood intervention programme under NRHM.

**Kishori Shakthi Yojana** is implemented by MWCD using the infrastructure of ICDS. The Scheme targets adolescent girls in the age group of 11 to 18 years, addressing their needs of self development, nutrition, health status, literacy skills, etc.

**Nutrition Programme** is also implemented by MWCD in 51 identified Districts where undernourished adolescent girls with body weight less than 30 kgs in age group of 11 to 15 years and 35 kgs in the age group of 15 to 19 years are provided nutrition. There is no mention of women with disability in the Annual Reports of the Ministry of Health, Ministry of Social Justice and Ministry of Women & Child Development.

The Eleventh Plan, in the Chapter, 'Towards Women's Agency and Child Rights' under the Section, Women with Disability, it states, "Although a rights-based approach today defines the disability rights movement, the specific concerns of women with disabilities have to be adequately reflected in the planning process. RCH programmes will pay attention to reproductive health needs of women with disabilities. Violation of their reproductive rights through forced sterilisation, contraception and abortion especially in institutions will be dealt with severely. In the Eleventh Plan, women with disabilities will be specifically included in gender equity programmes, both as beneficiaries and as project workers. The sensitisation programmes of government departments, police, and health care personnel will include sensitisation to the needs of women with disabilities. Laws will be strictly enforced in cases of discrimination."

### Concerns:

Women with disability have low access to Reproductive Health (RH) services and other related programmes. It is widely believed that women with disability are neither sexually active nor capable of bearing children. Attitudes of health professionals and negative beliefs about the worth of people with disabilities, lead to their not communicating the issues of RH with them.

Majority of women with disabilities in India suffer the triple discrimination of being female, being disabled and being poor. Women with disabilities face violations of their rights at every level. They are considered a financial burden and social liability by their families. Physical, sexual and mental abuse inflicted on them are manifold in nature and they are much more prone to face these violence than their non-disabled counterpart. (“Shampa Sen Gupta”)<sup>25</sup>.

The issues of women with disabilities are ignored by the disability sector and by the women’s groups. There are no schemes in the MWCD for women with disabilities. There is no system to track the number of girls/women with disabilities utilising the various services meant for poor women in the communities. Article 6 of UNCRPD focuses on women with disabilities (details in Annexure). India needs to take proactive measures to improve the quality of life for girls/women with disabilities.

## 2.10. HIV/AIDS

One of the National Programmes of the MHFW is National Aids Control Programme. The Ministry has various programmes for prevention, intervention and support. They also work on awareness creation and mainstreaming of people with HIV.

There is no mention about disability in the HIV Programmes of the Ministry of Health. Disabled people are generally excluded from HIV/AIDS Programmes because it is assumed that they are not sexually active and therefore they have no risk for HIV infection.

### GLOBAL SURVEY ON DISABILITY AND HIV/AIDS<sup>26</sup>

The Global Survey on Disability and HIV/AIDS conducted by Yale University and the World Bank has proven this assumption wrong. Individuals with disability have equal or greater exposure to all known risk factors for HIV infection. For example, adolescents and adults with disability are as likely as their non-disabled peers to be sexually active. Homosexuality and bisexuality appear to occur at the same rate among individuals with disability as among the non-disabled. Individuals with disability are as likely as non-disabled people to use drugs and alcohol (UNICEF 1999). Men and women with disabilities are even more likely to be victims of violence or rape, although they are less likely to be able to obtain police intervention, legal protection or prophylactic care.

Based on the Global Survey, it is important that HIV Programmes include disabled people who constitute atleast 5% of the population.

There are several barriers that prevent people with disabilities from accessing information on HIV. The HIV related communication are often inaccessible to people with hearing, visual disabilities and cognitive disabilities. Health service facilities are often not accessible to people with physical disabilities. The low levels of literacy also poses difficulty for persons with disability to understand issues related to AIDS.

#### **To reach disabled people:**

- Make sure that local disability organisations are on your distribution list so that they receive the same materials that are sent to local HIV and AIDS organisations.
- Invite disabled people to join HIV and AIDS training groups and have training materials ready in an accessible format.

<sup>25</sup> Shampa Sen Gupta; Memorandum to Smt. Renuka Chaudhary, Minister for Women and Child Development

<sup>26</sup> Groce N, Trasi R 2004. Rape of individuals with disability: AIDS and the folk belief of virgin cleansing. *The LANCET*, Vol. 363:1663-1664, May 22. Sourced from <http://globalsurvey.med.yale.edu/Fact%20sheet.pdf>

- Make sure that disabled people are depicted as members of the general population in posters, billboards or other materials about HIV and AIDS.
- Make sure HIV testing centers and AIDS care services are accessible. Different types of adaptations will be needed for different types of disabilities, but most adaptations can be easily anticipated. For example, ramps for those with physical impairments, sign language interpreters for those who are deaf, AIDS talks for those with intellectual impairments that are simple, straightforward and that emphasise repetition of key themes, talks for those who are blind that allow them to actually feel condoms rather than simply having someone in the front of the room hold one up.
- The nature of these services will depend on the individual disability, but ramps, sign language interpretation, and more verbal presentation and demonstration for blind people are some common measures that can easily be taken.
- Bear in mind that people with disabilities also engage in behaviors such as unprotected sex and drug injection with contaminated needles that place them in traditional groups at higher risk of HIV exposure.
- Train AIDS educators, outreach workers, clinic and social service staff on disability issues. When recruiting volunteers and paid employees, make sure that disabled people are considered and hired for these positions.
- Train police, lawyers and judges on disability issues related to protecting the safety and human rights of disabled people.
- Currently, there are virtually no data on the impact of HIV and AIDS on disabled populations. This means there is strikingly little information on the impact of the AIDS epidemic on 10% of the world's population and their families. Make sure to include a disability component when collecting data on HIV and AIDS.

*Source: Disability & HIV/AIDS at a Glance, World Bank*  
<http://globalsurvey.med.yale.edu/Fact%20sheet.pdf>

## 3. Budget Analysis

### Ministry of Health & Family Welfare

#### Annual Budget

The total outlay of the Ministry of Health & Family Welfare for the year 2007-08 was Rs.13875 crore.

Following are the budget heads related to disability:

- National Mental Health Programme (NMHP): Rs. 70 crore
- National Programme for Deafness: Rs. 5.42 crore
- Medical Rehabilitation (it was Zero in 2006-07): Rs. 1 crore
- National Leprosy Eradication Programme: Rs. 40 crore
- Iodine Deficiency Disorder Control Programme: Rs. 25 crore
- Pulse Polio Immunisation: Rs. 1341.48 crore

The proposed outlay for 2008-09, as given in the annual report is Rs. 21645.05 crore. The break up for the Outlay was not given.

#### Eleventh Five Year Plan

The allocation for Health & Family Welfare during the X Plan was Rs. 36,378 crore. The allocation for the XI Plan is Rs. 136147 crore (227% increase).

The Projected Gross Budgetary Support (in current prices) in the Eleventh Plan for some of the relevant programmes are mentioned below:

- NRHM: Rs. 86671 crore
- Health Insurance based NUHM: Rs. 4495 crore
- National Mental Health Programme (NMHP): Rs. 1000 crore
- Human Resources for Health: Rs. 4000 crores
- Pilot Project for 'Deafness': Rs. 100 crore
- Pilot Project for 'Medical Rehabilitation': Rs. 50 crore

There has been a substantial increase in the Budget for NMHP in the Eleventh Plan. Pilot initiatives for 'Medical Rehabilitation' and 'Deafness' have been introduced in the Eleventh Plan. The amount allocated particularly for Medical Rehabilitation is quite low!

### Ministry of Social Justice & Empowerment

#### Annual Budget

The total Outlay of the Ministry of Social Justice & Empowerment for the year 2007-08 was Rs. 2200 crore. Out of which, Rs. 233.38 crore was for 'Welfare of Persons with Disabilities'. The outlay was Rs. 241 crore in 2006-07 and expenditure was only Rs. 181.63 crore. It is interesting to note that the total outlay of the Ministry increased from Rs. 1686.11 crore in 2006-07 to 2200 crore in 2007-08, while the Budget for disability has gone down from Rs. 241 crore to Rs. 233.38 crore. The Budget for 2008-09 has not been given.

#### Eleventh Five Year Plan

The Gross Budgetary Support for MSJE in the Eleventh Plan (in current prices) is Rs. 13043.01 crore.

For Disability, the allocation is about **Rs. 1426.8 crore (about 11% of the Budget)**.

Disability related budget lines are given below:

- Funding for National Institutes: 359 crore
- ADIP: 500 crore; ALIMCO:12 crore
- Deen Dayal Disabled Rehab. Scheme: 500 crore
- NHFDC: 30.80 crore
- Implementation of The Disability Act: Rs.30.80 crore

The GRB for the Eleventh Plan has not taken into account the various provisions mentioned under the section 'Empowering People with Disability'.

### **Ministry of Women & Child Development**

The Projected Gross Budgetary Support (in current prices) for the Eleventh Plan is Rs. 54765 crore. For ICDS, it is Rs. 42400 crore. There is no provision for Child with Disability or Women with Disability, though there is a clear mention in the Eleventh Plan regarding the same.

Gender Budgeting is a focussed programme under MWCD. They have allocated Rs. 20 crore for this purpose. Eleventh Plan has introduced the concept of Disability Budgeting (3%). Similar plan should be developed for Disability Budgeting, under the MSJE.

## 4. Recommendations

- **The programmes for Health care should be planned based on provisions given in the Article 25 of UNCRPD.** It states very clearly that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. (Details of the Article 25 in Annexure).
- **A targeted Mission (National Disability Health Mission)** could be launched to ensure people with disabilities get health services that are accessible & affordable.
- **NRHM and NUHM should include disability as an important component.** Health infrastructure should be strengthened (PHC/CHC/District Hospitals) should be upgraded to cater to the health and rehabilitation needs of people with disabilities.
- **An Ordinance to be passed** for making all clinics, healthcare centres, pathological labs, etc. which are for the public, accessible to people with disabilities in a time bound manner.
- **MBBS Course should include a Module on Disability**, which should be prepared in consultation with rehabilitation professionals. Doctors are the first point of contact for parents of a disabled child for her/his treatment and rehabilitation.
- **The Accredited Social Health Activists (ASHAs)** should be trained in ensuring that they not only identify high risk babies but also refer them for appropriate service and do the necessary follow ups.
- **National Programme on Prevention of Disabilities** is currently focusing only on traditional causes of disability. However, there are many other causes ranging from malnourishment to medical negligence to social cultural reasons to impairments caused by disasters. These require urgent attention. A comprehensive programme on Prevention needs to be developed.
- **Eleventh Plan has a section on women with disabilities and children with disabilities.** Section on women with disability states, "Reproductive & Child Health (RCH) programmes will pay attention to reproductive health needs of women with disabilities. Violation of their reproductive rights through forced sterilisation, contraception and abortion especially in institutions will be dealt with severely. In the Eleventh Plan, women with disabilities will be specifically included in gender equity programmes, both as beneficiaries and as project workers. The Eleventh Plan mentions that sensitisation programmes of government departments, police, and health care personnel will include sensitisation to the needs of women with disabilities. Laws will be strictly enforced in cases of discrimination."

Regarding children with disability the Eleventh Five Year Plan states, "it is recognised that disabled children living in poverty are among the most deprived in the world. Discrimination and often abandonment is a reality for them. Ensuring access to education, health, and nutrition for children with disabilities is a formidable challenge for the Eleventh Plan. The Plan will ensure among other things, provision of ramps in schools, development of disabled friendly curricula, and training and sensitisation of teachers."

Therefore, MWCD should have a focused strategy for ensuring the provisions in the Eleventh Plan are implemented. ICDS and other relevant programmes have to be evaluated to see how they could include people with disability.

- **Rehabilitation services are available to only 5% of the disabled population.** The Eleventh Plan in the Health Chapter under the section, 'Disability and Medical Rehabilitation' talks of building capacity in Medical Colleges and District Hospitals to train adequate human resources required for medical rehabilitation programme at all three levels of Health Care Delivery System. It also mentions provision of Rehabilitation Services in Medical Hospitals and to evolve strategy of care in the domiciliary and community set up. In order to achieve this, a concerted rehabilitation programme requires to be developed and launched for systematically reaching to all disabled people in the country. Article 26 of UNCRPD, Habilitation & Rehabilitation mandates States Parties to take effective and appropriate measures, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organise, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes.
- **The National Mental Health Programme** has a lot of issues when it comes to implementation. There should be a proper implementing and monitoring mechanisms to ensure that the objectives of NMHP are met. Mental Illness should be included under the National Trust. The capacity of Primary Health Centres (PHCs) should be enhanced to provide the basic support to mentally ill patients. Para-health professionals and support staff need to be trained and sensitised to meet their medical needs and also help break stereotypes/misconceptions regarding mental illness.
- As mentioned in the Eleventh Plan, procedure for getting **Disability Certificate should be simplified** and streamlined so that a person gets her/his Disability Certificate within 30 days. One of the suggestions was to build the capacity of PHC Doctors, who can then be authorised to issue the Certificate.
- Disability sector should begin **discourse on redefining disability**.
- There is an **urgent need for a Comprehensive Health Insurance Scheme for people with disabilities and elderly**. Niramya could be extended to people with all disabilities and should be more comprehensive covering other aspects of medical care other than just hospitalisation. There should be a clear policy on non-discrimination in Insurance schemes. The doctors/professionals who assess for Insurance companies should be sensitised.
- **Aids/appliances/assistive technologies are essential for people with disabilities.** The Eleventh Plan states that income ceiling for availing assistance will be raised to Rs. 10000/- per month and the ceiling for purchase/fitting of aids and appliances should also be enhanced to Rs. 25000/- per month. It further states that for manufacturing these aids and appliances, there is need to enhance the production capacity and ALIMCO should not be a monopoly supplier. The approach should be to provide the best possible assistive devices by encouraging multiple manufacturers, and even through imports. The Eleventh Plan shall allocate adequate funds for strengthening ADIP. Incentives and subsidies should be provided to manufacturers of assistive devices.
- **Disabled people should be included in HIV/AIDS programmes.** (See the Box, 'To reach disabled people', given under HIV/AIDS section of this Report for more suggestions.)

- **Enhance awareness and improve communication strategies about health and rehabilitation measures** so that this information is disseminated to large number of people, including remote corners of the country.
- **AYUSH is a major component of the MHFW** which attempts to bolster and motivate traditional health care systems available in India. It is recommended that AYUSH research and care activities could be oriented to engage with disability more actively with an attempt to better understand traditional notions of disability and disability care and treatment.
- **Stronger focus on eradicating stigma against different disabilities** so that disability is not only considered as a preventable condition but as a kind of diversity that must be accorded respect. The UNCRPD emphasises that awareness-rising campaigns should keep in mind that disabled persons must be accorded respect and that above all their dignity must be upheld.
- **Some aspects of addressing disabled persons health concerns is not clearly delineated under either of the Ministries (MHFW, MSJE).** For instance while there is an intent to train the ASHAs under the NRHM, to address concerns specific to persons with disabilities in the rural areas, there is little mention of the kind of training they are to undergo and how they will be equipped with disability-specific information.
- The programme initiated by the National Trust to provide training **to caregivers of disabled people should be expanded** to reach all districts and villages of the country so that a fleet of trained care-providers are available in every remote corner of the country.
- Elderly people who acquire disability at a later stage in life also need cover for medical and rehabilitation services under Insurance Schemes. **There should be specific programmes targeting health needs of elderly people with disabilities.**
- As mentioned in the Eleventh Plan, each **Ministry should allocate 3% of their funds to disability.** The Health Ministry and Women & Child Development Ministry should earmark 3% funds for disability.



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## List of Abbreviations

NRHM	National Rural Health Mission
NUHM	National Urban Health Mission
NPCB	National Programme for the Control of Blindness
NIDDCP	National Iodine Deficiency Disorders Control Programme
IDD	Iodine Deficiency Disorders
NPPCD	National Programme for the Prevention and Control of Deafness
NMHP	Natioanl Mental Health Programme
DMHP	District Mental Health Programme
NCPEDP	National Centre for Promotion of Employment for Disabled People
ENT	Ear, Nose and Throat specialist
UNCRPD	UN Convention on the Rights of Persons with Disabilities
ALIMCO	Artificial Limbs Manufacturing Corporation of India
DRC	District Rehabilitation Centre
ASHA	Accredited Social Health Activist
RKS	Rogi Kalyan Samithis
RCH	Reproductive Child Health
NGO	Non-Government Organisation
MHFH	Ministry of Health and Family Welfare
MSJE	Ministry of Social Justice and Empowerment
MWCD	Ministry of Women & Child Development
PHC	Primary Health Care
CHC	Community Health Care
DH	District Hospital

# Annexure

## Relevant Articles related to Health & Rehabilitation in UNCRPD

### Article 25 - Health

States Parties recognise that persons with disabilities have the right to the enjoyment of the highest attainable standard of health without discrimination on the basis of disability. States Parties shall take all appropriate measures to ensure access for persons with disabilities to health services that are gender-sensitive, including health-related rehabilitation. In particular, States Parties shall:

- a. Provide persons with disabilities with the same range, quality and standard of free or affordable health care and programmes as provided to other persons, including in the area of sexual and reproductive health and population-based public health programmes;
- b. Provide those health services needed by persons with disabilities specifically because of their disabilities, including early identification and intervention as appropriate, and services designed to minimise and prevent further disabilities, including among children and older persons;
- c. Provide these health services as close as possible to people's own communities, including in rural areas;
- d. Require health professionals to provide care of the same quality to persons with disabilities as to others, including on the basis of free and informed consent by, inter alia, raising awareness of the human rights, dignity, autonomy and needs of persons with disabilities through training and the promulgation of ethical standards for public and private health care;
- e. Prohibit discrimination against persons with disabilities in the provision of health insurance, and life insurance where such insurance is permitted by national law, which shall be provided in a fair and reasonable manner;

### Article 26 - Habilitation and Rehabilitation

1. States Parties shall take effective and appropriate measures, including through peer support, to enable persons with disabilities to attain and maintain maximum independence, full physical, mental, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organise, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of health, employment, education and social services, in such a way that these services and programmes:
  - a. Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths;
  - b. Support participation and inclusion in the community and all aspects of society, are voluntary, and are available to persons with disabilities as close as possible to their own communities, including in rural areas.
2. States Parties shall promote the development of initial and continuing training for professionals and staff working in habilitation and rehabilitation services.
3. States Parties shall promote the availability, knowledge and use of assistive devices and technologies, designed for persons with disabilities, as they relate to habilitation and rehabilitation.

### Article 16 - Freedom from exploitation, violence and abuse

1. States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.

2. States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to avoid, recognise and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.
3. In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.
4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.
5. States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted

#### **Article 11 - Situations of risk and humanitarian emergencies**

States Parties shall take, in accordance with their obligations under international law, including international humanitarian law and international human rights law, all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and the occurrence of natural disasters.

#### **Article 6 - Women with disabilities**

1. States Parties recognise that women and girls with disabilities are subject to multiple discrimination, and in this regard shall take measures to ensure the full and equal enjoyment by them of all human rights and fundamental freedoms.
2. States Parties shall take all appropriate measures to ensure the full development, advancement and empowerment of women, for the purpose of guaranteeing them the exercise and enjoyment of the human rights and fundamental freedoms set out in the present Convention.

#### **Article 7 - Children with disabilities**

1. States Parties shall take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.
2. In all actions concerning children with disabilities, the best interests of the child shall be a primary consideration.
3. States Parties shall ensure that children with disabilities have the right to express their views freely on all matters affecting them, their views being given due weight in accordance with their age and maturity, on an equal basis with other children, and to be provided with disability and age-appropriate assistance to realise that right

#### **Article 10 - Right to life**

States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.