THE RIGHT TO HEALTH OF PERSONS WITH DISABILITIES IN INDIA

Access to and Non-Discrimination in Health Care for Persons with Disabilities

Indian Association of
Muscular Dystrophy (IAMD)

National Alliance on Access to Justice
for People Living with a Mental Illness
(NAAJMI)

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Report

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Access and Non-Discrimination in Health Care for Persons with Disabilities

Project Organised by:
Human Rights Law Network

Editors:
Jayna Kothari
Rajive Raturi

Design and Layout:
Hardeo Sharma

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Email: publications@hrln.org

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-Rajive Raturi

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I. INTRODUCTION

An estimated 70 million persons with disabilities in India are faced with problem of access to basic and specialized health care services. (United Nations Development Programme, Official Records, U.N. Document available at /disabilities/default.asp?id=18)

Some of the main problems faced by persons with disabilities are physical inaccessibility and financial barriers in accessing health care. In addition to these barriers, there is the general problem of qualitatively poor health care services. Despite the Government of India and the State Governments having introduced several health schemes for the needs of the disabled, these do not adequately ensure their right to full and equal healthcare.

As argued by Henry Shue, the right to access to health for persons with disabilities is thus a basic right as it is necessary for the existence of all other rights. [Henry Shue, Basic Rights, 98 (2nd Edition, 1996)]. Even rights such as the right to education and employment would be meaningless unless persons with disabilities have access to adequate healthcare as without adequate health care, no person would be able to avail themselves of any employment or education opportunities.

The right to health as covered under the UN Convention on the Rights of Persons with Disabilities ("UNCRPD"), ratified by India, requires that the State shall ensure that persons with disabilities have the right to enjoyment of the highest attainable standard of health without discrimination on the basis of disability and that the State shall take all measures to ensure that such a right is made a reality.(Convention on the Rights of Persons with Disabilities, United Nations, http://www.un.org/disabilities/convention/con ventionfull.shtml).

In spite of the Government of India having initiated a law reform process into 2009 harmonize the Persons with Disabilities Act of

1995 and the Mental Health Act of 1987, the paradigm shift that Article 25 of the UNCRPD promises to persons with disabilities is yet to happen. [Even as this report goes to print the Rights of Persons with Disabilities Bill has been introduced before the Parliamentary Standing Committee in the Rajya Sabha and the Mental Health Care Bill has been referred to the Cabinet by the Parliamentary Standing Committee on Health.]

II. METHODOLOGY

In order to facilitate a focused discussion, the Coalition of the Human Rights Law Network (HRLN), Indian Association of Muscular Dystrophy (IAMD) and the National Alliance on Access to Justice for persons living with mental illness (NAAJMI), commissioned The Centre for Law and Policy Research Bangalore, to draw up a background paper on the prevailing situation of accessing health facilities by persons with disabilities and was circulated to stakeholders prior to the consultations. Zonal consultations were organized in Chandigarh (North zone), Cochin (South zone), Kolkata (East zone) and Mumbai(West zone) and culminated in a national consultation in Delhi in April, 2014. Special emphasis was given to vulnerable disabilities and their needs and concerns in accessing the health system during the consultative process. The consultations brought together various disability rights groups from all over the country and included caregivers, doctors, health care professionals and experts. These consultations raised the issues faced by persons with disabilities regarding their right to health. The outcomes from the consultations have been referenced in this report in order to bridge the legal and policy analysis with practical and administrative recommendations.

The report is divided into two sections. The first section looks at the scope of the right to health both under international instruments and domestic legislation. The second part reviews the ground realities of the actual experiences of persons with disabilities in accessing their right to health care. This section is strengthened by an empirical study conducted to document the experiences of persons with disabilities in accessing health care. Individual questionnaires on different aspects of health care services and facilities were given to 130 people, in which detailed responses were sought on a range of health care related issues. We received responses from 61 persons

with disabilities, 39 caregivers, 17 disabled persons organisations and 13 health care professionals. The responses have been used in the second part of the report to give greater insight into the personal experiences of persons with disabilities in accessing health care services in India. The section also incorporates suggestions and recommendations from the zonal and national consultations. This report has been generated after examining the state of the right to health for persons with disabilities in India using the concept of "equal access" and "non-discrimination" as the central themes to evaluate the legal and practical dimensions of access to healthcare (or the lack of it), and thereafter suggests how these need to be modified to enhance the protection of health rights of persons with disabilities.

III. THE LEGAL FRAMEWORK FOR THE RIGHT TO HEALTH FOR PERSONS WITH DISABILITIES

(i) International Treaties and the Right to Health

By ratifying the UNCRPD in 2008, India took on a series of obligations and standards in the fields of education, employment and health care, whose aims were to transform the treatment of persons with disabilities from being objects of charity, medical treatment and social protection, to subjects with rights who can claim those rights, make life decisions based on free and informed consent, and live as active members of society. In this way, the UNCRPD addresses disability from a social model, not perceiving disability as an impairment or a deficiency, but focusing on the social discrimination that results from disability. (Mainstreaming Disability - Core Issues, UNCRPD India, available at http://uncrpdindia.org)

One of the core themes of the UNCRPD is to protect, promote and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and to promote respect for their inherent dignity. This includes the right to equality in receiving healthcare. Article 3 of the UNCRPD generally mandates the right to non-discrimination and access. Some of the other provisions of the UNCRPD that directly impact the right to health include:

a. **Article 4 (i)**: To promote the training of professionals and staff working with persons with disabilities in the rights recognised in the convention so as to better provide the assistance and services guaranteed by those rights.

b. **Article 9**: To ensure that all facilities and services including medical facilities are accessible for persons with disabilities.

c. **Article 10**: That persons with disabilities shall have the protection of their inherent right to life on an equal basis with others.

d. **Article 15**: That no one shall be subject to cruel or degrading treatment nor shall he or she be subject to any medical or scientific experiment without their free consent.

e. **Article 17**: Every person with disability has the same right as anyone else to respect for their physical and mental integrity.

f. **Article 19**: The right to live independently and have access to a range of in-home, residential and other community support services for living independently.

g. **Article 22**: The right to respect for privacy and the protection of privacy of personal, health and rehabilitation information of persons with disabilities on an equal basis with others.

h. **Article 25**: The Right to Health. This article of the UNCRPD provides for the right to the enjoyment of the highest attainable standard of health, without discrimination on the basis of disability. These measures shall be gender sensitive, shall ensure that persons with disabilities have access to information about the treatment they receive so that they know what they are agreeing to. Article 25 provides for free and affordable health care, sexual and reproductive health care, early identification and intervention services, services in rural areas, training of health professionals, and prohibition of discrimination against persons with disabilities in provision of health insurance.

i. **Article 26**: This provides for rehabilitation and mandates that governments must take effective steps to enable persons with disabilities to maximise their independence, develop their independent living and work skills, and manage their impairment or health condition.

Even before the UNCRPD was brought into force, the right to equal and accessible health care had been declared in several international documents. The UN International Covenant on Economic, Social and Cultural Rights 1966 ("ICESCR") includes the right to timely and appropriate health care, stating that health facilities, goods and services should be accessible to everyone without discrimination. This comprises physical accessibility, economic accessibility, information accessibility and nondiscrimination – where health facilities, goods and services are available to all but especially to those who are vulnerable or marginalised. Article 12.2 (d) of the ICESCR deals with the right

to the 'provision of equal and timely access to basic preventive, curative, rehabilitative health services and health education'. (International Covenant on Economic, Social and Cultural Rights, Article 12.2 (d), ICESCR (1976).

Articles 2.2 and 3 of the Covenant also prohibit discrimination in access to health care on a number of grounds, including physical or mental disability and health status. (International Covenant on Economic, Social and Cultural Rights, Article 2.3 & 3, ICESCR (1976).

The international community's support for the ideal of primary healthcare for all was first articulated in the Alma Ata Declaration of 1978. (Declaration of the Alma Ata, World Health Organisation,http://www.who.int/publications/almaata_declaration_en.pdf). It affirmed that health, which is a state of complete physical, mental and social well-being, and not merely the absence of disease or infirmity, was a fundamental human right and that the attainment of the highest possible level of health is a world-wide social priority and its realization requires action in other social and economic sectors beyond just the health sector.

Following the Alma Ata Declaration, the UN adopted the UN General Assembly's Standard Rules on the Equalization of Opportunities in 1993. (Compendium of the International and Regional Instruments, United Nations Enable, http://www.un.org/esa/socdev/enable/compendium.htm). These rules cover all aspects of life for people with disabilities and names preconditions and target areas for equal participation as well as implementation and monitoring measures. Although not specifically mentioning health services, Rule 5 of the UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities considers "accessibility" with reference both to the physical environment and to information and communications services. (The Standard Rules on the Equalization of Opportunities for Persons with Disabilities, United Nations Enable, http://www.un.org/esa/socdev/enable/dissre00.htm).

Further, in 1997, the General Assembly identified accessibility as a priority in promoting the equalization of opportunities for people with disabilities (U.N. General Assembly, Implementation of the world programme of action concerning disabled persons, Res.54/388, Sess. 54, U.N. Document available at ://www.un.org/disabilities/default.asp?id=46.)

This shows that a focus on accessibility is crucial to reversing exclusion and enhancing equalization of opportunities for persons with disabilities.

Thus many international treaties and instruments clearly focus on equal access to health facilities and services for all without discrimination.

(ii) The PWD Act and Other Domestic Legislation

The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995 ("PWD Act") was enacted in 1995. The enactment of the PWD Act brought with it the first glimpses of legal recognition of the socio-economic rights of persons with disabilities in India. Unfortunately, the PWD Act falls short of expectations and fails to provide the comprehensive protection of legal rights of persons with disabilities as it does not address concerns regarding the right to equal access and the right to non-discrimination of persons with disabilities.

The PWD Act has very few provisions regarding the right to healthcare. Section 25 of the PWD Act mandates the government to take appropriate measures for early detection, screening and prevention of disabilities, provide training to staff at primary health centres, organise or help organise awareness campaigns to disseminate information, and provide pre- and post-natal care to both mothers and children. Section 42 directs the Government to formulate and implement schemes to provide aids and appliances to persons with disabilities, and lastly, Sections 66 and 67 of the PWD Act mandate the government to undertake social security measures in the form of rehabilitation and insurance schemes for persons with disabilities.

Thus, conceptually, the PWD Act covers the aspect of healthcare only under three headings: (i) Early Detection and Prevention, (ii) Provision of Aids and Appliances, and (iii) Rehabilitation. These provisions are limited and do not adequately guarantee the right to health to persons with disabilities. The right to equal access to health and non-discrimination in healthcare services finds no mention under the PWD Act, and the PWD Act applies only to public institutions rather than including private institutions and hospitals, thus failing to fully comply with the UNCRPD.

The PWD Act also recognizes only 7 categories of disabilities, namely, blindness, poor vision, hearing impairment, locomotor disability, leprosy, mental illness and mental retardation. Other categories of disability have not been recognized in the 1995 Act and such a restrictive definition of disabilities affects the rights of persons with unrecognized disabilities.

While leprosy is included as a disability under the law, the PWD Act fails to take positive ameliorative measures for persons with leprosy. Leprosy still exists in a significant percentage in India and this community suffers the greatest prejudice despite being covered by the Act. There have been reported cases that women with leprosy have been thrown out of hospitals because of the stigma attached; social bias is so great that positive rights need to be provided to comprehensively cover the general health needs of persons with leprosy.

Other national legislation on disability includes The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999, which only relates to the setting up of a national trust for people with certain disabilities and for appointment of guardians. It does not cover health rights in any manner.

The RCI Act

The Rehabilitation Council of India Act, 1992 establishes the Rehabilitation Council of India, which lays down standards and qualifications for all rehabilitation professionals in the country, provides for the recognition of rehabilitation professionals, prescribes standards for rehabilitation courses and recognition of courses offered by universities and institutions and lays down standards of professional conduct and ethics for rehabilitation professionals. However, mental health illness has not been included under the Rehabilitation Council of India mandate.

The Mental Health Act 1987

The Mental Health Act 1987 provides for the admission of mentally ill persons to psychiatric hospitals or psychiatric nursing homes, for facilities for establishing guardianship or custody of mentally ill persons, and for the establishment of Central Authority and State Authorities for Mental Health Services. It also

regulates the powers of the Government towards establishing, licensing and controlling psychiatric hospitals and psychiatric nursing homes for mentally ill persons. Although the Mental Health Act provides for psychiatric hospitals and nursing homes, it does not make any mention of the rights of the mentally ill to dignity and treatment with consent. This is largely due to there being no legislation in the country recognizing the right to equality and equal treatment of persons with disabilities.

All the above laws address certain specific themes without any of them providing the core rights of equality and non-discrimination. Apart from existing legislation, there are numerous bills and pending legislation on disability. A draft Mental Health Care Bill, 2013 has been prepared by the Government. (The Mental Health Care Bill 2013 (available at http://www.prsindia.org/administrator/uploads/general/1376983253~~mental%20health%20care%20bill%202013.pdf)

There are criticisms as to whether having a separate law for persons with psychosocial disabilities would be a good idea because this group is always marginalized within the disability movement and a separate law would reinforce such marginalization.

Similarly, there is a draft Rights of Persons with Disabilities Bill, 2014 introduced by the Ministry of Social Justice and Empowerment in the Rajya Sabha that seeks to replace the Persons with Disabilities Act 1995. (The Rights of Persons with Disabilities Bill 2014 available at http://www.prsindia.org/uploads/media/Person%20with%20Disabilities/The%20Right%20of%20Persons%20with%20Disabilities%20Bill.pdf)

The government seeks to bring existing legislation in India on disability in line with the UNCRPD to which India is a signatory. With such a new bill, policy-makers and disability rights activists are actively attempting to ensure that the social model of disability is adopted by the legislation, thereby aiming to change attitudes towards disability in society. There is also a proposed draft National Health Bill, 2009, which provides an overarching legal framework recognizing the right to health. (The National Health Bill 2009, available at http://www.prsindia.org/uploads/media/Draft_National_Bill.pdf)

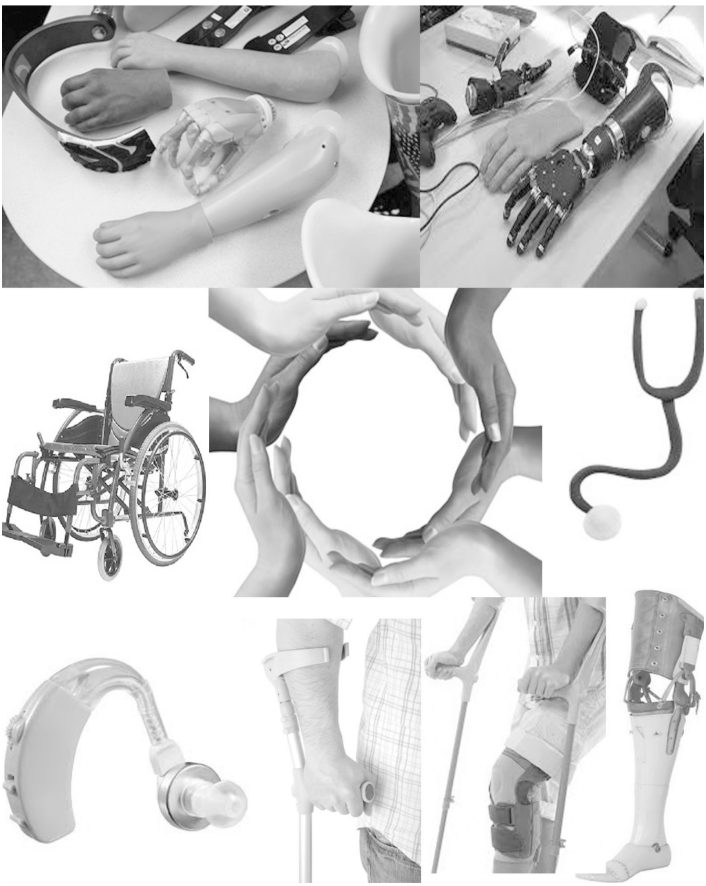
(iii) Case Law on the Right to Health

The right to health has been held to be a fundamental right in India by the Supreme Court under the ambit of the right to life protected under Article 21 of the constitution. In Consumer Education & Research Centre v. Union of India (Consumer Education & Research Centre v. Union of India, AIR 1995 SC 922) the Supreme Court held that the expression of the term 'life' as understood in Article 21 of the Constitution includes a much wider meaning of the term life, which includes the right to livelihood, better standard of life, and hygienic conditions. It also held that the right to health is a fundamental right under Article 21, to be read with Articles 39(e), 41, 43, 48A.

In Paramanand Katara v. UOI, (Paramanand Katara v. UOI, AIR 1989 SC 2039) the Supreme Court held the right to emergency medical treatment as an important facet of the Right to Health. It held that every medical practitioner was obligated to treat patients considered as emergency cases and that every individual has the right to prompt and effective medical treatment at the time of medical emergency. In Paschim Banga Khet Mazdoor Samity and Others v. State of West Bengal (Paschim Banga Khet Mazdoor Samity and Others v. State of West Bengal, AIR 1996 SC 2426), the Court held that by virtue of Article 21 of the Constitution of India, State Governments were obligated to provide adequate and proper medical facilities to all. The Court thus recognised the right to proper and adequate health care facilities as a right integral to the right to life under Article 21. It is thus an obligation of the State to ensure that persons with disability have access to quality healthcare.

In Suchita Srivastava v. Chandigarh Administration (Suchita Srivastava v. Chandigarh Administration, AIR 2010 SC 235) the Supreme Court had to decide whether a woman with mild retardation who was pregnant after a rape had the autonomy to decide against an abortion, and to what extent. By stating that "the State does have an important and legitimate interest in preserving and protecting the health of the pregnant woman," (21 ibid), the Court affirmed the sexual autonomy of the individual regarding her reproductive choices. Further, the Court also articulated the responsibility of the State to provide adequate healthcare to persons with disabilities.

The right to public health care was decided in the celebrated South African Constitutional Court decision in Minister of Health v. Treatment Action Campaign (Minister of Health v. Treatment Action Campaign, 2002 (5) SA 703), which revolved around access to the drug Nevirapine that prevented the transmission of HIV from mother to child. The Constitutional Court of South Africa held that right to access public healthcare in the South African Constitution placed the government under a constitutional obligation to achieve the progressive realization of this right. The Court ordered that the drug be made available at all healthcare centres of the country.



IV. DIMENSIONS AND PROBLEMS OF EQUAL ACCESS

It is an established fact that people with disabilities use public health services more than people without disabilities. Not only do they need health care and treatment for their disabilities, but also many people with disabilities need to take care of secondary health conditions like pressure sores, fatigue, pain, etc. for which they need medical care (The Current State of Health Care for People with Disabilities, National Council for Disability, http://www.ncd.gov/publications/2009/Sept302009)

Thus ironically, while people with disabilities use the health care system much more than others, there exists qualitatively poor health care services and ineffective access to health care facilities for them. The lack of specially trained health care practitioners, doctors and staff coupled with poor infrastructure and ill equipped hospitals and clinics, paint a very bleak picture for persons with disabilities seeking treatment and medical care especially suited to their needs. Added to this are issues of both physical and financial access, as well as discrimination and a failure to provide preventative and rehabilitative care. Accessibility needs to be made mandatory as a requirement of reasonable accommodation. The underlying justification for reasonable accommodation provisions lies in the social disability model – a model that focuses on how environmental barriers and not the person's disability is the cause of impediments. In other words, it is not a wheelchair user's disability that prevents him or her from accessing modes of transport, but instead it is the bus's lack of being designed as wheelchair friendly that causes the inaccessibility.

In the case of Syed Bashir-ud-din Qadri v. Nazir Ahmed Shah and Others (Syed Bashir-ud-din Qadri v. Nazir Ahmed Shah and Others, 2010 3 SCC 603), the Supreme Court recognized for the first time, the concept of reasonable accommodation. The Supreme Court stated that the doctrine of reasonable accommodation includes the provision of aids and appliances to enable a person with disability to carry out their daily duties effectively.

The same concept needs to be applied to providing health care that is accessible to all persons with disabilities. Accessibility, or lack of thereof, can be obvious, invisible, and at times insidious in preventing persons with disabilities from enjoying their right to health. It is an issue at nearly all levels of the healthcare system. Although questions of accessibility are complex and nearly inextricable from wider societal and administrative problems, this report attempts to isolate some of the most significant dimensions of accessibility that need to be addressed if we are to ensure persons with disabilities are able to exercise their right to health. Starting from the most basic elements, the structure of this section roughly mirrors the experience of persons with disabilities in the healthcare system, including:

a. awareness and training,
b. medical classification,
c. early intervention,
d. physical access,
e. financial access,
f. discrimination,
g. rehabilitation.

(i) Awareness and Training

A systemic problem with accessibility for persons with disability is inadequate awareness and training of health care professionals at various levels. The recognition of the right to health means that there should be trained medical staff at health care centres for persons with disabilities, yet there is a huge lack of medical staff that is trained or even sensitized to the needs of persons with disabilities. The schemes introduced by the government must make provision for efforts to train and educate doctors and medical staff so as to bring about a positive change in the quality of medical services offered to these people. These schemes must also work towards creating a sense of co-operation among different governmental and non-governmental organizations while actively encouraging their participation in taking up measures to address the health care needs of persons with disability.

This lack of awareness and training is not specific to any one disability, however taking a few particular disabilities as examples serves to illustrate the point.

a. **Haemophilia**: With the case of haemophilia, for example, there is such lack of awareness that even doctors are not aware of its symptoms and causes.

Haemophilia is an "invisible disability", i.e., there are no visible signs of a disability and therefore it is difficult to get certification of any kind. Physiotherapy for haemophilia is essential but very little knowledge of the same is available.

b. **Thalassemia**: Thalassemia is another condition, which has been grossly overlooked due to lack of awareness. Statistics reflect that one in thirteen people have thalassemia – dominant or passive (About, Thalassemia, http://www.thalassemia.org) The mortality rate is high because of lack of awareness and knowledge. If proper care is provided, then it is possible to live over 40 years with thalassemia. The Cochin Zonal Report recommended, for instance, that thalassemia be classified as a disability so that individuals can get certificates and pension and insurance benefits. The report also recommended genetic screening and counseling for thalassemia.

c. **Muscular Dystrophy**: Lack of awareness and sensitization is also a problem for persons with muscular dystrophy. Muscular dystrophy is progressive in nature and is caused by a genetic mutation. With genetic counseling, families can be made aware of how to help a person with muscular dystrophy, yet medical staff often do not recognize muscular dystrophy as such and lack the awareness to deal with it appropriately. There is an urgent need for caregivers, counselors, family members and health care professionals to be sensitive towards the needs of persons with disabilities. One way to help solve this problem would be to better organize and regulate the caregiving profession itself, for instance, by recognizing certain rights of caregivers and attendants by regulating or unionizing their employment. Also, training institutes could operate at a micro level with certification at several levels, with healthcare professionals training caregivers on how to cater to the needs and comforts of persons with disabilities. Healthcare professionals lack awareness of disabilities and usually, during check-ups, the doctors blame the health issues on the disabilities. There is a need to introduce a course on disability related issues such as rehabilitation and special healthcare needs of persons with disabilities in the MBBS curriculum.

One respondent in our study remarked that had his spinal cord injury been treated appropriately, with the right kind of medication and had medical care been. administered immediately after he was brought to the hospital, then his recovery would have been much easier. He stated that the lack of proper knowledge on the

part of the medical staff and the fact that he was only allowed to receive treatment after filing a police report (as his injuries were caused by gun shots) considerably changed the course of his recovery. In fact, several respondents felt that there is a serious dearth of trained medical personnel who could offer them timely and effective medical attention. Staff at hospitals, including medical practitioners, are largely insensitive and ignorant of the unique problems affecting persons with disabilities. During the zonal consultations, many participants recounted their personal experiences that doctors would usually link a particular ailment to the disability, even though there was no connection.

This shows that even the doctors need to be trained and sensitized to understand that persons with disabilities do face health issues that are common to all and that the disability is not the cause of all health issues. In addition to improved training and awareness among medical practitioners, several zonal reports recognized a need for greater awareness and training, both at the panchayat level and also among Disability Commissioners.

(ii) **Classification of Disabilities**

Related to the problems of awareness and sensitization are the gaps in proper classification of disabilities and this is a problem even with medical professionals.

a. **Autism**: For instance, autism is not traditionally covered by the MBBS curriculum as a disorder and legislation such as the PWD Act, which does not include autism, means that a child having autism would not get a disability certificate or would get a disability certificate stating that he or she has mental retardation or mental illness. This is highly problematic as mental retardation and mental illness and autism are entirely different categories of disabilities. The Kolkata Consultation Report emphasizes that autism is often misdiagnosed as a mental illness, rather than as a developmental disability, its proper classification. The Cochin Consultation recognized that this misclassification and lack of sensitization around autism also often resulted in heavy overuse of psychotropic drugs, adversely affecting persons with autism.

b. **Deaf-blindness**: Even in cases of patients with deaf-blindness, multiple disabilities, and the hearing impaired,

misclassification is a problem. Most states do not accept deaf-blindness as a separate category of disability and medical boards do not issue certificates mentioning "deaf-blindness". These kinds of misclassifications and knowledge gaps can have tragic consequences. For example, a common misunderstanding is that a person who is born with a hearing impairment will always have a speech impairment. Due to this ignorance, most children are not treated correctly for their form of disability and not even taught to speak. There are also communication gaps, especially with young girls around the age of puberty, where they are unable to communicate their uneasiness, which leads to behavioural issues and eventually a misdiagnosis.

The problem with classification will be inherent if we are to have a medical model of disability wherein only restricted forms of disability are covered under the law. In the PWD Act, only seven forms of disability are covered and a person with disability is one who has 40% or more of any of the seven disabilities. A more progressive approach would be to take the guidance of the UNCRPD, which defines persons with disabilities as including "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others" (UN Convention on the Rights of Persons with Disabilities, Article 1, UNCRPD (2006)

This legal approach, if adopted, will result in better facilities at hospitals and healthcare centres, thereby improving the institutional responsiveness to persons with disability.

(iii) **Early Intervention and Preventive Care**.

One of the biggest issues of access to health care for persons with disabilities lies in the failure of the healthcare system to anticipate health problems of persons with disabilities and to provide early intervention. The PWD Act emphasizes early intervention measures and Section 25 of Chapter IV of the PWD Act deals with the prevention and early detection of disabilities. According to Section 25, government and local authorities must take measures to reduce the incidence of disabilities and their related health concerns by:

a. Undertaking surveys, conducting investigations and researching the underlying cause and origins of disabilities,

b. The promotion of different preventive methods,

c. The process of screening all children at least once a year, for the purpose of identifying at-risk cases,

d. Imparting training to staff at primary health centres,

e. Sponsor and promote awareness campaigns that spread information about general hygiene, health and sanitation,

f. Measures that contribute towards better pre-natal, post-natal care for both mother and child,

g. Educating the general public through the work of pre-schools, schools, primary health centres, village level workers and aanganwadi workers, and

h. Spreading awareness amongst the general public on the causes of disabilities and their preventive measures through television, radio and other mass media outlets.

There are several early intervention schemes that have been introduced by the Central Government, namely: the National Program for the Control of Blindness,National Program for the Prevention and Control of Deafness, National Leprosy Eradication Program, Pulse Polio Immunization Program, Integrated Child Development Schemes, National Health policy and Child Survival and the Safe Motherhood program. A good example of an effective government scheme would be the Bal Arogya Abhiyan, which is focused on early detection and screening. Under this scheme, the government screens all children up to the age of 18 in all schools for any kind of disability. Although at the state level there are a few projects for prevention, early identification, intervention and rehabilitation of disability and its complications, it has largely been ignored in primary health care services by the State. Consequently, early identification of disability is not a priority for health care providers. The effective implementation of these sorts of initiatives requires a comprehensive strategy for expanding public health care centers and involving communities and organizations in disability prevention and rehabilitation. The need for this is highlighted in the answers of an overwhelming majority of persons who answered our questionnaires. Most never received early intervention and preventive care, which, according to most caregivers, would have had a tangibly beneficial impact on the patient. The family also plays an important role in early intervention processes. In most cases, families are not aware of

the advantages of early intervention and are often not guided by their consulting doctors on the same.

Addressing the need for specialized and preventative health care is complicated by the lack of accurate data. There is a complete dearth of information relating to the numbers, magnitude and nature of problems faced by persons with disabilities. This lack of information has led to the creation of systemic gaps in the health care system and undermined preventive care facilities. The low incidence of effective early identification and intervention in disability related health cases is related to the poor data collection practices of several Government authorities. In fact, children with disabilities are the concern of not one single ministry; rather their issues come under the purview of the Ministry of Health and Family Affairs, as well as the Ministry for Social Justice and Empowerment. This lack of concentration results in fragmented and incoherent government data.

According to the data collected by the organization Childline, around one third of most disabilities in children are preventable. (The Essentials of Child Protection, Publications, http://www.childlineindia.org.in/publications.htm)

Research shows that children are most responsive to treatment up to six years of age. Thus early identification and intervention can yield significant and positive outcomes in qualitatively improving the lives of children with disabilities. (Ibid) The Cochin Consultation echoed the need for early intervention and recommends notification of a legal provision to force parents to send children for early intervention, since there is none currently in the Juvenile Justice Act or elsewhere.

In rural areas, intervention is highly delayed because of the scarcity of trained professionals in primary healthcare centres or district hospitals. The Delhi Consultation identified a particular lack of pediatricians and specialists in rural areas. For many who are living in poverty, it boils down to the question of loss of daily wage versus right to health of the child. Even to take a child for regular intervention sessions would mean a loss in a day's worth of earnings. A cursory examination of some particular disabilities further demonstrates the need for more effective early intervention. Regarding multiple sclerosis, for example, the data in India reflects a relatively small number of cases, the reason for which could be either because it is less diagnosed or

less known, and therefore it is often misdiagnosed. The nature of multiple sclerosis is such that it affects various parts of the brain, which in turn affect several parts of the body. The various symptoms can take a long time for recognition but multiple sclerosis can be diagnosed through an MRI scan of the brain. For this reason, the focus of healthcare for persons with multiple sclerosis should be on early diagnosis, rather than later stage symptom treatment.

In response to our questionnaires, many respondents stated that while their disability was detected at a government primary health centre, they did not receive any early intervention treatment, nor did they receive any implants or surgeries. Many persons with disabilities such as multiple sclerosis, Down Syndrome, cerebral palsy, mental retardation and spinal cord injuries stated that early detection and treatment could considerably reduce the discomfort caused by their disabilities, sometimes even completely healing them. They responded that early detection of their disability and treatment by the appropriate specialized medical unit would have considerably alleviated their stress and suffering. However, such crucial early intervention and preventive measures are not often offered. Few of our respondents stated that they received early intervention in the form of corrective surgeries such as cochlear implant surgeries to aid in the improvement of speech and language.

Early intervention is not just a requirement for children, but for adults and the elderly as well. The Indian ethos encourages the idea that old age is a time for illness and health problems to set in, therefore inadequate attention is given to these problems. The elderly form a different social group for the mainstream healthcare system. They largely suffer from difficulty in mobility, partial or complete blindness, partial deafness, difficulty in moving joints, etc. Some of the major problems such as Alzheimer's require full time medical care and require well-trained caregivers and attendants, who are able to understand the needs and problems of elderly people with disabilities. This opinion is also shared by doctors, parents and caretakers who feel that early intervention, diagnosis and treatment are very important for all, including elderly persons.

The Government has initiated and proposed several schemes for early detection at the Central, State and District Levels in order to reduce the incidence of disability and its allied health

concerns among people from all parts of India. Many schemes and programmes issued by the Government already focus on practices of early screening and preventive care. While some of these schemes are meant for all persons, there are others specially introduced to benefit persons with disabilities. How effectively these schemes are being implemented, however, is questionable.

(iv) **Physical Access to Health Care:**

One of the biggest hurdles in equal access to health care for persons with disabilities is physical access to health centres. Article 9 of the UNCRPD states that state action must be taken with regard to ensuring that persons with disabilities have equal access to the physical environment, transportation, information and communications (including information and communications technologies and systems) and other facilities and services open or provided to the public, both in urban and in rural areas. This ties in with Article 19 and 20 of the UNCRPD which emphasises the right to an inclusive, yet independent life accompanied by the right to personal mobility which may be furthered through access facilitated by external aids and appliances. Articles 44, 45 and 46 of the PWD Act, strongly emphasise the need for non-discrimination in the areas of transportation, roadways and buildings – the measures to be undertaken by the Government must include accessible toilets, engraved zebra crossings, railway platforms and pavements for better wheelchair use; the use of Braille symbols and auditory signals in elevators; and ramps in hospitals, primary health care centres and other medical care and rehabilitation institutions. Additionally, the Delhi Consultation Report recommended the use of Braille on medicine bottles so that the visually impaired may be able to take their prescriptions on their own. However physical accessibility in health care centres and hospitals is not being implemented in the country. UNCRPD INDIA released a baseline report on accessibility in February 2009 which was meant to highlight access problems. (Baseline Report, UNCRPD India,http://uncrpdindia.org/files/reports/Baseline-Report-Accessibility.pdf)

Noticeable, however is the complete lack of data relevant to health care or health care facilities and physical access. There is however a Draft Report on Indian Accessibility Standards (Recommendations for Buildings and Facilities for Inclusion of Persons with Disability) submitted by members of Accessability,

which is currently under review (ibid). It is obvious from a look at the existing data, that there is a paucity of guidelines and regulations for ensuring physical access of persons with disabilities in public places. This includes accessibility and removal of architectural barriers in hospitals and health care facilities.

The issue of the accessibility of medical institutions is a serious one. In a study done, it was found that not a single medical institution in India was completely accessible to persons with disabilities due to physical barriers in libraries, lecture halls, and hospital campuses (ibid). The Medical Council of India has now issued directions to the Deans/Principals of all the medical colleges/institutions in India to submit compliance reports on access facilities for persons with disabilities (Gaurav Vivek Bhatnagar, MCI asks all medical institutions to be 'accessible'. The Hindu (18/04/2013), available at http://www.thehindu.com/todays-paper/tp-national/tp-newdelhi/mci-asks-all-medical-institutions-to-be accessible/article4628862.ece)

In response to our questionnaires on the issue of access, many respondents stated that government hospitals did not have ramps and only had stairs. While some hospitals may have ramps and elevators, there were no special railings, platform lifts or accessible bathrooms. Sometimes the angle of the ramp was too steep, causing difficulty. Many respondents having locomotor disabilities reported that they often found hospitals and health care facilities inaccessible. Respondents reported that there were no facilities for children available. For example, hospitals often do not have special wheelchairs for children. One respondent stated that he avoids his regular medical checkups because of the inaccessible nature of the health care centres he visits.

Another respondent stated that he avoids getting X Rays and scans owing to the narrow and uncomfortable tables he is asked to lie on which frighten him due to his involuntary reactions. One respondent stated that he ignores his health check-ups due to the inaccessible environment and insensitive doctors. Respondents stated that they often have to wait for hours at hospitals without any proper arrangements for resting or lying down. There is also a need to ensure that healthcare equipment is designed keeping in mind the needs of persons with disabilities and this was recommended in the South Zone Consultation in Cochin. For example, hospital beds are not wide enough to accommodate

persons with certain developmental disabilities. Many times, patients live in highly insalubrious conditions without adequate food, care and shelter. All these issues need to be addressed, as they only aggravate the problems faced by the patients.

Thus, clearly the experience of persons with disabilities show that physical accessibility in health care centres and hospitals is a huge issue that needs to be addressed if we are to ensure that the right to health of persons with disabilities is guaranteed.

a. The need for interpreters: Another big issue for access is the requirement of interpreters in hospitals and health care facilities. Most respondents to the questionnaires stated that they go to their health care facilities accompanied by their own interpreter. Only some stated that the hospitals or health care centres provided interpreters. The issue of sign language interpreters is a concern as there are in sufficient interpreters available and no effort is being made by hospitals to ensure that they have sign language interpreters available with them for persons with hearing impairment. This issue was raised in the case of The National Association for the Deaf vs. Union of India and Others(The National Association for the Deaf vs. Union of India and Others, 177(2011)DLT707) filed by the National Association for the Deaf before the Delhi High Court on the non-availability of sign language interpreters in public services. The petition complained of the lack of availability of an adequate number of sign language interpreters in various public places including hospitals and sought directives against the Ministry of Social Justice and Empowerment and other authorities to ensure access and better training of sign language interpreters. The Court noted the lack of availability of sign language interpreters, it agreed with the Petitioner Association that due to non-availability of interpreters, the hearing impaired were unable to avail themselves of medical, transport and banking facilities and also police help. The Court relied on the UNCRPD and held: "The United Nations Convention on the Rights of Persons with Disabilities adopted by the General Assembly and ratified by the Govt. of India on 1st October, 2007 also provides for taking appropriate measures to provide forms of live assistance and intermediaries including guides, readers and professional Sign Language Interpreters to facilitate accessibility to buildings and other facilities open to the public. Needless to state that all the said

rights are composite part of life enshrined in Article 21 of the Constitution of India "(Supra 30. courses and curricula for training of interpreters) Based on this, the Court issued specific directions to the respondent authorities, which included undertaking a survey to assess the availability and requirements for sign language interpreters, appointing nodal officers to seek information from concerned authorities and preparing a report to be used for the creation of new posts. It remains to be seen now whether the number of sign language interpreters appointed by public hospitals and health care centres will increase and if such employment is mandated. From the discussions at the zonal consultations, it would seem that despite the Court's orders, most hospitals lack sign language interpreters. The issue of interpreters in hospitals was also examined in the celebrated Canadian case of Elridge v. British Columbia, (Elridge v. British Columbia, [1997] 2 S.C.R. 624) in which the Canadian Supreme Court held that the failure to provide interpreters amounted to discrimination, as it was not merely an issue of internal hospital administration, but rather a question of how government policy was being effected. The Court called this adverse effects discrimination in that the need for sign language interpreters must not be looked at from the perspective of those persons not living with disabilities, but as a pre-requisite for persons living with disabilities, in their pursuit to access and benefit from what is being termed as comprehensive medical service. The reasoning of the court in the Elridge case carries forth a resounding need to re-consider the manner in which we choose to devise accessible health care services for persons with disabilities. Hospitals in India are quite inaccessible to persons with visual impairment. There are no directions given in Braille and the infrastructure is not disabled-friendly. A person with a disability cannot go to the hospital alone and always needs a companion. In the case of visually impaired persons, medicine bottles and tablet strips do not come with Braille instructions and in order to consume medicine, a person with visual impairment always requires the assistance of others. Hence, as written earlier, it is necessary that hospitals and government offices have sign language interpreters as it is an important means of communication for persons with speech and hearing impairment.

b. Accessible Transport Services: If there is no transport that is accessible for persons with disabilities, then even being able

to travel to a health centre for a health checkup or medical treatment would be impossible. Having accessible hospitals and health care centres would be meaningless if there was no accessible transport for persons with disabilities to get there. Equal access to transportation is not simply a right in itself, but a means to the enjoyment of other total rights. (Sharon Rennert, All Aboard: Accessible Public Transportation for Disabled Persons, New York University Law Review 63 (1988).

Many respondents stated in the questionnaires that there should be accessible transport facilities in order for them to access health care. In some cases, the health care schemes provide concessions only at certain hospitals, which are located far away without accessible transport, due to which those schemes cannot be utilised. Most often the primary health centres are not well-equipped with medical facilities so one is required to travel to the district hospitals for basic treatment. Due to the difficulty in traveling long distances to the district hospitals, many persons with disabilities are unable to receive treatment at the proper time. Transport facilities for persons with disabilities have to be factored into health care schemes and there needs to be a policy which requires hospitals to provide transport facilities to patients who have disabilities.

(v) **Financial Access**

A big hurdle to accessing adequate health care, aids, and corrective surgeries for persons with disabilities is the financial barrier. The National Policy on Disability interestingly refers to several programs for financial assistance for persons with disabilities in the field of employment but none for access to health care.

a. Government Schemes: While there are several kinds of government schemes that are available for providing financial assistance for medical care, purchase of aids and appliances and for surgeries, they are woefully inadequate. Participants in the study stated that government health care schemes provided insufficient financial assistance for medical treatment and health care. One respondent remarked that the assistance provided to him for his treatment by the Government was Rs. 75,000/- when the actual cost of his treatment was more than Rs. 10,00,000/-. Many respondents

were not at all aware of these schemes, indicating that these schemes need to be advertised a lot more. Many respondents also stated that application processes for these schemes were too lengthy and complicated.

b. Aids and appliances provided are not suitable: There are more schemes for purchasing aids and appliances but insufficient schemes for financial assistance in health care, medical treatment and corrective surgeries. One respondent stated that he uses an ordinary wheelchair as the specialized one is unaffordable. Wheelchairs that are being given out under various schemes by the State and Central Governments do not fit in most of the houses that the beneficiaries live in and therefore the wheelchairs are left outside to rust.

c. Health Insurance: Almost all respondents stated that it was difficult to obtain health insurance as persons with disabilities. Ideally disabled people should be able to access the government and private insurance (Government Initiatives for Redressal of Disability in India, MOSPI, available at http://mospi.nic.in/Mospi_New/upload/disablity_india_statistical_data_11mar2011/Chapter%208%20-National%20redressal.pdf) schemes easily as they require it more than others. But the reality is that many people with disabilities are being denied insurance on the grounds of their 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. If people have some kind of a mental disability, then obtaining insurance is almost impossible, especially for disabilities such as schizophrenia. The Niramaya insurance scheme was primarily initiated by the National Trust because of this reason and this has been reported to be by far the most used insurance scheme by all the respondents who answered our questionnaires. (Nirmaya Scheme, The National Trust, available at http://www.thenationaltrust.co.in/nt/images/stories/Niramaya_updates/niramaya%20-%20scheme.pdf). This is a health insurance scheme for the welfare of persons with autism, cerebral palsy, mental retardation and multiple disabilities. The scheme envisages delivering comprehensive coverage which will have insurance cover up to Rs.1,00,000/- (Rupees One Lakh only) and that there would be no exclusion for any pre-existing condition. The Treatment can be taken

from any hospital from anywhere. The entire scheme may be implemented & monitored by the National Trust through registered organisation with the active participation of the Local Level Committees.

(vi) **Discrimination**

This report has largely framed the question of access in terms of the need for equality and gaps in equality. Closely linked, however, is the question of discrimination and how certain groups are actively or systematically prevented from exercising their right to health. Are persons with disabilities being provided access to health care on equal terms as other citizens who are not disabled? Are there violations of their rights to dignity and privacy? The analysis of the questionnaires shows that this discrimination is indeed a large problem. The treatment of persons with disabilities at almost all healthcare centres, both public and private, has been found to be extremely unequal and discriminatory.

a. Women with Disabilities: With regard to special services for women with disabilities, especially reproductive health, the availability of health care has been almost non-existent. This discrimination on the part of medical staff stems from inadequate training as evinced from the answers of doctors and healthcare practitioners to our questionnaire. This absence of exposure to persons with disabilities (especially psychosocial disabilities) coupled with a lack of training leads to insensitivity while treating the patient. Women with disabilities responded that they did not get information or assistance about their health issues, especially with regards to fertility and reproductive health concerns. Indeed, the Cochin Zone Consultation found an overall lack of attention in disabilities policies to issues such as gender, age, and urban/rural environments. The lack of informed consent is a particular issue of concern for women with disabilities. First, the doctors and healthcare professionals do not provide them with adequate information. Secondly, the woman is usually not allowed to make the decision. Often women with disabilities are considered to be asexual and the concept of a family seems alien. The decision to undergo a particular treatment is taken either by the husband, the father or other caregivers and members of the family. Abortion is imposed on women often without their consent, notwithstanding

the decision of the Supreme Court in Suchita Srivastava v. Chandigarh Administration. The Cochin Zone Report cites mass hysterectomies, which have been performed on women in mental health institutions.

b. Children: Hospitals often did not have facilities for children with disabilities. Respondents stated that hospitals did not have any material to keep children engaged such as toys, reading material or playing rooms and thus getting medical treatment for children with disabilities was extremely difficult when they were made to wait in hospitals for the entire day.

c. Consent: One of the most common ways which persons with disabilities are discriminated against is through disrespect their consent. Treating the person with a disability as a subject with emotion requires the element of consent for all procedures. However, as some of our care givers answered in the questionnaire, doctors very often do not ask for consent while adopting a very patronizing, paternalistic approach towards persons with disabilities. Consent becomes a bigger issue when it comes to persons with psychosocial disabilities, where the problem is compounded because a common understanding amongst medical practitioners is that a person with psychosocial disability does not have the capacity to make decisions. One caregiver responded stating that doctors in the private hospital which she attends often take videos of her son with a psychosocial disability which are then aired in conferences sans any form of consent. Clinical trials are another issue faced by patients. Though informed consent is mandatory for clinical trials, in most cases, healthcare professionals conducting clinical trials do not provide detailed information on the effects of the trials. There is unequal bargaining power between the doctors and patients and thus, patients are made to be a part of clinical trials because of their desperate situation. In such cases, the right to health is completely violated. Indeed, the Mumbai Consultation recognized the lack of respect for informed consent and for incorporating persons with disabilities into decision making, and recommends that the Medical Council of India and doctors in general be brought under the strict purview of the anti-discrimination and equal rights provisions of the PWD Act.

d. The right to privacy and dignity: Most respondents felt that their rights to privacy and dignity were not protected during medical examinations. Persons with disabilities are routinely examined in the presence of other patients. For instance, one respondent stated that he was required to produce a picture of his legs without his trousers in order to get a wheel chair. He was also not examined in private. Another patient reported that he was asked to disrobe in the presence of a female nurse. One respondent with multiple sclerosis stated that nurses and support staff at hospitals do not respect the patient's privacy and that they enter the rooms and patient quarters without prior permission. Sometimes they violate the patient's privacy by barging in on patients, when they are urinating. Sexual needs and privacy arising therein of persons with disabilities is often overlooked. The predominant presumption is that persons with disabilities are asexual beings. This makes them susceptible to violent sexual harassment and violation, even rape, as their autonomy over their bodies is seen as non-existent. Sexual autonomy is rarely conferred upon persons with disability, particularly those with a mental disability, and reproductive choices are seen as outside the purview of their mental abilities. All these situations show that the rights to privacy and dignity of persons with disabilities are not recognised. In the context of healthcare, these rights become all the more important as disabled persons are at the mercy of doctors and medical staff, and are not in a position to object to the treatment to which they may be subjected.

e. Persons with psychosocial disabilities: There are four main reasons for detailing the right to health for persons with psychosocial disabilities:

    1. There is additional and intense discrimination faced by persons with psychosocial disabilities and institutional lacunae render these institutions in inept at responding sensitively to their needs;

    2. The pervasive incidents of cruel and degrading treatment meted out by health professionals;

    3. The lack of free and informed consent prior to the

performance of procedures on persons with mental disabilities;

4. Discrimination faced by persons with psychosocial disabilities at the hands of medical institutions is far more widespread and intense than other disabilities. This is because of the deeply entrenched prejudice against those with mental disabilities.

The World Health Organization has identified eight reasons why persons with mental and psychosocial disabilities form a vulnerable group. Some of these reasons are high levels of physical and sexual abuse, lack of access to emergency healthcare services, systemic marginalization in education and employment, higher mortality rates and high levels of stigma and discrimination stemming from common misconceptions about the causes and nature of mental health conditions. (Disabilities, World Health Organisation, available at http://www.who.int/disabilities/world_report/2011/en/)The shocking consequences of this discrimination came to light in the Erwadi tragedy that witnessed the death of 40 mentally ill inmates during a fire because they were chained to their beds. This form of discrimination has pernicious consequences in the quest for access to health for persons with psychosocial disabilities. Misconceptions abound as to the nature of the problem, leading many to enlist the services of quacks who perpetuate the prejudice and exacerbate the health problems of individuals.

There is a need to remove stigmatisation and discrimination, as they are significant barriers to accessing health services. Informed consent is also not consistently secured on contentious issues like ECT and sterilisation. The Mental Health Care Bill 2013 proposes a completely new system, the Mental Health Review Commission, which will possess administrative and adjudicatory functions. These institutions will lay down certain minimum standards and serve to monitor compliance with the standards by medical institutions. The glaring problem with the Bill, however, lies in the fact that it reflects the health needs only of persons with psychosocial disabilities- an approach that is being actively opposed by civil society groups and disability rights advocates. A comprehensive health care bill including a right to health care for all persons with disabilities would be a better approach.

Concrete steps need to be taken to do away with the practice of institutionalization of persons with psychosocial disabilities. Instead, robust community welfare programmes will create a much more salubrious environment for persons with psychosocial disability to live in. The Kolkata Zone Consultation also found a need for much greater emphasis on rehabilitation programs for persons with psychosocial disabilities, to provide re-employment assistance and other services.

Responses to questionnaires have revealed just how pervasive incidents of cruel and degrading treatment of persons with psychosocial disability are. Incidents range from the taking of videos while treatment is being given to rough handling of such persons. This is a manifestation of the internalized notion that persons with a psychosocial disability are lesser humans than others. Further, consent is seldom obtained from either the patient or the caregiver for procedures performed. Practices such as Electro-Convulsive Therapy and sterilization are conducted on patients without any information given about the nature and consequences of the therapy. The 2013 Bill takes this into account to an extent by including the protection of the rights of persons with mental illness. Barriers to the right to access healthcare are most tangibly felt by persons with psychosocial disabilities. This is because of the pervasive discrimination and prejudice that exists in society against persons with mental illness. This bias is a result of widespread misinformation about mental health problem which is itself a result of the marginalization and social exclusion felt by these persons. It has also been shown by scholars that persons with psychosocial disabilities experience poorer health than the rest of the disabled community. According to several zone reports, these issues can be compounded for children and adolescents with psychosocial disabilities since there is a lack of sensitization and family support services for psychosocial disabilities among these categories of people. Further, even if the individual manages to avail himself or herself of healthcare in a medical institution, unlivable conditions encourage the spread of infectious diseases(tuberculosis, HIV/AIDS, hepatitis), skin infections and respiratory and intestinal disorders, thereby leaving the patient in worse condition than earlier. These deplorable conditions have also resulted in fatalities in mental health institutions. Therefore, there is

a formal right to access healthcare on paper but in practice, we are far from achieving it.

An inclusive right to access healthcare on an equitable basis without discrimination must be recognized and implemented. Constituents of an inclusive and meaningful right to healthcare include access to potable water, food, shelter and access to health-related information. Finally, required provisions need to be made to facilitate informed consent for contentious issues such as ECT or sterilization. Therefore, an inclusive right to access healthcare includes within its ambit not just the existence of institutions of medical health, but the extension of the concept of reasonable accommodation to include persons with disabilities.

V. RECOMMENDATIONS AND THE WAY FORWARD

The consultative process undertaken reveals that there is a long way to go for making the right to health for persons with disabilities a reality. Article 25 of the UNCRPD is not yet being implemented in any meaningful way in India.

In order to make the right to health a reality, it needs to be internalised by the government and the health sector and recognised as a right to be provided equally to all persons with disabilities. Some of the recommendations for making this right a reality would be the following:

A comprehensive law is needed: The enactment of a comprehensive law relating to the rights of persons with disabilities, which would cover the right to health care that is accessible and non-discriminatory and which is in conformity with Article 25 of the UNCRPD. Additionally, the pending Right to Health bill should be revisited and made to conform to Article 25 of the UNCRPD.

These bills should include the following:

a. all persons with disabilities are provided health care in accessible environments through accessible procedures and with reasonable accommodation. Domiciliary services should be available wherever required to attain universal coverage;

b. all schemes and programmes devised to realize health care rights, entitlements and benefits are universally available with due consideration accorded to gender, age and socio - economic status;

c. persons with disabilities have access to free or affordable quality health care close to their communities particularly in rural areas. Health care services may be provided through multi-disciplinary teams who may undertake early identification, intervention and referrals to more specialized agencies wherever required.

d. Ethical Guidelines on informed consent and confidentiality to be framed which are non discriminatory.

e. Provision of medical and life insurance to persons with disabilities on an equal basis with others;

f. Formulation of schemes and programmes with the participation and involvement of persons with disabilities and care-givers that inter alia makes provision for:

    1. the minimization and prevention of further disabilities with requisite education, training, information and intervention;
    2. the health care of persons with disabilities during times of natural disasters and other situations of risk ;
    3. disability specific equipment and accessible infrastructure at all health care centres; public buildings and places; and all other such places that may be notified by the appropriate government from time to time;
    4. 'essential medical facilities' for all life saving emergency treatment and procedures;
    5. sexual and reproductive health especially of women with disabilities;
    6. pre-natal, peri-natal and post natal care of mother and child;
    7. nutritional intervention for children with disabilities;
    8. psychosocial care and support at every stage of the medical process be it investigation, evaluation, diagnosis, treatment or intervention;
    9. access to all Primary Health Care services especially within rural areas and for the urban poor;
    10. free or subsidized treatment and medical services (surgery, therapy, medicines, pathology and follow up) for weaker and indigent sections, as required;
    11. coverage of medical expenses, travel allowances and therapeutic intervention within a comprehensive insurance scheme for persons with disabilities.

Certain disability-specific recommendations:

A. **Autism**: It is strongly recommended that there be diagnosis facilities in district hospitals for diagnosing and detecting autism.

B. **Thalassemia**: Blood transfusion facilities in each hospital with recovery rooms. Such facilities should be made available in all district hospitals.

C. **Haemophilia**: RH factor to be made available free of cost, and provision of screening of blood and factors for transfusion at all district hospitals / PHC levels

D. **Down's Syndrome**: It should be mendatory for expectant mothers above 40 or below 20 years of age to be tested for detection of Down's Syndrome. In Canada, for example, mandatory tests for Down's Syndrome are conducted 6 weeks into the pregnancy. There is no such requirement in India.

E. **Budgetary Allocations**: In order to make the right to healthcare for persons with disabilities achievable, it is important to increase the allocation of resources for health care in the budget. The Planning Commission of India, in the 12th 5 year plan, adopts an inclusive definition of health as "not merely an absence of disease but instead as a state of complete physical, mental and social wellbeing".(Twelfth Five Year Plan, Planning Commission, available at http://planningcommission.gov.in/plans/planer/12thplan/welcome.html)

Thus, in order to provide complete health coverage which would address the physical, mental and social well-being of all persons with disabilities, the budgetary allocations have to increase substantially and have to be spent on health care and related measures.

Annexure 1

Government Schemes on Health Care Services for persons with disabilities.

The schemes and programmes for health care services for persons with disabilities are listed under the broad themes of Early intervention and Preventive Care, schemes dealing with the sponsoring, delivery and maintenance of aids and appliances for persons with disabilities, schemes that provide financial assistance and schemes that provide social security to persons with disabilities.

A. Early Intervention and Preventive Care

The Government has initiated and proposed several schemes for early detection at the Central, State and District Levels in order to reduce the incidence of disability and its allied health concerns among people from all parts of India. The following section attempts to identify and briefly outline some of these schemes, emphasizing their utility in early intervention practices and preventive health care.

(i) **Deendayal Disabled Rehabilitation (Revised DDR) Scheme**[1]:

The scheme was introduced with the objective of creating an environment that would foster equal opportunities, equity, social justice and empowerment of persons with disabilities and to encourage voluntary participation from various organizations to further promote this objective. The scheme aims to provide financial assistance to voluntary organizations that are capable of providing a range of services necessary for the rehabilitation of persons with disabilities. These services may include early intervention, development of daily living skills, education, skill-development oriented towards employability, training and the generation of awareness.

The Scheme sponsors the following projects:

1) **Project for pre-school and early intervention and training**: Covers the preparation and training of children up to 6 years of age, for special schools or for re-integration

1 http://www.socialjustice.nic.in/ddrs.php

into regular schools. The project also provides therapeutic services, counseling services and day care facilities.

2) **Special Schools**: Covers the establishment of special schools that provide spaces for children to develop communication and life skills, that can ultimately result in the acquisition of daily living skills or the re-integration into regular higher institutions of learning. The project does not cover orthopedically handicapped children, as there is no model project or framework.

3) **Project for children with cerebral palsy**: Covers the establishment of special school projects that cater to the needs of these children

4) **Vocational Training Centres**: Covers projects that encourage disabled persons between the ages of 15 – 35 years to acquire vocational skills that can ultimately result in a state of financial independence.

5) **Sheltered Workshops**: Similar to vocational training centres, however the projects are modeled along the lines of being income generators.

6) **Project for Rehabilitation of Leprosy Cured Persons**: Covers projects that are aimed at socio-economic empowerment

7) **Half-way home for psycho-social rehabilitation of treated and controlled mentally ill persons**: Project provides a facilitating mechanism for the rehabilitated by providing them vocational training, medical advice/ treatment and any other assistance in the process of re-integration.

8) Project relating to survey, identification, awareness and desensitization

9) Home based rehabilitation programs/management programs

10) Project for community based rehabilitation

11) Project for low vision centres

12) Projects for human resource developments

13) Seminars/Workshops/ Rural Camps

14) Environment friendly and eco-promotive projects for the handicapped

15) Construction of building

16) Project for legal literacy

(ii) National Program for Control of Blindness (the 'NPCB')

The reduction in the prevalence of blindness and loss of vision has been a long standing goal of the Ministry of Health and Family Welfare. This goal has been duly emphasized in the working of the National Rural Health Mission and is specifically dealt with through the National Program for Control of Blindness. Launched in 1976, this scheme is funded entirely by the Central Government and was launched to reduce the prevalence of blindness[2]. The program objectives include promoting the timely identification and treatment of blindness, the development of eye care facilities in every district, the development of human resources and infrastructure to provide eye care services, to qualitatively improve service delivery and to encourage the participation of voluntary organizations in the work of the scheme[3]. The NPCB has adopted the following strategies to secure its objectives of reducing incidence of blindness and low vision:

i) Providing assistance to develop the eye care program into a more comprehensive program that can deal with a range of eye care related diseases and problems other than cataract;

ii) Facilitate early screening of the population so as to reduce the backlog in the treatment of those suffering from blindness and low vision, and to arrange for eye camps;

iii) Increase provision of services to hitherto unreached areas through a public-private organization partnership;

iv) Qualitatively improve the health personnel force so as to provide people with better health care services;

v) Instill and spread community awareness regarding the problem of blindness through campaigns and workshops;

vi) Screening children from lower socio-economic strata for vision related diseases, and to provide them with required aids such as glasses;

2 http://npcb.nic.in/
3 http://npcb.nic.in/index.asp

vii) Develop and encourage medical institutions to become centres for ophthalmology and eye care services.

The NPCB lays great emphasis on preventive health care methods, and is a good example of a program that seeks to comprehensively include steps for early identification and care of blindness and loss of vision. The following schemes have been initiated by the Government, with the above strategies as their underlying premise.

a) **Scheme for training centres for the training of eye surgeons and their guidelines (No.L.11013/16/2007-Ophth/BC)**[4]: In an effort to further its goal of providing good quality eye care services to the general population, this Scheme under the NPCB provides short term training for 1000 eye surgeons in the specialized field of ophthalmology.

According to the General Guidelines for Training of Eye Surgeons under the National Programme for Control of Blindness (NPCB) during 11th Plan Period dated 3.12.2008[5], only an estimated 12,000 eye surgeons are available to provide for the eye care needs of India's population exceeding one billion. It is estimated that there is only 1 trained eye surgeon for every 20,000 people in the urban parts of the country and there is only 1 eye surgeon for every 2,50,000 in the rural parts of India[6].

The 11th Five year plan stressed the need for providing better health care services through a stronger implementation of its health programmes, by remedying the problem of deficient staff through the employment of Ophthalmic surgeons, Ophthalmic Assistants and Eye Donation Counselors[7]. In order to fulfil its targets for eye care services as provided in the 11th Five year plan (2007-12) and its need to train more eye surgeons, the NPCB in consultation with state health societies, can further identify more training institutions. The State Government authorities must however, ensure and show that the services of the trained eye surgeons are being utilized in the Blindness Control Programmes of the NPCB.

4 No.L.11013/16/2007-Ophth/BC; to be found at http://npcb.nic.in/writereaddata/mainlinkfile/File158.pdf.

5 No.L.11013/16/2007-Ophth/BC;p.2 to be found at http://npcb.nic.in/writereaddata/mainlinkfile/File158.pdf

6 No.L.11013/16/2007-Ophth/BC;p.2 to be found at http://npcb.nic.in/writereaddata/mainlinkfile/File158.pdf.

7 http://npcb.nic.in/writereaddata/mainlinkfile/File293.pdf

b) **Scheme for Participation of Voluntary Organizations**: An important scheme initiated under the NPCB is the Scheme for Participation of Voluntary Organizations, which was approved with the 11th Five Year Plan. This scheme has been introduced to encourage the participation of voluntary organizations in the overarching goal of providing better eye care services, and eye care facilities to the general population[8]. Although the NPCB has always encouraged voluntary participation since its inception, this scheme was enunciated clearly, as a result of the revised and streamlined goals of the 11th Five Year Plan.

Through its Circular F.NO. ADG/NPCB/101/SPO/2007 issued by the Directorate General Of Health Services[9], an incentive program was instituted for community based workers like ICDS and Asha, to further encourage their participation in the NPCB. In accordance with the programme, a sum of Rs.175 would be given for each eye operated on, for every patient brought by the community worker.

c) **State and District Level Schemes**: In keeping with the policies of the NPCB, a number of schemes and programmes have been introduced by the government at the state and district level. These specific schemes are in addition to eye care campaigns, training of surgeons and other goals that are conducted by the NPCB through various NGOs and health facilities.

(iii) The National Program for Prevention and Control of Deafness:

The high incidence of hearing impairment and deafness among people in India has prompted the Government to launch schemes and programmes that may prevent the onset of the disability at an early stage through screening or remedy its effects through the aid of corrective surgeries and aids.

Recognizing the need to combat deafness and loss of hearing, the Government of India launched the National Program for Prevention and Control of Deafness[10]. The program[11] primarily aims at preventing avoidable hearing loss on account of disease and injury. It includes the early identification, diagnosis and medical treatment of ear problems that are responsible for a loss of hearing. The program also aims at developing institutional capacity for ear

8 http://npcb.nic.in/writereaddata/mainlinkfile/File108.pdf
9 http://npcb.nic.in/writereaddata/mainlinkfile/File162.pdf
10 http://mohfw.nic.in/index1.php?lang=1&level=2&lid=343&sublinkid=343
11 http://mohfw.nic.in/showfile.php?lid=344

care services by providing technical infrastructure and human resource support. The major strategies adopted and promoted by the programme are as under:

1) Manpower training and development: In an effort to provide higher quality services, the central Government would undertake training of ENT and audiology specialists in medical colleges and workers in smaller districts and towns.

2) Capacity Building: Under the auspices of the program, the Government would back the financing of specialized health care facilities and other important infrastructure.

3) Service Provision including rehabilitation: The Government will sponsor camps and monitoring facilities so as to enable early identification and timely medical attention of those with problems of loss of hearing. They would also provide hearing aids.

4) Awareness generation through early intervention and care.

5) Monitoring and Evaluation.

   a) **Andhra Pradesh Arogyasri Scheme**:- The scheme of Cochlear Implant Surgery has been included in Aarogyasri-I for the benefit of those persons below six years of age with hearing impairments[12]. The cost of cochlear implant surgery is reimbursed by the trust up to a maximum of Rs.6, 50,000, for each case[13].

(iv) The National Leprosy Eradication Programme (NLEP)[14]

The NLEP was introduced in 1983, and soon became a huge success in the mission to reduce the incidence of leprosy. In 2005, India achieved the goal of having eliminated leprosy as an outstanding health problem[15]. Less than 1 case of leprosy per 10,000 people was being reported. An important aspect of the NLEP involves steps to reduce the incidence of the disability through preventive health care measures, and to rehabilitate those persons living with leprosy and the disabilities caused by it.

In the NLEP guidelines for disability prevention and rehabilitation

12 http://wcdsc.ap.nic.in/schemes_disabled.php
13 http://www.hrln.org/hrln/images/stories/pdf/HRLN-Using-The-Law-For-Public-Health-Dr%20Rajan%20Shukla-Dr%20veena.pdf
14 Chapter 6, P.104 , Annual Report 2011-12, MHFW
15 citation needed

laid down by the Ministry of Health and Family Welfare[16], preventive health care measures are meant to work in a three step process of (1) early case detection and adequate treatment, (2) prevention of leprosy related diseases and (3) rehabilitation. The disabilities that may be caused due to leprosy mainly include visual impairment, loss of locomotor ability owing to the lack of functioning of hands and / or feet. In severe cases, leprosy can lead to blindness, chronic ulcers and permanent deformities of a person's hands and feet.

The guidelines call for preventive health care treatment to be conducted at three levels – simple ulcers and physical reactions can be tended to in primary health care centres like dispensaries and clinics; slightly more complicated health issues like eye care problems can be recommended to district level health care facilities; and serious cases involving surgery must be taken to specialized health care centres that may be equipped with the right kind of resources to treat such medical issues.

Besides recommending institutional rehabilitation and health care, the guidelines also strongly advocate the need for community based rehabilitation efforts in order to better help persons living with disabilities with their efforts to re-integrate themselves into society. Components of preventive health care measures include health care facilities regularly monitoring nerve functions and physical reactions. The guidelines also emphasize capacity building measures in the form of better infrastructure and training for the health care staff.

(v) **Pulse Polio Immunization Programme[17]**:

Following the WHO resolution regarding the eradication of polio, the Government of India launched the Pulse Polio Immunization Programme in 1995. The strategies adopted by the Government as a part of this programme include the following:

a. A Rapid Response Team (RRT) and an Emergency Preparedness and Response Plan has been prepared by all State Governments, to be implemented at State and district levels, in response to an outbreak of polio.

b. The programme has called for the establishment of immunization booths at sites close to the international borders of the country so as to ensure that children entering the country are provided with the requisite preventive medication and polio drops.

16 http://nlep.nic.in/pdf/DPR_27Sept07.pdf

17 http://mohfw.nic.in/NRHM/Immunization/Brief%20Note%20on%20Pulse%20Polio%20Programme.pdf

c. A system of high surveillance has been put in place in order to check and monitor cases of polio and its incidence.

d. The Government has taken measures to examine hygiene, sanitation and ensure clean drinking water, in an effort to reduce the incidence of polio.

e. Social mobilization coupled with community participation is being encouraged in the effort to eradicate polio.

f. A great deal of emphasis is being laid on screening facilities and early immunization through the administration of polio immunization drops via immunization booths, found across the country. The booths were also meant to be made accessible in railway stations, major bus stops and similar places of public congregation. In several States such as Gujarat and Tamil Nadu, there are schemes for early detection and treatment of polio or spinal cord affected persons[18].

B. Aids and Appliances

This section briefly summarizes the key features of some of the schemes identified for the provisions of aids and appliances for persons with disabilities.

i. **Assistance to Disabled Persons for Purchase/Fitting of Aids and Appliances, (ADIP) 1995**: This Scheme[19] is meant to aid in the assistance of persons with disabilities who are in need of procuring durable, sophisticated and scientifically manufactured, modern aids and appliances. These aids and appliances are meant to promote the physical, social and psychological rehabilitation of persons

18 In Gujarat, the Gujarat Scheme of Operation and Subsequent Programme for Polio Patients was launched in order to provide for free surgical and medical treatment to the economically backward children affected by polio and to prevent the incidence of this disease, and its subsequent handicap. Conducted primarily with the help of voluntary organizations, the main motto of this scheme is to ensure the availability of free operation and subsequent treatment to the affected beneficiaries, who are not able to afford treatment. Details of this scheme can be found in the subsequent section of the paper dealing with current access to health care needs for persons with disabilities. This scheme is available at http://www.sje.gujarat.gov.in/dsd/showpage.aspx?contentid=1587&lang=English.
In Tamilnadu under the Tamil Nadu Free Surgical Correction for Polio and Spinal Cord Affected Persons, District Rehabilitation Centres conduct special medical camps for the identification and treatment of persons affected by spinal cord injuries and polio. Usually, the candidates identified are in need of surgical correction. Post identification, persons with disability in need of surgery are sent to the Medical College Hospital or the District Headquarter hospital for surgical correction.

19 http://www.socialjustice.nic.in/pdf/adipsch.pdf

living with disabilities, by reducing the ill-effects of their disabilities and enhancing their economic participation. The aids and appliances supplied under the Scheme must conform to ISI standards.

The implementation of the scheme is to be facilitated through the efforts of Implementing Agencies. The agencies are primarily concerned with the purchase, fabrication, distribution, fitting and post-fitting maintenance of aids and appliances. The scheme also plays an important role in various forms of mass communications that may be used to promote awareness. The scheme includes medical or surgical correction and intervention that may be required prior to the fitting of aids. The agencies are provided financial assistance under the ADIP Scheme, and the costs may range from Rs. 500 for the hearing and speech impaired; Rs. 1000 for the visually impaired and Rs. 3000 for the orthopedically disabled.

The ADIP Scheme lists certain requirements when identifying Implementing Agencies and encourages networking between Implementing Agencies in an effort to create more awareness and to better ensure the efficient accomplishment of the Scheme's goals.

In order to be eligible for the benefits under this scheme, the person with a disability must be an Indian citizen and must possess certification from a Registered Medical Practitioner that he or she is disabled and is required to use the prescribed aid or appliance. The person or their guardian must not be receiving an income greater than Rs. 10,000 per month and must not have already received government assistance in the past 3 years. This rule is relaxed to a period of 1 year in the case of children under 12 years of age.

The ceiling for the cost of appliances under this scheme is set at Rs. 6000 for nearly all cases with the exception of the visually, mentally, speech and hearing or multiple disabled during their post Standard IX study period, where the limit is Rs. 8000. The Scheme lists the various kinds of aids or appliances that can be made available for persons with visual, hearing, speech and mental disability.

ii. **Mizoram Scheme for Prosthetic Aids**: Persons living with disabilities are given aids and appliances in the form of artificial limbs, hearing aids, wheel chairs and so on based on their individual needs. This is done through the Red Cross Society, located at Chaltlang, Aizawl.

iii. **Orissa Scheme for the Supply of Special Aids and Appliances**: Aids and appliances are being provided to persons with disabilities on a case to case basis. Aids and appliances like tricycles, sticks for the blind, crutches, hearing aids and wheelchairs are provided to persons according to the following criteria:

- free of cost for those whose monthly income is Rs.5000/-
- at a 50% discount for those whose monthly income is between Rs.5000 and Rs.8000/-
- It full cost for those whose monthly income exceeds Rs.8000/-

In order to increase the scope of the scheme, an Action Plan was prepared by the Department in consultation with Government agencies like NIRTAR and ALIMCO and organizations like the Indian Red Cross Society and DRC. All these Agencies receive grant-in-aid from the Government under the ADIP Scheme for the distribution of aids and appliances.

iv. **Puducherry Supply of Prosthetic Appliances to Disabled Persons**: This scheme ensures the supply of prosthetic appliances like calipers, tricycles, crutches, hearing aids spectacles / low vision aids, and so on, on the advice of the specialist health care practitioners attached to the Government General Hospitals of Pondicherry, Karaikal, Mahe and Yanam. The scheme concerns those with an annual income that does not exceed Rs.35,000. One is required to prove that he or she has been a resident of Puducherry for a period of not less than 5 years.

v. **Tamil Nadu Scheme Free Supply of Aids and Appliances to the Disabled**: The following types of aids and appliances are provided to persons with disabilities free of cost, through District Rehabilitation Centres. The following aids are supplied:

- Tricycle

- Wheel chair
- Goggle
- Folding stick
- Braille Watch
- Hearing Aid
- Solar Rechargeable Battery
- Caliper
- Crutches
- Artificial limb.

vi. **Chandigarh Assistance to Handicapped Persons for purchase of Aids/Appliances**[20]: Financial assistance is provided to persons with disabilities for the purchase of aids and appliances. The quantum of financial assistance to be provided is determined on the basis of the income of the applicant. The monthly income of the applicant from all sources must not exceed Rs.8,000. The applicant is entitled to 100% the cost of artificial limbs/ aids/ appliances subject to a ceiling of Rs.20,000.

vii. **Dadra and Nagar Haveli Assistance for Purchase of Aids and Appliances**[21]: The quantum of assistance is as follows. If the person with a disability or their family is earning an income that does not exceed Rs.200 per month, then the financial assistance to be provided will cover 90% of the cost. If the income is within the bracket ranging from Rs.201 to Rs. 400 per month, then the financial assistance to be provided will cover 75% of the cost. If the income is within the bracket ranging from Rs. 401 to Rs. 600 per month, then the financial assistance to be provided will cover 50% of the cost.

viii. **Delhi Financial Assistance to the Physically Handicapped for the Purchase of Aids Scheme**[22]: This scheme is meant to provide financial assistance to persons with disabilities for the purchase of such aids and other special gadgets that may be necessary to increase their

20 http://www.chandigarh.nic.in/dept_social.htm

21 41 http://www.ayjnihh.nic.in/awareness/schemes4_files/schemes5.htm

22 http://delhi.gov.in/wps/wcm/connect/doit_socialwelfare/SocialWelfare/Home/Our+Services/Financial+Assistance+Welfare+Scheme+Details+and+Notifications+etc./Notifications-Welfare+Schemes, http://delhi.gov.in/wps/wcm/connect/9b546080411ed8dca653ff4ae5bc213e/Purchase+of+Aids.pdf?MOD=AJPERES&lmod=-1371280573&CACHEID=9b546080411ed8dca653ff4ae5bc213e

mobility and capacity, but which might be difficult to access owing to their high cost. Persons eligible for this scheme must be residents of Delhi and must benefit from the aids/ appliances. If employed, their salary cannot exceed Rs. 400 per month, and if unemployed the monthly income of their family members should not exceed Rs. 600 per month.

ix. **Haryana Scheme for Aids and Appliances to the Handicapped**: The programme for free operation and subsequent treatment of polio patients has been implemented through voluntary organizations that can provide health care facilities like hospital or clinical care and surgeons. This scheme is meant to ensure the availability of free operation and subsequent treatment to the poor polio affected beneficiaries. The annual income of the parents/ guardian of the beneficiary under this scheme should not be more than Rs. 11,000. The limit of expenditure to be made per beneficiary is Rs. 3,500/- (operation and medicine expenses – Rs. 2000/- and Rs. 1,500/- for Calipers).

x. **Gujarat Scheme of giving material assistance to handicapped persons**[23]: The scheme of material assistance to persons with disabilities is implemented with a view to minimize inaccessibility. In order to be eligible under this scheme, persons may be between 5 and 50 years of age, they must have more than 40% of handicapness, the family income must not exceed Rs. 25,000. The person must be from Gujarat and must be the holder of a handicapped identity card. The financial material assistance includes tricycles, bicycles, wheel chairs, ghodi, callipers, sewing machines, computer repair tools, aids of assistance to deaf persons and musical instruments for blind persons.

D. Financial Assistance for Health Care

i. **Karnataka State Disability Medical Relief Scheme for Corrective Surgeries for the Prevention of Disabilities**: The scheme aims at providing financial assistance to undergo corrective surgeries. In order to be eligible for the benefits under this scheme, a person must show that his or her and family's income does not exceed Rs. 25,000 in rural areas or Rs. 50,000 in urban areas. The medical treatment must be administered at Government hospitals or reputable and well-equipped specialized hospitals. Financial assistance of Rs.15,000 is extended under this scheme, and the amount

23 http://sje.gujarat.gov.in/dsd/showpage.aspx?contentid=1567&lang=English

is directly remitted to the concerned hospital.

ii. **Kerala Distress Relief Fund for the Handicapped**: This fund is constituted for the purpose of providing relief to persons with disabilities with reference to receiving medical treatment including operations, providing rehabilitative and medical aid to persons living with disabilities after an accident, and finally for any other purpose that is not explicitly covered under any existing scheme meant for persons with disabilities. An amount of one crore rupees is set aside for the " Welfare of the handicapped persons". This is a fixed deposit in the District Treasury, Trivandrum and the amount of interest accrued will be utilised as a distress relief fund. Donations from NGOs, public/private undertakings and philanthropists are also accepted. The maximum amount of relief per person annually is fixed at the sum of Rs.5000. The eligibility criteria includes that the income should not exceed Rs.12000 per annum. The fund was sanctioned in March 1995.

E. This section illustrates some social security and insurance schemes:

i. **Niramaya Health Insurance Scheme for Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities under the National Trust, Govt. of India**: This scheme[24] was introduced to alleviate the problems faced by persons with disabilities who are interested in attaining healthcare insurance. Besides providing health insurance, the scheme has been introduced with the objective of fostering health care seeking behaviour among persons with disabilities, thereby resulting in an improvement in their quality of life.

The scheme offers comprehensive coverage with a single premium across age groups and will provide the same coverage irrespective of the kind of disability – there is no system of 'selection' and all persons with developmental disabilities are eligible for this scheme. The entire scheme may be implemented and monitored by the National Trust through registered organizations with the active participation of Local Level Committees (LLCs), health service providers, State Nodal Agency Centres and other State Government Authorities.

24 http://www.thenationaltrust.co.in/nt/index.php?option=com_content&task=view&id=111&Itemid=168

ii. **Karnataka Insurance Scheme for Mentally Retarded Persons**[25]: Parents or guardians of persons with mental retardation and whose annual income is Rs.12,000 or less per year may take advantage of this life insurance policy. The Directorate of Welfare of Disabled and Senior Citizens contributes the annual premium to the Life Insurance Corporation of India towards a specially designed group insurance policy. Following the demise of the parents or guardians, the nominee will be eligible to receive a one time lump sum amount of Rs.20,000 meant to be maintenance for the person with the disability.

iii. Gujarat Insurance Assistance Scheme to the Family Members of Handicapped Persons has been sanctioned via Social Justice and Empowerment Department Resolution No.APG-102005-N.I.4-CHH-1, dtd. 28-03-2007.

F. REHABILITATION

The following section deals with some schemes that provide rehabilitative care to persons with disabilities.

(i) **Central Scheme for Setting up District Disability Rehabilitation Centres**: In accordance with this scheme, disability rehabilitation centres are being set up in remote and underserved districts of the country. These centres are required to provide services for prevention and early detection of disabilities, referral for medical intervention and surgical correction fitment of artificial aids and appliances, therapeutic services such as physiotherapy, occupational and speech therapy, provision of training for acquisition of skills through vocational training, job placement in local industries, etc. at district headquarters as well as through a camp approach. A hundred new DDRCs were meant to be set up by 2012.

(ii) **National Program for the Rehabilitation of Persons with Disabilities**: Under this scheme four rehabilitation centres have been set up with sophisticated/ modern infrastructure. The aim and objective of the scheme is to provide clinical facilities to disabled persons, mobility training and required rehabilitation services to persons with disabilities through an extensive network of facilitating centres from the Village to State Levels.

25 http://www.karunadu.gov.in/welfareofdisabled/Pages/schemes_rehabilitation.aspx

Annexure 2

QUESTIONNAIRES FOR STAKEHOLDERS

(1) Questionnaires for Parents and Care-Givers of Persons with Disabilities:

(Please tick the appropriate options and where required, fill in the blanks)

Personal information:

1) Name : _____

2) Relationship to the person with disability:
   a. Parent
   b. Family member – please specify_____
   c. Caregiver
   d. Other, please specify_____

3) Age of the person with disability: _____

4) Gender of the person with disability: _____

5) Describe the disability/disabilities of the person you are caring for:

   _____

   _____

6) Contact Number:_____

   Contact Email: _____

7) Address:

   _____

   _____

8) How often does the person with disability require specialized medical attention from a specialized medical practitioner?

   a. Regularly i.e. everyday

b. Once a week or a fortnight

c. Once a month

d. Any other, please specify _____

NOTE: Please answer all questions. The questions are arranged as follows: -

Questions 9 to14 - Early Intervention Measures

Questions 15 - 44 - Equal Access to Health Care

Questions 45 to70-Government sponsored health care schemes.

I. Early Intervention Measures

9) At what age was his / her disability detected?

_____

10) Was the disability was detected at :

a. A medical camp or screening facility organized at a Government Hospital

b. A private health care facility?

11) Did you receive any early intervention treatment for your disability, such as implants or surgeries?

a. Yes
b. No

If Yes (Please provide us details of the corrective procedure or implant you received)

_____

_____

12) Has the corrective surgery, implant or aid provided substantial relief to the person with disability?

_____

_____

13) Do you feel that early diagnosis or treatment could have reduced or prevented the disability?

a. Yes

b. No

14) Do you feel that there is a need for more and better early intervention facilities?

_____

_____

_____

II. Equal Access to Health Care

15) How often does the person with disability that you are caring for require specialized medical attention and healthcare services?

a. Regularly i.e. daily
b. Fortnightly
c. Monthly
d. Any other (Please specify) _____

16) Has there been any difficulty getting a disability certificate issued by a certified medical board?

a. No
b. Yes, please tell us about the problems faced _____

_____

_____

17) Does the person use any aids or appliance to reduce his / her disability?

a. No
b. Yes (Please provide details of the aid): _____

_____

_____

18) Are there specialized health care facilities for the needs of the person with disability, close to where you live?

a. Yes
b. No

19) Which institutions do you normally visit for the health care needs of the person with disability that you care for:

a. Private Hospitals and doctors

b. Government Hospitals and doctors
c. Both

20) Do you find the health care facilities that you regularly visit, to be accessible? Are there ramps, railings, special bathrooms, platform lifts, elevators or any other special architectural design elements/ infrastructure incorporated into the design of the building?

a. Yes
b. No

Please give some details: _____

_____

21) Where are the medical treatments/ procedures for the person with disability administered at:

a. Clinic, hospital or other health care facility

b. Home

22) For home based treatment, do you find that the doctors and medical staff are prompt and efficient with their treatment?

a. Yes
b. No

23) What are your major concerns with reference to administering home-based treatment?

_____

_____

_____

24) Is there any additional assistance provided to you by the government or other organizations, in the case of home based treatment?

a. No
b. Yes

Please provide details of the nature of assistance, and the institution/person providing it:

_____

_____

25) In the event of a medical emergency at home, do the government health care facilities provide you with prompt response?

a. Yes, and they usually send some form of assistance
b. No

26) How effective is the response of health care facilities in times of emergency? What are the areas you feel they must improve upon?

_____

_____

27) Do the local government healthcare facilities provide any services for any post-procedure rehabilitation?

_____

_____

28) In your opinion, is there a need for better community monitoring of health care facilities and programmes?

a. Yes, please explain how

_____

b. No

29) Do you encounter problems with government healthcare facilities? What are the problems that you usually encounter?

_____

_____

30) Do you encounter problems with private healthcare facilities?

_____

_____

_____

31) Do you find that persons with disabilities face discrimination from medical staff at health care facilities?

a. Yes
b. No

32) Is the patient or are you aware of the patient's legal rights against discrimination at health care facilities?

a. Yes
b. No

33) Have doctors and staff been careful to ensure the patient's privacy and dignity when administering medical treatment?

a. Yes

b. No

34) In your experience, have the doctors and health care facility staff respected the patient's confidentiality and not disclosed medical information to unauthorized persons?

a. Yes

b. No

35) Do doctors and medical staff always ask the person with disability for their express consent before proceeding with a medical procedure/treatment?

a. Yes

b. No

36) When meeting with a doctor to discuss medical treatment and other health care needs of the person with disability, does the doctor take efforts to explain the medical condition to the person with disability and the caregiver?

a. Yes
b. No

37) Have you encountered any instances of the use of force or coercion in the medical treatment of persons with disability?

a. Yes
b. No

38) When undergoing medical treatment, are the patient and the caregiver made aware of the risks involved in the procedure?

a. Yes, the patient and caregiver are made fully aware of the risk and benefits of the procedure

b. No

39) Is the patient's consent asked before every medical procedure?

a. Yes
b. No

40) What form of consent is usually taken by the doctors or medical staff?

a. Written
b. Oral

41) What is the procedure followed when the person with disability is not in a position to give consent to a medical procedure?

_____

_____

42) Are doctors generally open to your suggestions or inputs concerning decisions on treatments, procedures, medical aids and other healthcare needs of the person with disability?

a. Yes

b. No

43) Are you able to financially afford the medical treatments and health care needs of the person with disability/disabilities?

a. Yes

b. No

44) Have you currently or previously contacted any alternative sources for financial assistance?

a. No

b. Yes, and these alternative sources of financial assistance are:

(i) Government agencies

(ii) Private institutions

(iii) NGOs or DPOs

(iv) Other?

Please specify_____

_____

III. Government Schemes

45) Are you aware of early intervention and medical screening facilities of the government, for detecting disabilities?

a. Yes

b. No

Please tell us a bit more about the early intervention and medical screening services you are aware of. Are these screening services effective and affordable?

_____

_____

46) Are you aware of government schemes for providing pre-natal care or post natal care for prevention of certain disabilities?

a. Yes
b. No

47) Are you aware of any schemes that focus on early preventive care and screening in children to detect disabilities that might include loss of vision or hearing impairments?

a. Yes

If so, please mention what test is employed for certifying the existence of disability. For e.g., was the BERA testing technique used to show existence of hearing impairments?

_____

_____

b. No

48) Are you aware of any Government schemes for the reproductive health of women living with disabilities?

a. Yes, and if so please give details of what scheme and how you came to know of it:

_____

_____

b. No

49) What kind of measures should be provided for better protection of the reproductive health of women with disabilities?

_____

_____

50) Are you aware of any scheme that ensures access to specialized drugs, counseling and rehabilitation?

a. Yes, if so, please give details: _____
b. No

51) Are you currently availing the benefits of any of the Government sponsored schemes specific to the health care needs of the person you are caring for?

a. Yes;

i. Please let us know what these schemes are, and what is the nature of the benefits

_____

_____

ii. How did you come to know of them?

_____

_____

b. No

52) Have you received any aids/ appliances for the person you are caring for, that have been financed by existing government schemes like the Scheme of assistance for disabled persons for purchase/fitting of appliances (ADIP Scheme)?

a. Yes; if so, which scheme?_____

ii. Has there been any assistance provided for fittings and also post-fittings assistance at your home?

a. Yes

b. No , please give details

_____

_____

53) Has the person with disability been provided with any corrective surgeries or implants (like cataract related surgeries, or cochlear implants) under schemes financed by the Government?

a. Yes
b. No

54) Was the finance sufficient and was the process of receiving financial assistance for these surgeries, a smooth one?

_____

_____

55) Are you aware of the Niramaya Health Insurance scheme made available by the National Trust?

a. Yes

Please specify if you using this scheme_____

b. No

56) In your opinion, is it difficult to procure insurance for a person with disability?

a. Yes

b. No

Please give details:

_____

_____

57) Have you faced any inconvenience in availing any of the health related schemes from the Government as a care-giver?

_____

_____

58) In your opinion, are the existing government schemes sufficient to make medical procedures and treatments for disability, more affordable?

a. Yes
b. No

59) Do you feel that more can be done to raise awareness and disseminate information regarding the Government sponsored schemes specific to the disability/disabilities of the person you are caring for?

a. Yes. If so, please give details:

_____

_____

b. No

60) What are some of the problems faced when attempting to avail of benefits under these schemes?

_____

_____

61) Is there a need for the Government to introduce more health schemes that cater to gender related needs?

a. Yes

b. No

62) In your opinion, do you feel that there needs to be better community monitoring of health related schemes, programmes, services and facilities?

a. Yes

b. No

63) In a few words, please tell us what additional aid/services you would like government funded healthcare agencies and hospitals to provide with respect to health care needs of persons with disabilities.

_____

_____

64) Are you aware of any government schemes offering financial assistance for the health care of Persons with disability?

a. Yes

b. No

c. No, but I would like to find out more

65) Have you applied for any government schemes offering such financial assistance?

a. Yes

If yes, then please give details about the scheme

_____

_____

b. No

66) Do you feel that such schemes and programmes serve the interests of persons with disabilities and their caregivers? What are your major concerns with such schemes?

_____

_____

67) In your experience, how difficult is it to secure health or life insurance policies for persons with disability?

a. Very difficult
b. Moderately difficult
c. Easy

68) Are you aware of any specialized life or health insurance schemes for the family members of persons with disability? What are your major concerns with reference to health or life insurance for persons with disabilities?

_____

_____

69) What are your concerns relating to the availability of day care centres and allied facilities for persons living with disabilities?

_____

_____

70) Is there any additional information that you would like to share and any recommendations or suggestions that may be especially relevant to your work as a caregiver?

_____

_____

(2) Questionnaire for Persons with Disabilities and Disabled Persons Organizations ("DPO")

(Please tick the appropriate options and where required, fill in the blanks)

In the case of a Person with Disability:

1) Name: _____

2) Age: _____ Gender: _____

3) Your Disability: _____

4) If you are filling this on behalf of a person with disability, then please supply us the following details :

   a. Name of the person you are writing on behalf:

   _____

   b. Your relationship to the person with disability:

   _____

   c. Age of the person with disability: _____

   d. Gender of the person with disability: _____

   _____

   If you are filling this on behalf of a DPO, then please supply us the following details:

   a. Name of the organization:

   _____

   b. Your position/Role in the DPO: _____

_____

c. Purpose/Objective of the DPO:_____

_____

6) Contact Number: _____ Contact Email: _____

7) Address:

_____

NOTE: Please answer all questions. The questions are arranged as follows: -

Questions 1 to 5 - Early Intervention Measures
Questions 6 – 29 - Equal Access to Health Care
Questions 30 to 47 - Government sponsored health care schemes.
Questions 48 to 54: Specifically for DPOs

Early Intervention Measures

1) What is the nature of your disability?

_____

_____

2) At what age was your disability detected?

_____

_____

3) Was your disability was detected at a:

   i. Government Hospital or health centre or

   ii. Private institution

4) Did you receive any early intervention treatment for your disability, such as implants or surgeries?

   i. Yes
   ii. No

   If Yes (Please provide us details of the corrective procedure or implant you received)

_____

_____

5) Do you feel that early diagnosis and intervention could have reduced your disability?

i. Yes
ii. No

Equal Access to Health Care

6) How often do you require specialized medical attention and healthcare services?

a. Regularly i.e. daily
b. Fortnightly
c. Monthly
d. Any other (Please specify) _____

7) Have you had difficulty getting a disability certificate issued by a certified medical board?

a. No
b. Yes, please tell us about the problems you faced

_____

_____

8) Do you use any aids or appliance to reduce your disability?

a. No
b. Yes (Please provide details of the aid): _____

_____

_____

9) Are there specialized health care facilities for your needs close to where you live?

a. Yes
b. No

10) Which institutions do you normally visit for your health care needs:

a. Private Hospitals and doctors
b. Government Hospitals and doctors
c. Both

11) Do you find the health care facilities that you regularly visit, to be accessible? Are there ramps, railings, special bathrooms, platform lifts, elevators or any other special architectural design elements/ infrastructure incorporated into the design of the building?

a. Yes

b. No

Please give some details: _____

_____

12) In your health care facility, are you able to effectively communicate with doctors and staff?

a. Yes
b. No

If no, then please explain

_____

_____

13) Do you go to healthcare facilities accompanied by your own interpreter?

a. Yes
b. No, the health care facility usually provides someone to help interpret for me

14) Are you asked to give your consent before the doctors or staff, administer a particular medical treatment or procedure?

a. Yes
b. No
c. Sometimes

15) Have you ever encountered a situation where treatment was administered to you, without having obtained your express consent?

a. Yes

If so, did this lead to any further complications?

_____

_____

b. No

16) Do the doctors and medical staff, always explain in the best way possible, the risks and benefits associated with the treatment/ procedure before you undertake it?

a. Yes
b. No

17) Have any doctors and medical staff ever tried any experimental medical and clinical techniques on you?

a. Yes, if so what kind? Were the risks and benefits associated with this particular procedure explained to you? Would you describe this experience as good or bad?

_____

_____

b. No

18) Do you find doctors open to hearing your inputs when considering your treatment/procedures or medical services?

a. Yes
b. No

19) Have doctors and medical staff been mindful of your privacy and dignity, while examining you?

a. Yes
b. No

If no, then please explain how

_____

_____

20) In your experience, have doctors and staff adhered to patient confidentiality norms and not disclosed any of your medical information to an unauthorized entity?

a. Yes
b. No

If no, then please give details of how the confidentiality was breached

_____

_____

21) Have you ever faced discrimination from any staff or patients at a health care facility?

a. Yes
b. No

If yes, please provide details and examples of the kind of discrimination you have experienced

_____

_____

22) Please tell us if you have ever had any problems when being attended to by a doctor or staff at a health care facility? Was

there use of force while undergoing medical treatment? What was the inconvenience caused to you?

_____

_____

23) As a woman, please provide details of any additional health care needs that you have pertaining to your disability.

_____

_____

24) As a woman with disability have you had your health care needs addressed by:

a. government hospitals and health centres
b. private clinics
c. none

25) Are there any additional health care needs for children with disabilities that are not being provided by hospitals and clinics?
a. Yes; please specify:

_____

_____

b. No

26) In your opinion, are there any additional health care needs for senior citizens with disabilities?
a. No
b. Yes, and if so please give details

_____

_____

27) Are you able to afford all your medical treatment on your own income or your family's income?
a. Yes
b. No

28) Are you aware of any alternate sources of financial assistance for your health needs?
a. Yes, please specify

_____

_____

b. No

29) Are you satisfied with the quality of services provided by Government doctors, staff and hospitals?

a. Yes
b. In some cases
c. No

If no, why do you think this is?

_____

_____

Government Schemes

30) Are you aware of early intervention and medical screening facilities of the government, for detecting disabilities?

a. Yes
b. No

Please tell us a bit more about the early intervention and medical screening services you are aware of. Are these screening services effective and affordable?

_____

_____

31) Are you aware of government schemes for providing pre-natal care or post natal care for prevention of certain disabilities?

a. Yes
b. No

32) Are you aware of any schemes that focus on early preventive care and screening in children to detect disabilities that might include loss of vision or hearing impairments?

a. Yes

If so, please mention what test is employed for certifying the existence of disability. For e.g., was the BERA testing technique used to show existence of hearing impairments?

_____

_____

b. No

33) Are you aware of any Government schemes for the reproductive health of women living with disabilities?

a. Yes, and if so please give details of what scheme and how you came to know of it:

_____

_____

b. No

34) What kind of measures should be provided for better protection of the reproductive health of women with disabilities?

_____

_____

35) Are you aware of any scheme that ensures access to specialized drugs, counselling and therapeutic management required to treat your disability?
   a. Yes
   b. No

36) Are you currently availing the benefits of any of the Government sponsored schemes specific to your health care needs?
   a. Yes;

   i. Please let us know what these schemes are, and what is the nature of the benefits

_____

_____

   ii. How did you come to know of them?

_____

_____

   b. No; and is this because

      i. you are ineligible
      ii. you are not convinced that they will be of much help

37) Do you use any aids/ appliances that have been financed by existing government schemes like the Scheme of assistance for disabled persons for purchase/fitting of appliances (ADIP Scheme)?
   a. Yes;

   i. What scheme have you availed benefits under?

_____

_____

   ii. Have you been provided with persons to assist in fittings

and also to provide post-fittings assistance at your home? Was this satisfactory?

a. Yes

b. No , please give details

_____

_____

38) Have any of your corrective surgeries or implants (like cataract related surgeries, or cochlear implants) been under schemes financed by the Government?

a. Yes

b. No

39) Was the finance sufficient and was the process of receiving financial assistance for these surgeries, a smooth one?

_____

_____

40) Are you aware of the Niramaya Health Insurance scheme made available by the National Trust?

a. Yes

Please specify if you are a beneficiary of this sche me_____

b. No

41) Are there any life insurance policies or health insurance schemes that you are a beneficiary under?

a. Yes, if so, which ones?

_____

_____

b. No

42) In your opinion, is it difficult to procure insurance being a person with disability?

a. Yes

b. No

Please give details:

_____

_____

40) Have you faced any inconvenience in availing any of the health related schemes from the Government?

_____

_____

41) Are you aware of the Government sponsored health care schemes for the area of disability that you are either working with or living with?

a. Yes

How did you receive information regarding these?

_____

b. No

c. What are these schemes?

_____

_____

42) In your opinion, are the existing government schemes sufficient to make medical procedures and treatments for your disability, more affordable?

a. Yes

b. No

43) Do you feel that more can be done to raise awareness and disseminate information regarding the Government sponsored schemes specific to your disability/disabilities or the disability/ disabilities you are working with?

a. Yes. If so, please give details:

_____

_____

b. No

44) What are some of the problems you face when attempting to avail of benefits under these schemes?

_____

_____

45) Is there a need for the Government to introduce more health

schemes that cater to gender related needs?

a. Yes
b. No

46) In your opinion, do you feel that there needs to be better community monitoring of health related schemes, programmes, services and facilities?

a. Yes
b. No

47) In a few words, please tell us what additional aid/services you would like government funded healthcare agencies and hospitals to provide with respect to health care needs of persons with disabilities.

_____

_____

Questions Specifically for DPOs:

48) What is the disability/disabilities that your organisation works for?

_____

_____

49) What is the territorial scope of your organization's work? (Please tick as many as are relevant)

a. District/ city you are based in.
b. State wide
c. National i.e. across States.
d. International

50) Does your organization work with issues relevant to the health care needs of persons with disability?

a. Yes; and if so please provide details of the work your organization does for the right to health of persons with disabilities

_____

_____

b. No

51) Does your organization organize campaigns and workshops in areas related to disability specific health services?

a. Yes, very often
b. Sometimes
c. No, very rarely

52) Are any of these awareness programmes or campaigns supported by the local Government agencies?

a. Yes, all the time
b. Sometimes
c. No

53) Does your organization interact with local Government hospitals and other Government funded health care centres?

a. Yes
b. No

54) Does your organization interact with private hospitals, private clinics and other private health care centres?

a. Yes, if so, then in what manner?

_____

_____

b. No

(3) Questionnaire for Doctors and Health Care Practitioners

(Please tick the appropriate options and where required, fill in the blanks)

Personal Details:

1) Name:

Dr._____

2) Specialization: _____

3) Name of the Hospital/Clinic:

_____

4) Address: _____

_____

5) Do you have patients who are persons living with disabilities?

a) No

b) Yes

If yes, what disabilities are your patients living with?

_____

_____

6) Where do you examine/visit your patients who are persons with disabilities?

a) At a private Hospital/ Clinic

b) At a government hospital / health centre

c) Patient's residence/ Care – Home

d) Other - _____

NOTE: Please answer all questions. The questions are arranged as follows: -

Questions 7 to 12- Early Intervention Measures including Training

Questions 13 - 32 - Equal Access to Health Care

Questions 29 to 42- Government sponsored health care schemes.

Early Intervention Measures including Training

2. As a medical student, was the study of disabilities included in your MBBS curriculum as part of your training? Please give any details that may be relevant.

_____

_____

1) Do you provide screening facilities to new-born babies, in order to diagnose disabilities?

a. No

b. Yes, and if so what are the disabilities and impairment that you usually screen for?

_____

_____

2) Do you provide any early intervention treatment for disability, such as implants or surgeries?

a. Yes

b. No

If Yes (Please provide us details of the corrective procedure or implant you provide)

_____

_____

3) What special measures do you take with reference to ensuring proper pre-natal and post-natal care of the mother and the child for ensuring that there is prevention of disabilities?

_____

_____

4) Do you feel that early diagnosis and intervention through screening methods will reduce the incidence of disabilities among people?

a) Yes
b) No

5) Do you feel that there is a need for improved screening facilities for detecting disabilities? Please explain.

_____

_____

Equal Access to Health Care:

6) Is your hospital or clinic physically accessible to persons with disabilities through the use of ramps, elevators or any other specially designed infrastructure?

a) No
b) Yes

If so, please provide details of these special design structures:

_____

_____

7) Do you take the assistance of interpreters anytime when attending to patients with disabilities?

a) Yes
b) No

8) Are interpreters available in your hospital / clinic for assistance for persons with disabilities?

a) Yes
b) No

9) Do you ask patients with disabilities to bring their own interpreters?

a) Yes
b) No

10) Is your hospital or clinic adequately equipped with medicines for the treatment of patients with disabilities?

a) Yes
b) No

If no, what are some of the problems you face with reference to acquiring sufficient drugs and medicines?

_____

_____

11) Do you take any special measures when treating children with disabilities?

_____

_____

12) Are there any health care needs of children with disabilities that you are not able to respond to? Why is this so?

_____

_____

13) Do you take any special measures you take when treating women with disabilities?

_____

_____

14) What special measures do you take when attending to the reproductive health care needs of women with disabilities?

_____

_____

15) Are there enough women doctors and nursing staff to attend to the needs of women patients with disabilities?

a) Yes
b) No

16) Are there any special health care needs of women with disabilities that you are not able to respond to? If so, why?

_____

_____

17) Do you always take the consent of your patients with disabilities before treating them?

a) Yes

b) No

c) Yes, but only for some procedures

18) How do you obtain consent for treatment for persons with disabilities?

a) In writing

b) Orally

19) In the event that your patient is unable to provide consent themselves, who do you seek consent from?

a) Parents

b) Care-givers

c) Others; please specify _____

d) Only the patient's consent will be considered satisfactory

20) Do you inform your patients with disabilities of all the risks, benefits, consequences and alternatives to a treatment procedure, before obtaining their consent to it?

a) Yes

b) No

21) Are you required to periodically provide updates of a patient's medical condition to a higher authority in the hospital or in a registered medical board? In what circumstances would you do so?

_____

_____

22) What are some of the measures you take to ensure that the privacy and dignity of your patients with disabilities is being protected in the course of their treatment?

_____

_____

23) Under what circumstances do you disclose the confidential medical information of patients with disabilities and to whom?

_____

_____

24) Have you or your staff ever tried any experimental medical and clinical techniques on any of your patients with disabilities?

a. Yes

b. No

25) Yes, if so what kind? Were the risks and benefits associated with this particular procedure explained to the patient?

_____

_____

Government Sponsored Health Schemes:

26) Are you aware of any Government Schemes for early intervention and medical screening facilities for persons with disabilities?

a) No

b) Yes

If yes, then please tell us a bit about the schemes that you are aware of and that you provide in your clinic?

_____

_____

27) Are you aware of any schemes that focus on providing early preventive care and screening to detect disabilities in children that might include loss of vision or hearing impairments?

a) No

b) Yes

If so, please mention what are the tests used in your clinic or hospital when certifying the existence of disability. For eg, is the BERA testing technique used to show existence of hearing impairments?

_____

_____

28) Are you aware of government schemes for providing pre-natal care or post-natal care for prevention of certain disabilities?

a) No

b) Yes

If yes, then please tell us a bit about the schemes that you are aware of and whether your hospital or clinic provides any services under these schemes?

_____

_____

29) Are you aware of any Government schemes for the reproductive health of women living with disabilities?

a) No
b) Yes

If yes, please give details of what scheme and the services provided by your hospital or clinic with respect to the scheme:

_____

_____

_____

30) What are some of the shortcomings faced by your patients living with disabilities, when they avail services or benefits under Government sponsored health schemes? How can the schemes be modified to serve them better?

_____

_____

31) Are you aware of any scheme that ensures access to specialized drugs, counseling and therapeutic management required to treat persons with disability?

a) No
b) Yes
c) Yes, the hospital or clinic I work in provides services under these schemes

If your hospital or clinic provides services under these schemes, please mention the particulars of the scheme, and the benefits your health facility provides persons with disabilities under the scheme

_____

_____

32) Has your hospital or clinic previously received, or is currently receiving any financial support from any governmental scheme for either early intervention facilities, the supply of medicines or the supply of medical equipment to enable the treatment of persons with disabilities?

d) No
e) Yes

If yes, then please let us know what these schemes are and the

nature of financial aid given:

_____

_____

33) Are you aware of any Government schemes that finance aids and appliances to patients with disabilities? What are these, and does your healthcare facility provide aids and appliances to patients with disabilities, under these schemes?

_____

_____

34) What are the problems your patients face when attempting to avail financial aid under these schemes for providing aids and appliances?

_____

_____

35) Does your hospital or clinic provide fitting and post-fitting services as required under Government Schemes financing aids and appliances to persons with disabilities?

_____

_____

36) Does your health care facility provide any corrective services/ surgeries at subsidized rates under any Government Scheme? For example, cataract related surgeries, or cochlear implants. What are these schemes and how much is the financial benefit offered?

_____

_____

_____

37) Does your health care facility provide additional services to make corrective services or surgeries more affordable to patients with disabilities?

_____

_____

_____

38) What Government sponsored health insurance schemes for persons with disabilities, is your hospital or clinic affiliated to? What

health care services covered under such schemes, do you provide patients with disabilities? (For example, the Niramaya Health Scheme provided by the Government is specifically tailored for persons with autism, cerebral palsy, mental retardation and other multiple disabilities.)

_____

_____

39) Based on your experience, what are some of the problems patients with disabilities face with health insurance schemes in hospitals, clinics and other health care facilities?

_____

_____

40) Does your health care facility provide post-procedure treatment and rehabilitation to patients with disabilities? If so, is this done through the aid of a Government Scheme?

_____

_____

41) What additional measures or changes would you recommend to existing Government Schemes related to the health care needs of persons with disabilities?

_____

_____

_____

42) Is there any additional information you would like to provide, or any special comments you would like us to read:

_____

_____

Annexure-3

LIST OF EXPERTS/RESOURSE PERSONS

North Zone Consultation

On 11th and 12th January, 2014

Name	Organisation
Adv Veena Sharma, Director	HRLN Chandigarh
Rajive Raturi, Director	DRI, Delhi
Deepika Nair	Saathi/ NAAJMI, Delhi
Renuka Mallekar and Nina Kocher	Multiple Sclerosis Society of India, Delhi
Dr. V.J.S. Vohra	Nevedac Prosthetic Clinic
Mr. A.K.Dua	Social Advisory Board, Chandigarh
Dr. Dharamvir	Dept. of ENT, PGIMER, Chandigarh
Dr. Parneet Kaur	Brain, Spine & Joint Centre, Mohali
Dr. Jaya Bakhshi	
Dr. Chaya Prasad	RIMH, Chandigarh
Mr. Rajeev Arora, Secretary	Patiala Thalassemic Children Welfare Association
Ms. Ratnaboli Ray	ANJALI, Kolkata
Ms Geeta Chaturvedi	Vishwaas, Gurgaon
Mr. Vikas Goyal	Patiala
Dr. Sandeep	Patiala
Dr. A.S. Khehra	
Dr. Alma Ram	
Sanjana Goel	IAMD
Abdul Mabood	Snehi/ NAAJMI, Delhi

South Zone Consultation

On 26th and 27th October, 2013

Name	Organisation
Adv Sandhya Raju, National Director	HRLN
Rajive Raturi, National Director	DRI, Delhi
Deepika Nair	Saathi/ NAAJMI, Delhi
Noah Rosen	
Mr. Phillip Simon	
Ms.Suchitra Narayan, Founder - Director	(Education & Training) of SANSKRITI - Resource Centre for Inclusion, Cochin.
Ms.Jayshree Shankar, Director	Education & Training, SANSKRITI - Resource Centre for Inclusion, Cochin
Dr. Aboobacker CP	AWH, Calicut
Prof. KA Chandrasekharan, Consultant	
P.B. George, General Secretary	Mithram
Mr.Nazar Manayail, President	Kerala Vikalanga Samyuktha Samithi, Ernakulam
Mr. Sankararaman	IAMD
Dr. Sasidharan, Professor Hematology Department	Medical College, Kozhikode
Dr. Sudhir Kumar, Consultant Psychiatrist	Alzheimer's and Related Disorders Society of India
Mr. Narsappa, Chairman	Society of the Leprosy affected persons, Hyderabad
Dr. Ajith	Medical college Calicut
Ms. Ratnaboli Ray	ANJALI, Kolkata
Abdul Mabood	Snehi/ NAAJMI, Delhi

West Zone Consultation

On 22nd and 23rd June, 2013

Name	Organisation
Rajive Raturi	HRLN Delhi
Deepika Nair	SAATHI/ NAAJMI, Delhi
Sanjana Goel	IAMD Solan
Abdul Mabood	SNEHI/ NAAJMI Delhi
Ratnaboli Ray	ANJALI, Kolkata
CLPR, Bangalore	

East Zone Consultation

On 24th and 25th August, 2013

Name	Organisation
Rajive Raturi	HRLN Delhi
Deepika Nair	SAATHI/ NAAJMI, Delhi
Dr. Sudha Kaul, Founder	IICP
Dr. Chhetri	IICP
Abdul Mabood	SNEHI/ NAAJMI Delhi
Dr. Sebanti Ghosh	ASHA WB
Prof. Ruma Chatterjee	Society for Visually Handicapped
Ms. Snigdha Sarkar	ANWESHA
MS. Sanjana Goel	IAMD
Ms. Iona Kundu	MENTAID
Ms. Shampa Sengupta	Sruti Disability Rights Centre
Ms. Kuhu Das	Association for Women with Disabilities
Ms. Tulika Das	SANCHAR
Ms. Indrani Basu	Autism Society of West Bengal
Ms. Nilanjana Maulik	ARDSI
Ms. Ratnaboli Ray	ANJALI, Kolkata

National Consultation Delhi
On 19th and 20th April, 2014

Name	Organisation
Rajive Raturi	Human Rights Law Network, Delhi
Jayna Kothari	Centre for Law and Policy, Bangalore
Deepika Nair	SAATHI, Delhi
Praveen G	VSO Delhi
Dr. Satendra Singh	UCMS, Delhi
Adv Roma Bhagat	
Dr Ratna Devi	Alliance of patients organizations, Delhi
Merry Barua	Action for Autism
Renuka Mallekar	MSSI, Delhi
Mr. Narendhar	ARDSI, Delhi
Abdul Mabood	SNEHI, Delhi
Mr. Vijay Kaul	Society for Hemophilia Care, Delhi
Rajiv Arora	Thallassemic Children's Welfare Association, Punjab
Mamta Govil	Latika Roy Foundation, Dehradun
Seema Baquer	CAN
Mr Narsappa	National Forum, Parag Namdeo (Sense International)
Ratnaboli Ray	ANJALI, Kolkata
Sanjana Goel	IAMD, Solan

Annexure-4

LIST OF PARTICIPANTS

North Zone Consultation

Sr. No.	Name & Organisation
1.	G. P. Bansal, Manimajra
2.	Balbir Singh Guleria, CORD,
3.	Meenakshi Srivastava, Umang-Jaipur
4.	Rajeev Arora, Patiala, Thalassemic Children Welfare Association
5.	Astha Dhanda, Centre for policy research and advocacy
6.	Ruchi, # 962A/43A, Chd., Human Rights, Duties Punjab University
7.	Deepa, NAB, Sector-11, Chandigarh
8.	Kulwant Kaur NAB, Sector-11, Chandigarh
9.	Ravi Jawa, # 135-C, Model Town Panipat
10.	Puneet Jain, 106 Basant Avenue Amritsar
11.	Harshit Anand, # 1515, 23 B, Chandigarh
12.	Sarbjeet Singh, #1315, Lalrya Mandi, Mohali
13.	Pranshu Singhal,#214/9, Ambala City
14.	Kanish Jindal, #133, Sec 46-A,Chandigarh
15.	Sanjay Rana,#280, Sec 12-A, Chandigarh
16.	Anubhav Singh,#5139/2, MHC,Mani Majra, Chd
17.	Nandan Kandpal, Srajan Spastic Society, Nanital,
18.	Lalit Kumar Chauhan (Roshani), Haldwani (Nanital)
19.	Era Walton,#501/E-11 GH-79, Sec 20, Panchkula
20.	Dheeraj Ahuja,#1, Block No.2, BH-1, Meherchand Mahajan Hall, PU, Chandigarh
21.	Shiv Kumar Sharma,#824, Milk Colony, Dhanas, Chandigarh

22.	Sanjeev Kumar,#256, NAC, Mani Majra, Chd
23.	Ravinder Kumar,#3574, Sec 22, Chandigarh
24.	Harmesh Kumar Bhutta,#1-A, ITI Campus, Sec 28C, Chandigarh
25.	Renuka Melekar,#J-1829, CR Park, New Delhi
26.	Nina Kochhar
27.	Deepika Nain
28.	Ratnabohi Ranj
29.	Vikas Goyal
30.	Dr.Sandeep Samar
31.	Somesh Gupta, Zirakpur
32.	Anu Saigal ,(Chd)
33.	Rama Bhave
34.	Sonia Sharma
35.	Jai Dev, HRLN, Delhi
36.	Rajive Rarturi, HRLN , Delhi
37.	Sunil Kumar, Chandigarh
38.	Dr. Dharamvir, PGI
39.	Rayat, Sec 24 , Chandigarh
40.	Saptar, Sec 24, Chandigarh
41.	Veena Kumari, HRLN, Chandigarh
42.	Jatinder Kumar, HRLN, Chd
43.	Vijay Kumar,#3479, Mohri Jugva Complex, Chd
44.	Jarnail Singh,#1070, Sec 70, Mohli
45.	Y.P.ansal,#541/3, MHC, Mani Majra
46.	Dr.Amarjit Singh Khekra, Mohali Senior Citizens Association, #903, 3B, Mohali
47.	Vijay Valia, RajVala Road, Patiala
48.	Chitranjan Pal, #235, Sec 22-C, Chandigarh

49.	Sanjana, Indian Association Of Muscular Dystrophy, #1732/2, Hospital Road, Solan
50.	Ravinder Singh, BPO Balongi, Mohali
51.	Mandeep Singh,BH-1, 1/16 , Sec 19, Chandigarh
52.	Divya,#962 A/43 A, Chandigarh
53.	Rajpal,#962 A/43 A, Chandigar
54.	Shikha Kansa
55.	Bipam Kansa
56.	Darshan Ra,#25, Ward 11, New Defence Clony, Zirakpur,
57.	Sunny,#332, Sec 25-D, Chandigarh
58.	HardeepSingh,Village Khanpur GandyaTehsil, Rajpura Dist., Patial
59.	Rajider Singh, Cheema Khurd, Nor Mahal, Jalandhar
60.	Dr V.J.S. Vohra, Sr.Consultant, Artificial Limbs and Orthopaedic evedac Prosthetic Clinic,#1134/44-B, Chandigarh
61.	Manjbala
62.	Sh.K Dua, Secretary CSWB, Kauna Sadan, Sec-11, Candigarh.
63.	R. Parneet Kaur Bedi, Brain, Spine and Joint Clinic, Shivalik City,Sec 127, Greater Mohali
64.	Harinder Kaur,#11, Green Lehar, Pasi Road, Patiala
65.	Gganjot Singh,#11, Green Lehar, arsi Road, Patiala
66.	S.K. Kapoor, Retd. DDM, PLI, #244, Sec 25, Panchkula
67.	Gurbir Singh Kochhar
68.	Geeta Chaturvedi, VISHWAS, Gurgaon
69.	Alka Gupta, HRLN, Chandigarh
70.	D.R. Chamoli, CHD.
71.	Upma Sharma, M.H., Chandigarh
72.	Dr. Jaimati Bakshi, PGIMER, Chd.
73.	Baljeet Saroha,#186-P, Mela Ground Area, Huda Sector, Hisar

South Zone Consultation

Sr. No.	Name Of Participant	Organization
1	Ben Kurian Kuriakose	Snehabavan Gandhinagar P.O Kottayam
2	Madhukeshava. S	6th Cross, Hakchins Road, St Theresas Town Post Lingaraja Puram Bangalore -85
3	Noah Rosen	576 Masjid Road, Janpura New Delhi
4.	M. Muthu Selvi	Ba/ Perumal Koyil St.,Potheri, Kottangulathur P.O, Kanchepuram District- 603203
5.	Dr. Aboobacker C.P.	Association For Welfare Of Handicapped Paramani Road, Cahient
6.	Paresh C.Palicha (Charan Das)	Jamina, 8/1704. Mullakkal Bagavah Lane, Koovapadam, Kochi- 682002
7.	Sivadesam Nair P. K.	All Kerala Parents Association of Hearing Impaired (AKPAHI) Sree Valsam, Mahakkal, Alapuzha, 688011
8.	Sr. Alice	Ernakulam Social Service Society Providence Road, Kochi-18
9.	Sr. Carmelita Naresha	Ernakulam Social Service Society Providence Road, Kochi-18
10.	Sr. Judit Kannikkatt	Cottolengo Special School K.J. Herschel Road Fort Cochin-682001
11.	Sr. Mary John Kattikatt	Cotholengo Special School, K.J Herchel Road, Fort Kochi- 682001
12.	E. K. Sujatha	Executive Director, Faith India
13.	Y. Suresh Kumar	National Forum India (Leprosy)
14.	S. Ashok Kumar	Project Manager LC Project Nagapottinain Disability Resource Centre.No.18/79/ Saraswathi Nagar Manakuppam Pachaiyakuppam P.O Cuddalor 607003
15.	C. N. Thampi	AKPHI
16.	Rajive Raturi	HRLN. New Delhi
17.	Sushma Raturi	HRLN. New Delhi

18.	Abdul Mabood	SNEHI, New Delhi
19.	Prof K. A Chandrasekharan	Rehabilitation Consultant Kerala State Handicapped Person's Welfare Corporation Poojapura Trivandrum Distt (Nithya Chaithanya,Chotanikkara) Kottayam District
20.	Sarada T.K	Thekkinattu House Chengulam East, 686585 Kottayam Dist.
21.	Sr. Deena S.H	Pratiksha Bhavan Special School Thodupuzha Idukki, 685584
22.	Sr. Nirmal S.H	Prateeksha Bhavan Special School Thodupuzha Idukki, 685584
23.	Nitha	Sanskrit Resource Centre For Inclusion Chakiath Building Ravipuram
24.	Rex Mohan	Raksha Society- Snac National Trust
25.	Ratnaboli Ray	Anjali, Calcutta
26.	Deepika Nair	Sathi All For Partnership, Delhi
27.	Molcy Joseph	Faith -India Kokkapilly. P.O Vennikkulam. Ekm,
28.	SR. Vimalgrace C.T.C	Karuna Special School Nayarambalam
29.	Sudharani	SAMA Foundation Bangalore
30.	Muhammad Lukhman.K	Hemophilia Society, Calicut Chapter
31.	Reecha Das	Centre For Law & Policy Research Bangalore
32.	Diya Elizabeth Punnoose	Rajagiri College Of Social Science Kalamassery P.O Cochin
33.	Sona Jose	State Co-Ordinator.Bedtha-Katham A Program Of National Trust New Delhi
34.	Rajan George	Dist.President Kerala Federation Of Blind
35.	Shintovarghese	Asst.Professor Bharata Matha School Of Social Work Trikakara, Cochin
36.	Charandas.L. Palicha	Cochin, 682002
37.	Prema	
38.	Parvathi.R.Nair	Intern Hrln Christ University
39.	Arya Anil	Intern Hrln Christ University
40.	Shivpriya Anil	Intern Hrln Christ University
41.	Reeby Tijo	Welfare Services Ernakulam Ponnuranni, Vytila

42.	Aasaavari Soni	Intern HRLN Indian Law Societies Law College. Pune
43.	Divya Elizbeth Punnoose	Rajagiri College Of Social Sciences Kalamassery
44.	Biju K.O	KFZ. Ankamally C/O Kerala Pedestion of The Blind
45.	Rassal Janardhanan	Intern HRLN Christ Universtiy
46.	Sr. Abhaya	St C;Are Oral Higher Secondary School For The Deaf. Manickamangalam Kalady
47.	Jayshree Sankar	Sanskriti Ravipuram
48.	Ann Marie	Bmc, Faculty(Msw)
49.	Raju.M.A	Aluva
50.	Rajiv Rajan	General Secretary, Ektha
51.	A.Dhanasekhar	Member, Ektha(Personnel Asst. To Rajiv
52.	U. Amar Nata	Canara Bank Road
53.	Fr. Saji.J	Loyola College Of Social Sciences Sreekariyam Trivandrum

West Zone Consultation

Sr. No.	Name Of Participant	Organization Address
1	Dr. Sanchi Sharma	The Research Society Mumbai
2	Shubhangi Kamble	Adapt, Mumbai
3	Bhavna Pattanaik	CLPR, Bangalore
4	Dr. Vinita Kadan (P.T.)	Adapt, Mumbai
5	Priyanaka Kumari	NIHH
6	Shubhangi Khawale	NIHH
7	Deepika Nair	Sathi all for partnership, Delhi
8	Imran Qureshi	Paraplegic Foundation
9	Ratnaboli Ray	Anjali, Kolkata
10	Armaity Kelawala	TISS, Mumbai

11	Farida S. Jawadwala	Jai Vakeel School For Children Sp. Need
12	Prathimes Gaikwad	J. J. Hospital
13	Nishtha Taker Anand	IAMD
14	Suzette Titus	NAAJMI
15	Dilip Prabhulkar	The Research Society, Mumbai
16	Dr. P J Mathew Martin	AYJNIHH Bandra
17	HImanshi Bharadwaj	AYJNIHH Bandra
18	Nisha Pawar	AYJNIHH Bandra
19	Puneeet Kumar Gupta	AYJNIHH Bandra
20	Abdul Mabood	SNEHI/ NAAJMI New Delhi
21	Rahul Bais	Swarajya Mitra
22	Sanjana Goel	IAMD, HP
23	Naman Patankar	AAA
24	Mrs. Chhabria	Muscular Dystrophy Society, Mumbai
25	Dr. Ashok Dhabekar	IID, Nagpur
26	Mamta More	Janarth Aurangabad
27	Sadhna Dhabekar	IID, Nagpur
28	Raman Chandra	IMD
29	Neil Feedrick	AYJNIHH, Mumbai
30	Pauavi Kadan	NAB, Mumbai
31	Rupesh Phatkare	Malasopara Thane
32	Swapnil Ghume	HRLN, Mumbai
33	Gary Vaz	HRLN, Mumbai
34	Pooja	IAMD, Solan, HP
35	Govind	IAMD, Solan, HP
36	Sonu	HRLN, Mumbai
37	Raju Waghmare	HRLN, Mumbai

38	Lakshika Sachdev	HRLN, Mumbai
39	Amshi Magdani	HRLN, Mumbai
40	Varun Baliga	CLPR, Bangalore
41	Danesh	
42	Rajive Raturi	HRLN, Delhi
43	Jaidev Nautiyal	HRLN, Delhi
44	Robin	IAMD
45	Ira Roy	SLIC, Mumbai
46	Krishna Anand	IAMD
47	Annu Gautham	NIHH
48	Pushpa Raman Chandra	IAMD
49	Mahammad Husain	TISS
50	Jyoti Rajput	TISS
51	N. R. Vyas	Mumbai
52	Ayushman Verma	HRLN, Mumbai
53	Kushaal	HRLN, Mumbai

East Zone Consultation

Sr. No	Name Of Participant	Organization
1	Mr. K. Ananda	Orthopeadically Handicapped Welfare Association, Orrisa
2	Mr. Om Prakash Mohapatra	AAINA Orissa
3	Mr. Anil Pattnaik	AAINA Orissa
4	Ms. Dipti Dash	Open Learning Society, Orissa
5	Mr. Sambit Bhatta	SMRC, Orissa
6	Mr. Krishan Mohan	Adrash Viklang Seva Sansthan, Bihar
7	Dr. Sunil Kumar Singh	Adrash Viklang Seva Sansthan Bihar

8	Mr. Ram Prakash Misra	Dooars Institute for the Disabled Ramgaon, College Para Jaigaon Jalpairuguri Pin- 736182,W.B
9	Ms. Reecha Das	CLPR
10	Ms. Sudeshna Basu	Anjali, Kolkatai
11	Ms. Kuhu Das	Association For Women With Disabilities, Kolkata
12	Mr. Gautam Choudhury	Social Activist, Kolkata
13	Ms. Jeeja Ghosh	Indian Institute of Cerebral Palsy Kolkata 700 088
14	Prof. Ruma Chatterjee	Society for Visually Handicapped, Kolkata
15	Ms. Mithua Sen	Secretary of Deaf Blind Organization, Kolkata
16	Mr. Bubai Bag	Phd scholar at Jadhavpur Universtiy, Kolkata
17	Ms. Gunjan Chandak Khemka	Iswar Sankalpa, Kolkata
18	Beauty Mondal	Sanchar
19	Ms. Snigdha Sarkar	Anwesha, Kolkata
20	Mr. Bidyut kumar Dey	IDEA, Kolkata
21	Suchitra Dutta	Sanchar, AROD, Kolkata -14
22	Ms. Riddhi Kothari Shah	Sruti Disability Rights Centre Kolkata
23	Mrs. Nilanjana Maulik	ARDSI, Kolkata
24	Dr. Sudha kaul	Indian Institute of Cerebral Palsy, Kolkata
25	Dr. Chhetri	Physiotherapies, Kolkata
26	Ms. Indrani Basu	Autism Society of West Bengal
27	Ms. Tulika Das	Sanchar, Kolkata - 700 014
28	Ms. Shampa Sengupta	Sruti Disability Rights Centre, Kolkata
29	Priyanka Ghosh	Sanchaar AROD, Kolkata- 14
30	Ms. Iona Kundu	MENTAID
31	Ms. Alpna	Deepshika, Jharkhand
32	Mr. Rajive Raturi	HRLN, Delhi
33	Mr. Sumit Bhandari	HRLN, Delhi

34	MR. Jaidev Nautiya	HRLN, Delhi
35	Ms. Sanjana Goel	IAMD, Solan, HP
36	Ms. Deepika Nair	SATHI, New Delhi
37	Mr. Abdul Mabood	SNEHI, New Delhi
38	Ms. Ratnaboli Ray	Anjali, Kolkata
39	Ms. Indira Ghosh	NIHH, Kolkata
40	Suraj Kumar Dass	Open Learning Society, Orissa
41	Mr. Prakash Saha	Adrash Viklang Seva Sansthan Bihar
42	Ms. Aditi Basu	Anjali P23 Darga Road Kolkata – 17
43	Sukla Das Barma	Anjali P23 Darga Road Kolkata – 17
44	Nivedita Guhathakurta	HRLN, Kolkata
45	Debasis Biswas	DCW
46	Debashish Banerjee	HRLN, Kolkata
47	Rouddo Mitra	Anwesha
48	S. Sengupta	Anwesha
49	Prakash Sura	Samarth, GDOWA
50	Vinod Thakur	Kattwar, HC
51	Anita	Sayara Helper

National Consultation Delhi

Sr. No.	Name Of Participant	Organization Address
1.	Abdul Mabood	Snehi, Delhi
2.	Abhishek	Mind & Soul, Mumbai
3.	Anil Verma	Hemophilia Advocacy Society, Patiala
4.	Ankur	IAMD, Delhi
5.	Ankur Gupta	Intern HRLN Delhi

6.	Arajmand Makhdoomi	Chotey Tare Foundation, J&K
7.	Ashok Kumar	Deepshikha India, Ranchi
8.	Ashiq	IAMD, Solan
9.	Aghor Mukherjee	IPARW-Health Care Kolkata
10.	Ashutosh Dutta	IPARW-Health Care Kolkata
11.	Biswajeet M	IPARW-Health Care Kolkata
12.	Bharat Joshi	Blind People's Association, Vastrapur Cross Road, Ahmedabad Gujarat
13.	Binod Kumar	Astha, Basti Vikas Kendra, Bal Mukund Khand, Giri Nagar, Kalkaji, Delhi-110019
14.	Bittoo Singh	HRLN, Delhi
15.	B. Raghava	The Deaf Aid Society, Banglore
16.	Deepika Nair	Saathi all for Partnership Delhi
17.	Dr. Ajay Kumar	Physiotherapist, Patiala
18.	Dinkar Gwande	Mind & Soul, Mumbai
19.	Dr. Ratna Devi	Daksham, Health
20.	Dr. Satendra Singh	Delhi
21.	Geeta Sharma	NAD
22.	H. Malkiyat Singh	Gurukirpa Handicapped Association, Patiala
23.	Harjit Singh	Gurukirpa Handicapped Association, Patiala
24.	Jacob Oommen	Leprosy Trust India, New Delhi
25.	Jagdeep Kakkar	HRLN Delhi
26.	Jaidev Nautiyal	HRLN, Delhi
27.	Jayna Kothari	CLPR, Bangalore
28.	Joshika	Jindal Law School, Delhi
29.	Mukesh Waghle	Mind & Soul, Mumbai
30.	Mamta Govil	Latika Roy Foundation Dehradun
31.	Manju	IAMD, Solan

32.	Merry Barua	Action for Autism, Delhi
33.	MP Dubey	HRLN Delhi
34.	Manoj	Deepshikha India, Ranchi
35.	Rakhesh Yadav	Deepshikha India, Ranchi
36.	Mr. Sarang	APAL, Indore
37.	Murlidharan	NPRD
38.	Nandita Saran	Nab Delhi
39.	Narayanan	NAD
40.	Navjyoti Gupta	Office of the National Director cum CORD Training Centre, Sidhbari, District Kangra, HP-176057
41.	Nibha	Interpreter
42.	Nidhi	AADI - Action for Ability Development and Inclusion, 2, Balbir Saxena Marg Hauz Khas, New Delhi-110016
43.	Nina Kochhar	MSSI, Delhi
44.	Pramod	Parivartan , Bhopal
45.	Parag Namdeo	Sense International India, Delhi
46.	Paridhi	Jindal Law School, Delhi
47.	Pranab Hazarika	Shishu Sarothi, Guwahati
48.	Praveen Kumar	VSO, Delhi
49.	Preeti Johar	Family of Disabled
50.	Pushpa Gupta	HRLN, Delhi
51.	Rajender Shishatkar	Mind & Soul
52.	R. Narendhar	Delhi
53.	Rajiv Arora	Thalassemic Children Welfare Association, Patiala
54.	Rajive Raturi	HRLN, Delhi
55.	Ranu Benerjee	Parivaar, Delhi

56.	Ratnaboli Ray	Anjali, Kolkata
57.	Reji Oommen Philip	National Deaf Fellowship Kerala
58.	Renu	AADI - Action for Ability Development and Inclusion, 2, Balbir Saxena Marg Hauz Khas, New Delhi-110016
59.	Renuka Malaker	MSSI, Delhi
60.	Raj kishore	Deepshikha India, Ranchi
61.	Rizwan Ali	Latika Roy Foundation Dehradun
62.	Roma Bhagat	House No. S-185 Panchsheel Park, New Delhi-110 017
63.	Amarnath.R	The Deaf Aid Society, Bangalore
64.	R J Goyal	The Deaf Aid Society, Bangalore
65.	Sanjana Goel	IAMD, Solan
66.	Seema Baquer	CAN, Delhi
67.	Shaista	HRLN, Delhi
68.	Shamapika Mishra	Intern HRLN Delhi
69.	Shashi Yadav	NAD, Delhi
70.	Somesh Bajpai	SPARC, Lucknow
71.	Sonu Panday	Interpreter
72.	Subir Sen	Iswar Sankalpa Kolkata
73.	Sumit	HRLN Delhi
74.	Suzette Titus	NAAJMI Mumbai
75.	Usha Prasana	The Deaf Aid Society, Bangalore
76.	V. Narsappa	APAL Hyderabad
77.	Vijay Kaul	Society for Hemophelia Care Delhi
78.	Vijay Pahwa	Patiala Tahalassemic Children Welfare Association Patiala

79.	Vikas Goyal	NABHA, Patiala
80.	Vipul Goyal	IAMD, Solan
81.	Virendra Kalra	Muscular Dystrophy, Delhi
82.	Vivek Sharma	HAVS, Gwalior
83.	Yogesh Singh	Parivartan, Bhopal
84.	Zoya	HRLN Delhi