PUBLIC HEALTH FOUNDATION OF INDIA

UNLEASH YOUR DISABILITY

SOUTH ASIA CENTRE FOR DISABILITY INCLUSIVE DEVELOPMENT & RESEARCH
SACDIR

funded by

H T Parekh FOUNDATION

Administrative by

HDFC

WITH YOU, RIGHT THROUGH

Foreword

M. JAGADEESHWAR, I.A.S.,
Secretary to Government
Department for Women, Children,
Disabled and Senior Citizens
Government of Telangana

Foreword

The "Manual on disability" is being brought out by the Indian Institute of Public Health, Hyderabad (South Asia Centre for Disability Inclusive Development & Research, a centre of excellence of the Public Health Foundation of India) and the HT Parekh Foundation. The manual in particular provides a quick view on the issues pertaining to research on Disability in India and its relevance to Public Health.

The number of people having different disabilities is growing because of ageing populations and increasing chronic health conditions. The report covers key components such as the magnitude of disability in India, and the various systems in place for reducing disability. It also describes how to develop a program in disability, including the services that should be made available both in the government as well as in the non-governmental sector.

The report portrays the different approaches to the measurement of disability, including their advantages and disadvantages, and also discusses key challenges faced by people with disabilities and policy implementations of the new Act for their benefit.

There is now an ever growing emphasis on measuring disability in order to estimate the prevalence of disability, identify the needs of people with disabilities, and monitor the inclusion of people with disabilities. I hope the report will be a useful tool and reliable source of information. It will be an aid not only for policy makers and planners, but also for a range of stakeholders who are interested in learning about, and contributing towards, the body of evidence in disability research and practice. It will also be useful for lay-people and carers of people with disability.

The report is expected to serve as a baseline, and provide information on the State of the policy in disability and at the same time assist in formulating recommendations for efficient management of existing programs in disability.

I am confident that the report will be of immense help in preparing relevant action plans for the management of disability issues, and will also be useful in developing the strategies for program management and implementation. I congratulate the Director of SACDIR/IIPH Hyderabad, and his staff, for bringing out this immensely useful report.

(M. Jagadeeshwar)

Acknowledgements

The Manual on disability is a joint project of the Indian Institute of Public Health, Hyderabad and the HT Parekh Foundation. We thank the foundation for their generouosity in supporting this initiatives to the most vulnerable group in the society.

The manual in particular provides a quick view on the issues pertaining to research on Disability in India and its relevance to Public Health.

We are deeply indebted to the team at London School of Hygiene and Tropical Medicine (LSHTM), UK and International Centre for Evidence in Disability (ICED), UK for contirbuting to this manual. We are also grateful to the contribution by fellow colleagues - Prof. Hannah Kuper, Ms. Islay Mactaggart, Dr. Sarah Polack at the London School of Hygeine and Tropical Medicine for writing chapter(s).

Last but not the least, we would like to thank all the participants of the studies mentioned in this manual through which we are able to understand the phenomenon of disability better and are able to serve them in more effective way.

About HT Parekh Foundation

The H T Parekh Foundation (HTPF) is a Section 25 company, established by the Housing Development Finance Corporation Limited (HDFC).

It was established in October 2012 with the aim to undertake, pursue and be concerned with the welfare, betterment and advancement of society as a whole, irrespective of religion, race, community, caste, gender, language or social status. The Foundation is sector agnostic and works across a range of social interventions and development initiatives across India.

HDFC conducts a significant portion of its Corporate Social Responsibility (CSR) through the Foundation. The Foundation's objective is to support and partner socially relevant projects and activities through NGOs and community-based organisations operating across India. With a view to achieving this goal, HTPF works across sectors, geographical locations and size to facilitate deep and long-term impact with partner organisations for a developed and inclusive society.

HTPF partnered with Public Health Foundation of India (PHFI) to support the activities at 'South Asia Centre for Disability Inclusive Development Research (SACDIR)', a centre of excellence located at PHFI's campus at Hyderabad (Indian Institute of Public Health, Hyderabad).

The activities are aimed at attaining PHFI-SACDIR goals for promoting disability-inclusive development by addressing broad range disabilities through multiple public health interventions based on the multidisciplinary and multi-sectoral approach.

The activities supported by HTPF are to develop capacity in the region and provide evidence for action, augment skills through need-based training modules, assist in programme development and evaluation, and help in policy formulation and advocacy. HTPF also supports novel activities like disability skills lab with and without virtual/augmented reality. Other activities include developing new programs such as short courses, community-based interventions, research and evaluation projects, technical forums and conferences.

About SACDIR

South Asia Centre for Disability Inclusive Development & Research (SACDIR), a centre of excellence was established under the aegis of the Public Health Foundation of India (PHFI) in collaboration and support from the London School of Hygiene and Tropical Medicine (LSHTM), and its component institution, the International Centre for Eye Health (ICEH), London, UK.

The mission for the Centre is Inclusive Millennium: Evidence for Empowering Persons with Disabilities.

The World Health Organization (WHO) estimates that globally 650 million people live with some disability (physical, mental, visual, hearing, learning, speech and intellectual) and 80% of this burden is in low & middle-income countries. The Census 2011 in India estimated that 26.8 million people suffer from disability (2.2%) and 12% of them are children less than 10 years of age. It is now understood that disability is a public health problem but efforts to deal with it using a public health or health systems approach is negligible or lacking.

Though there are a large number of extremely successful service delivery initiatives in the South Asia region, there has been very little effort in looking at disability from a public health perspective. This leads to a paucity of evidence on the prevalence and magnitude of disability and valid evaluation of interventions. With resource constraints increasing every year, it is important to look at the costs and effectiveness of interventions. Such an approach allows a larger proportion of the population to benefit from successful interventions.

The Objectives of SACDIR are:

- Develop the evidence base for documenting the prevalence and magnitude of disabilities within the South Asia context
- Train and reorient health care personnel to concerns of persons with disabilities

- Organise modules on application of the International Classification of Functioning (ICF) recommended by WHO

- Run short and long-term training courses/modules on disabling conditions & inclusive development

- Develop a Masters Course in Disability Management & Research

- Conduct high quality need-based epidemiological, operations, sociological and outcomes-based research to improve the quality of life of persons with disabilities

- Evaluation of existing programs for persons with disabilities in India and other South Asian countries

- Develop innovative modalities for identifying persons with disabilities and providing appropriate care

- Advocate at appropriate congregations and forum for disability inclusive development

- Assist and influence policy development initiatives to foster disability inclusive development in the country and the region.

Over the past decade, SACDIR has functioned in four broad areas:

1. Developing research capacity in the region and provide evidence for action

2. Augmenting skills of existing and new professionals through need-based training modules

3. Assist in programme development and evaluation in South Asia Region, with a major focus on India

4. Help government, NGOs and other stakeholders in policy formulation and advocacy

Table of contents

PART 1

THE MAGNITUDE OF THE PROBLEM

Chapter 1

The measurement

Prof. Hannah Kuper, Dr. Sarah Polack, Ms. Islay Mactaggart

What to measure?

The terms disability, impairment, and handicap have been used synonymously. Each of these terminology convey three different meanings and it is very crucial to understand them at the first place.

Let's try to understand them

Impairment: any loss or abnormality of physiological or anatomical structure.

Disability: any restriction or lack of ability (due to an impairment) in performing an activity in a manner or range considered normal for a human being.

Handicap: a disadvantage for a given individual, resulting from a disability or impairment, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual.

Why to measure?

The World Report on Disability estimates that there are about one billion people with disabilities in the world[1]. However, there is currently little data on disability, and so this figure is very uncertain. A key reason therefore to measure disability is **to estimate how many people have disabilities** both globally and within different countries. This information is important for advocacy and for planning programmes.

It is also **important to understand the situation of people with disabilities** in different settings in order to best plan services that cater to their needs and provide equality of opportunity in accordance with the UN Convention on the Rights of Persons with Disabilities (UNCRPD)[2]. For instance, are children with disabilities less likely to go to school, so that efforts are needed to promote inclusive education? Are adults with disabilities excluded from employment, so that vocational programmes need to be established? Do

people with disabilities have poorer access to water and sanitation, so that adaptations of these facilities are required? We need to measure disability and its relationship with other factors in order to answer these questions and be able to plan services that meet the needs of people with disabilities.

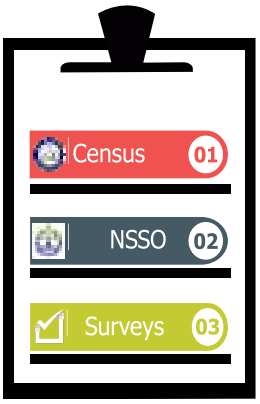
The new Sustainable Development Goals (SDGs) describe the need for inclusive development that "Leaves no one behind". We must ensure that data on disability is included in all reporting on achievements towards the SDGs so that we can assess how far each goal is achieved for people with disabilities compared to people without disabilities.

Monitoring inclusion in this way will help us to see where extra efforts are needed to achieve the full and equal participation of people with disabilities on an equal basis with others, and to ensure the SDGs can be reached for all.

How it is measured in India?

Estimates of the prevalence of impairments that lead to disability are available from a few sources at the national level, and research surveys conducted across India.

Three sources are



1. Census of India

Census[3] is the enumeration of the country conducted every 10 years in India since 1872. The disability data collected as a part of census has seen peaks and valleys in the past.

1872-1931: Data on disability was collected from 1872 to 1931 until the census commissioner remarked in 1931

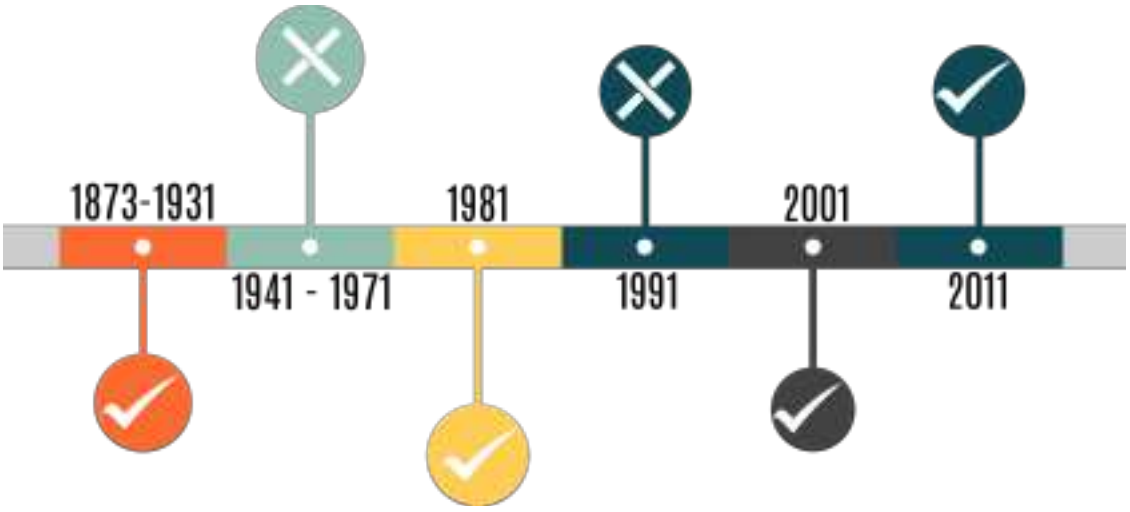


Figure 1

Canvassing Disability in Census of India

that the returns on infirmities at the Indian Census has probably never been satisfactory.

1941-1971: As a result, from 1941 to 1971, the data was not collected as a part of census.

1981: As 1981 was proclaimed as International Year for the Disabled, to emphasis the importance a renewed effort was made to collect data on disability through a simple question during the House listing Operations through three categories of disabilities: Totally Blind, Totally Dumb and Totally Crippled.

1991: The 1981 Census again supported the view that Census Operations do not lend themselves to the identification of people with disability. Hence, the questions on disability was again removed from the census.

2001: In Census 2001, the question was again included on five types of disability (In Seeing, In Speech, In Hearing, In Movement and Mental).

2011: Later in Census 2011, information on eight types of disability was collected (In Seeing, In Speech, In Hearing, In Movement, Mental Retardation, Mental Illness, any other and multiple disability).

Importantly, it should be noted that the definitions of each disability in Census has changed over the years.

2. Sample Survey (NSS)

NSS[4] conducts multi-subject integrated sample surveys since 1950. Mainly four types of surveys are conducted under NSS - Household, Enterprise, Village Facilities and Land & Livestock holdings. It has a well-defined cycle of the surveys extending over a period of 10 years. The socio-economic surveys cover the estimation of disability.

NSSO uses a two-stage sampling method to select the household. Initially, the villages/ urban blocks are selected randomly from complete list of villages/ urban blocks in India. Secondly, random households are visited from the selected villages / urban blocks for further interviews.

The 58th round of NSSO conducted in 2002 (July - Dec) estimated the disability in India. The NSSO considered persons as disabled if they had any of the five types of disabilities - mental, visual, hearing, speech and locomotor.

3. Surveys

Research surveys conducted across India use different methodology based to their objectives. Most commonly used survey methodologies include PHQ9,

Washington Group Questionnaire, Rapid Assessment of Avoidable Blindness (RAAB), Rapid Assessment of Disability (RAD), Key Informant Method (KIM) etc.

Ideal model for designing a disability survey

Disability is a complex and umbrella term with many culturally different meanings. As a result, many different methods are used to measure disability, which has made it difficult to compare the prevalence of disability over time or between countries. There is now a strong lobby to collect comparable data, which is advocated for in the World Report on Disability as well as during the discussions around the SDGs.

There are several models of disability. These include the medical model, where disability is viewed as a problem with the individual's body, and the social model, which sees disability as the barriers placed on a person by society. The most widespread model of disability currently is the International Classification of Functioning, Disability of Health (ICF) Model, which is a bio-psycho-social model.

The ICF Model (Figure 2 & table 1) defines disability as:

1. Impairments in body function and structure
2. Activity limitations
3. Participation restrictions

that result from the interaction of contextual factors related to both the environment and the individual and the health condition.

The UNCRPD defines people with disabilities as people who experience:

"*long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder (a person's) full and effective participation in society on an equal basis with others*".

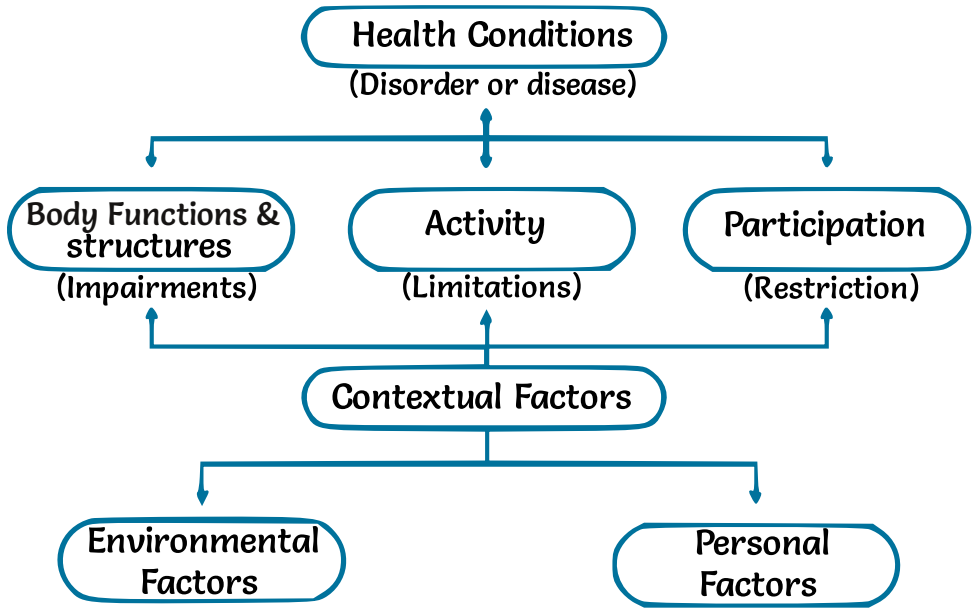


Figure 2

International Classification of Functioning, disability and health (ICF Model)

Table 1 Defining the International Classification of Functioning, disability and health (ICF Model)

Component of ICF	Definition	Example
Impairments in body function or structure	Impairments in physiological functioning or anatomical parts of the body	Acute muscular weakness and limb paralysis
Activity Limitations	Limitations in the execution of tasks or actions by an individual	Not able to walk
Participation Restriction	Problems experienced in involvement in life situations	Child is not enrolled in school because the local school is not accessible

Main approaches to measuring disability

Disability is both complex and experienced along a continuum. There are different approaches to measuring disability; some aim to classify people as having disabilities or not, whereas others focus on assessing the degree of disability that people experience.

The three main approaches are as follows:

1. Direct questioning on disability
2. Self-reported functioning
3. Diagnosing of impairments or health conditions

1. Direct questioning on disability

The first approach is to directly ask people whether they view themselves as being disabled or having a disability.

For instance, the Zambia census in 1990 asked each person "Do you have a disability? Yes/No". The advantage of this approach is that it is simple and quick. However, direct questioning is likely to severely under-estimate the prevalence of disability as people do not consider themselves to be disabled or do not want to define themselves as having a disability, for fear of stigma or discrimination. It is therefore recommended that direct questioning is not used to measure disability.

2. Self-reported functioning

A second approach is to assess self-reported functioning; that is, asking people whether they experience difficulties in different areas of life.

This approach is used by the United Nation's Washington Group on Disability Statistics[5], who have developed a short set of questions on functioning, intended to be used in census (Table 2). These questions ask whether a person experiences difficulties in six different functional domains. The purpose of the Short Set is to capture the proportion of the population most at risk of disability, and it focuses on the basic domains of seeing, hearing, walking, cognition, communicating and self-care. These

Table 2 Washington Group Short Set Questions

	No -no difficulty	Yes – some difficulty	Yes –a lot of difficulty	Cannot do at all
Do you have difficulty seeing, even if wearing glasses?				
Do you have difficulty hearing, even if using a hearing aid?				
Do you have difficulty walking or climbing steps?				
Do you have difficulty remembering or concentrating?				
Do you have difficulty (with self-care such as) washing all over or dressing?				
Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?				

questions can be used to estimate the proportion of the population living with different levels of functional limitation (i.e. how many have "some difficulty" in one or more domain, and how many have "a lot of difficulty" or "cannot do at all").

The Washington Group Short Set Questions are widely recommended for data collection on disability by global stakeholders. These questions are simple, quick and easy to translate into different languages. They are non-stigmatizing, as they do not ask about disability directly. The Short Set questions are most suited for use in censuses or in large surveys where only a few questions can be included to measure disability. Their widespread use will greatly improve the comparability and reliability of disability data over time and between countries. There are also potential limitations to this approach to measuring disability. The Short Set provides limited data on other key components of disability - including participation restrictions or impairments. Furthermore, they only focus on certain aspects of functioning, and do not capture mental health well.

The Washington Group have also developed an Extended Set of up to thirty-five questions, for use in surveys of disability and health, where more time is available to describe a more complete picture of disability. Additional domains included in the Extended Set include affect (anxiety and depression), pain, fatigue and upper body function, as well as more in-depth questions related to the basic domains of the Short Set (e.g. separately asking about near and distance vision). The Washington Group have also collaborated with UNICEF to develop an extended set of questions on functioning for children aged 2 to 17.

The **Model Disability Survey (MDS)**[6] is a general population survey tool that measures disability across a continuum that ranges from low to high levels of severity. All people are placed on this continuum, and the main objective of the MDS is to describe the distribution of disability in the population and identify the factors that contribute towards people experiencing high, middle or low levels of disability.

The core modules of the MDS takes around 20 minutes to be completed, and these are:

- *Capacity* (i.e. how a health problem affects how people function in multiple domains),
- *Performance* (i.e. how people actually function in multiple domains given health problems and environmental factors),
- *Environmental barriers* and *facilitators*.

Metrical scales of capacity and performance are built for the population using statistical methods, and participants who complete the questionnaire are each given an individual capacity and performance score. The distribution of these scores for the population of interest shows the range of disability in the population, from low to high levels. The difference in the proportion of people with severe problems in the capacity and performance scales shows the extent to which further interventions are needed in order to maximize performance and thereby reduce the level of disability.

The environmental barriers and facilitators module helps to identify where these interventions may be best targeted. A shorter set of the MDS is currently being developed and tested, and will aim to be approximately 20 minutes long.

The MDS is best suited for use in in-depth studies, focussing on disability as a core area of interest, rather than for use in a census or surveys that do not have disability as the main focus.

3. Diagnosing of impairments or health conditions

Impairments or health conditions are components of disability that can be measured directly (for example the presence of hearing impairment, visual impairment or physical impairment using an objective test). The Rapid Assessment of Avoidable Blindness (RAAB)[7] is one example of this type of tool. Collecting data on impairment or health conditions is important for planning appropriate health and rehabilitative services amongst those who would benefit from these (e.g. provision of cataract surgery, hearing aids, mobility devices, or other). These data may be particularly needed in low resource settings where inadequate access to health care is closely related to disability, and are not captured via either the Washington Group Questions or the MDS.

Clinical screens in isolation do not consider how the impairment or health condition affects the activities or participation of the individual, unless these additional components are also measured. It may also be more resource intensive to undertake clinical screens and measure impairments than to collect self-reported information. However, recent advances in technology are increasing the ability of non-clinical interviewers to undertake short screens of hearing, vision and mobility alongside self-reported functioning tools. One example is the Portable Eye Examination Kit (Peek)[8], which allows the assessment of visual acuity and other eye measures by a non-specialist using a smartphone.

Evidence from the field

A survey was conducted in India, funded by CBM, which compared the different approaches for measuring disability[9]. Approximately 4000 people were selected and screened from Telengana district. All people were asked to self-report on functioning using the Washington Group Questions (Extended set for adults, UNICEF set for children), and were assessed by clinicians for the presence of visual impairment, hearing impairment, physical impairment, epilepsy and depression. In India, people were also asked whether they considered themselves to have a disability.

Overall findings were that:

- Collection of the data on disability using the Washington Group extended set of questions was straight-forward and took on average 10-15 minutes per person, while the Short Set questions took 3-5 minutes. Prevalence of disability using this method was 7.5% in India.

- Measurement of impairments was more difficult and expensive, and depended on the presence of clinical staff. However, it provided important information on planning health service needs (e.g. the need for hearing aids). Prevalence of any clinical impairment was 10.5% in India.

- The combined prevalence of disability (Washington Group questions and clinical impairments) was 12.2% in India, showing the added benefit of collecting both impairment and self-reported data.

- In India, 3.8% of people reported that they had a disability on the single question, compared to 12.2% who were found to have any disability. This demonstrates that the single question severely underestimates the prevalence of disability and should not be used.

Summary Points

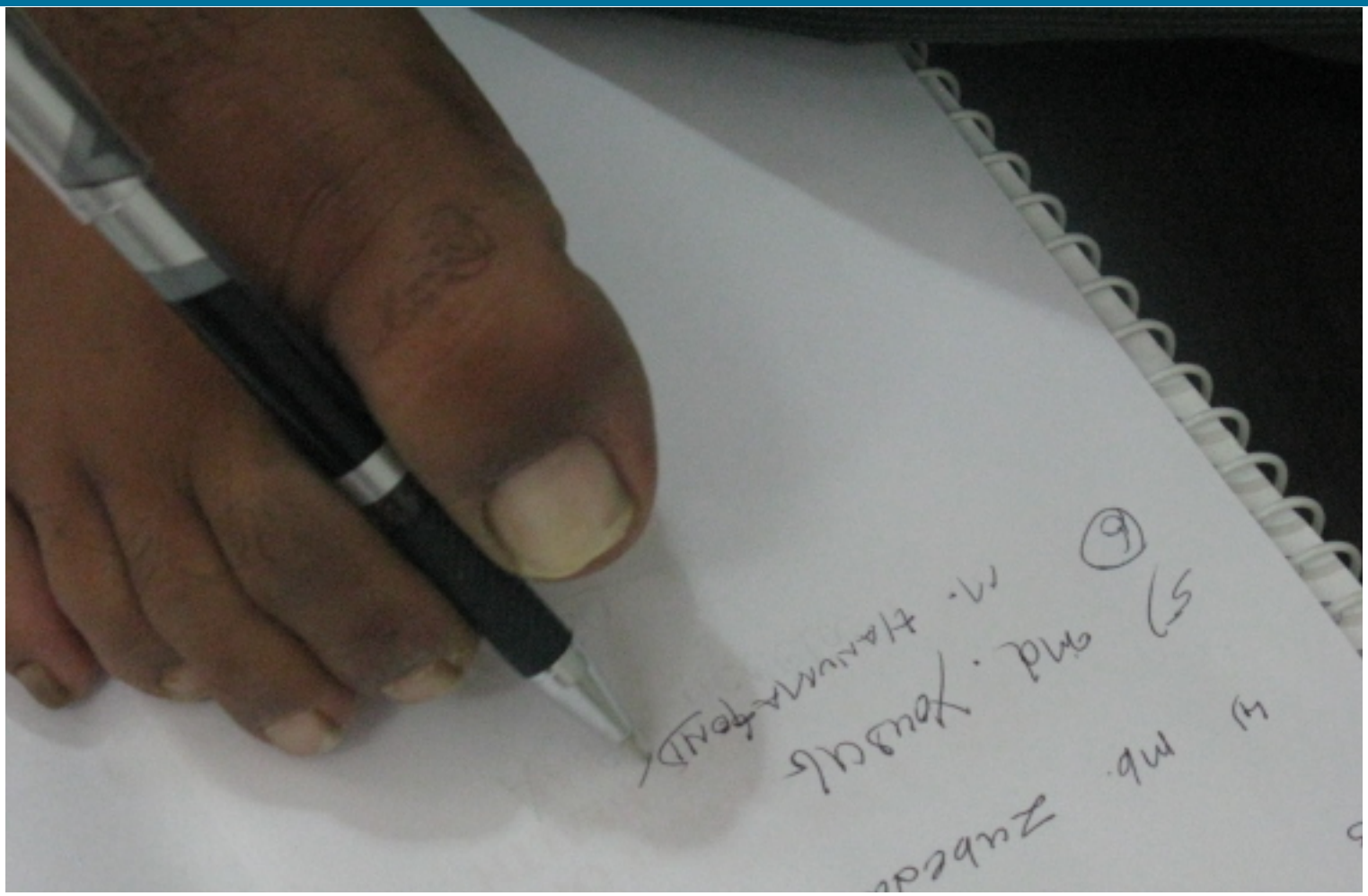
- Impairment is loss or abnormality of physiological or anatomical, disability is restriction or lack of ability to perform task of daily activities, and hadicap is social disadvantage which limits or prevents the fulfilment of a role that is normal for a individual.

- There is a growing emphasis on measuring disability in order to estimate the prevalence of disability, identify the needs of people with disabilities, and monitor the inclusion of people with disabilities.

- There are different approaches to the measurement of disability, which have advantages and disadvantages:

  - Direct questioning on disability will underestimate the prevalence of disability and should not be used.

  - Self-reported methods can be used to measure disability. Among these:
    1. The Washington Group Short Set and Extended Set are recommended for measuring disability in censuses or large surveys.
    2. The Model Disability Survey is recommended for use in surveys where more time is available to capture a more complete picture of disability and is used for planning and policy recommendations.
    3. Impairment can be diagnosed to help plan health services, but when measured alone will provide only one of the components of disability.
    4. A combined approach using both self-report and assessment of impairments may be beneficial.



References

1 http://www.who.int/disabilities/world_report/2011/en/
2 http://www.un.org/disabilities/convention/conventionfull.shtml
3 http://www.censusindia.gov.in/
4 http://mospi.nic.in/national-sample-survey-office-nsso
5 http://www.washingtongroup-disability.com/
6 http://www.who.int/disabilities/data/mds/en/
7 http://www.raabdata.info/
8 http://www.peekvision.org/
9 For full and summary country reports for India and Cameroon respectively, and for further resources related to this study, visit http://disabilitycentre.lshtm.ac.uk

Chapter 2

The numbers

Dr. Shailaja . T

Magnitude of the problem worldwide

People who have disability have profound difficulties in functioning and participating in their daily activities. According to the World Health Survey, approximately 785 million (15.6%) persons 15 years and older are estimated to live with a disability. These estimates are higher than World Health Organization's (WHO) previous estimates in 1970 which was around 10%. Of these, about 110 million people (2.2%) are estimated to have very significant difficulties in functioning. The Global Burden of Disease estimates that around 975 million (19.4%) persons live with some form of disability, of which around 190 million persons (3.8%) have severe disability. These severe disability conditions include quadriplegia, severe depression, or blindness. Only the Global Burden of Disease measures childhood disabilities (0-14 years), which is estimated to be 95 million (5.1%) children, of whom 13 million (0.7%) have severe disability[1].

Growing numbers of persons with disability

The number of people having different disabilities is growing because of ageing populations and the increasing chronic health conditions such as diabetes, cardiovascular diseases, and mental illness. In addition, medical advances that preserve and prolong life create overwhelming demands for health and rehabilitation services[2]. Types of disability in a particular country are influenced by the health conditions and trends in environmental and other factors - such as road traffic crashes, natural disasters, conflict, diet, and substance abuse. Though there is an increasing prevalence of disability worldwide, adequate attention has not been given in terms of evaluation, management and prevention of disability[1].

Income levels and disability

Disability disproportionately affects vulnerable populations like older people and people who are poor. Results from the World Health Survey indicate a higher level of disability prevalence in lower-income countries than in higher income countries[3] People who have low income, are out of work or have low educational qualifications are at an increased risk of disability. Data from the Multiple Indicator Cluster Surveys in selected countries show that children from poorer households and those in ethnic minority groups are at significantly higher risk of disability than other children[4].

Effects of disability

Every area of human life is affected by disability. People with disabilities face widespread barriers in accessing services (health, education, employment, transport as well as information). It affects their rights in terms of equality in health care access, employment, education, political participation, denied dignity or disrespect, in terms of violence, abuse, and prejudice from society. Due to these effects on education and employment, many people with disabilities are affected by catastrophic costs of health care, pushing them deeper into poverty.

Country	%	Year	Source
Bangladesh	5.6	2005	World Report on Disability
Maldives	4.7	2010	Human Rights Commission
Pakistan	2.65	2012	Helping Hand 2012
India	2.21	2011	Census 2011
Sri Lanka	2.0	2001	World Report on Disability2011
Nepal	1.94	2011	Census 2011

Source: World Bank & Disability in South Asia: A Portfolio Review 2003

Table 3

Sources of data for estimating disability in South Asia

Magnitude of the problem in South Asia

Table 3 gives the sources of data for estimating disability in South Asia. These sources range from the World Disability Report to the Human Rights Commission report.

Table 4 gives an estimate of disability in South Asia, according to the World Bank, with estimates hovering around 8-12%

According to some estimates in South-east Asia, the prevalence of disability is estimated to range from 1.5 - 21.3% of the total population[5]. The difference in prevalence in different countries is due to the difference in the definition of disability and its severity levels.

Magnitude of the problem in India

The prevalence of underlying impairments causing disability poses a major public health challenge in India.

Disability, as per the Person's with Disability Act (India), is defined as

'*A person suffering from not less than 40% of any disability as certified by a medical authority'. A disability may be physical, cognitive, mental, sensory, emotional and developmental or some combination of these. Thus disability is a complex phenomenon, reflecting an interaction between features of a person's body and features of society in which he or she lives*'.

Table 4

Country estimates of disability in South Asia

Country	Percentage disability
Bangladesh	10%
India	8-10%
Nepal	11-12%
Pakistan	8-10%
Maldives	8-10%
Sri Lanka	10-12%

Source: World Bank

Sources of estimates of disability in India

Estimates of the prevalence of underlying impairments that cause disability are available from a few sources at the national level, and research surveys in some states of India, as described below. The difference in distribution in each category of disability according to the two surveys could be explained by the methodological differences adopted in these surveys.

Table 5 Proportion of disabled population by age & sex in India (2011)

Age Group	Persons	Males	Females
All Ages	2.21	2.41	2.01
0-4	1.14	1.18	1.11
5-9	1.54	1.63	1.44
10-19	1.82	1.96	1.67
20-29	1.97	2.22	1.70
30-39	2.09	2.41	1.77
40-49	2.31	2.66	1.94
50-59	2.83	3.16	2.47
60-69	4.15	4.41	3.89
70-79	6.22	6.26	6.19
80-89	8.41	8.33	8.48
90+	8.40	7.88	8.85
Age Not Stated	3.07	3.21	2.91

Source: C-Series, Table C-20, Census of India 2011

Census

The Census of India (2001) included five categories of disability. It showed the prevalence of disability in India to be 2.13%, approximately 21.9 million, of which 12 million were males and 9 million were females. About 15% of the disabled were children aged <=10 years of age[6].

The more recent Census of India (2011) included eight categories of disability: 'Seeing, Hearing, Speech, Movement, Mental Retardation, Mental Illness,

Multiple Disability, and Any Other'. Results from the Census of India (2011) showed the prevalence of disability in India to be 2.21%, with a slightly higher prevalence among males (2.4%) than females (2%). But the decadal Increase in proportion is higher among females.

The percentage share of the disabled population by sex is 44.1% females versus 55.9% males[7]. The percentage of disabled persons in India has increased both in rural and urban areas during the last decade. While the Proportion of disabled population is higher in rural areas, the decadal increase in proportion is significant in urban areas. Table 5 and Figure 3 describe the proportion of disabled population by age in India (2011). It is evident from the table and figure that the prevalence of disability is increasing with age.

The National Sample Survey (NSSO)

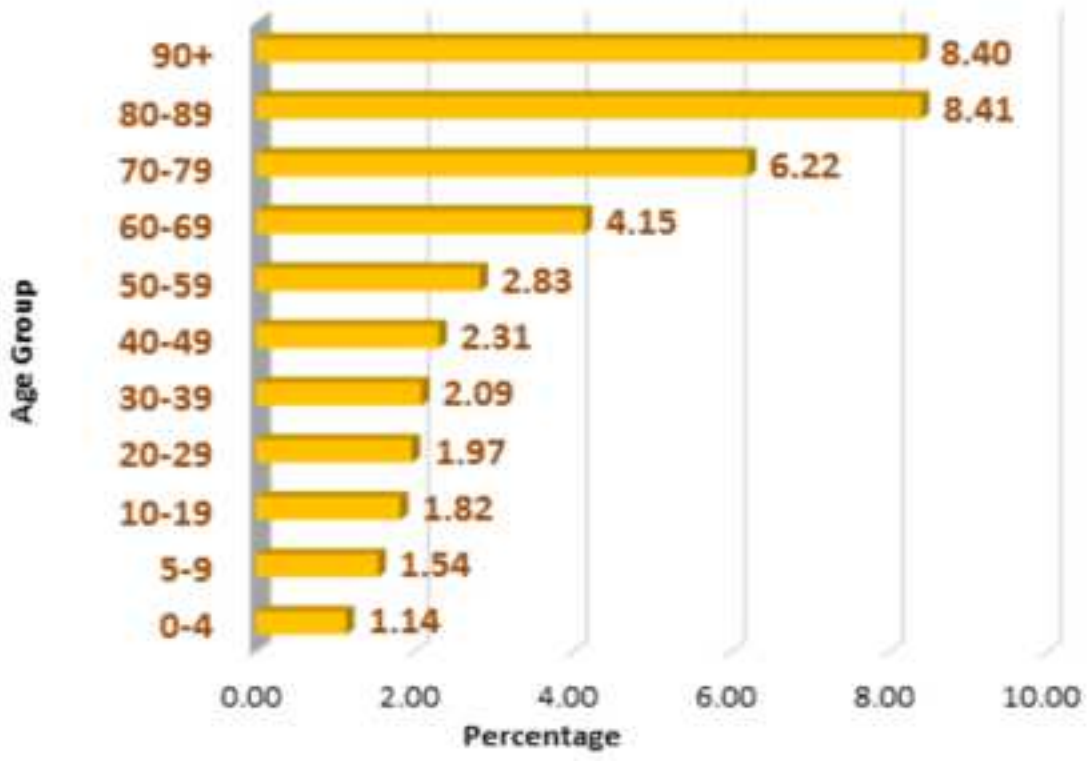
The NSSO round of 2002 revealed that 8.4% of rural households had at least one disabled person at home and that 10.6% suffered multiple impairments. The NSSO considered persons as disabled if they had any of the five types of disabilities - mental, visual, hearing, speech and locomotor[8].

As mentioned above, the prevalence of disability in India using various sources is different. Table 6 summarises the prevalence of disability in India, using the various sources mentioned. Census 2011 has higher estimates when compared to Census 2001 and NSSO 2002.

Surveys

Data is also available from a few surveys in the country. A recent survey in 4 villages of Karnataka observed that the prevalence of disability (all ages) was 6.3% and 80% had multiple disabilities[9]. Evidence from Karnataka also showed that prevalence of mental disability is 2.3% which is more prevalent among females (3.1%) than males (1.5%) and significantly higher among elderly people and illiterates[10].

Figure 3 Proportion of disabled population by age in India (2011)



Source: C-Series, Table C-20, Census of India 2011

Table 6 Comparison of prevalence of disability in India, using various sources

Impairment	Census 2001	NSO 2002	Census 2011
Locomotor	28%	51%	20.3%
Seeing (Visual)	49%	14%	18.8%
Hearing	6%	15%	18.9%
Speech	7%	10%	7.4%
Mental	10%	10%	2.6%
Mental Retardation			5.4%
Others			18.4%
Total	**2.13%**	**1.8%**	**2.21%**

A study in rural area of Chandigarh showed a prevalence of 4.8% with a significant increase among those aged >55 years (31%) compared to those aged 25-54 years (5.4%) and <25 years (0.1%) ($p<0.001$). Prevalence was also higher in females compared to males ($p<0.001$)[11].

A study from Kerala reported a disability prevalence of 2.7%. Disability due to underlying visual impairment was the commonest, followed by movement disorders. The literacy rate was 67% among the disabled people against the state literacy rate of 90.9%[12].

Evidence from Karnataka also showed that prevalence of disability was 2%, higher in 45-59 years age groups and slightly more among females (2.1%) compared to males (1.9%). The study observed that locomotor disability had the highest prevalence[13].

The Indian Council for Medical Research (ICMR) coordinated a survey of disability among children at three centres in India in 2005. Among children aged 0-6 years, the prevalence of disability was 8.8/1000 at Delhi, 6.5/1000 at Jaipur and 12.6/1000 at Lucknow[14]. There was a wide variation in the prevalence at the three locations, which are geographically very close. This perhaps is due to the differences in access to services at the three centres.

Data from the National Family Health Survey of India assessed the sex disparities in functional health among persons 55 years and older and compared the situation in the northern and southern parts of the country. The results showed a female disadvantage in physical impairments in the northern states, although these differences were not significant in the south[15].

A study from Vellore compared house-to-house survey and rapid rural appraisal as methods used to identify people with disabilities in a sample rural population in South India. While a few more people were identified through the house-to-house survey, the rapid rural appraisal was a better approach for identifying disability in the community because of the greater community participation[16].

Issues related to estimates of disability

Evidence generated from sources like census and NSSO may underestimate the true magnitude of disability. This is because only severe manifestations are reported and the early and moderate levels of disability may not be reported. Similarly, co-morbidities could be underestimated.

The Census data 2001 on disability did not cover the social aspects of disability. It helped to estimate the overall prevalence of physical impairment and helped to plan further services in the country, but it was an underestimate of the real burden of disability. The difference in distribution in each category of disability in various surveys is perhaps due to methodological differences adopted in these surveys. Further, most of these studies provide estimates of impairments and do not mention the societal response which causes disability.

Disability has been defined differently in different contexts, which makes it difficult for data collection, comparison and dissemination of disability-related data and information. There are lacunae of evidence in the field of promotion to update the knowledge level of disabled about their health conditions, or in building the capacity level of policy-makers and service providers, scaling up services, and most importantly protecting the rights and dignity of persons with disabilities.

The changing construct of disability

Till recently disability has been treated as a 'disease phenomenon' and therefore it was felt that efforts should be directed to identify and treat the physiology and pathology of the impairment. This traditional approach has recently been replaced by a more vibrant and positive

strategy to tackle disability using the 'social model' of disability wherein the individual's functioning is given more importance than the impairment.

The WHO has recommended the use of the International Classification of Functioning, Disability and Health (ICF) as the framework for measuring health and disability both at the individual and community level. The ICF domains are classified from body, individual and societal perspectives. There is an urgent necessity for generating need-based evidence and developing innovative strategies to reduce stigma and conflict; behaviour change, to integrate people with disabilities in society and the day-to-day functioning. One of the ways is to use the perspective of 'public health disability', which is the use of the full scope of health knowledge, skills and services to promote the quality of life of whole populations with special emphasis to persons with disabilities.

Summary Points

- The number of people with disability is estimated based on the results from the census, the national sample survey and other independent surveys.
- The magnitude of the problem is much more than the numbers from the method, this is because of the methodology used to define disability and also because of the underestimation related to stigma and discrimination in the society,
- The number of people with disability is growing

References

1 World disability report, 2011
2 Srivastava DK, Khan JA. Disability Needs Attention Now! Indian Journal for the Practising Doctor, 2008; 5: 3-4
3 http://www.who.int/healthinfo/survey/en/).
4 United Nations Children's Fund, University of Wisconsin. Monitoring child disability in developing countries: results from the multiple indicator cluster surveys. New York, United Nations Children's Fund, 2008
5 http://siteresources.worldbank.org/SOCIALPROTECTION/Resources/SP-Discussion-papers/DisabilityDP/1109.pdf
6 http://www.censusindia.gov.in/Census_Data_2001/Census_Data_Online/disability
7 C-Series, Table C-20, Census of India 2011
8 NSSO, 2002; Disabled Persons in India NSS 58th round
9 Ganesh KS, Das A, Shashi JS. Epidemiology of disability in a rural community of Karnataka. Indian J Public Health. 2008 Jul-Sep; 52(3):125-9
10 Patel SK. An empirical study of causes of disability in India. The Internet Journal of Epidemiology.
11 Kumar SG, Das A, Bhandary PV, Soans SJ, Kumar HNH, Kotian MS. Prevalence and pattern of mental disability using Indian disability evaluation assessment scale in a rural community of Karnataka. Indian Journal of Psychiatry, 2008; 50: 21 - 23
12 Singh A. Burden of disability in a Chandigarh village. Indian Journal of Community Medicine, 2008; 33: 113-115
13 Mini GK. Disabled People in Kerala. Disability Indian Network. 2006.
14 R. R. Pati. Prevalence and Pattern of Disability in a Rural Community in Karnataka. Indian Journal of Community Medicine, 2004; Vol. 29, No. 4
15 NFHS-2, 2005-2006
16 Kuruvilla S, Joseph A. Identifying disability: comparing house-to-house survey and rapid rural appraisal. Health Policy Plan. 1999 Jun; 14(2):182-90

PART 2

SYSTEMS IN PLACE FOR DISABILITY

Chapter 3

Rehabilitation

Dr. Suresh Kumar.K

Rehabilitation

According to the International Classification of Functioning Disability and Health (ICF), disability is an umbrella term for impairments, limitation in activities and restriction in participation [1-2]. It is a complex process, reflecting the interaction between an individual with a health condition and the environment[3]. For example, a stroke survivor may have mobility problems (impairment) that could reduce his/her opportunity to participate in social activities such as shopping and meeting friends (disability). However, the stroke survivor might be able to independently participate in most of his/her social activities with the help of a wheelchair. Although the impairment (mobility problems) of the stroke survivors is the same in the two aforementioned scenarios, the disability experienced by the stroke survivor is minimised by the use of a wheelchair in the latter. Figure 4 illustrate the disability and functioning framework of any health condition[4]. Disability is therefore, not limited to

Figure 4 Illustration of the ICF model with stroke as an health condition

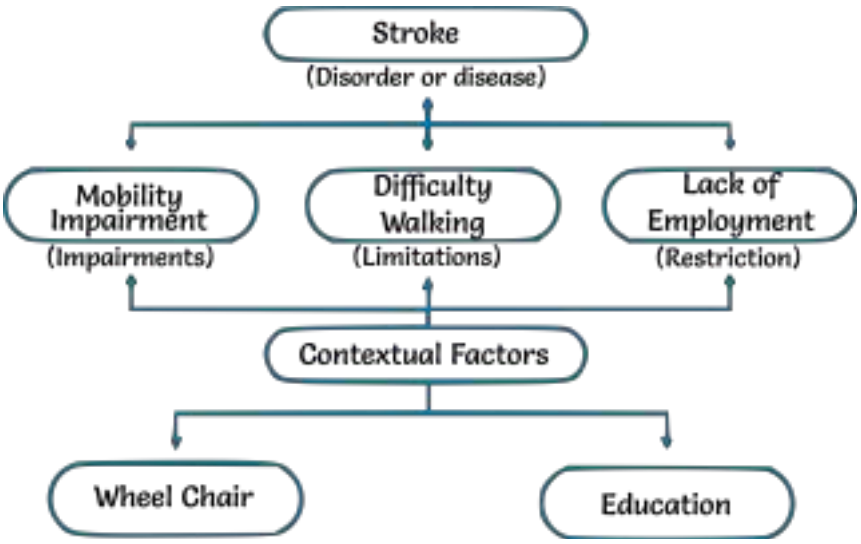


Figure 5 Illustration of what is rehabilitation

impairments, but is the interaction between an individual with a condition and the environment in which he or she experiences it[5]. The severity of disability depends on the degree of impairment (physical, mental, cognitive) as well as the personal and contextual environment of the affected individual.

What is Rehabilitation?

People with disabilities experience several limitation to perform their everyday activities and restrictions to actively participate in society. Rehabilitation, defined as "a set of measures that assist individuals, who experience or are likely to experience disability, to achieve and maintain optimum functioning in interaction with their environments"[6]. Rehabilitation is instrumental in restoring an individual with any kind of disability to his or her fullest physical, mental and social capacity[7]. It enables persons with disabilities to independently participate in their individual, family and social roles[8].

What is involved in Rehabilitation?

Rehabilitation of people with disabilities is not a single step. It is a process that continues throughout the recovery of the disabled, either short-term or long-term[9]. It involves several steps and decision making stages to help persons with disabilities perform their individual, family and social roles independently[10]. For example if a child is born with blindness, the parents might take this child to a different health professionals like the physician, optometrist, ophthalmologist, occupational therapist, special educator etc. Each expert from different disciplines will usually get together at different points in time and draft a therapy plan for this child who cannot see.

Figure 6 Rehabilitation process

Some of the key processes involved in provision of rehabilitation services are

1. Assessment
2. Goal setting
3. Therapy planning
4. Goal oriented training
5. Regular follow-up
6. Community integration

Who are involved in rehabilitation?

Rehabilitation is a team work[11]. It is impossible to help an individual affected by disability to become functionally independent using a unidisciplinary approach[12]. Uni-disciplinary approach is one person involved in provision of rehabilitation (e.g. Doctor or Physiotherapist) to an individual with disability and claiming that the disabled became independent only because of his therapeutic inputs[13]. Disabilities are multi-dimensional and so are the approaches to help people with disability become functionally independent[14]. Various professionals are involved in provision of rehabilitation services to people with disabilities. The composition of team is dependent on the impairment problem (physical, mental, social, vision, speech, hearing, intellect) and the severity of the problem in everyday life for the affected individual. The person affected by disability and his/her family are the core members of the rehabilitation team[15]. Health professionals involved in provision of rehabilitation services are only secondary to the person experiencing disability. This approach to rehabilitation is called patient-centred rehabilitation[16].

Common team members involved in physical rehabilitation

Some of the key rehabilitation team members for a person with physical disability may include:

1. ***Physician***: trained to diagnose, treat, promote a person's health
2. ***Physiatrist***: specialised in physical medicine and rehabilitation, trained to diagnose and treat various kinds of disabilities.
3. ***Nurse***: Trained to provide care and support for the patients
4. ***Physiotherapist***: trained to promote the physical aspects of health in an

Figure 7 Team members commonly involved in provision of rehabilitation services

individual especially strength, range of motion and endurance.

5. ***Occupational therapist***: Trained to help individuals with disabilities to get back to their usual activities of daily living.

6. ***Speech therapist***: Trained to help people with communication and eating difficulties.

7. ***Clinical psychologist***: Trained to assess human mind and behaviour and help with individualised psychotherapy

8. ***Special educator***: Trained to help people with academic and learning difficulties

9. ***Counsellor***: Trained to counsel people with psycho-social issues.

10. ***Vocational educator***: trained to teach people learn various vocational skills like binding, weaving, tailoring, crafts etc.

11. ***Prosthetist and orthoptist***: specialised in fabricating assistive devices and appliances.

12. ***Social worker***: trained to provide social care for people with disabilities.

13. ***Chaplain***: trained to motivate affected individuals through their religious faiths.

14. ***Dietician / Nutritionist***: Trained to advice on nutrition and food intake.

Key Principles of rehabilitation:

Patient centred care and Specific goals:

Setting Specific, Measurable, Achievable, Realistic and Time bound therapy goal is essential and fundamental to rehabilitation[17]. The rehabilitation team should be aware of the situation of the individual affected, the clinical problem and the context in which he experiences disability[18]. This would help the rehab team understand the problem better and set goals that are relevant to the needs of the affected individual[19].

Leadership and Team work:

As mentioned earlier, rehabilitation is a team work and it involves professionals with various kinds of expertise[20]. The team will usually be headed or led by someone experienced in physical medicine and rehabilitation[21]. The patient or individual with disability is a primary member of this team and his concerns have to be clearly understood before taking any decision about him/her. Thus communication becomes an essential

task of rehab team[22]. Communication is essential for good teamwork[23].

Learning a skill:

During rehabilitation, the disability experienced by an individual will either be remediated or compensated[24]. Whether its remediation or compensation, the affected individual will have to be initially taught to learn the skill for getting back to their activities of daily living and participate in social or family roles[25]. This skills will initially taught by the rehabilitation team and then the affected individual themselves should be allowed to practice on their own to become self-efficacious[26].

Some of the important points to remember during skill building in the process of rehabilitation are

1. The task or skill retrained or compensated should be task specific and purposeful.
2. Performance of the skill should involve use of correct movement pattern.
3. Repetition is a key to achieve the skill that is targeted.

Assessment of improvement:

Once the Smart goal is set, standardised or specific measurements have to be taken to determine the prognosis is essential[27]. It is very easy to complete as assessment related to the set goals rather conducting an assessment related only to impairments[28]. For example, if a person affected by polio is in need of a job, he will require a job skills assessment rather than an evaluation of his affected leg.

Appropriate care setting:

Rehabilitation services should be provided to the individual affected by disability in appropriate care setting. Rehabilitation setting should be disabled friendly environment. Rehabilitation should focus on everyday tasks in routine environment rather than ideal settings.

What exists for people with disability?

In High Income Countries, provision of rehabilitation services for people with disabilities, happen at every Primary Health Care Centers. Every PHC are equipped with a disabled friendly rehabilitation unit exclusively for specific types of disability (physical, mental, neurological, palliative etc.) with several departments and allied health care staff as mentioned before as a team. However, bringing this to a reality in many Low and Middle Income Countries is still far from reality. This is especially because; the awareness, knowledge and evidence about management of disability and disabling conditions prevalent in these countries are just emerging.

Summary Points

- Disability is not limited to impairment, but is the interaction between an individual with condition and the environment in which he or she experiences it.
- Rehabiilitation is not a single step. It is a process that continues throughout the recovery of the disabled.
- Rehabilitation is a team work and should be multi-dimentional.

References

1 International Classification of Functioning, Disability, and Health: ICF. Geneva: World Health Organization, 2001.
2 World Report on Disability 2011. Geneva: World Health Organization; 2011.
3 Kostanjsek N. Use of The International Classification of Functioning, Disability and Health (ICF) as a conceptual framework and common language for disability statistics and health information systems. BMC Public Health. 2011; 11(Suppl 4):S3. doi: 10.1186/1471-2458-11-S4-S3.
4 Stucki G, Cieza A, Melvin J. The International Classification of Functioning, Disability and Health: a unifying model for the conceptual description of the rehabilitation strategy. J Rehabil Med.
5 Majnemer A, Darrah J. New concepts in the rehabilitation of children with developmental disabilities: occupational therapy and physical therapy perspectives. In: Shevell M, ed. Neurodevelopmental Disabilities: Clinical and Scientific Foundations. International Review of Child Neurology Series. London:Mackeith Press; 2009:394 - 409.
6 Jette AM. Toward a common language for function, disability and health. Phys Ther. 2006;86: 726 - 734.
7 Mary Wickenden (2013) Widening the SLP lens: How can we improve the wellbeing of people with communication disabilities globally, International Journal of SpeechLanguage Pathology, 15:1, 14-20, DOI: 10.3109/17549507.2012.726276
8 Albrecht, G. L. , & Devleiger , P. J . (1999) . The disability paradox: High quality of life against all odds. Social Science and Medicine, 48, 977 - 988.
9 Groce , N . (2006). Disability, public health and social injustice. In B.Levy, & V.Sidel(Eds) , Social injustice and public health (pp. 145 - 154) . Oxford: Oxford University Press.
10 Reeve, D. (2006). Towards a psychology of disability: The emotional effects of living in a disabling society. In D. Goodley , & R. Lawthorn(Eds) , Disability and psychology: Critical introductions and refl ections. (pp. 94 - 107) . London: Palgrave
11 Lang, R. (2009). The United Nations Convention on the right and dignities for persons with disability: A panacea for ending disability discrimination. Alter, 3, 266 - 285.
12 Ostermann T, Bertram M, Büssing A. A pilot study on the effects of a team building process on the perception of work environment in an integrative hospital for neurological rehabilitation. BMC Complementary and Alternative Medicine. 2010; 10:10. doi:10.1186/1472-6882-10-10.
13 Shirey MR. Authentic leaders creating healthy work environments for nursing practice. Am J Crit Care. 2006;15: 256 - 267.
14 Hope JM, Lugassy D, Meyer R, Jeanty F, Myers S, Jones S, Bradley J, Mitchell R, Cramer E. Bringing interdisciplinary and multicultural team building to health care education: the downstate team-building initiative. Acad Med. 2005;80(1):74 - 83. doi: 10.1097/00001888-200501000-00020.
15 Blau R, Bolus S, Carolan T, Kramer D, Mahoney E, Jette DU. The experience of providing physical therapy in a changing health care environment. Phys Ther. 2002; 82:648 - 657.
16 Malone, D.M. & Koblewski, P.J. Professionals' Attitudes and Perceptions of Teamwork Supporting People with Disabilities. Journal of Developmental and Physical Disabilities (1999) 11: 77. doi:10.1023/A:1021886818693
17 Khan F, et al. Multidisciplinary rehabilitation for adults with multiple sclerosis. Cochrane Database of Systematic Reviews. 2007:2CD006036.

18 Forster A, et al. Rehabilitation for older people in long-term care. Cochrane Database of Systematic Reviews. 2009:1CD004294.
19 Al-Sawai A. Leadership of Healthcare Professionals: Where Do We Stand?Oman Medical Journal. 2013;28(4):285-287. doi:10.5001/omj.2013.79.
20 Collins D, Holton E. The effectiveness of managerial leadership development programs: a meta-analysis of studies from 1982 to 2001. Hum Resour Dev Q 2004;15(2):217-248 .10.1002/hrdq.1099
21 Greig G, Entwistle VA, Beech N. Addressing complex healthcare problems in diverse settings: insights from activity theory. Soc Sci Med 2012. Feb;74(3):305-312 10.1016/j.socscimed.2011.02.006
22 Henry JD Jr, Gilkey RW. Growing effective leadership in new organizations. In: Gilkey RW, editor. The 21st century healthcare leader. San Francisco: Jossey-Bass; 1999.p. 101-10.
23 Mann S. Unleashing your leadership potential: seven strategies for success leadership and organization development,2011, vol 32, iss 8.p 855-56.
24 Wiseman L, McKeown G. Multipliers: how the best leaders make everyone smarter. New York: Harper Collins. Garman, A. N. "Evidence update: Linking leadership Practices to organizational outcomes." Presentation to the NCHL Leadership Excellence Networks web meeting, August 21, 2016.
25 Rimmer JH. Use of the ICF in identifying factors that impact participation in physical activity/rehabilitation among people with disabilities. Disability and Rehabilitation. 2006;28: 1087-1095.
26 Stucki G, Reinhardt JD, Grimby G. Organizing human functioning and rehabilitation research into distinct scientific fields. Part II: Conceptual descriptions and domains for research. Journal of Rehabilitative Medicine: official journal of the UEMS European Board of Physical and Rehabilitation Medicine. 2007;39: 299-307.
27 Beswick AD, et al. Complex interventions to improve physical function and maintain independent living in elderly people: a systematic review and meta-analysis. Lancet. 2008;371: 725-735.
28 Velema JP, Ebenso B, Fuzikawa PL. Evidence for the effectiveness of rehabilitation-in-the-community programmes. Leprosy Review. 2008;79:65-82.
29 Convention on the Rights of Persons with Disabilities. Geneva: United Nations; 2006.
30 Haig AJ, et al. The practice of physical and rehabilitation medicine in sub-Saharan Africa and Antarctica: a white paper or a black mark? Journal of Rehabilitation Medicine: official journal of the UEMS European Board of Physical and Rehabilitation Medicine. 2009;41: 401-405.

Chapter 4

Systems in place in India

Dr. Suresh Kumar.K

What are rehabilitation systems?

A rehabilitation system is termed as the organization of people, institutions and resources for delivering rehabilitation services to meet the needs of people with disabilities.

The important components of any rehabilitation systems are

1. *Leadership and Governance*
2. *Rehabilitation Financing*
3. *Rehabilitation workforce*
4. *Rehabilitation products and Technology*
5. *Information management*
6. *Service delivery*

The ultimate goal of any health and rehabilitation system is to promote efficient and effective functioning of these important components synergistically to achieve equitable, responsive, good quality rehabilitation and care for people with disabilities.

Leadership and Governance for Rehabilitation

Institutions like the World Health Organization (WHO) and United Nations (UN) along with other bilateral and multi-lateral agencies like International Labour Organization and World Bank provide global leadership and support for creating sustainable rehabilitation systems globally. The disability and Rehabilitation department of WHO coordinates various activities related to rehabilitation of people with disabilities worldwide. Similarly, The UN has various departments and special interest groups such as the UN Convention for the rights of persons with disabilities (UNCRPD) that protects and promotes the rights of people with disabilities. India is one of the first countries to sign the UNCRPD bill for people with disabilities. However ensuring equitable access to health and rehabilitation services for people with disabilities has been quiet challenging.

Figure 8 Pillars of health or rehabilitation system

Rehabilitation financing

The rehabilitation systems are usually funded by the countries health systems itself. In India, programmes related to people with disabilities are primarily funded by the ministry of health and family welfare. In addition, department of education, human resources, women and child development, ministry of social justice and empowerment financially support various disability and rehabilitation programmes and projects to improve the quality of life of people with disabilities. For example, the project called Sarva Siksha Abhyan meaning education for all managed by the department of education includes a separate sub-programme for inclusive education to children with disabilities. The ministry of social justice and empowerment coordinates various programs related to managing teaching institutions for creating the allied health workforce cadre, vocational training and for provision of financially support to people with disabilities.

Rehabilitation workforce

In many High Income Countries, several specialised professional education and training programmes for learning about helping people with disabilities. However, in India, these courses are conducted in very few centres. Therefore there is not much awareness about various health or allied health professionals involved in provision of rehabilitation services not just among the general public but also among the health professionals. For example, many medical doctors do not know who is an occupational therapist and what he does for people with

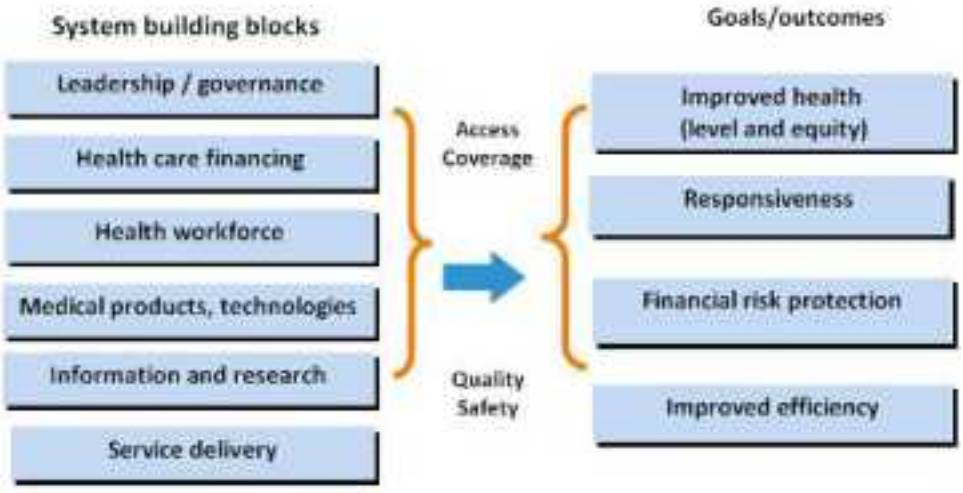
disabilities. Similarly the general public, when they see or experience permanent disability, they assume that medicines and surgery would help them completely recover from their disability. A recent report by Public Health Foundation of India revealed that there is an acute shortage of nearly 650,000 allied health professionals in India.

Rehabilitation products and technology

Similar to health products and technologies like drug, injections and surgical equipment, there are also specific products and technology for rehabilitation. For example there are positioning pads, gaiters and splints to prevent deformities following an injury or a disabling health condition. There are technologies like the brain computer interface, environmental control units, hoists and myo-electric prosthesis that helps people with disabilities to independently manage their lives irrespective of their disabilities. These products and technologies are available globally.

In India, many of these products are not manufactured and hence we have to import these products from HICs. This implies the cost involved in procuring these products. A government agency called the All India Limb Manufacturing Company (ALIMCO) [http://alimco.in/] currently manufactures and sells some of the basic rehabilitation products and technologies like wheel chair, walker, artificial hand and foot made of wood and fibre through its state offices in all parts of our country. There are many private companies located in many urban areas and metropolitan cities that

Figure 9 WHO Health Systems Framework



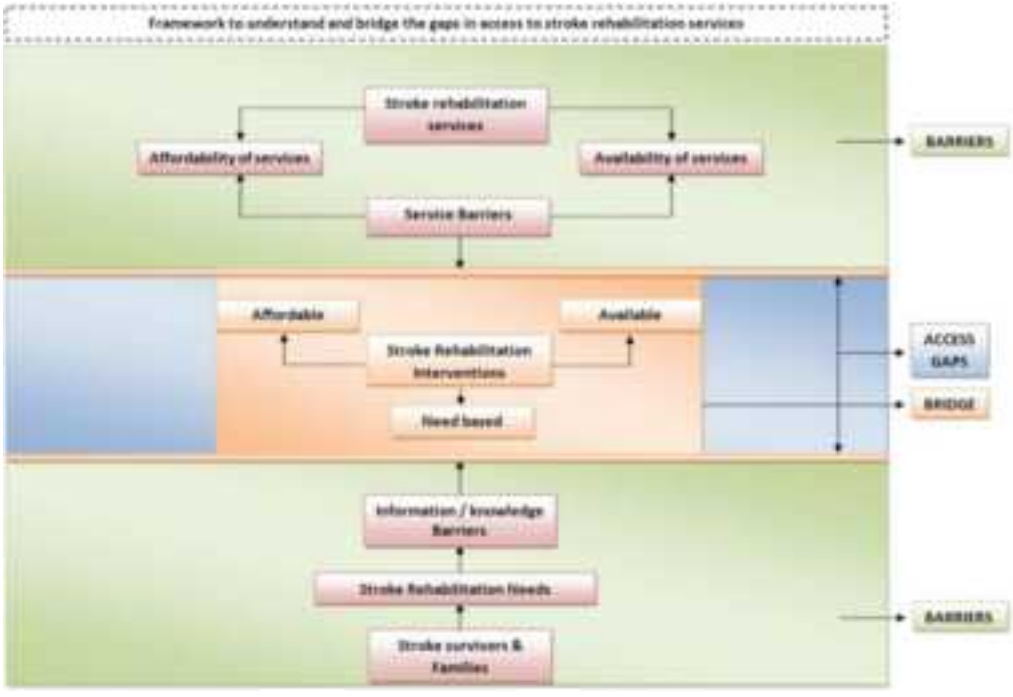
http://www.wpro.who.int/health_services/health_systems_framework/en/

sells some of the sophisticated rehabilitation products like myo-electric prosthesis, motorised wheel chair, ROHO Cushions and pressure relief mattress etc. health professionals involved in helping people with disabilities could explore more information about this through the web link provided above and help people with disabilities access these products and help in their recovery and rehabilitation.

Information management

This is a crucial component of any health and rehabilitation system. Information about the magnitude of a problem would help plan and organize programs to support people with disabilities effectively and efficiently. Many HICs have integrated information management systems that would track or access the complete details of a person just by their hospital number. However such kind of systems does not exist in India. South Asia Centre for Disability and Inclusive Development Research has contributed tremendously to this gap. More information on this is provided in detail in another chapter of this manual. Exclusively focusing on rehabilitation, SACDIR has recently conducted a rehabilitation needs assessment study among stroke survivors. This study identified several gaps that has to be bridged to meet the rehabilitation needs of people with not just stroke but any kind of disabling condition in India. It also found that people with disabilities needed information to manage their disability more than rehabilitation services.

Figure 10 Rehabilitation needs framework



Rehabilitation service delivery

This is an important component of any rehabilitation system. This is about what is available for people with disabilities in a country. As mentioned earlier, in many HICS, rehabilitation services are a part of general health services even within a primary health care centre. However in India, provision and access to rehabilitation services are very limited. Rehabilitation services are available only in certain government tertiary hospitals and predominantly in private hospitals situated in urban or metropolitan cities. These services are usually led by a specialist doctor or a physiotherapist. Accessing rehabilitation services from private hospital or therapists is usually very expensive.

Some of the important rehabilitation services that is available for persons with any kind of disabilities are detailed below. In India, a person with any kind of permanent disability can avail a disability certification and a disability identity card. This card is provided through a panel of disability experts in every state coordinated by the state disability commissioner. There have been several laws and acts related to the benefits available for different kinds of disabling conditions and any person with a disability certificate can avail the benefits.

Some of the important acts and laws that provide benefits for people with disabilities are

1. Persons with disabilities act – 1995
2. Mental Health act – 1987
3. Rehabilitation council of India act – 1992
4. The National Trust act for welfare of children with cerebral palsy, autism, mental retardation and multiple disabilities – 1999
5. Rights of persons with disabilities bill – 2014 amended December 2016

Key Benefits for persons with disabilities if they have disability certificate

1. Education

a. Books and Stationery allowance
b. Uniform Allowance
c. Transport allowance
d. Scholarships
e. Reimbursement of tuition fees
f. Vocational training and higher education

2. Railway Travel concession
3. Reservation of jobs

a. Age relaxation in jobs
b. Roster and carry forward
c. Priority posting
d. Promotions

4.Income tax concession / Professional tax exemption
5. Dealership by oil companies
6. Economic assistance

7. Reservation in public sector bank jobs
8. Subsidy on the rate of interest – loans

Most of these key benefits can be availed by persons with disabilities.

Within the aforementioned laws and acts, the main provisions that are covered for any person with disabilities include

- Prevention and Early Detection of Disabilities
- Education
- Employment
- Non-Discrimination
- Research and Manpower Development
- Affirmative Action
- Social Security
- Grievance Redressal

A recent project "Unique ID for Persons with Disabilities" is being implemented with a view of creating a National Database for PwDs, and to issue a Unique Disability Identity Card to each person with disabilities. The project will not only encourage transparency, efficiency and ease of delivering the government benefits to the person with disabilities, but also ensure uniformity. The project will also help in stream-lining the tracking of physical and financial progress of beneficiary at all levels of hierarchy of implementation - from village level, block level, District level , State level and National level.

The Prime Minister's Office recently suggested that the term 'divyang' (divine body) instead of 'viklang' be used for persons with disability.

This proposed change in nomenclature is being worked out at the ministry of social justice which handles disability affairs.

Summary Points

- The In India, programmes related to people with disabilities are primarily funded by the ministry of health and family welfare.
- In addition, department of education, human resources, women and child development, ministry of social justice and empowerment financially support various disability and rehabilitation programmes and projects to improve the quality of life of people with disabilities.
- There a many benefits a for person with disability if they have relevant certificate


Building Capacity for

PART 3

DEVELOPING A DISABILITY PROGRAM

Chapter 5

Planning a disability program

Mr. Dinesh Raj P, Ms. Jayanthi Sagar

The first and the foremost thing to do is to set up a planning committee. All the stakeholders should be involved in the committee. Often the program managers miss out the receivers - people living with disability. As the slogan goes "Nothing about us without us."

A planning committee may be set up at

* National level
* Provincial level
* Project level

The functions of the Committee will be to

1. Plan programme
2. Mobilise resources / funding for the programme
3. Implement activities
4. Evaluate progress and results

The structure of the Committee should be small and active and should have members from

* Ministry of Health
* Public health
* Disability welfare department
* Rehabilitation services
* Health care services
* Community
* Local NGO/Service Organisation
* People living with disability

Planning is the key for the success of any program. We have to plan to move from where we are to where we want to be. It is very crucial how we start and move to the desired benchmark. Figure 11 will explain in a nutshell how to successfully plan a program.

Where you are

Situational analysis of needs

Firstly, we should understand where we are by conducting a situational analysis of needs of the people with disability. The population to be served must be

Figure 11 Process of planning for a disability program

well-defined (for example children, people living with polio, stroke survivors etc). The distribution of the population and characteristics of the area/geography should be studied.

Estimate the prevalence, incidence (the numbers). Also look at age and gender specific data if need be. Additional sources of information (not as reliable) may be obtained from hospitals, disability related organizations, research publications etc.

The key principle of planning a disability program is to include people living with disability in all phases of planning the program. As disability is highly discriminated and stigmatized in Indian scenario, it is advised to conduct qualitative research methodology to understand the needs of the people living with a disability. Conducting such research studies will enable us to understand the barriers faced by them and to formulate a possible solution.

Situational analysis of the resources

Secondly, assess the resources available to bridge the gap.

The resources are

1. Manpower

Identify available manpower required for the program. E.g. Specialized Medical doctors, nurses, health allied professionals, managers, technicians, rehabilitation workers and expertise. Work out a ratio between the population and the required manpower (health care units/workers: population at each district). Also consider the manpower placed by the government. E.g. primary health care workers, ASHA workers, Anganwadi workers.

2. Materials and infrastructure

List all the equipment's needed for the program.

Hard Materials: Assistive devices, equipment, hospitals, beds, vehicles
Soft Materials: drugs and surgical consumables

3. Management

- Structures and information system

Identify key stake holders involved in programme for management of disability care, if present and also their function.

Functions of the Committee

- Planning of the regional disability programme
- Mobilisation of resources for the programme
- Implementation of activities of the programme
- Evaluation of the progress and results of the programme.

Structure of the Committee

- It should be small and active.
- It should meet 3 or 4 times each year.
- It should comprise representatives from -

-Regional and district disability and health department
-Professional and community stakeholders
-Local NGOs / service organisations
- People with disability / disability organizations

4. Money (capital and running costs)

The disability programme should be a horizontal programme, integrated into the regional and district level health services. The resources in terms of financial stability to run the program should be well assessed.

Where you want to be

Define the Aim

This is the generalised direction of the programme.

Specify the Objectives

The objectives of a project should be "SMART"

Specific: clear about what, where, when, and how the situation will be changed;
Measurable: able to quantify the targets and benefits;
Achievable: able to attain the objectives (knowing the resources and capacities);
Realistic: able to obtain the level of change reflected in the objective; and
Time bound: stating the time period in which they will each be accomplished. They should be measurable and time limited.

How to get there

Define the Priorities and Strategy

The strategies for disease control, human resource development and provision of infrastructure need to be defined.

It is important to understand the needs of the community and the existing services.

Prepare a Timetable

List the activities that are necessary to reach each of the objectives. Prepare a timetable showing each of these activities, indicating when they will be undertaken and when they will be completed.

Prepare a Budget

Prepare the budget on the expenditure and income for the activities planned and for the resources.

Expenditure and Income

Expenditure

a) Capital (one-time)
   Buildings, vehicle, equipment
b) Running (recurrent)
   Salaries, consumables, overheads

Income

a) Fees
b) Government grants
c) Local support
d) International donors

Getting there

Management

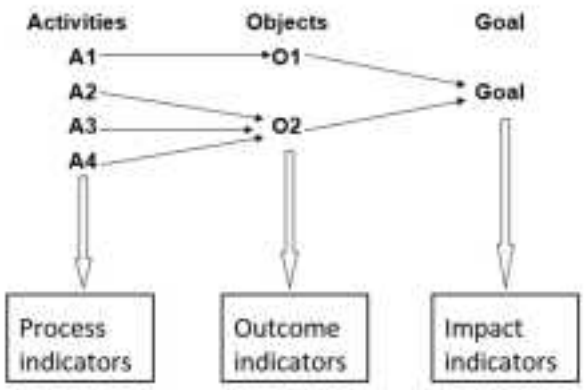
Form a Project committee and if possible appoint a manager/administrator. Monitor resource utilisation for efficiency. The two main resources to "look after" are money and more importantly "people."

Monitoring

Monitoring is a continuous function that provides an early indication of the quality, quantity and timeliness of progress towards delivering intended results. This allows the key stakeholders, project managers to know that the project is on track and running to schedule. Monitoring should be done at regular pre-planned intervals.

What gets monitored is more likely to get one. If we don't monitor performance, if we can't tell success from failure. Process indicators report achievement of activities. Outcome indicators report

Figure 12 Process of planning for a disability program



achievement of objectives. Impact indicators report achievement of goals.

It is advised not to collect to many indicators or collect indicators too often. All the monitoring indicators collected should be used and the unused indicators should be discarded.
Monitoring should be used as a tool to encourage to perform better and take ownership but not as a disciplinary tool.

Summary Points

- Planning is the key for the success of the program
- Always develop 'SMART' objectives
- No planning without the beneficiaries.

PART 4

THE ROLE OF SACDIR

Chapter 6

The role of SACDIR

Ms. Jayanthi Sagar, Mr. Dinesh Raj P

The South Asian Centre for Disability Inclusive Research (SACDIR) functins to fulfill the following four objectives

1. ***Training and Education***
   Train and reorient health care personnel to concerns of persons with disabilities.
2. ***Research***
   Develop the evidence base for documenting the prevalence and magnitude of disabilities with in the South Asia context.
3. ***Programme development***
   Evaluation of existing programmes for persons with disabilities in India and other South Asia Countries
4. ***Advocacy***
   Advocate at appropriate congregations and forum for disability inclusive development.

Four Board areas of Functioning

1. Developing research capacity in the region and provide evidence for action

2. Augmenting skills of existing and new professionals through need based training modules

3. Assist in programme development and evolution in the South Asia Region, with a major focus on India

4. Help government, NGOs and other stakeholders in policy formulation and advocacy

The work done by SACDIR can be best explained under the following

a. Research
b. Policy
c. Practice
d. Capacity building

Research

1. Multi - Centric Collaborative study on the impact of Global warming and Ultra Violet Radiation (UVR) exposure on ocular health in India

This case study was conducted in three regions Northeast region, coastal region in South India (Prakasam district, Andhra Pradesh) in comparison to Delhi/NCR (National Capital Region) of the country to assess the impact of increased UVR on the prevalence of cataract, dry eye, pterygium in people over 40 years of age and allergic disorders in children between 5-15 years of age.

The study estimated the change in stratospheric ozone and suspended particles to investigate the effect of environmental factors and global warming on the prevalence and /or exacerbation of eye diseases.

Data was collected from 3,589 individuals over 40 years of age from 34 clusters, and clinical assessment was done on 3,015 individuals. Preliminary analysis shows that the prevalence of blindness is 1.9% and cataract is the leading cause of blindness.

2. Incidence of cause specific blindness in Andhra Pradesh

The Andhra Pradesh Eye Disease (APED) study in India was first initiated in 1996. It is one of the most rigorous population based studies in low income settings.

Over the period June 2009-May 2010, a study was undertaken by the L.V.Prasad Eye Institute and the International Centre for Eye Health (ICEH) to trace the original subjects examined in the APED Study in the 3 rural areas where APEDs was originally undertaken.

One of the objectives of the tracing exercise was also to obtain information on mortality and it was observed that there was a mortality differential among those who were blind compared to those who were not blind at baseline, among those aged 40+. The mortality among the blind was 2.3 times higher than among those who were not blind at baseline. This is a significant observation as it helps to plan eye care services for the future.

3. Validation of INCLEN Neuro Developmental Screening tool (NDST)

The study assessed the prevalence of ten (10) common neuro-developmental disabilities (NDDs) among children aged 2-9 years in India and gathered information on potentially modifiable risk factors.

4. Monitoring and Evaluation of the RS10 Road Safety Intervention plan in Hyderabad, India

Funded by Bloomberg Philanthropies, USA (sub contract from Johns Hopkins Universtity)

The scope of work to be carried out by IIPHH was: i. Conduct several rounds of observational studies of drink driving and helmet use, ii. Conduct many rounds of roadside surveys of knowledge, attitudes, and practices (KAP) related to drunk driving, helmet use and awareness of social marketing campaigns among motorists in the RS-10 intervention districts; one survey every three to four months, iii. Conduct in-depth interviews and focus group discussions with personnel from general public, police, hospital, and related ministries iv. Establish hospital-based surveillance in 2 hospitals to gather road traffic injury data on monthly basis, v. Conduct a household survey of residents on injury events, risks, attitudes, and behaviors in the RS-10 intervention districts, vi. Collect routine data on road traffic crashes, fatalities, and injuries from traffic police on a monthly basis, vii. Collect available data regarding road safety from non-governmental organizations.

The study found that 86% of RTI victims had some form of disability.

5. Behavioural problems in impaired children and associated caregiver strain in India - A descriptive study

The goal of the study was to find the determining factors that contribute to the differences of psychosocial difficulties in hearing impaired children compared to another group of hearing impairment children that do not develop the psychosocial difficulties. This study is the first hand information from LMICs.

Parents of children with hearing impairment are at increased risk of mental health morbidities. We examined the predictive factors associated with caregiver's strain and psychological morbidities in parents and family caregivers of children with hearing impairment. In total, n =201 parents and family caregivers of children with and without hearing impairment aged 3 to 16

years were recruited. Caregiver's strain and psychological morbidities were measured using the Zarit Burden scale and the World Health Organization's Self-Reporting Questionnaire (SRQ-20).

Presence of behavioural problems in children was measured using the Strengths and Difficulties Questionnaire. After adjustment, low educational attainment and domestic violence were found to be associated with caregiving strain, whereas dissatisfaction with social support from family, behavioural problems in children, and domestic violence strongly predicted psychological morbidities. Addressing the mental healthcare needs of parents may help in downsizing the impact of psychological morbidities on the well-being of children with hearing impairment.

6. The National Survey of Blindness, Visual Impairment, Ocular Morbidity and Disabilities in Sri Lanka

The National blindness, visual impairment and disability survey in Sri Lanka is the first ever national level study on blindness and visual impairment in Sri Lanka. A survey of self-reported eye complaints of the preceding month and self-reported disability at household level was also embedded within this survey. The survey was designed in 2012; the field work took place in 2013-2014; and the data analysis was completed in 2014-2015.

The prevalence of blindness in Sri Lanka was 1.7% (95% CI: 1.3 -1.99) among those aged 40+ years. The highest prevalence of blindness was in Uva, Eastern, North Western and Northern provinces while

the lowest was in the Western and Southern provinces.

Policy

1. Barriers to employment and employability for persons with disabilities in Hyderabad, Andhra Pradesh, India

The study was undertaken to ascertain the barriers to employment and employability for persons with disability in the IT and IT Enabled Services sector in Hyderabad, Andhra Pradesh India.

The main aim of the study was to work towards orienting Indian employers on disability inclusiveness with regard to employment of persons with disabilities.

It showed that there were significant differences in the perceptions of employers vs. employees on certain barriers to employment. As a bottom line, this study throws some light on the ways in which the industry is gearing up to the needs and requirements of the persons with disabilities.

A total of 147 employees with disability (EWD) were included in the study. Majority of the respondents were educated to at least the undergraduate level. All the respondents (persons with disabilities) had a physical impairment and 91.2% of these impairments were present since birth. Overall, 72% of employees with disability stated that the impairment had at least a mild effect on their activities for daily living. 72.8% of the employees had declared their impairment at the time of their interview and majority of the employees mentioned that the potential employers had made reasonable adjustments to facilitate their job interview and also after their employment. There was no discrimination / prohibition in the selection process, as a result of the impairment /disability.

Fifty three employers from 6 work places were included in the study. More than 90% of the employers stated that they encouraged applications for all positions from persons with disabilities. Only 3.8% of the employers were aware that their company had a written policy on employing persons with disabilities.

2. Gender as a determinant of uptake of services in persons with disabilities

This project aims to understand and generate evidence for disabilities and understand if gender is an important factor in the uptake of care and support services for persons with disabilities.

Findings shall inform better planning and service delivery and bears relevance to care issues for self and family with relevance to health matters like antenatal care, immunization, care for chronic conditions like TB and acute care. The study is being conducted in two blocks/mandals of Medak in Andhra Pradesh and Bidar in Karnataka, where health, nutrition and development parameters are poor.

In the first stage, key informants (KIs) were recruited from the study area and trained to identify people with disability using a specially designed and pretested flip book with pictorial depictions of the different impairments. Next, 20 KIs were trained per selected block to cover a population of 2000-3000 persons over a period of 4-6 weeks, going house to house. At the end of 6 weeks, trained field investigators reconfirmed the findings of the KI and simultaneously identified age-matched neighbourhood controls, without any disability. All identified individuals were administered a questionnaire to elicit responses regarding reproductive health care issues, in addition to recording basic demographic data. Disability status was also ascertained from the disability certificates and disability pension records available with the people with disability. All field investigators and KIs were people with disabilities.

In the second stage, a team of a medically trained physician and a therapist visited all listed individuals (people with disability and controls) at home to confirm the diagnosis, conduct a medical examination and for re-ascertaining information collected by field investigators.

3. Review of the rural and urban mental health program undertaken by the Banyan

This study reviewed the rural and urban mental health program implemented by the Banyan from evolution till date. It also developed and assessed process/implementation indicators, proximal and distal outcome indicators, cost per unit intervention and cost for retaining one patient in both the programs.

The study also conducted Knowledge, attitudes and practices (KAP) study to assess awareness about mental health disorders and their health seeking behaviour in the respective communities served by rural and urban mental health program.

4. Eye health with in the Public Health System in India: A review of its functioning in five identified locations in the country

This study 'Eye Health Within the Public Health System in India: A Review of its Functioning in Five Identified Locations in the Country' was planned to look at the access of eye health policies, programmes and schemes at the implementation levels in identified locations in the country to understand its impact as well as identify gaps in its implementations. The following five locations in India were identified each with an active Operation Eyesight Universal (OEU) India partner: 1. Kullu district (Himachal Pradesh) 2. Siliguri district (West Bengal) 3. Srikakulam district (Andhra Pradesh) 4. Ernakulum district (Kerala) 5. Udaipur district (Rajasthan).

5. The Emerging Epidemic of Diabetic Retinopathy (DR) and Retinopathy of Prematurity (ROP) in India: Evaluation of Existing Programme for screening and Treatment and using lessons learnt, to Develop and Evaluate an Approach that strengthens Health System

The aim of this study, funded by the Queen Elizabeth Diamond Jubile trust, is to evaluate existing approaches for the detection and treatment of sight-threatening DR in India to document best practices in relation to responsiveness, acceptability, efficiency, equity and sustainability. As part of this study PHFI has reviewed the policy on NCD's focussing on diabetes in India; conducted a situation analysis of services for diabetes and DR in 10 cities, interviewed physicians, counsellors, nutritionists, and 664 patients in 86 eye care units and 73 diabetic care units; evaluated programs for detection of sight- threatening DR in consultation with VISION 2020 and other leading international eye NGO'S, and held a well-attended national summit on DR.

Practice

1. Validation of Key Informants for identifying children with disability in Bangladesh and Pakistan

Using the project costs in Bangladesh to screen a child population of 258,000 using KIM and 8,120 children via door-to-door survey, we can estimate what the costs would be to use either a KIM or a door-to-door survey to screen a total population of 1,000,000 (of which an estimated 413,000 are children). Comparing these costs shows that KIM costs approximately ten times less than a door-to-door survey to cover a total population of the same size.

KIM identified almost 100% of children with severe visual impairments, significant physical impairments and epilepsy in Bangladesh. KIM was less effective at identifying children with

hearing impairments in Bangladesh. Key Informants in Pakistan identified approximately 75% of all children with targeted impairments and conditions, with more evidence needed. Key Informants showed interest in maintaining a long-term role as community disability advocates (piloted Community Module in Bangladesh on further training, coaching and mentoring of Key Informants). 57% of children with targeted impairments/ health conditions in Bangladesh, and 83% of those in Pakistan had never previously received rehabilitative support or services. KIM is a more cost effective method of identifying children with targeted impairments and health conditions than a door-to-door survey covering a population of the same size. Promising findings from KIM in Bangladesh suggest the potential benefit of using KIM in other settings to identify children with targeted impairments and health conditions.

2. The public health impact of folate deficiency and strategies to improve maternal and child health outcomes in India.

A formal screening program is neither feasible nor cost effective in LMICs like India due to high costs and lack of trained personnel. KIM still offers an alternative to door-to-door surveys of disability in children. KIM is preferred when apart from studying epidemiology the goal is also to increase the uptake of community-based interventions through increased community awareness and empowerment. As the community gets empowered, even hidden cases and less prevalent birth defects can come to the fore. Use of frontline workers from the health and social welfare systems also reduces costs and ensures linkage with existing services. The programs such as Rashtriya Bal Swasthya Karyakram (RBSK) can use KIM approach to reach out to children with deformities and disabilities backed by specialized treatment and rehabilitative centres for these children.

3. Use of Child-to-Child approach for visual and hearing impairment

The study aims to identify the best modality to engage children in identifying persons with visual and hearing impairment in their families and neighbourhood.

4. Family led Rehabilitation after Stroke in India: The ATTEND Trial

The ATTEND Trial was a multicentre, randomised, blinded outcome assessor, controlled trial, which looked at whether a family-led caregiver-delivered home

based rehabilitation intervention versus usual care is aneffective, affordable early supported discharge strategy for those with disabling stroke in India. The Trial was conducted at 14 centres across India. This is one of the largest stroke trials ever undertaken. 1250 stroke patients were followed up over six months.

5. Improving the evidence base on disability

It's a population based survey methodology to estimate the prevalence of disability, in children and adults, in low and middle income countries, using WHO's ICF (International Classification of Functioning, Disability and Health) framework. PHFI and LSHTM are testing the tool in the Indian context in Mahabubnagar district of Telangana state. The project will compare the extent to which people with and without disabilities access key mainstream services and opportunities including health, education and livelihood. Overall prevalence of disability from this study is estimated 12.2% (95% CI 10.6-14.1) which does not vary significantly by gender.

6. Rapid Assessment of Disability (RAD)

A Rapid Assessment of Disability (RAD) Survey was conducted through the community health global network (CHGN). The RAD was conducted during the months of September 2014 to January 2015 in Prakasam district of Andhra Pradesh state. The main objectives of the study are to measure the prevalence of disability within a

target population and to understand the impact of disability on well being and access to services, including barriers to access and further contribute to the evaluation of disability development project.

Rapid assessment of disability survey showed that the prevalence of disability in Prakasam district was 10.1%. The case definition of disability in the survey was according to the UNCRPD case definition of disability.

Post RAD Survey a disability inclusive development program is being implemented in the surveyed villages of the Prakasam district. As a part of this program all the members of disabled persons organizations and self help groups were combined into a single unit in order to impart the basic knowledge about preventing the various disabilities, identifying the children with disability at the early age, awareness programs at the school level and stigma alleviation programs at the village level.

7. Disability Prevalence Study using RAD Tool in Urban Slums of Ranga Reddy District

Another study also seeks to provide a quantitative estimate on disability and provide data regarding different dimensions of disability in urban slums of Serilingampally in Ranga Reddy district. This study is also focused on clinical assessments of impairments related to vision, hearing and musculo-skeletal impairment. The prevalence of different types of impairments and adult wellbeing are being assessed among the people with disability in these slums. A comparative assessment of tools is also being used to measure disability in terms of their outcomes.

8. To improve the Quality of life of Persons with Disabilities through Community Health Global Network (CHGN) in Uttarakhanad and Andhra Pradesh.

The is study was conducted to improve quality of life for persons with disabilities in Uttarakhand (Dehradun District) and Andhra Pradesh through promoting their equal participation in community life and fulfilment of the rights to health, education, employment and social participation.

In Uttarakhand (Dehradun District) and Andhra Pradesh the poor are 4.4 times and 3.28 time more likely to have a disabling condition compared to middle and rich households respectively.

Approximately 70% of participants in both the sites were unaware of disability

right. Only 31% of participants thought that people with disability had a right to marry.

For people with disability, there is a significantly poor access to health, community participation, rehabilitation facilities, government social welfare services, work, disabled persons organization and education.

9. DAS Simple- Disability Assessment and Support made Simple

A mobile application that can guide assessment, automate calculation, provide instant analysis, certify, and then link the person to customized benefits and also continuously track the outcomes has been developed. As part of the project, the world's first real time augmented reality based goniometer for measuring Range of Movements (RoM) has also been developed. This initative is supported by Grand Challenges, Government of Canada.

10. Smartphone-enabled, Carer-supported Educational intervention for management of Post- Stroke Disability in India

This formative research study aims to systematically develop an educational intervention to bridge the gaps in service access for rehabilitation of individuals with stroke-related disability in India. The feasibility and acceptability of delivering the intervention using Smartphones and with caregiver support is being evaluated. The research study is being conducted in Chennai, India. If successful, it will help realize the potential of using Smartphone-enabled, carer-supported educational interventions, providing valuable information for clinicians and policy makers.

This research is underway as part of doctoral studies of Dr Suresh Kumar Kamalakannan from the London School of Hygiene and Tropical Medicine, UK. It is supported by the PHFI-UKC Wellcome Trust Capacity Building Programme.

11. Trusted Mobile Platform for self-management of chronic illness in rural areas (TRUMP)

This initiative is exploring the potential of mobile phone technologies and the development of a platform to support chronic disease management considering the needs of rural areas of India and to do this in a manner which fully addresses various issues of trust. Two common chronic conditions - diabetes and depression - provide exemplars for the development of this m-health platform and its evaluation.

Capacity Building

1. South Asian Hub for Advocacy, Research and Education on Mental

Health (SHARE)

The study aim is to reduce the mental health treatment gap in South Asia by generating evidence and building capacity. The ultimate goal was to facilitate evidence-based mental health policy and programme was implemented by established a network of collaborating institutions to utilized and implemented the research.

2. District level training on building capacity for management of disability

This activity was supported by HT Parekh Foundation and a team of public health disability experts visited all the districts of Telangana and conducted two-day training for primary health workers on the issues faced by disability and management of disability at primary health centres. This program has a unique role play session to

PART 5

LIST OF ORGANISATIONS FOR PEOPLE WITH DISABILITY IN TELANGANA


Shri E. Sridhar, IAS

S.No	Name of the organization	Project	Address	District
1	Samakshana welfare society for Intellectually Disabled Children, Municipal Quarters, Dwarakanagar, Adilabad district.	Special School for Mentally Retarded	Municipal Quarters, Dwarakanagar, Adilabad district.	Adilabad
2	New Don Bosco, H.No.12-2-118, Ravindra Nagar, Seethaphalmandi, Secunderabad, Hyderabad District	Alambana Special School for Mentally Retarded Children (Day Care Centre)	H.No.12-2-118, Ravindra Nagar, Seethaphalmandi, Secunderabad, Hyderabad District	Hyderabad
3	PAMENCAP –MAYUKHA, 12-1-922/9/D/2, Old Noble Talkies Road Asif Nagar,Hyderabad	Early Intervention & Pre-Schooling Centre for M.R	12-1-922/9/D/2, Old Noble Talkies Road Asif Nagar,Hyderabad	Hyderabad
4	Sri Vidhya Centre for the Special Children, H.No.10-3, Plot No.41, East Marredpally, Secunderabad, Hyderabad District	Residential School for Mentally Challenged	H.No.10-3, Plot No.41, East Marredpally, Secunderabad, Hyderabad District	Hyderabad
5	Devnar Foundation for the Blind, Plot No.185, Road No.1, West Marredpally, Secunderabad, Hyderabad	Special English Medium School for the Blind	1-10-125, Mayurmarg, Begumpet, Hyderabad - 500016. & 6-6-270, Opp:Home for Blind for Disbled, Bansilapet, Secunderabad, 500016	Hyderabad
6	LEKHADEEP – Parents Association of Accountants ,C-49, A.G.'s Colony, Road Opp : to ESI, Hyderabad district	Special School & Vocational Training Cum Rehabilitation Centre for Mentally Handicapped children	C-49, A.G.'s Colony, Road Opp : to ESI, Hyderabad district	Hyderabad
7	Sweekaar Academy of Rehabilitation Sciences, Upkaar Complex, Upkaar Junction, Secunderabad, Hyderabad.	Special School for Deaf	Upkaar Complex, Upkaar Junction, Secunderabad	Hyderabad
8	Ashray Akruthi, H.No.8-3-1027/A2 & A3, Opp : Indian Bank, Srinagar Colony, Hyderabad District	Special School for Hearing and Speech Impaired	H.No.22-4-578/A, Beside Tezab Hostel, Yakutpura, Hyderabad	Hyderabad
9	Ashray Akruthi, H.No.8-3-1027/A2 & A3, Opp : Indian Bank, Srinagar Colony, Hyderabad District	Special School for Hearing and Speech Impaired	H.No.18-1-350/22/46,opp. Metro Function Hall, DRD Road, Fathima Nagar, Chandrayanagutta Hyderabad	Hyderabad
10	Sweekaar Academy of Rehabilitation Sciences, Upkaar Complex, Upkaar Junction, Secunderabad, Hyderabad.	Special School for Mentally Retarded Children	Upkaar Complex, Upkaar Junction, Secunderabad	Hyderabad

S.No	Name of the organization	Project	Address	District
11	Durga Bai Deshmukh, Andhra Mahila Sabha,Vidyanagar, Hyderabad	Spl. Education unit for Mentally Retarded & Hearing Impaired	Andhra Mahila Sabha, Vidyanagar, Hyderabad	Hyderabad
12	Aathmeeya Manasik Vikasa Kendram, H.No.12-13-830/15 Steet No.1, Tornal, Secunderabad, Hyderabad District	Spl. School & VTC for MR Children	H.No.12-13-830/15 Steet No.1, Tornal, Secunderabad, Hyderabad District	Hyderabad
13	PAMENCAP MANOKRUSHI H.No.12-922-/2/9-C/2, Zhirra, Gandhi Statue Road, Asifnagar, Hyderabad	Spl.Edn. & Training and Rehabilitation Centre for MR Children	H.No.12-922-/2/9-C/2, Zhirra, Gandhi Statue Road, Asifnagar, Hyderabad	Hyderabad
14	People with Hearing Impaired Network(PHIN), Malakpet, Hyderabad	The School for Hearing Imparied(Deaf) Children	Malakpet,Hyderabad district	Hyderabad
15	Durga Bai Deshmukh, Andhra Mahila Sabha,Vidyanagar	VTC & Rehabilitation Centre	Andhra Mahila Sabha, Vidyanagar, Hyderabad	Hyderabad
16	PAMENCAP MANOCHAITANYA, H.No.12-1-922-/2/9-1A, Old Noble Talkies Road, Asifnagar, Hyderabad	VTC and Shelterat workshop for MR	H.No.12-1-922-/2/9-1A, Old Noble Talkies Road, Asifnagar, Hyderabad	Hyderabad
17	Sri Chaithanya Kalanjali Rural Development organisation H.No.15-9-Anbedjar Bagar Desaipeta, Vatapalem(M) Prakasam	Spl. School for Intellectural disabilities	H.No.4-1/5 Siddipet Road Shameerpet(V) Janagam dist.	Janagam
18	Sai Seva Sangh, Plot No.99, Road No.12, Vivekanada nagar Colony, Kukatpally, Hyderabad	Bhagawan Sri Satya Sai Spl. School & VTC for Mentally Retarded	Jammikunta, Karimnagar district	Karimnagar
19	Parents Association for the Mentally Handicapped Persons, Q.No.B-28. Sector-1, Godavarikhani, Karimnagar district	Manochaitanya Vocational Training Centre Special School & Early Intervention Centre & Home based Programme for MH	Q.No.B-28. Sector-1, Godavarikhani, Karimnagar district	Karimnagar
20	Parents Association for the Mentally Handicapped Persons, Opp; Ujwala Park 2nd Gate, Karimnagar district.	Manovikas Special School, Vocational Training Ventre & Early Intervention Centre for Mentally Handicapped Children	Ujwala Park 2nd Gate, Karimnagar district	Karimnagar

S.No	Name of the organization	Project	Address	District
21	Freedom Fighters Trust ,LMD Colony, Thimmapur(M), Karimnagar district	Special School cum Vocational Training for MR Children	LMD Colony, Thimmapur(M), Karimnagar district	Karimnagar
22	Seva Sadanam 1-920 1st ward Madhira, Khammam	Day &Residential School for MR children	1-920 1st ward Madhira, Khammam	Khammam
23	Bhadrachalam Agency Rehabilitationand Educational Society for Handicapped 9BRESH), Shanthi	Residential School cum RehabilitationCentre & Vocational Training Centre for differently	Shanthinagar, Bhadrachalam, Khammam district	Khammam
24	Mephi Mentally Rehabilitation Center, H.No.3-46, Jalagamnagar, Khammam(Rural), Khammam District	Special School for Mentally Retarded	H.No.3-46, Jalagamnagar, Khammam(Rural), Khammam District	Khammam
25	Manasika Vikasa Kendram, Door.No.2-3-117, Amberpet,Hyderabad district	Special School for Mentally Retarded Children	urahanapuram, Bypass Road, Khammam district.	Khammam
26	Theressa Mentally Challenged Rehabilitation Centre, NSP Quarters No.D-108 to 111,	Special School for Mentally Retarded Children	NSP Quarters No.D-108 to 111, Tekulapally,Khammam district	Khammam
27	Residential School for Blind, Gadwal, Mahaboobnagar - 509125	Resi. School for blind	Resi. School for blind, Raghavendra Colony, Gadwal, Mahabubnagar - 509125	Mahbubnagar
28	ECO - Club,Brahma institute for the Mentally Handicapped, H.No.8-2-15/B/1,Teachers	Spl.School for Mentally Retarded	H.No.8-2-15/B/1, Teachers colony, Mahabub Nagar	Mahbubnagar
29	Prakasham yuvajana sangam H.No.13-336, christian colony, shadnagar, Mahabub Nagar	Vocational Training Rehabilitation Centre for Disabled	H.No.13-336, christian colony, shadnagar, Mahabub Nagar	Mahbubnagar
30	Sabitha Educational Society Quarters No.B2,Opp: Joint Collector Residence Sanga Reddy, Medak Dist	Special Education cum VTC for MR	Quarters No.B2,Opp: Joint Collector Residence Sanga Reddy, Medak Dist	Medak

S.No	Name of the organization	Project	Address	District
31	Helen kellers school for the Deaf& MR children D.No.19/30, Medichal dist.	Residential school for the Deaf & MR children	Helen kellers school for the Deaf& MR children D.No.19/30, Medichal dist.	Medichal
32	Society for Education and Rehabilitation of the Disabled (SERD), Kasarabad X Roads, Suryapet,	Apoorva Res. Spl. School for Deaf and Dumb	(SERD), Kasarabad X Roads, Suryapet, Nalgonda District	Nalgonda
33	Society for Education and Rehabilitation of the Visually Handicapped, Nalgonda District	Community based Rehabilitation programme	H.No.11-81 Venkateshwara Nagar, Chinthapally, nalgonda	Nalgonda
34	Sadhana Society, for Mentally Handicapped, Tekulasomaram (V), Valigonda (M), Nalgonda district	Res. School for MR children	Tekulasomaram (V), Valigonda (M), Nalgonda district	Nalgonda
35	Asha Jyothi Welfare Association for the Disabled, H.No.3-156/2/A, Ravindranagar, Miryalguda,Nalgond	Residential School for MR	H.No.3-156/2/A, Ravindranagar, Miryalguda,Nalgonda	Nalgonda
36	Sanagala Radh Krishna Swachananda Seva Samstha, H.No. 6-21/1, Ashoknagar, Kodad Mandal,	Special School for Mentally Handicapped	H.No. 6-21/1, Ashoknagar, Kodad Mandal, Nalgonda district	Nalgonda
37	Development and Welfare Association for the blind, Dendayalnagr,Nalgonda district	Spl. School and Hostel for VH Persons	Spl. School and Hostel for VH Persons Dendayalnagr,Nalgonda district	Nalgonda
38	Gracy Organisation for Development Services, Behind Sathyanarayana Temple, Boargaon(P),	Special School for Hearing & Speech Impaired	Behind Sathyanarayana Temple, Boargaon(P), Nizamabad distict.	Nizamabad
39	SNEHA society for Rural Reconstruction, C/o Industrial Exhibition society, Gudise School,	Special School for Visually Challenged	H.No.11-2-31, Opp.Kanteshwar Temple, Kanteshwar, Nizamabad	Nizamabad
40	A.P. State Forum for Economically Weaker Section,,H.No. 6-9-7, Namdevwada, Nizamabad district	Spl. School for mentally Challenged	A.P. State Forum for Economically Weaker Section,,H.No. 6-9-7, Namdevwada, Nizamabad district	Nizamabad

S.No	Name of the organization	Project	Address	District
41	SNEHA society for Rural Reconstruction, C/o Industrial Exhibition society, Gudise School.	Spl. School for Mentally Challenged	H.No.11-2-31, Opp.Kanteshwar Temple, Kanteshwar, Nizamabad	Nizamabad
42	Balavikas Educational Society for the Disabled Children, H.No.3-2-29, Baghameer,Near	Balavikas Special School for the Mentally Retarded Children	H.No.3-2-29, Baghameer,Near bus stop, kukatpally, Ranga Reddy district	Ranga Reddy
43	Balavikas Educational Society for the Disabled Children, H.No.3-2-29, Baghameer,Near	Balavikas Special School for the Deaf	H.No.3-2-29, Baghameer,Near bus stop, kukatpally, Ranga Reddy district	Ranga Reddy
44	Shantiniketan, H.No.8-6-260, Srinivasa puram, L.B Nagar, Municipality, Vanastalipuram,	Half-way Home for Psycho-social Rehabilitation for Treated and Controlled, MR	H.No.8-6-260, Srinivasa puram, L.B Nagar, Minicipality, Vanastalipuram, Ranga Reddy	Ranga Reddy
45	Thakur Hari Prasad Institute of Research and Rehabilitation for the Mentally Handicapped,	Institute for Mentally Handicapped	Vivekananda Nagar, Dilsukhnagar, Ranga Reddy district	Ranga Reddy
46	Hellen Keller's School for Deaf Children, Door No.10/301, Trunk Road, Cuddapah district.	John Peters Higher Secondary School for the Deaf	John Peters Higher Secondary School for the Deaf,Bank Colony, Ramakrishna puram, Secunderabad Ranga	Ranga Reddy
47	Sadhana Society for Mentally Handicapped, H.No.A7/51,Road No.6 P.Nacharam,Uppal(	Residential School for Mentally Handicapped	H.No.A7/51,Road No.6 P.Nacharam,Uppal (M), Ranga Reddy district	Ranga Reddy
48	Lakshya Sadhana Society, H.No.B.No.466, Balaram Nagar, Safilguda, Malkajgiri, Ranga	Residential School & VTC for Mentally Retarded	H.No.B.No.466, Balaram Nagar, Safilguda, Malkajgiri, Ranga Reddy district	Ranga Reddy
49	Shekinah Foundation, H.No.4-3-2,Hayathnagar Ranga Reddy	Residential School for & VTC for Disabled	H.No.4-3-2,Hayathnagar Ranga Reddy	Ranga Reddy
50	Shantiniketan, Plot No.-10,Goutham Nagar, Vanasthalipurram, Ranga Reddy district	Residential School for MR	Plot No.-10,Goutham Nagar, Vanasthalipuram, Ranga Reddy district	Ranga Reddy

S.No	Name of the organization	Project	Address	District
51	Jeeyar Educational Trust, JIVA Campus, Sriramnagar, Manchintal Road, Shamshabad,	Special Junior College for Visually Handicapped	IVA Campus, Sriramnagar, Manchintal Road, Shamshabad, Ranga Reddy district	Ranga Reddy
52	Sri Sai Educational Society, 3-16-108/4/6, Kamakshipuram, Ramanthapur, Ranga Reddy	Special School & VTC for Mentally Challenged	3-16-108/4/6, Kamakshipuram, Ramanthapur, Ranga Reddy district	Ranga Reddy
53	Arun Special Centre, Block No.8-15-5(2), Shastripram, Near Mir-Alam Filters Ranga Reddy	Special School and VTC for MR children	Block No.8-15-5(2), Shastripram, Near Mir-Alam Filters Ranga Reddy District	Ranga Reddy
54	Parents Association for Persons with Autistic Children, H.No.4-180/136, Saibaba Officers Colony, Sainikpuri,	Special School for Autism (M R)	Special School for Autism (M R)	Ranga Reddy
55	Radha Institute for Mentally Retarded, D. No. 1-129, Kothapet 'X' Road,Telephone Exchange,	Special School for Mentally Retarded	Telephone Exchange, Hyderabad, Ranga Reddy district	Ranga Reddy
56	Child Guidance Centre, H.No.7-6/21, Santhosh nagar, Peerzadiguda Ghatkesar(M),RR	Spl. School cum VTC for MR	H.No.7-6/21, Santhosh nagar, Peerzadiguda, Ghatkesar (M),RR	Ranga Reddy
57	KIRANAM, plot No.100,Survey, No.212/5, Laxminagar, Kammaguda Panchayat (GP),	Spl. School for MR	Plot No.100,Survey, No.212/5, Laxminagar, Kammaguda Panchayat (GP), Turkayamzal Village,	Ranga Reddy
58	Ushodaya Educational Society, plot No.23,Chintalakunta, L.B. Nagar, Ranga Reddy dist	VTC and Physically Handicapped	Plot No.23,Chintalakunta, L.B. Nagar, Ranga Reddy dist	Ranga Reddy
59	MANOCHETHANA chukka ramaiah marg, Agricultural Market yard, Cherial (post) Siddipet Dist.	Special School for Children with Mental Retardation	Chukka ramaiah marg, Agricultural Market yard, Cherial (post) Siddipet Dist.	Siddipet

INDIAN
INSTITUTE OF
PUBLIC HEALTH
HYDERABAD

Indian Institute of Public Health, Hyderabad
Plot No 1, ANV Arcade, Amar Coop Society,
Kavuri Hills, Madhapur, Hyderabad