# MAINSTREAMING DISABILITY ISSUES

## Experiences in Enhancing Civil Society Participation

# Mainstreaming Disability Issues

---

## Experiences in Enhancing Civil Society Participation

**Published by**

उन्नति

**UNNATI - Organisation for Development Education**
G-1/200 Azad Society, Ahmedabad 380 015, Gujarat.
Phone : 079-26746145, 26733296. Fax : 079-26743752.
E-mail: psu_unnati@unnati.org, unnatiad1@sancharnet.in
Website: www.unnati.org

**Book Designed by** Ramesh Patel, UNNATI

**Printed at** Bansidhar Offset, Ahmedabad

**Suggested contribution** Rs.30/-
This will enable us to produce similar development related educational material

# Contents

# Introduction

Development efforts the world over have realised and proved that the fruits can only be reaped when the vulnerable – poor, oppressed, *dalits*, women and persons with disabilities recognise their own strength and solve their own problems. This approach is complex as it calls for challenging the existing socio-political and cultural structures that continue to create barriers and divide society into the 'haves' and the 'have-nots'.

Attitudes to development have indeed shifted in the past 50 years, from welfare to empowerment based approach. This has not been adequately so in the field of disability. Persons with disability are often recipients of only rehabilitation programmes and have limited or no role in the decision making processes that affect their lives.

Globally, persons with disabilities are marginalised and excluded due to the fear and indifference of civil society. Other reasons for exclusion lie in the fact that the area of disability is viewed as a medical or a technical issue, where the needs of people with disabilities are considered 'special'. It is true that depending on the extent and type of disability, they may need specific support or aids and appliances, but their social, emotional and economic needs, including their aspirations are the same as other human beings. Most of the existing literature portray a negative picture of 'disability' where often they are ridiculed or enact an insignificant role. This has added to the negative image building and perpetuation of stereotypes. Little effort has been made to highlight examples of people with disabilities' positive contributions and often satisfaction is derived from glorifying the success of a few achievers. Other than playing a charitable role little attempt has been made by the civil society to overcome the social and attitudinal barriers related to disability issues.

Added to these there are barriers in the physical environment like uneven roads, no visual and audio signage and signals, unfriendly toilets and transport facilities that restrict the mobility of persons with disabilities, confining them to the four walls of their homes or institution. As they are thus excluded, their scope for interaction with the non-disabled is restricted, limiting the latter's understanding to their special needs and not of their common needs. Hence, the vicious cycle of exclusion is further strengthened. As they remain isolated they are not able to collectively organise and voice their concerns and needs.

Many a times amidst other development issues i.e. environment, water and sanitation, health, livelihood; the issues of disability are accorded a low priority with the logic that a larger number of people are affected by the aforementioned issues. However, there is a close link between poverty and disability as it creates and exacerbates poverty (malnutrition, mothers weakened by frequent child birth, inadequate immunisation and accidents all contributing to having a greater impact on the poor than people living in easier circumstances) by increasing isolation and economic strain. Moreover, the social exclusion and the absence of accessibility for people with disabilities to most of these development services (education, health, employment, credit etc.) negate their rights as citizens with equal opportunity. [1]

Persons with disabilities who belong to marginalised/ discriminated groups of women, *dalits*, tribals and religious minorities, are further marginalised and continue to live at the edge of survival with little or no support. Women with disabilities face the triple burden of discrimination, first on grounds of their disability, secondly on grounds of their gender that women in general suffer from in almost every given context and thirdly on the basis of the status of their community especially in the Indian social hierarchy i.e. caste and class.

---

[1] *Disability and Development, the Basics by Dane Auret in Disability, Development and Development by Peter Coleridge, Published by Oxfam UK and Ireland.*

For persons with disabilities to take their rightful place and contribute to the process of development, social, attitudinal and physical barriers need to be removed. An initiative for 'Enhancing the Participation of the Civil Society for Mainstreaming Persons with Disabilities in Development,' was carried out by UNNATI - Organisation for Development Education in collaboration with Handicap International (HI). This campaign involved a wide range of stakeholders in the civil society i.e. rehabilitation institutions, NGOs, INGOs, academicians, architects, designers, planners, builders, the service industry and the various Government departments in Gujarat to facilitate the process for mainstreaming persons with disabilities so that they become active members of society.

Disability issues touch all of us alike. Unlike other oppressed groups like the poor, *dalits*, tribals, disability can affect anybody at any time in their life cycle, irrespective of their background, class or country. Even if it does not affect us directly, it may affect us significantly if a member of the family is temporarily or permanently affected by an impairment. During our experience a positive response was received from the various stakeholders. The outcomes and lessons learnt from this initiative have been documented and published in various issues of our quarterly news bulletin VICHAR – in Gujarati and Hindi languages during the past five years.

In this booklet on **Mainstreaming Disability Issues: Experiences in Enhancing Civil Society Participation**, articles have been produced in English for usage by a wider readership.

The first article on **Disability and Disaster: Issues and Strategies**, by Catherine Naughtaun and Alana Officer, first explores the definition of disability moving on to developing an understanding of the social, attitudinal and physical environment that create a situation of handicap. Further, it attempts to explore the strategies for mainstreaming disability issues in the context of the Gujarat earthquake.

In the second article A. Prasad narrates his personal **Experience of**

**Setting up a Community Based Rehabilitation Project** in Chittoor district, Andhra Pradesh.
In the third article, Catherine Naughtaun and Alana Officer suggest the **Role of CBOs for Mainstreaming Disability Issues.** These have been supplemented by case studies from our experience of enabling other CBOs/ NGOs to include these issues in their on-going programmes/ activities.

In the article on **Barrier Free Environment: A Critical Step for Inclusion**, Geeta Sharma, Arindam Mitra and Archana Shrivastava explore the possibilities of involving/ influencing other stakeholders i.e. architects, planners and builders in building in the agenda of mainstreaming disability issues to make public places accessible for all.

Arindam Mitra in his article **Why I Can't Be Michael Rivers** narrates his personal experience of dealing with an unfriendly physical environment.

The article **Working towards Inclusion: Experiences with PRA on Disability**, Alice Morris, Geeta Sharma and Deepa Sonpal narrate their experience from a participatory action study carried out in Gujarat to develop a deeper understanding about the prevailing attitudes and behaviour of communities towards issues of disability.

In the end a **Training Module on Mainstreaming Disability Issues in Development** has been elaborated to enable other development actors incorporate disability issues in their on-going work.

We hope that these articles will provide strength for persons with disabilities and enable the civil society to build their sensitivity towards dealing with these issues in future.

# Disability and Disaster: Issues and Strategies

## Introduction

According to the United Nations, one person in 20 has a disability. More than three out of four of these live in a developing country[1] . More often than not, they are among the poorest of the poor. Recent World Bank estimates suggest they may account for as many as one in five of the world's poorest[2] . Disability limits access to education and employment and leads to economic and social exclusion. Poor people with disabilities are caught in a vicious cycle of poverty and disability; disability being both a cause and a consequence of poverty. Eliminating world poverty is unlikely to be achieved unless the rights and needs of people with disabilities are taken into account.

A large proportion of disability is preventable. However, general improvements in living conditions will not be enough. Specific steps are still required, not only for prevention, but also to ensure that persons with disabilities can participate fully in the development process, obtain a fair share of the benefits and claim their rights as full and equal members of society.

An integrated approach is required, linking prevention and rehabilitation with empowerment strategies and changes in attitude. This article

---

[1] *E Helander, Prejudice and Dignity; An Introduction to Community Based Rehabilitation, UNDP, 1992. One in 20 is a conservative figure with some sources suggesting 1 in 10 of the world's population may be defined as having a disability.*

[2] *Anne Elwan, Poverty and Disability, a background paper for the World Development Report, World Bank, October 1999.*

*This article was prepared by Ms. Alana Officer (Country Director) and Ms. Catherine Naughtaun (Physiotherapist) from Handicap International (HI) based on their work experience in Kutchch after the earthquake in 2001. The section on the census was written by Ms. Priya Varadan, an independent consultant.*

examines the significance of disability as a development and a disaster issue, its importance in relation to poverty and the barriers in the physical, socio-cultural environment creating a situation of handicap and the relevance of including persons with disabilities in the Census.

## Poverty and Disability

Defining disability is complex and often controversial. Although it arises from physical and intellectual impairments, disability has social implications as well as those related to health. A complete understanding of disability issues recognises that it is often associated with social exclusion and increased exposure and vulnerability to poverty. Hence, it is an outcome of complex interactions between the functional limitations arising from a person's physical, intellectual or mental condition and the social and physical environment. It has many dimensions and is more than an individual health or medical problem and one that has a powerful rights dimension.

The Department for International Development (DFID), UK, in its working paper on 'Disability, Poverty and Development' uses the following definition of disability: "Long-term impairment leading to social and economic disadvantages, denial of rights and limited opportunities to play an equal part in the life of the community".

The World Health Organisation (WHO) International Classification of Impairments, Disabilities and Handicaps (ICIDH-2, 1980) defines all the terms separately:

**Impairment:** In the context of health experience, impairment is any loss or abnormality of psychological, physiological or anatomical structure or function.

**Disability:** In the context of health experience, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

**Handicap:** In the context of health experience, a handicap is a disadvantage for a given individual, resulting from an impairment or a disability that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual (WHO 1980).

Impairment is considered to be occurring at the level of organ or system function. An assessment of the impairment requires judgement of the mental and physical functioning of the body and its component parts according to accepted standards. The classification of impairment is hierarchical, allowing considerable specifics for those needing to record such detail.

Disability is concerned with functional performance or activity, and limitations therein, affecting the whole person. The disability codes attempt to encompass those activities considered important in daily life. Like impairment, the classification of disability is hierarchical but allows for an additional parameter to record the severity of disability.

Handicap focuses on the person as a social being and reflects the interaction with and adaptation to the person's surroundings.

The handicap codes attempt to classify those consequences which place that individual at a disadvantage in relation to his/her peers. The classification system for handicap is not hierarchical, but comprises a group of 'survival roles', with each survival role having an associated scaling factor to indicate the impact on the individual's life.

The United Nations in the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities, 1994[3] uses the following definitions for disability and handicap; 'Disability' summarises a great number of different functional limitations occurring in any population in any country. People may be disabled by physical, intellectual or sensory

---

[3] *The Standard Rules on the Equalisation of Opportunities for Persons with Disabilities 1994, United Nations.*

impairment, medical conditions or mental illness. The term 'handicap' means the loss or limitation of opportunities to take part in the life of the community on an equal level with others. It describes the encounter between the persons with disabilities and the environment. The purpose of this term is to emphasise the focus on the shortcomings in the environment and in many organised activities in society, e.g. information, communication and education, which prevent persons with disabilities from participating on equal terms.

According to the Persons with Disabilities Act, 1995, a person with disability is a person suffering from not less than 40 per cent of any disability as certified by a medical authority. The conditions included as disability are blindness, low vision, hearing impairment, locomotor disability, mental retardation, leprosy and mental illness. Autism, cerebral palsy and multiple disabilities (e.g. mental and visual impairment) have been listed as disabilities in the National Trust Act of 1999.

### Poverty, a Cause and a Consequence of Disability

Poverty is both a cause and a consequence of disability. Although the link is not well documented, poverty and disability reinforce each other, contributing to increased vulnerability and exclusion. Recent research in rural India found that a higher proportion of households with self-reported disabled members was below the poverty line, had lower total assets, smaller land holdings, and greater debt than households without disabled members.[4]

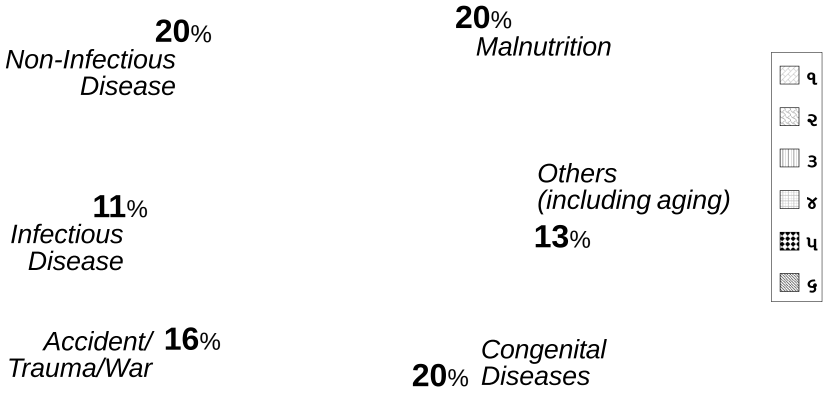
The majority of people with disabilities find that their disability affects their chances of going to school, working for a living, enjoying family life and participating as an equal in social life.

Poor nutrition, dangerous working and living conditions, limited access to vaccination programmes, and to health and maternity care, poor

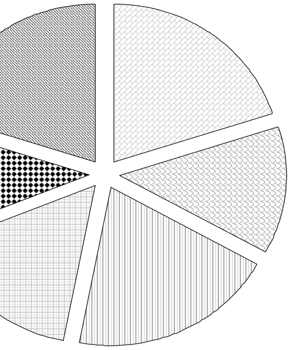
---

[4] *Erb, S. and Harris-White, B. (2001), Outcast from Social Welfare: Adult Disability and Incapacity in Rural South India, Books for Change, Bangalore.*

**Causes of Impairment**



hygiene, bad sanitation, inadequate access to information about the causes of impairment, war and conflicts and natural disasters all cause disability (see Figure). The number of persons with disabilities is expected to grow because of two trends: increased aging and violent conflict, both of which are highly correlated with disability.



ese causes are preventable. According to estimates from the
h Organisation (WHO), as many as 20 million women per year
o a disability and long-term complications related to pregnancy
rt . The most common causes of locomotor disabilities are
n accidents on the road, at home or the work place, war and
rth trauma and infectious diseases such as polio and leprosy.
ten become disabled as a result of malnutrition. Children with
are more likely to die young, or to be neglected, malnourished
A survey in India found a very high proportion of households
on with disability, but very few children with disabilities[5] and
the author hypothised that these children may die disproportionately as a result of neglect. These 'missing children' may account in part for the significantly lower prevalence rates between 2 and 5 per cent in developing countries compared to the rates in developed countries, i.e. between 13 and 18 per cent. One estimate shows that the mortality rate

---

[5] *ActionAid Disability News, 2(2), cited in Harris-White, p.4.*

among children with disabilities under 5 years is 80 per cent, and the overall mortality rate among children under five is just 20 per cent. A gender bias is also evident. Estimates from India indicate male disability rates to be higher than female rates. A 1995 study suggests that the lower overall number of women than that of men with disabilities, despite women's usually longer life span, could indicate that girls and women with disabilities receive less care and support, and die earlier.

Disability exacerbates poverty by increasing isolation and economic strain, not just for the individual but also for the family. Persons with disabilities who are denied education are less likely to find employment which drives them further into poverty. Breaking out of the vicious cycle of poverty and disability becomes more and more difficult.

The result of this vicious cycle is that persons with disabilities and their families are often the poorest of the poor. Women with disabilities suffer double discrimination both on the grounds of gender and impairment. The literacy rates of women with disabilities are lower than men with disabilities as more boys with disabilities are likely to attend school than girls with disabilities. Studies show that women with disabilities are two to three times more likely to be victims of physical and sexual abuse than non-disabled women. Their access to reproductive health care is minimal and as a result they suffer greater vulnerability to reproductive health problems. There is a general lack of awareness regarding women with disabilities and their reproductive health care needs. More often they are not targeted because women with disability are considered sexless and hence not capable of performing a vital function.

### Disability is Costly!

Disability not only affects the individual and his or her family but has an impact on the community. The cost of excluding persons with disabilities from taking an active part in the community is high and has to be borne by society. The exclusion of persons with disabilities leads to loss in productivity and human potential. The cost of disability has three components:

- The direct cost of treatment, including costs of travel and access

- The indirect costs to those who are not directly affected (i.e. the care givers)
- The opportunity costs of income foregone by the unutilised capacity.

If we examine the Indian statistics, there are 21.9 million (or 2.13 per cent of the population) that are reported to have a disability (Census 2001). The lives of their families, those people affected directly and indirectly by disability, amount to perhaps four to five times this number, i.e. 88 million.

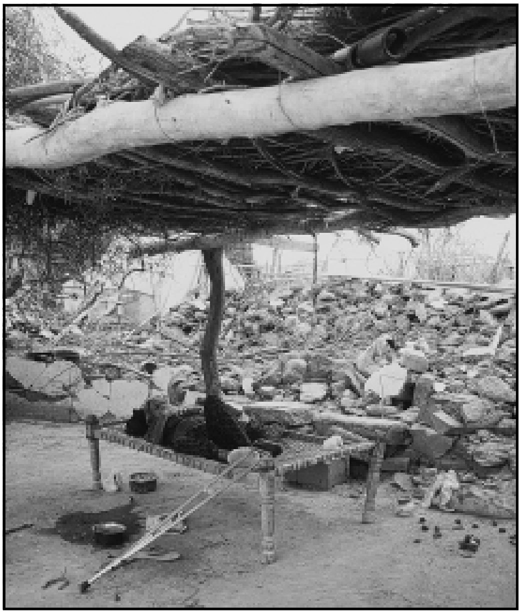
In 1996 Smith and Smith estimated that the global cost in terms of productivity of blindness was 193 billion USD[6] .

In a study conducted by the National Centre for the Promotion and Employment of Disabled Persons (NCPEDP), there are 7 million employable persons with disabilities in India, out of which only one lakh were employed in the Government sector during 1958-'98. They also claim that there are about 60 million persons with disabilities in the country and, taking Rs. 500 as the nominal cost of living per person, the amount is Rs. 36,000 crore per annum. The direct costs of disability are usually unequally shared. The burden most often falls on family members, usually mothers or other female relatives. Caring for a child with a severe disability further increases the workload for women living in extreme poverty and takes valuable time away from the daily struggle to make a living. The burden of care also often falls on the other children, usually girls, who may have to miss school to stay back home and care for a sibling or other relative with a disability.

The benefits of reducing the preventable disabilities and morbidity to the Indian economy are numerous and include increased productivity, greater opportunities to obtain better paying jobs and longer working lives.

---

[6] *Smith and Smith, The Economic Burden of Blindness – the Price is too High! British Journal of Ophthalmology, 1996*



## Disability and Disaster

On the morning of January 26, 2001, a massive earthquake measuring 7.9 on the Richter Scale hit the district of Kutchch in northwest Gujarat, killing 20,000 people and injuring an estimated 160,000 others. Hundreds of people lost limbs, thousands broke their bones and many more were left paralysed. Due to the huge loss of human life and the destruction of the infrastructure, the possible long-term consequences of the earthquake were physical, emotional, economic and social. Everyone became vulnerable in some way or the other, resulting in an enormous challenge for the survivors to rebuild their lives from the ruins. For those particularly vulnerable[7] , notably persons with disabilities, the path was longer and tougher. When considering persons with disabilities in a disaster situation, we must also consider those persons with disabilities in Kutchch

---

[7] *Handicap International defines vulnerability as the incapacity of a person, a group, or a community to absorb the effects of gradual or sudden loss of equilibrium. Vulnerability is a relative notion that depends on individual factors (age, gender, and state of health) in addition to the political, economic, social and cultural contexts. The first criterion for vulnerability is the loss of autonomy where an individual or group is unable to meet its basic needs, which induces a situation of handicap.*

who were already living with a disability before the earthquake. Many of them did not know about the benefits or had an opportunity to access rehabilitation facilities and remained excluded from all other development initiatives.

Following the earthquake, most of the major health services were destroyed and rendered partly or completely non-operational. There was a huge national and international response to the provision of emergency medical relief which complimented the local medical efforts in providing intensive care to the huge number of injured people. The Government responded quickly with the supply of assistive devices to address the mobility needs of people injured and impaired.

After the initial stages of treatment, where people underwent surgeries, fractures were put in plasters and wounds were stitched, they were discharged soon. For many, there was no home to return to, for others the fear resulting from the earthquake forced them to go elsewhere. Due to the emergency and the number of people injured and requiring medical relief, it was not possible to maintain records of all the persons who had received treatment which would have facilitated follow-up care and rehabilitation. Furthermore, the breakdown in the local medical and rehabilitation service delivery system meant that there was no systematic referral or repatriation of persons for rehabilitation after discharge. In many cases people waited in the hope that they would get better, rather than seeking assistance which would have speeded up their recovery. This failure to seek further help could be due to lack of knowledge of the

benefits and the availability of services locally, poverty, or in many cases it may not be a priority as there were many other issues, i.e. shelter and income generation being placed higher than health care. This is, however, very dangerous, because a minor injury can become a disability and have a significant effect on the persons' functional abilities due to lack of rehabilitation facilities and may later create a situation  of handicap, deeply affecting them and affecting their ability to perform their daily life functions and activities.

The following constitutes a series of observations made by the staff of Handicap International (HI)[8] , while working on disability issues in Gujarat The primary goal of the HI is to work towards a more equitable society for persons with disabilities, regardless of the cause of disability. This implies a global approach to the situation of handicap[9] which is not only a medical issue but also a social and developmental one. Hence, we believe that multifaceted actions have to be conducted for persons in a situation of handicap to address all issues at all levels; medical risk prevention, rehabilitation, accessibility and social integration, recognition of rights. Moreover, these actions need to be carried out in such a way that the adverse effects of stereotyping the beneficiaries are avoided; hence promoting integration and not exclusion.

In a disaster such as the one that struck Gujarat and in consideration of the large numbers of people injured and disabled, it was understood from the outset that a short-term initiative would not suffice in addressing the issues that this situation had provoked. Disability triggers complex interactions between the functional limitations arising from the changes in the person's physical abilities, the intellectual and mental condition and the social and physical environment. It has multiple dimensions and

---

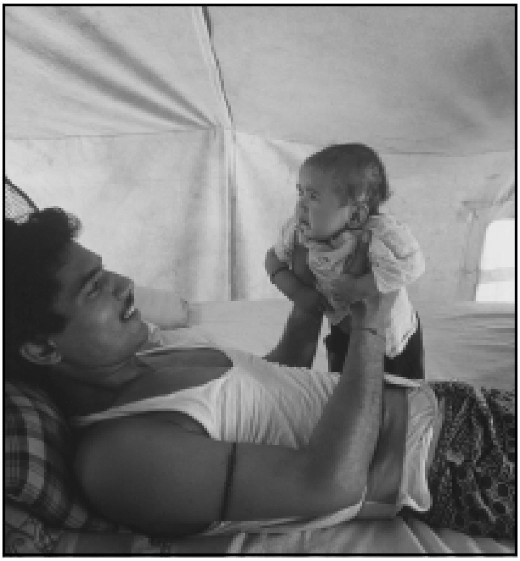
[8] *Handicap International (HI) is a French NGO which works in over 50 countries and has been present in India since 1986. HI has been working in earthquake relief/ rehabilitation in Kutchch since March 2001.*

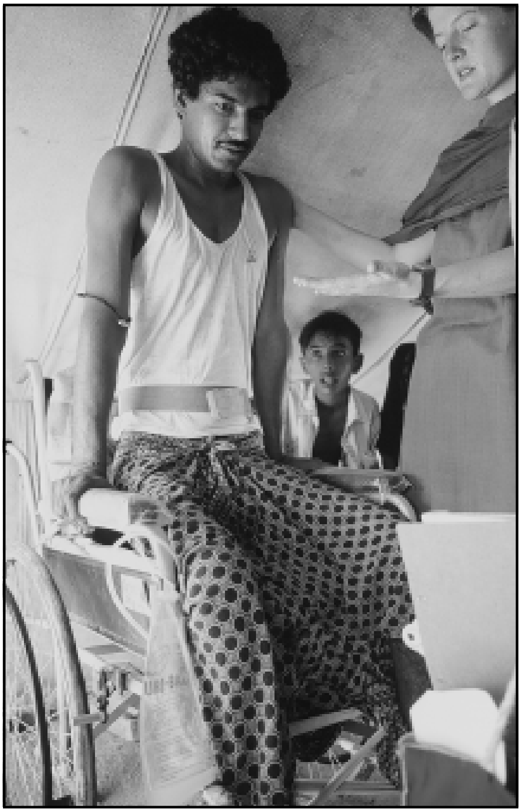
[9] *The situation of 'handicap' refers to those factors that impede the person's autonomy and his or her ability to participate fully in the social, economic and cultural life of his or her society, i.e. poverty, environmental and attitudinal barriers, etc.*

is far more than an individual's health or a medical problem.

The initial phase of the HI emergency response focused on limiting the impairments and to restore, where possible, the abilities of those persons injured and disabled, especially people with spinal cord injuries, through physical rehabilitation and the supply of need-based appliances. This was done in collaboration with other agencies to avoid duplication and ensure effective use of the available resources. Where specialised skills were not locally available, i.e. the physical rehabilitation at community level of people with spinal cord injuries, HI complemented with direct support and training to local development and allied health personnel to enable them to progressively assume more of the rehabilitation responsibilities.

Thus rehabilitation continued, but the scope of the programme broadened to look at other factors and issues for persons with disabilities in general, such as access to services, education and rights. Though in Gujarat our focus





is on disability issues and persons with disabilities, no separate and segregated programme has been set up for persons with disabilities. The strength of the programme rests and will remain with the local organisations which are actively working to address the needs of vulnerable persons, including persons with disabilities, in their communities. The activities of these organisations cover a broad spectrum of human and social development programmes beginning with education and covering water and sanitation, shelter, income generation and others. Capacity building of local physical rehabilitation services is also ongoing.

## Community-Based Rehabilitation of the Injured

Many organisations adopted a community-based rehabilitation approach, using community resources to rebuild the area. Several organisations established physiotherapy services that rehabilitated people in their home environments, using the help of community-based organisations (CBOs) and their networks of field staff familiar with the people and the area. Through this network of community workers it was possible to locate people who were injured. As there is a remarkable sense of community and family in Kutchch, with a little help and advice from physiotherapists, the families and the community members actively facilitated the rehabilitation of injured people. To enable the community workers to locate and identify the injured persons with disabilities, and address their needs, HI in collaboration with UNNATI provided training to sensitise people on the needs of persons with disabilities and worked together to identify how they could be included in their ongoing activities. In turn the CBOs demonstrated by their actions that they understood the needs of persons with disabilities and the value of addressing disability issues in their development and relief activities (For example, many organisations hired staff with disabilities).

The rehabilitation process is multidimensional. Following a serious injury, there is a need for physical rehabilitation. There may also be a need to work with such individuals so that they can be reintegrated into the normal activities of the community, be it getting back to school for a child or getting back to work for previous wage earners. The goal of complete rehabilitation is to enable individuals and their families and community to become as independent as possible.

Bearing this in mind, a co-ordination system between the development and rehabilitation agencies was developed. This assisted the physiotherapy teams in identifying the people in need of physical rehabilitation, and to have close contact with organisations which were dealing with global human development needs like psycho-social support, housing, income generation, etc. Accurate advice and follow-up were available to people in their homes. The reinforcement of appropriate rehabilitation centres (physiotherapy and orthopaedic centres) ensured that the community can in the medium-term access the more specialised rehabilitation services which, for reasons of viability, cannot be sustained at the community level. The injured persons, the family and the entire community benefited from this approach, a global follow-up was possible and the persons were cared for in terms of all of their difficulties, psychological, physical, economic, and social. Good foundations have been established which will facilitate, in the long term, the independence and integration of people injured and persons with disabilities as full participating members of their communities.

## Moving from Relief to Rehabilitation

This early link which was developed between different agencies and the Government provided a good basis for long-term planning of projects and facilities for persons with disabilities. The end of the relief phase and the transition to the rehabilitation phase laid the foundations for the elaboration of a comprehensive community-based rehabilitation (CBR) programme for persons with disabilities, involving the Government and CBOs. With this approach, if we assure the involvement of persons with disabilities from the beginning, a system can be established which can go towards meeting their needs in terms of health care and physical rehabilitation, and also their inclusion in the community through social and economic rehabilitation.

**The characteristics of such a programme should be:**

- Persons with disabilities to be involved from the beginning in the development, implementation and monitoring of the programme.
- There is a strong emphasis on training, skill transfer and capacity building of local people, maximising sustainability of the programme. Particular attention should be paid to training persons with disabilities, systematically promoting their autonomy and socialisation.
- All the needs of persons with disabilities are addressed and recognised as being the same as the needs of the non-disabled.
- Basic rehabilitation services are available at the community level and are participatory.
- Specialist inputs like appropriate medical and orthopaedic care are made available taking into consideration the local needs, context and available resources.
- The geographical coverage is coherent with the needs.
- Positive approaches and attitudes are developed. We consider the environment in which we live as being the biggest obstacle to the full integration of persons with disabilities — both the physical environment, and the mental environment — our attitudes. In recognition of this, we realise that before we expect to attain full integration of persons with disabilities we must look at how welcoming our buildings are to them and how welcoming we are in our approach.
- Community members, both with and without disabilities, are considered to be the most important resource. Active community support is essential for the success and sustainability of the programme.

### Obstacles to Working with Disability Issues in a Disaster Situation

1. One of the greatest obstacles, which we encountered in Gujarat, was that with such massive destruction, **disability was not a principle concern of many organisations.** Moreover, many organisations working in disaster relief were not aware of disability issues nor could they perceive their strengths to be able to address these issues in their emergency relief and rehabilitation activities.The process of collaboration with regard to disability is **hindered by the other**

**important and extensive concerns of CBOs.** When there is no clean water available, the schools are not open and few people have shelter with the monsoon coming, it is difficult to find the time to look at and be sensitised to or trained in inclusion methods for persons with disabilities. Disability issues should be addressed as part of any disaster preparedness initiatives so that organisations are ready and capable of ensuring that their relief and rehabilitation services reach all vulnerable persons.

2. To ensure the medical rehabilitation of persons with acute injuries, specialised health personnel, i.e. physiotherapists are required. In India there is a paucity of physiotherapists working at the community level with most being concentrated in urban areas. **In general, very few physiotherapists were interested to work in rural areas following the earthquake. Furthermore, most lacked the necessary skills to manage and follow up the diverse range of acute traumatic injuries.** Emergencies such as in Gujarat demanded a certain level of skills. Our experience has shown that training is required also for qualified physiotherapists to be able to address the needs that this type of situation provokes. This can of course be done. Yet, as the relief needs subside, this approach has to be promptly complemented with the identification and training of **community workers dedicated to disability issues,** which is the only sustainable way of working on the issue on a medium to long-term basis.
3. Actual **localisation of people who had been injured** was a momentous task as the records at field hospitals were inaccessible or incomplete and many people having lost their homes were relocated. We found that informal searching in the villages and towns was effective, though time consuming. Another beneficial source of information had been the local Government functionaries.
4. Another factor which contributed to the difficulty of localising people in the disaster situation was that **persons with disabilities were not in a position to have their voices heard**, and were confined to where they lived. Where so many people were grieved and had suffered losses, the voices of persons with disabilities would be even harder to hear. Invisibility of persons with disabilities is a common

phenomenon in our society as they are seriously marginalised.

5. Common to all programmes operating in a disaster-struck area are the **logistical problems** associated with the destruction of the infrastructure.

**Strategic Reasons for Working on Disability Issues in Disasters:**

a) One major problem faced by persons with disabilities in all societies is the taboo associated with disability. For a period of time following a disaster, injury and impairment affects the lives of many individuals. Hence, this is an opportunity to influence the attitudes that society has towards persons with disabilities. **We are always more sensitive when we ourselves or people close to us have suffered**. Thousands of people after the earthquake in Kutchch were affected by disability, either temporarily or permanently. It is hoped that we may all use this personal experience to better understand the issues involved and to broaden our understanding of disability issues, irrespective of the causes (earthquake related, polio, leprosy, etc.) or nature (orthopaedic, mental/ psychological) of the disability.

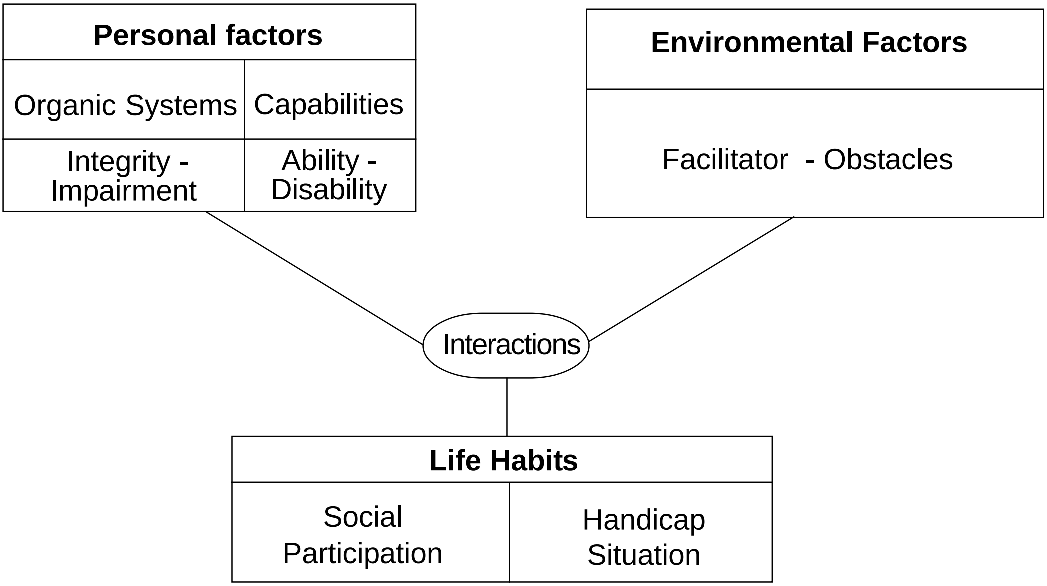
b) In Kutchch, due to the earthquake many persons with disabilities have had access to rehabilitation services, even those who had acquired one before the disaster. In one artificial limb fitting camp in Kutchch by an NGO, limbs or callipers were fitted for over 200 people. Only around ten had earthquake-related injuries, the others had difficulties walking due to polio, or loss of their limbs in accidents long before the earthquake. Many of these people never had access to this service.

c) The orientation of the programme towards the physical rehabilitation and supply of devices for people at the community level was timely and has shown excellent physical recovery rates, especially for people with spinal cord injuries and strong positive signs for inclusion.

d) The earthquake destroyed the infrastructure and all the buildings in the region and many of these were rebuilt. This provided Gujarat with a unique opportunity to make a model environment by creating a barrier-free environment for all. The Gujarat Government made the commitment to make the Civil Hospital and public health facilities accessible to persons with disabilities. UNICEF modified its building plans and some of the schools were made accessible so that children with disabilities or their parents with disabilities can gain access. Certain CBOs followed the guidelines distributed for accessible housing for persons with disabilities. The need doesn't end here; every public building or service should, where possible, ensure that the buildings are open and accessible to all.

In Kutchch it has been very useful to have specialists in physical rehabilitation, because by nature of the disaster so many people were injured. However, the most fundamental needs of persons with disabilities will only be met when all actors working in disaster situations are aware that persons with disabilities have the same needs and rights as the non-disabled; but because of their disability the possibilities of satisfying their needs are less likely. There was much talk of turning the disaster situation in Kutchch into an opportunity well utilised. It is of course up to the local communities to evaluate whether this has been the case.

Figure 1 - **Human Development Model**



*Adapted from Handicap Creation Process, Fougeyrollas et al., 1997*

To work on disability issues in a disaster situation is challenging in many ways, but full of potentiality. In every disaster, relief organisations try to provide services to the most vulnerable, to the poor, and to people who have incurred huge losses.

## Human Development and the Handicap Creation Process

To better understand all the factors that combine to create a situation of handicap, it is first interesting to look at the human growth cycle. The Human Development Model (see Figure 1) is a simple model, which is applicable to everyone, and takes into account the dynamics between personal factors (intrinsic) and environmental factors (extrinsic) which interact to determine our life habits. The terms are defined as follows:

**Personal factors:** A personal factor is a person's characteristics such as his or her age, sex, and socio-cultural identity, i.e. a 30-year-old *Bhil* tribal man or a 25-year-old *dalit* woman.

**Environmental factors:** An environmental factor can be a physical or socio-cultural dimension that determines the organisation and context of a society i.e. nomadic lifestyle covering the desert plains of Kutchch.

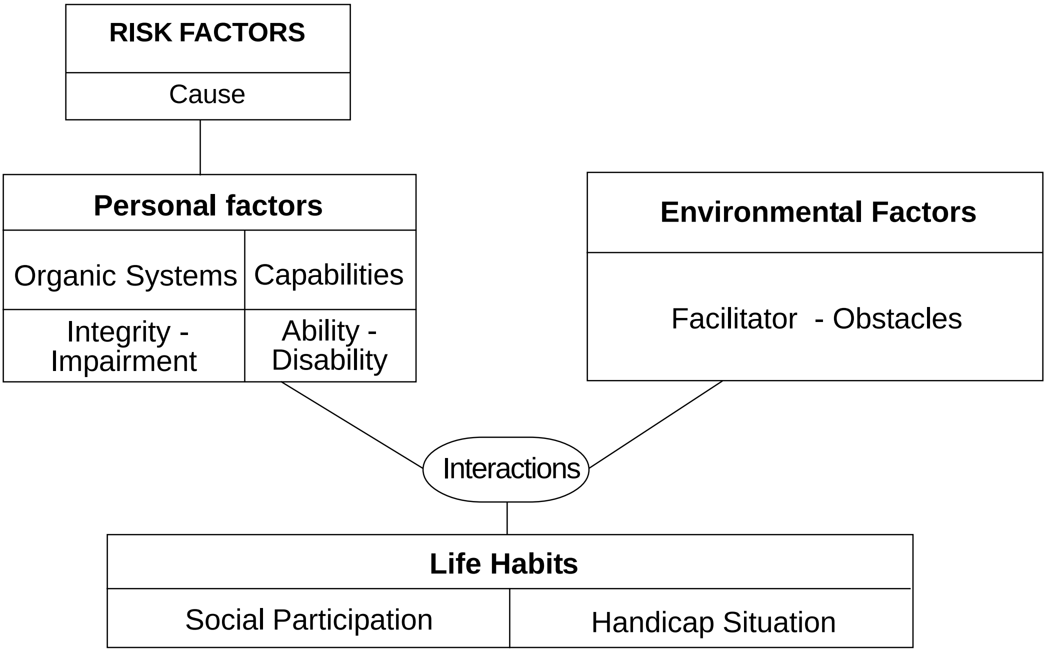
**Life habits:** A life habit is a daily or domestic activity which is recognised by the person's social and cultural environment according to his/her age, sex and socio-cultural identity like farming, cattle rearing.

## Handicap Creation Process

Before reading on, please see Figures 1 and 2 and identify the difference between the two drawings. If we use the development model as a base, we see that the process creating a handicap is only a variation of the human development model. Do you find the difference?

The **only** difference between the two models is the presence of **risk factors,** i.e. the only difference between a person without a disability and a person with disability is that the latter has been exposed to a risk

Figure 2 - **Handicap Creation Process**



*Adapted from Handicap Creation Process, Fougeyrollas et al., 1997*

factor which has caused a disability and later a situation of handicap. A risk factor is an element that applies to either the individual or his/her environment and is likely to cause disease, trauma or another type of disorder that affects the person’s health or development, i.e. water that is contaminated by the virus that causes poliomyelitis or a house that is not earthquake proof. A cause is a risk factor that has led to a disease, trauma or other disorder, i.e. drinking the water and catching poliomyelitis or the collapse of a house when an earthquake occurs.

It is important to avoid falling into the trap of identifying somebody in relation to his or her disease or trauma or rather to his/her diagnosis i.e. this person has polio or this person has a spinal cord injury. Diagnostic information is helpful; however, it doesn’t explain what has happened to the person’s internal organic structures and functions, or the level of capability and the subsequent impact on his or her life habits.

An organic system is simply all the components that make up our body and includes all the parts that you see and all the ones inside. Our bodies are finely tuned machines that perform best when all the parts work together. The word integrity refers to a situation in which this system or machine functions well. In contrast, impairment relates to changes in the way our system works. The degree of function of the organic system will have a direct effect on a person's capabilities and hence on his or her potential to perform a mental or physical activity.

Hence, when we look at a person's performance, we see it on a scale ranging from its optimal ability to disability. It does not, however, take into account the person's environment. The real life environment of a person (physical, attitudinal and socio-cultural) can either facilitate (help) or obstruct (hinder) what the person does, i.e. his/her life habits. A situation of handicap is created when the person is unable to perform his/her life habits as a result of the interaction between his/her personal factors (impairments, disabilities and other personal characteristics) and the environmental factors (positive approach of the facilitator, barrier-free environment and obstacles – negative approach, steps, etc).

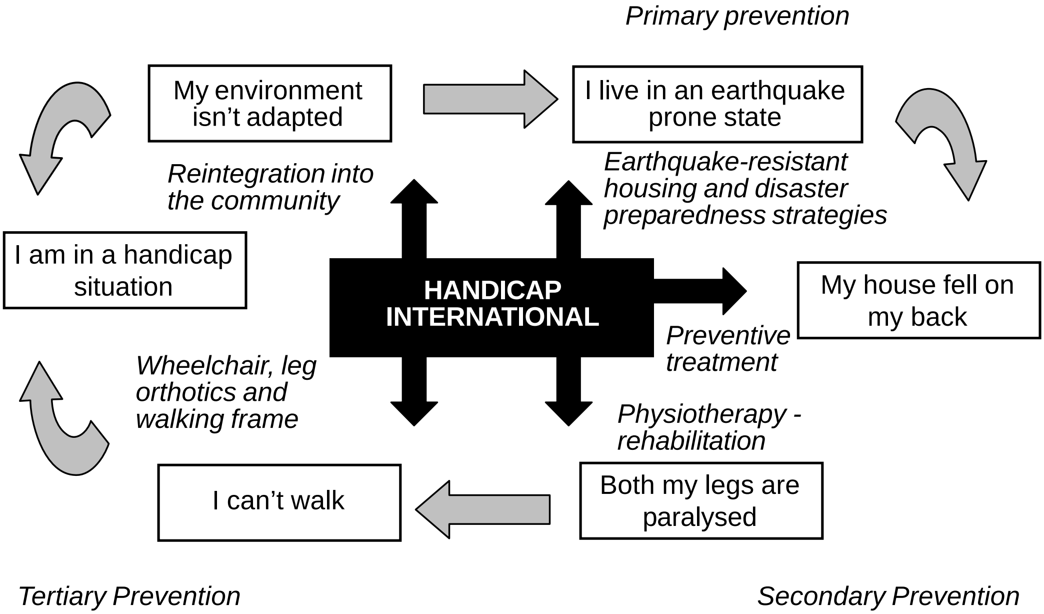
### Situation of a Person with Spinal Cord Injuries

An example of the 'handicap creation processes' and a 'global approach to handicap', for a woman with a spinal cord injury following an earthquake is shown in Figure 3. Here we see that the situation of handicap results from a number of factors of which the pathology (spinal cord Injury) is only one factor among many. Here, the approach that Handicap International (HI) employed was to act both on restoring the person's capacities to reduce the effects of the disability and on her environment to adapt it to her capabilities.

To effectively address all the rehabilitation needs of the woman in addition to her social needs so that she can fully participate in the social, cultural and later economic life of her society, a multidisciplinary approach is required at the community level. The physiotherapist, whose role can, with appropriate training, be partly delegated to a community worker, has a central part in acting on the capacities of the woman with a spinal

## Figure 3

## Handicap Creation Process and the Global Approach to Handicap applied to a woman with a spinal cord injury



cord injury to reduce the consequences and correct (where possible) the physical and functional deficits. It is imperative that the therapist takes the woman's detailed personal history along with her family situation, geographical and socio-economic data, clinical picture of the extent of paralysis and secondary deformities her family projects, expectations, medium and long-term needs. Furthermore, it is vital that the woman and her family are aware of the treatment objectives, interests and constraints and are involved in any decision making.

The orthotic appliance must allow the woman to recover as much autonomy of motion as possible. Different technical and technological solutions can be envisaged for the orthotics and wheelchair. The decision will in part be dependent on what is available locally, the human resources available, i.e. who is there to help make the right selection, their training and the capacity for follow-up both within the community and outside. The final decision about the usage of the wheelchair and orthotics needs to be based on a thorough analysis of the medical, socio-economic and technical objectives in connection with the woman's needs, desires, social and cultural environment.

The woman may have had the best physiotherapy possible and may possess orthotics and a wheelchair which are well adapted to her physical needs. However, if the rubble hasn't been cleared and the buildings that she wants to access (i.e. home, health centre, shops, banks) have steps,

### Spinal Cord Injury

Our backs are made up of a column of bones called the spine. Running down through the middle of the spine is the spinal cord, which is a band of nerves that act as a communication system in the body. When someone has a complete spinal injury, there may be parts of the body which he/she can neither feel nor move, because the messages no longer travel up to the brain, or down to the rest of the body.

Often a person with spinal cord injury cannot walk the same way as he/she used to, or not at all. It is common for him/her to use a wheelchair to move around. S/he may need to use catheters to pass urine, and might need to manually empty their bowels. They often have long-term problems with incontinence (inability to control when going to the toilet), infections and constipation.

There are generally a lot of problems in looking after such a person's skin, which tends to be very delicate because of the poor circulation and nerve supply and vulnerable to damage if s/he cannot feel it. If s/he has had a spinal injury, the person is at risk of developing pressure sores.

A pressure sore is an area of dead tissue, which occurs where there has been unrelieved pressure on the skin. Pressure sores can become infected and very deep. Without adequate care they are life threatening. Once a pressure sore develops, it is very difficult to heal, often taking up to one year to heal, even with good nursing care.

how will she move around with dignity and be able to actively participate in society? Furthermore, if she is confronted by people who see only her disability and not her abilities, how will she utilise her full potential? Changing the environment from handicapping to a facilitating one means not only changing the physical environment but also the attitudes of the civil society towards persons with disabilities.

This global approach takes in the diversity of the woman's requirements, respects her specific needs as well as those more general needs of a group for the implementation of a development process. It is a coherent approach which makes the most of the individual's capacity, for themselves, in their families and their communities. See the case

There were many organisations working in Kutchch in the post-earthquake relief/ rehabilitation programme. HI had a team of physiotherapists who were working in the community, locating with the assistance of community development workers the injured and persons with disabilities in their homes, and helping them and their families to recover their independence. Physical recovery alone is not enough to really change the life of a person with disability, and for that reason HI works in co-operation with local CBOs who are doing community-based rehabilitation. HI also established links with the Spinal Injury Centre (based in the Government Civil Hospital in Ahmedabad) and followed up the rehabilitation of people when they were discharged. The staff at the Spinal Injury Centre provided HI with all the details of the patients. Despite this they were sometimes hard to locate because many of them had changed their place of residence as their houses had been destroyed in the earthquake.

study on Nilaben for further information.

### The Process of Rehabilitating Nilaben in the Community

The following case study illustrates many of the concepts and practical ideas that have been discussed. The story is about a girl called Nilaben who was injured in the earthquake at Kutchch on January 26, 2001.

Nilaben was 20 years old. She lived in a village with her family. She did not go to school, and could not read or write. Nilaben belonged to the *dalit* community, and was not married.

During the earthquake Nilaben was caught in the kitchen when her house collapsed. Her backbone (spine) was fractured. She was moved to a specialised centre in Ahmedabad and underwent an operation to stabilise her back. The weeks Nilaben was in hospital, after the earthquake, were spent on recovering from her injury, and starting to learn to do things for herself again. The wound from her operation healed, and she was given a corset to wear to immobilise her back and hence allow it to heal. The injury to her back damaged the nerves of her spinal cord, which means that she had difficulty moving her legs, could not feel them, and could not walk. She also found that she could not go to the toilet without help from the nurses, because the spinal injury damaged the nerves that control her bladder and bowel movements.

Nilaben was sent home from hospital in April 2001. She had to lie in bed in a temporary shelter in her village because her home had been destroyed. Her mother was nursing her — washing, dressing, helping her to pass urine, and to empty her bowels. Nilaben had to lie down in bed all the time. The braces which she had been given in hospital to help her stand were broken. She had big sores on her legs as she had tried putting her legs into hot water. As she had no feeling in her legs, she did

not realise how hot the water was and her legs were badly burned. The family became depressed and felt that the situation was hopeless.

A physiotherapist from HI found Nilaben lying in bed, where she had been so for some days. She had been recovering in the hospital, but since she came home, and then burned her legs, things had become very difficult. She was not able to walk, and was fully dependent on her family. The signs of stress on all of them were obvious.

In the village that Nilaben lived, one of our partner CBOs was also working. It had a centre there with two volunteer community workers to look after the vulnerable people in the village. They were based with the *dalits* in the village to make their services more accessible to this community. HI visited the centre and brought the volunteers around to meet Nilaben and her family. A few hours were spent that afternoon with Nilaben's family and the community workers. The physiotherapist spent a lot of time focusing on what Nila could do. She could do most of the things such as feeding and washing herself without any help. The physiotherapist and Nilaben's father mended the brace with some *sari* material and the family watched Nilaben practising standing. She could stand up only for a few seconds at a time, and needed help as her arms were very weak, and she was feeling dizzy having been confined to the bed for so long. The physiotherapist suggested the family make parallel bars, which would be useful for Nilaben to practise walking. The family was very despondent and said it couldn't be done. It said that it was poor and couldn't buy wood. No amount of convincing would get the family to agree to try, so the subject of the parallel bars was dropped. Nilaben's mother would not speak at all, and kept staring into the distance.

The physiotherapist recognised the many dimensions to Nilaben's situation.

- She needed medical attention for her sores on her legs.
- She needed physical rehabilitation to gain enough strength to be able to be more self-reliant, to be able to move around in her wheelchair, get in and out of bed and dress herself.

- Her family needed social support and practical help to look after her.
- Nilaben needed support and companionship.
- Some practical things had to be done to the environment — Nilaben should be sleeping on a good mattress, parallel bars should be made, and the area should be adapted to allow her to move around easily in the wheelchair.
- The community needed to be involved to help take the load off the family and to provide extra support to all of them.
- Eventually Nilaben should be independent in looking after herself and participating in all that was happening around her. However, many improvements, modifications were needed to be made in the environment before this could happen.

Because Nilaben's problems were multifactorial, the solutions were also complex and many people needed to be involved. The physiotherapist gave the family some dressings for the sores and showed Nilaben's mother and aunts how to clean the sores and put clean dressing on them to enable them to heal. Nilaben was taught several exercises to help her regain her strength. She was advised to eat properly and drink a lot of water, and sit out of bed during meals. (There is a tendency for people to eat little if they have their meals in bed). The community workers were to consult the villagers on how they could clear the pathways in the village.

The physiotherapist arranged to return the next week, and asked the community workers to visit Nilaben's family every day and to accord her a priority in the community housing work undertaken by their NGO.

The next week, when the physiotherapist arrived, parallel bars had been constructed with scraps of wood and Nilaben was walking up and down several times a day. The community workers had helped Nilaben's father to find the wood, and they had put up the bars together. Nila was looking a lot better though she was in bed when the physiotherapist arrived. She was chatting a little, and had been feeding herself. Her mother was still helping her with other things and did not communicate much, but she was dressing Nilaben's sores every day which were now looking better. The community workers had obviously got to know the family quite well. They were planning to take Nilaben around to their centre to look after the children when she recovered.

Soon Nilaben had her shelter in the middle of the village, in a place where people pass through all the time. This provided her with an opportunity to closely interact with other people in the village. This was great for her confidence and as she developed her physical strength she could move about more frequently in her wheelchair. The people around had made all the surfaces smooth enough for her to wheel herself around easily. The sores on her legs took some time to heal but they got better. Nilaben enjoyed herself visiting the centre with the community workers to chat with people, she could go there by herself in the wheelchair. Because her arms became stronger due to the exercises she could do everything for herself. Her mother became a lot happier. She went back to working in the fields as Nilaben could look after herself. It was a big relief to the family as they all could go back to their regular routine including earning to meet the daily needs of the family.

The community workers planned income generation activities for the village and Nilaben was keen to get involved. She had been doing some embroidery, and wanted to try to earn an income. The CBO mobilised the women into self-help groups which got together every week to plan; Nilaben became involved in all these meetings. She went to the meetings on her wheelchair, and sat down on the floor and chatted with all the other women.

The future for Nilaben and her family became a lot brighter. She is still not able to walk, but she can move about independently in her wheelchair. She is now well integrated in the community and the family is happier. Physical rehabilitation alone would not have achieved this. Going away to a special hospital would not have achieved this either. Regardless of the kind of rehabilitation support Nilaben would have received at a special hospital, factors crucial to her recovery would not have changed. Only by working on the physical environment around her, the attitudes of the people, and Nilaben's own perception of herself, could her situation of handicap be changed to enable her to live a full and active life.

## The Indian Census and Disability

One of the difficulties of addressing disability in a disaster situation after the earthquake was the absence of data on persons with disabilities in a particular area. This problem is not, however, restricted to Gujarat.

In India, until after the 2001 Census, we did not have the basic data on the number of persons with disabilities in the country. It is generally quoted between 5 and 6 per cent of the total population. This figure is based on estimates made by the National Sample Survey Organisation (NSSO) and is only a representation of the total.

The Census has been carried out in India regularly over the past 130 years. The questionnaire of 1872, called the 'House Register', included questions not only on the persons with physical disabilities but also persons with intellectual disabilities and persons affected by leprosy. This practice, however, was discontinued after the 1931 Census[10]. The comeback of disability Census in 1981, after a gap of nearly 50 years, corresponded to the 'International Year of the Disabled'. After a gap of another 20 years persons with disabilities were again counted.

We shall now examine how and why the Census was carried out, what impact the 2001 Census may have on persons with disabilities and its possible limitations.

## The Census and its Purpose

Practically, it means head count. An effort is made to count every person in the country, and to collect basic details of the socio-economic status

---

*[10] Unpublished Report on Disability in India by Bupinder Zutshi*

of each household.

India is one of the few countries which have been conducting Census operations regularly for over a century. The first non-synchronous Census was held in 1872 and the first synchronous Census was held in 1881. Census 2001 is the 14th in this series and 6th since Independence. The Census not only provides the population figures for India but also is a tool for measuring growth and development. Census data are crucial for the development of any programme, policy or plan of any government or development organisation.

### How is the Census Conducted?

Census is conducted once every ten years. The preparation for the Census operations begins about three years before the actual head count starts. Please see the Table given below for a brief note on the stages of the Census operation. Enumerators (those who ask questions to the respondents) are chosen from every corner of the country and trained by the Census Commission a year before the counting begins.

The training is designed to ensure that all the enumerators collect accurate and consistent information throughout the country. They are taught what questions to ask, how to ask each question and how to record the answers. All information collected is in the same format.

Enumerators visit every household/ individual/ family and gather information on age, education, income, and record it in the given questionnaire. **Accurate, precise information is essential. It is the responsibility of the enumerators and the people to ensure this.**

### Why Is Accurate Information Important?

Accurate information will give the country a true picture of its status in terms of socio-economic development and population increase. Census data is a perennial source of information for State or non-State organisations which are involved in planning social, economic or educational programmes or policies. The most obvious example in practice in India is in the formulation of plans for population control. Only through analysis of the Census Report can the Government of India form long-term strategies that will tackle the root causes of population explosion, the solution for which will be fundamental to India's progress.

### How Will the Inclusion of Persons with Disabilities in the Census Help the Country?

As mentioned earlier, no one till today knows exactly how many persons with disabilities there are in India. The results of Census 2001 have enabled us to have some information on how many persons with disabilities live in the country and with what kind of disability. One can now hope that Government policies and programmes for persons with disabilities will be better and more appropriately focused, both at micro and macro levels. More importantly, persons with disabilities, NGOs, organisations working for the persons with disabilities have figures on the prevalence and the kinds of disabilities. These facts and figures will give them more clarity in their work, planning services where they are most needed. So it really matters to be counted.

### How Will it Help the Government?

Census data helps formulate policies suited to every region, culture and community. For instance, the Census Report states that the largest population of persons with visual impairment in Gujarat are located in Ahmedabad district; based on this data, the Government can initiate or increase prevention, rehabilitation, awareness campaigns for the people in this district. The State Government can develop programmes keeping in view the local dialect, culture, and tradition. Budgetary allocation from both the Centre and the State Government can increase to tackle this issue.

### How Will the Census Help the NGOs?

When the magnitude of the problem is understood, the NGOs can cater to the community better, be it through service provision (provide equipment, therapy, education), research and advocacy. This sector can lobby for better facilities much more vigorously than ever when they have official and concrete data on persons with disabilities in their locality. There is potential for the results of the Census to influence the choices that many organisations may make for working on disability issues.

### How Will the Census Affect International/National Funding Organisations?

These organisations will have a clearer idea of where to target their resources, i.e. which regions are most needy and which are the most common disabilities.

### How Will the Census Affect Private Sector/Commercial Organisations?

Census data can enable this sector to realise and acknowledge the extent and prevalence of disability and to take actions such as participation in and encouragement of social causes. They can also make and market products/ aids friendly for persons with disabilities if they realise the scope of benefit for themselves as well as for persons with disabilities.

The overall Census data will create an impact, and could contribute to raising awareness on disability issues at all levels of our society in the same way as the facts and figures on population growth have influenced general awareness.

In fact, Census data will for the first time enable persons with disabilities realise the extent and magnitude of disability in the country, and thus enable them not to feel alone. Perhaps, these numbers will give them the strength to seek their rightful place in society.

### How Reliable Can the Census Data on Disability Be?

This will depend on how well the enumerators are trained to ask and record the data. My experience will perhaps best illustrate the possible shortcomings of the data collected and one contributing factor:

During the Census operation, an enumerator came to my house, and sought answers to all the queries in the questionnaire, except the one on disability. When he was about to leave, I told him “Perhaps you have missed out a question or two in between”. He replied “No, none”. I said,

**Facts and Figures on Census 2001 Operation**

- The preparation for the operation started as early as February 1997.
- Over 20 lakh enumerators were trained in July 2000.
- House listing was conducted before the Census operation during April-September 2000 (to gather information on availability of power, water, kind of house authorised/ unauthorised)
- Census operation began on 9 February and ended on February 28, 2001
- The enumerators collected data from 6.4 lakh villages, 5564 *tehsils/ talukas*, 5161 towns and villages, from about 22 crore households and over one billion people.
- Revision rounds were conducted between 1 and 5 March 2001 (for those left out during the initial operation).
- The Census 2001 Provisional Report was made public in May–June 2001. It contains figures on literacy rate, sex ratio, etc.
- The data on disability was released in 2004 and indicates that there are 2.2 per cent persons with disabilities in India.

"The two on disability". His response was, "I noticed that you have a problem in walking and I thought I could fill those columns myself without bothering you". I said, "You should ask me now and record the response here." Finally, he finished the task with me. As a parting shot, he told me something which raises doubts about the authenticity of data – he said, "People feel offended with this question so I avoid asking them".

So, if people are not aware like I was, or unwilling to come forward with the information, and the enumerators are not comfortable with asking the questions owing to the sensitivity to the issue, the Census operation would be a futile effort with regard to disability. The true picture might not emerge, and, as a result, funds or programmes may not be drafted with the right perspective. The end result would be that the situation of persons with disabilities may not in any way improve as a result of the Census and India might revert to NSSO figures. So it matters to be counted.

## Bibliography

1. Fougeyrollas P., Cloutier R., Bergeron H., Cote J., Cote M., and Michel, *G., Handicap Creation Process,* SCCIDIH-CQCIDIH, 1997, Quebec
2. Handicap International, *Acting on Behalf of the Disabled and Particularly Vulnerable.*
3. *Handicap International*, 1998, France

# My Experiences of Setting up a Community-Based Rehabilitation Project

After two years, it's a rewarding feeling to look back on my experiences of setting up the Bahuda community-based rehabilitation (CBR) project. The experiences naturally are those of a mixture of failures, successes, frustrations and fulfilments.

During my stay at the Training and Research Centre in Rehabilitation (TRCR), I learnt that a true CBR programme cannot be an extension or an outreach of any particular institution. It ought to grow from the grass roots and reach out for services from a host of institutions.

With this idea in mind, the Bahuda CBR started to take shape in mid-1998 as a people-centred movement. The organisational support for this movement came very aptly from an NGO called Movement for Rural Emancipation (MORE), which believed in galvanizing constructive initiatives for the benefit of the poor and the marginalised. This organisational support gained impetus by the technical and financial inputs from ActionAid (AA) India.

## Breaking the 'Culture of Silence'

MORE works with illiterate women to free them from oppression by breaking their 'culture of silence' and facilitating them to take appropriate action by themselves. This backdrop suited the outlook of the Bahuda CBR Project wherein persons with disabilities were to improve upon their physical and mental abilities, have access to regular services and achieve full social integration within their communities. Bahuda in Sanskrit language means 'to extend a supporting hand'. There is a rivulet by the

*This article was prepared by Mr. A. Prasad, Director, Bahuda CBR Project (MORE), Chittoor District, Andhra Pradesh* name of Bahuda cutting across the project area. As per local folklore, 'extending a supporting hand' connotes enabling and empowering somebody in daily life. Hence, it was considered appropriate to call the CBR project Bahuda.

The first step towards the CBR movement at Bahuda was to bring together a team of committed social workers who could facilitate interventions in the identified area comprising three revenue *mandals* (Vayalpadu, Madanapalle and Kurabalakota) of Chittoor district in Andhra Pradesh. It was visualised that each social worker would look after CBR interventions in a cluster of 8 to 12 villages. Each revenue *mandal* was divided into four clusters and looked after by a team leader (TL) who provided the managerial support. It took us six months to enroll, familiarise and deploy 12 social workers and three TLs. This was a fascinating experience. There was not much theory involved and things unfolded in a very practical manner. Once the field team understood its mandate, it went about on its own to identify its area and group.

Each social worker was able to bring together about 60 persons with disabilities who were formed into 3 different self-help groups (SHGs). These SHGs endeavour to strengthen the bonds between persons with disabilities and integrate them into the mainstream society. Within three months the Bahuda team was able to form 36 SHGs at the community level. The SHGs comprised no fewer than seven and not more than 20 members each. The members are either persons with disabilities or their immediate relatives. Normally children with disabilities, less than 14 years of age, are represented by a family member at an SHG.

## Training Programmes

Having formed the SHGs, the CBR project arranged training for the members on issues relating to persons with disabilities. These trainings not only raised awareness but also motivated them to initiate action. There were 18 such training programmes arranged for SHG members at different clusters during different times of the year. About 500 persons (persons with disabilities, parents of children with disabilities and others) participated in these training programmes. Through these it was revealed that the members themselves had immense knowledge of how to go about the rehabilitation process.

The office bearers of an SHG include the president and the secretary. While the president is the political head of the group, the secretary is the executive functionary. The secretary is referred to as *vikalanungua karyakartha* (VK) —'*vikalangulu*' in Telugu means a person with disability. During 1999, the Bahuda CBR Project arranged five training programmes exclusively for the office bearers. These had a tremendous impact since the participants for the first time came away from their homes and communities to look objectively at several issues of persons with disabilities. This programme generated a lot of solidarity among the persons with disabilities. All the 36 SHGs formed by the Bahuda CBR have selected a VK each. Of them, 24 are female and the remaining 17 are male. Of the total VKs, eight are persons with disabilities. The average age of a VK is 25 years.

The persons with disabilities are scattered and unorganised with a diversity of problems concerning day-to-day living. Bahuda facilitated the setting up of community centres in four nodal villages where persons with disabilities and other members are able to get together and carry out therapeutic exercises, group meetings, health camps, etc. These centres are provided with facilities such as newsletters, therapy equipment and educational materials.

## The Message Spreads

The Bahuda team conducted awareness programmes through local cultural activities like group songs and group dances. A team of community members (including SHGs) designed and developed a package of cultural programmes. Stories from the epics were told through puppets and other street theatres. Some messages on disability prevention and rehabilitation were also spread. These programmes were arranged in five nodal villages where a large number of people participated.

As part of involving teachers in the CBR work, 55 primary school teachers were oriented towards disability rehabilitation. The TLs and social workers of the project were able to design and organise these workshops for educating the staff. The response from the education department within the target area was very encouraging. Teachers are now joining hands with the project staff for early identification of and interventions for persons with disabilities. As a result, the admission of children with disabilities at regular schools has significantly improved.

Keeping this in mind, MORE conducted one-day orientation programmes for primary health care centre staff in collaboration with resource agencies within the identified area. Eighty five health sector personnel were covered under this activity during 1999.

### Economic Rehabilitation

Economic rehabilitation forms a significant component of MORE's work on disability issues. Income generation programmes (IGPs) were planned for persons with disabilities in three areas: 1) on-farm activities based on agriculture and allied sectors, 2) off-farm activities based on market prospects and availability of skills within the community, and 3) apprenticeship linkages which are planned in collaboration with local artisans.

While the employment scenario of the able-bodied is grim, it is indeed a difficult task to consider the employment avenues for persons with disabilities. Yet, for them some form of vocation is more important since self-esteem and financial gain generated out of it reduces to a considerable extent the negative impact of society's often disdainful attitude. Keeping this objective in view, the CBR ascribes due emphasis to economic rehabilitation of persons with disabilities in on-farm and off-farm initiatives.

## Multiple Benefits

On-farm initiatives will have multiple benefits (economic, psychological and vocational) for persons with disabilities. It is also found that persons with disabilities relate well to animals and therefore the CBR project also carried out a programme to rear sheep and goats during 1999. Sixty persons with disabilities were provided one sheep each to rear and later return the little ones to the SHG. The SHG in turn will pass on the offspring to another person with disability.

MORE pursued off-farm initiatives to cover activities like *beedi*-making, mat weaving, leaf-plate making, tamarind business, *agarbatti*-making and flower/vegetable vending. The project covered 40 persons with disabilities under these activities and closely monitored the IGP initiatives.

In contrast to institutionalised vocational training programmes, the CBR encouraged individual apprenticeship linkages between appropriate persons with disabilities and appropriate village artisans. Twelve local artisans adopted an equal number of persons with disabilities during 1999 to train them in trades such as sericulture, tailoring, carpentry and cycle mechanism. The CBR facilitated this linkage by supporting the artisans and persons with disabilities in terms of tools and with professional fees.

## Medical Rehabilitation

Medical rehabilitation is the core sector of Bahuda's CBR work. The medical rehabilitation has three dimensions. Firstly, preventive care which strives to minimise the incidence of disability. Secondly, primitive care wherein the persons with disabilities will be encouraged to avail themselves of the various provisions available to them both by Government and non-Government agencies. Thirdly, the rehabilitation measures should include both the 'needs assessment' and 'supportive care'.

As part of preventing the occurrence of disability, antenatal care and post-natal care at the village level were initiated during 1999. The project staff worked closely with the primary health care workers and ensured complete primary immunisation of pregnant mothers and children. The CBR staff conducted regular meetings as part of the awareness building process where more than 200 mothers took part.

Altogether 30 villages were identified where awareness on health issues was found to be inadequate. Health awareness camps were conducted at these villages where audio-visual and other mass media equipment were used. Clinical conferences were held at the community level where issues pertaining to a particular person with disability were discussed and explained by specialists. Based on these discussions, 31 action plans were prepared during 1999. The details are as follows: Disabilities are often aggravated due to lack of timely and appropriate intervention. This results in general apathy among persons with disabilities. To prevent the occurrence of disability and for persons with disabilities to ensure appropriate and timely interventions, leading to the correct action plans and provision of suitable aids and appliances, individual assessments are taken up. The CBR conducted an assessment of 211 persons with disabilities through therapy camps and ensured that all eligible persons were systematically assessed with necessary registration and documentation. Monthly tour plans were worked out between the project staff and the therapists/specialists to visit them at the household level and to conduct necessary assessment. These assessments were carried out according to the 'needs assessment schedules' prepared in consultation with AAI/Sydney University/NIMHANS.

Persons with disabilities in the identified area are socially and economically backward. They are not aware of any corrective or supportive appliances. Moreover, they are also not in a position to afford to procure these appliances and make these available to 70 persons with disabilities at a subsidised rate. Due to social and economic backwardness, persons with disabilities are not in a position to meet the expenses on referral requirements. MORE supported 45 needy families to meet part of these expenses.

### Inclusive Education

As part of the social rehabilitation, Bahuda attempted to facilitate education for both children and adults with disabilities. For children, the CBR ensures inclusive education (IE) as far as possible. The key focus of the education programme was 'transfer of skills' to persons with disabilities, family members, community and other change agents.

The projects conducted disability-specific workshops for 153 parents and imparted to them the knowledge and skills on how to bring up their children with disabilities. Although the Government of Andhra Pradesh has adopted IE, not much effort is being made to actually include children with disabilities in regular schools. This is mainly because the teachers are not only unaware of the methods but are also unable to cope with the exorbitant pupil strengths. During 1999 the project staff worked closely with the formal schools to initiate IE.

### Family Visits

MORE developed teaching/play material pertaining to different disabilities last year. These materials are being used by the social workers during their family visits. It is found that the material used greatly facilitated the interaction between persons with disabilities and the project staff.

The project staff makes special efforts to leverage support from different sources. We have been working out partnerships with both Government agencies and non-Government agencies to leverage more benefits to persons with disabilities. Although we are yet to see any significant progress on this front, our focus has been on agencies like the District Rural Development Agency (DRDA) and Handicap Welfare Department for financial and other assistance.

# Role of CBOs in Mainstreaming Disability Issues

## Introduction

Throughout the world there has been a movement for and appreciation of the benefits of community-based rehabilitation in all areas of development. It has been realised that solutions to the problems faced by people everywhere are more sustainable and useful if they are locally tackled and governed. The needs of a community, including those of persons with disabilities, are actually addressed if they are enabled to solve their own problems.

Community-based rehabilitation (CBR) of person with disabilities must be instrumental in designing and implementing initiatives to address their specific problems. When we consider the cycles of poverty and marginalisation that prevent persons with disabilities from living a fully productive life in their community, it becomes clear that the only way to tackle their exclusion is by working together to ensure that they find their rightful place in  existing community development programmes.

In doing so, there is an opportunity to open our eyes to the barriers that persons with disabilities face in their everyday life and prompt us to try and create a more enabling environment. Working side by side in development with them should help evolve programmes that reach the most vulnerable in society. A separate development programme for them will only reinforce the feelings and reality of exclusion, which already exist.

*This article was prepared by Ms. Catherine Naughtaun and Ms. Alana Officer, Handicap International, K-3, South Extension Part-I, P.O. Box 3837, Andrews Ganj, New Delhi 110 049. The case studies placed in the boxes have been added by Ms. Geeta Sharma, UNNATI based on the HI and UNNATI collaborative initiative of 'Enhancing the Participation of the Civil Society for Mainstreaming Disability Issues'.*

Of course, there is a need for technical expertise to address many issues related to disability, and it is necessary that some specialised services are made available. But, besides these, globally the needs of all human beings are the same. Every human being, disabled or not, has the need for shelter, and the need for family, for love, for education, for the ability to support one's family. In pursuance of these goals, community-based organisations (CBOs) can include disability issues and person with disabilities in their programmes, which will maximise development resources as well as interaction and acceptance of such persons.

This article describes in simple and practical terms how community-based development work can be enhanced if persons with disabilities and disability issues are included. By 'enhanced' we mean persons with disabilities who are often systematically excluded from development programmes will have the chance to benefit from community development.

**What are the first steps to make a CBO interested in disability issues?**
These will depend on what the activities of the organisation are and the kind of resources it has. The key points the authors seek to make here is that ongoing projects implemented by development organisations have the potential for including persons with disabilities. This article is divided according to activities generally carried out by CBOs. It is not comprehensive, but is designed to generate ideas on where to start. Generally, CBOs are addressing issues related to:

- Human rights
- Employment/ Income generation
- Education/ vocational training
- Building/shelter/construction — access for persons with disabilities
- Health and prevention of disability

It is up to the CBOs to identify their focus and integrate work on disability issues appropriately.

### 1. Human Rights

All citizens in India have their basic rights enshrined in the Indian Constitution. In 1995, an Act relating to the rights for persons with disabilities was enacted, i.e. The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995. All people have a right to demand for their basic rights, and persons with disabilities are more likely to be denied their rights. If we work for human rights, we must ensure that we are aware of persons with disabilities and the extent of their vulnerability. Some of the first steps that can be easily followed are :

- Get a copy of the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 (Persons with Disability Act, 1995) from the local social defence department and circulate a copy among your staff.
- Sensitise and orient your staff to the rights of persons with disabilities as part of a regular training on rights issues, or as a separate session. You may invite a speaker from a local disabled people's organisation (DPO) or an NGO that works with persons with disabilities.
- Whenever you do a survey for a programme, it would help if you could identify persons with disabilities residing in the areas where you implement your programmes. Being conscious of their presence is the first step for any intervention that you may want to take in this direction.
- If you have staff that specialise in rights issues, they may already be familiar with the basics of the Persons with Disability Act. But are

they actively using it?

- When you run a workshop on gender issues, do you include the particular rights of women with disabilities? Make sure any work you do on human rights, women's rights or children's rights include reference to extending these basic rights to persons with disabilities who are usually left out.
- If you produce educational materials that enable people understand their human rights, you may consider printing copies in Braille, large print, placing the information on audio cassettes or CD formats, ensuring simple language versions. This will ensure that this information is accessible to people, irrespective of their abilities.
- With this groundwork done, your organisation will be in a better position to give persons with disabilities the basic information on their rights.

## 2. Employment/Income Generation

Persons with disabilities are more likely to be poor than the non-disabled. The latter may have had the advantage of some education or skill development and are less likely to become disabled or to have disabled children. If persons with disabilities have access to your organisation, this may help them break the cycles of poverty by earning a living and supporting their families, in addition to getting more involved with the social life of the community.

If persons with disabilities can earn a living, their self-respect and potential for growth, for marriage, for a full and productive life will rise, with a bearing on how others view them: they are no longer seen as dependents or a burden on the family, but as fully participating members of the community. A CBO may adopt the following to include persons with disabilities in their income generating activities:

- Think in terms of ability rather than disability, i.e. what a person can do, rather than what he or she cannot do. Also remember that, in addition to having talents and skills, persons with disabilities will have likes and dislikes. Ask them what they enjoy, what they are good at, and let that direct the course of the work you will embark on together.

Your organisation can provide ideas, build confidence, and support, where necessary. You do not need to decide what people will do for a living, but you may help them to achieve their goals.

- In some cases, you may need to link the person with the local disability rehabilitation institution to obtain aids and appliances that could help him or her to be mobile, hear better and improve her/his functional ability.
- There are all kinds of myths and beliefs about the abilities and potential of persons with disabilities. Explore what these are through informal conversations with employers in and around your area and, based on these, you could attempt to dispel the negative beliefs that are acting as barriers. One way to do it constructively would be to share positive experiences or success stories of employers who have employed persons with disabilities.
- Contact the local disability rehabilitation institutions and see the types of vocational training they provide. Are there areas of expertise that could be shared or used? The other CBO may have excellent marketing experience, or links with employment agencies/ employers, an area in which they might want to contribute.
- Your CBO may work with a disability rehabilitation institution by either offering persons with disabilities the opportunity to avail themselves of schemes they offer for loans, etc. or linking them with employment opportunities through employment-related services or a bureau that such organisations may have.
- You may link together for developing cooperatives by pooling resources that may expand your activities and improve the integration of persons with disabilities at the same time.
- In any income-generating activity (IGA) that you promote find out whether any persons with disabilities are involved. If not, find out the reason(s). Identify if any of them would be interested in participating. If they are indeed involved, it is important to ascertain the quality and level of their involvement i.e. are they consulted; do they take leadership roles, etc.?
- Are persons with disabilities in your area a part of self-help groups? If not, you would need to find out the reasons. Sensitise and encourage

the leaders of self-help groups to include them in the groups.

- Under the Persons with Disability Act, a provision has been made for 3 per cent reservation for persons with disabilities in Government establishments and mainstream poverty alleviation schemes. You could obtain the Government resolution to this effect from the social defence department and create awareness about this. There is also a National Handicapped Finance and Development Corporation (NHFDC) established by the Ministry of Social Justice and Empowerment which helps entrepreneurs with disabilities to access loans with low interest rates. You could find out about this scheme and link persons with disabilities who are involved in your IGAs. Also, if any person is denied employment because of his or her disability, you could direct him or her to the office of the Commissioner for persons with disabilities who is empowered to handle such cases. For those who are unemployed, in some States there is an unemployment allowance that is provided by the social defence department.

## 3. Education and Vocational Training

Does your organisation work in the field of education, either formal or non-formal? Are there children with disabilities in your school, or adults with disabilities in any of the educational or vocational training programmes you may be running?

If there are no adults or children with disabilities attending, do you know why this is so? Would it be easy for a person with disability to get admission to your school, vocational training facility and to access the building, including the toilet facilities? Are your training materials accessible to children who are visually or hearing impaired or have learning difficulties? Would the teachers and trainers be confident and happy to have a child or an adult with disability studying in your school or organisation? Are you aware of the vast advantages of this, socially and developmentally, for the individual?

### Education:

In Gujarat, for every 10 children with disability at a mainstream school, the Government provides for one special educator who can assist the teacher to fully integrate them. These special educators are trained to make learning more interesting for all the children. Through access to education, children with disabilities not only get a chance to learn to read and write, but most crucially, they have the chance to make friends, learn about the world around them and enjoy playing and learning with their age group. This access to education is an essential start to a life fully engaged with the social and economic life of the community.

Simple steps can be taken to include children with disabilities in the on-going educational activities:

- Find out if there are any children with disabilities in your schools/ educational programmes. If there are, observe how well these children are integrated. If the situation is working well, you can use this positive example when you are trying to facilitate other children with disabilities coming to school.
- If there are no children with disabilities in your schools/educational programmes, find out if they are locally going to school. Often the other school children will know. Try to meet children with disabilities not attending school, and know their families. Explore why they are not attending school. The family may not believe it is important, or parents may have had trouble bringing them to school. See if the problems can be overcome through discussions with the teachers and disability rehabilitation institutes or other local organisations. Try to emphasise the manifold benefits for the children in going to school. If the parents are willing, it is far more likely to happen.
- Run a sensitisation programme for all the school children and parents about disability so that they can better understand that children with disabilities are children first and foremost with the same aspirations and rights as other children. This will help ensure children find their place in school faster.
- If your organisation runs the school then make sure the teachers are trained and supported to include children with disabilities in their classrooms.
- Progressively start to increase the level of physical accessibility of

## Sakhi Mahila Mandal

Anita, nineteen years old, lives in Valmiki Nagar in Ahmedabad. She attended school up to the seventh grade, as is common for girls in her community. Since then she has been at home, struggling to counter the perceptions of her family and community of what a young girl with polio should or should not do.

However, today, Anita's renewed zest for life is evident when she shares, "I am going to buy a computer. I can do some typesetting work and rent it out to others for their use too." This new-found energy and enthusiasm has a lot to do with the assistance and guidance provided to her by Kiranben who works for the Sakhi Mahila Mandal, a CBO promoted by an NGO, *Saath*, based in Ahmedabad, Gujarat.

Kiranben works with women in Valmiki Nagar, helping them supplement their incomes through small business initiatives. It was only recently – after she received training on the special needs and rights of persons with disabilities – that she began to make special efforts to include people such as Anita in her activities

"Anita has needed no special mentoring since I first began to visit her," says Kiranben, now on the look-out for ways to get Anita more involved in community life. "She came out of her shell as soon as I understood that she, like any of the other women I work with, wants to feel a part of society, to experience the joy of earning some money and contributing to society."

"I want to live a whole life," says Anita, nodding in agreement. "People like Anita were invisible to us before we were sensitised to their needs and rights," says Mansinghbhai, another functionary at *Saath.* Now, he is keen to find out exactly how many of the 2,100 families he visits regularly live with disability.

He estimates that there may be over a hundred, but he is not keen on starting a special programme for them. "It is a better idea to make sure that persons with disabilities can access the facilities and benefits that are meant for all," he insists. "The rights to health, wealth, love and laughter belong to everyone."

your buildings. It will benefit all students/ teachers and not only those with disabilities. If you have boarding facilities for students, you will also need to consider how these can be made accessible. Ask a local rehabilitation institution if they can carry out an access audit to help you identify the priority areas (See notes on building construction - section 4 of this article). If you can not make the accommodation facilities accessible immediately, ask other NGOs if they have safe convenient and accessible facilities.

- Try to include children with disabilities in any social/ musical/ sporting activities that you organise. If there is a local school for children with disabilities, run joint cultural events. This will encourage them to know

**The Vikas Jyot Trust**, an NGO working in Vadodara district in Gujarat, was sensitised to the need for integrating disability issues in all its work. One of its interventions was through educational programmes for street and working children. It had also previously worked with municipal corporation schools. Realising that many children with disabilities were left out of the educational programmes, it decided to enhance the sensitivity of teachers, schools, parents and children to the need and rights of children with disabilities.

Using films, games, experience sharing and informal discussions, the Vikas Jyot Trust facilitated interactions between children with disabilities and non-disabled children; teachers from mainstream schools that had admitted children with disabilities and those that had not done so; and parents of children with disabilities and parents of non-disabled children. These one-day interactions helped both the groups in each case to share their experiences and feelings, their desires and hopes, barriers that they were facing and what they would like to do and could do. It helped in highlighting the need for the inclusion of children with disabilities, the support available from the Government or otherwise for children with special needs, and the positive experiences as well as challenges of those who had attempted to be inclusive.

each other and play together.

- Some children may benefit more from special schools. For this, contact the local disability rehabilitation institution. Identify the support and services available and provide necessary linkages. Or obtain a list of special schools or schools promoting integration from the social defence department and refer the children to these institutions.
- A positive way to promote inclusion of children with disabilities would be to facilitate informal but structured interactions between children with disabilities and children without disabilities; between parents of both the groups and teachers from mainstream schools and special schools.
- Sensitise teachers, principals, village education committees, etc. to the need for the inclusion of children with disabilities. Invite a resource person from a rehabilitation institution (whether specialised or not in children's issues).

### 4. Building/ Shelter/ Construction – Access for Persons with Disabilities

For many people who have difficulties in walking, or managing steps such as elderly people or persons with disabilities, most public buildings are very difficult to use. Someone who needs a wheelchair to go around can have problems even visiting the local shops, temple, or health care centre, with no possibility of using public transport. For persons who are visually impaired (and others), roads and pathways that are cluttered or uneven surfaces make walking difficult.

When we build a place which is supposed to be welcoming to vulnerable people, we should bear this in mind. If you look at step one in this article and read the Persons with Disability Act, 1995 you will see that there is a commitment that all public buildings should be made accessible to vulnerable groups. As an organisation that is promoting an equal society, we should make concrete statements about this equality by not creating or fostering barriers which already exist and exclude persons with disabilities. These barriers are both physical in the sense of a building space to which persons with disabilities have to struggle to enter; and mental in the sense of our attitudes, beliefs and behaviour towards them. We need to remember that unless accessibility is created, reservation in education and employment and creation of equal opportunities cannot be realised. Building a physically accessible environment is one step in breaking down the barriers that exclude persons with disabilities in our societies.

Simple steps that can be easily followed:

**PARAKH**, a community-based organisation in Himmatnagar, Sabarkantha district, Gujarat, conducted a survey of all the persons with disabilities in their area. Another survey done by it in the same region revealed that majority of the public buildings and offices were inaccessible for persons with disabilities. Informal interviews with architects, builders, etc. indicated that there was very little awareness about this issue that in principle there was no resistance to the need and importance of a barrier-free environment. To inform the people, especially those who could make a difference, PARAKH, with the help of other organisations, organised a public awareness event at a public park that was partly accessible. The event attended by people from different walks of life, including persons with disabilities, helped to highlight the needs for and the rights of persons with disabilities to barrier-free environment, the existing barriers, Government rules and provisions under the Act, what different people can do to help create accessibility and the benefits of accessibility for everyone in society. Representatives of the Government, NGOs, architects and persons with disabilities shared the viewpoints. Media representatives helped to highlight the issues and disseminate them.

Such an event can help bring the issues into the limelight. The CBO can link up with disability organisations and other institutions concerned and provide necessary linkages among them and those who can help create accessibility.

- If you are building or looking for a new office, think of the following aspects – is the door wide enough for a wheelchair? Are there steep steps that somebody might find hard to climb? Are there protruding objects above the ground or at head level such as air-conditioners, windows which do not open out flat against the wall, and low tree branches that could pose a danger to somebody who is visually impaired? Are there tactile paths/maps/signs and audio signals in the building that can guide persons with visual impairment to find their way unaided? Are there enough signage in contrasting colours to guide persons with hearing impairment, low vision and for all visitors to move around with independence and dignity?
- If your organisation is involved in participatory town planning, make sure that persons with disabilities in the area attend all the relevant planning meetings. You may need to facilitate this yourself. If someone is not used to being invited to participate, he or she may not have the confidence to attend. When arranging the meeting, make sure persons with disabilities will be able to get into the building and move around freely.
- If construction is one of your major activities, make sure your engineers or architects are aware of the standard guidelines issued by the Central Public Works Department (CPWD), Ministry of Urban Affairs and Employment, in which the Government details its recommendations for a barrier-free environment.

## 5. Health and Prevention of Disability

Health is a specialised area of work. But where ill health exists, it is impossible to ignore it. The authors do not recommend that all organisations should take the responsibility for health care, if it is not in their mandate. However, if we are working in the community, we should be aware of the available health services.

The causes of disability include a variety of factors that are largely preventable with public awareness and basic health care. If your organisation is working directly in the community, even if you are not active in the area of health care, you can act as a useful link between the community and the available health services or schemes, once you are aware of the available services. Providing information to people on where services are, how to access them, what costs they might incur will all serve to improve access to these services.

Here are some ideas to help your organisation provide the community with useful advice on health services:

- Do you know where the local hospitals are? Make a list of local health facilities/health care workers so you can refer such persons to them or give information when needed.
- Do you know which organisations are interested in providing services to persons with disabilities? Contact them and find out what they can offer. As a first step, get a list of such organisations from the social defence department.
- Does the local Lions Club or Rotary Club offer any facilities? Let these organisations know about your activities and ask them to inform you when they are running health camps, etc.
- If your organisation is working with people who are not in direct contact with health care systems and do not routinely vaccinate the children, you can still do something about this using a development approach. Find out if the children are being vaccinated. Speak to the nearest health centre or *anganwadi* staff to work with the community by organising a meeting so that the people can meet the health care staff and talk about their concerns.
- The same can be done for malnutrition in women and children, which is another cause of disability. So as a concerned local organisation, your responsibilities are to ensure that the people you are working with have access to the services available.

A summary of key starting points and general ideas your organisation can follow to work with persons with disabilities is enumerated:

- Contact neighbouring NGOs working with persons with disabilities and see what they are doing. Maybe, there are ways in which you can collaborate with them through your programmes.
- Try to recruit persons with disabilities as staff or as volunteers.

- Influence SHGs or women's groups to try to include persons with disabilities. They can ask among the communities in which they are working about women with disabilities in the area and meet them to see what their needs are. There may be some aspects where you cannot help such as providing equipment or health care, but you can act as their link with the available services. The main thing to do is, wherever possible, encourage persons with disabilities to come along, to join in, to make friends and to be fully part of what is going on in the community.
- Be aware of all the local services for health care and disability.
- If you are looking for new premises, consider how easy it would be for persons with disabilities to use it.
- If you provide advice on legal issues, make sure the staff is familiar with the Persons with Disability Act, 1995 and the services such as loan schemes, Government resolutions passed for promoting the rights of persons with disabilities.
- Raise awareness on their issues through linking with groups who are well versed with them. It would be especially worthwhile to create awareness about the Persons with Disability Act and the schemes being implemented by the Government among persons with disabilities and their families.

## In Conclusion

NGOs and CBOs in general are overworked. We are unable to respond to the needs that we are aware of and can hardly look for more work to do. The purpose of this article is not to try to convince organisations to take up more work, but to provide ideas on how you can open up your programmes to include persons with disabilities without the need to have experts on disability issues. Knowing where to locate the expertise is useful, and information is one of the most valuable things we can give to people. If we all act together to include persons with disabilities in our work, we will come closer to our goal of sharing the world's resources in a more equitable way.

# Barrier-Free Environment : A Critical Step for Inclusion

"Disability is not something you have, it is something that happens when one group of people create barriers by designing the world only for their style of living". There is a growing recognition today that barriers exist in our physical design and also because of the way we design our technology and information systems. The present paper dwells on the physical barriers and creation of accessible environment for improved, unhindered and safe mobility.

Contrary to popular perception, a barrier-free environment benefits many other people in society in addition to people with disabilities; among them are those who either temporarily or permanently require some kind of support – the elderly, children, pregnant women and people with temporary impairments. Of all these groups, people with disabilities are probably the worst affected as 'designers' have limited opportunities to get to know and understand their needs and requirements for a barrier-free environment. For people with disabilities, physical barriers have been one of the several but critical factors leading to their exclusion and segregation from society. Lack of interaction between them and society has resulted in non-recognition of their potential, of their needs and aspirations and consequently a low degree of sensitivity to their right to 'inclusion'.

In India, as in many other parts of the world, the slow but gradual movement from the 'medical' and 'welfare' models of rehabilitation of persons with disability to the 'social' model has led to a shift from the

*Handicap International (HI) and UNNATI Organisation for Development Education had worked in collaboration with several partners in Gujarat, India, on an initiative to enhance civil society participation for inclusion of persons with disabilities. This paper attempts to recount our experience over the past five years and share our learning. It has been documented by Ms. Geeta Sharma and Mr. Arindam Mitra from UNNATI and Ms. Archana Shrivastava from HI.*

‘need’ for inclusion to ‘inclusion’ as a human right. For inclusion, providing equal opportunities and opportunities for full participation are imperative and these cannot be realised through measures of positive discrimination unless the environment is barrier-free and accessible.

Let us first review the steps taken for inclusion through accessibility in India. Some initiatives that have been taken on the legal and implementation front are as follows:

a. The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act passed by the Government of India in 1995, with ‘integration and inclusion of persons with disabilities’ as two of the key goals, makes specific reference to the importance, need and measures for creating accessible environments. While making provisions for reservations in education and employment for people with disabilities, it also urges the State governments to make appropriate provisions to ensure that people with disabilities have access to physical spaces and buildings. Sections 44-46 in Chapter VIII of the Act emphasise positive measures to prevent discrimination against persons with disabilities in various transport facilities, on the roads and pavement and in the built environment.
b. Being a signatory to the Declaration of 1993-2002 as the Decade for the Disabled by **Economic, Social and Cultural** ESCAP for the Asia-Pacific Region has helped to strengthen the commitment and provide impetus to the process *of* creating barrier-free environments.
c. At the Central level and in a few States, selective projects and initiatives have helped demonstrate the benefits of such environments.
d. Guidelines have been prepared by the Central Public Works Department incorporating features and specifications that can make built environments barrier-free. The National Building Code is another supportive document.
e. Some States have incorporated in their building by-laws (applicable in various urban local bodies) model by-laws prepared by the Ministry of Urban Development to provide facilities for physically handicapped persons. However, enforcement remains a matter of concern.

It is heartening to note that at least ‘accessibility’ has been recognised and acknowledged as a need and is beginning to be viewed as a human rights issue. There is information on what needs to be done and how it can be done. There is also some experience that has helped dispel myths related to factors like cost, special designs benefiting only persons with disabilities and many others. Based on localised experience and that of

designers all over, some of the major learnings that seem to emerge are:

a. A built space must be designed both for the people with disabilities and the non-disabled. It should not remain exclusive for either of them – a universal design for all.
b. An 'inclusive' architecture or design integrates rather than segregates – comfort, safety and affordability are key parameters.
c. An accessible environment allows all persons to live and function independently with dignity, respect and pleasure and can help remove the artificial distinction of 'ability' and 'disability' that a barrier-ridden environment creates.
d. Most special details required in an environment for the persons with disabilities are just different and sensitive variants that do not necessarily cost more to build, especially if incorporated at the planning stage.

Despite the fact that most of us have at some time or the other experienced the crunch of 'inaccessibility' in our lives either personally or through a close relative or friend, the irony is that 'accessibility' is still not an important enough priority for designers, architects, planners, policy makers, academics or researchers. Nor have all the persons affected by barriers, temporarily or permanently, voiced their problems sufficiently enough to accord it a priority.

Considering that until now most designs are 'exclusive' in approach and have tended to disregard the access needs of people with disabilities, the task ahead is enormous and challenging.

In the above context, an initiative in Gujarat (India) seeks to use a multi-pronged strategy for creating awareness at various levels and collective action for creating 'barrier-free environments through:

### A. Awareness Building

**Public event:** A public meeting was held at Law Garden, Ahmedabad (a visible, frequently visited, reasonably accessible public park) on March 20, 2003. This was a collaborative venture of rehabilitation institutions, development organisations, government bodies, professionals and concerned citizens aimed at creating awareness about the need for barrier-free accessible spaces and environment. Approximately 250 people participated in the event and through mainstream and the local print as well as electronic media, the message reached over a lakh population. Such public events have also been organised in other districts of Gujarat by local NGOs who are a part of this initiative.

16

Propagating a barrier free environment

Need stressed for barrier-free public places

'THE ASIAN AGE' Daily Ahmedabad 30.12.2004

NGOs push for barrier-free access

**Media Sensitisation:**

In collaboration with a Development Media Network, media representatives (print and electronic) from different districts were sensitised on disability and development and accessibility issues from a rights and inclusion perspective. As a result of this, a series of articles were being featured on disability as a development issue, positive image building and field-level interventions in this area.

## B. Partnership Building

In the process of awareness building, a need was felt to broadbase the stakeholder group as well as to create opportunities for various groups to reflect, realise and 'strategise' their role towards creating barrier-free environments.

In collaboration with a Resource Group on Accessibility, a series of small workshops were organised in July 2003 with the service industry, academic institutes, NGOs, media, architects/planners and designers. About 400

**Who all can make a difference and how?**

- **The government** - by making policies, bylaws and specifications and ensuring their implementation.
- **Town planners, architects, builders, designers, etc** - by incorporating the necessary features in their designs, buildings, roads and spaces, transport, products, etc.
- **Service Industry** – by creating appropriate infrastructure and offering need-based services.
- **The media** - by creating awareness on this, raising the issue and advocating the change.
- **The consumer** - by highlighting the needs, ensuring correct information and feedback, by demanding their rights.
- **Society at large** - by changing mindsets, creating the necessary awareness and being the prime movers to bring about the change.

individuals and groups participated, shared, deliberated and articulated the need and possible future strategies and expressed their commitment. The media gave a wide coverage in that week, reaching out to at least 2 lakh population. Since then, through researched and investigative coverage, they have demonstrated their proactive stance on the issue.

Subsequently the architects, who were a part of the sensitisation workshops, have assumed the responsibility of reaching out to builders' groups and associations of architects and civil engineers. They have also been making presentations and providing linkages to interested groups such as Airports Authority of India, Government institutes etc.

### C. Collating, Developing and Disseminating Material

The process of awareness building and sensitisation highlighted the need for collation, development and dissemination of material. Collation of materials created opportunities for reaching out to various groups and individuals, enhancing team awareness on availability and limitations of accessibility features and material, information on initiatives and strategies, identifying interested individuals and groups, forming relationships and developing solidarity towards a common goal.

Collection of guidelines and building by-laws, A-V aids, articles and reading materials was an output of this process.

Development of materials helped broaden perspective, enhanced consciousness and sensitivity not only of the involved team but also of many others. The output is a photo exhibition, awareness brochure, Multi-Media Presentation, 'Freedom of being' – A film on universal design for all, Design Manual for a Barrier Free Built Environment – a guideline for professionals on the what and how of accessibility. This manual has also been prepared in an interactive CD format. Material collated and developed has become a rich resource and is being used as a tangible tool for dissemination and reaching out to newer constituencies. Significantly, a lot of this material has been developed with inputs from people with disabilities and is based on the needs and learnings shared by them.

### D. Networking, Linkages and Creation of Resource Pool

Information sharing and strategic thinking for achieving the goal are the core pre-requisites for networking and linkage building between individuals and organisations. Various stakeholders from different professions have come together to form a resource pool towards creating accessibility at the city and district level. The varied group composition has resulted from deliberations and exchanges that highlighted the need for architect and designer groups to collaborate with NGOs and persons with disabilities for receiving constant inputs from a user perspective and the support to create parallel awareness in society.

The resource pool has a mandate of 'strategising', collating and developing need-based materials, capacity building through technical training, initiating an information bank and helpline and advocacy for policy change.

The evolving and dynamic group meets frequently, defines roles of various stakeholders, does strategic planning, divides responsibilities and follows up on the action points. The group has been receiving requests for conducting access audits and guiding the process of modifications in existing buildings. In the two and a half years of its existence, the group has conducted 9 audits in Ahmedabad, 7 in Vadodara and 4 in Kutchch. These include Government offices (Office of the Commissioner for persons with disabilities, Government of Gujarat, Sardar Patel Institute of Public Administration, Department of Social Defence etc.), service providers (Planet Health, ICICI bank, Eklavya Education Foundation) public spaces (Law Garden, Kamati Baug etc.)

## E. Advocacy

Advocacy for the issue is an on-going process in which multiple strategies are being used:

i. Media advocacy: through different programmes and events is helping to reach the masses and in keeping the issue alive.

ii. Access audits: Conducting access audits, preparing reports and demonstration have led to many positive outcomes during the last quarter. Demonstrating 'access' through minor modifications in offices, other existing buildings and spaces and suggesting accessibility features in new plans and buildings and spaces are some of the strategies for demonstration and model creation. The same reports have also proved useful as a tool for advocacy with concerned

Government authorities and civil society at large. A strategy for the future proposes to select a visible and highly used area in a city within a 2 km. radius and conduct audits and demonstrate modifications to the user and designer group.

iii. Building by-laws, technical material and the PWD Act, 1995 are being utilised as strategic tools for lobbying and effecting change in policy for mandatory implementation.

iv. Need-based presentations for different groups to provide them with information on specific steps they can follow to make their spaces barrier-free.

## The Way Ahead

The steps in the entire process are definite, firm, full of excitement and joy. The response from different quarters has been encouraging, enthusiastic, and has served as a guide for what needs to be done. The message by itself has not been difficult to propagate – it was important who propagated it and how.

While there has been enough stimulation for positive thinking and action, the group has also tried to be aware of and recognise the need to address concerns linked to the future. Some of these are related to the sustainability of this varied interest group, maintaining its cohesiveness, maintaining the respect, credibility and role of the involved professionals and generating adequate finances.

Strengthening and consolidating the initiatives in the foregoing areas would be a major thrust in the days ahead.

*The vision is an environment that provides equal opportunities, equal participation and basic rights to all to live a life with dignity.*

## Partners to the Initiative

Ahmedabad, Kutchch & Vadodara (In alphabetical order)

Abhikram/ Panika, Ahmedabad Municipal Corporation, Ahmedabad Study

Action Group (ASAG), Asher Developers, Blind Peoples Association, Builders Association of Vadodara, Centre for Environmental Planning and Technology (CEPT), Charkha, Commissioner of Disabilities, Gujarat, Department of Architecture - M.S. University, Vadodara, DISHA, Eklavya Education Foundation, Environmental Planning Collaborative, Faculty of Social Work - M.S. University, Vadodara, Handicap International, HCP Design and Project Management Pvt. Ltd, Kamal Mangaldas Architects, Karan Grover Associates, Members of the Media, Minds Eye Design, Mitul Shukla Architects, National Institute of Design, Parakh, Planet Health, Sardar Patel Institute of Public Administration, Shri Navchetan Blind Men's Association, Shri Yuva Viklang Mandal, United Way of Baroda, UNNATI – Organisation for Development Education, Vastu Shilpa Foundation .

# Why I Can't Be Michael Rivers

Michael Rivers* is a Management Consultant in the US. A serious spinal injury left him paralysed and a quadriplegic. But Michael is able to live a full life like anybody else. Whenever he wants to, off he goes on his motorised wheelchair to work in his office, to the supermarket and the library. Weekends are full of meeting friends, going to the cinema and having a good time. A full life like anybody else.

I, too, am a spinal injury quadriplegic but why can't I be Michael Rivers? I too have a wheelchair, then why am I not able to go out and around for work, chores or socialising? Why am I stuck at home and have to work from home?

Because, very simply, while Michael's entire movement route is made accessible with ramps, pavement ramps, wide doorways, reachable worktops, switches, counters and shelves, etc, I and millions of others like me face an insurmountable obstacle course every day.

Starting from the absence of ramps (with proper gradient) and railings where there are stairs or level changes, narrow doorways and passages, uneven floor surfaces to unreachable controls, counters, shelves and switches, and inaccessible toilets, the built environment for me is not conducive to allow free and safe movement and participation. My friends with visual impairment face the hazard of protruding objects, sudden level or direction changes without proper warning or information and the

** Name changed*

*This article has been prepared by Mr. Arindam Mitra, UNNATI. He has a background of chemical engineering, project & marketing management and comes from the corporate world. He was the victim of a hit-and-run accident a few years ago that caused a spinal injury and resultant quadriplegia. He stays in Ahmedabad and works from home.*

Most people feel that a ramp and an elevator/lift is all that is needed to make a built space barrier-free. It must be clearly understood that barrier –free goes far beyond just a ramp and has many necessary aspects. These range from door and passage widths to flooring surfaces, from counter heights to door handles and railings, from signage to auditory signals. And, very importantly toilets also need to be accessible–an aspect often overlooked.

absence of contrast colour markings and tactile signage. Those with hearing impairments can find it to be very tough if proper signages are not visually displayed. And, it is not just the buildings that are the problem. Our roads, railway stations and bus stops are far from being accessible and trains and buses are completely out of question.

I belong to Kolkata and I have not been able to go home for the last 8 years simply because trains are not accessible. Just think, even if I manage to get people to put me in the coach, how do I move around inside and how do I manage the 40 hours' journey without visiting the toilets as today they are totally inaccessible? Even if I can afford to fly, the airlines here in Ahmedabad have mentioned that I will have to be bodily lifted from the ground by four people into the aircraft. A highly dangerous proposition and one, of course, that does wonders for one's dignity. I refuse to go because I refuse to be treated like a sack of potatoes!

So, though I am able and willing, I have to perforce remain confined to my home and a few other places to continue my work and life as best as I can.

Unfortunately, at the moment, for me or for many others like me, living like Michael Rivers is a distant dream. Persons with disabilities – whether they be mobility challenged, visually or hearing impaired or with other difficulties – face a plethora of barriers, effectively ruling out their participation in social or economic life. And, these barriers affect many other sections of people such as the elderly, the temporarily infirm, children and pregnant women.

In many countries the entire surroundings are automatically designed to be inclusive. As opposed to this, in our country, we are decades behind and the environment around us is not barrier free. These barriers result in denying many their rights and opportunity to full participation and eventually culminate in their exclusion from society.

## A Closed Door And A Full Stop?

Hopefully not. Things have started moving in India and a faint light at the end of the tunnel seems to be visible.

In India, various estimates put the number of persons with disabilities at more than 6 crores.

However, in connection with physical accessibility, people affected include the elderly, children, pregnant women and people with temporary difficulties – more than 20% of the population – more than 20 crores

In the past few years, there have been many individuals and organisations that have actively advocated the concept of barrier-free environment. These include many committed individuals, rehabilitation institutions and associations, NGOs, INGOs, and many architects, planners and designers.

Some heartening examples are like the Metro rail system, Dilli Haat and the Garden of Five Senses in Delhi that are totally accessible and have been made so with inputs from Samarthya, a Delhi-based organisation advocating accessibility. The National Centre for Promotion of Employment of Disabled Persons (NCPEDP) and Mobility India are some other organisations fighting for the rights of people with disabilities and promoting accessibility.

While working on issues of disability during the past five years, it was realised that, besides social and attitudinal barriers, physical obstacles in the environment pose a major hurdle in inclusion and together, these barriers result in non-participation and exclusion.

Through the collaborative effort of HI and UNNATI a unique committed group, informally called the ‘Access Resource Group’, which consists of members and advisers from various stakeholder groups such as architects and town planners, designers, NGOs, special institutions, disability associations, etc., has come together to actively promote accessibility in Gujarat; a group of people that rarely get together on one platform.

This group is actively advocating and implementing accessibility. Not only this, but many architects, builders and designers have taken a conscious decision to ensure barrier-free features in their buildings and spaces. To name a few, senior architects like Shri Kamal Mangaldas, Shri Hasmukh Patel and his organisation, HCP, Shri B V Doshi and his organisation, Vastu Shilpa Foundation, builders of M Cube Shopping Mall in Vadodara and many others.

**Accessibility is not costly**

The cost of incorporating features for access are a minute fraction of the total cost of any building or space – especially if done at the planning stage itself

This Access Group has also compiled and published a design manual for barrier-free spaces – a detailed guideline to aid designers and architects in corporate accessibility. The group has also made multimedia presentations and video films for advocacy and creating awareness.

The work of this group has shown results with many buildings, gardens and other spaces being in the process of becoming barrier free.

The recently renovated Jehan Numa Palace Hotel in Bhopal is perhaps one of the latest examples of barrier-free spaces. The hotel, renovated with guidance from a local NGO, Arushi, has features that make it accessible to all, including persons with visual or hearing impairment, wheelchair and crutch users and others.

The news that Indian Railways has started to have at least one accessible coach with accessible seats as well as toilets in some trains has come as a breath of fresh air.

I have not been to a cinema or restaurant for years – this just illustrates that the service sector like banks, entertainment, hospitality and tourism are losing a very sizable chunk of clientele by not being barrier-free.

**Thumb rule tips for building access**

- Ramps / slopes, with proper gradient, wherever there are level changes on a movement route. In case of floor changes, lifts if ramps not possible.
- Railings ( in two levels) alongside all ramps and stairs and wherever there are level changes and grab rails in lifts.
- Make doorways and corridors wide enough for easy passage.
- Use textured non-slippery flooring materials.
- Avoiding all protruding or obstructive objects on movement routes.
- Contrast colouring to ensure differentiation of objects and levels.
- Use contrast colour markings on floors at places where direction and surface level change, to aid people with low vision.
- Use lever-type handles instead of smooth and round knobs for doors, taps, etc.
- Make counters, work tops and switches/taps at reachable heights.
- Ensure accessible toilets with wide doorways, grab bars and all fixtures at recommended heights.
- For lifts, ensure wide doorways and safe door open timing. Have a mirror on the wall opposite the lift door to enable people on wheelchairs to view the floor numbers. For visually impaired, use auditory signals
- Have proper signage to aid the hearing impaired. Braille and tactile maps and signs for the visually impaired.
- Use auditory signals at traffic crossroads to enable persons with visual impairment and the elderly to cross safely.

## The PWD Act and Other Statutory Regulations – Laws Or Pieces of Paper?

A major step has been the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995, or the PWD Act 1995, that specifies the law and the role of the State in creating access. Besides, the National Building Code, CPWD guidelines as well as the bylaws of various urban development bodies have shown the direction towards building a barrier-free environment.

However, the lack of implementation of clauses in the PWD Act and the fact that most building by-laws for accessibility are not mandatory stand in the way of moving ahead and seriously question the government's commitment to the issue.

## The Way Ahead

It is heartening to note that the changes are occurring and barrier-free spaces are already a reality in many places – not just in the developed and the affluent countries, but in our country itself. There are many examples, especially in cities like Bangalore, Delhi, Kolkata and some even in Ahmedabad. These serve not only as models but also as a source of encouragement.

A lot of efforts have gone into this. But much, much more needs to be done. The first and foremost need is perhaps a change of mindset and to acknowledge the need to remove barriers. Also, to understand that creating accessibility is neither difficult nor costly - just requires the willingness.

There is also a need to acknowledge and respect not only the rights of others but also their potentials to contribute to society.

The road ahead would require a concerted strategy involving multiple stakeholders and the needs of the hour, as mentioned below, will require to be addressed :

- Civil society understands and accepts the need for accessibility.
- Stakeholders like architects, designers, planners and builders

consciously ensure that their designs and buildings are barrier-free.

- Government and urban authorities make bylaws mandatory and ensure compliance with these bylaws as well as legal instruments such as the PWD Act.
- The subject of universal design and barrier-free environment needs to be included in the curriculum of all design and engineering schools as a mandatory course.

The world and India is moving ahead and it is time we moved in step with them. And today, it is also time for all responsible citizens to get together and reflect on how we can take those steps and move ahead.

# Working Towards Inclusion: Experiences with PRA on Disability

## Introduction

In India, persons with disabilities, especially the poor, suffer from profound social exclusion. This limits their participation in all spheres of life – social, cultural and political - resulting in denial of their rights. Women with disabilities suffer double discrimination on account of both disability and gender. Yet, data provides a limited picture of the extent of exclusion that persons with disabilities experience. They rarely get opportunities to share their perspective with the community as they remain hidden and excluded from mainstream activities of society. Also, there is very little understanding of their abilities, skills and potential. This, in turn, contributes to society's ignorance of and apathy towards including them.

This paper is based on the experience of UNNATI Organisation for Development Education and Handicap International (HI) in, 'Enhancing the Participation of the Civil Society for Mainstreaming Disability issues' during April 2002 - December 2004. It aims to describe the processes, the outcome and the learnings derived from the implementation of the initiative to develop awareness. A collective understanding was generated of the needs, potential, rights and aspirations of persons with disabilities as well as the prevailing attitudes, beliefs and behaviour of the community towards them, including persons with disabilities by

*This paper has been written by Ms. Alice Morris, Ms. Geeta Sharma and Ms.Deepa Sonpal, UNNATI. This would not have been possible without the support of the other team members viz. Ms. Shankharupa A. Damle, Ms. Archana Shrivastava (HI), Mr. Arindam Mitra, Ms. Swati Sinha and Mr. Hitendra Chauhan who were involved either in facilitating the PRA and/or in providing inputs and suggestions for the paper. We would also like to thank the 13 grass-root NGOs who were our partners in the programme and the members of the community at the village level, without whose involvement and co-operation this initiative would not have generated the present learning and outcome.*

listening to their views and perspective.
For this, a collaborative participatory action research (PAR) was facilitated by UNNATI and HI, in partnership with 13 grass-root organisations. Using Participatory Rural Appraisal (PRA) techniques, the study represents the voices of 1,154 people with disabilities in 55 villages and 8 urban slums across four districts in Gujarat – Ahmedabad, Sabarkantha, Patan and Vadodara. The study complements an overall effort to promote civil society participation in mainstreaming persons with disabilities.

## Methodology

Using some selected PRA tools and techniques, a pilot study was conducted in a few villages of Dholka *taluka*. This provided the group of facilitators with an opportunity to arrive at a common understanding on how to use the PRA tools for addressing disability issues. The tools included Transect walk, Social mapping, Mobility mapping, Venn diagram, Stakeholders' meet and Focus group discussion. This was followed by the PRA in collaboration with the 13 grass-root organisations. Interactions between persons with disabilities and the community in an enabling environment helped explore many interpersonal perceptions on the issues, which were rooted in ignorance about one another and lack of interaction based on the principles of equality and respect.

Additionally, a questionnaire-based survey and detailed interviews of persons with disabilities were conducted. A format was also developed to record information at the village and family level generated during these interactions. After the completion of the PRAs, a two-day workshop was organised in which all the partner organisations shared their observations.

## Summary of Findings

**Profound exclusion:** Overall, the study revealed that for lack of access, stigma and poverty, persons with disabilities were forced to spend their lives in seclusion and isolation. Their needs, aspirations and potential were hidden because they lacked the opportunity to interact with the larger community, who in turn expressed their lack of information on how to relate/interact with people with disabilities.

**Mobility, access and social participation:** Mobility was restricted for all people with disabilities due to barriers in the physical environment and dependence on friends and relatives, who were not always around to assist them. They also experience 'social restrictions' on their mobility. For example, persons with disabilities were barred from attending social functions such as marriages, but they were not stopped from attending religious functions. Women with disabilities (and their families) reported feeling highly insecure about moving outside on their own, which doubly restricted their mobility.

**Family life:** More men with disabilities were married and a large section of them could find non-disabled partners. Women with disabilities, on the other hand, were more often single or married to another person with disability.

**Rehabilitation needs and services:**
The study reveals that the general needs of persons with disabilities are similar to those of non-disabled persons. For example, their experience of poverty is the same as that of non-disabled persons and they seek to reduce their poverty in a similar manner. In addition, however, they have special rehabilitation needs such as aids and appliances to overcome the limiting effects of their impairment. This places a double burden on them.

**Public health services:** Inadequate primary health care services increase health risks for persons with disabilities. The study reveals that 27 per cent of disabilities were caused due to poor medical services provided, especially at the village level. Medical professionals were perceived as being inadequately trained in early identification and treatment of disabilities, especially mental illness and mental retardation. Besides access to health services, access to other basic services like transport, proper roads, telephone booths were limited, making it almost impossible to reach the nearest town to seek medical help.

**Access to rights:** Overall, awareness of rights was fairly low among people with disabilities in the areas surveyed. About 30 per cent of the people did not even own a disability certificate, the precondition for obtaining benefits and services from the State. They reported physical barriers and cumbersome procedures as obstacles for accessing these services.

**Livelihoods:** The study reveals that in the peak earning age group between 18 and 45 years, 93 per cent of the people with disabilities have not received any income generation or vocational training. Even if they did have stereotyped skills of basket making, weaving, embroidery, they could not meet their financial needs. More women with disabilities (84 per cent) were found to be engaged in household chores as well as in agriculture or tailoring as opposed to men with disabilities.

**Education:** Communities reported a high drop-out rate of children with disabilities from schools. Girls with disabilities dropped out more frequently than boys due to several reasons, including vulnerability to abuse and exploitation, lack of proper accessible toilets and the prevailing social belief that it is not worth investing in education for girls.

**Mainstreaming persons with disabilities:** The study found that the attitudes and behaviour of others – family, friends, and society – can become a barrier to the participation of people with disabilities in society. Equally important is the way that persons with disabilities perceive themselves. A positive attitude on both sides can inculcate a sense of confidence and generate the support provided/received, improving the quality of life of society as a whole.

The study clearly revealed that non-disabled people were not insensitive to the issues faced by people with disabilities, but largely ignorant about them. This in turn affected their ability to respond appropriately. With greater awareness about these issues came a greater willingness to encourage their participation in society. Building trust and positive attitudes is therefore the key starting point for any mainstreaming initiative.

## Methodological Issues - Some Learnings

### 1. Communicating the objective of the exercise clearly to the community

The teams would go in the evening on the day before the PRA to the village with the purpose of building a rapport with various stakeholders and create an enabling environment in the village for the PRA. In Sangma village of Vadodara district, this did not have the intended impact and on the following day, a large group of disabled people gathered in anticipation that a team of doctors would visit and provide them with medical advice and aids. It took almost 2 hours to communicate the actual purpose of the PRA and ensure that other members of the community participate. Initially, they were very reluctant to even talk. At first, time was spent to listen to their problems and then the purpose of the exercise was clearly explained.

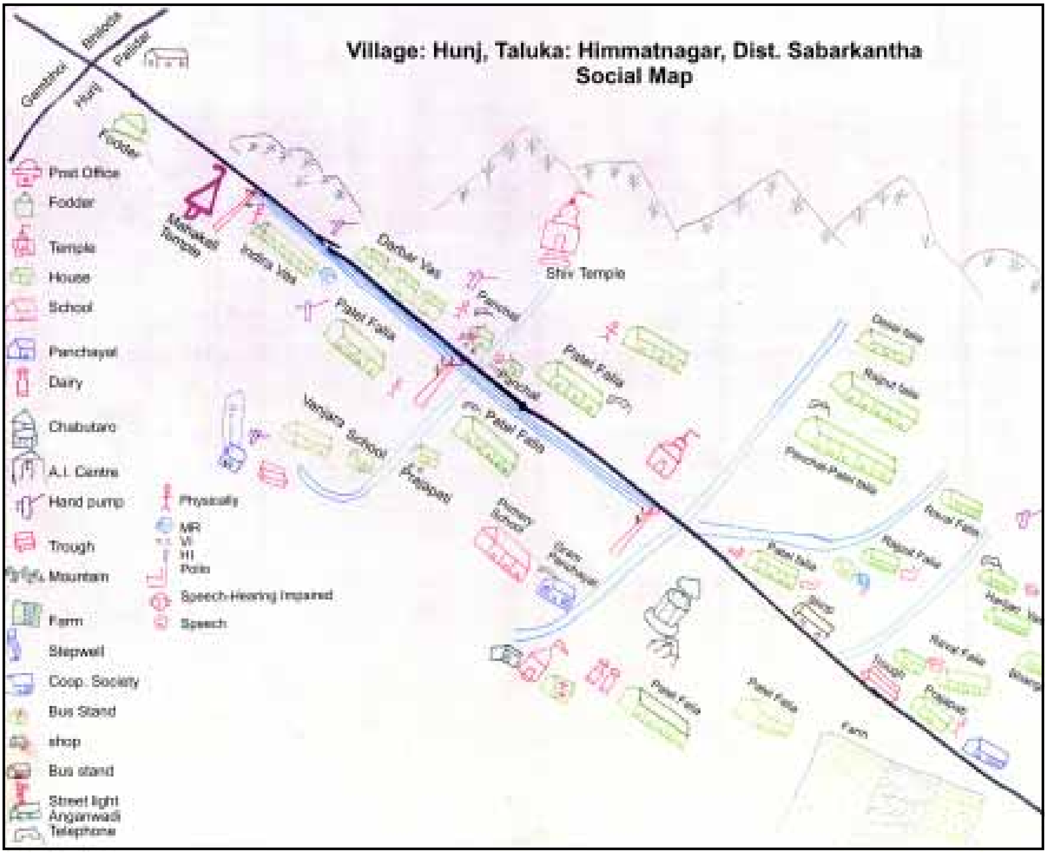
Hence, our learning in this context was that it is important to adequately and effectively communicate the objective of the exercise to the community and to some local institutions prior to conducting the PRA, so as to avoid creating unrealistic expectations. Also, this can lead them to share the onus of enabling persons with disabilities to participate in the PRA and at the same time periodically reiterate the objective of the exercise to keep the focus during the discussion. The right information needs to go to the community at each stage and this is specially important at the first stage on which the whole relationship is based.

### 2. Social mapping as an entry point for awareness

Generally, social maps help in developing a comprehensive understanding of the economic, social and physical aspects of the village. However, considering our specific focus, the exercise was modified. Instead of documenting householdwise information, the group indicated only those houses where persons with disabilities lived.

This served as a critical entry point for developing a collective understanding of who the community would consider as disabled and why. In most villages, before this exercise, the estimates of persons with disabilities ranged anywhere between 5 and 10 persons. These figures were quoted by the community leaders who are expected to have a better understanding of the situation and needs of the community. In all the cases, this number increased at least 5-6 times once the mapping was complete.

This difference existed because of the variation in the definition of disability used by the people. Most often, physically disabled persons were included while the visually impaired, people with low vision, speech



and hearing impaired, deaf-blind, persons with multiple disabilities, mental retardation or mental illness were left out. This was also due to the fact that in the vernacular language the word for 'disabled' literally means 'one without limbs'. During the discussions with the community, it was the persons with disabilities themselves and their families who participated in arriving at a common definition of disability. In most communities, a person with disability was defined as a person who, because of a physical or mental condition, was unable to look after herself/himself and required special support. Those who could support themselves financially were not counted as disabled despite having an impairment.

Mapping helped generate some baseline data for the village as a starting point for concrete community-led interventions. It initiated a process whereby the community started reflecting upon the situation of the persons with disabilities in their area. Many persons who were excluded because of their disability, albeit unintentionally, were acknowledged as in need of support from the community.

Special efforts were also made to include representatives of all communities of the village. However, in some cases, exceptions had to be made. Factors like a conflict or differences between two groups on the basis of caste or religious differences necessitated that separate social maps be prepared for each group.

## 3. Seeing beyond the visible

In our attempt to understand the mobility patterns of persons with disabilities, we used the 'Services and Opportunities map'. This helped us to understand the services available in and outside the village and the frequency with which these were accessed. While doing this, we realised that it was not merely the need of the persons with disabilities that determined their access to a service but, to a large extent, this depended on the availability and willingness of the person escorting them. In the absence of a barrier-free environment, the dependency on 'others' for mobility is extremely high. Hence, in the context of mobility patterns, it was important to go beyond the mapping exercise and to explore and understand the role of 'significant others' in facilitating the mobility of persons with disabilities.

## 4. Special efforts required to overcome factors hindering participation

Most communities are not used to listening to what persons with disabilities have to say as they do not acknowledge their presence and abilities. Hence, one can expect both direct and subtle resistance in the community.

To quote just one instance, before our visit to Hunj village of Prantij taluka in Sabarkantha district, we had contacted the *sarpanch*[1] and he not only extended his co-operation to gather the community members but also helped in explaining the objectives of the PRA.

Persons with disabilities were especially encouraged to participate in making the services and opportunities map. Jalaben,[2] a person with disability, showed a special interest and she was motivated to participate in the actual preparation of the map. However, after a while, when the group was engrossed, we noticed that Jalaben had left. Later, we learnt that the *sarpanch* had signalled Jalaben to leave, probably because he

---

[1] *elected leader of the village-level governing body*

[2] *'ben' is used at the end of a woman's name in the local language as a form of respect*

was embarrassed at the sounds she was making in her attempts to communicate as she had a hearing and speech impairment.

Perceptions and attitudes are not easy to change. Hence extra efforts need to be made to orient the team to be aware of these subtle coercive forces and handle them appropriately so as to include and sustain the participation of people with disabilities while retaining the interest of the other group members.

### 5. Different realities and priorities

The Venn diagram was used in identifying institutions existing at the village level and also in developing an understanding of the community's perception and their expectations from these institutions. It helped to understand the importance of each institution in the life of persons with disabilities and their relationship with these institutions.

While doing these exercises, in most places, the group of persons with disabilities consisted of men and women, varying in age, caste, class, and nature of impairment. The response of these groups while drawing the Venn diagram was quite varied. For instance, for women, drinking water facilities, health centres, *mahila mandals* (women's groups) were more significant. While for men, institutions like co-operatives, public transport, communication facilities, and water for irrigation were more important. For the youth, educational facilities, recreational centres and youth groups were of higher importance. Persons with physical disabilities were more responsive as compared to those with mental retardation. Even among the physically disabled, most of them had not stepped outside the village and hence they were able to rank only those services available within the village but were able to mention those that were important but not available within the village.

In such situations, it is important to note down the nature of the groups who were involved. As different sections of community have different sets of priorities, it is important that everybody's views are noted and analysed separately. Alternatively, the exercise can be done separately with small groups and the responses consolidated.

### 6. People's priority vs our priority

In Gandhi Kotar, one of the slum areas of Vadodara district, the team was unable to enlist the co-operation of the local residents. Informal interactions revealed that the slum had been shifted recently and the people did not have access to basic facilities. Many of the residents had died of cholera, as the only water available to them for drinking was from the gutter-cum-stream running near by. In this light, we had to postpone the PRA and discussed with the partner organisations how they could address the immediate needs of the people. After sometime, the team revisited the slum to conduct the PRA and this time it was possible to elicit the participation of the people.

### 7. Sensitivity towards all stakeholders

In Hasanpura village of Sabarkantha district, the villagers were initially resistant as they had been deeply affected by the recent riots in the State (2002). When the purpose of the exercise was explained to the community during the transect walk, a few people joined the mapping exercise. The number increased and gradually diminished. At one point, some youth interrupted us as they seemed to have doubts on the purpose of our visit. We spent considerable time convincing them and even showed a few social maps prepared in other villages. Slowly, they began to take interest in the mapping exercise.

On the following day, we met the *sarpanch* who was not present for the above exercise. He shared that the village consisted of people from both the Muslim and Hindu communities. The day the PRA exercise was conducted was exactly a year after the riots had taken place, hence the people were in a different frame of mind. Any effort for identification of families with persons with disabilities was likely to arouse the suspicion of the villagers.

A high level of sensitivity towards different sections of the community is essential and considering their priorities and listening to them is crucial for any effort to seek their participation. Also, we need to look at the situation while making a choice of location or else adequately equip the team with prior information and sensitivity.

### 8. PRA as a starting point for community interventions

One of the main objectives of this exercise was to understand the nature and degree of interest shown by different stakeholders in the community in including people with disabilities in their ongoing activities. In addition to individual discussion with some stakeholders, group discussions involving multiple stakeholders were also facilitated. This enabled all stakeholders to examine their attitudes, share their viewpoints and efforts. In this process, persons with disabilities were included to provide them a platform for sharing their experiences and expectations. Stakeholders came up with many ideas on the envisaged role they could assume for inclusion. For instance, one *Sarpanch* shared her willingness to include this in the agenda of the village and *taluka*[3] *panchayat* meetings.

### 9. Understanding disability issues from a woman's perspective

Women with disabilities suffer double discrimination, both on grounds of gender and impairment. They not only face the difficulties imposed by the impairment, but are also more socially excluded in comparison to men. However, there are very few studies that focus on the experiences of women with disabilities. The special needs of women have long been neglected and there is a need to have an understanding of disability issues from a woman's perspective.

Persons with disabilities were keen to interact but often did not feel free in large groups and felt more relaxed in smaller groups. Comparatively, men participated more than women in larger groups. Hence, separate focus group discussions were facilitated by women field workers with the disabled women. Women who had a disabled spouse or disabled member in their family were also included in this group. The need for maintaining

---

[3] *An intermediate administrative division between Village Panchayat and District Panchayat.*

confidentiality of the issues discussed was stressed and the discussions were steered from general to specific. In order to create an enabling environment for Focus group discussions, the facilitators used audio-visual aids such as flash cards and short films to start a discussion. This encouraged them to openly share their views, needs and specific problems. As most of them had similar experiences, sharing by one helped the others to open up. This proved to be not only a cathartic experience but also provided a supportive platform where the women could share their problems,  and feel a sense of bonding with the other group members.

## Way Ahead

The use of PRA for understanding issues of persons with disabilities with their involvement and active participation generated several learnings and awareness for all those involved. It provided a rare opportunity to persons with disabilities to interact with the community on an equal platform. It created an understanding and awareness of perceptions, attitudes and initiatives as well as the existing gaps in inclusion. It helped provide directions for working towards developing an authentic database (qualitative and quantitative), improved access to rehabilitation services and information, creating a barrier-free environment, supporting networks of persons with disabilities and articulating and facilitating the involvement of civil society in inclusion.

# Training Module: Disability and Development*

A person with disability is one with physical and/or intellectual impairment due to disease, genetic factors, trauma, malnutrition or accident. But disability is not merely an isolated health issue for a particular individual. It also has distinct social implications. Disability is the outcome of complex interactions between the functional limitations arising from a person's physical, intellectual or mental condition and the social environment. It has many dimensions and is often associated with social exclusion, increased vulnerability and poverty.

Traditionally, disability has been treated as a health and welfare issue, to be addressed either by health officials or personnel specialising in the physical rehabilitation of persons with disabilities. The very term 'welfare provision' denies those with disabilities the right to be treated as fully competent and autonomous individuals.[1] A 'rights-based approach' is necessary to recognise 'disability' as a development issue and for persons with disabilities to become actors and advocates for change.

The earliest efforts for rehabilitation of persons with disabilities focused on institution-based care and services for individuals. Later, as the need for more accessible services became apparent, the scope for rehabilitation widened to include families of persons with disabilities and the rehabilitation of the person in his/her own community. As the understanding of the social nature of disability improved, it was equally important to change the environment and context in which the persons

---

* *The module described in this section has been developed based on trainings conducted on this theme with several NGO groups. The design was jointly developed by Handicap International & UNNATI teams.*

[1] *Ann Darnbrough (2003), Disabled Women in Society: A Personal Overview, in Asha Hans and Annie Patri (eds.), Women, Disability and Identity, Page 149, Sage Publications.*

live. This includes protection of their rights, provision of equal opportunities in education and employment and promoting community ownership of programmes whose goal is the inclusion of persons with disabilities.

It is necessary to acknowledge disability as a human rights issue.[2] A human rights-based approach to disability will ensure that people are aware of persons with disabilities, their vulnerability and their rights. Hence, the issue of disability needs to be viewed from a human rights perspective to ensure that they can lead a dignified life. Therefore, the role of stakeholders like the State, development organisations, community and civil society in addition to special institutions is extremely important.

However, due to the limited interaction between persons with disabilities and members of the civil society, the latter are ignorant of their needs and rights and of the role that they can play to promote their inclusion in society. On the other hand, persons with disabilities are also not necessarily equipped with the information and skills for creating an improved understanding of their situation and their rightful demands. Hence, the process of inclusion of persons with disabilities requires that all the different stakeholders who can contribute towards this are sensitised and enabled to articulate their role. This is the first critical step towards promoting 'inclusion'.

**Objectives:**

A workshop aimed at sensitising participants to disability issues and development would seek to develop an understanding of:

- the meaning and extent of 'disability' as well as the situation of persons with disabilities
- the factors that are responsible for exclusion of persons with disabilities from society
- the need to address disability as a development issue and not merely

---

[2] *Oliver Barnes (2005), Discrimination, Disability and Welfare: From Needs to Rights in John Swain, Vic Finkelstein, Sally French and Mike Oliver (eds.), Disabling Barriers – Enabling Environments, Sage Publications.*

as a health and welfare issue
- the importance and ways of involving persons with disabilities and issues of disability in their ongoing programmes
- the specific role that they can play in facilitating inclusion of persons with disabilities.

**Participants**

The participants in this training should include representatives of NGOs, community-based organisations and/or the Government – people who are either involved in the formulation or implementation of development programmes. Shorter modules may be developed using this design as a base for sensitising other civil society stakeholders such as academics, professionals, the media and the service industry. For the training to be effective, the number of participants should not exceed 30.

**Duration:** 1 1/2 days

**DAY 1**

**Session 1: Welcome, Introduction and Objectives (100 minutes)**

**Objectives:**

1. To familiarise the participants with one another
2. To share the objectives and design of the workshop
3. To set the stage for networking.

**Method:**

Each participant should be asked to pair with a person unknown to him/her and get to know about each other's name, nature of organisation, role in organisation, expectations from workshop and adjectives that come to his/her mind when he/she thinks of a person with disability. Each person should then introduce his/her partner. The facilitator should note on a flip chart the responses that are shared regarding the expectations and adjectives and put it up in the room for future reference.

To clarify the objectives of the workshop and the overall design, a participant may be asked to read out the expectations noted on the flip chart. The facilitator could then clarify which of these expectations can be met and, using a visual presentation, briefly share the objectives of the workshop mentioned above.

**Outcome:**

This process would enable the participants to know about the focus of each others work and the different ways in which people think about persons with disabilities. This would set the stage for future reflections.

**Facilitators Note:**

Through this exercise, the facilitator will understand broadly the kind of work that the organisations represented and the participants are doing – this will serve as important baseline data for subsequent sessions wherein the inclusion of disability in ongoing activities would be discussed. Also, it would help the facilitator to understand the perceptions of the group towards persons with disabilities.

The objectives of the workshop need to be articulated in simple language so that participants can understand them and be clear what they would gain at the end of the workshop.

### Session 2: Understanding the Meaning, Definition and Scenario of Disability (60 minutes)

**Objectives:**

To develop a common understanding of the existing definitions and meaning of disability and share an overview of the disability scenario.

**Method:**

Participants would be first asked to briefly share their understanding of what disability connotes and includes. Using visual presentations, the accepted definitions of disability and the main causes leading to some disabilities should be shared. It should be highlighted that ability and

## Definitions

Disability is defined as a restriction or lack of ability as a result an abnormality of structure or function of the body. (WHO ICIDH 1980)

- Difficulty or limitation in activity
- Problem of function or shape of body
- May happen by disease, accident or birth

## Impairment-Disability-Handicap

The 1980 ICIDH provides a conceptual framework for disability which is described in three dimensions — Impairment, Disability and Handicap:

**Impairment:** In the context of health experience, impairment is any loss or abnormality of psychological, physiological or anatomical structure or function.
**Disability:** In the context of health experience, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.
**Handicap:** In the context of health experience ,a handicap is a disadvantage for a given individual, resulting from an impairment or a disability that limits or prevents the fulfillment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual (WHO 1980).

Impairment is considered to occur at the level of organ or system function. An assessment of impairment requires judgement of mental and physical functioning of the body and its component parts according to accepted standards. The classification of impairment is hierarchical, allowing considerable specifics for those needing to record such detail.

Disability is concerned with functional performance or activity, and limitations therein, affecting the person. The disability codes attempt to encompass those activities considered important in daily life. Like impairment, the classification of disability is hierarchical but allows for an additional parameter to record the severity of disability.

Handicap focuses on the person as a social being and reflects the interaction with and adaptation to the person's surroundings. The handicap codes attempt to classify those consequences which place that individual at a disadvantage in relation to his/her peers. The classification system for handicap is not hierarchical, but comprises a group of 'survival roles', with each survival role having an associated scaling factor to indicate the impact on the individual's life.

disability is a continuum; disabilities can occur due to reasons before, during and after birth; many disabilities can be prevented and cured; and that most persons with disabilities do not necessarily require institutional care and can function within their own community. Some statistics on disability at international, national, and State levels should be shared and the reasons for differences at various levels explained. The different types of disability as recognised under the laws of the country and the concepts of impairment-disability-handicap must be elaborated.

**Outcome:**

The participants would develop a common understanding of what the term disability connotes, what specific conditions are considered as 'disability' under the prevailing law and the comparative scenario of disability at different levels.

**Facilitators Note:**

This session would form the basis of subsequent sessions as it would help develop an understanding of the overall scenario of disability. The facilitator needs to be well prepared with statistics across levels and countries. S/he would also need to have basic data and an understanding of the variations in definitions of disability and the reasons. It is essential that the facilitator pay special emphasis on the differences between the terms – impairment, disability and handicap – to draw their attention to the social implications of disability.

### Session 3: Developing Sensitivity Towards Persons with Disabilities (165 minutes, including 80 minutes for lunch)

**Objectives:**

1. To develop sensitivity towards the needs, feelings and reactions of persons with disabilities and understand the reactions of society towards them and their impact
2. To understand the expectations of persons with disabilities from society.

**Method:**

Participants should be divided into pairs. For example a person with a visual impairment may be coupled with a person with locomotor disability. In some cases, the partner may be a non-disabled person who can act as an assistant/ observer and can assist when asked or to ensure safety of the person with disability.

To enable participants to assume the role of a person with disability, the facilitator could use blindfolds for visual impairment, prism glasses for low vision, wheelchair, crutches, walking frame etc. for locomotor

**Suggested Activities**

The activity assigned to the pair could be any activity of daily living. The task assigned should be challenging for the person who is in the role of a disabled person. For eg. asking a person who is an upper limb amputee (with both hands tied at the back) to xerox a document back to back or arranging a newspaper that is all mixed up according to page number or trying to remove and put on shoes and socks. Some other activities that may be assigned are:

For visual impairment: Using the public phone, paying the partner an amount that requires the person to figure out several denominations of the currency, climbing up the steps etc.

For wheelchair user: Accessing an article from a shelf that is difficult to reach, seeking help from a person across a counter of a height at which the person on the wheelchair cannot see the person at the other end, using the toilet etc.

For speech impairment: asking the neighbour directions to a multiplex cinema, asking the neighbour to make a phone call to his family to inform them he is going to be late, telling the partner that the recent earthquake has led to a lot of disability in the region

For persons using frame: Going down the steps, getting the water from water store to room

For persons using crutches: going with blind folded person who is climbing up and down the steps, going out to the park swing area disability (one leg to be folded and strapped with a bandage or strap), tapes or strapping splints on fingers for persons afflicted with leprosy, head phones or ear plugs for hearing impairment etc.

Based on pre-designed activities (please refer Box for suggested activities) participants should be explained the task that they are expected to carry out before breaking for lunch. Participants should be asked to continue being in their roles while having lunch e.g. a person with speech impairment would continue to communicate with others through gestures and so on.

After lunch, persons with disability may be divided into groups based on their type of disability. People who were in the roles of assistants may form a separate group to discuss their observations and experiences.

The groups should be asked to discuss the following questions and record their responses:

**People with disabilities:**

- How did it feel to be disabled?
- What difficulties did you experience while performing the task?
- What difficulties do you think a person with disability can face in daily life?
- What may be the expectations of persons with disabilities from the society?

**Observers Group:**

- What was your experience as an observer/assistant?
- Did you offer help on your own or waited for being asked for help?
- What difficulties did you experience as an observer or assistant?
- What factors helped in understanding your partner?
- What was the reaction of other people around you while your partner was performing the assigned role?

All the groups will be asked to present their discussion points. Disabilities not covered through this exercise may also be discussed at the time of summing up for eg. mental illness, mental retardation, learning disabilities deaf-blind, etc.

While debriefing, statistics on the actual situation and impact of social and attitudinal barriers faced by persons with disabilities on their education, employment, utilisation of budget allocated for disability, extent and nature of media coverage etc. should be highlighted.

**Outcome:**

This session is the most critical for sensitising participants to the needs and situation of people with different types of disabilities. It would enable them to experience and observe the attitudes and behaviour of the non-disabled towards persons with disabilities. Furthermore, it would develop an understanding of the impact of such attitudes on the lives of persons with disabilities. On the other hand, it would also help them to be sensitive towards their expectations from society.

**Facilitators Note:**

Conducting this session requires a great deal of pre-workshop preparation on the part of the facilitator. It would require developing:

(a) a clear and lucid list of tasks that people with different types of disabilities may find difficult in performing because of their physical disability;

(b) a list of the roles of the other two members of the triad. While conducting the session, the facilitator would require at least 2-3 people to assist him/her in preparing, (tying blind folds for those who have been assigned to perform the role of visually impaired or fitting calipers for the locomotor disabled, etc.) assigning and explaining the tasks to the triads.

Some participants may express their unwillingness to perform the assigned roles, especially those of persons with disabilities. This resistance may be more pronounced during the lunch break as it would lead them to eat in positions that are new to them and require adaptation. To maximise the outcome of this session, it is important that the facilitator be polite but firm in emphasising the importance of abiding by the expectations of the participants during the session.

While facilitating the sharing by participants, it is important that they are continually motivated to reflect on as many feelings, thoughts and observations as are possible. This is important as this is the only session that is aimed at providing a simulated experiential learning and helping the participants to experience the disability at the feeling level. It is important that through the consolidation, the facilitator highlights:

(a) the potential and abilities of the person with disability and (b) the social implications of disability, i.e.. the handicap that a person with disability faces due to the attitudinal barriers of society and due to his/her own conditioning that together result in exclusion from society, and (c) the importance of promoting interaction between persons with disabilities and society to enhance an understanding of their needs and rights.

## Optional Session: Communicating Attitudes and Their Impact (60 minutes)

### Objective:

To develop an understanding of attitudes towards the persons with disabilities reflected in different modes of communication (sayings, beliefs, media portrayals, etc.) and their impact on persons with disabilities.

### Method:

The participants should be divided into small groups (5-7 members) and asked to list the terminology/sayings/beliefs/media portrayals that are commonly used in their region for persons with disabilities. They can then be asked to reflect and discuss the impact that these can have on them.

While consolidating, draw the attention to the following:

a) attitudes reflects and has an impact on the behaviour of people
b) trends of positive and negative attitudes and the types of disabilities that figure more in participant's responses
c) need for developing IEC material that can help develop positive attitudes and draw the attention of society towards the potential and rights of persons with disabilities.
d) role that participants can play in effecting change in the current scenario.

**Outcome:**

This session would enable the participants to focus on how, through different modes of communication, our attitudes towards a vulnerable group get reflected and how these in turn have an impact on the group. It would also provide them with a starting point for developing their own communication material based on the new knowledge being acquired through this workshop.

**Facilitators Note:**

The facilitator should do a bit of preparatory work before this session by way of collecting some information on the regional sayings/beliefs and clippings or examples of mainstream media portrayals of persons with disabilities. These could be used to either initiate discussion or else as add-ons once the discussion is over. It is important that some common sayings about other vulnerable groups are shared and the participants are enabled to relate to this to consolidate the learnings.

**Note:**

This session could be concluded by showing a film on persons with disabilities titled 'Unheard Voices' in English or 'Sunjo Re Koi Saad' in Gujarati. The film highlights the perspectives of persons with disabilities on their situation, rights and strategies used to realise their rights. It portrays their abilities and struggles and is an effective sensitisation tool.

## DAY 2

## Session 4: Approaches for Rehabilitation of Persons with Disabilities (60 minutes)

### Objective:

To familiarise the participants with various approaches in relation to rehabilitation and integration of persons with disabilities, with specific reference to their relevance, scope and evolution.

### Method:

Participants should be asked to share in a large group the various approaches/measures that they know of and are being currently used for rehabilitation and integration of persons with disabilities. They could then be asked to comment on the strengths and weaknesses of each approach and identify gaps that needs to be filled to promote integration of persons with disabilities in mainstream development processes.

Using examples of various approaches, i.e.. charity, welfare, institutional, community-based rehabilitation and community approaches to handicap in development (CAHD) for mainstreaming disability in development — a rights-based approach, the evolution of approaches and perspectives in the field of rehabilitation could be traced. The focus, relevance and gaps of each approach as well as the main actors implementing these approaches should be shared using a lecture-cum-discussion mode.

### Outcome:

This session would help participants to understand the different approaches and perspectives that have evolved over the years in the area of rehabilitation. It would help focus on (a) the need and importance of using a rights-based approach both in policy formulation and programme implementation, (b) focusing on the ‘context and environment’ of the individual as much as on the ‘person’, (c) the causes of exclusion in addition to the ‘excluded’, (d) need for involving various civil society members and organisations in promoting the inclusion of persons with disabilities.

### Facilitators Note:

The facilitator would be required to collate points related to various approaches. It is important that a balanced view is presented such that participants understand the specific and complimentary roles of institutional services, rehabilitation institutions, community-based services and development organisations. If it is a mixed group comprising of the different actors in the field of rehabilitation, it is important that their respective roles are duly acknowledged and the ways in which they can complement and supplement each other are highlighted.

## Session 5: Information on Schemes and Acts for Persons with Disabilities (40 minutes)

### Objective:

To provide information on the different Government schemes for rehabilitation and the Acts passed by the Government

### Method:

Using a presentation through charts or Power Point, or alternately using films available on this subject, participants should be provided some basic information on schemes and Acts and sources of obtaining details so that they have the requisite baseline information for their future work. The mechanisms that can be used by persons with disabilities to avail themselves of schemes and their rights, if they are denied the same, these should specially be highlighted. Printed information on these subjects should also be provided as handouts.

### Outcome:

The participants would be equipped with some basic details that they can use to empower persons with disabilities in their areas with information. They may not know all the details of the various schemes but should know whom to approach and where to get the details from. They should be able to provide guidance to persons with disabilities and their caretakers and establish necessary linkages.

### Facilitators Note:

Since lack of information is one of the basic factors that contribute to vulnerability, it is important that the facilitator access all resources and obtain the relevant information for this session. Providing handouts is necessary in addition to using presentations so that participants have some ready reference materials that they can use in their work. It is also important that the participants are informed of the redressal mechanisms provided for under the Disability related Acts so that they can guide persons with disabilities to utilise them.

## Session 6: Inclusion of Persons with Disabilities — Approaches and Experiences (75 minutes)

### Objective:

To share some of the field experiences of a holistic, inclusive and rights based approach for inclusion of the persons with disabilities.

### Method:

The facilitator should use a participatory mode and, using some key questions, should help participants to reflect on the causes of the situation of persons with disabilities, identify the gaps and the attitudes that are required to facilitate a change in their situation. Questions that may be asked could be: 'What are the feelings you experience when you think of 'disability?', 'How are persons with disabilities portrayed in society and what are the images that come to mind when one thinks of disability?' 'What are the needs of a non-disabled person and a person with disability?', 'What do you think persons with disabilities and the non-disabled need to do so that the former get their rights?

Approaches used by various organisations can then be shared to provide examples of what has been tried and what has worked or what has not. The session must highlight the following:

- importance of understanding the abilities of persons with disabilities to contribute
- the only difference in the needs of the non-disabled and persons with disabilities is the special needs related to the disability – all other needs are common

- the manner in which the needs of these two groups are perceived and addressed by society is different
- lack of involvement, absolving ourselves of our responsibility, focusing more on special needs and inabilities contribute to our varied response to the needs of the two groups
- organising persons with disabilities is important for them to collectively voice their perspectives and realise their rights – it is important that in doing so they are not merely at the receiving end but also contribute to their family and society.

**Outcome:**

This interactive session would help participants to reflect on the causes of exclusion and be acquainted with some of the approaches that have been used to promote inclusion – both by persons with disabilities and by other groups. It would help them to examine their own attitudes and understand some of the causes. It would also help highlight what needs to be done to change such attitudes and the role of organised efforts in promoting inclusion.

**Facilitators Note:**

It is important that the facilitator be aware of the different approaches that have been tried for inclusion. It may also help to have such people come in as resource persons to share their experience. It would also help to invite persons with disabilities to share their perspective on their needs, reactions to the exclusion they face, expectations from society and what they feel they should do to facilitate their inclusion. Inviting people who have demonstrated positive attitudes is exceedingly important while selecting resource persons. Write-ups on experiences of inclusion can also be given as handouts, for which some search would be required.

## Session 7: Planning for Action (60 minutes)

**Objective:**

To reflect on the measures required for integration of disability issues in ongoing activities

**Method:**

Participants should be asked to sit in groups, preferably with members of their own organisation, if present, or with others who are doing similar work. Representatives from each group should be asked to note down on cards the activities that their organisations are engaged in and the specific ways by which they can include the issues of disability in their ongoing programmes.

This should then be shared in the plenary where additional comments and suggestions should be sought. A time-frame needs to be decided to promote concerted and timely action.

**Outcome:**

This session would help participants to understand that if the overall objective of development initiatives is to reduce vulnerability, it is important that the issues of persons with disabilities are integrated and addressed. This does not require and should not lead to the creation of exclusive opportunities or facilities but instead including them in ongoing development initiatives. Doing so could pose challenges as civil society's attitudes are not very conducive to inclusion. Participants would understand that a major factor for the existing attitudes is the lack of interaction between persons with disabilities and the non-disabled. This limits their mutual understanding of needs, potential and roles. Hence, by creating equal opportunities for participation in their ongoing activities, organisations can help bridge the gaps and facilitate inclusion.

**Facilitators Note:**

For participants who are attending a workshop on this theme for the first time, it may be difficult to envisage how they can promote inclusion. It is important that activities are spelt out and some targets set to provide a definite sense of direction. The possibility of participants chalking out plans for separate programmes (e.g. a separate training for local leaders on disability issues) is likely. The facilitator needs to constantly remind them of the need to focus on integration rather than segregation.

# Acts and Legislation for Persons with Disabilities

1. **The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995**

   The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 is guided by the philosophy of empowering persons with disabilities. The Act seeks to promote equality and participation of persons with disability on the one hand, and eliminate discriminations of all kinds, on the other. It encompasses provisions for the prevention of disability, promoting education, employment, affirmative action, non-discrimination, research and manpower development, recognition of institutions for persons with disabilities and monitoring the implementation machinery. The Act provides for appointment of a Commissioner in every State to look into complaints relating to deprivation and denial of rights of persons with disabilities.

2. **The Rehabilitation Council of India Act, 1992**

   The Rehabilitation Council of India Act, 1992 was created to provide for the constitution of the Rehabilitation Council of India for regulating training of the rehabilitation professionals and maintaining of a Central Rehabilitation Register and for matters related to these issues.

   The professionals who come under the purview of the Act are:
   - Audiologists and Speech therapists
   - Clinical Psychologists
   - Hearing aid and ear mould technicians
   - Rehabilitation engineers and technicians
   - Special educators for teaching and training the handicapped
   - Vocational counsellors, Employment officers, and Placement officers
   - Multi-purpose rehabilitation therapists and technicians

- Speech pathologists
- Rehabilitation psychologists
- Rehabilitation social workers
- Rehabilitation practitioners in mental retardation
- Orientation and mobility specialists
- Community based rehabilitation professionals
- Rehabilitation counsellors/administrators
- Prosthetists and Orthotists
- Rehabilitation workshop managers

### 3. The Mental Health Act, 1987

The Mental Health Act, 1987 aimed to consolidate and amend the law relating to the treatment and care of mentally ill persons, to make better provision with respect to their property and affairs and for matters connected therewith or incidental thereto.

The Act has been divided in six chapters dealing with different matters. Central and State authorities have been appointed. The chapters deal elaborately with the establishment of psychiatric hospitals and nursing homes, admission to such institutions of mentally ill patients, procedures of inspection, discharge, leave of absence and removal of mentally ill persons. The enactment also deals with custody of mentally ill persons, their property and its management. It has been sought that persons liable to maintain such ill persons will bear costs of maintenance, besides the costs to be borne by State in special cases.

There are some provisions as well which make certain contraventions penal. The penalty and procedure have been provided in the Act to deal with such offences. The Act gives protection also for action taken in good faith.

Pensions payable to mentally ill persons and also to provide legal aid has been provided. The Act empowers the Central and State government to make rules.

4. The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999

   The Government of India has become increasingly concerned about the need for affirmative action in favour of persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities. In acknowledgement of a wide range of competencies among these individuals, the Central government has set up a National Trust. The Trust will be promotive, proactive and protectionist in nature. It will seek primarily to uphold the rights, promote the development and safeguard the interests of persons with autism, cerebral palsy, mental retardation and multiple disabilities and their families.

   Towards this goal, the National Trust will support programmes which promote independence, facilitating guardianship where necessary and address the concerns of those special persons who do not have their family support. The Trust will seek to strengthen families and protect the interest of such persons after the death of their parents. It will extend support to registered organisations to provide need-based services during the period of crisis in the family of persons with disability.

*Sources*

1. *The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 and The National Trust for the Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act, 1999 – Bare Acts: Universal Law Publishing Co. Pvt. Ltd., 2004*
2. *www.disabilityindia.org*

उन्नति

UNNATI

## About us

UNNATI - Organisation for Development Education is a voluntary non-profit organisation. It was registered under the Societies Registration Act (1860) in 1990. Currently, we are engaged in providing strategic issue based support to development initiatives in Gujarat and Rajasthan. The primary aim is to promote social inclusion and democratic governance so that the vulnerable sections of our society are empowered to effectively and decisively participate in mainstream development and decision making process.

The above aim is accomplished through undertaking collaborative research, public education, advocacy, direct field level mobilisation and implementation with multiple stakeholders. While we work at the grassroot level to policy level environment for ensuring basic rights of citizens, we derive inspiration from the struggles of the vulnerable and strength from the partners. Presently, all the activities are undertaken under the following themes:

1. **Social Inclusion and Empowerment**
   In order to promote social inclusion of the vulnerable in the development process and for their empowerment, several activities are carried out in collaboration with various stakeholders like awareness campaigns, perspective building workshops, public education campaigns, direct mobilisation of the community on rights of the dalits, disabled and for gender equity. Field level activities are coupled with research and advocacy to establish their legitimacy and rights.

2. **Civic Leadership in Governance**
   In order to enable citizen leaders effectively participate in governance in a democratic way, several activities are carried out to strengthen the capacity of elected representatives (Panchayats and Nagarpalikas), through training and information support. Through public educational campaigns, the participation of citizens in(gramsabha and wardsabha) is mobilised for building responsive citizens.