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**Understanding Disability:  
Attitude and Behaviour Change for  
Social Inclusion**

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## **Understanding Disability: Attitude and Behaviour Change for Social Inclusion**

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**The text of this booklet is available on a larger font size on request.**

Any part of this publication may be used as training or educational material with due acknowledgement to the publishers.

### **Acknowledgements**

This research study was carried out by UNNATI - Organisation for Development Education and Handicap International (HI) in 4 districts of Gujarat namely Ahmedabad, Sabarkantha, Patan and Vadodara, in collaboration with 13 grass root partner organisations. We sincerely express our thanks and gratitude to all those who have given their valuable time, inputs and suggestions for conducting the research and putting this report together.

We would especially like to thank Prof. Ajit Dalal, Reader at the Department of Psychology, University of Allahabad and Dr. Maya Thomas, Consultant, for their invaluable support and guidance not only in preparing the design of the study but in the entire research process. This study would not have been possible without the involvement of the 13 partner organisations and their efforts to facilitate the process in their field areas. We are grateful to our colleagues Arindam Mitra, Amrut Rathod, Hitendra Chauhan and Swati Sinha of UNNATI and Sonia Lokku, Snehal Soneji and Hetal Thaker of HI for their inputs in the study process. We also sincerely acknowledge the time spent and the interest shown by the members of the community where the study was conducted. This has contributed to developing a collective understanding of the situation of persons with disabilities, causes of their exclusion and measures that can promote their inclusion in society.

# Preface

During the Gujarat earthquake rehabilitation response UNNATI - Organisation for Development Education and Handicap International closely understood the needs of vulnerable groups, particularly the orphans, single women, widows and persons with disabilities who struggled to get included in the rehabilitation process. The families of persons with disabilities became more vulnerable.

This booklet is an outcome of the joint initiative of Handicap International (HI) and UNNATI in vulnerability reduction. It aims to invoke the participation of civil society in the inclusion of persons with disabilities in the mainstream development process. The assumption was that an oriented and sensitised civil society would create an enabling environment for enhancing the participation of persons with disabilities in the development process and for engaging them in decision making on issues concerning them.

A participatory action research was initiated in 4 districts of Gujarat, namely Ahmedabad, Sabarkantha, Patan and Vadodara during January 2003 - April 2004 in partnership with local NGOs. Along with the study, several activities, including training, workshops and preparation of educational material were also initiated to orient the partner organisations and sensitise the community. This report presents the process as well as the key findings of the study. The study itself led to a campaign for sensitising civil society.

We hope that the findings of the study will enhance the understanding of the situation and context of persons with disabilities among those who desire to work for their inclusion. We also hope that this report will provide an impetus to the initiatives, which focus on creating an enabling environment for the inclusion of persons with disabilities in development processes, and will motivate several groups in society to act and contribute to enable persons with disabilities to lead a life of dignity.

The text of this report has been prepared by Alice Morris, Geeta Sharma and Deepa Sonpal from the field notes prepared by Shankharupa A. Damle and Archana Shrivastava.

Binoy Acharya  
UNNATI

Alana Officer  
Handicap International

## List of Abbreviations

ADA	American Disability Act, 1991
ADD	Action on Disability and Development
BPA	Blind People's Association
CBO	Community Based Organisation
CBR	Community Based Rehabilitation
DDRC	District Disability Rehabilitation Centre
GHFDC	Gujarat Housing and Finance Development Corporation
GOI	Government of India
HDI	Human Development Index
HI	Handicap International
ICDS	Integrated Child Development Scheme
ID	Identity Card
IEC	Information Education Communication
NAB	National Association for the Blind
NCPEDP	National Centre for Promotion and Employment of Disabled Persons
NHFDC	National Housing and Finance Development Corporation
NSS	National Sample Survey
ONGC	Oil and Natural Gas Corporation
PHC	Primary Health Centre
PRI	Panchayati Raj Institution
PWD Act, 1995	Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act 1995
SC	Scheduled Caste
SDO	Social Defence Officer
SHG	Self Help Group
ST	Scheduled Tribe
ULB	Urban Local Body
WG	Women's Group
WHO	World Health Organization
YG	Youth Group

# Glossary

Anganwadis	Run under ICDS, provides supplementary nutrition and informal education to children.
Census	10 yearly enumeration of population.
Dai	Mid wife facilitating child birth at home.
Gram Sabha	Consists of all the voters of Village Panchayat.
ICDS	Centrally Sponsored Scheme implemented by the State Governments. Provides for nutrition for children under 6 and pregnant women and pre-school education.
Mahila Arthik Vikas Nigam	State-run corporation, working for economic empowerment of women.
NSS	Central Organisation conducting yearly socio-economic surveys.
Panchayat	Local self government at Village, Taluka and District levels.
PHC	Primary Health Centre responsible for providing primary health care at village level.
Sarpanch	Head of the Village Panchayat.
SC	Scheduled Castes. Provided political reservation under the Indian Constitution. Lies at the lowest strata in caste system.
SDO	Social Defence Officer, district level administrative head responsible for implementation of various social security schemes.
SHG	Group of persons engaged in economic activities of savings and credit as well as production and sale.
Snellen	Is a chart which measures the visual acuity of a person.
Special educators	Educators specially trained for educating persons with disability
ST	Scheduled Tribes known as tribals mainly living in hilly areas, known as Scheduled areas.
Talati	A person working as a secretary of a Village Panchayat.
Taluka	An intermediate administrative division between Village Panchayat and District Panchayat.

# List of Partner Organisations

## **Ahmedabad Study Action Group**

In front of Hasanali School, Khodiar Chowk, Dholka, Ahmedabad-387 810.

## **Bhansali Trust**

Highway Char Rasta, Radhanpur, Patan-385 340.

## **Gram Vikas Sewa Trust**

Kharid Vechan Sangh, 1st Floor, S T Road, Idar, Sabarkantha-383 430.

## **Faculty of Social Work**

M S University, Opp. Fatehganj Post Office, Vadodara-390 002.

## **Lok Seva Yuva Trust**

Daramali, Taluka Idar, Sabarkantha-383 110.

## **PARAKH Trust**

Ambawadi Vistar, B/h. Kutchi Samaj Wadi, Nr. Bungalow No. 12, Opp. Railway Station, Himmatnagar, Sabarkantha-383 001.

## **Rural Development Society**

At & P.O Zinzawa, Taluka Prantij, Sabarkantha.

## **SAATH Charitable Trust**

O/102, Nandanvan V, Near Prenatirth Derasar, Jodhpur, Satellite, Ahmedabad-380 051.

## **Sarvodaya Mahila Jagruti Seva Trust**

At P. O. & Taluka Vadali, Sabarkantha-383 235.

## **Shri Ambedkar Education Trust**

Kump. Post. Jambudi, Taluka Himmatnagar, Sabarkantha-383 001.

## **Shramik Vikas Seva Sanstha**

Opp. Taluka Panchayat Office, Bhiloda, Sabarkantha-383 245.

## **Vikas Jyot Trust**

Nagarvada Char Rasta , Vadodara-390 001.

## **Vinoba Bhave Seva Sansthan**

Sector 2/76, Samay, Mahakali Kanknol Road, Gayatri Mandir Vistar, Himmatnagar-383 001.

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# Executive Summary

In India, people with disabilities, especially those who are poor, suffer from profound social exclusion. This limits their participation in all spheres of life – social, cultural and political and results in a denial of their rights. Women with disabilities suffer double discrimination on account of both disability and gender.

Yet, data base available in India provide a limited picture of the exclusion that people with disabilities experience. For example, the very definition of disability, as accepted by law\* , recognizes only seven kinds of people with disabilities – those with blindness, low vision, leprosy-cured, hearing impairment, locomotor disabilities, mental retardation and mental illness. It leaves out many types of disability such as haemophilia and AIDS. This varied understanding of disability is only the beginning of the problems associated with obtaining a thorough understanding of disability in India.

## **The participatory research and action study**

In 2003, UNNATI - Organisation for Development Education and Handicap International (HI), in partnership with thirteen grassroot organisations, designed a participatory research and action study to gather a collective understanding 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. It also explored ways in which development stakeholders can play a supportive role in promoting inclusion of persons with disabilities in their ongoing activities. The study complements an overall effort to promote civil society participation in mainstreaming people with disabilities.

Using a participatory approach (PRA) to capture the point of view of people with disabilities themselves, 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. In most communities, the study provided an opportunity for people with disabilities to interact with members of the general community on an equal platform for the first time.

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



The study focused on:

- Building the capacities of the thirteen participating organisations to conduct the study (developing manuals, questionnaires, and conducting demonstrations as well as tracing the close link between poverty and disability)
- Engaging women in all discussions (holding separate focus group discussions with women with disabilities where they were not comfortable with sharing their thoughts and feelings in the larger group)
- Including all stakeholders from the community in discussions, especially those in a position to influence the increased participation of persons with disabilities in the development process
- Acknowledging challenges (the study offered no 'tangible' benefits to people with disabilities participating in the exercise)

## Summary of Findings

**Profound exclusion:** Overall, the study revealed that for reasons of 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.

**Data map:** In the sample surveyed, there were more men (60%) than women (40%) with disabilities. The largest number of persons with disabilities was found in the school going age (6-18 years). Most of them were disabled from birth (54%). Physical disability, due to its apparent nature, accounted for 62% of the cases surveyed.

**Family life:** More men with disabilities were married, a large section of whom were able to 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 healthcare services increases 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 amongst people with disabilities in the areas surveyed. About 30 per cent of 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 18-45 years, 93 per cent of 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 were not able to 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.

This participatory research and action study facilitated a process by which the attitudes of the community towards persons with disabilities were openly

discussed and various stakeholders committed to include them in their ongoing activities as a first step towards inclusion. The village headman (*sarpanch*) in 75 per cent of villages expressed a willingness to include them in the village meetings (*gram sabhas*) and said that the village government body (*panchayat*) would take responsibility for attending to the special needs of people with disabilities. Other village institutions such as youth co-operatives, community-based organisations and self help groups also expressed an interest in sharing this responsibility, especially in facilitating the disability certification process.

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.

# 1. The Context

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.<sup>1</sup>

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 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 person with disabilities.

It is necessary to acknowledge disability as a human rights issue.<sup>2</sup> 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. 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.

## Defining 'Disability'

Defining 'disability' is complex and often controversial. There is confusion regarding the terms 'impairment', 'disability' and 'handicap' and when it is appropriate to use each of these terms. Disability is broadly understood in a continuum as shown below:

**Disease/Accident → Impairment → Disability → Handicap**

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<sup>1</sup> Oliver, Barnes, 'Discrimination, Disability and Welfare: From Needs to Rights' in 'Disabling Barriers – Enabling Environments', Sage Publications, 2003

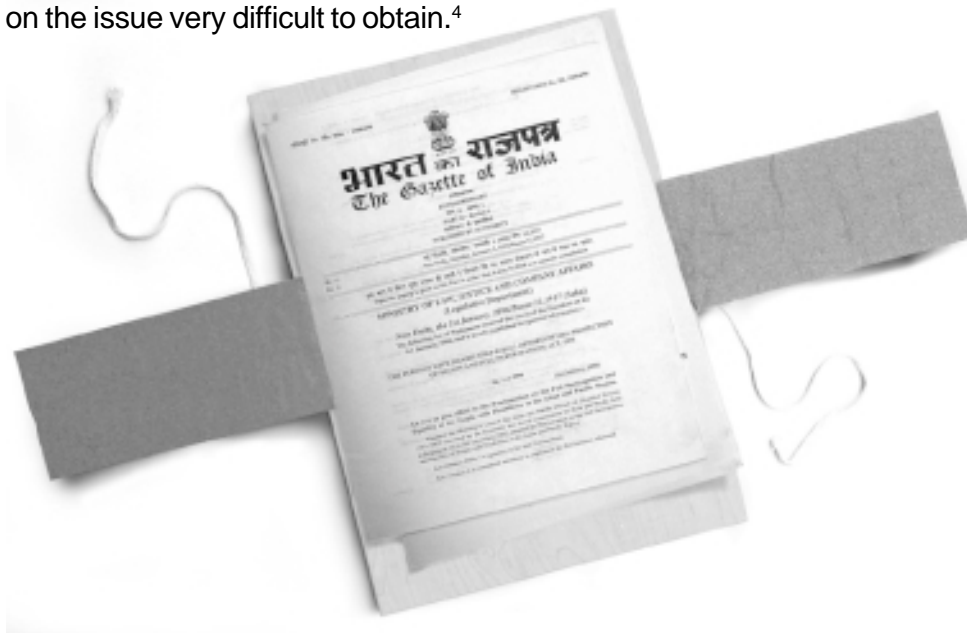
<sup>2</sup> Darnbrough, Ann, 'Disabled Women in Society – A Personal Overview'

Impairment can generate disability, which in turn can generate a handicap. A handicap further leads to social and economic exclusion. Exclusion, intentional or not, keeps increasing. The more the exclusion, the less aware is the community of or concerned about the needs and barriers faced by persons with disabilities. This alienation leads to a widening gap in the understanding of persons with disabilities and their needs in day-to-day life.

Till date, most studies on the status of disability in India have concentrated on physical disability. Professor Ajit Dalal in his book 'The Mind Matters: Disability Attitudes and Community Based Rehabilitation'<sup>3</sup>, comments that, "due to the lack of a clear definition of 'disability', the estimates of the number of disabled have widely varied." Dr. Uma Tuli, Chief Commissioner for Persons with Disabilities, New Delhi, agreed in an interview that the lack of consensus on the definition of disability makes authentic data on the issue very difficult to obtain.<sup>4</sup>

The first major step towards recognition of the rights of the persons with disabilities was the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 (PWD Act, 1995), which was the result of several years of advocacy for an understanding of the issue.

The Act covers seven types of disabilities: blindness, low vision, leprosy cured, hearing impairment, locomotor disability, mental retardation and mental illness. Blindness means total absence of sight, visual activity not exceeding 6/60 or 20/200 (Snellen) in the better eye with correcting lenses or limitation of the field of vision subtending an angle of 20 degrees or worse. Low vision means a person with impairment of visual functioning even after treatment or standard refractive correction but who uses or is potentially capable of using vision for the planning or execution of a task with an appropriate assistive device.



<sup>3</sup> 'The Mind Matters: Disability Attitudes and Community Based Rehabilitation' published by Centre for Advanced Study, University of Allahabad, Sept. 2000. Professor Dalal is a Reader at the Department of Psychology, University of Allahabad.

<sup>4</sup> In an Interview for Labour File, Vol. 7, No. 10 & 11, Oct.-Nov. 2001.

Leprosy cured refers to a person who is cured of leprosy but is suffering from loss of sensation in the hands or the feet as well as loss of sensation and paresis in the eye and eyelid but with no manifest deformity, and paresis but has sufficient mobility in the hands and feet to engage in normal economic activity; or extreme physical deformity as well as advanced age which prevent the person from undertaking any gainful employment. Hearing impairment means loss of 60 decibels or more in the better ear in the conventional range of frequencies. Locomotor disability means disability of bones, joints or muscles leading to substantial restriction of the movement of the limbs or any form of cerebral palsy. Mental retardation refers to a condition of arrested or incomplete development of the mind of a person, which is specially characterised by sub normality of intelligence. Mental illness refers to any mental disorder other than mental retardation. The Act, among other provisions, highlights the educational, economic and accessibility needs and rights of persons with disabilities. However, as Dr. Tuli admits, it still excludes major disabilities like autism and cerebral palsy.



The National Trust for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities Act was enacted in 1999 for the protection of rights of persons with the aforementioned conditions.

The District Disability Rehabilitation Centre (DDRC), Ministry of Welfare, Government of India (GOI), has a simple definition of disability – the opposite of ability. The American Disability Act<sup>5</sup>, (popularly known as the ADA) 1991, defines disability as any physical or mental impairment that results in a substantial limitation of one or more major life activities. This definition covers all types of disabilities.



'Disability' is seldom seen as an important social issue and persons with disabilities are often left out when vulnerable groups are considered. The specific problems confronting persons with disabilities have rarely been explored, still less so from their perspective. Their potential contribution to the community has also been ignored.

<sup>5</sup> American Disability Act [www.disabilityinfo.org](http://www.disabilityinfo.org)

The World Development Report, the Human Development Report and the Asian Outlook, the three major authorities on international data published annually, have no data on the number of persons with disabilities in the countries included in their studies. Even the much proclaimed Human Development Index (HDI) does not include this very significant aspect of human life, which is an indication of the level of interest on the issues of persons with disabilities at the international level.

Statistics, however, do exist, although primarily in industrialised countries, e.g. in the United States, more than 8 per cent of the population are disabled; in Australia, the figure is 14 per cent. Among the Asian countries, China claims a 5 per cent disabled population, Pakistan 4.9 per cent, the Philippines 4.4 per cent and Nepal 5 per cent.

### **Status of Persons with Disabilities in India**

In India, national level statistics on the persons with disabilities are not collected regularly. Apart from a few sporadic studies, there is no authentic source that can provide concrete, desegregated data. National and international sources quote different figures. The higher percentage of persons with disabilities in developed nations as compared to that in India is partly due to the very narrow definition of disability used in India.

The National Sample Survey (NSS) figures of 1991 claims that about 1.9 per cent (16.2 million) of the total population

of the country has physical or sensory disabilities. According to estimates by the National Centre for Promotion and Employment of Disabled Persons (NCPEDP), this number is more likely to be between five and seven per cent<sup>6</sup>. World Health Organization's (WHO) estimate is between five and six per cent while other UN organisations put the figure at as high as 10 per cent.<sup>7</sup>

Since Independence, the first Census that considered disability was in 1981. In the 1991 Census, the issue was again ignored. In 2001, after intense lobbying, one question on disability was added to the Census. The data has just been released. The Census of India 2001 gives an estimate of 2.2 per cent of the population as persons with disabilities in India of which 1.6 per cent is in urban areas and 0.6 per cent in rural areas.

### **Women with Disabilities**

Women as a group are vulnerable regardless of the caste, class and religion to which they belong. Undoubtedly, several problems concerning girls and women with or without disabilities are common. Disability adds to this vulnerability and aggravates the situation.

Women with disabilities are not considered able enough to fulfil the role of a homemaker, wife and mother and conform to the stereotype of beauty and femininity in terms of physical appearance. Women with disabilities are looked down upon not only by their communities but also by their families.

<sup>6</sup> NCPEDP: Bare Facts, [www.ncpedp.org](http://www.ncpedp.org)

<sup>7</sup> E. Helander, 'Prejudice and Dignity: An introduction to Community-based Rehabilitation', UNDP, 1982. One in 20 is a conservative figure with some sources suggesting that 1 in 10 of the world's population may be defined as having a disability.

The most vulnerable and neglected among women are therefore those who are disabled. Women with disabilities suffer double discrimination, both on the grounds of gender and impairment. They not only face the normal difficulties disability imposes, but also are socially excluded. However, there are very few disability studies that focus on the experiences of women with disabilities. As in many other

research studies, general conclusions are drawn based on data obtained primarily from the experiences of men. While men with disabilities have specific and valid concerns, the same is true for women with disabilities. As such, 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.



## 2. Methodology and Process of the Study

UNNATI - Organisation for Development Education and Handicap International undertook a joint initiative on 'Enhancing the participation of civil society in mainstreaming persons with disabilities in the development process'. It seeks to provide information and change the attitudes among the various actors of civil society so as to facilitate full participation of persons with disabilities in the process of development. The wider aim of the project is to include persons with disabilities in the mainstream by (a) creating awareness on the need and measures to promote inclusion of persons with disabilities, (b) identifying stakeholders in civil society who can play a critical role in inclusion, (c) orienting them to issues of disability and the role they can play, and (d) establishing linkages and networks among various stakeholders.

The present participatory action research study was undertaken as an integral part of this project and aims to develop a better understanding of the needs, potential and rights of persons with disabilities in Gujarat. It also tries to explore the ways in which various stakeholders can contribute in making public spaces barrier free, enhancing the access of persons with disabilities to government schemes, services and other facilities and including them in their ongoing activities.

Efforts have therefore been made to define 'disability' in its local context that

varies from village to village, depending on the existing culture. This study also offers a synthesis of the views and experiences of persons with disabilities themselves through formal and informal group discussions. Emphasis has been placed on understanding the issues of women with disabilities.

### 2.1 Methodology

The study was designed as an action-research project using participatory research methods as well as the questionnaire survey method. The Participatory Rural Appraisal (PRA) process raised awareness in the community about the rights and potential of persons with disabilities and explored the role of various stakeholders to achieve the overall goals of the project. Most importantly, the persons with disabilities participated actively and decisively along with other members of the community for the first time to examine the issues related to disability.

The study was carried out in partnership with 13 organisations working in four districts of Gujarat, namely Ahmedabad, Patan, Sabarkantha and Vadodara, and covered a total of 7 talukas, 55 villages and 8 urban slum areas.<sup>8</sup> A team that included members from partner organisations, UNNATI and HI, conducted the study. This team was oriented and sensitised to the methodology and the issue before undertaking the exercise.

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<sup>8</sup> The partner organisations selected three to five villages from their work area for undertaking the study, depending on the time and resources available to them.

Participatory methods were used to develop a joint understanding of the disability issues. This was followed by a questionnaire based survey. A total of 1154 persons with disabilities were surveyed who were identified by the community or by themselves as persons with disabilities during the PRA. The PRA methods used included Transect walk, Social mapping, Mobility mapping, Venn diagram, Stakeholders' meet and Focus group discussion. Interactions between persons with disabilities and the community in an open environment helped explore many interpersonal perceptions on the issues, which were rooted in ignorance about each other and lack of interaction based on concepts of equality and respect.

The qualitative and quantitative data were separately analysed and used to look at various aspects of the life of a person with disability. The data was shared with partner organisations through workshops to ensure that information, particularly the qualitative aspects, were not missed out in the process of analyses and documentation.

Some of the key steps followed in the study are as follows:

#### **(i) Orientation of Community Based Organisations**

During our work in earthquake-affected areas, it was realised that development organisations need to interface with persons with disabilities in their ongoing work. Development organisations have a major role to play in mainstreaming disability. Poverty and vulnerability reduction initiatives often lacked a strong understanding of the issues of persons with disabilities. The participation of

persons with disabilities was severely limited and constrained in many ways leading to the intervention being welfare oriented rather than rights based.

Given this context, a workshop was organised to dialogue with the community based organisations (CBOs) working on vulnerability reduction. The objective was to build a collective understanding on the issues of persons with disabilities. Altogether 16 CBOs attended this workshop.

During the consultation with the CBOs, it was felt that the use of PRA methods as well as conventional methods (quantitative methods) would enhance the understanding of the issues. It was also felt that the research study itself would raise awareness of the community on the issues, rights, aspirations and potential of persons with disabilities. It would also provide them a platform to express their needs, views and perceptions.

#### **(ii) Designing the Study**

The next step was designing the steps for the participatory action research. Many of the organisations had used PRA as a tool while addressing other issues. However, using PRA for understanding disability issues was new. Therefore the plan was collectively evolved.

PRA tools that were to be used during the study were outlined. A manual with guidelines for using each tool was prepared. It included the objective for using each tool, the procedures and the information to be collected through the use of the tool. It also provided a list of do's and don'ts for undertaking participatory research. As part of designing the study, a pilot PRA was undertaken in one village

of Dholka *taluka* of Ahmedabad district. This helped in finalising the tools to be used and designing a questionnaire for collecting quantitative data. Most importantly, it provided an opportunity for the group to arrive at a common understanding on how to use PRA tools for addressing disability issues.

The nature and scope of the study and the sample was discussed individually with each organisation and also in the group. Each organisation selected the sample area according to their field activities. 3-5 villages from their work area were selected for undertaking the study based on the time and resources available with them.

### **(iii) Field Level Activities**

#### *(a) Demonstration of Tools*

To further build the capacity of the research team of all the organisations a demonstration of tools was organised. A team from UNNATI and HI visited each organisation and, along with a 2-3 member research team conducted the first PRA in one village selected by them. The participants were introduced to PRA tools. This was followed by a visit to the village. The team stayed in the village for three days and demonstrated each tool and built an understanding of how each tool could be used to collect and collate data as well as created awareness among the community on the issues. At the end of each day, the team reviewed the information collected and the tools used. This helped in refining the process further.

#### *(b) Conducting the PRAs*

The PRAs helped collect information through interaction with the community and persons with disabilities. It helped in exploring the needs and potential of persons with disabilities by listening to

their views and ascertaining their specific problems.

The participatory methods used included Transect walk, Social mapping, Mobility mapping, Venn diagram, Stakeholders meeting and Focus group discussion.

Transect walk through the village helped the team to get familiar with the village and served as an entry point. The existing services and facilities, settlement pattern of the village, existing trades, cropping pattern, social and economic status and other specific aspects of the village were documented through observation and informal dialogue with the community during the transect walk.

The community prepared the social map of the village. It helped in developing a comprehensive understanding of the economic, social and physical aspects of the village. This exercise helped in identifying the houses of persons with disabilities. It initiated a process whereby the community started reflecting upon the situation of the persons with disabilities in their area and their specific needs and abilities. Many persons who were not recognised as persons with disabilities were identified during the process.

The mobility mapping exercise carried out with the persons with disabilities and the community helped to collect details on services that are available to the persons with disabilities within the village and the closest point to access services that are not available in the village.

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 expectation 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.

The stakeholders meet helped in identifying various individuals and institutions within the village that influence the life of persons with disabilities. Through this process, areas where persons with disabilities are excluded were identified and ways and means of achieving inclusion with the help of various stakeholders were explored.

The focus group discussion with women by women field workers allowed women with disabilities to openly share their views, needs and problems faced.

*(c) Collecting Quantitative Information*

Quantitative tools were used to collect specific information on persons with disabilities. A questionnaire was prepared in consultation with the partner

organisations. This questionnaire filled by the person with disability or their families' generated information on their general profile, status of education, vocational training, employment and earnings.

*(d) Documentation*

A format was prepared for documentation in consultation with partner organisations. A pre-defined format was developed to record information at the village and family level. It also helped to document information collected during the PRA.

**(iv) Workshop for Experience Sharing**

After the entire process was completed a two-day workshop was organised in which all the partner organisations shared their data and observations. The purpose of this workshop was to get an overview of the information and to reflect on the factors that had helped or hindered the inclusion of persons with disabilities in the



PRA process. The field areas varied and therefore there were learning values from the field. It was important that the participants shared their experience to help enhance their learning. It also helped to ensure that information, particularly the qualitative aspects, were not missed out in the process of analyses and documentation.

The workshop helped in a joint analysis of the issues faced by persons with disabilities. One issue that was mentioned by all the participants was the relation between 'Disability and Poverty'. It was noted that when poor people faced disability they did not have the means to overcome it. The second issue highlighted was that persons with disabilities were not only excluded from social, cultural and economic process but also deprived from schemes and facilities that were specially meant for them. This provided the partner organisations a direction to work on the issue.

The workshop also explored the possibility of using PRA methods in researching other issues, thus, highlighting their advantages and disadvantages. While discussing the drawbacks of the methods, the teams also described the methodological innovations and changes that they made to achieve the intended objectives of the study, thus adding to the collective understanding of the process.

It was clear from the beginning that the study process would not be providing any tangible benefit to the village community. A need was felt to contribute to the knowledge and information on the village. Therefore a format for a model village profile was prepared to document the information. The profile would provide comprehensive information on the villages and would be available in a simple usable form at a central point either at the panchayat office or with the organisation involved in the study. This information can

be used for future planning and action for the village. Information on the village was collated and some data has been put in the format. This needs to be updated as and when required. The organisations and the community took up the responsibility of updating the information on an ongoing basis and mainstream disability issues in the development work. It is a reiteration of commitment to pro-active social inclusion.

## **2.2 Inclusive Social Enquiry: Challenges**

In the study, efforts were made to include all stakeholders of the society so as to understand how each of these groups can be integrated with the other. This facilitated the process of direct interaction of persons with disability with the community and thus promoted their inclusion. In the process the team had to face several challenges. It is important to note that to overcome these challenges different partners/CBOs have used different methodological innovations. Some of them have been documented here along with the challenges.

Many families were apprehensive to send the persons with disabilities to the PRA. It was difficult to seek co-operation of people in such cases. In one of the villages, there was one woman with disability who was reluctant to speak to the outsiders; till the end it was not possible to seek any co-operation from her. In many instances persons with disabilities were brought to the meeting by friends and relatives with the expectation of receiving some benefits even though it was communicated that the PRA is being conducted to share and learn about the issues of persons with disabilities with their participation. This was because it was for the first time in many villages that

the issues of disability were being discussed.

Persons with disabilities were keen to interact but often did not feel free in large groups and felt more relaxed in smaller groups. During group discussions, most of the persons with disabilities sat at the back and participated only when specifically asked to. When asked about this, they said they were embarrassed to express their opinions in front of other people since they had never done it before. In order to create an enabling environment for focus group discussions, the facilitators used flash cards in many cases; in other cases, a film on 'disability' was shown. In most cases, *sarpanch*, school principal, and other leaders of the community were very co-operative. In such cases it was not difficult to seek co-operation from the community.

During the group meetings and participatory exercises, the persons with disabilities did attempt to talk. However, it was observed that in 44 per cent of the cases they were interrupted either by their family members, the *sarpanch* or others in the group. This discouraged them and in some cases they even left the meeting midway. This was particularly so in the case of women with disabilities. They were dominated by all groups and discouraged from interacting in the meetings. Special efforts were made to interact with them individually at their homes and with their families. In many cases persons with disabilities prepared a separate map on the ground with natural colours that they themselves had managed to collect. Subsequent collective analysis of the PRA process helped in generating awareness on attitude and behaviour towards people with disabilities.

Similar was the case in villages having a *dalit* and *non-dalit* divide. Villages having mixed community of Hindus and Muslims were quite sceptical about the PRA. In the backdrop of the communal riots (2002) the villagers were reluctant to express anything openly. Spending time with the community for some days at a stretch helped. During that time, the team explained to them and the village leaders the reasons for conducting the PRA. It was difficult to prepare just one social map in such villages. In large and heterogeneous villages, separate social maps were prepared for separate groups of people. Moreover, the social map did not point out every house separately. Instead, the localities were just pointed out, with the mention of the houses of the persons with disabilities.

An important factor that helped in the process was the awareness of people themselves. Some of the villages that had been chosen for the PRA were already involved in conducting community based rehabilitation (CBR) work. Therefore they had some knowledge of the issue of 'disability'. In such cases, local people were very co-operative.

The priorities of the persons with disabilities were different from those of the rest of the community. Given this situation

some of the PRA methods had to be modified to look into the access to basic services from their perspective.

During the Venn diagram, the community drew the picture of the services they wanted to access, on the circular piece of paper kept for the purpose. The importance given to each service was pointed out with respect to the persons with disabilities. For example if school was considered the most important institution for common people, it was not necessarily the same for persons with disabilities; this was because the school had a flight of stairs, which is a barrier for them.

Mobility mapping was done to find out the pattern of mobility of persons with disabilities: how they commute and what mode of transport they use etc. The Mobility map was also modified to some extent to understand whether persons with disabilities commute alone or whether they take help from others. This map was also used to denote the frequency of their travel to certain places. Therefore this was plotted on the Services and opportunities map itself; and it allowed one to understand how often the persons with disabilities traveled outside their village – or whether they always remained confined to their homes.

### 3. Barriers Faced by Persons with Disabilities

It is important to have a clear understanding of the current situation of persons with disabilities, the physical and social barriers they face on a daily level and how their own attitude and behaviour are shaped. Since women are vulnerable, particularly women with disabilities, it is important to understand the problems faced by this group and their special needs. This would be useful in making the right intervention and in achieving the goal of inclusion of persons with disabilities.

This chapter looks at the profile, needs, barriers, attitudes and behaviour of persons with disabilities. Special effort has been made to understand disability issues from a woman's perspective.

#### 3.1 Types and Causes of Disability

It has been found that there are more men with disabilities (60 per cent) than women (40 per cent).

One possible reason for this is that women disclose their disabilities less frequently than men with similar problems due to existing prejudices. It was also observed during the study that since women in rural areas continued working in spite of their disability, many of them were not recognised as being disabled. "It has been found that often in India, families do not disclose the disability of their family members to others due to the stigma attached. There are also cases where family members may not be able to recognise minor disabilities"<sup>9</sup>.

The age profile is as follows: 5 per cent are below 6 years; 28 per cent are between 6-18 years; 7 per cent between 18-45 years and 13 per cent between 45-60 years. In 60 per cent of the cases disability occurred below the age of 1, in 10 per cent cases during the period 1-6 years i.e. 70 per cent were disabled before they could go to school. Since this is the most critical age for future health, it is imperative that

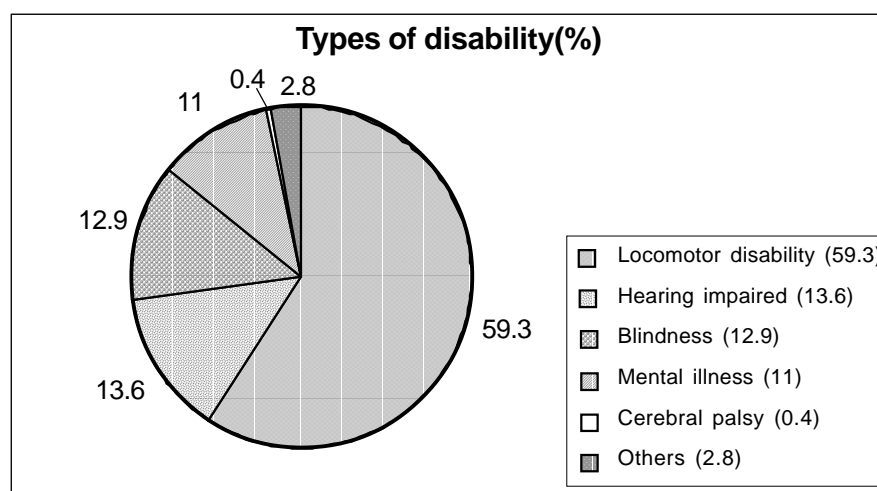


Fig. 3.1

<sup>9</sup> 'Disability in India' in 'Just People... Nothing Special, Nothing Unusual'... Action Aid India



a high standard of nutrition and care be maintained during this period. 15 per cent were disabled between 18-45 years.

Physical disability (polio and others) accounted for 62 per cent of the cases. There were 13 per cent visually impaired, 11 per cent mentally impaired and 14 per cent speech and hearing impaired persons in the sample. See Fig. 3.1

The cause of disability was not known to the persons with disabilities or to their family members. 54 per cent were disabled from birth and the reasons for this are not understood by the family or community. About 27 per cent of the disabilities were caused due to certain illness, disease or delayed medical attention. Many families reported that their child had high fever or had been given an injection that led to the disability. 12 per cent of the disabilities were due to accidents. It is important to note that many of the causes enunciated by the community were related to the availability of and accessibility to basic services and hence are also issues for advocacy.

The physical abilities of persons with disabilities vary a great deal which gives a clear indication for the need to create opportunities and an enabling environment so that they are capable of performing independently within their community. 74 per cent of the persons with disabilities in our sample can stand, 70 per cent can walk and 87 per cent can eat and bathe on their own. However, only 55 per cent could go out of their house on their own without support. We also found that only 44 per cent can read. This is because books in Braille or audio formats are not readily available for those with visual

impairment. This could also be due to the fact that fewer children with disabilities go to school and those who go also drop out due to various barriers. Only 20 per cent of the persons with disabilities in our sample could do their own exercises.

## 3.2 Social Engagement and Needs

### 3.2.1 Social Needs

People with disabilities like anyone else have social and psychological needs. They need to interact with friends, neighbours and other members of the society. Many people have no experience of interaction with persons with disabilities. For reasons of access, social stigma and poverty, many of them live their lives in virtual isolation; they are kept in their homes and are denied a normal life in the community. As Javed Abidi of the NCPEDP has noted, "There are hundreds of thousands of households where the kids are just hidden away."<sup>10</sup>

Many persons with disabilities were brought by others to participate in the group discussions held during this study, although it was clearly stated that they were not to receive any material benefit from the process. The discussions were about persons with disabilities and since 'disability' as a subject *per se* had probably never been discussed with them before they were motivated to participate.

The findings highlight that the participation of persons with disabilities in activities within the community was limited. In our study area 47 per cent of persons with disabilities attended both social and religious functions, of which 53 per cent attended only religious functions. Persons

<sup>10</sup> In his article 'This Country has to Change' in David Bornstein, 'How to Change the World', Oxford University Press, New York, 2004



with disabilities are discouraged from attending social functions like a marriage, while most of them take part in religious functions.

The group discussion revealed that there were cases where friends have stopped visiting the persons with disabilities and since mobility is limited they find it difficult to visit others. Relatives usually take them to temples and mosques during religious celebrations. This could also be due to the fact that most villages (65 per cent) had at least one temple and many had 5-6 temples and some (6 per cent) had mosques also. They do not visit religious places outside their communities because of the physical hurdles (staircase leading to temple) they have to face. Sometime the non-disabled carried the persons with disabilities to the temple but this did not happen in the case of other social occasions.

Women with disabilities are found to be socially insecure. The study highlighted

several situations in which women were abused and exploited. To protect them, girls are not sent outside the village and in homes for the mentally retarded, women are sterilised to avoid pregnancies.

*In Kalyanpura village in Banaskantha district a mother related her story of how she has to keep constant watch over her 19-year old daughter who is mentally retarded. She fears that her daughter will be abused by the village youth.*

*In Kanotar village of Dholka taluka of Ahmedabad district we were told the story of a woman with disability who was abused several times in the mill where she worked. She was economically backward hence she could not leave the job. Her husband abandoned her when she became disabled. She was the sole support for her children.*

### 3.2.2 Family Life

The marital status of persons with disabilities is crucial to understanding their social status. 54 per cent of disabled adults are not married, 6 per cent are widowed and 1 per cent is divorced. In many cases the reason for divorce was the disability of the spouse that may have occurred after marriage. There were many instances where couples are not divorced yet they live separately, especially when the wife becomes disabled. Many men also force their disabled wives to leave home so that they can live with other women. Women on the other hand continue looking after the needs of the husband and families even when their husbands are disabled and unable to earn a living. This is particularly true in cases where the disability occurs after marriage. There are cases where men marry a second time while the wife who has become disabled continues doing the household chores.

*Ramilaben (name changed) lives with her husband in a small village of Prantij taluka of Sabarkantha district of Gujarat. Her husband suffers from hysteria and often cannot go for work. Ramilaben takes care of her family and earns a living by selling bangles in the neighbouring villages. She is also involved in the development activities of her village. She continues to live with her husband and two children bearing all the responsibilities despite her husband's disability.*

Data shows that while 59 per cent of the men with disabilities are married, only 41

per cent of the women with disabilities are married. In all age groups the number of men who were married was higher than women. In the older age group (40-50 years and above 50 years) there were twice as many married men as compared to women.

Interestingly, the group discussions showed that men with disabilities look for non-disabled partners, while women with disabilities are married either to men with disabilities or to men who belong to socially and/or economically weaker sections of society.

**Table 3.1 Disability at married couple level**

Sex	Non-disabled spouse (%)	Disabled Spouse (%)
Male	81	19
Female	55	45

Several reasons emerged from the discussions with non-disabled and persons with disabilities from the community. The community seemed to look down upon persons with disabilities as 'creatures of mercy' and hence incapable of marriage. Similarly, they seemed to consider themselves as 'useless' and see marriage as a burden.

- Half the adult persons with disabilities find it difficult to find marriage partners
- 60 per cent adult women could not get married
- 40 per cent adult men could not get married
- Among married persons with disabilities 19 per cent of men with disabilities have wives with disabilities.

- *Among married persons with disabilities 45 per cent of women with disabilities have husbands with disabilities. See Table 3.1*

### 3.3 Economic Engagement

#### 3.3.1 Economic Needs

Disability creates poverty and vice versa. A person with disability is poor as a result of the loss of income due to his/her disability. Similarly, poor people are more likely to suffer from preventable disabilities, particularly those involving malnutrition and birth injuries. Despite the PWD Act, 1995, persons with disabilities are still denied employment on the grounds of their disability. Those who acquire disability during their period of service are either generally asked to leave or are forced to resign through direct and indirect pressures in the working environment.

Persons with disabilities who have shown their proficiency in certain fields (Beethoven, Stephen Hawking) are still considered by the general population as exceptions rather than the rule.

It is also important that the skills and potential of persons with disabilities are

*Samir Ghosh, an employee of Tata Steel, who lost his hands and arms in an accident, explains: "I was turned down for the IAS exams because I wouldn't be able to ride a horse; I am yet to see an officer ride a horse to work."<sup>11</sup>*

recognised. In the absence of any recognition of their potential, they remain uneducated and unemployed, leading to increased vulnerability and exploitation.

In 1977, the GOI announced a three per cent reservation for persons with disabilities in Government jobs, but limited its notification only to jobs in the 'C' and 'D' categories (clerical grades). Sadly, two decades later, the percentage of persons with disabilities employed has not reached even one per cent.<sup>12</sup> The GOI has also identified 1400 jobs that are reserved for persons with disabilities. However, it has been noted that many of these jobs require high levels of skill and qualification and are more appropriate for the urban population. It is not easy for the rural youth to make effective use of this reservation.

Assistance is also provided by the National Housing and Finance Development Corporation (NHFDC) to set up self - employment projects. In Gujarat such assistance is routed through the *Mahila Arthik Vikas Nigam*. However, loans have not been granted for the past 2 years since the organisation gave up the responsibility.

Our study reveals that 93 per cent of the persons with disabilities in the age group of 18-45 years have not received any income generation skill training (vocational training). Considering this age as the most productive period, we lose out on the contribution of this group to the economy. Studies conducted by various organisations claim that there are 7 million employable persons with disabilities in India, out of which only 1 lakh were

<sup>11</sup> Pritha Sen, et. al in their article 'Trying to Grow', Feature story in Outlook, June 1998.

<sup>12</sup> Bare Facts by NCPEDP, 1999



employed in the government sector during the period 1958-98.<sup>13</sup> Further NCPEDP claims that India has 6 crores of persons with disabilities and taking Rs. 500 as a nominal monthly cost of living per person the amount is Rs. 36,000 crores per annum. If persons with disabilities were made self-reliant, India's wealth creation would increase by a minimum of Rs. 36,000 crores per annum.<sup>14</sup>

In all the villages studied, the persons with disabilities were trained in limited skills, which included basket making, weaving, embroidery and typing.<sup>15</sup> In the absence of special training and opportunity to contribute their full potential, they end up doing manual work for small sums of

money. In many cases their employers also exploit them. Even the training that they had undergone did not help them to earn a living. 53 per cent were not earning; 34 per cent of the persons with disabilities in the age group 18-45 years were earning less than Rs. 1000 per month, 8 per cent were earning Rs. 1000-2000 and 7 per cent were earning above Rs. 2000 per month. Only 35 per cent of the persons with disabilities in the age group 45-60 years were earning.

The main source of economic activity in the village being agriculture and dairy, persons with disabilities, particularly women, found employment in this sector. 60 per cent of the villages have milk

<sup>13</sup> NCPEDP: Bare Facts, [www.ncpedp.org](http://www.ncpedp.org)

<sup>14</sup> As quoted in the poster published by NCPEDP in 1999

<sup>15</sup> In Gujarat people learn these crafts from members of their family.

cooperatives. But in many villages it is situated in the upper floor, which makes it inaccessible.

Women with disabilities are engaged in both household and economic activities while men with similar disabilities may not be working. Our study revealed that 84 per cent of women with disabilities are engaged in either household or economic activities. In rural areas while women were involved in agriculture, in urban areas they were engaged in tailoring, embroidery, vegetable vending and in daily wage labour.

Relating the status of employment/income of persons with disabilities with the number receiving vocational training, it can be said that people in rural areas should be given need-based training. It is important to note that 80 per cent of all economic activities in India are in the informal sector. Therefore, the kind of skills required for jobs in the informal sector need to be recognised. This would not only help people to become economically independent, but also lessen the burden on the government to provide social security measures to large numbers of unemployed youth.

Without equal opportunity for gainful employment, persons with disabilities are dependent on their family members and others for their living. They remain at the mercy of the non-disabled. However, in our

*Karsanbhai (name changed) residing in Umedpura village of Idar taluka is a person with disability. He learned basket making as a part of his vocational training. However, he is generally found dragging himself around the village with his feet affected by polio. Although, he had tried his best to establish a business, hoping to utilise his vocational skills, he had problems in managing accounts and marketing the products. He was forced to close down before he even got started. In his words, "Soon I realised that there are too many people already in this business, with better skills."*

study area we came across cases where persons with disabilities took up the economic responsibility of their families.

The media often portrays persons with disabilities in the traditionally accepted roles of begging and as dependent on others. However, there is a gradual shift in the media towards highlighting the potential of persons with disabilities, their needs, skills and adaptability to the external environment. Films<sup>16</sup> can have a very powerful impact on sensitising people. Therefore, there is a need to produce and screen more audio-visual aids in changing the mindset of the community.

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<sup>16</sup> Action on Disability and Development (ADD) India has made a documentary film 'Unheard Voice' on the abilities of persons with disabilities. ADD India is an organisation working in Bangalore for the empowerment of persons with disabilities along with other related issues. This film was dubbed in Gujarati and screened in all the villages where the study was carried out. This helped to create awareness among the communities on the potential of persons with disabilities and also in creating a better understanding of the issue.

### 3.4 Special Needs

Persons with disabilities have needs similar to those of any other person; however they also have certain special needs. The GOI has made certain provisions in the PWD Act 1995. This Act was formulated to ensure that all persons with disabilities get their right to lead a dignified life. Some of the key provisions include providing a disability certificate, which would help the persons with disabilities to avail themselves of government services that are provided specially for them.

In the 63 areas studied, 71 per cent of persons with disabilities have a disability certificate. For the rest the main reasons for not having a certificate were that camps for certification were not held in their village and the institution that was issuing the certificate was far. They did not have relatives or friends who could take them for certification. 19 per cent did not know about the disability certificate.

Even those who had certificates had used it only to access certain benefits like getting a bus pass or educational scholarship. Most families were not aware that children with disabilities, if certified by a doctor, are entitled to educational scholarship. Those who availed themselves of scholarships had used their certificate for Scheduled Caste (SC) under the reserved category. Only 3 per cent of the persons with disabilities had received monetary support from the government on a regular basis.

There is a provision under government schemes to provide aids and appliances to persons with disabilities free of cost through institutions established specially for the purpose. However, many of them have no access to these devices and have compensated in other ways due to lack of awareness. In the study area, 75 per cent were not using aids and appliances and 20 per cent did not provide any information on this.

Many of the persons with disabilities did not want to use aids and appliances since they had adapted to their condition and they did not want to change their pattern. Another reason was that they found it difficult to repair the aids and appliances in the village. Wheelchairs were not being used because in rural areas they found it difficult to use it on muddy and uneven roads. Tricycles were a preferred mode of transport. Many were also not aware that aids and appliances are available free of cost through government schemes on submission of income and disability certificates.

### 3.5 Access to Services

Persons with disabilities face a number of obstacles simply because of environmental and physical barriers. Often, they are left out and remain excluded from the mainstream society because most public places are out of their physical reach. Roads, transport, public buildings and toilet facilities are all designed with able-bodied persons in mind.<sup>17</sup> Barriers deny people the

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<sup>17</sup> Professor S. Balaram in his article 'Barrier-free Architecture', "We design buildings for people who are assumed to be always young and in perfect health." "Are built spaces accessible to the children, to the elderly, to the pregnant, to those of us with any form of disability - temporary or permanent?" According to him, the indifference to this section of society thus is nothing but a violation of basic human rights such as equality and non-discrimination.

## **Government Provisions for Persons with Disabilities**

*To provide support to persons with disabilities and to help them become as self-reliant as possible, the Government of India has made several provisions for them and their families. These include free education till 18 years of age, reservation in particular jobs and educational institutions, concessions for travel, provision of aids and appliances, income tax relief measures, housing finance, vocational training, entrepreneurship and finance for self-employment.*

*To improve the accessibility of buildings and infrastructure in Gujarat as per the regulations of the Gujarat Town Planning and Urban Development Act, 1976, Chapter 28 of the Ahmedabad Regulations provides for making buildings and public places accessible and barrier free. However, such provisions are not implemented in practice. The state of rural accessibility is even worse given the poor quality of roads, transport and lack of awareness among builders and contractors.*

opportunity to participate fully in life. This includes exclusion from educational, economic, social and cultural spheres.

Access to basic services and support system, on account of long and cumbersome procedures and the bureaucratic system, is also another major form of barrier for a person with disability. In addition, people have very little information about many things that could make their lives more comfortable.

Some of the services that persons with disabilities would access are schools, health centres, bus stops, telephone booths, religious places, banks and shops.

### **3.5.1 Access to Education**

43 per cent of persons with disabilities in the study were illiterate and 57 per cent were literate. However, there were more literate men (48 per cent) than women (35 per cent). 65 per cent of the women

**Table 3.2 Literacy among persons with disabilities**

<b>Sex of persons with disabilities</b>	<b>Illiterate</b>	<b>Literate</b>	<b>Total</b>
<b>Male</b>	52%	48%	706 (61%)
<b>Female</b>	65%	35%	448 (39%)
<b>Total</b>	656 (57%)	498 (43%)	1154 (100%)

Ignorance about the existence of services, aids and appliances are also barriers.

have never been able to go school, while boys are encouraged more to go to school. *See Table 3.2.*



If we look at the percentage of boys/ girls with disabilities in each level of schooling, it is clearly seen that more boys go to school than girls. As we go to higher levels this gap widens. See figure 3.2

Girls with disabilities drop out of school more frequently than boys with disabilities. Parents point out that their disabled daughters are vulnerable to men who tend to take advantage of their weakness. Given this social insecurity, parents refrain from sending their daughters with disabilities to schools outside the village. In addition, lack of access to facilities like toilets and drinking water makes going to school even more difficult for these girls.



Primary schools exist in 98 per cent of villages, while there are high schools only in less than 20 per cent villages. This makes education beyond the primary level less accessible to children in rural areas who have to travel long hours and walk long distances to get to school. For children with disabilities, such conditions

are the main barriers to access to educational institutions. In addition, the physical structure of schools is not barrier free. Problems in dealing with uneven roads, stairs in the building structures, lack of toilet facilities, etc. dissuade children with disabilities from seeking formal education.



Those children with disabilities who do manage to enrol in primary schools because of their strong determination are often deterred by their own families from going outside the village to attend high school. In the study, there are 354 children with disabilities between 4 and 18 years, who are of school-going age. Out of these children, only 203 (or 57 per cent) are actually attending school.

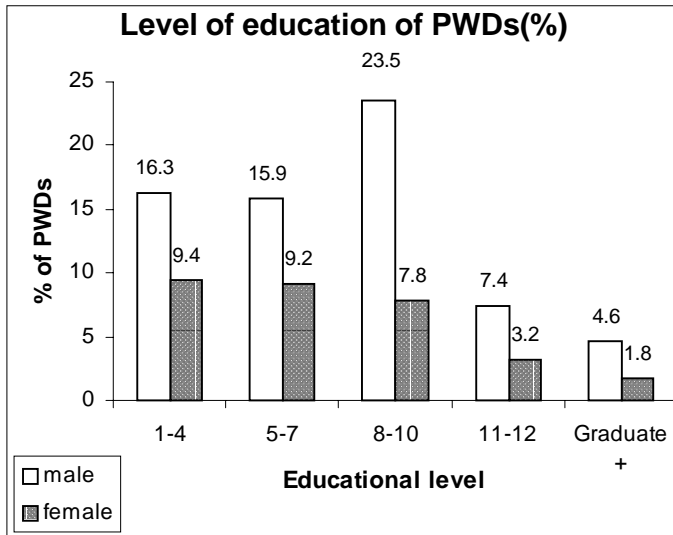


Fig. 3.2

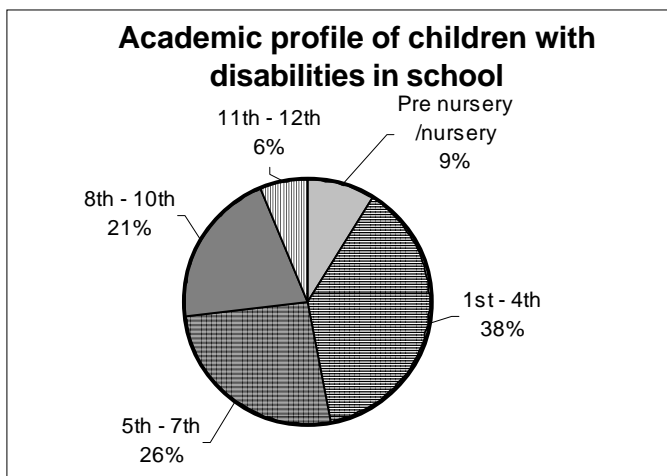


Fig. 3.3

Figure 3.3 highlights the profile of children with disabilities going to school. It reveals that 38 per cent of children are in primary school (1<sup>st</sup>-4<sup>th</sup> standard), 26 per cent are in middle school (5<sup>th</sup>-7<sup>th</sup> standard), 21 per cent in secondary school (8<sup>th</sup>-10<sup>th</sup> standard) and 6 per cent in the higher secondary (11<sup>th</sup>-12<sup>th</sup> standard). Of the 203 children with disabilities going to school, only 6 per cent have completed their 10<sup>th</sup> standard and are continuing

their studies. More than 45 per cent of the disabled population going to school is studying below the 5<sup>th</sup> standard, i.e. in primary school.

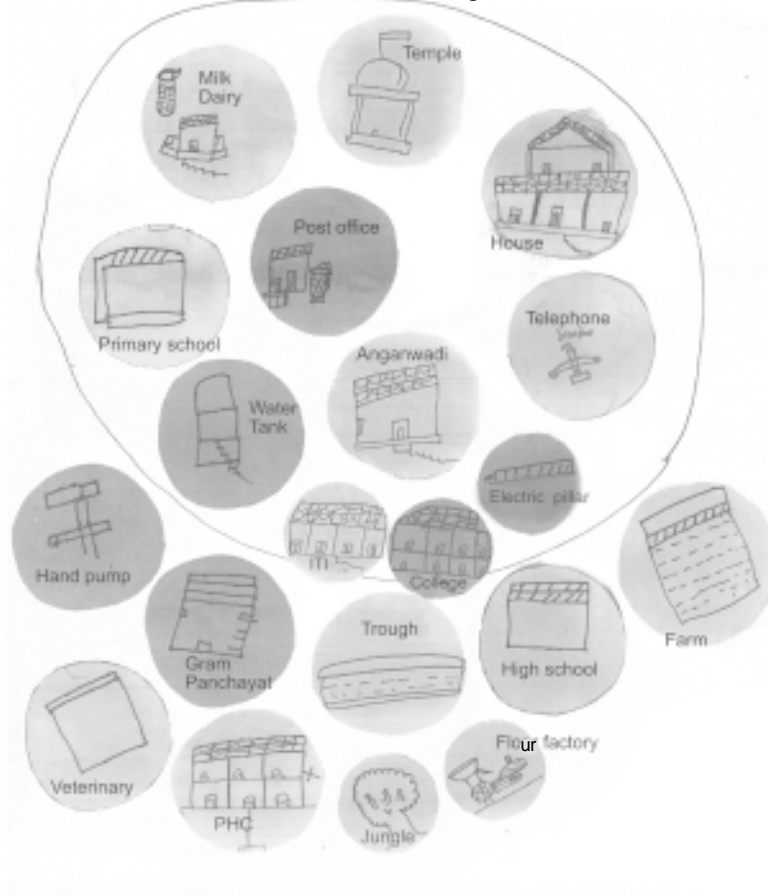
Many children with disabilities drop out of school for various reasons. It was found that there are drop-outs either after primary (class IV) or after secondary school (class VII). The reasons quoted for drop-outs are similar to those for low enrolment. The causes of high rate of drop-outs, particularly among girls, are the absence of toilet facilities at schools and the belief that women will anyway get married and take care of their families and do not have any reason to be educated.

Girls in general and girls with disabilities in particular have greater restrictions on attending school outside the village. Discussions with their mothers revealed that their daughters are prone to abuse and exploitation



### Venn diagram

Urban Cluster: Pravin Nagar, Ahmedabad



The discussion with the community revealed that a government nurse visits every village regularly on certain days. Studies on primary health in Gujarat show that in many PHCs the doctor's presence is irregular<sup>18</sup>. In rural areas 60 per cent of the population do not access a PHC and prefer to go to a private clinic. This percentage is 90 in tribal areas.

A participatory exercise - Venn diagram<sup>19</sup> - was undertaken at the village level to collect data on the ranking of institutions/services in the village in terms of their function and importance for persons with disabilities. In many villages the size of the circle denoting the PHC

was small reflecting poor/inaccessible services. In some villages in Sabarkantha district no circles were placed for the PHC since the doctor never visits the centre.

by those who tend to take advantage of their weakness. Parents are unwilling to send their daughters to schools outside the village because of their vulnerability to abuse.

### 3.5.2 Access to Primary Health Care

63 per cent of the villages that were covered under the study do not have primary health centres (PHC) in the village. These villages are covered by the PHC located in a nearby village.

Data shows that about 27 per cent of disability was the result of disease and/or poor medical treatment. This also indicates the low standard of health services and lack of access to primary health care at the village level. Specialised care is usually available only at the district/taluka level,

<sup>18</sup> Health Monitor, Foundation for Research and Health Systems, Ahmedabad, 1997 and The State of Our Primary Health Centres – A Study of 40 PHCs in Gujarat, UNNATI, 1997.

<sup>19</sup> The exercise uses circular pieces of paper to denote the level of reference for a particular institution/service existing at the village. The size of the circular piece denotes the level of importance. The larger the size of the circular piece the greater the preference and vice versa.



making these services even more inaccessible to persons with disabilities.

Often, we found that village health workers were unaware that mental illness and mental retardation are also types of disabilities and that, in general, the staff of most PHCs have limited information on the various causes of disabilities. Educating health workers on types of illnesses that can result in disability could be effective in reducing the overall level of disability.

Anganwadis are part of the Integrated Child Development Scheme (ICDS). They are expected to provide supplementary nutrition to expecting women, mothers and children up to 6 years of age. In 95 per cent of the villages where the study

was carried out Anganwadis exist. However, the community is not able to access these services.

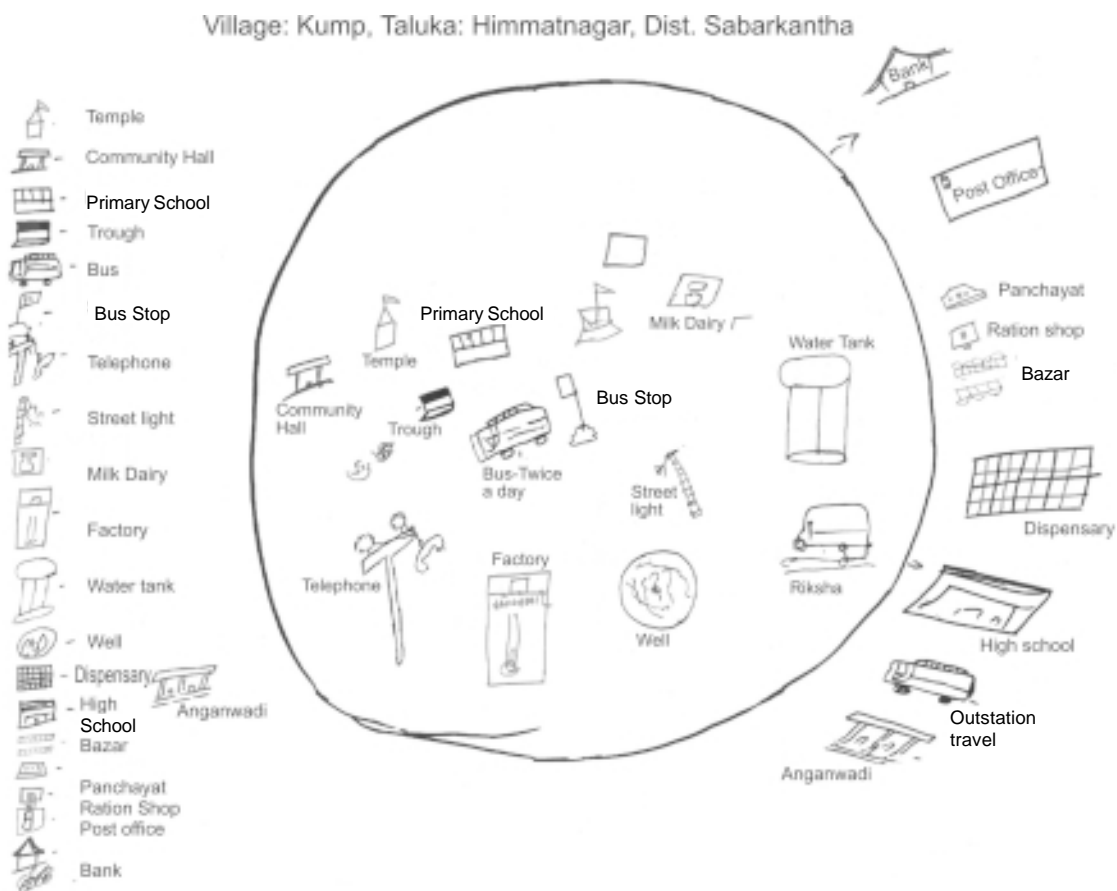
More than 50 per cent of the persons with disabilities in our study have been disabled from birth<sup>20</sup>. Often such disability can be related to poor antenatal care, inadequate nutrition and lack of complete immunisation during pregnancy. Such children do not avail themselves of anganwadi services at all.

### 3.5.3 Access to Other Services

93 per cent of the people responding (from villages and slums) do not have access to a public telephone booth. While more than 60 per cent of these villages have small shops, goods are more expensive and they do not cater to the bulk needs of

<sup>20</sup> The study has been carried out in partnership with 13 grassroot organisations, out of which 9 belong to Sabarkantha district of Gujarat. The water in these areas contains high levels of fluoride and arsenic. There is a locally prevalent belief that the high level of disability from birth is caused by this factor.

## Services and opportunities map indicating location and existence of services



the community, for which they have to go to the market at a considerable distance from the village.

Most villages did not have a bus stop. Expecting women and persons with disabilities found it difficult to access the hospital in the nearest city for lack of transport facility. Childbirth at home is common in rural areas. Childbirth in the hands of untrained dais can also add to

the risk of the child being born with impairment.

Most villages (76 per cent) do not have banks. People generally visit banks outside the village, which is a barrier for a person with disability. Even the meagre sums that they manage to earn cannot be securely saved. Group discussions revealed that in most cases such income becomes the property of family members.

**Table 3.3 Availability of other services in the study area (%)**

	Post Office	Bank	Shop	Telephone	Bus stop
<b>Yes</b>	26	24	65	7	32
<b>No</b>	74	76	35	93	68

### 3.6 Social and Attitudinal Barriers

The overall development of a person depends largely on the attitude of one's family, friends and the larger community's attitude and behaviour. A positive attitude implies belief in the skills and potential of the other and gives encouragement to be involved in various activities. A negative attitude implies non-cooperation. The same holds true for attitude and behaviour towards persons with disabilities. In our study we looked at the attitudes and behaviour of society towards persons with disabilities as well as of persons with disabilities towards themselves.

Based on formal and informal interactions with the community, we have tried to develop an understanding of the attitude of the non-disabled towards the persons with disabilities. These interactions involved discussions on the skills and potential of persons with disabilities and close observations of the interactions between them and others. The study also provided scope for interviewing several stakeholders at the village level who

*In a village in Sabarkantha district the sarpanch has tried to include persons with disabilities in the gram sabha. He showed the research team the register used during panchayat meetings in which he had specially marked the names of persons with disabilities who had attended the meetings. He also added that he sends out messages individually to inform persons with disabilities of meetings and gram sabha. This way he had made an attempt to bring the persons with disabilities into the mainstream of the local development process.*

influence the life of persons with disabilities, including the village Sarpanch, the Talati, the health officials, the school teacher(s), and the various local groups- CBOs, Women's Groups (WGs), Self-Help Groups (SHGs) existing at the village, with the goal of documenting their attitude towards persons with disabilities.

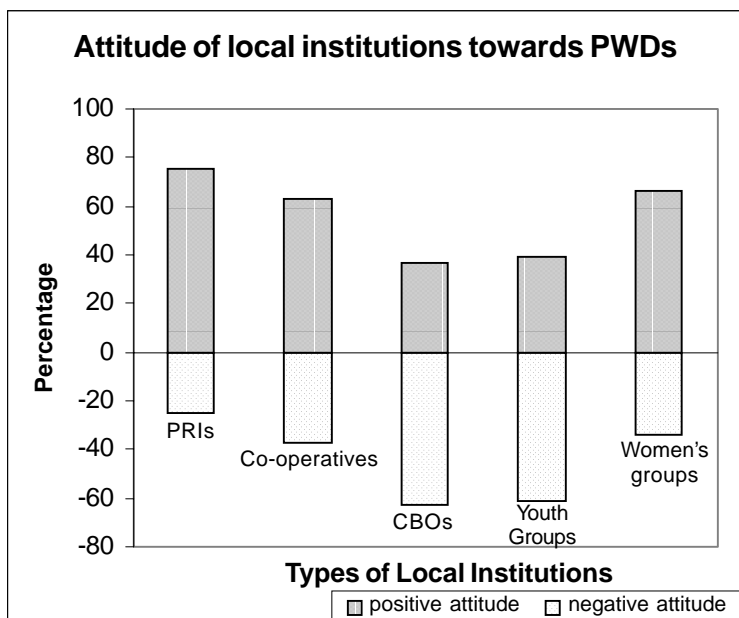


Fig. 3.4

In 75 per cent of the villages the Sarpanch showed interest and promised to extend co-operation in working with persons with disabilities. Special efforts were being made in some villages to inform the persons with disabilities about the Gram Sabha and motivate them to present their needs so that the panchayat may try to address them. In more than 65 per cent of the area studied, the

women's groups were positively inclined towards conducting awareness campaigns in the community on the needs and barriers faced by the persons with disabilities and in highlighting their skills and potential. They also felt the need to create awareness on the PWD Act 1995.

Youth groups, co-operatives schools and CBOs were not oriented to the needs of the persons with disabilities. But they expressed an interest in taking responsibility, particularly for certification of persons with disabilities of their village.

*A school in Memadpura in Prantij taluka in Sabarkantha district encouraged the participation of children with disabilities in their cultural programmes. The teachers also showed great pride in the performances of their children.*

Efforts were made to encourage them to interact freely in a group. Behaviour of persons with disabilities and the non-disabled were observed. In 75 per cent of the cases nothing specific was observed. In 11 per cent cases the non-disabled laughed at the persons with disabilities and in 13 per cent cases they were indifferent towards them.

The behaviour of family members, particularly to women with disabilities, is a matter of concern. Women who became disabled after marriage face many hardships in the family. It was found during the focus group discussion that some of the women were forced to do work at home and outside despite it being physically painful. Many women did not respond to our questions because the mothers-in-law were also present. However, there were some cases in which the women with disabilities said that the family took good care of them.

### 3.6.1 Recognition of Skills and Potential

It was found that the people in general are not sure of the skills and potential of persons with disabilities. This could be due to the fact that they rarely interact with them.

It is commonly believed that persons with disabilities lack the capacity to perform certain tasks. They are dependent on non-disabled persons (friends and/or family members) in many ways. *Bechara* (helpless) is the word often used for them in the local context. Their potential and capabilities are in most cases not known as they are not questioned. As seen in figure 3.5a, 75 per cent of the respondents

#### Belief in potential and skills of persons with disabilities

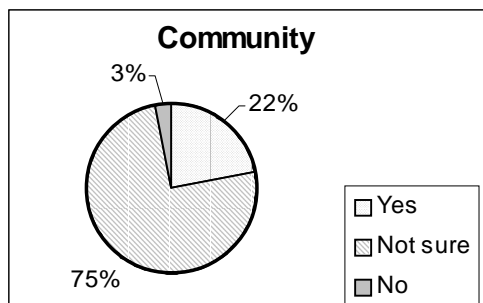


Fig. 3.5a

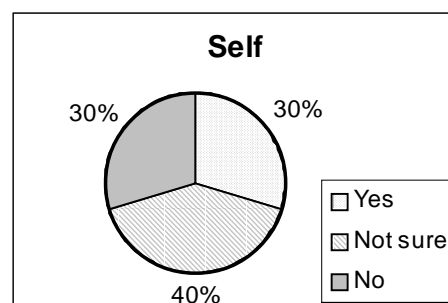


Fig. 3.5b

*Haribhai and Rameshbhai (names changed) are visually impaired. Haribhai is a tailor and Rameshbhai is a farmer from Pedhmala village of Himmatnagar taluka of Sabarkantha district. They are the sole bread winners for their families. Haribhai skilfully continues with his family profession although he is visually impaired for 15 years. Rameshbhai looks after his family and even takes them out to the market occasionally. Unless told, it is difficult to notice that he is visually impaired.*

were not sure of the abilities of the persons with disabilities, 22 per cent believed in their skills and potential and only 3 per cent did not believe in their skills and potential.

However, we came across cases where persons with disabilities have proved their skills, though the fact remains that people rarely recognise them. Hence, there is a need to document such success stories so that they become a reference for advocacy for their rights. This will also help in increasing interaction between persons with disabilities and the non-disabled.

Just as attitudes of others are important, the attitude of persons with disabilities towards themselves also determines the way they interact with the others. This also determines the way the community perceives them. Looking at the attitude of persons with disabilities towards themselves, we find that only 10 per cent did not believe in their abilities; 52 per cent were not sure and 38 per cent believed

that they had the potential and skills which they can use.

Opportunity/space and faith in their potential and abilities are important factors that help persons with disabilities to interact with others and be part of the mainstream. They certainly want to participate in the decisions that affect their own lives.

In most situations people behaved in a strange manner with persons with disabilities, not because they were insensitive but because they were not aware of how to interact with them. The study and field observations have shown that while people would like to work with persons with disabilities, few have a clear idea on how to do this. It shows the need for awareness campaigns to highlight the abilities of the persons with disabilities and for equal opportunities to enable them to achieve their full potential.

*There is nothing so special about Rambhai (name changed) of Dholka taluka of Ahmedabad district who has a locomotor disability. He weaves ropes into a special type of accessory called 'gophan' used to scare monkeys from the paddy fields. He was the only one in the village with this skill. The product had special value in the local markets. He used to sell in the village market. Youth from the community helped him to get a mobility aid, which helped him to sell his products outside the village and earn more. He also gained confidence and shared his skill with others in the village.*



## 4. Way Forward - Action Points

These action points were arrived at based on the findings of the PRA study, field based interventions carried out in partnership with development organisations, field observations, dialogue with institutions and agencies.

### **Authentic Data**

Definition of disability and identification of persons with disabilities is a major issue of concern. The inclusion of disability in the Census should be a rule rather than an exception. Mass awareness campaigns, prior to the collection of Census data, on the purpose of collecting this data need to be organised. Training of officials to overcome attitudinal barriers while collecting data could help overcome the problems arising out of lack of authentic data. There is a need to look at possible involvement of local institutions to support officials during the Census exercise to ensure maximum coverage.

### **Identification and Prevention**

Early identification of disability is important so that timely intervention can be made. Medical and paramedical staff should be trained in early identification to reduce the incidence of preventable disabilities. ICDS can play a major role in early identification of disability and in timely intervention. Outreach services in rural areas need to be expanded to facilitate professional intervention at early stages that can minimise the extent of disability. It is important to create awareness regarding possible causes of disability and therapies

that can help cure or reduce the impact of disability.

Awareness on prevention needs to be raised through Information Education and Communication (IEC) material so that we can reduce the number of persons with preventable disabilities.

### **Access to Rehabilitation Services**

Co-ordinating and building linkage between referral services, persons with disabilities and other agencies involved in their rehabilitation can help improve access to basic and specialised services. Information on the referral services should be documented and made available to persons with disabilities at the local level.

The Social Defence Officer (SDO) or District Disability Rehabilitation Centre (DDRC) in districts where it exists should act as the nodal agency to co-ordinate important services and the delivery of services at the district and village level. The social defence office can play a proactive role in establishing linkages among institutions and facilitating the process of providing identity cards (ID) and in simplifying improved access to services and schemes by persons with disabilities.

The system of certification should be simplified through camps at the local level. Information on camps should be disseminated more widely so that persons who are not linked to institutions can also access these services.

### **Access to Health Services**

There is a need to ensure proper health care systems at the village level. The existing system can also be improved to work more effectively. Strengthening of health care delivery, particularly prenatal and postnatal care, can reduce the incidence of disability. Establishing linkage between various levels of health care can also be useful in reducing the incidence of preventable disabilities.

### **Access to Education**

Schools should be supported and encouraged to enrol all children, irrespective of their physical/mental disability. The integrated education programme should be spread extensively. Not only special educators but all teachers should be trained to work with children with disabilities. Most approaches employed for children with disabilities can also be used very effectively with children without disabilities. Including such training in their curriculum would help teachers to support children with disabilities to reach their full potential and promote inclusion.

### **Access to Employment**

Skills should be imparted to persons with disabilities in the areas of their interest and in accordance with market demands. Vocational training as per demand needs to be provided. The government has identified 1400 jobs for persons with disabilities. This list needs to be expanded and developed in consultation with persons with disabilities. Currently, the training is not linked to the employment opportunities available. There is a need to identify newer areas of training that will provide them a sustainable livelihood. Linking the persons with disabilities to existing Community Based Rehabilitation (CBR) programmes within the area can help in providing training using local resources and keeping the local context in mind.

At present the government jobs for persons with disabilities are reserved at all levels A, B, C and D. However, it has been found that they are able to get jobs mostly in the C and D categories. They are unable to avail the benefits of



reservation in A and B categories since in many cases they do not have the required qualification. There is a 3 per cent reservation of jobs in the public sector. There is a need to disseminate this information among the persons with disabilities and employers.

Private sector employers need to be encouraged and oriented to employ persons with disabilities. A draft policy on employment of persons with disabilities has been formulated. This needs to be followed up and promoted. The CBR programme, which identifies and lists the persons with disabilities in the local area, can be a potential link between persons with disabilities and employers at various levels.

### **Access to Information**

There is very little awareness on the PWD Act 1995, which is the first legal provision to ensure the rights of the persons with disabilities. Due to lack of awareness, the persons with disabilities are not able to access government schemes. Information should be disseminated in a simple format and through awareness campaigns. Along with this, other information in user-friendly formats (Braille, audio, large print, etc.) should be made available.

Information on services available for persons with disabilities needs to be collated at the decentralised level (*village, taluka* and district) and disseminated for promoting accountability.



Stories of positive images can be documented and disseminated widely. Much of the negative attitude society has is due to ignorance and limited understanding of the potential and abilities of persons with disabilities. Positive stories can help effect a change in the attitudes and behaviour of the community. A supportive environment and public acceptance can help persons with disabilities to realise their potential and be fully integrated in the community.

### **Role of Civil Society**

Most institutions engaged in the rehabilitation of persons with disabilities are located in the urban areas whereas a fairly large section of persons with disabilities are in rural areas. Moreover, many persons with disabilities do not need specialised or institutional care. Apart from local bodies/organisations at the village level, development organisations are well positioned to be in contact with persons with disabilities and including them in their

on-going development activities.

Recently disability has been recognised as a development issue, however, in reality, most development organisations are not focusing on the development needs of persons with disabilities within their programmes. Our experience in this project suggests that orienting development organisations to the issues of persons with disabilities and concerted dialogue on addressing disability as a cross-cutting issue in all development work has led to conscious initiatives for inclusion of persons with disabilities.

In order to strengthen and broad base such initiatives, it is important that academic courses for social workers and perspective building programmes on development issues incorporate disability as a cross-cutting issue and highlight the role of development organisations for inclusion of persons with disabilities in the

mainstream. Linkages with the academia can be fostered for inclusion of disability as a cross-cutting issue in their professional courses.

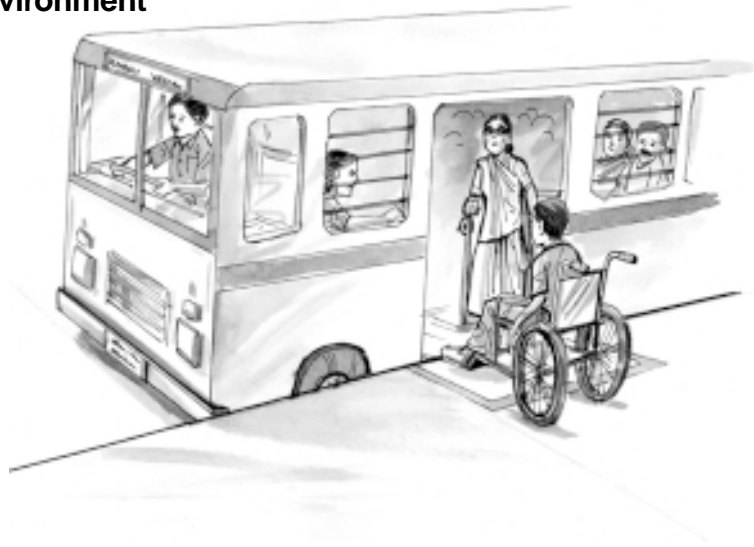
Development organisations can not only directly involve persons with disabilities in their work but also build partnerships with different stakeholders of civil society towards achieving the goal of inclusion of persons with disabilities in the mainstream. For instance, sustained linkages with architects, designers and planners can help further the goal of creating a barrier free environment; linkages with local elected representatives/bodies can help place the issues of persons with disabilities on the local development agenda. It is also equally important for development organisations and institutions for rehabilitation to interact on a common platform to complement and supplement their efforts.



## Creating a Barrier-Free Environment

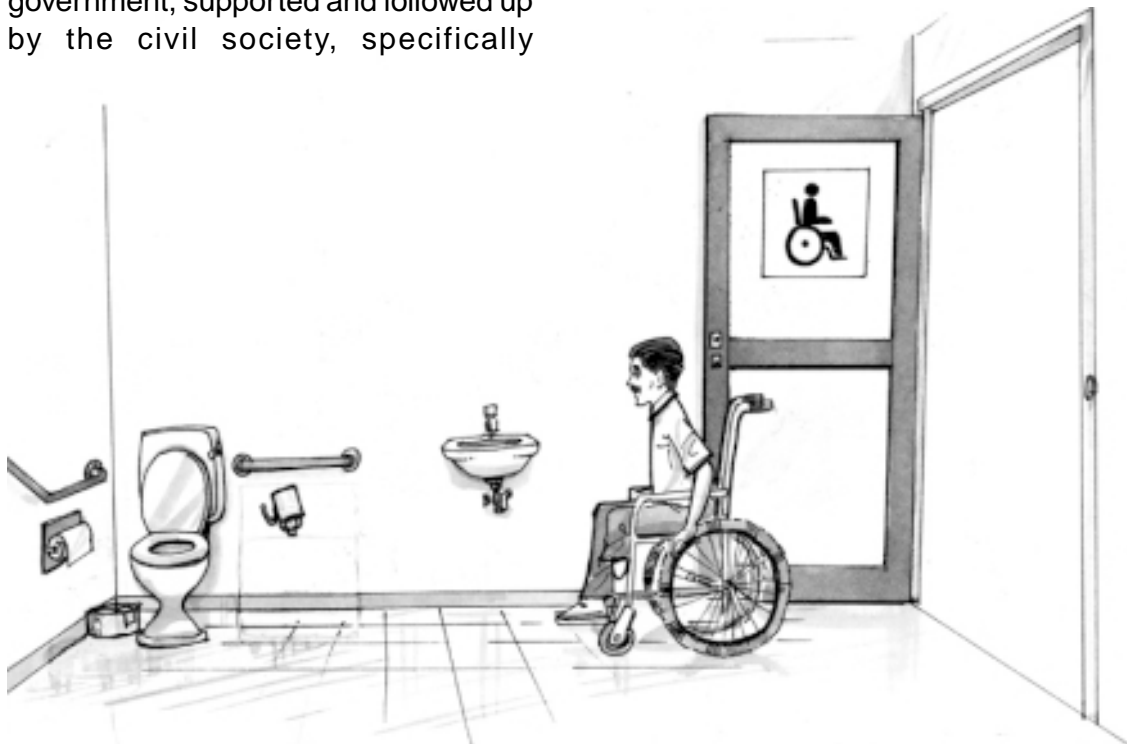
There are numerous structural barriers in public buildings be they schools, hospitals, government offices, parks, temples etc. Although there are guidelines and information on how the environment can be made barrier free, we need to have platforms for dialogue between the designers and architects and the end users of the built environment, transport and public spaces.

Organisations working on issues of persons with disabilities can help create such platforms so that the plans are need based. The Government of Gujarat has been pro-active in this regard and has passed a resolution (No. P R C H/102000/1184/6 dated 22 June, 2004) making it mandatory to incorporate barrier free features in all public buildings. This needs to be enforced by the government, supported and followed up by the civil society, specifically



associations of architects, builders, persons with disabilities and development organisations.

Orthopaedic departments in hospitals, physiotherapy centres, Social Defence Offices and other agencies working primarily on issues of disability should be made physically accessible.



**Gender and Disability**

Special needs of women with disabilities should be focused on wherever gender related policy is being formulated. The Gujarat State Gender Equity Policy can include a section on gender and disability. Gender should be a cross-cutting theme for all government programmes. Wherever there are reservations, efforts should be made to include women with disabilities, especially in institutions like *panchayats* and boards of institutions.

**Network of Persons with Disabilities**

Network of persons with disabilities needs to be expanded and developed. Support should be provided to improve their advocacy skills so that they can mobilise themselves and share their needs in various forums/platforms for the same to be addressed. Increased opportunities for interaction between the persons with disabilities and multiple stakeholders will certainly help to bridge the gaps in the implementation of their rights.

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**HANDICAP INTERNATIONAL (HI)** is an international non-government organisation present in India since 1988. HI works to support actions towards an inclusive, barrier-free and rights-based society for persons with disabilities and other vulnerable persons in India.

To this end HI works with people\*, local and international organisations and Governments which share the vision of an inclusive society where vulnerable people have equal rights and opportunities and live their lives with dignity, experience joy as well as a sense of fulfilment, irrespective of the cause, nature and the environment underlying the situation.

\*People are understood to include people with disabilities and other persons in situations of vulnerability, their families and their communities, irrespective of religion, caste or creed.





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