

CIVIL SOCIETY ENGAGEMENT FOR
**MAINSTREAMING
DISABILITY**
IN DEVELOPMENT PROCESS

Report of an Action Research Project
initiated in Gujarat with Multi-stakeholder Partnership

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Contribution of Shreedhar Printers in printing this book is immense and noteworthy. It has helped us to publish the efforts undertaken to mainstream disability in development process through civil society partnership.

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introduction

In recent years, there have been some efforts to engage civil society groups and institutions in mainstreaming disability, based on the understanding that service provision alone cannot holistically address the needs and rights of persons with disabilities. UNNATI Organisation for Development Education and Handicap International jointly took up a three-year action research (2002-2005), in Gujarat, to understand the prevailing situation and invoking the participation of civil society groups for mainstreaming disability.

THE PRESENT SCENARIO

It is estimated that nearly one in ten people has a disability. More than three out of four persons with disabilities live in a developing country (Helander, 1992). The Census of India, 2001 enumerates 2.19 crore persons with disabilities in the country, which is 2.13 per cent of the total population. However, the UN cited figure of ten to twelve per cent remains popularly acceptable amongst rehabilitation institutions and development agencies. This discrepancy can be attributed to definitional, methodological and study design quality issues (Mont, 2007).

Drawing from the social model, it is recognised that disability is the outcome of complex set of interactions between the functional limitations arising from a person's physical, intellectual or mental condition and the social and physical environment. The impact of disability is closely linked to the barriers in the environment. The greater the barriers, the greater will be the disability.

THE VICIOUS CIRCLE

All individuals need services to satisfy their needs, but society's understanding and response to the needs of persons with disabilities are not adequate, resulting in their exclusion and lack of access to the most basic services. This leads to their increased vulnerability and poverty. Poverty is not only a consequence of disability, but also a major cause. Poverty and disability reinforce each other, trapping people with disabilities in a vicious cycle (DFID, 2000) contributing to their increased vulnerability and exclusion.

Traditionally, based on the medical model, 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 term ‘welfare provision’ denies those with disabilities the right to be treated as fully competent and autonomous individuals i.e. as citizens and as equal participants contributing to the process of development.

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 people live. This includes protection of their rights, provision of equal opportunities in education and employment, creating accessible environments and promoting community ownership of programmes that aim at their inclusion.

DISABILITY – A HUMAN-RIGHTS ISSUE

It is necessary to acknowledge that disability is a human-rights issue. A human rights-based approach to disability will ensure that society is aware of persons with disabilities; their vulnerability and their rights and interventions are appropriate and aimed at them leading a dignified life. Therefore, in addition to service providing institutions, whose focus is the rehabilitation of the individual, other stakeholders like the State, development organisations, community and civil society must recognise that it is imperative that they too play their role in creating an enabling environment.

It needs to be recognised that the invisibility and exclusion of persons with disabilities has its roots in society and not in their biological, physical or mental condition. Until this happens, it will be difficult to convince policy makers that disability is a human-rights issue and mainstreaming disability is an effective strategy for inclusion, both to reduce poverty and achieve equality in development. The challenge for members of civil society today is to understand the vulnerabilities of persons with disabilities, enhance their own sensitivity, change the prevailing attitudes and influence the environmental and contextual factors, to promote their social integration.

THE NEED FOR DOCUMENTATION

In this overall context, the project undertaken by UNNATI and Handicap International has been documented to understand how an enabling environment can be facilitated for civil society engagement. The four key strategies adopted in the project have been detailed to share how civil society groups can be mobilised and invoked to take concrete action for promoting participation of persons with disabilities on local issues, creation of a barrier-free environment, developing materials for public education and social communication and influencing development organisations for mainstreaming disability.

Lessons learnt on strategies and steps for mainstreaming disability have been presented for eight thematic areas. This document will be useful for a wide audience in enhancing learning on mainstreaming disability.

Several individuals and organisations, including many persons with disabilities, have lent meaning and value to this initiative. We hope that we have been able to capture their views and contribution.

UNNATI team

Handicap International team

**STRATEGIES
IMPLEMENTED**

1 partnership
building

2 joint action for a
barrier free environment

3 public education
and communication

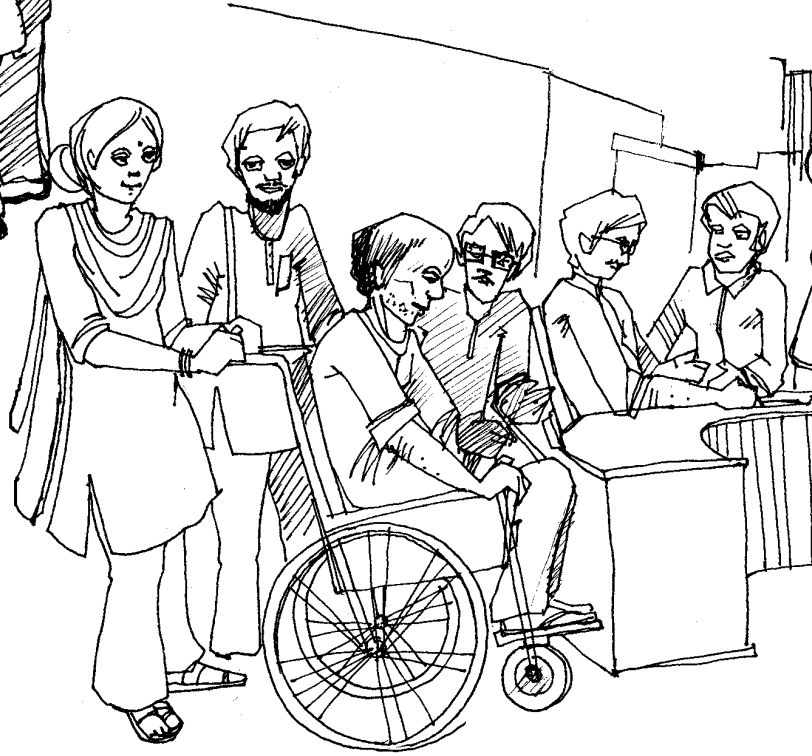
4 mainstreaming disability
in the development process

Handicap
International

UNNATI



Formal Collaboration





Formation of the Access Resource Group



Stakeholder
Collaboration

partnership building

UNNATI and Handicap International met during the 2001 Gujarat earthquake rehabilitation work, in several inter-sectoral consultations. While UNNATI was working with community groups on reconstruction and rehabilitation, Handicap International was involved in supporting the rehabilitation of persons with disabilities. During this phase, UNNATI realised that any intervention for vulnerability reduction will be incomplete without striving for inclusion of persons with disabilities as one of the vulnerable groups. Handicap International on the other hand realised that for mainstreaming disability it was essential to include development organisations as key partners.

It was new and exciting for a development organisation and an international rehabilitation organisation to work together to examine disability from a development perspective. The initial phase of the partnership began informally with developing public education materials for providing information on care and rehabilitation to persons with disabilities and their families, initiating discussions on disability at the community level and examining the prevailing attitudes. During this phase, it became clear that the strengths and experience of both the organisations were complementary. UNNATI has skills on participatory research and training, preparation of educational material and building partnership with a large number of Non Government Organisations (NGO) in the state, while Handicap International's strengths lie on a technical knowledge base and wide experience of working on disability, internationally and nationally.

FORMAL COLLABORATION

UNNATI and Handicap International agreed to collaborate for 'Enhancing civil society participation in mainstreaming disability'. The key objective was to strengthen civil society participation in designing and implementation of programmes for the inclusion of persons with disabilities in order to increase their effective participation in mainstream development processes. Prior to the formulation of the proposal, several meetings were organised not only between UNNATI and Handicap International, but also with other NGOs. The overall purpose was to learn from each other's experience and develop a partnership-based work culture. Throughout the project, both the institutions worked with an extremely professional approach while maintaining good personal relationships as well.

Handicap International already had a full team set up at the country office in Delhi and the project office in Bhuj, Kutch. In 2003, Handicap International also set up a state office in Ahmedabad which enabled frequent and intensive interaction between both the institutions.

The key objective was to strengthen civil society participation in designing and implementation of programmes for the inclusion of persons with disabilities in order to increase their effective participation in mainstream development processes

One of the main thrusts of the project was to develop mechanisms and processes to engage multiple stakeholders of civil society to mainstream disability

UNNATI set up a new team with professional skills for the project, consciously including persons with disabilities among the project staff. The final core team had backgrounds in promoting social inclusion of vulnerable groups viz. dalits, women and children; project management and communication; research, documentation and preparation of development educational material.

The Handicap International team comprised of technically skilled professionals including physio-therapists, occupational therapists, accessibility experts and disability rights experts. Additional support was mobilised from external sources as per need.

Besides the staff designated for the project from both the institutions, the other senior members also actively participated in the formulation and execution of the project.

STAKEHOLDER COLLABORATION

One of the main thrusts of the project was to develop mechanisms and processes to engage multiple stakeholders of civil society to mainstream¹ disability. We began by meeting numerous individuals and organisations to generate ideas and develop an understanding on the ‘why, what and how’ of mainstreaming disability. We met development organisations, community based organisations (CBO), disability and rehabilitation institutions, Disabled People’s Organisations (DPO), persons with disabilities and their families, government departments and agencies, experts in inclusion, access etc. and academia and professional institutions.

Initially, some of the people we approached were ambivalent towards the idea of collaboration as they subscribed to the popular belief that disability should be the concern only of health and welfare professionals.

However, there were also many others who were open minded, willing to consider and spend time to explore how they could contribute. The fact that UNNATI, a development organisation, which had not earlier included disability in its programmes, was proposing this initiative may have contributed to the openness of organisations to examine why disability needs to be mainstreamed.

Five distinctive partnerships emerged during the project with:

- a) development organisations
- b) designers, architects and builders
- c) rehabilitation institutions
- d) DPOs and persons with disabilities and
- e) media.

The initiative was implemented with the partners in five districts of Gujarat viz. Ahmedabad, Kutch, Patan, Sabarkantha and Vadodara (Refer Annexure 1 for map).

A. Reaching out to development organisations

The visits, meetings and discussions resulted in 16 organisations showing interest. All the 16 partners came together in a workshop, where members from Handicap International used simulation exercises, presentations, group discussions and a field demonstration of participatory research to sensitise them to the various aspects of disability. Beginning with the definitions and meaning of 'disability', participants were provided an opportunity to experience disability in a controlled situation, appreciate the situation of persons with disabilities and the causes of their exclusion from society. The need to address disability as a development and rights issue, the importance and ways of involving persons with disabilities in their ongoing programs and the specific role that they can play in facilitating inclusion of persons with disabilities were discussed at length. The field based demonstration created a unique and novel opportunity for development organisations to openly observe and discuss the construct of disability, led by persons with disabilities from the village they were visiting.

Mr. C. Mahesh of Mobility India (MI)², Bangalore, briefed the group on MI's experiences and activities on empowerment, rights and inclusion.



Members at a workshop on disability engaged in group work

B. Networking with designers, architects and builders

While working towards mainstreaming disability, it was further confirmed that besides social and attitudinal barriers, physical obstacles in the environment posed a major hurdle in inclusion i.e. in enabling the participation of persons with disabilities. If a barrier-free environment was to become a reality, the key people responsible for planning, designing and creating spaces had to be part of the process.

We started with a public access audit of Law Garden, a municipal park in Ahmedabad, in partnership with Blind People's Association (BPA). Well-known architects, builders and engineers actively participated in the audit with the user group which included persons with disabilities and the senior citizens. The event was a success as many of them agreed to champion the cause of accessibility. After this regular meetings were held to enlist the support of decision makers in the service industry, government departments, academic institutions and other professional groups and associations.



The formation of the Access Resource Group: a collaboration of diverse stakeholders

A new group, The Access Resource Group – consisting of rehabilitation and development organisations, architects, engineers, persons with disabilities and academic and technical institutions – began to emerge. Simultaneously, requests for information and assistance in conducting audits also began to be received. UNNATI and Handicap International identified one person for public interface and for co-ordinating the response to such demands. The unique aspect of this group is that it is voluntary and informally organised with a high degree of commitment.

It was a challenge to keep the group together and going with the same momentum. While there was no question about anyone's commitment, over time some people tend to move away. Taking this into account, the informal nature of the group was maintained and new activities planned to draw in more people and build their capacity for meaningful participation and engagement.

C. Learning from rehabilitation institutions

Rehabilitation and special care institutions have invaluable experience and expertise on addressing disability. When we contacted such institutions, particularly BPA, the reception was very encouraging. They felt that the involvement of developmental organisations in community sensitisation would help in better enumeration, early detection, strengthening community approach to rehabilitation and help in building an inclusive society. This association resulted in learning more about the technical aspects of disability, associated practices and laws.

BPA became a resource and support organisation for many activities through their expertise, information bank, infrastructure and network. It is a partnership that enriched this experience we continue to value.



Interactions between the members of various NGOs and persons with disabilities

D. Partnering with DPOs and persons with disabilities

Persons with disabilities are best placed to inform policy and practice for their rehabilitation and removal of existing barriers to their inclusion. Unless they articulate and demand their rights, the initiatives would continue to hinge on society's understanding of their needs.

Interactions with persons with disabilities highlighted that there have been few efforts directed at building their capacities and mobilising them to collectively articulate and demand their rights. They also do not occupy positions of leadership that can be used to articulate their priorities. Women with disabilities face discrimination at multiple levels due to gender, caste and class.

Guided by this understanding, this partnership aimed at involving them in all activities in the initiative. Support was provided at two levels - to address their specific concerns through development of individual plans and enhancement of their interface with civil society groups. For this, they were organised and enabled to share, collectively articulate and represent their interests in appropriate forums. The civil society groups, with some initial resistance, developed an openness to listen to them and acknowledge the importance of their 'voice' in matters that affect their lives. This led to an increased demand from them to include persons with disabilities in their initiative to mainstream disability.

E. Linking with the media

An analysis of print and electronic media and review of studies on portrayal of disability in the media revealed that the coverage on disability was not only limited in its range and scope, but also in frequency and duration. The observations were shared and discussed with the media persons through a series of sensitisation workshops in the project districts. The positive response and willingness of many participants to revise their strategy led to a long-term relationship with the media. This resulted in a series of issue-based articles, cover stories and serials on disability.

Through these interactions we learnt that with timely and periodic support, and relevant resource material, the media could ensure an in-depth issue based coverage that can serve to build the perspective of society.

A critical factor that was identified as an obstacle to the inclusion of persons with disabilities was their lack of access to physical spaces. The presence of barriers in the built environment led to development of plans for joint action for creation of a barrier free environment

CAPACITY ENHANCEMENT OF PROJECT STAFF

At the outset, efforts were made to increase the familiarity of the team on the subject through perspective building, developing a knowledge base, interacting with sectoral institutions and persons with disabilities. The team spent time in reading literature, meeting institutions and individuals and attending meetings. Some of the key people and institutions who guided the process during the period include Dr. Bhushan Punani, Executive Director, BPA, Dr. Maya Thomas, Independent Consultant on Disability Rights, Dr. Ajit Dalal, Professor, Department of Psychology, Allahabad University, U.P. and Mr. C. Mahesh, Training Co-ordinator, MI, Bangalore.

PROGRAMME PLANNING

By the end of six months, the team had developed an understanding that there are several factors that work in conjunction and lead to the marginalisation of persons with disabilities. A critical factor that was identified as an obstacle to the inclusion of persons with disabilities was their lack of access to physical spaces. The presence of barriers in the built environment led to development of plans for joint action for creation of a barrier free environment.

It was also observed that the awareness in society and among persons with disabilities about the rights of the latter was very limited. Providing information in accessible formats was not being given due importance resulting in the denial of the right to information of persons with disabilities. To overcome this barrier to inclusion, strategies were identified for public education and communication.

By now, the team had also begun to appreciate that disability has remained a specialised field within the realms of rehabilitation, medicine, social welfare and charity.

Despite it being, along with gender, the cross cutting ‘construct’ affecting people across ethnicity, class, caste, nationality, religion and even gender, disability does not get considered in development discourse. That vulnerability reduction cannot be addressed without including persons with disabilities in development processes was also becoming more apparent.

The importance and ways of engaging with multiple stakeholders for all the strategies was also becoming clearer. Based on the above understanding, the programme was accordingly planned.

ORIENTATION OF STAFF

As a beginning, a need was felt to orient all staff of UNNATI for which Handicap International conducted a workshop to sensitise them on the construct of disability and enable them to examine the need and ways for inclusion of disability in their work.



Simulation exercises for increasing the familiarity of the team on the subject

The workshop also served as a pilot project and test case for future trainings and sensitisation of other development organisations. Training modules and patterns were finalised in the process.

To ensure accessibility to persons with disabilities, modifications and adaptations were made in the UNNATI office premises. These changes included a new approach and entrance, ramp with railings and widening of doors.

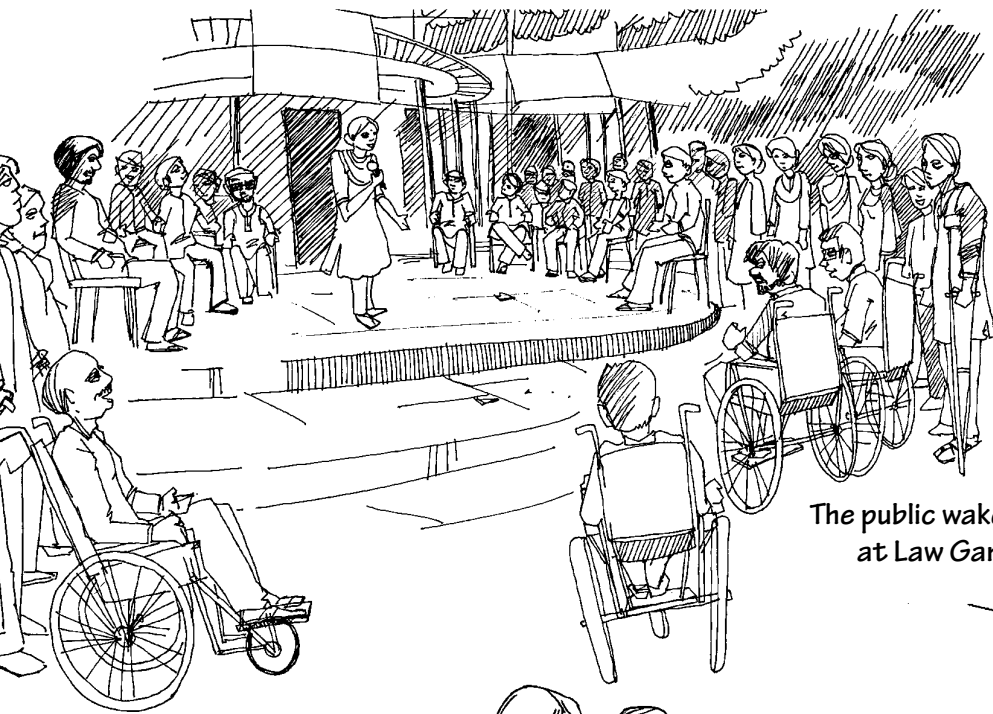


Modifications made in the office premises to enhance accessibility

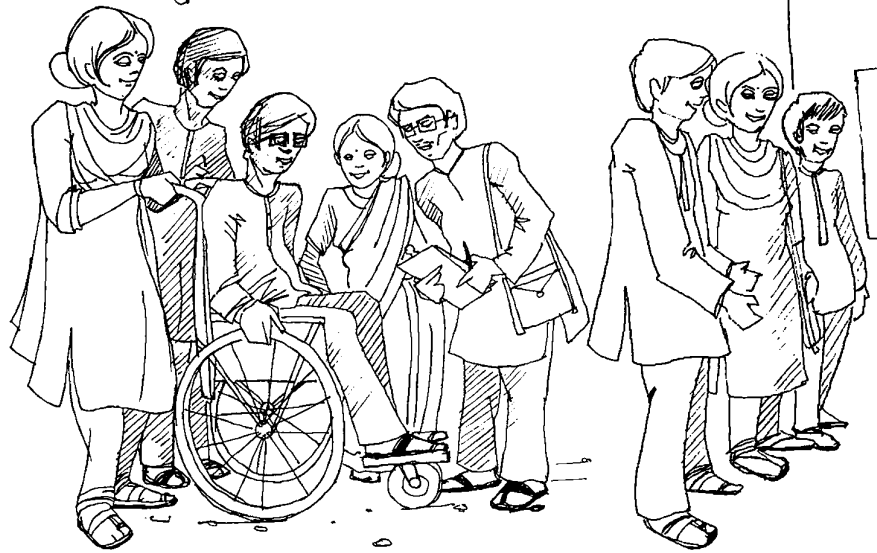
REFLECTIONS PROVIDE DIRECTIONS

About nine months after the initiation, the key processes were discussed in the quarterly review meetings and four major changes were introduced:

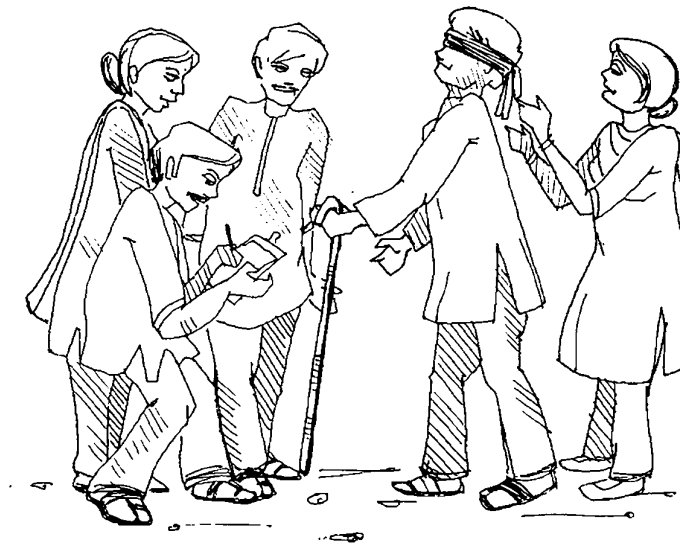
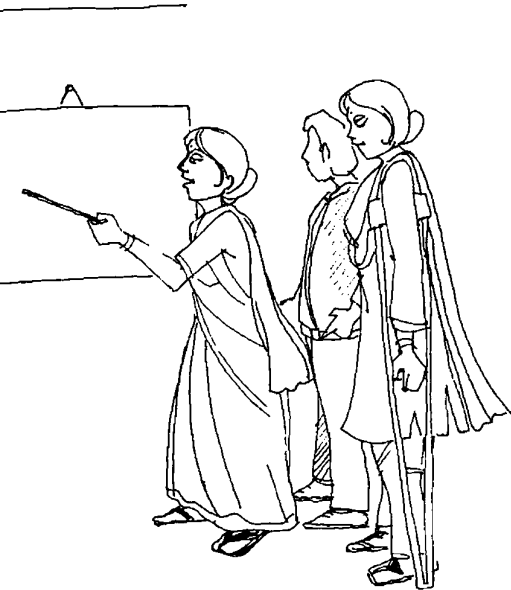
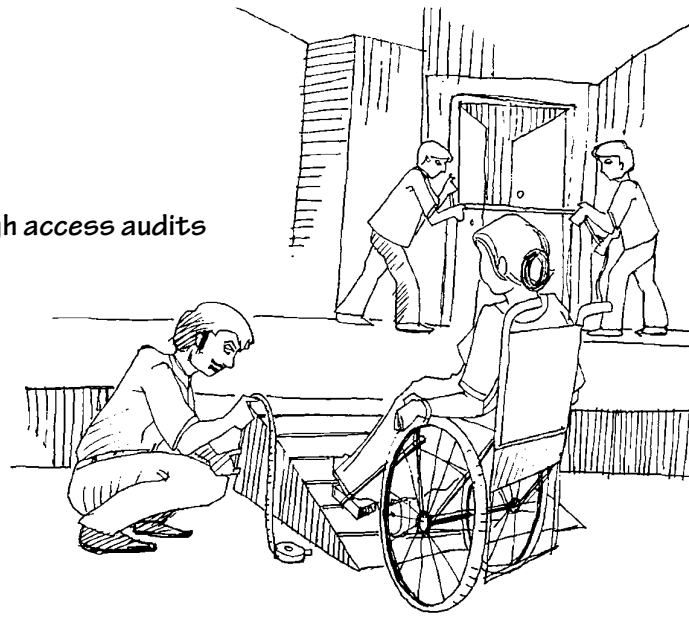
- 1 Initially, it was planned to conduct a household based survey, through a questionnaire, on the prevalence and extent of disability. In the discussions it was realised that the sample size was too small or inadequate for establishing the rate of prevalence that would be scientifically acceptable by research standards. Hence, along with studying the prevalence rate to develop a local database, it was decided to explore the prevailing attitudes and behaviour of persons with disabilities themselves and that of the community with a focus on perceptions about/of women with disabilities. Along with a questionnaire, the participatory rural appraisal (PRA) tools and techniques were used to enable persons with disabilities to participate in the process of enquiry (Refer Annexure 2 for areas where PRA was conducted).
- 2 It was also decided that while the overall process in the initiative will not follow the Community Approaches to Handicap in Development (CAHD)³ framework in totality, it would be guided by CAHD, taking into account the principles of participation and gender.
- 3 It was observed that slowly the project was developing a distinct identity of its own forming a separate unit within UNNATI. This was considered as a danger signal as the main purpose of the project was to develop mechanisms to mainstream disability in all the programmes rather than establish a separate unit. Whenever such tendencies were observed, these were examined and corrected.
- 4 For preparing educational material and facilitating a larger educational process, strategic partnership was developed with rehabilitation institutions to derive benefit from their expertise and experience. Prominent institutions like BPA, United Way of Baroda (UWB) and National Association for the Blind (NAB) were included as key strategic partners.



The public wake up call
at Law Garden



Setting standards through access audits



Workshops for awareness through simulation exercises

**joint action
for a barrier free
environment**

What happens when a person in a wheelchair is faced by a flight of stairs or a narrow doorway, or when a person with visual impairment is faced by dangerous obstructions, or when a person with speech and/or hearing impairments has no guiding signs? Such barriers in the environment lead to a restriction or denial of opportunities in everyday life for persons with disabilities and also their participation in the development process. This was reconfirmed by the access audit, conducted at the initial stage of the project.

There is very limited understanding about the need for creating a barrier-free environment and that accessibility is a matter of right (Refer Annexure 3 for legal provisions). Most stakeholders feel that accessibility is an issue affecting only persons with disabilities; ignoring the fact that it affects all groups irrespective of class, caste, gender and age. A large user group consisting of the elderly, the ailing and temporarily disabled, pregnant women, children and people carrying luggage are not being considered. A commonly held perception that a ramp is enough to make spaces barrier-free, restricts the understanding of the scope of accessibility.

BARRIER-FREE ENVIRONMENT

A barrier-free environment is a space that allows for free and safe movement, function and access for all, regardless of age, sex or condition - a space or a set of services that can be accessed by all, without obstacles, with dignity and with as much independence as possible. The environment means buildings, roads, parks, gardens and other places, services, modes of transportation and products of daily use

THE PUBLIC WAKE-UP CALL

The informal access audit of Law Garden (Ahmedabad) was the first event where the issue was discussed in public. The team felt that this was just the sort of wake-up call Ahmedabad and Gujarat needed. BPA supported the event with their expertise and resources.

As a preparation for the event, live visual images of physical barriers and positive features of access in public buildings were collected. These were put together as a photo exhibition for public awareness. A brochure was also developed in English and Gujarati to inform society that access must not begin and end with a ramp. BPA put up a large hoarding for six months with a message for removal of physical barriers in public buildings.

The access audit of Law Garden (Ahmedabad) was the first event where the issue was discussed in public. The meeting was attended by more than 200 people, including senior architects, planners, designers, policy makers, academicians, media persons, persons with disabilities, NGOs and other stakeholders

The meeting was attended by more than 200 people, including senior architects, planners, designers, policy makers, academicians, media persons, persons with disabilities, NGOs and other stakeholders. The Mayor of Ahmedabad, who was the chief guest at the function, led an 'Access Walk' through the park. After this, various invitees shared their views on the subject.

The print media took active interest, with the event opening up opportunities to discuss this issue with many other people, receive their inputs and views and involve them in the collective civic action. Once interest was generated among various people, demands for more information kept coming. As a result, point persons from Handicap International and UNNATI started addressing all public queries and suggestions.

Similar public awareness events were subsequently organised in Sabarkantha, Vadodara and Kutch districts involving multiple stakeholders. Specific advocacy initiatives were undertaken with concerned government departments in Kutch and Ahmedabad districts to orient and sensitise officials on the need for incorporating accessibility features in the built environment.

BUILDING UNDERSTANDING AND SKILLS

A series of workshops were held to raise awareness and demonstrate the various aspects of creation of a barrier-free environment. Anjlee Agarwal and Sanjeev Sachdeva of Samarthaya facilitated these workshops. The fact that both were persons with disabilities gave an additional dimension and perspective. They were invited to Gujarat to interact with various stakeholders in Ahmedabad, Vadodara and Kutch.



Public wake-up call at Law Garden at Ahmedabad, Gujarat

The simulation exercises used in the workshops were very effective in making the participants experience different types of impairments and obstacles that exist in the environment. In response to a demand from some of the architects and NGOs, who attended these workshops, a series of trainings were organised with Samarthaya's support on how to conduct an access audit, prepare and present the audit report. Subsequently, many people came forward with requests for more information, assistance in audits, and most importantly, for being involved in the movement. This entire process served to provide multiple opportunities and exposure to the team to build their own understanding and expertise on the issue.

It is interesting to note that, initially, most architects and designers were aware of the barrier-free environment and some of its aspects. However, their interest changed to commitment only when they understood how barriers can effectively deny participation and rights of, not only persons with disabilities, but many other segments of society such as the elderly, the temporarily affected, pregnant women, children, etc. Perhaps the most convincing argument was that, any one could face difficulties or disabilities at any time in their lives. Accessibility was a universal need – the basic premise for ‘Universal design’⁵ .



Simulation exercises at a sensitisation workshop on accessibility

There is a popular belief that a ramp and an elevator/lift is all that is needed to make a built space barrier free. It must be clearly understood that there are several other necessary features that need consideration. These range from door and passage widths to flooring surfaces, from counter heights to door handles and railings, from signage to auditory signals

VOLUNTEERING FOR ACCESSIBILITY

These workshops not only resulted in many people coming to know about and understand accessibility but also resulted in one of the most significant milestones of our journey – formation of the Access Resource Group. A major stride forward was the fact that some of the most reputed architects and their firms in Ahmedabad and Vadodara internalised the concept and took a conscious decision to ensure that all future designs by them were barrier free. The group members volunteered to conduct access audits of many buildings and spaces.

These audits were conducted at the request of the owners and they committed to incorporate the barrier-free features. Ahmedabad based public institutions like Ahmedabad Municipal Corporation (AMC), Airport Authority, Eklavya School, Sardar Patel Institute of Public Administration (SPIPA) and some business groups came forward. In Vadodara, Narmada Bhavan where the Department of Social Defence is located, Sayaji Baug and a mall were audited. Similar exercises were undertaken in Kutch for the Zila Panchayat office and public and service buildings constructed by Save the Children Federation (SCF) and United Nations Children's Fund (UNICEF) in the post-earthquake phase in 2001.

A significant aspect was that various facets of this movement, ranging from co-ordination of activities to providing technical expertise on accessibility, from getting the group together to communicating and creating awareness, were all steered and led by persons with disabilities

SETTING STANDARDS

Throughout the initial days of audits, there were many discussions with architects on the issue of building guidelines and standards on accessibility. Though there are the UN Standards, the American Disability Act (ADA), UK Standards, India's National Building Code etc. none of them are being popularly practised. The group soon realised that there was a need for developing clear, concise, handy and indigenous technical design guidelines for creating barrier-free spaces. It would be a set of guidelines anybody, especially architects, could refer to for any aspect of accessibility.

Some members of the Access Resource Group took on this task. After extensive research as well as field tests, 'Design Manual for A Barrier-Free Built Environment' was compiled in little more than a year. For easy use, the manual was also made available in an interactive CD format. It was released in December 2004 by Shri Surendra Patel, Chairperson, Ahmedabad Urban Development Authority (AUDA), along with eminent architects Shri B.V. Doshi and Shri Has Mukh Patel.

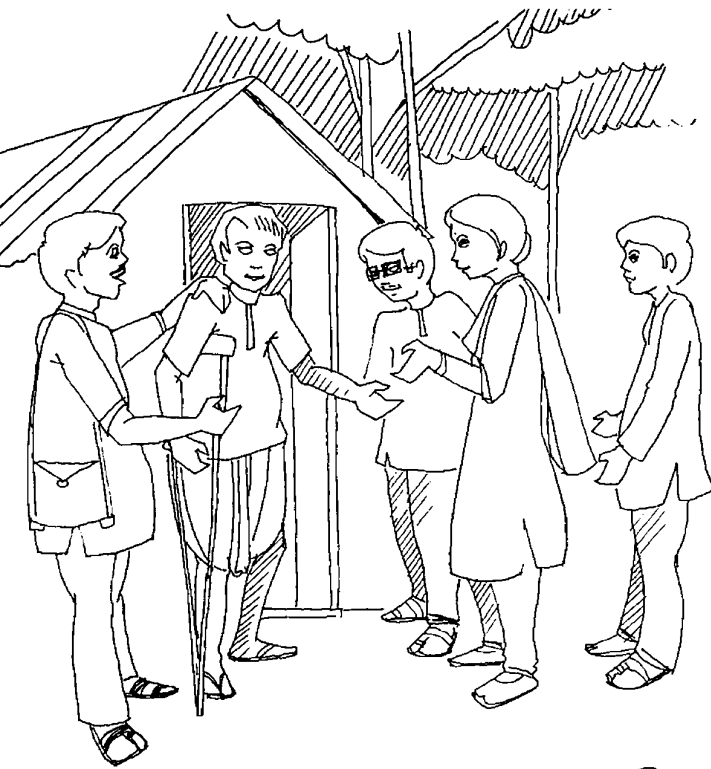
The manual, with an insight into the background and needs for a barrier-free environment, has detailed guidelines with technical drawings on various features of accessibility in the built environment. The manual also discusses some of the legal provisions and existing by laws. The unique feature was the commitment among different members to set standards on universal design. The manual has been widely appreciated and covered by the media. Diverse groups are using it extensively. Many design and architecture institutes have shown their appreciation and it is hoped that this would become a part of their curriculum in the near future.

The learning during the project duration was consolidated by the Access Resource Group and developed into a film on barrier free environment — ‘Freedom of Being’ in English and ‘Azad Astitva’ in Gujarati with same language subtitles.

A significant aspect was that various facets of this movement, ranging from co-ordination of activities to providing technical expertise on accessibility, from getting the group together to communicating and creating awareness, were all steered and led by persons with disabilities.



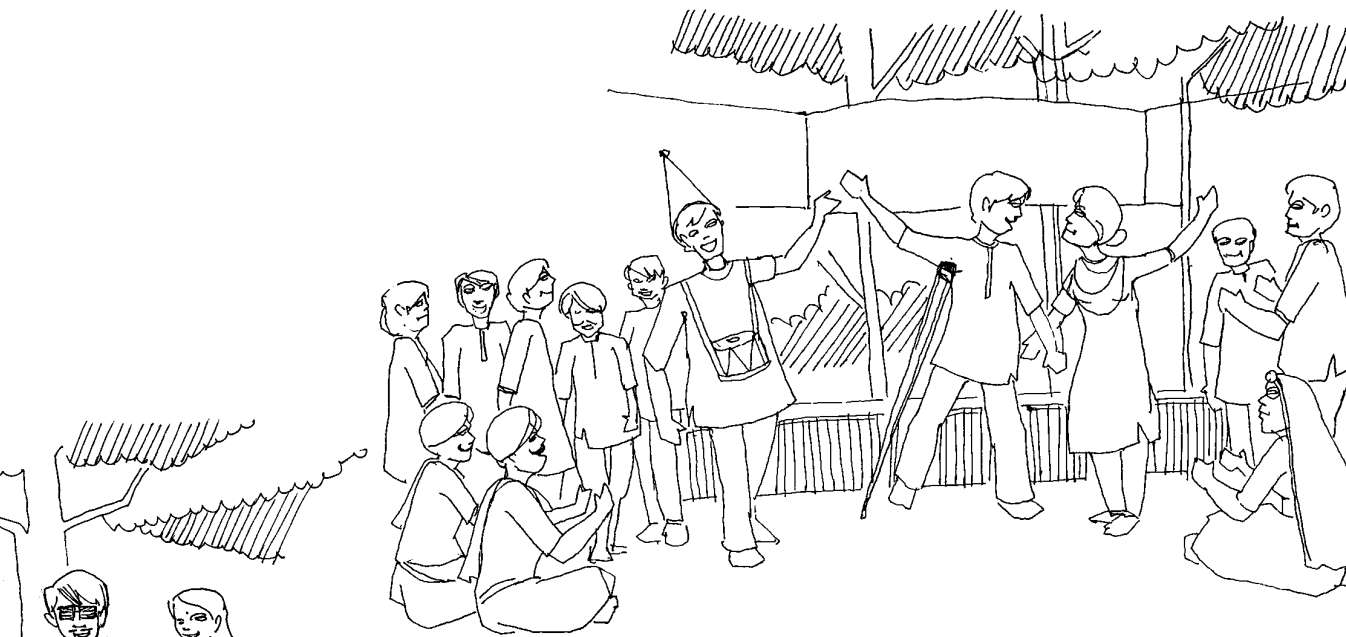
Mid-term access audit of a public institute to verify standards



Removing barriers for all



3



Street plays involving Persons with Disabilities



Creating awareness in villages with
the help of flash cards

public education and communication

People do learn to change the way they think, relate and act vis a vis persons with disabilities. Handicap International in its work has used a large number of methods, tools and techniques to prepare community workers to initiate discussions at the community level, share information and provide support to persons with disabilities. In the post-earthquake phase, Handicap International and UNNATI prepared flash cards, pamphlets, video films and posters on care and rehabilitation of persons with paraplegia and spinal cord injury. In this project, the public education themes were derived from active interaction and engagement with persons with disabilities.

CHANGING THE PARADIGM: WELFARE TO RIGHTS

Our field-level PRA-based enquiry (UNNATI & Handicap International, 2004) in partnership with 13 organisations (Refer Annexure 3 for list of partner organisations) in 55 villages and eight slums of Gujarat (Refer Annexure 4 for list) revealed that common people have a negative image about persons with disabilities. It is reflected in the patronising form of care and sympathy leading to inhuman or derogatory ways of addressing the person. In Hindi, persons with disabilities are addressed as *bechara, besahara and akela*⁶. It was not difficult to understand why with few exceptions, the portrayal of persons with disabilities through the media, literature or any other source is similar to what people were saying. Low visibility and limited interaction with society restricts the opportunity to develop a realistic perception about each other's capacity, competencies and feelings.

Interactions with family members of persons with disabilities revealed a common response with regard to the inclusion process. The response was “why do you want them (persons with disabilities) to come to the meetings or other public events, we can tell you about their needs.” The family's focus at most times was on ‘what they cannot do’ rather than ‘how they can contribute’. The family was supportive to include the person with disability in the public discourse in only a handful of cases, while many others actively dissuaded to the extent of making demeaning statements. The data collated on the education and employment status of the persons included in our sample was also a clear reflection of such attitudes. Except for some idea about their rehabilitation needs, people in the community were by and large unaware of the potential and capabilities of persons with disabilities.

Another factor contributing to the exclusion of persons with disabilities was related to gaps in information. Persons with disabilities, their families and even the

Our field-level PRA-based enquiry in partnership with 13 organisations in 55 villages and eight slums of Gujarat revealed that common people have a negative image about persons with disabilities

community had little or no idea about the rights, schemes and services for them not only because the information had not trickled down to the village level, but also because most of it was not available in user-friendly formats.



Interactions with the community on issues of persons with disabilities

A third significant aspect related to exclusion was the presence of physical barriers in the environment. The absence of information and accessible environments are major barriers to the realisation of the rights and entitlements of persons with disabilities. The barriers in the built environment were created more by default rather than design. “I have been teaching students for several years now, but this is the first time I realised the kind of power that an architect has, to either provide a life of comfort or one that can be hell for the resident for the rest of her life,” reflected a Professor of Architecture.

A simulation helped him to realise that there is a difference between what he had read in books and in the practical realities. Lack of information, sensitivity towards the need for access, limited skill and will to implement appeared the most important causes for the existing barriers.

Bearing in mind that the attitudes of both the society as well as persons with disabilities are responsible for the current situation, it was important that positive images of persons with disabilities were utilised to transform the focus from 'disability' to 'ability'. Visual and audio-visual modes were developed and used to enable people to reflect, understand and appreciate the needs and potential of persons with disabilities. '*Sunjo re koi saad*' (listen to our voices) – a dubbed version of the film 'Unheard Voices' developed by Action on Disability and Development (ADD) India, Bangalore was used extensively for sensitisation.

The maxim 'Catch them Young' was the motivation to develop an illustrated picture book for children capturing the life of a young girl with disability. *Niyati ne Padkarnara* (Challenging their destiny), a booklet containing challenges and achievements of persons with disabilities and *Garbh thee Kabra Sudhee* (From the womb to the tomb) focusing on women with disabilities were printed in the local language and widely disseminated.

Posters with simple messages from children with disabilities were adapted from a book 'Why Are You Afraid to Hold My Hand?' (Dhir, S. 1999). A group, including persons with disabilities, developed two street plays and used them to raise awareness on the issue of disability.

The communication material helped bring attitudes out in the open and generate discussions, where persons with disabilities got an opportunity to share their perspective.

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PARTICIPATION OF PERSONS WITH DISABILITIES

It was important first of all to interact with and understand the perceptions, attitudes and expectations of persons with disabilities. During the PRAs it was clear that they were not used to being addressed directly. Having a space, where they could talk about themselves, their views and feelings was a novel experience for most. It led to apprehensions, doubts and questions as to why this was being done. Once the purpose of the interactions was clarified, the response was positive, though marked with diffidence. Gradually, they began seeing it as an opportunity to interact with the community and participate decisively on equal terms. This led to a change in the biases at both ends. However, special and continuous efforts had to be made to motivate them to talk, share and participate in the process.



Going to a PRA to share her views on disability

It was decided that whatever the method used, it was important to place the skills, tools and agenda in the hands of this marginalised group in order to help them better understand and change their situation. It was equally important to ensure that the process empowered rather than persuaded people; it fostered debate among and between citizens, among and between communities, and between people and the government.



Mapping of available services by a community in district Sabarkantha

It was decided that whatever the method used, it was important to place the skills, tools and agenda in the hands of this marginalised group in order to help them better understand and change their situation

This form of horizontal communication allowed people to communicate with each other easily and inexpensively. The information generated through the PRA was given back to the *panchayats*⁷ in each village as database for action.

The highlights of the PRA process were presented in a popular document titled 'Understanding Disability: Attitude and Behaviour Change for Social Inclusion'. At the suggestion of Prof. Robert Chambers, Institute of Development Studies (IDS), Sussex, methodological innovations were documented for wider dissemination and published in 'Participatory Learning and Action (PLA) Notes', (Morris, A., Sharma, G., & Sonpal, D., 2005), a bulletin published by IDS.

CHAIN OF EDUCATORS AND CHANGE MAKERS

The 13 teams from the partner organisations set in motion a chain of learning processes at the ground level. Persons with disabilities came to know that they could approach an organisation for information and linkages; the organisation was better placed to address the needs.

For any gap in information regarding disability data, services, schemes, legislation and success stories, the Department of Social Defence, Ministry of Social Justice and Empowerment, Department of Information and the rehabilitation institutions are the authentic sources. With their active co-operation and inputs, user-friendly information was developed.

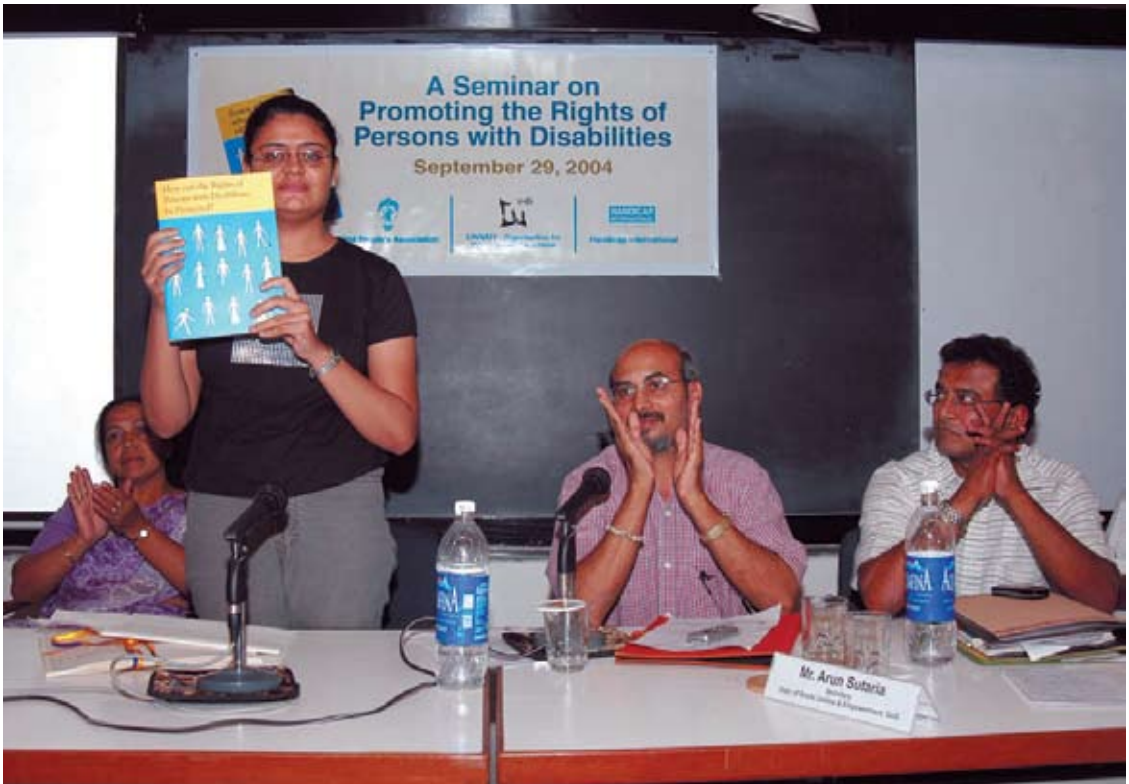
The task was challenging but the expression of willingness and support by several groups made it meaningful and viable.

Non availability of and lack of access to information on the government schemes and services and the rights as enacted in the Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 (PWD Act) was an important factor for the high vulnerability of persons with disabilities.

When Kiran Parmar, Project Co-ordinator at Sakhi Mahila Mandal (SMM), a CBO promoted by the NGO SAATH in the slums of Vasna in Ahmedabad tried to gauge whether people in her community knew about the PWD Act, she was surprised that more than 50 per cent of the people had no idea what she was talking about – even though 10 years had elapsed since the PWD Act was passed. An immediate need that emerged was that the Act had to be made available in simplified language.

As a first attempt, the key provisions of the Act were simplified and made available in the local language in a brochure format. Subsequently, informed by the priorities of persons with disabilities, a booklet titled “How can the Rights of Persons with Disabilities be Protected?” was published. This focussed on the education, employment and access rights and the experiences of people who had used the Act to realise them. To enhance the accessibility of the booklet, it was converted into audio as well as Braille formats in English and Gujarati and Jaws (text to speech) compatible version. The materials were released at a public function, covered by the media (electronic and print), and disseminated through several partner rehabilitation institutions. Requests have since been coming in from other states as well and it has led to interactions among persons with disabilities to learn about how they can best utilise the provisions of the Act.

Non availability of and lack of access to information on the government schemes and services and the rights as enacted in the PWD Act, 1995 was an important factor for the high vulnerability of persons with disabilities



Release of the booklet on PWD Act, 1995 at a public function

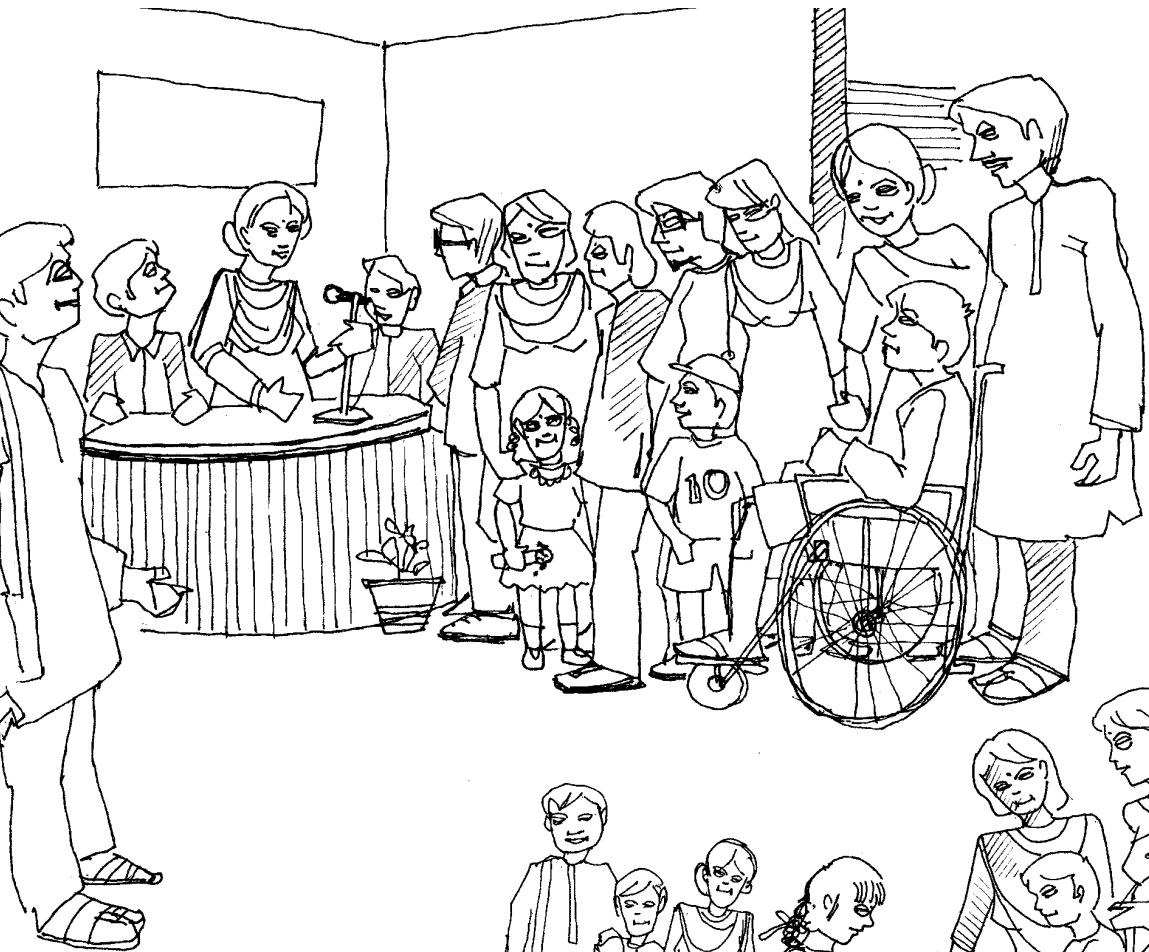
A district-level Directory of Services was also developed subsequently for four districts (Ahmedabad, Vadodara, Sabarkantha and Kutch) for improved access to services for persons with disabilities and as a tool for referrals. Films on education and employment rights developed by the Office of the Chief Commissioner, Persons with Disabilities, were dubbed in Gujarati and used for awareness, training and advocacy (Refer Annexure 5 for the list of educational materials).

In Kutch, 10 Information resource centres were set up with the help of local organisations and equipped with all the information and resources on disability for wider outreach and timely response.

This included materials that were developed as a part of this initiative as well as resources collected from other sources. Kutch Viklang Sankalan Samiti (KVSS), a network of DPOs provided support to these centres.

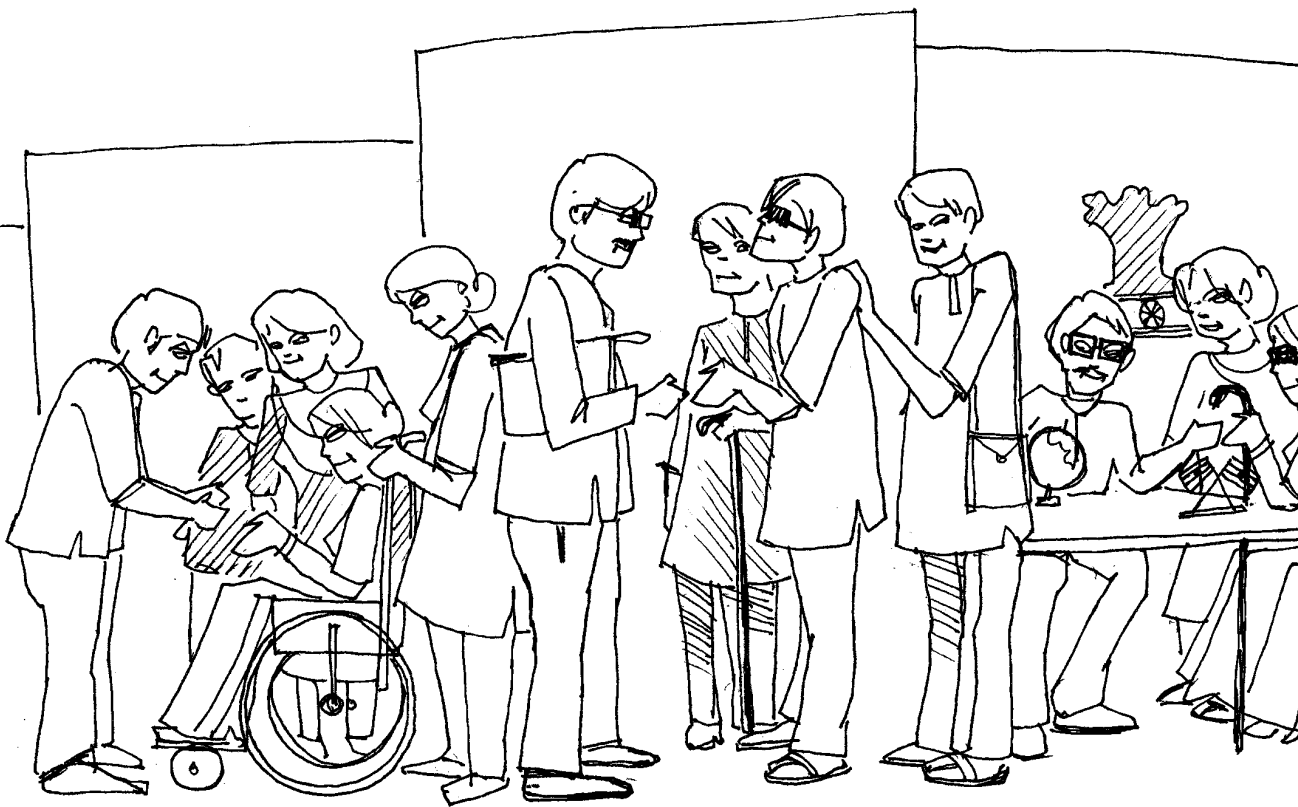
It was a challenge to simplify concepts and perspectives for common understanding. One of the main concerns throughout the initiative was the capability to respond to the demands that any form of communication created; of being able to identify, form and sustain relationships with stakeholders who could share the responsibility of developing and disseminating communication materials and tools to the appropriate audiences. Another major challenge was to measure the impact of the communication, especially where it involved attitudinal change. Such attempts were made through ongoing monitoring efforts with partner organisations.

As a part of this project, the team has prepared several documents on the different programmatic components and developed social communication materials, which are available on request. Some of these are available in accessible and user friendly formats (large font, Braille, audio/video formats).



Meeting of teachers and
parents with their children
towards inclusion





Persons with disabilities advocating with the Government officials

mainstreaming disability in development process

It is possible to conjecture from the above experience that disability is not an isolated medico-clinical construct. The social model of disability clearly indicates that persons with disabilities and their families are the poorest among the poor and if efforts are not made to integrate this analysis in poverty reduction strategies, a new chronic poverty group is created that not only suffers from economic or productive deprivation, but also faces discrimination, isolation, alienation and social exclusion. The above project has not been an intellectual or academic assumption by all those people and institutions directly and indirectly involved in the study process. It was an experiential learning - hence understanding, awareness and action were organically linked.

PLANNING WITH PARTNERS

After the initial orientation and the PRA exercise, several planning meetings and workshops were held with partner NGOs to generate ideas of activities they could undertake to include disability on their agenda of vulnerability reduction. It was clear that as a development organisation UNNATI would need to perform a facilitator's role rather than being a service provider. There were already several organisations, which were performing the latter role.

What was missing was a link between the persons with disabilities and the service providers. There was also a need for a link between persons with disabilities and the influential stakeholders of civil society. Hence, development organisations could play this role of a 'bridge'. Some of the activities that emerged through the planning as ideas for exploration are:

- (i) Undertaking citizen education (sensitisation of government functionaries, teachers for inclusive education, caretakers of public places for access, of public in general)
- (ii) Formation of a resource centre which could pool and provide information to persons with disabilities and their families on services, institutions and programmes
- (iii) Enhancing access to services for parent counselling, economic rehabilitation, marriage counselling and other critical areas
- (iv) Building in a component of disability in ongoing capacity building initiatives or, where required, facilitate specific need-based initiatives such as workshops on rights of persons with disabilities, access audit training and mobility training to family members of persons with disabilities with the help of available resources

What was missing was a link between the persons with disabilities and the service providers. There was also a need for a link between persons with disabilities and the influential stakeholders of civil society. Hence, development organisations could play this role of a 'bridge'

(v) Supporting groups of persons with disabilities by building their capacity to organise, mobilise, represent their views, advocate for their rights; and access to information.

(vi) Utilising opportunities in the field (events such as Disability Day, Acquired Immunodeficiency Syndrome (AIDS) Day, Women's Day, Human Rights Day etc.) to highlight the rights and needs of persons with disabilities.



An exhibition on Barrier-free environment at a development fair

SPECIFIC INITIATIVES BY PARTNERS

In the Annual Plan of 2003, the community-based organisations (CBO) promoted by SAATH, an NGO based in Ahmedabad, made a decision to identify persons with disabilities and the elderly in the community, make visits, identify their needs and potential and provide support for their rehabilitation and inclusion. “Earlier we used to provide support to people who approached us, but now the difference is that we approach people and together we identify what needs to be done,” shares Kiran, Project Co-ordinator at Sakhi Mahila Mandal (SMM).

She goes on to explain how, after she participated in the orientation workshop in November 2002 facilitated by UNNATI and Handicap International and the PRA exercise, she became aware of the persons with disabilities in her area. After the PRA, she made personal visits to the people who were identified and developed plans based on their needs and potential. Word spread gradually and more people began approaching her, even from the neighbouring areas.

Gradually, with linkages established with the rehabilitation organisations in Ahmedabad as well as access to the resource directory of services located in the city, she felt better equipped to provide support. Proudly sharing SMM’s achievements in the past three years, Kiran mentions the support SMM provided to over 25 people in getting aids and appliances. A step ahead, it was able to include four women with disabilities in the savings and credit programme. Children with disabilities in the area were also motivated to attend the *balwadi*⁸ run by another organisation.

Inclusion of the agenda for mainstreaming disability in the programme plans, periodic orientation to staff, provision of support, regular monitoring and demonstration of models can help overcome the barriers to inclusion

Has this been easy? “Including people in programmes has not been difficult but when it comes to including them as staff, we have had to face strong reactions,” says Kiran. Although she shared what she had learnt during the orientation workshop with her colleagues, they were not convinced about their capabilities. The one sure way of countering such attitudes is to demonstrate that unless opportunity is provided to them, their potential cannot be gauged.

Kiran motivated Vinod who had been provided support to set up a tuition class for a group of 15 children of SMM staff to apply for a post in the Human Immunodeficiency Virus (HIV) and AIDS programme being implemented by SAATH. Seeing his potential and commitment, Kiran felt that having him in the team would be an asset. Vinod now does both jobs and his induction has definitely helped alter her colleagues’ mindset. She is hopeful that with inclusion of the agenda for mainstreaming disability in the programme plans, periodic orientation to staff, provision of support, regular monitoring and demonstration of models and examples, SMM will be able to overcome the barriers to inclusion.

Like SAATH, other partners also planned to mainstream disability in their on-going activities. Some of these are presented here.

Vikas Jyot Trust (VJT), Vadodara, implements a rehabilitation programme for street children and facilitates education-related interventions for children living in slum areas. They identified several children who could benefit from educational interventions in their area through the PRA. VJT conducted seven one-day workshops aimed at promoting interaction among parents, teachers and children from mainstream and special schools to highlight the importance, methods and challenges of promoting inclusive education.

Gram Vikas Seva Trust (GVST), Sabarkantha, had been organising self-help groups and working through community leaders, but without persons with disabilities as members. Nine one-day workshops and six half-day workshops were organised for community-based groups and leaders on why and how they can promote inclusion of persons with disabilities in their on-going work.

Sri Yuva Viklang Mandal (SYVM), an informal group of persons with disabilities in Kutch working since the pre-earthquake phase, assumed the responsibility of pro-actively addressing collective concerns after the earthquake.



One of the street play performances on issues of persons with disabilities

Capacity building, development of individual livelihood plans, articulation of their role in advocacy and building awareness, developing leadership skills and building linkages between this group and other civil society groups were some of the strategies that were employed to strengthen this DPO. The process also led to the coming together of other smaller DPOs and individuals, which resulted in Kutch Viklang Sankalan Samiiti, a network of DPOs.

The network has led to:

- **Collectivisation of issues**
- **An enhanced visibility of persons with disabilities, who have also developed greater awareness about their own rights, roles and responsibilities**
- **Increase in demand for rights by persons with disabilities**
- **Linkages between DPOs and other development actors**
- **Emergence of a new cadre of leaders at the local level who engage in advocacy with government and civil society groups using a rights-based approach**

Discussion on issues of persons with disabilities is not common, nor is it easy to initiate such discussion listening to their voices. Two street plays were developed on ‘Handicap Creation Process and Role of Society’ during a workshop held at Bhuj to develop materials that could be used by community facilitators for citizen education. Two teams of 12 persons each, including persons with disabilities from Bhuj and Sabarkantha, participated in the workshop and performed the plays in 10 communities in their respective districts. The plays have been documented in digital format.

REDEFINING SOCIAL INCLUSION AND VULNERABILITY REDUCTION

It was essential to create a body of knowledge, tools and techniques to enable practitioners to mainstream disability. This role was taken up by Handicap International and UNNATI throughout the project by developing training modules, materials and study reports. Through interaction with resource people, experts and persons with disabilities, a cadre of educators and researchers was created.

Over a period of four months in 2003, the voices of 1,154 persons with disabilities were heard in 55 villages and eight urban slums across four districts in Gujarat – Ahmedabad, Sabarkantha, Patan and Vadodara.



Discussions on the issues of persons with disabilities

Addressing disability does not require a special project. When all development programmes include persons with disabilities an inclusive development paradigm can be achieved. Sensitisation on disability can be integrated in ongoing sensitisation programmes on development themes

The use of participatory techniques such as social mapping, service and opportunities mapping, focus group discussion, stakeholder analysis and Venn diagram, provided an opportunity for persons with disabilities to interact with members of the general community on an equal platform for the first time. These methods and techniques are used by many organisations in their daily practice.

In UNNATI's own ongoing rural governance programmes, *panchayats* were mobilised to include disability in their programmes. *Gram sabhas*⁹ and *panchayats* took responsibility to attend to the special needs of persons with disabilities. Other village institutions such as co-operatives, community-based organisations and self-help groups also expressed an interest in sharing this responsibility, especially in facilitating the disability certification process.

People were not insensitive to the issues faced by persons with disabilities, but largely ignorant about them. With greater awareness about these issues came a greater willingness to encourage their participation in society. Building trust and positive attitudes emerged as the key starting point for a mainstreaming initiative.

Addressing disability does not require a special project. When all development programmes include persons with disabilities an inclusive development paradigm can be achieved. Sensitisation on disability can be integrated in ongoing sensitisation programmes on development themes. For certain technical aspects, specific projects can be undertaken. Those organisations, which were working in close contact with the education department, could explore how teachers could be introduced to the concept of inclusive education. Those associated with capacity building of *panchayat* representatives could orient them on the

panchayats' role in addressing the needs of persons with disabilities among other vulnerable groups.

This can be done through improving information systems for improved access to schemes and services and by establishing linkages with other significant stakeholders. It is important to plan in a way where inclusion can be promoted within the existing resources.

Another intervention that is likely to lead to significant changes in attitudes is a periodic and active interface and linkage between rehabilitation and development institutions. Such crossovers increase the scope in promoting inclusive social development and poverty reduction. Furthermore, they are essential if disability is to break out of its 'special' enclave.



Rehabilitation and Development Institutions interface

At the outset, this would require that both develop an understanding of the complementary nature of their respective roles in promoting inclusion. In this case, a beginning was made which has led to development of meaningful partnerships between UNNATI, Handicap International, BPA and UWB and also linkages of the CBOs with several rehabilitation institutions. Similarly, linkages with academia have created new platforms for sharing and fostering continued learning.

MOBILISATION OF RESOURCES AND SUPPORT

All stakeholders, be it the government, business houses, NGOs, media and most importantly persons with disabilities played a critical role. Mainstreaming requires the ability to convene with the participation of all.



Media coverage on the issue of accessibility

Besides the skills of writing letters and petitions, holding meetings and discussions, organising presentations and seminars, conducting group, village or cluster level meetings, briefing the media, maintaining interest and hope among all stakeholders are more important. It requires organisational set up and resources to follow up. It also requires a credible organisation to lead. BPA's involvement in the programme provided credibility and legitimacy.

The media are some of the most powerful agents to create awareness and influence a change of mindset. It is important to enlist their support by advocating with them on all the issues and involving them in the programmes. Charkha, a development communication network, which acts as a bridge between development institutions and media, played a supportive role.

On matters of accessibility, the Access Resource Group stands with commitment to maintain the momentum generated.

Such committed and credible institutions and individuals are present everywhere. The three years' experience shows that with systematic and organised intervention enough support can be solicited which can make a difference.

lessons

learnt

Implementation of the collaborative initiative helped identify not only the barriers but also the strategies and steps that are helpful for mainstreaming disability. Broadly speaking, this initiative helped highlight eight thematic areas where, through sustained interventions, mainstreaming can be promoted. Given below is an overall assessment of the barriers and steps for mainstreaming vis a vis each of the identified areas. These are by no means all-inclusive and are an outcome of our learnings based on the strategies that we adopted and the processes that we followed.

1. PHYSICAL ACCESSIBILITY

Barriers to Inclusion

PHYSICAL STRUCTURES, OPEN SPACES (PUBLIC AND PRIVATE) AND TRANSPORT SYSTEMS ARE LARGELY INACCESSIBLE IN URBAN AND RURAL AREAS

LIMITED AWARENESS AMONG IMPLEMENTERS ABOUT 'HOW' AND 'WHAT' OF ACCESSIBILITY

LIMITED INTERFACE AND DIALOGUE BETWEEN USERS AND IMPLEMENTERS

PERSONS WITH DISABILITIES NOT INCLUDED AS STAKEHOLDERS IN DECISION MAKING PROCESS

Steps for Mainstreaming

Orient, sensitise and train all stakeholders who can influence the creation of a barrier free environment

Support development and dissemination of technical guidelines on accessibility

Develop popular awareness materials

Facilitate formation of Access Resource Group and build their capacity to conduct access audits of existing buildings and spaces. This must include the user groups viz. persons with disabilities and reduced mobility

Advocate for incorporation of accessibility in upcoming plans for public buildings, spaces and transport systems and into systems of architectural firms

Advocate for making accessibility mandatory in building by-laws and transport systems

Create and publicise models of barrier free buildings and spaces

Advocate for earmarking funds for accessibility with appropriate monitoring mechanisms

Involve media in highlighting the issue with positive stories

Choose highly visible / well frequented public places to launch an access campaign

Make the issue of 'accessibility' public and highlight it as a 'right for all'

Advocate for incorporation of accessibility issues into professional courses

Involve persons with disabilities in decisions related to accessibility

Start access awareness, advocacy and any support initiatives early after a disaster

2. ACCESSIBILITY TO INFORMATION AND AWARENESS

Barriers to Inclusion

ABSENCE OF ACCURATE
DATA ON PREVALENCE OF
DISABILITY


LIMITED AWARENESS AMONG
PERSONS WITH DISABILITIES
AND THEIR FAMILIES
ABOUT THEIR RIGHTS AND
ENTITLEMENTS, SCHEMES
AND SERVICES

INFORMATION NOT READILY
AVAILABLE IN ACCESSIBLE
FORMATS


Steps for Mainstreaming

Advocacy for
enumeration of
persons with
disabilities in the
Census on a regular
basis

Develop need-based
communication
strategy for specific
target groups with the
participation of persons
with disabilities as
decision makers



Involve community-based organisations, DPOs and citizen leaders for information dissemination, monitoring schemes and advocacy at all levels



Ensure that information on rights and services are available in regional languages, accessible and user friendly formats

3. ATTITUDES OF SOCIETY AND PERSONS WITH DISABILITIES

Barriers to Inclusion

Steps for Mainstreaming

LIMITED INTERACTION BETWEEN PERSONS WITH DISABILITIES AND SOCIETY, THEREBY LIMITING THE UNDERSTANDING OF DISABILITY - RESPONSES RANGING FROM OVERPROTECTION TO NEGLECT

ATTITUDES OF PERSONS WITH DISABILITIES ABOUT THEMSELVES FOSTER DEPENDENCY AND FATALISM

INAPPROPRIATE AND INADEQUATE REPRESENTATION IN THE MEDIA

Use participatory action research at the community level for awareness creation, generating data and facilitating attitude and behaviour change

Develop understanding on the prevalent attitudes towards disability (including of persons with disabilities) and the cultural beliefs and practices

Develop and use appropriate materials and information, education and communication (IEC) strategies for awareness and sensitisation

Facilitate forums for interaction between persons with disabilities and other civil society stakeholders

Orient and sensitise civil society on disability as a rights issue

Sensitise media to ensure adequate and appropriate coverage on disability, especially concerns of women with disabilities

4. MAINSTREAMING AT INSTITUTIONAL LEVEL

Barriers to Inclusion

DISABILITY HAS NOT YET BEEN ACCEPTED AS A DEVELOPMENT ISSUE AND IS PRIMARILY VIEWED AS A HEALTH AND WELFARE ISSUE

POLICY FOR MAINSTREAMING DISABILITY IN SOCIAL DEVELOPMENT PROCESSES NOT FORMULATED

ORGANISATIONS DO NOT HAVE THE UNDERSTANDING AND CAPACITY TO SUPPORT MAINSTREAMING STRATEGIES

Steps for Mainstreaming

Develop a clear mandate for disability, a disability policy and a time bound implementation strategy with measurable targets and outcomes

Develop methods and practices to ensure that disability is adopted as a cross cutting issue

Develop and implement sensitisation training on disability

Appoint a disability focal point and adequate staff with relevant skills

Earmark resources for mainstreaming initiatives

Collect disability disaggregated data and develop a system and appropriate tools for disability related analysis

Conduct relevant research for informing policy and synthesis in practice

Develop appropriate tools for monitoring progress and outcomes in consultation with DPOs

Document and disseminate experiences and good practices

Enable other organisations to formulate disability policy

5. CIVIL SOCIETY PARTICIPATION IN MAINSTREAMING DISABILITY

Barriers to Inclusion


STAKEHOLDERS WHO CAN CONTRIBUTE TO MAINSTREAMING DISABILITY ARE NOT AWARE OF THEIR ROLE AND CAPACITY

LIMITED INTERACTION BETWEEN CIVIL SOCIETY AND PERSONS WITH DISABILITIES

Steps for Mainstreaming

Identify, orient and sensitise key stakeholders (development and rehabilitation organisations, government, donor organisations, professionals, media, academicians, service industry, DPOs, persons with disabilities, elected representatives, community leaders) on disability and rights of persons with disabilities

Promote and support forums for interaction between different stakeholders and persons with disabilities



Facilitate
articulation of the
roles of different
stakeholders

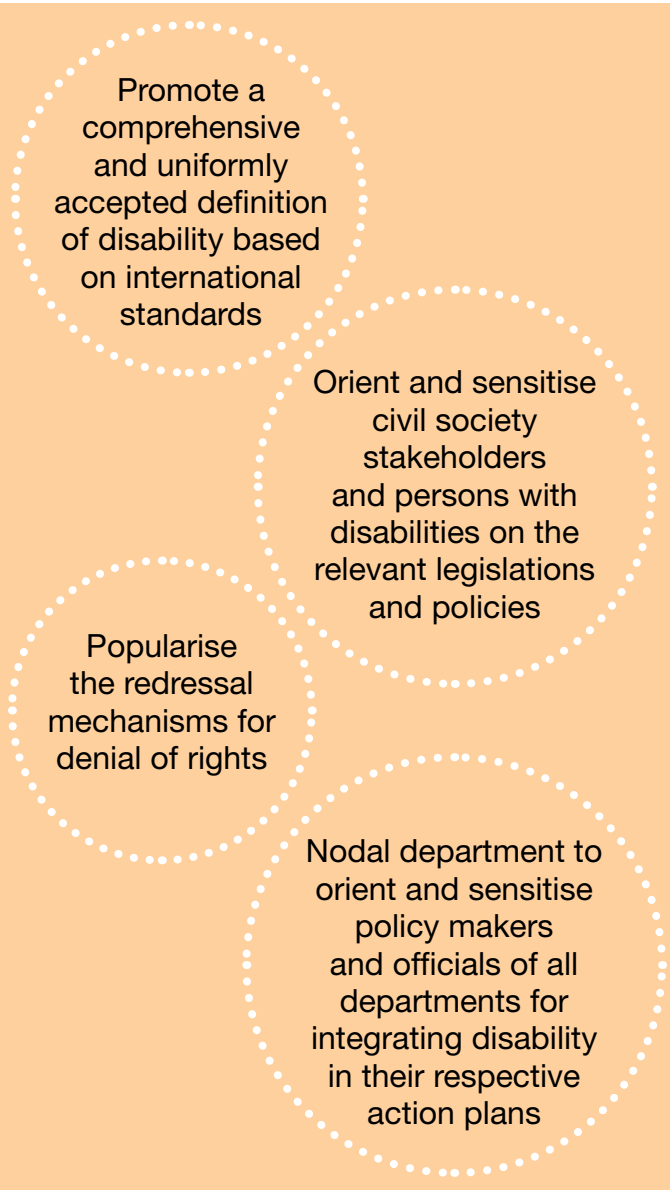
Build capacity
of stakeholders
to integrate
disability into their
ongoing work

6. POLICY

Barriers to Inclusion

NARROW DEFINITION OF DISABILITY WITH NO UNIFORM UNDERSTANDING
LOW AWARENESS OF LEGISLATION AMONG USER GROUPS, POLICY MAKERS AND IMPLEMENTERS
LEGISLATION/POLICY NOT FRAMED FROM A HUMAN RIGHTS PERSPECTIVE
INEFFECTIVE IMPLEMENTATION OF LEGISLATION
LACK OF FOCUS ON INTEGRATING DISABILITY AS A CROSS CUTTING ISSUE IN CONCERNED DEPARTMENTS
LITTLE INVOLVEMENT OF CONCERNED STAKEHOLDERS IN POLICY DESIGN

Steps for Mainstreaming



Make information on the legislative/policy available in user friendly formats in local languages

Facilitate the involvement of persons with disabilities in the development/review of domestic and international conventions / policies from a human rights perspective

Provide necessary support to DPOs and other civil society groups for effective implementation of legislation/policy

Facilitate interaction between DPOs and other groups to monitor government plan of action and budget allocation at local and national levels

Facilitate interaction between DPOs and the policy makers for enhancing understanding of their issues

7. EDUCATION AND EMPLOYMENT OPPORTUNITIES

Barriers to Inclusion

LIMITED AWARENESS IN SOCIETY ABOUT THE RIGHTS OF PERSONS WITH DISABILITIES

HUMAN RESOURCE POLICIES ARE NOT INCLUSIVE - LACK OF OPPORTUNITIES IN MAINSTREAM EDUCATION AND EMPLOYMENT

INADEQUATE ATTENTION GIVEN TO IDENTIFYING THE POTENTIAL AND CAPABILITIES OF PERSONS WITH DISABILITIES

LIMITED UNDERSTANDING LEADS TO STEREOTYPING OF ROLES, RESPONSIBILITIES AND EMPLOYMENT OPPORTUNITIES

MINIMAL INVOLVEMENT OF PERSONS WITH DISABILITIES FOR ENHANCING UNDERSTANDING OF THEIR NEEDS AND POTENTIAL

Steps for Mainstreaming

Raise awareness on the education and employment rights of persons with disabilities

Facilitate linkages between mainstream education initiatives and the special initiatives to promote mutual understanding and learning

Sensitise parents, teachers and children to better appreciate the needs and potential of children with disabilities

Sensitise and build the capacity of development organisations to include persons with disabilities in their ongoing programmes and within their organisations

Establish linkages with organisations implementing livelihood initiatives at community level for inclusion of persons with disabilities in their programmes

Create forums for interaction between parents, teachers and children from mainstream and special schools

Rehabilitate individuals with acquired disability in their current employment or field of specialisation in a similar position or grade

Develop individual plans with persons with disabilities for educational and economic rehabilitation based on their interests and aptitudes

Involving persons with disabilities, explore new areas of vocational training and livelihood opportunities

8. MOBILISING PERSONS WITH DISABILITIES AND STRENGTHENING DPOS

Barriers to Inclusion

LIMITED MOBILISATION OF PERSONS WITH DISABILITIES TO COLLECTIVELY ARTICULATE AND DEMAND THEIR RIGHTS

PERSONS WITH DISABILITIES ARE NOT IN POSITIONS OF LEADERSHIP AND UNABLE TO ARTICULATE THEIR PRIORITIES

WOMEN WITH DISABILITIES FACE DISCRIMINATION AT MULTIPLE LEVELS DUE TO GENDER, CASTE AND CLASS

LIMITED THEORETICAL UNDERSTANDING BASED ON PRACTICE OF MAINSTREAMING DISABILITY

Steps for Mainstreaming

Support and strengthen persons with disabilities and DPOs to represent a unified voice when lobbying with governments and service providers, with an equal emphasis on women with disabilities

Influence and facilitate DPOs to monitor inclusion of their concerns in manifestoes and action plans of political parties

Capacity building for persons with disabilities, especially women with disabilities to take on lead roles in DPOs and other organisations

Strengthen DPOs to demand for inclusion as voters and candidates

Influence DPOs to advocate for reservation and inclusion in local self governing bodies in all the 3 tiers in rural and urban areas

Promote research (both applied and action) to assess the current situation and practices for mainstreaming at all levels with/ under the leadership of persons with disabilities

Develop understanding on the issues of women with disabilities

Facilitate the process of mobilisation of women with disabilities

Accord equal importance to support/rehabilitation services for persons with disabilities along with awareness, mobilisation and advocacy

Facilitate linkages of groups of women with disabilities with other movements specially the women's movement and local level women's networks

Focus on the inclusion of women with disabilities at all levels and within DPOs also.

NOTES

1. Mainstreaming is the process of ensuring that the concerns, needs and experience of persons with disabilities is integrated into all aspects of policies, plans, programs and society so that they benefit equally. Mainstreaming is about 'inclusion' – not just 'involvement'; promotes participation, empowerment, self-determination and equality and is a human rights and political issue.

2. MI is an organisation based in South India that seeks to promote an inclusive society where persons with disabilities have equal rights and a good quality of life. It promotes mobility for persons with disabilities, especially those in rural areas, those who are poor and with a special focus on women and children.

3. Community Approaches to Handicap in Development (CAHD) is a rights-based strategy for inclusion of persons with disabilities in mainstream development activities. It is a strategy promoting social change. The community is targeted as a whole in order to recognise the existence of persons with disabilities in society, to change the attitudes towards them and to find ways of providing services to meet their needs. Positive attitudes remove barriers and create opportunities for persons with disabilities to participate equally in development processes. The strategy focuses on four main components viz. Social communication, Inclusion, Management and Rehabilitation. CAHD builds on the Community Based Rehabilitation (CBR) approach, which focuses on meeting the needs of persons with disabilities within their own environment, involving family members and community. It refers to measures taken at the community level to use and build on locally available resources of the community. These resources include the disabled persons, their families and others in the community. (Handicap International 2006). The focus in CBR is more on assisting the individual to fit in the system whereas CAHD emphasises the role of community to change the context and remove barriers within the system so that it can include persons with disabilities in mainstream development.

4. Samarthaya, based at New Delhi is a group accredited by UN – ESCAP as accessibility experts.

5. As per the United Nations Convention on the Rights of Persons with Disabilities, 2006 'Universal design' means the design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialised design. 'Universal Design' shall not exclude assistive devices for particular groups of persons with disabilities where this is needed.

6. Poor, helpless and alone

7. The Panchayat is an elected body and the local self government at the village, block and district levels.

8. Balwadis are day-care centres for early childhood care and education for the age group of 0-5 years established under the government-promoted and supported scheme of Integrated Child Development Scheme of the Government of India.

9. The Gram Sabha is the constitutionally mandated village level assembly that has been provided to facilitate direct democracy. It comprises of all the registered voters of a village and is a forum to discuss village level issues and plans.

10. The World Health Organisation (WHO)'s international classification of impairment, disability and handicap was developed in 1980 and revised in 2001, to become the International Classification of Function (ICF). The ICF explains the disability process from the point of view of participation in activities and society. It defines Impairment, Disability (Activity Limitation) and Handicap (Restricted Participation) as follows:

Impairment

Loss of part of the body and/or its function. It could be physical or psychological.

Disability (Activity Limitation)

Due to an impairment a person is unable to do his/her functional activities like sitting, standing, walking, feeding, toileting, hearing, seeing, etc. Disability can be reduced by equipment and/or specific techniques that allow a person with disabilities to function.

Handicap (Restricted Participation)

Handicap is caused by barriers in the built environment, negative societal attitudes and poverty – things that restrict a person's ability to undertake activities of daily living and to perform his/her life roles in society, including participation in community planning and decision-making.

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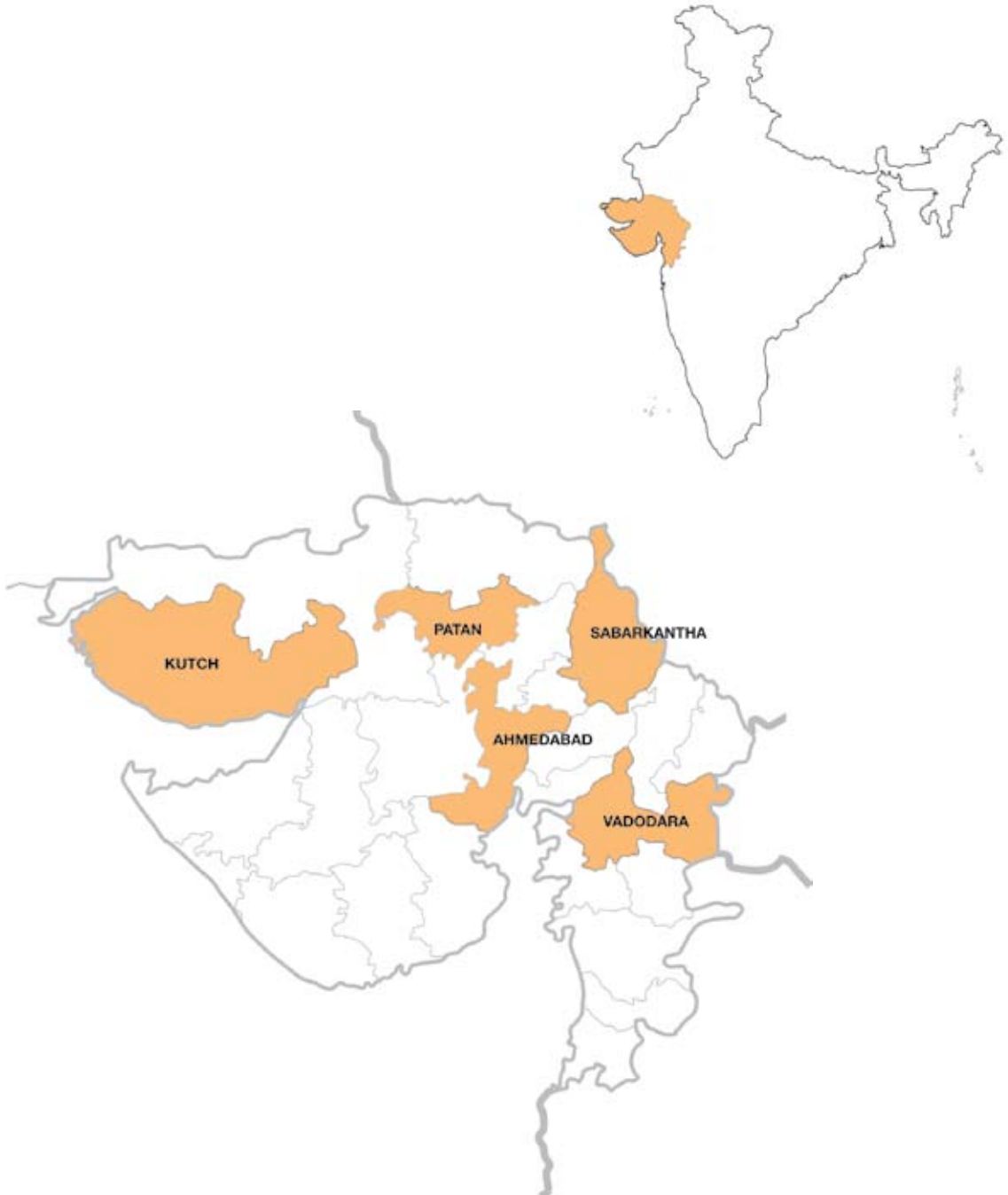
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ACRONYMS AND ABBREVIATIONS

ADA	Americans with Disabilities Act
ADD India	Action on Disability and Development India
AIDS	Acquired Immunodeficiency Syndrome
AMC	Ahmedabad Municipal Corporation
AUDA	Ahmedabad Urban Development Authority
BPA	Blind People's Association
CAHD	Community Approaches to Handicap in Development
CBO	Community Based Organisation
CBR	Community Based Rehabilitation
CD	Compact Disc
DPO	Disabled People's Organisation
GVST	Gram Vikas Seva Trust
HIV	Human Immunodeficiency Virus
IDS	Institute of Development Studies
IEC	Information, Education and Communication
KVSS	Kutch Viklang Sankalan Samiti
MI	Mobility India
NAB	National Association for the Blind
NCPEDP	National Centre for Promotion of Employment for Disabled People
NGO	Non-Government Organisation
PLA notes	Participatory Learning and Action notes
PRA	Participatory Rural Appraisal
PWD Act	Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995
SCF	Save the Children Fund
SCI	Spinal Cord Injury
SMM	Sakhi Mahila Mandal
SPIPA	Sardar Patel Institute of Public Administration
SYVM	Sri Yuva Viklang Mandal
UNESCAP	United Nations Economic and Social Commission for Asia and the Pacific
UNICEF	United Nations Children's Emergency Fund
U.P.	Uttar Pradesh
USADA	United States Americans with Disabilities Act
UWB	United Way of Baroda
VCD	Video Compact Disc
VJT	Vikas Jyot Trust

ANNEXURE 1

MAP OF INDIA AND GUJARAT WITH PROJECT DISTRICTS



ANNEXURE 2

VILLAGES AND SLUMS WHERE PRA WAS CONDUCTED

District Ahmedabad – Rural and Urban

Kanotar
Sarla
Rohika
Jansali
Mithapur
Sakalchand-Baherampu
Sulemaniroza
Sankalitnagar
Yogeswarnagar
Pravinnagar-Guptanagar

District Sabarkantha – All Rural

Jumsar
Bhetali
Dholvani
Malasa
Lilchha
Rasulpur
Ujedia
Aasroda
Maucha
Memadpur
Zinzva
Pedhmala
Bhadardi
Jethipura
Kanda
Kenpur
Poshina Ghati
Devasan
Upendragadh
Mangadh
Dhudhar
Hunj

Kump
Dhabal
Balochpura
Lei
Kava
Umedpura
Mathbhojayat
Ranasan
Pahadiya
Sisodara
Arjuhirola
Vasana
Jemana

District Patan – All Rural

Kamalpura
Lakhapura
Nava Amirpura
Kalyanpur
Indranagar

District Vadodara – Rural and Urban

Gandhikotar
Navi Dharti
Godadivas
Malimohalla
Navanagar
Dharod
Vadgamda
Therasana
Talsat
Sangama
Raipura
Laxmipura
Saniyala

ANNEXURE 3

PROVISIONS ON ACCESSIBILITY

I. UN Convention on the Rights of People with Disabilities (UNCRPD)

Article 9: Accessibility

1. To enable persons with disabilities to live independently and participate fully in all aspects of life, States Parties shall take appropriate measures to ensure to persons with disabilities access, on an equal basis with others, to the physical environment, to transportation, to information and communications, including information and communications technologies and systems, and to other facilities and services open or provided to the public, both in urban and in rural areas. These measures, which shall include the identification and elimination of obstacles and barriers to accessibility, shall apply to, inter alia:

- a) Buildings, roads, transportation and other indoor and outdoor facilities, including schools, housing, medical facilities and workplaces;
- b) Information, communications and other services, including electronic services and emergency services.

2. States Parties shall also take appropriate measures:

- a) To develop, promulgate and monitor the implementation of minimum standards and guidelines for the accessibility of facilities and services open or provided to the public;
- b) To ensure that private entities that offer facilities and services which are open or provided to the public take into account all aspects of accessibility for persons with disabilities;
- c) To provide training for stakeholders on accessibility issues facing persons with disabilities;
- d) To provide in buildings and other facilities open to the public signage in Braille and in easy to read and understand forms;
- e) To provide forms of live assistance and intermediaries, including guides, readers and professional sign language interpreters, to facilitate accessibility to buildings and other facilities open to the public;
- f) To promote other appropriate forms of assistance and support to persons with disabilities to ensure their access to information;
- g) To promote access for persons with disabilities to new information and communications technologies and systems, including the Internet;

h) To promote the design, development, production and distribution of accessible information and communications technologies and systems at an early stage, so that these technologies and systems become accessible at minimum cost.

II. Regional Policies: the Biwako Millennium Framework (BMF, 2002)

This is a policy framework for the Asian and Pacific Region, where States have agreed to work towards an inclusive, barrier-free and rights-based society for persons with disabilities. One of the seven targets and action in the priority areas is:

E. Access to built environments and public transport

Targets 13 – 15: Governments should adopt and enforce accessibility standards for planning of public facilities, infrastructure and transport, including those in rural/ agricultural contexts. All new and renovated public transport systems, including road, water, light and heavy mass railway and air transport systems, should be made fully accessible by persons with disabilities and older persons; existing land, water and air public transport systems (vehicles, stops and terminals) should be made accessible and usable as soon as practicable. All international and regional funding agencies for infrastructure development should include universal and inclusive design concepts in their loan/grant award criteria.

Action required for achieving targets:

1. Governments, in collaboration with disabled persons' organizations, civil society groups such as professional architecture and engineering associations and others in the corporate sector, should support the establishment of national and/ or regional mechanisms to exchange information on means to realize accessible environments, with display, library and research facilities, and information centers and should network with research and/or educational architectural and engineering establishments.
2. Ensure that professional education and academic courses in architecture, planning and landscape and building and engineering contain inclusive design principles; "teaching the teachers" courses in effective teaching of practical accessible design are established for all design schools in the region, including traveling workshops which involve the active participation of persons with disabilities;

and support continuing education professional development courses on best practices in inclusive design techniques for experienced practitioners, including those professionals who work closely with the end-users, such as community-based rehabilitation personnel.

3. Encourage innovative techniques, such as through design competitions, architectural and other awards and various other forms of support, to identify particular applications that enhance accessibility and apply local knowledge and materials. Local materials to make built environments accessible, e.g., tactile blocks and non-slip floor tiles, should be developed and made available. Networks to disseminate innovative techniques should be developed.

4. Support the establishment of appraisal mechanisms on how codes and standards have been developed, applied and enforced and how they have increased accessibility in various countries. Feedback and case studies on areas (rather than on a single new or upgraded building) are important, with publicity and dissemination of the findings, and show how improvements could be made.

5. Ensure that the accessibility needs of persons with disabilities be included in all rural/agricultural development programmes, including but not limited to access and use of sanitation facilities and water supply through a process of consultation that includes disabled user-groups.

6. Create access officers or posts which include the function of access officers at local, provincial and national levels whose functions include providing architects/designers/developers with technical advice and information on access codes and application of inclusive design, and appropriate technology in the natural and built environments in rural, peri-urban and urban contexts.

7. Disabled persons' organizations should implement confidence-building and advocacy measures to present their needs collectively and effectively in the built environment in one voice representing the needs of different disability groups, including not only persons with physical, visual and hearing disabilities but also persons with intellectual disabilities.

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

Section 44. Establishments in the transport sector shall, within the limits of their economic capacity and development for the benefit of persons with disabilities, take special measures to :

- a) Adapt rail compartments, buses. Vessels and aircrafts in such a way as to permit easy access to such persons;
- b) Adapt toilets in rail compartments, vessels, aircrafts and waiting rooms in such a way as to permit the wheel chair users to use them conveniently.

Section 45. The appropriate Governments and the local authorities shall, within the limits of their economic capacity and development. Provide for :

- a) Installation of auditory signals at red lights in the public roads for the benefit of persons with visually handicap;
- b) Causing curb cuts and slopes to be made in pavements for the easy access of wheel chair users;
- c) Engraving on the surface of the zebra crossing for the blind or for persons with low vision;
- d) Engraving on the edges of railway platforms for the blind or for persons with low vision;
- e) Devising appropriate symbols of disability;
- f) Warning signals at appropriate places.

Section 46. The appropriate Governments and the local authorities shall, within the limits of their economic capacity and development, provide for :

- a) Ramps in public buildings;
- b) Braille symbols and auditory signals in elevators or lifts;
- c) Braille symbols and auditory signals in elevators or lifts;
- d) Ramps in hospitals, primary health centers and other medical care and rehabilitation institutions.

ANNEXURE 4

PARTNERS IN THE INITIATIVE

Non Governmental Organisations

- Ahmedabad Study Action Group, District Ahmedabad
- Bhansali Trust, District Patan
- Gram Vikas Sewa Trust, District Sabarkantha
- Lok Seva Yuva Trust, District Sabarkantha
- PARAKH Trust, District Sabarkantha
- Rural Development Society, District Sabarkantha
- SAATH Charitable Trust, District Ahmedabad
- Sarvodaya Mahila Jagruti Seva Trust, District Sabarkantha
- Shri Ambedkar Education Trust, District Sabarkantha
- Shramik Vikas Seva Sanstha, District Sabarkantha
- Vikas Jyot Trust, District Vadodara
- Vinoba Bhave Seva Sansthan, District Sabarkantha

Academic Institutions

Faculty of Social Work, M. S. University, District Vadodara

PARTNERS IN ACCESSIBILITY

Individuals

Ashkha Naik, Amit Sheth, Anagha Muzumdar, Anand Patel, Arpit Dutt, Aruna Khasgiwala, B R Balachandran, Balkrishna Doshi, Bhushan Punani, Bimal Patel, Bindu Nair, Brinthalakshmi Subramanian, Dilip T Mehta, Govind Kerai, Has Mukh Patel, Jyotish Chowdhary, Kamal Mangaldas, Kanchan Patel, Kahan Vyas, Karan Grover, Kinnari Desai, M M Patel, Meghna Patel, Mitul Shukla, Nandini Rawal, Narendra Amin, Nimish Patel, O Ravi, Prabha Mehta, Pradeep Makhijani, Praveen Nahar, Raajesh Moothan, Rohit Patel, S Balaram, Sanjay Dave, Sushma Oza, Sweta Bhayut, Uday Shelat, Vishnuprasad Raval, Vijay Matai, Vijay Patel, Yatin Pandya

Institutions

Abhikram / Panika, Ahmedabad Municipal Corporation, Ahmedabad Study Action Group, Blind People's Association, Centre for Environmental Planning and Technology, Charkha, Commissioner of Disabilities-Gujarat, Department of Architecture-M.S. University, DISHA, Eklavya Education Foundation, Environmental Planning Collaborative, Faculty of Social Work-M.S. University, HCP Design and Project Management Pvt. Ltd, ICICI Bank, Members of the Media, Mind's Eye Design, National Institute of Design, Parakh, Planet Health, Shri Navchetan Blind Men's Association, Shri Yuva Viklang Mandal, United Way of Baroda, Vastu Shilpa Foundation

ANNEXURE 5

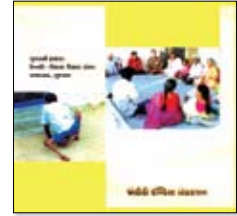
EDUCATIONAL MATERIALS DEVELOPED DURING THE INITIATIVE



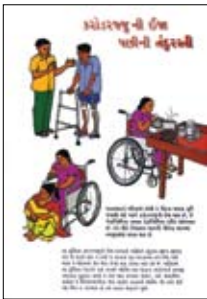
Paraplegia and Quadriplegia.
March 2002, VCD.
Gujarati



Saathe Madine Jeevun.
March 2002, Flash Cards.
Text in Gujarati and manual
in English



Sunjo Re Koi Saad –
a film, VCD.
Gujarati



Care of SCI patients.
March 2002, Pamphlet.
Gujarati



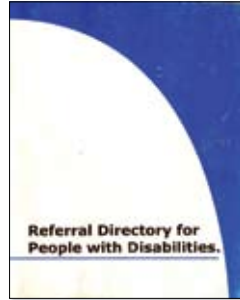
If Buildings were
Barrier-free I could...
March 2003, Brochure.
English and Gujarati



Summary of PWD Act.
December 2003, Brochure.
Gujarati



Directory of Services for Persons with Disabilities in Kutch District.
December 2003, Print.
Gujarati



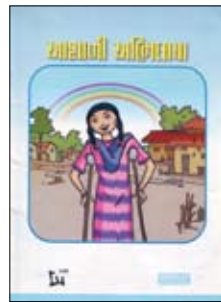
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December 2003, Print.
English



Posters.
September 2003, Print.
Gujarati and Hindi



How can the Rights of Persons with Disabilities be Protected.
September 2004, Booklet, Audio CD, Audio Cassette and Braille.
English and Gujarati



Asha ni Abhilasha.
September 2004, Print.
Gujarati



Sammilit Shikshan – a film on inclusive education.
September 2004, VCD.
Gujarati



Rozgar – a film on employment.
September 2004, VCD.
Gujarati



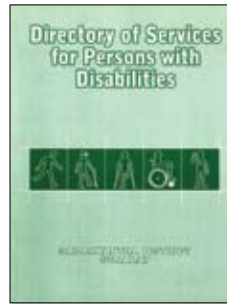
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December 2004,
Manual and Interactive CD.
English



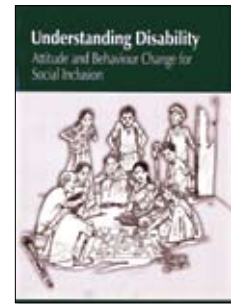
Directory of Services for Persons with Disabilities
Vadodara District.
December 2004,
Print and CD.
English and Gujarati



Directory of Services for Persons with Disabilities
Ahmedabad District.
December 2004,
Print and CD.
English and Gujarati



Directory of Services for Persons with Disabilities
Sabarkantha District.
December 2004,
Print and CD.
English and Gujarati



Understanding Disability:
Attitude and Behaviour
Change for Social Inclusion.
December 2004, Print, JAWS
compatible version and CD.
English and Gujarati



Ajab Gajab Ni Doorbin
a street play.
December 2004, VCD.
Gujarati



Khule Man ni Bari
a street play.
December 2004, VCD.
Gujarati



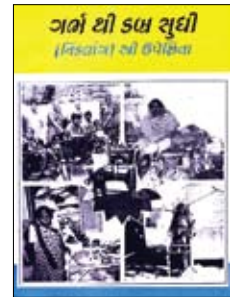
Freedom of Being
a film on Access.
December 2004, VCD.
English



Azad Astitva
a film on Access.
October 2006, VCD
Gujarati



Niyati ne Padkarnara.
July 2004, Booklet.
Gujarati



Garbh thee Kabra Sudhee.
August 2004, Booklet.
Gujarati

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About UNNATI

UNNATI - Organisation for Development Education, is a voluntary non-profit organization registered under the Societies Registration Act (1860) in 1990. It is our aim to promote social inclusion and democratic governance so that the vulnerable sections of society are empowered to effectively and decisively participate in mainstream development and decision making processes.

It is an issue based, strategic educational support organization, working in Western India with people's collectives, NGOs, elected representatives in local governance and the government. Collaborative research, public education, advocacy, direct field level mobilisation and implementation with multiple stakeholders are the key instruments of our work. The interventions span from the grassroot level to policy level environment in ensuring basic rights of citizens. In this, inspiration is drawn from the struggles of the vulnerable and strength from our partners. Presently, all the activities are organised around the following programme centres:

- a. Social Inclusion and Empowerment**
- b. Civic Leadership and Governance**
- c. Social Determinants of Disaster Risk Reduction**

The learning derived from our field experiences are consolidated and disseminated in print and electronic forms for wider sharing through a Knowledge Resource Centre. It is our endeavour to build an academy for community leaders, especially dalits and women, so that they can effectively address local issues.

About Handicap International

Handicap International is an unbiased international solidarity organisation working alongside persons with disabilities through assisting and supporting in their efforts to become self-reliant. It has presence in over 60 countries and responded in many emergencies across the world.

Handicap International is committed to help persons with disabilities worldwide since its inception in 1982 through its well networked national associations based in Belgium, Canada, France, Germany, Luxembourg, Switzerland, United Kingdom and USA.

In India, Handicap International began its work from 1988 through rehabilitation and support projects. The initial projects have gradually scaled up to programmes focused on creating a barrier free surrounding, right based approach, inclusive public health systems, equal opportunities in terms of education, employment and quality of life for persons with disabilities. Over the past seven years, Handicap International has initiated, supported and facilitated projects in different parts of the country including emergency response in situations such as the Gujarat earthquake, post-tsunami development work in Andaman and Nicobar Islands. Handicap International has been closely associated with Government departments and other local partners to implement public health project in Gujarat, capacity building of state government officials of Orissa, West Bengal and Andaman and Nicobar Islands for integrating disability issues in disaster risk reduction.

Handicap International is the co- laureate of Nobel Peace Prize for its role in International Campaign to Ban Landmines in 1997.



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