

# Working towards inclusion: experiences with disability and PRA

by ALICE MORRIS, GEETA SHARMA, and DEEPA SONPAL

## Introduction

In India, persons with disabilities, especially those who are poor, suffer from profound social exclusion. This limits their participation in all spheres of life – social, cultural, and political – resulting in denial of their rights. Yet, data provides a limited picture of the extent of exclusion that persons with disabilities experience. They rarely get opportunities to share their perspectives with the community, remaining hidden and excluded from the mainstream activities of society. There is very little understanding of their abilities, skills, and potential. This, in turn, contributes to society's ignorance and lack of interest in taking steps to include them.

This paper describes the processes, outcomes, and learning from collaborative participatory action research facilitated by UNNATI–Organisation for Development Education and Handicap International (HI)<sup>1</sup>, in partnership with thirteen grassroots organisations. The study was part of an overall effort to promote civil society participation in mainstreaming persons with disabilities. Its aim was to develop awareness and a collective understanding of the needs, potential, rights, and aspirations of persons with disabilities, and of the prevail-

ing attitudes, beliefs, and behaviour of the community towards them. Including persons with disabilities in this process, and listening to their views and perspectives, was the special focus.

The study represents the voices of 1154 persons with disabilities in 55 villages and eight urban slums across four districts in Gujarat – Ahmedabad, Sabarkantha, Patan, and Vadodara.

## Methodology

Using selected participatory rural appraisal (PRA) tools and techniques, a pilot study was first conducted in a few villages of Dholka *taluka*<sup>2</sup>. This allowed the facilitators to arrive at a common understanding of how to use PRA tools for addressing disability issues. Tools included: transect walks; social mapping; mobility mapping; Venn diagrams; stakeholders' meetings; and focus group discussions. This was followed by the PRA itself, in collaboration with 13 grassroots organisations. The process helped persons with disabilities and the community to explore perceptions of disability, which are often rooted in ignorance and lack of interaction.

<sup>1</sup> UNNATI – Organisation for Development Education works towards the social inclusion and empowerment of vulnerable parts of society, mainly the *dalits* and persons with disabilities, in Gujarat and Rajasthan.

<sup>2</sup> An intermediate administrative division between village *panchayat* and district *panchayat*.

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

### Summary of findings

#### Profound exclusion

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

#### Mobility, access, and social participation

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

#### Family life

More men with disabilities were married, and many had non-disabled partners. Women with disabilities, on the other hand, were more often single or married to another person with disability.

#### Rehabilitation needs and services

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

#### Public health services

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

#### Access to rights

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

#### Livelihoods

The study reveals that, in the peak earning age group (between 18 and 45 years of age), 93% of persons with disabilities had not received any income generation or vocational training. Even if they had the stereotypical skills of basket making, weaving, and embroidery they were not able to meet their financial needs. More women with disabilities (84%) were found to be engaged in household chores, agriculture or tailoring compared to men with disabilities.

#### Education

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

### Mapping the village and households of persons with disabilities



Photo: UNNATI PRA Team

#### Mainstreaming persons with disabilities

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

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

#### Methodological issues – some learnings

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

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

We learnt that it is very important to communicate the

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objective of the exercise to the community and to some local institutions prior to conducting the PRA, so as to avoid creating unrealistic expectations. This also helps in sharing responsibility for enabling persons with disabilities to participate in the PRA. It is also important to reiterate periodically the objective of the exercise, to keep the focus during the discussion.

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

Social maps help in developing a comprehensive understanding of the economic, social, and physical aspects of the village. For our specific focus, we modified the mapping. Instead of documenting information on all households, the group indicated only those houses where persons with disabilities lived.

This was a critical entry point for developing a collective understanding of who the community considered to be disabled and why. In most villages, before this exercise, community leaders estimated that between five and ten persons per village had disabilities. In all the villages, the actual number was at least five or six times this, as shown by the mapping.

This difference existed because of variations in the definitions of disability used. Most often, physically disabled persons were included while those who were visually impaired, had low vision or impaired speech and hearing, were deaf-blind, had multiple disabilities, or were mentally retarded or mentally ill were left out. This was partly due to the fact that, in the vernacular language, the word for ‘disabled’ literally means ‘one without limbs’. During the discussions with the community, it was the disabled persons themselves and their families who participated in arriving at a common definition of disability. In most communities, a disabled person was defined as a person who, because of a physical or mental condition, was unable to look after herself/himself and required special support. Those who could support themselves financially were not counted as disabled, despite having an impairment.

Mapping helped generate some baseline data for the

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

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

#### Seeing beyond the visible

To understand the mobility pattern of persons with disabilities, we used a ‘services and opportunities map’. This helped us to understand the services available inside and outside the village, and the frequency with which these were accessed. While doing this, we realised that access to a service for the disabled depends to a large extent on the availability of someone to escort them. Hence, in mapping mobility patterns, it was important to go beyond the mapping exercise and to explore and understand the role of ‘significant others’ in facilitating the mobility of those with disabilities.

#### Overcoming barriers to participation

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

To quote just one instance, prior to our visit to Hunj village in Prantij *taluka*, Sabarkantha district, we contacted the *Sarpanch*<sup>3</sup>, who was very helpful in gathering community members and helping to explain the objectives of the PRA. Persons with disabilities were especially encouraged to participate in making the services and opportunities map. Jalaben<sup>4</sup>, a disabled woman with a hearing and speech impairment, showed a special interest and wanted to participate in the preparation of the map. However, after a while, when the group was engrossed, we noticed that Jalaben had left. Later, we learnt that the *Sarpanch* had signalled to her to leave, probably because he was embarrassed at the sounds she was making in her attempts to communicate.

Perceptions and attitudes are not easy to change. The teams needed to be very aware of these subtle coercive

<sup>3</sup> Elected leader of the village-level governing body.

<sup>4</sup> ‘Ben’ is used at the end of a woman’s name in the local language as a word of respect.

**Prioritising services based on importance and accessibility**

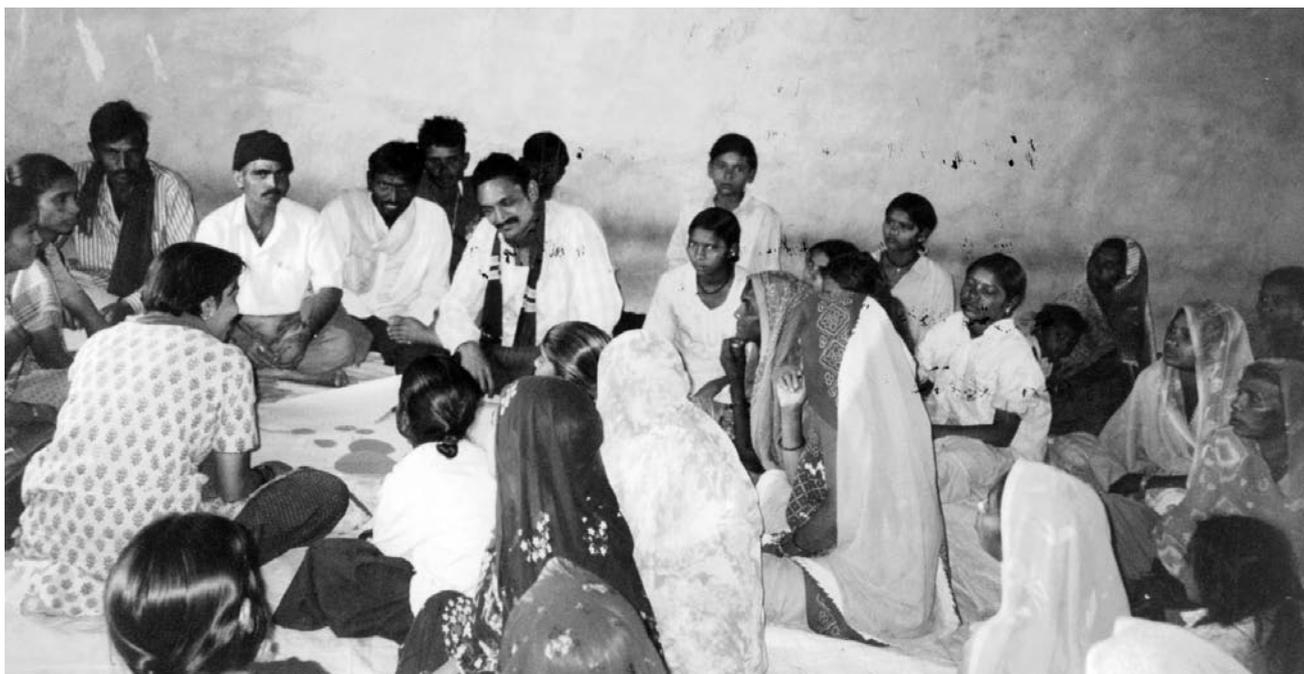


Photo: UNNATI PRA Team

forces and handle them appropriately so as to include and sustain the participation of persons with disabilities, while retaining the interest of other group members.

### Different realities and priorities

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

The response of different groups was quite varied. For instance, for women, drinking water facilities, health centres, and *mahila mandals* (women's groups) were more significant. For men, institutions like cooperatives, public transport, communication facilities, and water for irrigation were more important. For the youth, educational facilities, recreational centres, and youth groups were of higher importance. Persons with physical disabilities were more responsive as compared to those with mental retardation. Even among the physically disabled, most of them had not stepped outside the village and hence they were able to rank only those services available within the village, but they were able to mention those that were important but not available within the village.

As different sections of the community had different sets

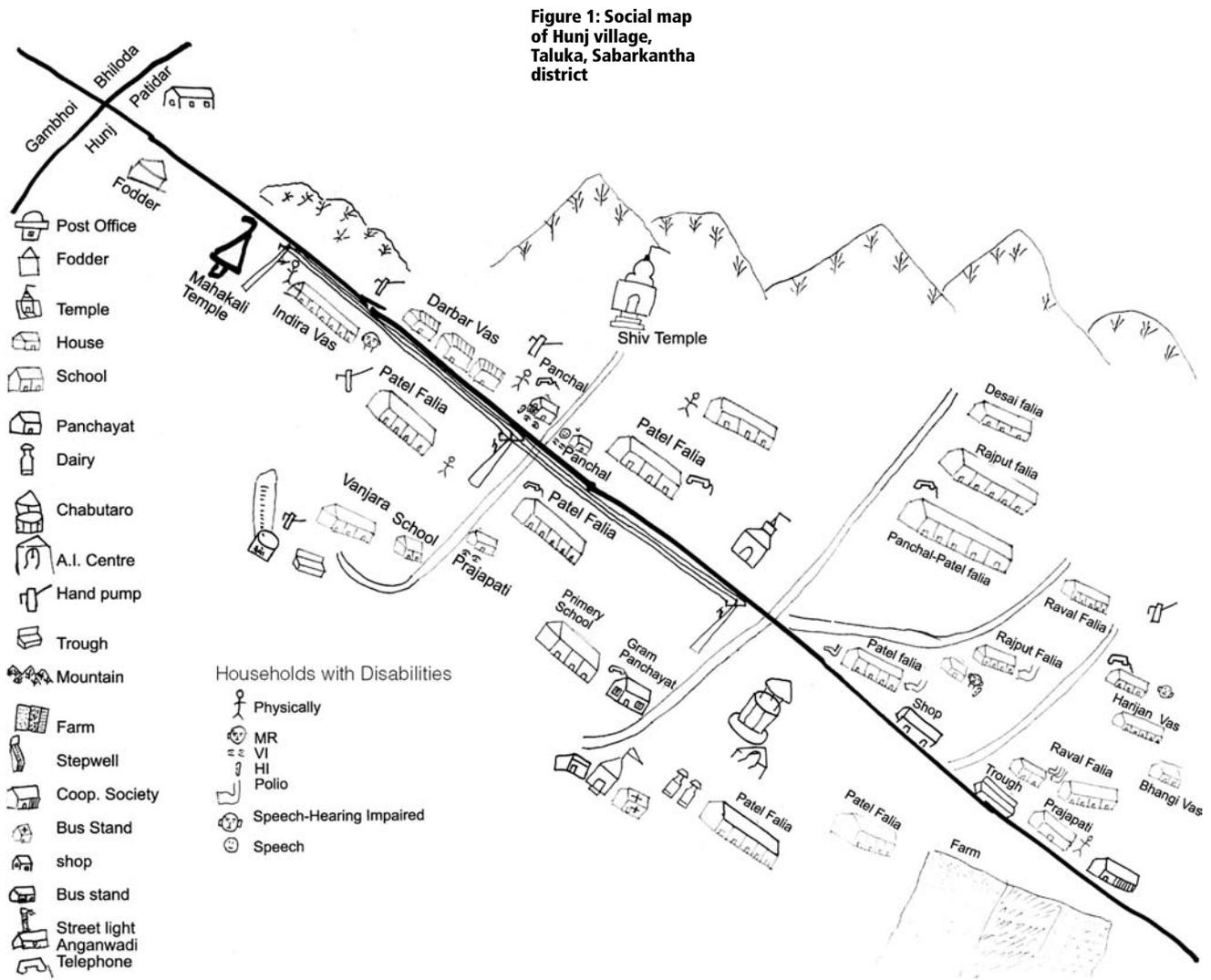
of priorities, it was important that everybody's views in the groups were noted and analysed separately. The exercise can also be done separately with small groups, and the responses consolidated.

### People's priorities versus our priorities

In Gandhi Kotar, one of the slum areas of Vadodara district, the team was unable to enlist the cooperation of the local residents. Informal interactions revealed that the slum had been shifted recently and people did not have access to basic facilities. Many of the residents had died due to cholera, as the only water available to them for drinking was from the gutter-cum-stream running along the side of the slum. In view of this, we had to postpone our priorities and discuss with the partner organisation how they could address the immediate needs of the people. After some time, the team revisited the slum to conduct the PRA and this time it was possible to elicit the community's participation.

### Sensitivity towards all stakeholders

In Hasanpura village, Sabarkantha district, the villagers were initially resistant to participate. When the purpose of the exercise was explained to the community during the transect walk, a few people joined the mapping exercise. At one point, some youths interrupted us as they seemed to have doubts about the purpose of our visit. We spent consider-



able time convincing them, and even showed a few social maps prepared in other villages. Slowly, they began to take an interest in the mapping exercise.

The following day, we met the *Sarpanch*, who had not been present for the above exercise. He told us that the day the PRA exercise was conducted was exactly a year after serious riots, involving violence against Muslims, had taken place in the State. This was much on people's minds, and also led to tension between the Hindu and Muslim sections of the village.

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

### PRA as a starting point for community interventions

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

### Understanding disability issues from women's perspectives

Women with disabilities suffer double discrimination, both on grounds of gender and impairment. They face the difficulties imposed by the impairment, as well as being more socially excluded than men. Very few studies focus on the experiences of women with disabilities and a better understanding of disability issues from women's perspective is needed.

In this study, men participated more than women in larger groups, so separate focus group discussions were facilitated by women field workers with the disabled women. Women who had a disabled spouse or disabled member in their family were also included in this group. The need for maintaining the confidentiality of the discussions was stressed, and discussions were steered from the general to specific experiences and needs. The facilitators used audio-visual aids, such as flash cards and short films, to begin the discussion, and this encouraged people to

share their views, needs, and specific problems openly. As most participants had similar experiences, sharing by one helped the others to open up. This proved to be a cathartic experience for the women. It provided a supportive platform where the women could share their problems, were heard, and felt a sense of bonding with the other group members.

### Way ahead

The PRA provided a rare opportunity for persons with disabilities to interact with the community on an equal basis. It created an understanding and awareness of perceptions, attitudes, and initiatives, as well as gaps in inclusion. It helped provide directions for working towards developing an accurate database (qualitative and quantitative), improved access to rehabilitation services and information, creating a barrier-free environment, supporting networks of persons with disabilities, and articulating and facilitating the involvement of civil society in inclusion.

#### CONTACT DETAILS

Alice Morris, Geeta Sharma, and Deepa Sonpal  
UNNATI  
Organisation for Development Education  
G-1/200, Azad Society, Ahmedabad  
Gujarat – 380 015  
INDIA  
Tel: +91 79 26746145, 26733296  
Fax: +91 79 26743752  
Email: unnatiad1@sancharnet.in  
Website: www.unnati.org

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In the social map, in the Key given on the left, we have said 'visually impaired' or 'hearing impaired' etc. This refers to houses of people with the respective disabilities. We hope that this is clear, if not, please feel free to change it to make it clearer.