

ENABLED ENVIRONMENTS

REDUCING BARRIERS FOR LOW-  
INCOME PEOPLE WITH  
DISABILITIES IN INDIA

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## ACRONYMS

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BC	Bhumiheen Camp
BM	Bhatti Mines
CAN	Concerned Action Now
CAP	Community Action Planning
CBR	Community-based Rehabilitation
CSIR	Centre for Scientific and Industrial Research
CWD	Child with a Disability
DDA	Delhi Development Authority
DMRC	Delhi Metro Rail Corporation
DUEIIP Project	Delhi Urban Environment and Infrastructure Improvement
EE	Enabled Environments
ESCAP	Economic and Social Commission for Asia and the Pacific
JJ	<i>Jhuggi-Jhopri</i>
KP	Kusumpur Pahari
MCD	Municipal Corporation of Delhi
MLA	Member of Local Authority
NGO	Non-governmental Organisation
NHFDC	National Handicapped Finance Development Corporation
NSSO	National Sample Survey Organisation
PAR	Participatory Action Research
PWD	Person with a Disability
SBI	State Bank of India

SC	Subhash Camp
SEE	Special Employment Exchange
SS	Sulabh Sauchalaya
VRC	Vocational Rehabilitation Centre
VSS	Viklang Sahara Samiti

# CHAPTER 1

## CONCEPTS AND QUESTIONS

### Introduction

This report arises from a two-year, comparative study, funded by DfID<sup>1</sup>, with case studies in Pretoria, South Africa and New Delhi, India. The research set out to understand the processes by which people with disabilities living in urban informal settlements are prevented from fully participating in the socio-economic development of their community and the wider society, and to suggest ways in which greater inclusion can be achieved in the future.

Why, despite the existence of disability legislation and service provision, do people with disabilities living on low incomes often ‘fall between the gaps’? They may find themselves unable to access dedicated services for people with disabilities because such services contain no special provision for the poor. However, they may also be unable to take advantage of policies and programmes aimed at the poor, as they make no attempt to facilitate uptake by people with disabilities. The attitudes of individuals and institutions can constitute a further barrier to the participation of people with disabilities in society. Whilst patterns and mechanisms of exclusion may differ from culture to culture, the outcome is often the same – disability and chronic poverty go hand in hand (Yeo, 2001).

This opening chapter outlines the concepts and research questions underpinning the project.

### The Social Model of Disability

Within the field of disability studies, disability has come to be understood as a social rather than a medical phenomenon. This means that disability is the product of the interaction between individuals and their environment, rather than a problem of the individual in isolation (Hahn, 1986). Enabled Environments adopts this social definition of disability and studied the quality of the linkages between people with disabilities and their physical, social and economic environment. The term ‘impairment’ is used to refer to an individual’s condition, which can include physical, sensory, intellectual or behavioural impairment. The project adopted the WHO definition of impairment - ‘Any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being’. The majority of the participants in the research project have either a sight, hearing, physical or intellectual impairment (i.e. the disabilities listed in the Disability Rights Bills in South Africa and India<sup>2</sup>). However, the emphasis was placed not on identifying people through their type of disability, but on including those people

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<sup>1</sup> Department for International Development, Research Project No. R7653. The UK Department for International Development (DFID) supports policies, programmes and projects to promote international development. DFID provided funds for this study as part of that objective but the views and opinions expressed are those of the author alone.

<sup>2</sup> ‘Leprosy-cured’ also appears in the Indian Disability Rights Bill, but none of the sample reported this form of disability.

who identify themselves as experiencing the WHO concept of a 'restriction or lack of ability'.

As well as considering the environmental barriers to the integration of people with disabilities, the project also considers attitudinal barriers. People with disabilities all over the world mention that the major problem they face throughout their lives is the attitudinal behaviour of the non-disabled. This negative social process is often described as "disabilism" and occurs as a combined and cumulative effect of prejudice, humiliation and discrimination. The widespread circulation of a series of negative assumptions about people with disabilities must be understood and eradicated in order to achieve full participation for people with disabilities (Baquer, 1994).

### **Disability, Poverty and Social Exclusion**

The UN Decade of People with Disabilities (1983-1992) brought the issue of equality for people with disabilities onto the human rights agenda, and the end of the decade was followed by a series of promotional programmes. However, despite this increased awareness, people with disabilities (PWDs) continue to be disproportionately represented amongst the poor, the unemployed and the uneducated (Imrie, 1996). Some countries, including South Africa and India have introduced a range of legislative measures to support the greater inclusion of PWDs. However, such measures do not necessarily have an impact on the lives of PWDs living in poverty. In Uganda, the government has made a great effort to empower PWDs politically. Although this has resulted in 47,000 PWDs becoming elected representatives, recent assessments suggest that the changes have had little impact on PWDs living in low-income communities (Yeo, 2001). It is clear that the process of translating rights into specific measures and programmes that effectively reach PWDs living in poverty is far from complete.

In 1995, the UN estimated that there were 500 million people with disabilities worldwide, and that there are clear differences between the nature and extent of disability in developing and developed countries. The majority (75 per cent) of people with disabilities live in developing countries, and approximately 50 per cent of those people become disabled in the first 15 years of life. In comparison, most developing countries see a majority of the population with a disability are over 65. (Disability Awareness in Action (DAA), 1995)<sup>3</sup>

There is a strong relationship between poverty and disability. Poverty can be identified as being linked to causes of disability. The major causes of disability are malnutrition, non-infectious diseases and congenital diseases, followed by accidents, trauma and war and infectious diseases. (DAA, 1995, p.9). Insufficient money to buy food or lack of land to grow food can lead to malnutrition. Some congenital conditions are linked to malnutrition, and therefore, in turn are linked to

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<sup>3</sup> Figures relating to the incidence of disability internationally are all rough estimates as they based largely on incomparable information. USAID currently works with a global estimate of 10 per cent, whilst DFID works with an estimate of 4-7 per cent. (Yeo, 2001, p.8)

poverty. Similarly, many infectious and non-infectious diseases are secondary to poverty-related factors such as the drinking of polluted water.

Whilst living in poverty can be linked to a higher risk of acquiring a disability, once a person has a disability they are more vulnerable to becoming poor and remaining poor. Within such countries where the poor are already recognised as a vulnerable group within the process of economic development (Aslenbegui, Pressman and Summerfield, 1994), people with disabilities living in poverty are even more vulnerable to social exclusion. Barriers to PWDs' full participation in society can be classified as physical, attitudinal, economic and structural. Barnes' (1991) work in the UK highlights that PWDs require higher income in order to maintain equivalent living standards but most have lower wages, and there is no reason to suppose it is any different for PWDs living in developing countries.

Access to education, income-generating activities, health care and sanitation are recognised as key indicators of reduced poverty, as seen by the focus of the Millennium Development Goals. For a person living in poverty, the introduction of user fees, the excessive cost of a school uniform, the level of transport costs may prevent them from accessing health care, education and employment opportunities. In order to support people living in poverty, governments and NGOs may provide programmes and services aimed specifically at the poor. However, for someone living with poverty and with a disability, there may be additional barriers to greater inclusion. Prejudice and limited mobility makes it difficult for such people to compete for the limited number of unskilled jobs available (Baquer and Sharma, 1997), to take part in subsidised education and training places, and to take advantage of other services and opportunities aimed at the urban poor. People with disabilities living in developing countries, if engaged in paid work at all, are more likely to be engaged in home-based employment, such as piecework, which increases the likelihood of exploitation (ILO, 1999). The potential for people with disabilities to engage in self-directed employment is limited by a lack of credit and business training available to them (Neufeldt and Albright, 1998).

Political decisions regarding policy and budget allocation may also lead to the further exclusion of PWDs. Welfare services often take a much lower priority to the provision of primary and critical health care<sup>4</sup>. This is borne out by the fact that 98 per cent of PWDs living in developing countries have no access to rehabilitation services (DAA, 1995, p.8). The community-based rehabilitation (CBR) approach to service provision for PWDs was expected by some to be more cost-effective. However, it has been shown that good quality CBR makes considerable demands on resources (Finkenflügel, 1993), and that when external funding is withdrawn they are not sustainable (Momm and König, 1989). Where social support or community care is available to PWDs, it is often the first set of services to be cut or scaled back (DAA, 1995). Within the education sector, investment in making buildings accessible to children with disabilities may not be priority if the main indicator is increasing primary education coverage. Money may not be available for children requiring translators in order to enter mainstream education and may find themselves in 'special schools' that are not appropriate to their needs. 98 per cent of male disabled children receive no education (DAA, 1995, p. 14). In general,

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<sup>4</sup> The 2002 World Development Report on Access to Services has a chapter on Health and Nutrition but has no specific section on welfare services.

schools are inaccessible, there is no appropriate transport, children may be forced to attend 'special schools' but there may be none available in the area (DAA, 1995, p.14). No country in the world has a fully accessible transport system and therefore, there is little hope that countries with very limited resources will be able to provide fully accessible systems.

## **The Research Focus of the Enabled Environments Project**

In 1994, the UN launched the 22 rules for achieving equality for the disabled and identified 8 areas of participation that should be recognised by governments when legislating for the integration of people with disabilities into society: accessibility; education; employment; income maintenance and social security; family life and personal integrity; culture; recreation and sports; religion (United Nations, 1994). Five years later, the UN recognised that the process of translating the Rules into actual policy and practice was a 'major challenge' and in response to this, called for empirical research be carried out into the social, economic and participatory issues affecting the lives of the disabled and their families (United Nations, 1999). It was argued that the results of such studies would make it possible to propose approaches to translating rights into action which would be appropriate to the realities of the human environment, and therefore, of maximum benefit to people with disabilities. Enabled Environments adds to this body of work by carrying out research with people with disabilities and their families living in low-income, mainly informal settlements in Delhi and Pretoria.

The project began with the hypothesis, based on our own observations in the course of working on other field research and on the data discussed above, that despite the existence of disability legislation and service provision, people with disabilities living on low incomes often 'fall between the gaps': they find themselves unable to access dedicated services for people with disabilities because such services contain no special provision for the poor and yet, are unable to take advantage of policies and programmes aimed at the poor as they make no attempt to facilitate uptake by people with disabilities. Furthermore, the attitudes of individuals and institutions can constitute a further barrier to the full participation of people with disabilities.

The research explores the nature of the breach that exists between disability legislation and support programmes and the everyday reality of people with disabilities living in low-income neighbourhoods. It identifies and examines the environmental and attitudinal barriers that work against legislation and support programmes achieving the full integration of people with disabilities. By gaining new insights into the nature of the interaction between people with disabilities and their environment, we wish to achieve a greater understanding of the barriers that hinder their entry into education, employment, training, the full use of services and access to appropriate shelter. Having identified these barriers, the research explored practical means of overcoming them through consultation and practical collaboration with people with disabilities, their families, their communities and the service providers.

In order to frame the research, the project concentrated on four of the 8 areas identified by the UN's Standard Rules, accessibility; education; employment; income maintenance and social security. These areas tie in with the specialist

knowledge of the three key members of the research team. The main objective of this project is to generate new knowledge concerning the ways in which people with disabilities living in low-income areas interact with their environment and how such environments may be made more enabling.

## **Research Themes and Questions**

### **Accessibility**

Under the theme of accessibility, the project focused on accessible housing, communities and public buildings. The Habitat Agenda<sup>5</sup>, of which both South Africa and India are signatories, requires that governments provide laws and policies that create inclusive environments that give people with disabilities full access to new public buildings and facilities, public housing and public transport system.

The Economic and Social Commission for Asia and the Pacific (ESCAP) (1995, p.7) argues there are 6 key elements to achieving barrier-free environments:

- A complete legal system (from law to standards)
- A full set of instruments (e.g. master plan, town plan, detailed plans)
- Administrative effectiveness (from permission to control)
- Professional undertakings from guidelines to expertise
- Political transparency (openness of information, public attendance and involvement)
- Democratic control (from awareness to participation)

Enabled Environments examines the success of local and national efforts in translating accessibility policies into practice for people living in low-income informal settlements. It considers the 6 elements of the ESCAP guidelines from the perspective of people with disabilities.

Enabled Environments posed the following two questions regarding accessibility:

- To what extent does the physical environment found in low-income neighbourhoods limit the mobility, and thus, the social integration of people with disabilities? What measures could be taken to make the neighbourhood environment a more inclusive one?
- What examples are there of self-help low-cost alterations to housing in order to make it more appropriate for people with disabilities? To what extent are such examples suitable for other disabilities and housing types? In what ways could the implementation of such alterations be supported at an institutional level?

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<sup>5</sup> For more information on the Habitat Agenda, see <http://www.unhabitat.org/unchs/english/hagend>



## **Employment and Education**

As mentioned earlier, the right to education and the right to earn a livelihood are often denied to people with disabilities. The Standard Rules call for governments to ensure equality of educational opportunities for PWDs and to actively support the integration of PWDs into open employment. The message is one of integration as opposed to segregated facilities such as ‘special schools’ and ‘sheltered workshops’ that encourage social exclusion.

Enabled Environments focused on the following issues:

- How and why are people with disabilities are excluded from the education and employment opportunities open to non-disabled members of their communities and how greater inclusion could be achieved.
- What level of contribution people with disabilities make to low-income households in terms of income-generating and non-income-generating activities.

## **Contributions to and Support from the Household**

Having considered the physical environment and access to education, training and employment, the third key focus of Enabled Environments looks at the nature of the contributions PWDs make to the household and the level of support they require and succeed in obtaining.

The Standard Rules have a key section entitled ‘Income Maintenance, Social Security and Services’ which calls for states to ensure that people with disabilities who, owing to their disability, have lost income or have been denied employment opportunities be provided with adequate income support.

Whether or not income support is available is only the first consideration, however. For those living in low-income households, one needs to consider the importance of income support within the household. PWDs may also contribute to the household in non-economic ways by taking on certain domestic roles that free other household members to work.

- How can existing dedicated grants and services for people with disabilities be improved in order to ensure they are of the maximum benefit for people with disabilities living in poverty and their families?

For all the research areas, the project considers the implications of empirical findings for existing policies and implementation processes. It should be noted that although these the themes were given equal importance at the beginning of the project, as a project committed to participation the research participants were given the opportunity to decide which of the issues were of greatest importance to their lives. In the case of the South African participants, this led to a greater focus on access to housing, whilst in India, participants were most interested in access to toilets.

## **The Choice of South Africa and India**

The research was carried out in low-income settlements in the cities of Pretoria and Delhi. The two case studies offer suitable areas within which to study the nature of the linkages and barriers that exist between people with disabilities and their socio-economic environments.

Both the Indian and South African national governments have kept pace with current international trends in responses to disability. Both countries have adopted disability rights measures and have made attempts to move away from the traditional medical model of disability to a social model. Therefore, it is not a question of raising awareness about the need to focus on people with disability as a group vulnerable to being denied access to various aspects of society, but to suggest ways in which the realisation of those rights can be achieved through policy and practice. In this way, both countries offer the opportunity to study the translation process noted by the UN at the micro-level.

As well as introducing disability rights legislation, both India and South Africa are implementing economic reform packages that encourage privatisation, deregulation, removal of subsidies, and increased efficiency in state institutions. Such economic reforms in cities such as Delhi and Pretoria, which are undergoing rapid expansion and modernisation, place additional pressures on those people living with a disability and on a limited income. As welfare provision is reduced, an ever-expanding unskilled labour force increases competition for jobs. Thus, people with disabilities may find they have less funded state support and fewer opportunities to find jobs and training.

However, despite these similarities, the two countries offer an interesting contrast in historical and geographical context within which economic reform and increasing disability awareness are taking place.

India has enjoyed a tradition of a high-level of NGO activity and a concept of state provision of welfare. There are a number of NGOs and local, state and national programmes that focus on the needs of people with disabilities, and since December 1995, the Indian Parliament has created legal safeguards. However, based on field experiences of the Indian research partner, the challenge created by the incidence and prevalence of disability has received an inadequate response in terms of the combined efforts of all agencies. In comparison, South Africa is a country that is attempting to build a new, equitable society on limited resources after the end of a regime that provided little or no welfare for the its poorest citizens. This contrast offers the opportunity to illuminate interesting differences between the way in which established welfare systems and new welfare systems implement disability rights legislation.

There is also a contrast to be made at city-level. Delhi is a city that has high-density neighbourhoods, the majority of which consist of informal housing and limited services and amenities. It witnessed one of the largest programmes for rehousing the urban poor through the development of 44 re-settlement colonies in the late 1970s, but failed to tackle problems of overcrowding and congestion. In comparison, Pretoria is a city that still has sufficient space for development along with a national housing scheme that provides upgraded sites and housing grants.

Therefore, many of Pretoria's low-income neighbourhoods are low density and fully serviced. This contrast allows us to consider the role of formal housing and services in increasing the participation of people with disabilities in society.

## **Research Approach: Working Towards Participation and Action**

As explained earlier, the project uses a social definition of disability, which understands disability to be the product of the interaction between the individual and his/her environment. The project worked as far as possible with a participatory action research (PAR) approach to explore the nature of the relationships that PWDs living in low-income urban settlements maintain with their families, their communities, service providers, employers and their physical environment.

A PAR approach is important, as many people with disabilities complain that services and other measures are put in place by well-meaning organisations without consulting the disabled themselves. Some countries, including South Africa and India have introduced a range of legislative measures to support the greater inclusion of PWDs. However, such measures do not necessarily have an impact on the lives of PWDs living in poverty. In Uganda, the government has made a great effort to empower PWDs politically. Although this has resulted in 47,000 PWDs becoming elected representatives, recent assessments suggest that the changes have had little impact on PWDs living in low-income communities (Yeo, 2001). It is clear that the process of translating rights into specific measures and programmes that effectively reach PWDs living in poverty is far from complete. By using a PAR approach, people with disabilities will be involved in generating knowledge about their own condition and how it can be changed. A key slogan of the disability rights movement has been 'Nothing About Us Without Us' and it was felt the use of participatory approaches would be the best way of ensuring the voices of people with disabilities were heard and that they could play a role in shaping the focus of the project. We recognise the project was not fully participatory, as in a truly participatory process the original design of the project would have been created by the project participants themselves. It was hoped however that by using this approach, a parallel achievement of the project would be some level of empowerment through raising people's awareness of disability rights, providing exposure to research and advocacy and facilitating meetings and discussion between participants and service providers. An assessment of how successful the project team were in achieving this can be found in the conclusion.

PAR allows local people to gain something more immediate from the research process than the abstract sense of 'influencing international policy'. As Chambers (1999, p.106) explains, PAR has the potential '... to enhance local people's confidence and awareness and to empower their action.' By using accessible, often visual methods such as mapping and time-use analysis, the research process is demystified and people can be empowered through a greater understanding of themselves and the value of their knowledge. For this project, people with disabilities came together for the first time to share experiences, both positive and negative, and to develop ideas about how they wished their environments to be transformed. Having initiated participative processes, the challenge for any project that uses a PAR approach is sustaining the participatory dynamic beyond the life of the project. The Enabled Environments project created new partnerships across

low-income communities and people with disabilities took collective action for the first time. An assessment of the success of the action research aims of the project and their sustainability can be found in the conclusion. Chapter 3 discusses the different elements of the research in more depth.

## **The Research Team**

### ***UK:***

Dr. Justine Coulson, the principal investigator, brought knowledge of social development issues and participatory methods to the project, and had worked in Delhi and Pretoria prior to Enabled Environments.

### ***India:***

Prof. Ali Baquer has worked on disability issues internationally for a number of years and runs Concerned Action Now (CAN)<sup>6</sup>, an NGO based in Delhi that specialises on research and advocacy on disability. He has developed and used action research approaches throughout his career.

Malancha Tandon has worked on disability issues since joining CAN in 1997. She has experience in conducting research and coordinating projects with people with disabilities in the slums of Delhi.

### ***South Africa:***

Dr. Mark Napier is a senior project manager in the Sustainable Settlements Programme at CSIR<sup>7</sup>, Pretoria. He brought his experience of research and development in informal settlements and knowledge of physical environmental issues to the project.

Gertrude Matsebe worked as a social worker with the Deaf Federation of South Africa for 5 years before joining the Enabled Environments project. She speaks Sign Language and has experience in running workshops and working in informal settlements.

## **Report Structure**

As the project was committed to producing results that could form the basis for national advocacy approaches and developing local research initiatives, findings from South Africa and India have been presented in two separate reports. A shorter report of comparative highlights is also available.

**Chapter 2** outlines the sampling approach and characteristics of the four Delhi informal settlements included in the study. **Chapter 3** deals with methodology and discusses the workshop content in some depth. **Chapter 4** covers the key issues

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<sup>6</sup> For more information on Concerned Action Now, see <http://www.indev.nic.in/can>

<sup>7</sup> For more information on CSIR, see <http://www.csir.co.za>

relating to physical environment that were identified by the participants in the workshops. **Chapter 5** looks at access to concessions, contributions to the household and social life, and the final chapter, **Chapter 6**, looks at the issues of education, training and employment. Access to the open labour market was a key concern for people with disabilities from one of the communities where the research was conducted. The development of human capital through education and training is obviously linked to employability and therefore all three issues are considered.

## CHAPTER 2

### COMMUNITIES AND PWDS IN THE INDIAN STUDY

#### INTRODUCTION

The first section provides a brief overview of the legislation that affects people with disabilities in India. The second section discusses the rationale for selecting communities for the study and compares the characteristics of the four communities. The third section discusses the role of the community facilitators who were key for the success of the project. The final section looks at the sampling approach and summarises key characteristics of our sample.

#### GENERAL BACKGROUND ON DISABILITY AND LEGISLATION IN INDIA

India has a range of legislation, policy and intervention in matters relating to upholding the rights of the citizens of the country. This is especially true of minority communities, including tribal groups, scheduled castes, people with disabilities and socially marginalised groups, among others. The government, having acknowledged the fact that people with disabilities need to be integrated into society, has provided them with legal safeguards. This recognition led to the tabling and passing of The Persons with Disabilities (Equal Opportunities, Protection of Rights and Full Participation) Act, 1995 without a single dissenting voice in both Houses of Parliament.

This section provides a brief overview of the extent of disability, legislation and policy, and government and non-government groups representing people with disabilities.

#### *Rights Legislation And Policy In India*

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

The main objective of this Act is "...to provide for recognition by the State of the rights of the Persons with Disabilities to enjoy equality of opportunity and full participation in national life..." By introducing the Act, the Government has responded positively to the collective demand made by disability activists in India for an appropriate legislative framework to safeguard the rights and dignity of people with disabilities. The Act also enshrines the United Nation's declaration in the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities, which says "National legislation, embodying the rights and obligations of citizens, should include the rights and obligations of persons with disabilities. States are under an obligation to enable Persons with Disabilities to exercise their rights, including their human, civil and political rights, on an equal basis with other

citizens.” ... “States may consider establishing formal statutory complaints mechanisms in order to protect the interests of persons with disabilities.”

## **The Indian Disability Act**

This is a bold and significant attempt to reform the existing situation and increase opportunities for people to participate in mainstream activities. The highlights of this Act include:

- Advising government, policy makers and programme planners of the development of policies, legislation, programmes and project with respect to their impact on disabled people.
- Promoting the integration of disabled people, including women and children, in national plans, programmes, services and projects.
- Monitoring and evaluating the impact of policies and programmes on the full participation and equality of disabled people.
- Parts of the Act relate to the prevention of impairments, rehabilitation, education, employment and vocational training, affirmative action, non-discrimination, research and manpower development, licensing of institutions, social security and care and protection of people with disabilities.

The Act recognises seven categories of disability – blindness, low vision, leprosy-cured, hearing impairment, locomotor disability, mental retardation and mental illness.

The Central Government has taken certain steps to combat communicable, non-communicable and other major diseases that cause disability so as to improve the health status of India’s population and to prevent and control disabilities. The concerned Ministers directly run several National Health Programmes. For example, the National Leprosy Eradication Programme (NLEP) is implemented by central government to achieve the elimination of leprosy. Other such programmes are the National Programme for Control of Blindness, the National Iodine Deficiency Disorders Control Programme, the National Mental Health Programme and other health programmes aimed at the prevention of disability.

Rural health services have been strengthened to provide primary health care relevant to the actual needs of the community. This includes training of Traditional Birth Attendants (*dais*), upgrading of facilities for emergency obstetric care, and the extremely successful Pulse Polio Immunisation programme, both in rural and urban areas. The Universal Immunisation Programme has been declared as a part of the overall national strategy to bring down infant and maternal mortality in the country.

### *Approach to Rehabilitation*

Rehabilitation is high on the agenda of the Government of India. A number of schemes, programmes and projects are being implemented and are supported by a range of national institutes specialising in specific types of disability located

around the country<sup>8</sup>. There is also the Rehabilitation Council of India (RCI), Artificial Limbs Manufacturing Corporation of India (ALIMCO) and a series of Rehabilitation Centres at district level.

There is also a strong legal framework for empowerment of persons with disabilities through the Persons with Disabilities Act, National Trust for welfare of Persons with Autism, Cerebral Palsy, Mental Retardation and Multiple Disabilities and the Rehabilitation Council of India Act.

The Office of the Chief Commissioner of Disabilities has responsibility for ensuring that the rights of people with disabilities are recognized and the legislation included in the Disability Act is implemented as policy. The office has reported that more than 4,400 complaints were received by her office from people with disabilities from April to December 2001. Out of this 3,380 were disposed off while 1,175 complaints were under process<sup>9</sup>.

#### *Representation of People with Disabilities*

India is noted for the strength and number of organisations representing people with disabilities. There are more than 1600 non-government and voluntary service organisations engaged in the service of people with disabilities.

The vast number of disability NGOs based all over India, both PWD and parent organisations, concentrate on advocacy and developmental work aimed at empowering people with disabilities. These range from the professional, well-managed, high profile organisations to the small localised groups, well-meaning, motivated but lacking in resources. Many of these organisations are project funded while others receive grants from the government. Together and individually they negotiate and develop common visions for the equalisation of opportunities for PWDs. Most organisations work with particular sectors of the disability community i.e. the deaf, the blind, the physically disabled, those with cerebral palsy, those with autism, and those with mental health problems, etc. HIV AIDS affected people; the aged and those with cancer are not included in the list of disabilities.

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<sup>8</sup> National Institute for the Visually Handicapped (NIVH), Dehradun; [National Institute for the Orthopaedically Handicapped \(NIOH\), Calcutta](#); [National Institute for the Mentally Handicapped \(NIMH\), Secunderabad](#); [National Institute for the Hearing Handicapped \(NIHH\), Mumbai](#); National Institute for Rehabilitation, Training & Research (NIRTAR), Cuttack; [Institute for the Physically Handicapped \(IPH\), New Delhi](#)

<sup>9</sup> Taken from a Government of India press release issued on February 21, 2002.





Figure 1 Tricycles to be handed out by NGO Disha during an open day in Delhi.

## **The Communities**

### *Selecting The Case Study Areas*

There were four key criteria used to select the case study areas:

#### **a) Well-established Informal Settlements**

Informal settlements are where the majority of Delhi's poor population live. In 2000, just over 20 per cent (3 million) of Delhi's 14 million people lived in informal squatter settlements. In India, these are known as 'jhuggi-jhopri' (JJ) clusters. Whilst JJ-clusters are illegal land encroachments, slums are settlements that have been officially recognised by the government but have substandard housing. A further 3 million of Delhi's population live in slum settlements (DUEIIP, 2001b). As Enabled Environments focuses on PWDs living in poverty, all four case study areas are informal settlements.

All four case study areas have been in existence since the 1970s. Choosing better-established informal settlements reduced the risk of areas being cleared during the study. Furthermore, longer established settlements are more likely to have experienced some infrastructure improvement: this would provide the opportunity to look at the extent to which such improvements benefit people with disabilities.

#### **b) Contrasting Environments**

Although all the four case study areas are informal settlements, they have different environmental characteristics. As PWDs' experiences of their physical

environment is one of the key themes of EE, it was important to gather information on a range of informal environments. Bhatti Mines is a low-density rural-style community set in a nature reserve, Kusumpur Pahari is built on a ridge with undulating dirt paths running through the community, Bhumiheen Camp is a very high-density settlement with double-storey dwellings and paved pathways, and Subhash Camp resembles Bhumiheen Camp on a smaller scale.

### c) Existence of Community-Based Services

As one of the themes of the study was access to services, we wanted to include areas where there was a range of NGO-run services.

### d) Pre-Existing Knowledge of Community or Good Contacts

The Indian team had worked with the community in Kusumpur Pahari for 10 years. The PI had worked in Bhumiheen Camp on a previous project in 1999. Bhatti Mines and Subhash Camp were chosen after two community disability activists approached the Indian team about establishing links with Concerned Action Now. They were keen to be involved in EE and were selected as community facilitators.

Table 1. Case Study Area Characteristics At A Glance

Community	Bhatti Mines (Sanjay Colony)	Kusumpur Pahari	Bhumiheen Camp	Subhash Camp
Location	Rural land on border with Haryana	On edge of upper middle class neighbourhood of Vasant Vihar	Between commercial area Nehru Place and Okhla Industrial Estate	On edge of city forest – surrounded by residential neighbourhoods
Origin	Migrant quarry workers who stayed after quarry closed	Sporadic land encroachment	Refugee population (Bengalis) + sporadic land encroachment	Sporadic land encroachment
Settlement Types	Informal – eviction pending	Informal	Informal – offered resettlement in 1990s	Informal
Year	Late 1960s	1960s	Early 1970s	Mid 70s
Number of Households	Not known	Approx 3,600	Approx 2,500	Approx 2,500
Registered to vote	11,600	18,000-21,600	12,500	12,000
Key Sources of employment	Men as daily migrant construction workers	Domestic work in Vasant Vihar and Vasant Kunj Small-scale enterprise. Paid work outside community.	Piecework from Okhla, domestic work in Kalkaji neighbourhood. Some govt workers. Home-based business.	Domestic work for women. Home-based business.
Main water source	Private water sellers plus pipelines from reservoir with detachable hand pumps	Municipal water tankers bring water once a day	Stand pipes plus some individual electric water pumps	Government provided community taps. Some detachable hand pumps.

## *Bhatti Mines*



**Figure 2 A traditional mud-walled house in Bhatti Mines.**

There are three villages in the Bhatti Mines area, which were settled in the late 1960s by migrants coming to work in the stone quarries. EE worked in one of these villages, Sanjay Colony, which is inhabited mainly by people of the Odh tribe, a caste of earth diggers. There are also Kumhars in this area, a caste of clay potters.

The Bhatti Mines area had formal status originally, and their current tenure status is heavily contested. In 1975, Sanjay Gandhi gave the settlements legal status by designating them official ‘labour colonies.’ In 1986, the Asola Wildlife Sanctuary was set up on the adjacent land. In 1990, the mine closed down. Suddenly, in 1991, the Bhatti Mines dwellers were notified of the new status of their community as ‘encroachment by slum dwellers’ because the area had been designated for another wildlife sanctuary. At the time of the fieldwork, the latest reason for wanting to evict the Bhatti Mines people was that a Kargil memorial site was to be constructed on the land. At the time of writing, the Bhatti Mines community continue to fight the eviction notice in the courts.

As a rural area, the community is low-density with wide dirt paths running between the dwellings. The housing is a mixture of traditional single-storey mud dwellings with thatched or plastic roofing, some brick managers’ quarters remaining from the mine company and some self-built brick dwellings. The Bhatti Mines case study covered the largest area of all the four case studies, but based on the number of registered voters it had the smallest population.<sup>10</sup>

Under their ‘labour colony’ status, the community secured a number of services. A regular bus service runs through the main road in the community and provides a vital link with urban Delhi for daily commuters. There are primary and secondary schools, a community hall, a temple, a Ram Lila<sup>11</sup> ground and a number of shops. A mobile clinic comes to the area once a week. There are 5 *anganwadis* in the area, which provide crèche facilities and dietary supplements to children 0-6 and

<sup>10</sup> Each of the three villages has a leader who ensures that everyone is registered to vote.

<sup>11</sup> A piece of land where a traditional Hindu play is performed once a year.

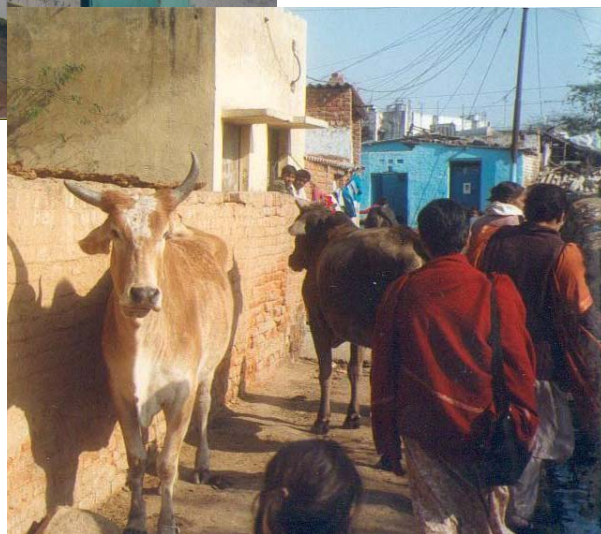
pregnant women. The greatest problem in this area is a severe shortage of water. Families are forced to buy water from private operators who sell the water by the bucket. Apparently, there were efforts to install a piped water network in 1992, but this was sabotaged by the private operators (Soni, 2000, p.90). At the time of the research, groups of households had sponsored the laying of water pipes that run from the community water tank. They use private detachable hand pumps to access water and pay a monthly maintenance fee.

### *Kusumpur Pahari*



**Figure 3 Kusumpur Pahari is characterised by white-washed single-storey dwellings, and wider lanes than Bhumiheen Camp and Subhash camp.**

**Figure 4 In all the communities, cows wander through the lanes. In some areas, there are also pigs and goats. Participants mentioned a fear of being knocked over by the animals.**



Kusumpur Pahari is the largest community in the study with approximately 3,600 households. It has no single story, style or identity in the way Bhatti Mines does. The area is made up of urban migrants from different castes that live in separate pockets within the community. For example, one area where the ‘sweeper caste’ live is avoided by others who associate this group with dirt and social inferiority, and also because the group slaughter pigs in the area. All the dwellings in the community are constructed from brick and most are single storey. Many dwellings are painted and have small courtyards.

The area has had some service development: Sulabh constructed four toilet/shower blocks in the area but at the time of fieldwork only one of these was operating sporadically. There is a school/community hall/clinic compound at the centre of the community with a play area. This is run by volunteers from the community.

The settlement is located on the edge of Vasant Vihar, an upper middle-class residential neighbourhood that is a source of domestic employment for many of the settlement's inhabitants. Built on the Delhi ridge, the open land on the other side of the community is rocky which accounts for the uneven paths in the community and also why the area has never been cleared for development.

### ***Bhumiheen Camp***



**Figure 5**  
**Bhumiheen**  
**Camp has**  
**the highest**  
**level of**  
**commercial**  
**activity of**  
**all the four**  
**research**  
**areas.**

Whilst Bhatti Mines and Kusumpur Pahari are areas that have unlimited space in which to develop, Bhumiheen Camp occupies a clearly defined area closed in by main roads on two sides, an upgraded slum on the third and another informal settlement on the fourth. The result is a very high-density settlement with narrow labyrinthine alleyways. The area is situated amongst three key sources of employment: Okhla Industrial Estate with many factories producing for export, Nehru Place, a key commercial centre in South Delhi and the Kalkaji residential area.

Following a fire in the 1980s, many homes were rebuilt and today almost all dwellings are constructed from brick and most are double-storey. Also, following the fire, the paths through the community were upgraded and are now paved with a drain running down the middle.

Whilst Bhatti Mines is associated with two specific castes and Kusumpur Pahari is a mixed caste area divided into sectors, the key characteristic of Bhumiheen Camp's population is the number of Bengali refugees who fled from East Bengal in the 1970s.

The settlement has a higher level of commercial activity than in the other three case studies. As well as fish and vegetable stores, there are jewellers, electrical shops

and tailors. There are also ambulant sellers moving through the community. This suggests the area is home to higher earning households<sup>12</sup>.

The area is well serviced in comparison to the other communities. As well as a functioning Sulabh block, the area is notable for the number of households with illegal electricity connections and electric water pumps. Households complained of overly high electricity bills, but did not suffer the same water and electricity shortages as found in other settlements. There was also a problem with garbage collection: Bhumiheen Camp had the dirtiest lanes of all four communities because government sweepers charged Rs.10 per household once week, which many households cannot afford. As a result, the lanes often go unswept and piles of rubbish are left to fester. There are schools and clinics in the surrounding area and within the settlement there is one NGO offering mother and child health care and another that offers a range of educational services.

### *Subhash Camp*



**Figure 6** Narrow lanes run through Subhash Camp. Here, the deep drainage channel, washing and water carriers are all potential hazards to people with impaired mobility or sight.

Subhash Camp is very similar to Bhumiheen Camp in its style – a high-density settlement with two-storey brick dwellings, paved paths, narrow alleyways and no space to extend further. The community backs onto designated urban forest that is bordered by a brick wall. On two sides, the community is bordered by upgraded settlements, and on the fourth there is a commercial lane that has shops on either side running the entire length.

The majority of residents in Subhash Camp are from Uttar Pradesh in North India. The settlement has approximately the same number of registered voters as Bhumiheen Camp. However, unlike Bhumiheen Camp, the area had no

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<sup>12</sup> We also saw a door-to-door Kashmiri shawl salesmen. Kashmiri shawls are never cheap and it is unlikely a salesman would visit an area unless he thought there was a potential market for his product.

functioning toilet block and people use the urban forest land behind the community<sup>13</sup>. There area does not feel as prosperous as Bhumiheen Camp due to the lack of commercial activity inside the community.

Access to water is a key problem in the community. Although the government recently installed piped connections to community taps, there is very often no water available. Verbal and physical fights regularly break out over queuing for water and how much each person takes.

## **The Community Facilitators**

As well as having a full-time researcher that had experience of working with people with disabilities, it was important to identify key community members that had experience of disability issues. The community facilitators were responsible for identifying potential participants for the study, inviting people to key events, carrying out the reconnaissance and main surveys and serving as information contact points and resource persons for other participants on the study from their own and other slums.

The community facilitators were selected not only on the basis of their experience of disability issues, but also because they displayed a commitment to community development. In order for the project to have sustainable outputs, it was important that there was a core of key participants at the end of the study who were willing to carry any initiatives forward with occasional support from the local researcher. The community facilitators for the Delhi study live in the slums included in the project and were selected on the basis of their standing within the community as well as their record of community work, their social skills and their ability to provide local leadership

As a study that drew on values underpinning action research, a central aim of the project was to have some immediate impact upon the participants' lives. This was not so much an impact through providing relief to individuals but by demonstrating that people in the slums have the potential and capacity to tackle their own problems, to get involved in a process that leads to empowerment. An assessment of the project's achievements can be found in the concluding chapter.

Dhanpati Devi, popularly known as **Sonia** is in her late 50s, and has been living in Kusumpur Pahari, with her two daughters and son for the last two decades. She is a member of the All India Federation for Women (AIFW) and is active in development activities, working in the community and travelling to other areas of the city. She has represented her area of Delhi in national conferences, which are held by the AIFW in other parts of India. Sonia was an ideal community facilitator because she has experience of dealing with government officials, diplomats and professionals outside her community, and has been instrumental in getting recognition and benefits for the people with disabilities in Kusumpur Pahari. Sonia had been associated with various activities of CAN in the past.

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<sup>13</sup> During the fieldwork, a new toilet block was constructed in the community under a collaboration between the Municipal Corporation of Delhi and the Government of Japan. Attempts by the EE team to ensure this block was accessible are discussed in chapter 4.



**Figure 7 Sonia (far right), with workshop participants from Bhatti Mines.**

**Kapil Aggarwal**

(30), the community facilitator for Bhatti Mines has a detailed knowledge of disability rights, legislation and concessions. He works closely with government agencies and activist lawyers who take up Public Interest Litigations on behalf of PWDs who have been discriminated against. Kapil also heads a small NGO, Viklang Sahara Samiti (VSS). Kapil’s organization provides training exclusively to PWDs in shorthand, typewriting, computer skills, and stitching. Kapil has qualifications in Taekwondo, a form of martial art, and gives regular demonstrations.



**Figure 8 Kapil (far right) with the field researchers from India and South Africa, Malancha and Getrude, and the Director of Concerned Action Now, Prof. Ali Baquer.**

The community facilitator of Subhash Camp, **Arvind “Buddh” Singh** (36), is an artist by profession, and he attended the International Abilympics held in Czechoslovakia. He is the recipient of numerous awards for his art and activism and is a popular and well-liked person in his community. As a result of the Enabled Environments project, a Vocational Training Centre has been set up in Subhash Camp where Arvind teaches papier-mâché work. He supervises similar activities elsewhere in Delhi. When the new public toilet block was being built in



Subhash Camp, Arvind kept a keen eye on the construction and went to check the blueprints in the Municipal office for accessibility features.



**Figure 9 Arvind (right) discusses mobility issues with an EE workshop participant in Kusumpur Pahari.**

**Molina** (late 50s), the community facilitator in Bhumiheen Camp, came to the area as a young refugee from East Pakistan, and is a women's rights activist. She has been in the forefront of many campaigns to ensure that Bhumiheen Camp residents get the benefits they are entitled to. She has been a member of a number of women's self-help groups and is well known in the community. During the collection of data for EE, her knowledge about the PWDs living in the area and service providers was invaluable.

## **The Sample**

### *Sampling Process*

In constructing the sample, a key concern as a project that set out to be participatory was to identify a size of sample that was large enough to allow us to highlight patterns of experience and small enough that it was manageable for a single full-time researcher. As the workshops were key to finalising our research themes (see Chapter 3), and as we felt we could not run successful workshops with the number of staff we had available with more than 50 participants, we decided to work towards a sample of 50 PWDs in each of the four research sites.

As a participatory study with a small sample, statistical representativeness was not our main concern. It was more important that our sample;

- Included people with all types of disability
- Included people who wanted to participate in project-related activities (e.g. field visits and workshops)

- Included PWDs who were linked to service providers and those who were not
- Included PWDs who worked and those that did not
- Included PWDs with different levels of mobility – within the plot, the community and the city and beyond
- Included PWDs who were living in areas that could be reached by our community facilitators

In each case study area, PWDs were identified through door-to-door visits by the community facilitators and other local assistants. Despite training on identifying disability and conducting the door-to-door visits, 7 of the original 198 people identified did not have a disability. By the time the fieldworkers returned to do the survey, the size of the sample reduced further from 185 to 159<sup>14</sup>.



**Figure 10 Field researcher, Malancha and community facilitator, Kapil visiting PWDs in Bhatti Mines with three residents.**

## **Types of Disability**

In the initial survey, people were asked to identify their ‘main’ disability and to name any other disabilities they experienced. ‘Main’ or ‘first’ in this respect means the disability that the respondent considers to have the greatest impact upon their life.

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<sup>14</sup> Reasons included death, return to rural villages, lack of interest in the study, no free time.

Table 2: Main disability across all case study areas

	Frequency	Percent
Blind	6	3.8
Low Vision	3	1.9
Deaf	12	7.5
Physical/locomotor disability	118	74.2
Mental retardation/intellectual disability	11	6.9
Mental Illness	1	0.6
Hard of Hearing	0	0.0
Speech problem	0	0.0
Epilepsy	0	0.0
Multiple	8	5.0
Total	159	100.0

As can be seen from Table 3, our sample differs considerably in terms of the levels of different disabilities recorded in the 1991 NSSO household survey on disability. Although statistical representativeness was not our key concern, it is still necessary to consider why our sample should differ to such a great extent.

Table 3. Comparison between Enabled Environments sample and levels of disability by type in India and the world.

Sight (Blind and low vision)	5.7	44.9	13.95	11
Hearing (Deaf and hard of hearing)	7.5	12.3	13.96	14
Physical/Locomotor	74.2	6.7	42.86	32
Mental	7.5	34.9	10.42	26
Not specified	0	0	0	13
Epilepsy	0	0	10.26	4
Leprosy Cured	0	1.2	3.43	0
Multiple	5.0	0	5.15	0
Total	100	100	100	100

What is most notable in our sample is the very low levels of sight-related disability and the very high levels of locomotor disability.

Locomotor disability is often the most visible form of disability. This is borne out by the fact that a wheelchair is the symbol for disability in public signs internationally. Similarly, in our own study the higher incidence may be due to the fact that despite our efforts to include all types of disability equally, when we asked various sources for information on people with disabilities living in the area there was a tendency to identify people with locomotor disabilities. Also, the most common word for 'disability' in Hindi is *viklangta*, which is often understood to refer only to a disability that is visible, like blindness or locomotor disability.

The low incidence of sight and hearing disabilities could also be attributable to the low percentage of elderly included in the sample. There is a high correlation

between age and disability. Impaired hearing and sight are associated with the ageing process, but only 8.2 per cent of the EE sample were aged 60 or over.

Table 4. Age Ranges of PWD

Age	Frequency	Per cent
0-9	17	10.7
10-19	62	39.0
20-39	53	33.4
40-59	14	8.8
60+	13	8.2

Information on household composition suggests that the reason for the small numbers of elderly is that few households have a third generation living in them. Of all the households surveyed, 70.3 per cent contained no one aged 60 or above. A further 22.2 per cent had only one person in the household aged 60 or over.

83.5 per cent of households were headed by men, and only 16.45 per cent were headed by women. The majority (65.8 per cent) of household heads were aged between 30 and 49, and as explained earlier few household heads had elderly relatives living with them (70.3 per cent of households had no one aged 60 or over). Almost 49 per cent of PWDs aged 20 and over are household heads. Of this 49 per cent, 20.5 per cent of heads with disabilities are women and 79.5 per cent are men.

In Delhi, most families living in low-income settlements, including those in the sample, have migrated to the city from rural areas in search of jobs and a better life. A majority are nuclear families and it is almost certain that the elderly and some disabled members of the family, if any, have been left behind in the villages. The chance of their being taken care of back home is greater because of extended families and the community feeling in rural areas. Since medical and health facilities in the villages from where the migrants belong to are poor quite a few of the disabled also arrive in cities looking for treatment. These factors result in making the sample not totally representative of the general population. All families living in the city go back on annual vacations to their home towns/villages.

## CHAPTER 3

### RESEARCH APPROACH AND METHODS

#### Overall Approach

As explained in Chapter 1, the project team were committed to encouraging the participation of PWDS in the study as much as possible. Although 'participation' is a popular and frequently recommended concept in developmental interventions the mechanics of participation and its extent remain rather illusive. In this project an attempt was made to use various stages of research project as an instrument of participation, offering active or partial involvement to the members of a community being studied according to their interest, availability of time and the perception they had of the 'benefits' to them from their taking part.

The range of research methods used is listed below. As such methods are common, there is little to be gained from discussing them in depth here. However, the community workshops drew on action planning methods and were a key stage in encouraging active participation in the project. For this reason, the workshop approach and outcomes are discussed at some length.

#### *1) Reconnaissance Survey*

This was short survey used to identify participants through door-to-door visits. It gathered base information on age, disability type, household size, carer name where appropriate and levels of mobility.

#### *2) Community Workshops*

These workshops introduced a participatory element into the project by allowing PWDS to identify issues that were of importance to them, which we then focused on in the later stages of the research.

#### *3) Focus Groups*

We ran a number of informal focus groups to discuss in more depth some of the issues that came up at the interviews.

#### *4) Interviews with Service Providers*

Wherever possible, participants in EE were brought along to take part in the interview.

#### *5) Field visits*

Participants were taken to a number of places to conduct interviews, take photographs and assess accessibility for themselves.

## 6) Household Survey

This gathered information on a wide range of issues including education status, employment status, income, access to services, and social life.

## The Community Workshops

### *The Aims of the Workshops*

Although the research covered a number of themes, these initial workshops focused on identifying problems the PWDs faced moving around their community. We chose to focus on the physical environment, as opposed to the other key project themes of education and training and contribution to the household, because this was an issue potentially affecting all PWDs, regardless of age, household composition, or severity of disability. However, the workshops were planned in such a way that there was the opportunity for participants to raise issues other than those concerned with the physical environment. In this way, although there were three overarching themes to be researched, the priorities of the participants informed the research process by identifying which aspects of the experiences of PWDs should be focused on under each theme.

The workshops had a number of key aims:

- To identify the problems PWDS face moving around their community
- To identify other key issues that PWDS would like to be addressed by the enabled environments project
- To create a group dynamic and develop a sense ownership of the project
- To identify key participants who were keen to be actively involved in the research
- To identify issues/events where the research team could support the participants in a spirit of collaboration

The workshop method drew on the tools developed by Hamdi and Goethert (1997) for their Community Action Planning model. Hamdi and Goethert argue that the top-down urban development process inevitably overlooks the needs and demands of those living in informal settlements as the demands of donors, government departments and contractors take precedence. When community consultations do take place, they often come after key decisions have been made and are limited in scope. Top-down planning ‘displaces the very processes which are vital to the health and survival of low-income communities – the opportunity to be *spontaneous*, to *improvise* and to build *incrementally*’ (Hamdi and Goethert, 1997: 19). The result is cities that limit opportunities for poor communities, rather than encouraging their improvement.

There is a clear overlap in the way in which Hamdi and Goethert conceptualise the planning process as one that excludes the poor, and the way in which people with disabilities discuss their own feelings of exclusion from the planning process in UK cities (Imrie and Kumar, 1998). The key reasons for the failure of the built environment to be fully accessible for all people with disabilities are identified as 1) the lack of influence people with disabilities have over the planning process in

comparison to other stakeholder groups, 2) the low priority disabled access has in comparison to aesthetic and economic concerns and 3) the imperfect knowledge planners have of disability and the way in which full accessibility can be achieved. Although these concerns were raised by people with disabilities living in what would be termed a 'developed country', studies of cities in the 'developing world' suggest that the issues are similar (Imrie, 1996).

Hamdi and Goethert offer an alternative planning process that enables low-income communities to take a more active role in the planning of their environments. Community Action Planning is aimed at identifying and responding to the problems of the immediate built environment as experienced by a heterogeneous group that has been excluded from the planning process. The participants in the Enabled Environments study could be characterised in a similar way: 'people with disabilities' constitute a diverse section of society whose varied needs are often at the bottom of the planning agenda. Community Action Planning has a number of characteristics that were important for Enabled Environments: it is problem-led, participatory, community-based and focuses on achievable goals (op.cit., p.30).

It is important to note that whilst the Enabled Environments workshops drew on the values and methods of Community Action Planning (CAP), it did not aim to replicate the full model. CAP involves all stakeholders in a community, uses a range of methods in an intensive process over a period of one to two weeks and should result in short medium and long term plans for environmental improvement that the communities themselves can carry forward. The aims of the Enabled Environments workshops were more modest – a one to two day process that would highlight the key problems faced by people with disabilities in their communities, shape the agenda for the rest of the research project and, wherever possible, identify issues where the research team could support the participants in their endeavours.

### *Workshop Participants*

In each community, there were between 31 and 50 people registered with the project. As the main focus of the workshop was access and mobility in the immediate community, participants were selected based on their level of mobility, which had been recorded in the reconnaissance survey. Therefore, those participants who regularly travelled beyond the community were not invited (although, if they expressed a strong desire to come along, they were welcome). Some invitees were unable to come – for example, people with incontinence problems did not want to be away from home for an entire day, some participants could not come without a carer and no carer was available, others were too confused or frail, whilst others were simply too busy or not interested.

The community facilitators participated in all of the workshops. The experience of visiting other communities and hearing about the problems PWDs faced, along with helping to run the workshops formed an important aspect of capacity-building and also helped to build up a strong network amongst the community facilitators.

Those participants who had problems with communication were encouraged to bring along a member of their family to facilitate communication.

Table 5: Workshop Participants By Community and Type of Disability

Disability Type	Bhatti Mines	Kusumpur Pahari	Subhash Camp	Bhumiheen Camp
Intellectual	2	2	2	4
Locomotor	16	9	10	10
Deaf/hearing impaired	1	1	0	1
Blind/Low Vision	0	0	1	2
Epilepsy	0	0	0	1
Total	19	12	13	18
Children (16 and under) (inc. in total)	1	5	1	8

The workshops were held in central community locations and the atmosphere was informal; family and friends of the participants were invited to drop in during the workshops and other community members also showed some interest. .

## Workshop Stages

### Workshop Stage 1: “To Identify Places that you want to go to but cannot or find it very difficult”

Although there were no formal maps of the communities, EE hired four students to draw basic plans of each community that showed key features e.g. shops, telephone booths, water tanks.

After a brief introduction and discussion of the purpose of the workshop, the group was divided into 2-4 smaller groups. The first step was for each person to identify where his or her house was on the map. This gave everyone a chance to get used to the map and see how it related to the community.

The group then discussed the places they wanted to go but could not or found it very difficult. The group placed stickers on the map to represent the problem areas. They used text and pictures to indicate what the sticker referred to. A group ‘scribe’ kept notes of the group’s discussion. The focus of the group, however, was not a written chart but the map as we were aware that many people are illiterate.



**Figure 11 A group at the Kusumpur Pahari workshop identify problem areas on a map of the community.**



The next stage was to discuss why certain places and activities were problematic. With some groups this discussion took place as participants were identifying the places. Other groups found it easier to focus on the map and highlight all the places and activities first of all, and then discuss why they caused PWDs difficulties. The group facilitators encouraged participants to think about what was wrong with the way in which their physical environment was arranged, rather than simply listing the nature of their disability. It had become clear during the reconnaissance survey that many of the participants, who are doubly excluded from society due to poverty and disability, continue to discuss their disability from a medical perspective. Therefore, in order for the workshop to be successful, the concept of the social model of disability was introduced at the beginning and reinforced throughout the day.

## **Workshop Stage 2: Plenary Feedback**

Once each group had listed all their problems, the nominated spokesperson fed back to the plenary group. During the reporting process, one of the project coordinators summarised the problems on a central chart and stressed those problems that were shared across the group. The process of pulling out common themes across the group is important. The day began with a group of people of different ages and with different disabilities, many of whom had never met, listing their individual problems. By this stage in the day, common problems had been identified and it was possible to talk about approaches to the problems as a group.

The results from the plenary feedback session in each community are summarised in Table 6 on the following page

Table 6: Summary of Key Problems and Reasons for Problems in Each Community

	Bhatti Mines	Bhumiheen Camp	Subhash Camp	Kusumpur Pahari
Toilet	No public toilets; Have to go to 'jungle' which is far away on the outskirts of community Bad roads	There are not sufficient toilets and showers for everyone – queues are very long Although sweepers have been employed by the government, they still charge money from the residents to clean the toilet; even then these are not cleaned regularly; there is always the danger of slipping and getting hurt; Steps to the toilets are steep;	No water in the toilets - public toilets are very dirty Government built public toilets but does there's no system to look after them- sweepers fight with us if we ask them to clean them We have to go out in the open - after dark it becomes very difficult to use the jungle. Also lots of wild pigs which is frightening. During the rainy season it's easy to slip and fall when going to toilet	No water supply to Sulabh blocks = toilets are unclean Have to use open land – a long distance from the house Uneven land means people on tricycles cannot get across – people must go hands and knees Hands and knees get covered in mud and faeces and get cuts and grazes
Water	MCD supply comes once in two days <sup>15</sup> In spite of pipelines there is no water Have to buy water from private tankers; Tankers leak resulting in waterlogged roads that PWDs cannot walk on	People said water supply was good – one tap for 10 houses and water comes every day 1pm – 5 pm	Earlier there was no water- but water problem has eased a little – the govt has put in some taps	Tanker does not come at a fixed time or to a fixed place - they have to keep going round and round the community to see if the tanker is coming. There is a big rush to get to the tanker – to get water out people have to climb up and put own tube into tanker – people with disabilities cannot do this

<sup>15</sup> Group 1 has said water is supplied on alternate days but it is not sufficient. Jal Board supplies water and fills in cemented tank. However, Group 2 says that there is no water at all, in spite of pipelines.

	Bhatti Mines	Bhumiheen Camp	Subhash Camp	Kusumpur Pahari
Roads	Bad roads: water logged; full of stones; full of garbage; full of potholes Tricycles and wheelchairs are difficult to use on gradients and uneven surface	Garbage in the lanes, people keep their <i>charpoy</i> s <sup>16</sup> in the lanes, also cycles and rickshaws; Very congested Drains are clogged and spill over; This area is low lying and all the garbage and sewage water from other parts collect here; During the rains water logging prevents us from going to Sulabh toilets	Narrow, uneven – get slippery when wet. Fixed metal steps make lanes even more difficult to negotiate	Note problems related to ‘school’ and ‘toilet’ are also related to ‘roads’
Garbage	(See ‘roads’)	Garbage is not taken away for weeks at a time Lanes are full of garbage - it is difficult for everyone to walk through these lanes, more so for PWDs Drains are not clean and lanes are flooded Some people throw their rubbish in the lanes and not in the bins.	Not mentioned	Not mentioned

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<sup>16</sup> A common piece of furniture – a four-legged wooden cot woven with jute string that serves as a bed and also a place to sit during the day

	Bhatti Mines	Bhumiheen Camp	Subhash Camp	Kusumpur Pahari
Bus	Cannot get on or off: high footboards and buses don't stop for enough time Seats not always available – buses are crowded	As a rule, PWDs are supposed to board and get off the bus through the front door, drivers and conductors don't allow us to do this.	Bus stand is far away, it takes 1hr 30mins to reach bus stand for Rita, she has to walk slowly Footboard needs to be lower - scared that the bus may start to move before they board Buses are always crowded - can't get a seat although two seats are meant for PWDs, nobody gets up and even the "for disabled people" sign is scratched out Disability passes are not recognised on private buses	In the bus a person with a locomotor disability cannot climb up because the footboard is so high. Because bus is crowded they can't find space in the bus
Employment	Since the mines closed local employment is nil: digging soil is the only local job available but can't be done by PWDs Can't use bus – so can't get work outside community	Not mentioned <sup>17</sup>	No jobs for people with disabilities, especially in private companies. They throw us out when they learn that we are disabled No opportunities for self-employment	Not mentioned
Electricity	Private contractors charge a lot of money for connections;	Exposed electric wires hang low in the alleyways and people are electrocuted; Private contractors charge too much for electricity;	People have illegal connections but the electricity keeps going off, no continuous supply	Not mentioned <sup>18</sup>
Liquor	Alcohol is easily available and is sold from house to house;	Not mentioned	When people are drunk they do not bother where they are going and they hit against disabled people in the narrow alleys. Disabled people get hurt	Not mentioned

<sup>17</sup> This is the most affluent of the four communities. Most households included in the study had a last one source of income and therefore the pressure on PWDs to work may be less.

<sup>18</sup> The municipal government had recently installed meters in all dwellings in Kusumpur Pahari, which are serviced by private contractors.

	Bhatti Mines	Bhumiheen Camp	Subhash Camp	Kusumpur Pahari
Housing	Some houses are made of mud and are prone to collapse during the rains.	Not mentioned	Not mentioned	Not mentioned
School	Not mentioned	Not mentioned <sup>19</sup>	Not mentioned	The road to school is not good - pebbles, holes etc School is outside the slum area so it is difficult to go there – it's a long distance

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<sup>19</sup> Although access to education was not mentioned in the workshops, participants did tell us later that children with disabilities find it difficult to cross the main road between settlement and the school.



**Figure 12**  
**Waterlogged**  
**roads in**  
**Bhatti**  
**Mines were**  
**a key**  
**concern for**  
**the**  
**workshop**  
**participants.**

### **Workshop Stage 3: Prioritising Issues**

Having drawn up a central chart that summarises all of the problems identified by the subgroups, the participants were asked to identify the problems they considered most important. Over lunch, each participant was given 1, 2 or 3 stickers and was invited to place them against the problems that s/he considered of greatest importance. As mobility was a problem and some participants were illiterate, a workshop facilitator took the list to each individual and read out the list of problems.

As can be seen from the table below, despite the distinct geography of each community, there are common problems across all sites. Paths through the community and using public buses were voted key problems in all the workshops. In Subhash Camp and Bhumiheen Camp, lack of suitable toilet facilities was considered an important problem. Other problems were not necessarily related to the participants' status as PWDs: in Bhatti Mines and Bhumiheen Camp, the non-existent or unreliable electricity supply was considered a key issue, but this is a problem that affects all residents of the communities equally, regardless of whether or not they have a disability. Kusumpur Pahari was the only group that considered water one of the most important problems. Bhatti Mines was the only group that selected employment: this is understandable as Bhatti Mines is an area that had a local source of employment and now, following the closure of the mines, community members are a 30 minute bus journey away from the urban job market. In comparison, the other three communities are located close to middle class residential areas, and, in the case of Subhash Camp and Bhumiheen Camp, commercial and industrial areas.

**Table 7: Results of Prioritising Problems in Each Community**

Issues	Bhatti Mines	Bhumiheen Camp <sup>20</sup>	Kusumpur Pahari	Subhash Camp
Electricity	22 (1)	1 (3)	Not mentioned (NM)	1
Toilet	6	5 (2)	1	7 (2)
Water	5	0	3 (1)	1
Pathways	9 (3)	8 (1)	2 (2)	7 (2)
Garbage	5	0	0	5
Bus travel	9 (3)	1 (3)	3 (1)	9 (1)
Housing	6	0	NM	NM
Alcohol	3	NM	NM	0
Employment	13 (2)	NM	NM	5
School	NM	NM	1	NM
Animals in jungle	NM	NM	NM	5

### **Workshop Stage 4: What can we do Next?**

Having worked from a series of individual problems to three key problems that are of importance to the majority, the next stage is to consider what can be done about those problems. Based on the CAP model, we expected to work with a similar chart to that used by Hamdi and Goertz:

Problem	What we can do ourselves	What we can do with help from others	Done by others

However, for the India EE workshops, the headings were changed slightly to ensure clarity, as the extract from the Bhatti Mines workshop report shows:

**Table 8. Extract from Bhatti Mines Workshop Report**

Problem?	What could be done?	By whom?	What resources would we need?
Water tank is far away for many PWDs; Water becomes unsuitable for drinking; People have to buy water from private contractors – charges are arbitrary; Water does not come on time; Concerned person has political connections;	There should be one tap for ten houses;	Community members;	Money will be needed to lay pipe lines / tap;

### **The Missing Stage – The Fieldtrip**

An important stage in CAP prior to discussing the nature of the problems is a field visit. This involves participants walking around the area taking photographs, making notes and sketches, interviewing local people.

<sup>20</sup> Participants chose to have one vote each

We wanted to do something similar for Enabled Environments and had envisaged small groups taking photographs of problem areas and describing the problem into a dictaphone. However, there was little enthusiasm amongst the participants for this type of fieldtrip: some people did not have the time and others felt it was unnecessary. As an alternative, the community facilitators and the researcher accompanied individual EE participants on the daily routes they took through the community.

### **Workshop Results**

Rather than summarise the results here, they are used to frame the focus of the following chapters.



## CHAPTER 4

### PWDS AND ACCESS IN THE PHYSICAL ENVIRONMENT

#### Introduction

The Enabled Environments project set out to establish to what extent the physical environment found in low-income neighbourhoods limits the mobility, and therefore, the social integration of people with disabilities. There were a number of issues relating to the physical environment that were raised in the community workshops. These are summarised in Table 9.

Table 9: Problems with Access in the Physical Environment

Toilets	Have to go to the 'jungle' – long distance, bad roads, dangerous in rain (BC/SC/KP) No water supply for community toilet blocks (KP/SC) Poor management (KP/SC) Not enough toilets and steps at entrance too steep (BC)
Pathways	Rubbish not collected, drains blocked and flooded, charpoys in the lane (KP/SC) Paved walkways get slippery when wet (KP/SC) Uneven, potholes, rocks (BM/KP)
Bus Travel (All comms)	Can't get on and off – high footboards Buses don't stop for long enough – scared we will fall Crowded – no seats available Reserved seats for PWDs are never recognised Bus drivers on private buses do not honour disability bus passes and make us pay

Limited access related to toilets, pathways and public and transport all combine with the result that people with disabilities who took part in EE, experience movement through the spaces of home, community and beyond as disjointed or interrupted process, rather than the one of continuity. Uneven pathways and inaccessible or non-existent toilets mean that PWDs who need to go to school or to work must rise very early to negotiate the route to the open land in their community and then return to the house to change for work. During the rainy season, the paths become waterlogged and inaccessible or slippery. Once ready for work or school, they must negotiate the route out of the community and in many cases head for the bus stop. Once at the bus stop, they have to hope that the bus will stop for long enough for them to get on and that fellow passengers will help them up onto the bus.



**Figure 13 Participants from Bhumiheen Camp complained about the piles of rubbish that gathered in the narrow lanes and made it more difficult for people with mobility and sight impairment to move around.**

ESCAP Guidelines (1995, p.1) argue that universal accessibility arises out of barrier-free design, which means ‘...giving users the possibility to use space in a continuous process – to be able to move around without restriction.’ The concept of accessibility covered by Rule 5 of the Standard Rules (United Nations, 1994) also draws on the idea of space as a continuous process; the ‘physical environment’ is understood to include ‘... housing, buildings, public transport and other means of transportation, streets and other outdoor environments.’ The individual should be able to move from home to community to public buildings without barriers in his or her way. One could argue that such guidelines are not applicable to unplanned informal settlements such as those studied in EE. However, slum policy in Delhi has recently changed from one of relocation to one of in-situ upgrading, and the United Nations has called for all slum upgrading and relocation projects to incorporate accessible design in order that people with disabilities and the elderly are not excluded from the benefits of such improvements. The current National Slum Policy in India fails to follow these recommendations.

From the 1970s through to the 1990s, resettlement and slum clearance was pursued as the solution to Delhi’s overcrowding and pressure on services. However, the National Slum Policy now recognises that,

Slums are an integral part of urban areas and contribute significantly to their economy both through their labour market contributions and informal production activities. This Policy, therefore, endorses an upgrading and improvement approach in all slums. It does not advocate the concept of slum clearance except under strict guidelines set down for resettlement and rehabilitation in respect of certain slums located on untenable sites. (Section B, para 1)

Rather than seeing slums and their inhabitants as a blight on the city landscape that need to be removed, slums are now recognised as part of the city and slum dwellers as an important element of the urban labour force that contribute to urban economic development (Section B, para 7). The recognition of the importance of slum communities leads to the slum development policy advocating integration. Integration includes the ‘... the core principle that households in all urban informal settlements should have access to certain basic minimum services irrespective of land tenure or occupancy status.’(Section B, para 2)

However despite the focus on integration of slum areas and access to services for all households, the National Slum Policy fails to touch on the issue of the integration of people with disabilities. The Policy argues for community involvement in the planning, implementation and maintenance with sufficient flexibility in approaches to upgrading, so that interventions can be shaped to the needs and wishes of the community. The needs of women, children and the urban poor are specifically referred to as needing special attention (Section 8, para a, (i)) but there is no discussion of universal accessibility. It is recommended that community participation is achieved through Residents Associations and each household should be represented by a woman (Section 5, para c). If Residents Associations are to be used to empower and integrate those who are often isolated from community decision-making and general involvement, then Residents Associations should actively enrol people with disabilities to represent households. The policy suggests that households register for services through an identity card that would list a ‘few details’ i.e. household name, address, details of family members (Section 2, para c). These identity cards should also carry information about any members of the household who have a disability.

There are various points within the National Slum Policy where the issue of universal access could be highlighted. Under sanitation, where individual household latrines are not feasible, cluster twin-pit toilets are recommended. The policy document details cost and the need for awareness campaigns but includes no discussion of the need to incorporate accessible design features (Section 8, para a, (ii)). Paving and drainage are discussed as a way of achieving physical integration between neighbouring areas, but again there is no discussion of the way in which design features can facilitate access for all.

## **General Living Conditions of Enabled Environment Participants**

### *Housing*

Although all four communities included in the study are informal, over 60 per cent of the participants live in brick dwellings. In Bhatti Mines, there are few brick dwellings other than the single-room offices built by the telephone company for their employees, and most community members live in traditional mud walled houses with thatch roofing. Bhumiheen Camp and Subhash Camp, as higher density inner-city informal settlements have mainly two-storey brick dwellings with external steps or ladders leading up to the second floor. Kusumpur Pahari has mainly one-storey brick dwellings, many of which have a small courtyard. In two-storey structures, the ground floor rooms and upper floor rooms will often be owned by separate households.

The majority of participants live in two-storey, brick dwellings. We expected that one of the key difficulties for someone with limited mobility through disability, chronic illness or frailty would be climbing up an often steep ladder or steps to get to the top floor. However, as can be seen from Table 10, only one participant in the entire study lived in a dwelling on the top floor of a two-storey brick structure.

Table 10: Type of Room/House that PWD Lives In

	Frequency	Per Cent
Adobe House	55	34.8
Non- Permanent (bamboo matting walls etc) ('kutchra')	6	3.8
Brick structure – one storey	31	19.6
Brick structure – ground floor	65	41.1
Brick structure – upper floor	1	0.6
Total	158	100.0

A noticeably small percentage lived in non-permanent dwellings (3.8 per cent), and almost 93 per cent of the sample lived in households that owned the dwelling where they lived. This indicates that the majority of households in the study had sufficient income either to buy their own building materials or to buy the dwelling<sup>21</sup>.

Although the households in the study had sufficient resources to either buy or build a brick dwelling, most of the EE participants live in very small living spaces. Almost 58 per cent of the sample live in single room dwellings, and another 33.3 percent live in two room dwellings. When one considers that almost three quarters of the sample live in households with between 4 and 7 members, the pressure on space in urban informal settlements is evident.

Table 11: Number of Rooms in PWD's Dwelling

No. of Rooms	Frequency	Per cent
1	92	57.9
2	53	33.3
3	7	4.4
4	4	2.5
5	2	1.3
6	1	0.6
	159	100.0

12.6 per cent of households have a landline phone in their house, and a further 39 per cent have access to a phone within their community. This means that 51.6 per cent have no access to a phone nearby and would have to leave their community and seek a Public Call Office (PCO) outside the community.

<sup>21</sup> Although the dwellings are in 'unauthorised colonies' and therefore there can be no legal ownership as there is no legal tenure, there is a 'black' housing market that deals with dwellings in informal settlements.

### *Electricity*

Although the settlements are informal, 97.5 per cent of the participants live in households with some form of electricity supply. 65.8 per cent of EE participants live in households with legal connections, and 31.6 per cent in households with illegal connections.

Problems with electricity connections were brought up as a key issue in the workshops held in Bhatti Mines, Bhumiheen Camp and Kusumpur Pahari. The issues raised were not related to disability, but were issues of cost, cuts and safety that affect all households. In many informal settlements, local contractors legally buy the power from electricity companies and then resell it to the residents, and workshop participants felt they were charged too much for this service. Complaints of inflated charges and blackouts have been voiced in other informal settlements in Delhi, with one group of residents attacking the house of the local contractor (Kumaraswam and Sharma, 2003). Also, in the narrow alleyways of Bhumiheen Camp exposed overhead cables hang very low and people are often electrocuted, especially in the monsoon season. PWDs with impaired mobility or sight face a greater risk of electrocution than community members with no disability.

### *Water Supply*

There was a range of water supply systems in the communities included in EE:

Bhumiheen Camp and Subhash Camp have a similar water system – there is one government-installed tap for every 10 houses which links to the main city water system. Water in Bhumiheen Camp is available from 1 p.m. to 5 p.m. and the workshop participants had no complaints about the system. Subhash Camp experiences more water shortages and the community facilitator explained there were often fights as people are queuing for water.

In Bhatti Mines, there are 20 small and 3 large underground water storage tanks owned by the Delhi water board. These are filled sporadically by the water board and community members connect their own hand pumps to communal pipes to pump the water out.



**Figure 14 Using a hand pump to collect water in Bhatti Mines.**

There is also a

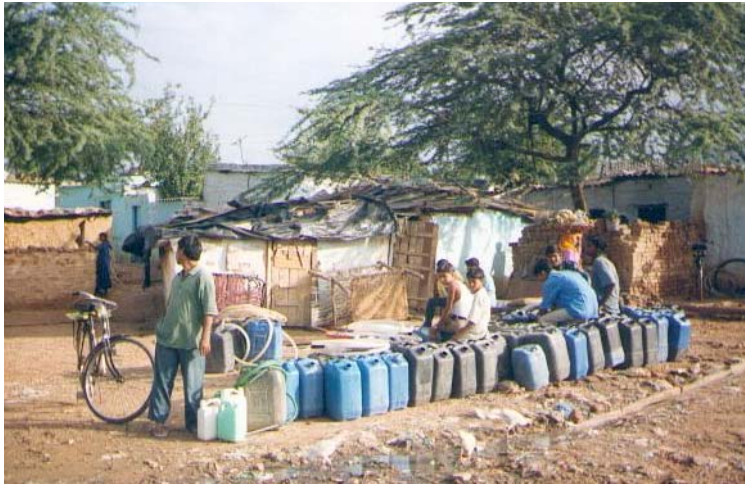
central pump house that draws up underground water. Groups of 8-10 households pay for a piped connection from their area in the community to the pump house, each household then pays the pump house manager R/.10 per month for maintaining the pump house and each household buys its own hand pump to attach to the pipe every time they want water. The third source of water is private water sellers who drive small tankers into the community and sell the water for R/.1.5 per 20 litres.



**Figure 15 A private water seller drives his tank through Bhatti Mines looking for customers.**

Water shortages sometimes occur in Bhatti Mines due to poor management of the pump house, failure of the water board to fill its reservoirs and attempts by private water suppliers to sabotage any public supply. In the past, a pipe network that would have delivered water to a greater number of taps across the community was dismantled by the private water sellers (Soni, 2000).

Kusumpur Pahari experienced the greatest water shortages. The water table in the area has fallen to a very low level and therefore drilling boreholes is banned. The community has no water board reservoirs as found in Bhatti Mines and no connection to the city water system. At the time of the research, water was brought into the community each day in water board tankers. Although the water is free, the system is unreliable and time-consuming. The water tankers come at no fixed time and to no fixed place. Therefore, younger members of the household who are at home are sent to walk around the community to see if the tanker is coming.



**Figure 16 Waiting for the tanker to arrive in Kusumpur Pahari.**

Once the tanker arrives, there is no organised system of dispersal. The youngest, most agile climb onto the top of the tanker, open the hatch, put in their tube and fill their water bottles.



**Figure 17 The water tanker arrives in Kusumpur Pahari.**

Only three EE participants in Kusumpur Pahari had sole responsibility for fetching water, 2 boys aged 8 years and one aged 13. One young woman explained in the workshop that due to the uneven surface of the roads, people with locomotor disabilities find it difficult to carry the full water containers and maintain their balance. When she goes on her own she would often spill a lot of water on the way home and get scolded. A much greater number of PWDs (30 per cent) support other members of the household to get water by watching for the tanker or by carrying smaller, supplementary containers of water.

## Access to Toilets

### *Introduction: Range Of Toilet Provision And Key Problems*

Approximately 70 per cent of Delhi's population does not have access to sanitation facilities that are linked to the municipal sewerage system (Master Plan for Delhi, 2001, p. 30). In response to this problem, there are essentially two options – individual or communal toilets. Individual household toilets are often impractical in densely populated informal settlements where houses have little or no open plot space, the cost of installation is much higher, and households may be reluctant to have a pit toilet so close to house unless they can be sure of the quality of pit construction. As a result, those informal settlements that have had some infrastructure improvement are more likely to have communal toilet and shower blocks. Many of the communal toilet blocks in Delhi are constructed and managed by Sulabh International. Sulabh works with a range of funders, including the Municipal Corporation of Delhi, international and national charitable and community-members themselves, and the MCD provides the water supply.

Table 12: Type of Toilet Facility Used

Toilet Type	Frequency	Per cent
Open Public Land	105	66.0
Community Toilets	43	27.0
Informal Pit Toilet	4	2.5
Septic tank toilet inside house	7	4.4
	159	100.0

The majority (66 per cent) of EE participants use open land to defecate. This group includes almost all the participants from Bhatti Mines (1 participant had an informal pit toilet), and the majority of participants in Kusumpur Pahari and Subhash Camp. As can be seen from the summary provided in Table 13, problems related to using open land are specific to people with disabilities: the long distances to open areas over uneven ground are difficult for people with locomotor and sight disabilities to negotiate.



**Figure 18 The protected woodland behind Subhash Camp that is used as a rubbish dump and a toilet area**





**Figure 19 Similar rubbish-strewn open land that is used by residents in Kusumpur Pahari.**

Twenty seven per cent of the sample use community toilets. This group is made up of almost 93 per cent of the participants from Bhumiheen Camp and four participants from Kusumpur Pahari. In Bhumiheen Camp, which has functioning Sulabh blocks for men and for women, the issues raised by workshop participants relate to insufficient provision, poor administration and building design. Only the latter issue relates specifically to disability, and accessible design in community toilet blocks is discussed in this chapter. Kusumpur Pahari and Subhash Camp are examples of where the infrastructure for community toilets exists but the toilets do not function: at the time of the research, Subhash Camp had one government toilet block that was completely run down and Kusumpur Pahari has four Sulabh blocks, but only one is functioning. The key problems raised at both workshops were lack of water supply and poor management. Although these are not specifically issues related to disability, it is these issues that then make it necessary for PWDs to use open land and encounter the sorts of difficulties mentioned by Mintoo. (See Box 1.)

Only four participants in the study have access to an informal pit toilet on their plot, 3 in Bhumiheen Camp and one in Kusumpur Pahari. Dwellings in Bhumiheen Camp and Subhash Camp have no private space attached to them and most doors open directly onto narrow paved walkways. Therefore, private pit toilets are not an option. Many dwellings in Bhatti Mines and Kusumpur Pahari do have private plots or courtyards, but people prefer not to construct informal pit toilets so close to the dwelling, even when someone in the household has a disability. 7 PWDs in Bhatti Mines live in households that have an indoor toilet with a self-built septic tank.

Table 13: Summary of Toilet Types and Key Problems in each Community

Community	Type of toilet provision	Problems
Bhatti Mines	No infrastructure - Use open land	Distance to 'jungle area' – bad roads
Bhumiheen Camp	Functioning Sulabh block No open land available	Insufficient toilets and showers – very long queues Toilets are not cleaned Steps to the toilets are steep
Kusumpur Pahari	Four Sulabh blocks – three non-functioning and one functioning intermittently Use open land also.	No water supply to Sulabh blocks means toilets are unclean or closed Have to use open land – a long distance from the house – bad roads
Subhash Camp	One community toilet block constructed by Delhi authority – non functioning  Open land on edge of community	No water in the toilets - public toilets are very dirty No maintenance system – sweepers get angry when community ask them to clean toilets 'Jungle' is dangerous – wild pigs During the rainy season it's easy to slip and fall

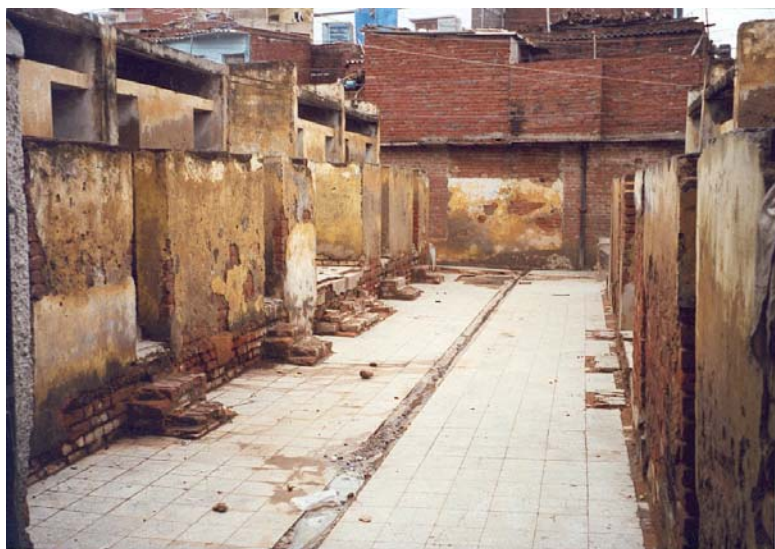
### Box 1: Walking to Open Ground in Bhatti Mines

Mintoo (25) lives in Bhatti Mines with her husband, two children and mother-in-law. Due to polio, she has difficulty in walking long distances. She does most of the housework, but is unable to fetch water from the private water tankers or the community water tank, because of the distance involved and the weight of the water. Despite the difficulties she has walking long distances, each morning Mintoo must walk to the open land in the Asola Bird Sanctuary, as do most people in her community, because there are no other toilet facilities.

It is about 350-400 metres from Mintoo's house to the wall that marks the boundary of the Bird Sanctuary. There is no single path to the wall as people come from a number of directions: the most direct route that Mintoo takes every day was strewn with rocks and involved crossing a shallow ditch that becomes waterlogged in the rainy season. It takes Mintoo over 20 minutes to get to the wall and she is out of breath and sweating by the time she gets there. Once Mintoo has passed through a gap in the wall, she has to walk for another 5-10 minutes to find a suitably secluded spot. The ground on the sanctuary side of the wall is as uneven as that on the community side. Mintoo also carries a one-litre bottle of water with her that makes it more difficult for her to maintain her balance over the rough ground. Most days it will take Mintoo over an hour to get to the sanctuary and return to the house. However, in the rainy season the dry dirt turns to mud and the trip is even more tiring and time-consuming.

As the research team were committed to an action research approach, addressing the issue of toilet provision needed to be linked to some positive or potentially positive outcome or action for the EE participants and the wider community. With this in mind, research related to toilets did not focus on Bhumiheen Camp. Whenever we visited the complex during the day, it was always quiet and relatively clean, and appeared to be well-managed. The main problem is that the complex cannot cope with the number of users. It gets dirty and overly busy in the early

hours of the morning, when everyone wants to use the facilities. As there is no space in the densely populated community to extend the current block or build another one, the workshop participants found it difficult to come up with any practical steps that could be taken to resolve the issue. One possibility is to reduce the cost of using the facility later in the day to encourage those who can, to come after the morning rush and thus, ease congestion. However, work, school and domestic responsibilities mean that few people would be able to do this. The design of the Sulabh block did raise issues about accessible design for PWDs and these are discussed below.



**Figure 20 The derelict toilet block in Subhash Camp has no water supply and no caretaker.**

Due to the threatened eviction in Bhatti Mines, it was difficult to engage community members on the issue of possible practical solutions to the problem of toilet provision. We had wanted to look at the possibility of constructing formal pit latrines based on the Sulabh model, as many of the men in the community had the construction skills required, and a number of the EE participants were keen to launch such a project. However, in such a climate of instability, people were understandably unwilling to invest time or resources

As the government-built block in Subhash Camp had not functioned for a number of years, had infrastructure that was completely rundown and had no caretaker system, we believed it would take a much greater effort to the block functioning again. However, whilst the research was being undertaken, the block in Subhash Camp was demolished and a sanitation project funded by the Government of Japan was initiated. The new complexes were not designed with accessibility in mind, and efforts to influence the design process are discussed here. As Kusumpur Pahari could also offer a possible model of toilet provision for Subhash Camp, the Subhash Camp community facilitator took part in the interviews on toilet facilities in order that he could learn more about the Sulabh system.

Kusumpur Pahari offered the best opportunity for ‘action research’ as the infrastructure was already in place and one block was already functioning. The key focus of the research was to find out:

- What could realistically be done to get the other blocks open and functioning regularly?

- Is there any need for the Sulabh blocks to be altered to make them more accessible to people with disabilities?

#### *Attitudes Towards Communal Toilets in Kusumpur Pahari*

There are four Sulabh toilet blocks that are located at different points in the community. However, because Kusumpur Pahari has no piped water supply and the water table level is very low in the area, maintaining the blocks is difficult. As a result, three toilet blocks are closed, and the only one that is currently functioning relies on an electric pump to draw up ground water.

For PWDs, lack of toilet facilities means that each day they must go through the community and onto the scrubland bordering the community in order to defecate. The unevenness of the pathways means that someone will often need to accompany a tricycle-user to help push them up slopes and over bumpy, rocky ground, a person with a sight disability might need help to negotiate the route, and those able to walk with an assistive device will find the walk every morning a long, laborious one, and even treacherous during the heavy rains of the monsoon season. Once they reach the scrubland the tricycle-user must get out of his/her tricycle, and either be carried or crawl to a place to defecate. As the land is used more and more regularly, community members inevitably have to move further and further away from the boundaries of the community to find what they consider to be a ‘clean’ piece of ground. In the workshop, one young woman, Poona, a paraplegic tricycle-user explained how she has to crawl on her hands and knees over the scrubland. Her hands and knees get grazed by the stones and rubbish and dirtied by mud and faeces. She always has to return home to wash herself, but sometimes there is no water available, and she has to sit and wait until the water tanker arrives. As well as the obvious risk of infection, Poona spoke of the humiliation of having to crawl through the dirt and then return through the community on her tricycle.

After the workshop, we realised that Poona lived close to the functioning Sulabh block in E block, and yet went to the scrubland everyday. When Poona was interviewed at home with her family on the issue of services in the community, it was clearly not the lack of facilities that made Poona choose the scrubland but her family’s preferences. Although Poona’s family lives only 20 yards from a functioning Sulabh block, none of them ever use it. The reason given by Poona’s mother for the family not using the Sulabh is that it is in “the opposite direction” and they have no reason for going in that direction. Poona’s older brother said he would never use a Sulabh block, even if it were free. When we asked why this was the case, he responded by vehemently repeating that he would never use a Sulabh block and that he preferred the open air. The house has its own bathing area, so the family do not need to use the Sulabh block for bathing. Whilst in the workshop, Poona was very clear that using the open scrubland was an unpleasant, humiliating experience, but when she was interviewed with her family, she said that she did not mind it. Now that Poona has started school, the problem has been partly resolved as she uses the toilets at school. However, it is clear that the attitude of her family heavily influence her choice.

Having discovered that the presence of a functioning Sulabh block does not necessarily lead to people giving up using open land, even when a person has a

disability, we discussed the issue with other people, with and without disabilities, who live close to the functioning Sulabh block. People who never use the block were adamant that they would never use it: the reasons given suggested lack of information as people thought the prices were higher than they actually were, and the opening hours shorter. There was also a strong conviction that closed-in toilets were unclean and smelt bad, and some people simply wanted to carry on doing what they had always done<sup>22</sup>. In contrast, people who did use the service regularly said that they could not imagine going out into the scrubland. A few highlights from the discussions with community members are presented in Box 2.

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<sup>22</sup> Choice of location for defecation is a complex cultural issue in India, rather than simply a question of convenience. Scavengers, i.e. people who collect night soil, form a low-status caste that is shunned by other groups in society, despite Ghandi's efforts to end their stigmatisation (Bindeshwar, 2001). Therefore, working in a toilet block or even frequenting a toilet block used by others can have negative connotations for some people. This explains why, even when a public toilet block is well-run and convenient, people may still chose to use open land and may not want to be involved in community efforts to reopen or establish community toilet blocks.

### **Box 2: Reasons Why People Don't Use the Sulabh Block**

Kashidas is 12 years old. He has an artificial leg and uses crutches. When we spoke to him he was on his way to school and explained, 'I live a short distance away from Sulabh in E Block but I don't use it because it opens at 9 o'clock. Besides I don't go because it is uncomfortable. I prefer to go out in the open. They take money from us to use the toilet. I have to climb up and sometimes I fall down.' (We were not sure what Kashidas meant by 'climbing up' – there are few low steps into the facility that should be manageable for someone with crutches)

An elderly woman explained that "No, I don't use the Sulabh, because they charge money and I don't have any to give". Beena, who lives opposite the Sulabh block, said that she does not use the facility because the one time she went in she found it dirty and smelly. She prefers to go in the open because 'there are no doors to close in the smell'. This was a common point. When we pointed out that the ground can become very dirty if everyone goes out of doors, all of the respondents said that they look for space that is clean. The women also admitted that they have to go very early in the morning, before it gets light, for some privacy. However, despite this, they will not go to the Sulabh block because they do not like enclosed spaces. The women go out in groups, most times very early before dawn, because of the risk of rape. The community facilitator in Kusumpur Pahari told us that many women have kidney and urinary tract problems because they do not urinate as frequently as they ought to.

Kavita, who lives very close to Beena, had a completely different opinion of the Sulabh block; 'I go only to the Sulabh block, I never go to the jungle. The Sulabh caretaker is very nice. He takes only one rupee from adults and nothing from the children. Sometimes, if I have no money he does not take anything at all. It is because I use it regularly: those who use it once in a while will have to pay properly. And the toilet is not dirty at all, I use it everyday.' Kavita told us that the block is normally open from 5 am until 11 pm. When the caretaker has to go to the Sulabh office, as he had done on the day we visited, he entrusts the keys to a person living in the neighbourhood. When we told Kavita some people had said that children had to pay, she explained that this is because when younger children come alone they do not use the toilets properly and dirty the pans or slabs. So, the caretaker insists that an adult accompanies younger children, and when the adult comes he/she has to pay the one rupee. Kavita added that the local councillor had given instructions that senior citizens must not be made to pay.

We could establish no pattern as to who does and does not use the Sulabh block. What was clear is that there is considerable misinformation regarding opening times and charges. Lack of information or bad management were offered as excuses for non-use, when in reality the choice to not use the toilet block was based on cultural values for many people. Children accompanied by adults and the elderly do not have to pay; yet many non-users were unaware of this. Even if all Sulabh blocks were opened in Kusumpur Pahari, it is clear that not all people would choose to use them. However, it is important that PWDs are in a position to

make an informed choice about whether or not they use the toilet blocks, and not be pressurised by their families into using open ground<sup>23</sup>.

### *Why Don't the Toilet Blocks Function?*

The main reason why the toilet blocks in Kusumpur Pahari closed down is the lack of a reliable water supply. Therefore, not surprisingly, when we discussed what could be done to address the lack of toilet facilities during the workshop, the group focused on improving the water supply to the community. The suggestion was that the water board should come and drill new bore holes, as the original bores holes have since dried up. However, creating new boreholes in the area is not a possibility as the water table has dropped to such a low level that new drilling would not be permitted. A member of the research team suggested that a more immediate solution could be for one of the water tankers that comes to the community each day to fill water tanks in each of the Sulabh blocks<sup>24</sup>. At the time of the workshop, this suggestion was rejected by the whole group as impractical.

Following the workshop, we talked to one of the non-elected community representatives, who has lobbied the member of the local authority (MLA) about water provision. Shibu has a moderate disability and uses a walking stick. He argued that the only way to get the Sulabh blocks functioning would be to solve the water problem, and in turn, the way to solve the water would be to get the MCD (Municipal Corporation of Delhi) to lay a pipeline down to the River Yamuna, in the same way there is a pipeline to bring water to the residential areas of Vasant Kunj and Vasant Vihar. He said that water tankers would never be able to solve the problem in the way that we had suggested. Shibu rejected water tankers as even an interim solution to toilet provision in the community due to previous problems with tankers. He explained that, '... the MLA had promised to send water in tankers but did not keep his promise. When he finally sent tankers we boycotted them and refused to take water from the tankers. We did not have electricity for five days. On 23 Jan we 'gheraoed'<sup>25</sup> him till the electricity was restored. He threatened me and told me that I had better leave the community within the next two months or something bad will happen to me.'

Toilet provision is a political issue in Kusumpur Pahari because it is related to water supply. In South Delhi, formal households consume 450 litres per individual per day, whilst a third of Delhi's population consumes only approximately 30 litres (Roy, 2001). As there are severe water shortages already, it is clear that any increase in water provision to informal settlements will put increased pressure on the system, and therefore such a measure is resisted by more affluent voters in Delhi. Party politics can also put an obstacle in the way of service provision to low-income communities. In the case of Kusumpur Pahari, the MLA belongs to the

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<sup>23</sup> The National Slum Policy suggests that non-use of toilet blocks is due to limited understanding of the importance of sanitation, especially amongst males and calls for awareness campaigns to accompany any community sanitation project (Section 8, para A, (i)).

<sup>24</sup> It should be noted that Sulabh toilets are designed in order that they can be flushed clean with a minimal volume of water.

<sup>25</sup> Gherao – from Hindi word 'gherna' - to surround. Demonstrators will literally surround a person and not allow them to leave the spot until their demands are met or until there is police action. The 'gherao' could continue for several hours.

Congress party, whilst the MP for the area, whom the MLA reports to, belongs to the BJP. Similarly, the councillor who is supposed to work in tandem with the MLA is also from the BJP. Community members we spoke to complained that there was no coordination between the councillor and the MLA, and therefore trying to achieve change was difficult.

### *Seeking a Solution*

It would seem as though there are insurmountable problems to ensuring functioning toilet blocks in the community: rejection of formal toilets by some, the challenge of getting a regular water supply to the community, and political wrangles. However, in the neighbouring informal settlement, Rahul Gandhi Camp (RGC), which experiences equally severe water shortages, there is a very clean, functioning Sulabh block. It was important to find out why the block functioned so well in Rahul Gandhi Camp and whether there were lessons to be learnt for Kusumpur Pahari.

The block is managed by a full-time caretaker who lives inside the block with his wife and two children. As well as free accommodation, Sulabh Sauchalaya (SS) pays him Rs 1500 per month. SS also pays 950 per month to a sweeper. These are standard SS rates, and the caretaker and sweeper in the Kusumpur Pahari (KP) E block complex earned the same. Every 3-4 days, an SS representative for the area comes to check that everything is running smoothly and to collect the fees. All SS blocks must be open from 5 am to 10 pm, and beyond these hours it is left to the discretion of the caretaker.

The charge to use the toilets is 1 rupee and the block has at least 150 visitors per day. From the daily takings, Rs 45 goes to SS office, and some of the money is used to pay for water. Daily takings at the KP E block complex are also in the range of Rs 90 and Rs 150.

In RGC, water used to be pumped up from underground sources into overhead storage tanks (there are two 2000 litre tanks). However, over a year ago, the water table dropped drastically and since then the block has relied on tankers to supply water. They have now installed ground-level storage tanks and they are filled once every three days and the caretaker pays Rs 300/- per visit. If the storage tanks run dry, users bring in their own water. The caretaker never closes the block. Also, in order to make the complex more sustainable, bathing and washing clothes have been prohibited and the toilets are now cleaned once a day rather than twice a day.





**Figure 21 The water storage tanks at the Rahul Gandhi Camp Sulabh block need to be filled every three days and ensure a regular supply of water, if water use is controlled.**

Water management in KP E block is not as carefully controlled. The complex uses much more water, yet often takes less money in fees, and the complex is often closed due to water shortages. As well as the toilets, there is unlimited bathing and washing clothes. People also collect water to take home to drink. Users are charged R 1/- for using the toilet or more for bathing. Washing is charged at 50 paise per large piece of laundry. There are two 5000-litre storage tanks that are filled by electrically by pumping up underground water three times a day. Whilst the complex in Rahul Gandhi Camp uses 10000 litres every three days, the KP E Block complex is using this amount as a daily minimum. If there is a shortage of water, the SS office is notified and the complex remains closed.

In Rahul Gandhi Camp, there are no concessions for adults, but the caretaker has explained the importance of the income to keep the complex open, with the support of the *pradhan* (elected community representative). Most people understand and abide by the unwritten rules. Small children are not allowed to use the complex without supervision, but children who come with adults do not pay. Since the caretaker has been living at the complex for over four years, he knows most of the residents and users. He admitted that there are a few users that do not pay occasionally, but he does not complain as it could cause problems for his family. During the 30-minute interview, 9 adults came to use the complex and every one paid. In comparison, the caretaker of the KP E block complex had more problems with people refusing to pay, and the confusion amongst community members regarding fees and opening hours seem to stem from the fact that many regular users refuse to pay rather than there being a formal system of concessions.

### *Lessons Learnt*

The comparison the Sulabh complexes in Rahul Gandhi Camp (RGC) and Kusumpur Pahari (KP), identifies the following points as being important for the successful management of a Sulabh complex:

- Regular visits by water tankers can provide a more reliable source of water than pumped ground water, if adequate storage tanks are in place. However, many in KP thought water tankers could be used as an appropriate water supply for Sulabh complexes.

- Water use needs to be controlled. By providing toilet facilities only, the RGC experienced much fewer water shortages. Another option would be to charge more for bathing and washing which uses much larger quantities of water.
- Users fees are essential for the sustainability of a Sulabh complex. By charging almost all the users, the RGC complex was able to purchase water, which ensured a regular supply. In comparison, many users in KP had got into the habit of not paying.
- Communication is important. Whilst in KP, community members were unsure what the fees and opening times were, in RGC the caretaker had worked closely with the community leader (*pradhan*) to ensure that everyone understood why the 1 rupee charge was essential to keep the block open. Reliability is also important: a key difference between RGC and KP is that in the former the caretaker would always keep the facility open and encourage people to bring their own water. Erratic opening hours may put off potential users.



**Figure 22 Example of a twin-pit Sulabh toilet at the Sulabh head office in Delhi.**



## **Current Status and Future Action**

Although the research is now completed, Concerned Action Now continues to work with community members in Kusumpur Pahari to get the Sulabh blocks reopened. The first step was to gain the support of the local councillor. The Kusumpur Pahari community facilitator and the EE researcher visited the Sulabh Sauchalaya (SS) office in Delhi to talk about the situation in KP. They presented a letter from SS addressed to the local councillor that stated that SS would be willing to manage the Sulabh blocks in KP, if water could be provided either by boring or by tanker delivery. They then discussed with the councillor what they had learnt from their visits to Rahul Gandhi Camp and how such a system would work in KP.

Despite the support of SS and the evidence of success from the neighbouring informal settlement, the councillor did not support the plan. She argued that tankers should not be used to provide water for toilets, although she did not explain why. She said that she would discuss the possibility of digging bore wells with the head of the Slum Development Wing, but was not hopeful. We already knew that boreholes in the area of KP would not be approved, as the water table is already so low. Also, boreholes are not sustainable as they eventually run dry, and the community would need to lobby again to get another one dug. In the meeting, the community facilitator showed the councillor diagrams of the Sulabh twin-pit composting toilet, which uses minimal water. The councillor was dismissive of the idea.

As the local councillor was unwilling to support the idea, the next step had been to organise a number of 'field trips' for KP community members to visit the complex in Rahul Gandhi Camp to generate community interest in reopening the toilet blocks. In this way, it was intended that residents from KP would begin to see the feasibility of using water tankers to maintain the water supply to the Sulabh complexes. However, Rahul Gandhi Camp was demolished before the field visits could be arranged. Even though the residents are living in temporary dwellings in the same area, the toilet block ceased to function.

At the time of writing this report, the community facilitator in Kusumpur Pahari continues to work with community members to organise the reopening of the toilet blocks.

### *Communal Toilets And Accessible Design*

Rule 5 of the Standard Rules stresses the need for states to ensure that accessibility requirements are included in all construction projects from the beginning of the design process and that states ensure that relevant professional are accessibility design and legislation (United Nations, 1994, p.22). Whilst the Rules do not specifically refer to people living in informal settlements, ESCAP guidelines on accessible environments argue that any form of improvement, rehabilitation or relocation in an informal settlement should ensure equal access for PWDs and the elderly (ESCAP, 1995, p.20). Therefore, any improvement in toilet provision in an informal settlement should include design features that allow PWDs and the elderly to use the facilities.

Within the Indian disability Act, access to toilet facilities is listed under Non-Discrimination (Chapter VIII, 46 b), and calls for governments and local authorities ‘... to provide for adaptation of toilets for wheelchair users’. This is an overly narrow understanding of accessibility in toilet facilities, as accessible design should also include taps that can be operated by people with impaired movement in their hands, urinals should be designed in such a way that they can be used by men with locomotor disabilities who are able to walk, and appropriate colour contrast should be used to assist those people with low vision. At the time of the Act, there was no official document in Delhi on developing barrier-free environments. However, in 2000, the Office of the Chief Commissioner for Persons with Disabilities published a set of guidelines entitled ‘*Planning a Barrier Free Environment*’. Despite the fact that such a high percentage of the Delhi population live in informal settlements, the design guidelines are aimed at formal public environments and the publication makes no reference to how barrier free design could be extended to informal settlements.

Sulabh International and the MCD are the two main bodies responsible for constructing and maintaining communal toilet blocks in informal settlements in Delhi. The Sulabh-constructed toilets in Bhumiheen Camp and Kusumpur Pahari and the MCD-constructed block in Subhash Camp all have non-accessible features. All three examples have traditional Indian squat toilets. For people with locomotor disabilities, squat toilets can be very difficult, if not impossible to use, especially as there are no grab rails for support. The block in Bhumiheen Camp has toilets on the second floor with a series of steep, narrow steps leading upstairs. Participants in the Bhumiheen Camp workshop mentioned how difficult they find it to get up these stairs. This is especially difficult when the toilet block is crowded in the early morning. The blocks in Subhash Camp and Kusumpur Pahari are raised above ground level to prevent flooding and entrance is by a series of steps. There are no handrails alongside the steps, and there are no ramps into the blocks any of the communities.

Although Sulabh International has well-developed manuals for constructing communal blocks with septic tanks and individual twin-pit toilets, they do not incorporate any accessible design features. An interview with a representative of SI revealed that the issue of accessibility for PWDs had never been raised with the organisation before. Similarly, interviews with members of the MCD office with responsibility for sanitation and construction highlighted the fact that when toilet facilities are provided to the poor, there is no consideration of those people who live in poverty *and* have a disability or have impaired mobility due to illness or age.

When the community facilitator in Subhash Camp became aware that the demolished toilet block was to be replaced, the project team went to meet with the MCD representative responsible for construction in order to look at the plans. The Yamuna Action Plan is a project run by the Slum and JJ Wing of the MCD that aims to improve services to people living in slums and informal settlements with funding from the Government of Japan. Part of the plan includes building 800 toilet complexes, known as ‘Jan Suvidha Complexes’, in informal settlements, including Subhash Camp. At the time of the interview, the blueprints for the

complexes showed that there were no accessibility features incorporated into the design.

EE recommended that the design should incorporate:

- Ramps with appropriate gradient, sufficient flat landing space at the top
- Steps should have handrails and each step should be no higher than 15 centimetres
- Grab rails should be built into the squat toilet cubicles
- Each block should have one western-style toilet with grabrails in a cubicle large enough for a wheelchair user
- Accessible design features must follow international guidelines, otherwise they will not achieve access for PWDs. EE recommended the document published by the Office of the Chief Commissioner for Person with Disabilities
- PWDs should not be charged to use toilet facilities as this means that households will not be able to cite lack of money as a reason for household members with a disability not using the facilities

The EE team met with the MCD office in February 2002, wrote a letter to the head of the Yamuna Action Plan project and ensured the issue was on the agenda for the next Yamuna Action Plan committee meeting. However, because the blocks had to be constructed before the end of the financial year, the only accessibility measures incorporated were a ramp to the entrance and one cubicle with a western style toilet.

Whilst the introduction of an accessibility feature is to be welcomed, ramps have a relatively limited impact in terms of making toilet blocks more accessible when they are the only accessibility feature. Whilst 74.2 per cent of the EE sample have a locomotor disability, only 0.6 of our sample used a wheelchair. PWDs with a locomotor disability who are able to walk can find a ramp more uncomfortable to negotiate than a small number of shallow steps. Also, a ramp into a toilet is of little use if once the wheelchair user enters the toilet complex, he or she is confronted by a series of narrow cubicles containing squat toilets.

The need for a series of guidelines for barrier free design in communal toilet blocks is of utmost importance. In 2001, the law stated that unauthorised colonies that came into existence before March 1993 could be considered for regularisation and be provided with basic services. This has seen a shift in MCD slum policy from relocation to in-situ upgrading. As our study suggests that there is currently little or no awareness of accessible design amongst those responsible for construction in the city's unauthorised colonies, it is highly likely that any upgrading of services will not be accessible to PWDs through design.

The Office of the Chief Commissioner for Persons with Disabilities should produce a short document with guidelines for those aspects of the environment that affect people with disabilities living in informal settlements. Therefore, aspects of the current guidelines, such as car parking spaces and the design of lifts could be left out, whilst guidelines relating to toilets and bathrooms, steps and walkways should be included and made relevant to the environment of an informal settlement. As resources are often limited, the guidelines should explain which types of design features are going to benefit the greatest number of people. For example, if wheelchair use is very low whilst the numbers of people using callipers is much higher, spending a limited budget on access ramps will potentially have a much smaller impact than using the money to install one western-style toilet. The document should be published in Hindi and English and written in clear, non-technical language so that NGOs and PWDs based in informal settlements can use the guidelines to lobby for accessibility features at community level. This document should be adopted by the MCD as the guidelines for forthcoming upgrading.

NGOs working on disability issues in Delhi need to more actively lobby the MCD and organisations such as Sulabh International to incorporate accessible design features. The current Indian Disability Act provides little legal support as the act states that governments are only obliged to ensure barrier-free built environments ‘within the limits of their economic capacity’ (Chapter VIII, Clause 46).

International donors involved in supporting urban improvement projects should place much more emphasis on ensuring the inclusion of accessible design features.

## **Transport**

The India Disability Act (Clause 44) calls for trains, buses, ships and aircraft to be adapted to ensure ‘easy access’ to people with disabilities. There is a specific reference to toilets on transport and in waiting rooms to be made accessible to people with wheelchairs.

The main mode of transport for people with disabilities participating in EE is public bus. The criticisms made of the accessibility of buses were the same in all four community workshops and highlighted the fact that bus operators have failed to respond to the Disability Act’s demand for adaptation:

- The footboards on buses are too high
- Bus drivers do not stop for long enough to allow people to get on and off and therefore PWDs are frightened they will fall
- Buses are often very crowded. There are no seats available, people do not get up to offer them a seat and people do not acknowledge the ‘For disabled people’ seating at the front of the bus



**Figure 23**  
**Regular**  
**public buses**  
**connect**  
**Bhatti Mines**  
**with central**  
**Delhi.**

In the Subhash Camp workshop, participants also mentioned that their disability bus passes have not been recognised by drivers of the new gas-fuelled (CNG) buses, even though they should be.

Adapting the design of the footboards on buses to allow easier access for people with disabilities and the elderly would be relatively simple to do as it would be an external change. Delhi Transport Corporation should also look at the feasibility of including grabrails in order that people feel more secure getting on and off the bus.

The other issues raised by EE participants relate to the bus drivers and the sheer volume of people using the buses. The size of the buses and the numbers of people getting on and off at each stop mean that most bus drivers are likely to be unaware of whether or not there are people with disabilities getting on and off. During key commuting times, buses in Delhi are very full, and therefore, even if people are willing to give up the dedicated seats for people with disabilities and the elderly, it can be impossible for PWDs to push through the crowds to reach those seats. Therefore, we would argue that there is little that can be done to raise the awareness of drivers and passengers of the needs of PWDs, until there is a better-organised bus system with adequate capacity.

The first phase of the Delhi Metro Rail System was recently opened, and offers an example of accessible design can be successfully integrated into transport design. Footboards onto the train are at the same level as the platform, and there is one coach located next to the driver's cabin, which can accommodate up to five wheelchairs. The station is fully accessible with ramps, lifts, directions in Braille and display boards for the hearing impaired. Delhi Metro Rail Corporation (DMRC) has advertised its commitment to developing barrier-free stations and trains<sup>26</sup>. The disability NGO Samarthyaa has worked closely with the Delhi Metro design team to ensure all issues of accessibility have been considered. The NGO is

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<sup>26</sup> From an interview with Public Relations representative of Delhi Metro Rail Corporation. Also see [www.delhimetrorail.com](http://www.delhimetrorail.com) for additional information.

arguing that concessions such a reduced travel costs potentially works against the full integration of people with disabilities by treating them as people with special needs.<sup>27</sup> Whilst ideally PWDs should not require travel concessions because should they have the same opportunities as non-disabled members of society to access employment, people with disabilities are more likely to live in poverty. Bus travel, the most common form of transport, is currently inaccessible to PWDs in Delhi, and therefore, there is a strong argument for reducing the cost of metro travel for PWDs on future phases of the metro system to facilitate access throughout the city.

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<sup>27</sup> From an interview with Mr. Sachdeva, a senior member of Samarthya.



## CHAPTER 5

### PEOPLE WITH DISABILITIES AT HOME: INCOME, ROLE AND SOCIAL LIFE

#### The Income of PWDS and their Households

Of the 92 people aged 18 and above, only 37 had wage income. Of the 13 people in the study aged 60 and above, only 3 had a pension. Therefore, just over half of the adults (56.6 per cent) had no individual income.

Table 14. PWD's Source of Income 18+

Income Type	Frequency
No source of income	52
Daily wage labour	11
Piecework	5
Domestic Help	2
Driver	2
Government job	1
Shop in community	7
Telephone Kiosk	6
Pension	3
Other	3
Total	92

Of the adult PWDs who do have a source of income, a clear majority (85 per cent) said they earned less than R/. 2000 per month. The daily minimum wage for unskilled labour in Delhi is Rs. 103.10<sup>28</sup>, which totals a monthly wage of R/.2474.40 for a 6-day week. This suggests that when PWDs do find work, they do not earn an adequate wage. However, earning a below-minimum wage is not related to the worker's status as a PWD according to EE respondents: none of the participants reported having suffered any form of discrimination in the workplace as a result of their disability, nor of being paid a different wage to their non-disabled work colleagues.

Table 15. Amount of Income PWD Earned Last Month

Income Total in Rupees	Frequency
Less than 250	4
250- 500	3
501-1000	13
1001- 1500	5
1501- 2000	9
2001+	6
Total	40

<sup>28</sup> From official rates issued by Ministry of Labour, Government of Northern Capital Territory of Delhi in August 2002.

Male PWDs are much more likely to work than female PWDs. Over three quarters of adult male PWDs had a source of income as opposed to less than a quarter of all women. Therefore, although the majority of adult PWDs do not have a source of income, the relationship between disability and access to the labour market is heavily bound up with gender identity. The only community where unequal access to employment for PWDs was mentioned in the workshops was Subhash Camp. Training and access to employment are discussed in the following chapter.

Table 16. PWDs Aged 18+ with source of income by gender

Gender	Frequency		Per cent	
	Yes	No	Yes	No
Male	31	20	77.5	39.2
Female	10	31	22.5	60.8

Levels of poverty in households that participated in EE become apparent when one considers income per head<sup>29</sup>. The generic minimum subsistence income of \$1 per day per person totals a monthly income per head of R/.1350 (\$1=R/.45). In the EE sample, 57 per cent of participants lived in households with a monthly income per head of R/.500 or less, and a further 25 per cent lived in households with a monthly income per head of between R/.501-900.

### **The Disability Certificate and other Concessions**

The Standard Rules have a key section entitled ‘Income Maintenance, Social Security and Services’ which calls for states to ensure that people with disabilities who, owing to their disability, have lost income or have been denied employment opportunities be provided with adequate income support (United Nations, 1995, p.27). There is no universal income support system for PWDs in India. However, under the India Disability Act there are a series of concessions available to PWDs, which include reduced travel costs, education benefits, and job reservations. In order to access these concessions, an individual must possess a disability certificate. Therefore, even though a person with a disability may not bring any income into the household, possession of a disability certificate is one way in which s/he can support the household by reducing expenditure.

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<sup>29</sup> Calculated by dividing household income by number of people in the household. We did not weight for consumption differences between adults and children.

Table 17. Key Concessions available to holders of Disability Certificate<sup>30</sup>

Type of Concession	Target Group	Value
Reservation in job	18-60	3% of government jobs reserved for PWDs
Reservation in allotment of DDA shops/kiosks	18-60	5%
Age relaxation	18+	Upper age limit for govt job extended by 10 years
School Uniform Allowance	8-18 years	R/. 300
Scholars allowance	8-18 years	Class 1-5 Rs. 50/-p.m. Class 6-8 Rs.70/-p.m.
Scholars transport and prosthetic/orthotic aids maintenance allowance for locomotor disability	8-18 plus higher education	Aids Rs.25/-p.m. Transport Rs.50/-p.m.
Reimbursement of tuition fee	School students who pass their exams	Class 1-8 R/. 840 p.a. Class 9+ R/.1500-2400 p.a.
Train allowance	PWDs and escorts	Both pay 25% of fare,
Allowance for maintenance of assistive devices	All PWDs with income of R/.600 p.m. or less	Between 90 and 50 per cent of cost
Disability pension	PWDs aged 55+	R/.200 per month
Unemployment allowance	PWDs registered in special employment exchange <sup>31</sup>	Rs.50/-p.m.
Bus Pass on Delhi public buses	All PWDs and Escort	Free for PWD/50% for escort
Assistance for self-employment - Under Prime Minister's Income Generation Scheme	18+	R/. 50 000 to R/. 1 500, 000
Economic assistance- one time grant	All PWDs	Rs.1000 PWDs – one time grant

The Disability Certificate is issued by Government and district hospitals. In order to apply, an individual must have a ration card, an election card and be resident in Delhi, and be 40 per cent disabled. Certificates are only applicable within the state where they are issued, and when a person moves to a different state they must apply again. The only exception to this rule is certificates issued in Delhi, which can be used throughout the country.

Despite the importance of the disability certificate, a surprisingly low percentage of EE participants had the disability certificate – less than a quarter of the sample in Bhumiheen Camp and Kusumpur Pahari and just under a third in Subhash Camp. The Bhatti Mines sample is notable for the high percentage of EE participants who do have the certificate.

<sup>30</sup> All concessions are available once applicant has submitted Ration Card, disability Certificate, photo, Disability ID (given by the Sub Divisional Magistrate), medical certificate and voter's ID. These certificates need to be attested by the councillor and then presented to the Social Welfare Board. The Board then disburses the money.

<sup>31</sup> The Special Employment Exchange is a government-run initiative that aims to place people with disabilities in permanent jobs. It is discussed at more length in Chapter 7.

Table 18. Access to Disability Grant by Community

	<b>Bhatti Mines</b>	<b>Bhumiheen Camp</b>	<b>Kusumpur Pahari</b>	<b>Subhash Camp</b>	<b>Total</b>
Uses it	81.5	21.0	24.0	32.3	38.8
Has never heard of it/Knows very little	0.0	23.7	48.0	22.6	25.5
Knows about it but hasn't tried to get it or failed <sup>32</sup>	18.5	50.0	28.0	35.5	32.5
Does not want it	0.0	5.3	0.0	9.7	3.2
N	39	39	50	31	159

For those PWDs who do not have a disability certificate, one problem is lack of awareness. More PWDs in Bhumiheen Camp had never heard of the certificate than had successfully applied for it. The percentage of EE participants in Kusumpur Pahari who had never heard of the disability certificate was particularly high at almost half of the sample. Again, the Bhatti Mines sample is notable for the fact that all EE participants are aware of the disability certificate.

However, not having a certificate is clearly more than an issue of awareness: overall, 32.5 per cent of the sample knew about the certificate and had not applied for it, or in a small number of cases, had been turned down. Why do PWDs living in very low-income households not apply for a certificate that can help them to reduce travel costs, and, in the case of children, education costs? In order to answer this question, it is necessary to look at the experiences of PWDs in Bhatti Mines.

The reason why PWDs living in Bhatti Mines have been more successful in accessing the disability certificate, despite being the most peripheral community, is because a small NGO that focuses on enabling PWDs to access concessions works in the community. Viklang Sahara Samiti Delhi (VSSD) takes a group of PWDs once or twice a month to apply for the certificate at Safdarjung Hospital in Delhi. People pay R/. 10 to register with VSSD and VSSD organises public buses to take people to the hospital. However, even with this support, 18.5 per cent of EE participants in Bhatti Mines had not applied for the certificate. For those cases where people did offer a reason, the most common explanation was that the family had not had time to apply. A small number of people also mentioned lack of money as being a reason for not applying, as they assumed they would have to pay a bribe in order to be awarded the certificate.

<sup>32</sup> In the original questionnaire 'Hasn't tried to get it' and 'Applied but failed to get it' were two separate categories. However, the fieldworkers classified a lot of people who knew about the certificate but had not applied for it as 'Applied but failed to get it'. We estimate only 10 cases of people who had their applications turned down. For this reason, the two categories are combined here.

### **BOX 3. The 9 Steps to Getting a Disability Certificate<sup>1</sup>**

1. Queue up to get an outpatient card registration card at the hospital where you intend to apply for your disability certificate.
2. Wait to see a doctor who, in the case of locomotor disability will assess the person with an X-ray (in the case of an accident) or muscle chart. The muscle chart grades one's muscles from 0 to 5 - 5 is full strength and no disability. Normally anybody who scores between 3 and 2.5 or below is suitable for a DC. People with sight and hearing disabilities are similarly assessed in terms of levels of impairment. Sometimes doctors will simply look at the individual and send them away, rather than conduct the test.
3. Wait to pick up the results.
4. Make an appointment to see a doctor who will evaluate the results and decide whether or not the person should be recommended for a certificate.
5. Take the doctor's recommendation to another department to make an appointment to go before the application panel made up of four doctors.
6. An individual will often be told to go back to the doctor to recheck the result before being allowed to book an appointment to go before the panel
7. Go through a retesting with the application panel. If a person was originally assessed as having a muscle strength of 2½, but the panel believe s/he is raising his leg to level 3, they will ask him to retake the test and s/he must start the process all over again
8. If the panel says 'yes', you must sign triplicate forms, which you fill out with the clerk
9. Visit the medical records section 6 weeks later to pick up the certificate

Whilst the steps in the application procedure may seem logical, the whole process is extremely time consuming. Based on the comments made by EE participants, it would seem this discourages people from applying. For those PWDs who need assistance, they must wait for a family member to be free to accompany them. One man in Kusumpur Pahari explained that he had done the muscle test but had never gone back because no one was willing to go with him. Once at the hospital, the

queuing and moving from department to department can be problematic for someone with limited mobility.

Individuals who apply through VSSD find the process quicker. An individual applicant is often told to go back and recheck his result with the doctor before going to the panel, but VSSD argue on the behalf of the individual to bypass this step. Applying through VSSD, most applicants take 6 weeks to get their certificates. The individual application process takes much longer. Based on his experience, the head of VSSD said that it takes an individual with a locomotor disability an average of 4 months to get a certificate, and those with sight and hearing disabilities can wait up to 12 months. One woman who applied to VSSD for help had waited 2.5 years to get a disability certificate, even though she was completely blind.<sup>33</sup>

Over the eight years that VSSD has been supporting PWDs applying for the grant, the system has been a fair one in the opinion of the head of VSSD. There is no discrimination and little or no corruption. The key problem lies with the assessment process. Why does it take a total of six doctors to evaluate whether or not someone is eligible for a disability certificate? Even when the assessment by the initial doctor and the panel place the individual at a level of muscle strength that makes them eligible for a certificate, even 0.5 difference in assessment requires the individual to restart the application process.

### *Recommendations*

If PWDs living on low-incomes were applying for the certificate despite the laborious application procedure, there would be less need for change. However, the current procedure is preventing the people who have the greatest need for government concessions from accessing them. Based on VSSD's experiences, the following changes are recommended:

- Mobile clinics and community-based health NGOs need to promote the disability certificate more widely. Even in Kusumpur Pahari where two disability-focused NGOs have a presence, 48 per cent of EE participants knew nothing about the disability certificate.
- The application process should be able to be completed in a day. Tests should only be available during the morning in order that everyone who starts the application process can be confident they will be assessed by the end of the day.
- Ideally, assessment by a panel should be replaced by a second assessment by a single doctor. Only those cases where there is a discrepancy between the opinions of the two doctors should be referred to the panel.
- All stages of the application process should be made available in a single building, if possible.

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<sup>33</sup> Safdarjung Hospital does not monitor the time it takes to process applications and therefore it not possible to find out what percentage of certificate applicants experience delays of 4-12 months.

- VSSD has found that people get better attention from the staff when they go with VSSD than when they go alone. Support and advice provided by VSSD makes the application process less overwhelming for PWDs. Bearing this in mind, hospitals and NGOs should work more closely to make the application procedure more efficient.

## Non-Financial Contributions and Dependency

Whilst many people with disabilities from low-income communities may find it difficult to find paid employment or travel to places of work, they may make important non-financial contributions to the household through involvement in domestic tasks. Such a contribution potentially frees other non-disabled members of the household, especially women, to seek paid employment.

The survey contained a list of 16 common domestic tasks (Qu 71-86) and respondents were asked whether they had sole responsibility, helped out or were not involved at all. The maximum contribution score is 32. However, 7 of the tasks listed could be irrelevant in some households (i.e. tending livestock, gardening, childcare, mending clothes, working in a home business, getting firewood and making a fire). Therefore, any score in the range of 18 and above indicates a high level of involvement in running the household.

Table 19: Domestic Contribution Score

Score Range	Frequency	Per cent
0	35	22.0
1-5	40	25.2
6-10	38	23.9
11-15	13	8.2
16-20	16	10.1
20+	17	10.7
Total	159	100.0

As can be seen in Table, 20.8 per cent of PWDs had a contribution score of 16 and above. A further 8.2 per cent made a substantial contribution with a score between 11-15.

Not surprisingly, it is the very young who make smaller contributions to the household. Whilst PWDs aged between 0-9 make up 17 per cent of the sample overall, they make up 28.6 per cent of PWDs who make no contribution to the household.

Having a disability does not alter traditional gender roles. As can be seen from Table 20, women are overly represented in the higher scoring groups for contribution to household tasks.

Table 20: Contributions Score by Gender

	Contribution Score				
	0	1-5	6-10	11-15	16-20
Female	31.4	25.0	52.6	46.2	81.3
Male	68.6	75.0	47.4	53.8	18.8
	100.0	100.0	100.0	100.0	100.0

Whilst most domestic chores can be postponed to fit around work or even forgone, childcare requires constant input. We were interested to find out whether PWDs are taking responsibility for childcare and thus freeing other members of the household to leave the house to do other things, such as work or collect water. PWDs do play an important role in childcare: 26 per cent of PWDs aged 18 and over had sole responsibility for childcare and 25 per cent helped out.

As well as considering the non-financial contributions that PWDs make, the project also looked at the extent to which PWDs require care or support from other household members. If people with disabilities require a high level of care from other members of the household, it would be necessary to look at whether this dependency prevents adult members of the household from working. If so, there would clearly be a strong argument for more community-based rehabilitation and support. A list of self-care activities (Qu. 69) was used to calculate a dependency score with 9 indicating a high level of dependency. Our findings show that the participants in EE aged over 5 years require little support from their families – 66.6 per cent require no help with self-care activities whatsoever. Only 8.3 per cent of the sample scored between 6 and 9 indicating a higher level of assistance is required.

For the majority of households participating in EE, having a person with a disability in the household places no additional burden on time as a household resource, and in over a quarter of households involved in the study, people with disabilities, especially women, make substantial contributions to the running of the household. 45 per cent of adult PWDs involved in the study made financial contributions to the household. This contribution could potentially be greater if more people with disabilities had the disability certificate and were able to access concessions.

## Social Connectedness

Rules 9, 10 and 11 of the Standard Rules touch on more qualitative aspects of life. Rule 9 stresses the right of PWDs to full participation in family life, Rule 10 discusses the right of PWDs to creative expression and involvement in cultural activities and Rule 11 discusses the involvement of PWDs in recreation and sports.

During the initial workshops, there was an opportunity for participants to discuss aspects of their home and social life. The concerns most widely shared by the four groups related to toilets, water, roads and transport, and, therefore, the report focuses on these issues. However, the workshops did explore whether or not people with disabilities are excluded from social events that other members of the household take part in. Only one of the participants discussed feeling excluded from social events: Meena, a 16 year old tricycle-user from Kusumpur Pahari,



explained that although no one stops her from attending parties and weddings, she feels she can't go because she cannot get made up like the other girls.

The information gathered through the survey confirms that PWDs are not routinely excluded from regular social activities. The community facilitators agreed on 7 key activities that they would expect members of their communities to take part in at least once a year.

Table 21: Frequency of Social Activities

	Never	Daily	At least once a week	At least once a month	At least once in the last 6 months	At least once in the last 12 months	Total
Visits friends and family in community	17.6	57.9	22.0	1.3	0.0	1.2	100
Visited by friends and family	18.2	47.2	27.0	5.7	0.0	1.9	100
Visits friend/family outside community	28.5	25.3	20.9	5.7	5.7	13.9	100
Takes part in festivals	9.7	0.0	16.8	5.8	35.5	32.3	100
Attends Weddings, funerals, parties	22.4	0.0	17.9	3.8	24.4	31.4	100
Takes part in running comm. organisations	97.3	0.5	1.1	0.5	0.5	0.0	100
Takes part in 'committees' <sup>34</sup>	92.5	0.6	4.4	0.0	1.3	1.3	100

The most common activity for EE participants is taking part in religious festivals, which include annual events such as *holi* and *diwali*<sup>35</sup>. Over four fifths of the sample have friends and relatives in their communities who they see at least once a month. Almost 60 per cent of the sample drop in to visit a friend in their community every day and just under 50 per cent receive visitors at home every day. Not surprisingly, due to the inaccessibility and prohibitive cost of public transport, fewer EE participants visit friends and family outside their community – almost 30 per cent never visit anyone outside their community.

Although the majority of EE participants clearly have strong social networks and take part in key community events such as festivals and weddings, very few are involved in community organisations or rotating savings schemes. None of the participants questioned felt they were excluded from such groups and saw it as a matter of choice not to take part. However, when we raised the issue of the non-involvement of women with disabilities in a women's self-help group in one of the communities, the response of the group was to suggest that a separate group be set up for women with disabilities because women with disabilities have different needs.

<sup>34</sup> Rotating Savings schemes

<sup>35</sup> Holi is a Spring festival, welcoming the advent of spring and to celebrate the harvesting of the new crop. Diwali is the festival of lights, when homes are cleaned and illuminated with candles or "diyas" - earthen lamps and new clothes are worn.

We had hoped to investigate this non-involvement further by encouraging EE participants to join groups that they were interested in and following their experiences. However, none of the participants felt there were any community-level groups or organisations they wished to join. Everyone presented their non-involvement as a question of individual choice as opposed to the attitude of group members towards people with disabilities.

## CHAPTER 6

### TRAINING AND EMPLOYMENT

#### Legislation

People with disabilities in developed and developing countries face discrimination in the open labour market (DAA, 1995). Aware of the challenges faced by PWDs seeking employment in the open labour market, Rule 7 of the Standard Rules calls for states to ensure non-discriminatory employment legislation and to support the integration of people with disabilities through a range of measures including vocational training, reserved or designated employment, loans or grants for small business and financial assistance to employers taking on workers with disabilities (United Nations, 1994, p.25).

When judged against the recommendations of the Standard Rules, Indian disability legislation appears to be very thorough. Chapter 6 of the 1995 Disability Act requires governments and local authorities to;

- Reserve 1 per cent of government jobs for people with sight, hearing and locomotor disabilities (3 per cent in total)
- Establish of a Special Employment Exchange where employers can advertise vacancies for PWDs
- Set up schemes dealing with training, welfare, relaxation of upper age limit, regulation of employment and health and safety for PWDs
- Reserve three per cent in poverty alleviation schemes for PWDs

#### Participants' Experiences of Education, Training and Employment

In the initial workshops, participants in Bhatti Mines and Subhash Camp brought up the issue of employment. For PWDs in Bhatti Mines, the issue of employment is closely tied to the closure of the mines. As a settlement that began as a labourers' camp, community members were used to having a source of employment close to their home. Complaints were not related to discrimination against PWDs in the open labour market, but focused on the fact that now there was no local source of employment, workers had to use the bus to get to work and some PWDs could not get onto the bus without assistance. The problem, therefore, is one of inaccessible transport which is discussed at more length in Chapter 5. Participants in Subhash Camp did bring up the issue of discrimination in the open labour market. One participant argued that the private sector was especially resistant to employing PWDs. Another participant discussed the fact that when an employer finds out the person has a disability they will dismiss them. Although other members appeared to agree with this, when we asked for any examples of this happening, none of the group could think of any. When asked whether self-employment could be a viable alternative to wage employment, members of the group argued that whilst this is what they would like to do, there were few opportunities for setting up one's own business locally.

There are no statistics available for levels of unemployment amongst low-income PWDs in Delhi or India<sup>36</sup>. However, as explained in Chapter 6, in our small sample of adults, 45 per cent had some form of wage employment. Of those who do work, only 32.5 earn close to the recommended minimum wage for Delhi. However, this is an issue of low wages in general not wage discrimination for PWDs, as PWDs who worked reported that they earned the same as their non-disabled work colleagues. The key issue for EE participants that did not have jobs was accessing opportunities for employment in the open labour market and for setting one's own business.

76 per cent of PWDs between the aged 10 and over had never received any form of vocational training<sup>37</sup>. We were particularly surprised by the low number of adults in the 20-29 age group who had received training (only 5 out of 27), as this group would normally be targeted for such training. Literacy skills were also poor amongst the group. 52.5 per cent of adults aged 18 and over do not know how to read and write. Illiteracy is particularly high amongst women with disabilities; 61 per cent of women as opposed to 27.5 per cent of men are illiterate. Despite the low levels of literacy and the fact that just over 74 per cent of adults had dropped out of school in their childhood, only 17.3 per cent of adults expressed an interest in returning to education. Lack of skills and illiteracy were not issues that were brought up as problems in the workshops. However, skills and literacy can improve employment chances and therefore, this section looks at employment placement and training opportunities available and the extent to which EE participants are taking advantage of them.

## **Availability of Training and Employment Placements**

### *The Special Employment Exchange*<sup>38</sup>

Special Employment Exchanges (SEE) and Special Cells within general Employment Exchanges exist throughout the country and are funded by State-level governments. Their role is to link up employers with employees from sectors of society that are routinely disadvantaged in the open labour market. As well as people with disabilities, exchanges provide services for people from tribal and scheduled castes, women, ex-servicemen. It is mandatory for public sector employers to send details to SEEs as part of the legal requirement to fill job reservation quotas, whilst private sector employers are welcome to advertise but are under no legal obligation. SEEs registers both candidate and employer, matches the requirements and suitability of both and then sends the prospective candidate for an interview. They do not guarantee employment of a candidate.

Any PWD over the age of 14 who has a disability certificate can register, regardless of whether they are skilled or unskilled, qualified or illiterate. PWDs

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<sup>36</sup> The 1995 Act requires employers to keep information regarding the number of PWDs they employ and to submit an official form quarterly. However, this information, if collated, was not accessible.

<sup>37</sup> This included training provided by private sector, government and NGO, formal apprenticeships, and learning a skill through employment more informally.

<sup>38</sup> Information taken from interview with District Employment Officer based at the Special Employment Exchange in Delhi.

who have been to school have to bring proof of age and a PWD who is illiterate must bring a letter signed by 'a responsible person' giving his/ her date of birth.

There are some unskilled jobs that come into the Exchange, especially in the private sector. The most common requests from government departments, however, are for skilled personnel, especially chair caners, and stenographers and typists who educated to Grade 6. At a higher skill level, there is a great demand for trained teachers. Recognising the low level of skills of many applicants, the SEE works closely with the Vocational Rehabilitation Centre, which offers training to PWDs before they register at the SEE.

Although the high levels of illiteracy and lack of skills amongst the EE participants would be no barrier to them seeking work through the SEE, very few had registered.

Table 22. Adult PWDs registered with SEE and receiving unemployment allowance

	Registered in SEE (per cent)	Unemployment Allowance
Uses and is satisfied	1 (1.3)	2
Uses it and is dissatisfied	8 (10.6)	1
Has never heard of it	31 (41.3)	33
Tried to get it and failed	9 (12)	4
Knows about it but has not applied	16 (21.3)	22
NA <sup>39</sup>	0	13
N (Aged 14-60)	75	75

It is clear from Table 22, that the majority of adult PWDs who would be eligible to register at the SEE were not aware of its existence. Almost equal numbers had either registered and were unhappy with the service they had received or had tried to register and had been turned away, despite the very open requirements. A further 20 per cent of the sample knew about the SEE but had not applied. This suggests that SEEs are failing to cater for the needs of the very people they were set up to benefit i.e. people who are potentially doubly excluded due to their disability and low income.

We also asked about the unemployment allowance. If an individual has been registered at the SEE for more than two years and they have not been offered a job, they become eligible for a monthly unemployment allowance of R/.50 per month for as long as they remain registered with the SEE and fail to find employment. As can be seen from Table 22, a similar number of eligible adults PWDs were unaware of the unemployment allowance. For a low-income household any additional income can be beneficial and knowledge of the benefits available could encourage more people to register at the exchange.

<sup>39</sup> 13 people who were employed at the time of the survey answered the question on unemployment allowance as 'not applicable'

There is clearly a strong argument for making PWDs living in informal settlements more aware of the SEE. Currently, PWDs come to know of the SEE by word of mouth through community NGOs or other PWDs. The SEE does not advertise its services, has no leaflets and no fieldworkers that visit communities to raise awareness of the scheme. Knowledge within the SEE itself is also a problem: the district employment officer at the SEE in Delhi was unaware of the unemployment allowance. In a community such as Bhatti Mines where PWDs work closely with an NGO dedicated to raising awareness of disability concessions, only 20 per cent of eligible PWDs are unaware of the SEE. In comparison, in Bhumiheen Camp and Kusumpur Pahari over 66.6 and 60 per cent respectively of eligible PWDs were unaware of the SEE.

Whilst registering at the SEE would allow an individual to claim unemployment benefit after two years, does registration do anything to increase an individual's chance of finding a job? 12 per cent of adults who are eligible to register at SEE have done so, but this figure is made up of 1.3 per cent who are satisfied with the SEE and 10.7 per cent who are dissatisfied. Viklang Sahara Samiti Delhi has encouraged members to register at the SEE, but they find that when they go for the interview they are regularly told that they are 'unsuitable for the job'<sup>40</sup>. One member of VSSD has been registered with the SEE for over 10 years and renews her registration every 3 years, yet has never found a job. We came to know of one man from Subhash Camp who had got a job through the SEE. However, when we tried to set up an interview, he had paid a bribe and did not want to get into trouble or lose his job<sup>41</sup>.

It is difficult to assess how successful the SEE is at placing PWDs in jobs, as we were told they keep no records of the numbers of PWDs who are offered employment. However, statistics from 1997-8<sup>42</sup> show that 4370 PWDs were registered with the exchange in March 1998. In that year the number of unskilled PWDs who came to the exchange, registered for vocational training and then found a job was 146 (p.46). Clearly, the SEE is not playing a major role in training and securing employment for unskilled PWDs living on low-incomes, such as the participants in our study

### *Central Training and Business Development Loans*

There are a number of training and loan facilities available to PWDs in Delhi. Enabled Environments asked participants about their involvement in/access to the following:

### **Vocational Rehabilitation Centre (VRC)**

These government- funded centres provide technical and non-technical training in tailoring, carpentry, radio repair/ electrical work, making dies, and typing for

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<sup>40</sup> From interview with Director of Viklang Sahara Samiti Delhi

<sup>41</sup> During previous projects in informal settlements in Delhi, various members of the team had come across people who had had to pay a bribe to secure even the lowliest of government jobs, and other people who explained that they would never consider applying for such jobs because they could not afford such bribes.

<sup>42</sup> These are the most up-to-date figures available to the public.

people with a range of disabilities. Trainees are male and female, and aged between 18 and 45. The VRC evaluates the ability and aptitude of the applicant and provides them with appropriate technical training. Trainees are closely monitored during the 3-6 months training and are registered at the special employment exchange. Although the numbers of PWDs registering for training are low, for those who do register the chances of finding a job are high: in Delhi, the VRC claims a 75 per cent success rate in finding employment for PWDs who complete training.

#### *National Handicapped Finance Development Corporation*<sup>43</sup> (NHFDC)

NHFDC is an NGO that provides minimum-interest 'soft' loans (1-5 per cent interest) to people with disabilities and micro-credit finance schemes to Self Help Groups made up of PWDs and parents of PWDs. NHFDC has traditionally offered loans directly to self help groups or through state organisations, but high levels of default in the past have encouraged the organisation to channel loans through NGOS because of their closer community links.

The organisation offers a range of loans for PWDs include a general enterprise loan, a scheme to promote the production of assistive devices, assistance with training costs, a scheme to promote self employment amongst persons with mental retardation, cerebral palsy and autism, and loans for cooperative societies of PWDs. Self-help groups can be made up of 75 per cent PWDs and 25 per cent people without disability. NHFDC's past experience has shown that the 25 per cent non-disabled members can marginalise PWDs and monopolise the group's funds. NHFDC hopes that by working more closely with NGOs, this problem can be avoided. It plans to develop a range of dissemination materials to be distributed at community level.

### **State Bank of India Loan**

The bank offers low-interest loans to PWDs. In 2002, the State Bank of India (SBI) launched a range of "Special activities for the Physically Handicapped" which includes credit for enterprise development and vocational training. However, although such schemes exist on paper, this is no guarantee that bank staff will know about them or be supportive of applicants. Sanjeev lives in Subhash Camp and wants to establish an arts and crafts business. He was dismissive of the new SBI scheme as his previous attempts to apply for one of the loans for PWDs had not got him anywhere,

They announce these schemes every year on the 2<sup>nd</sup><sup>44</sup>. Last year I went to the main SBI and they told me to go to the bank in my neighbourhood. Since then I have made numerous trips to the Dakshinpuri branch to no avail. They either say that they are not aware of such schemes or they fob me off by saying the manager is not in today, and so on. (Sanjeev, Subhash Camp)

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<sup>43</sup> Notes taken from meeting of NHFDC and Delhi NGOs at Ministry of Social Justice & Empowerment, Delhi, 6<sup>th</sup> October 2001.

<sup>44</sup> The 2<sup>nd</sup> of October is Mahatma Gandhi's birthday. Many government schemes are announced on that day.

Table 23. PWDs' access to central training and credit schemes

	VRC	NHFDC	State Bank of India loan	One-off Delhi Govt Grant
Uses it	1.2	0.6	0.6	6.3
Never heard of it	45.3	19.5	17.6	39.9
Tried to get it and failed	1.3	6.9	9.4	11.4
Knows about it but has not tried to get it	27.0	56.6	56.6	41.2
NA	25.2	16.4	15.7	20.9
N	159	159	159	159

Based on the experiences of EE participants, it is clear that one of the reasons why the Special Employment Exchange sees so few PWDs achieve what they term as 'rehabilitation' (i.e. acquire skills at the Vocational Rehabilitation Centre and then find employment through the exchange) is because many PWDs living in low-income settlements are unaware of the Vocational Rehabilitation Centre. Over 45 per cent of participants had never heard of the VRC. A further 27 per cent knew about the centre but had never applied. Although the VRC has a relatively high success rate finding employment for those PWDs who complete training, those who know about the SEE believed that nothing would come of them applying

What is also notable from the responses of EE participants is that although they are aware of formal credit schemes they choose not to apply for loans. The State Bank of India loan is clearly better advertised than many other schemes as only 17.6 per cent of the sample had never heard of it, whilst over half of the sample knew about the loan scheme but were not interested in applying.

#### *Community-level Training*

As well as central training and credit facilities, there are local training and credit facilities in each community. None of these are specifically for PWDs. It is clear from Table 24 that the range is very limited with the only choices in training being tailoring or computers. There are no locally available microcredit schemes other than the women-only self help group in Kusumpur Pahari.

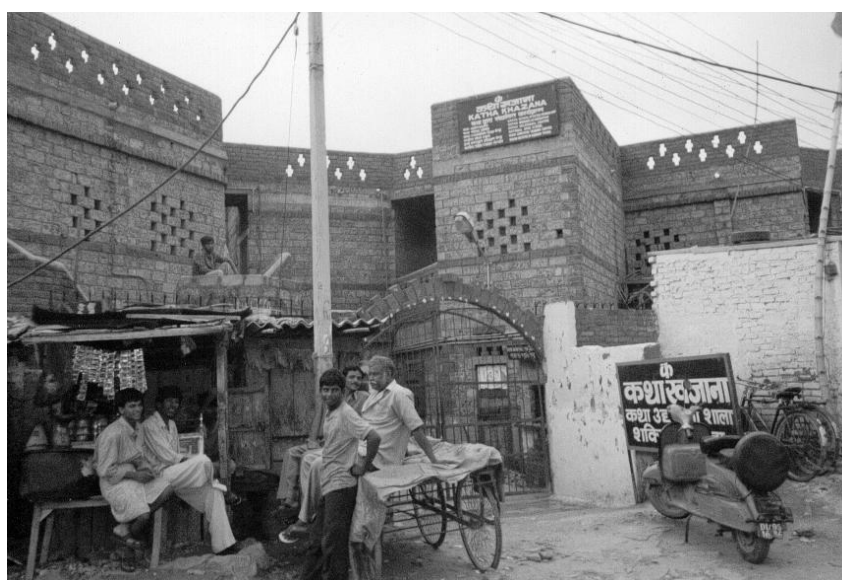
Table 24. Training and Credit Facilities at Community Level

	Tailoring NGO	Computer NGO	Adult Literacy	Women's SHG (govt)	Income generation scheme NGO
Bhatti Mines	✓✓	X	X	X	X
B. Camp	✓	✓	X	X	✓
Kus'pur Pahari	✓(WO)	X	✓	✓	X
Subhash Camp	✓✓	✓(WO)	✓	X	X
* WO = Women Only					

Between a tenth and a quarter of PWDs choose to take part in the various general training schemes in their local community. The tailoring training centres will



accept PWDs and have hand-operated sewing machines for those who cannot use a foot pedal. Some of the EE participants already have tailoring and hand sewing skills: 2 work as tailors and 3 do handsewing on a piecework basis. 5 of the workshop participants at the Subhash Camp workshop had machine skills and wanted a job rather than further training. In all the communities, participants have expressed an interest in opening a micro-enterprise in their community. What is clearly lacking at community-level is enterprise training and small loans to get enterprises started.



**Figure 24**  
**Katha**  
**Khazana is**  
**the main NGO**  
**providing**  
**training in**  
**Bhumihien**  
**Camp.**

**Table 25. Uptake of Community Training Schemes (% of eligible PWDs)**

	Tailoring NGO	Computer NGO	Adult Literacy	Women's SHG (govt)	Income gen.scheme NGO
Bhatti Mines	15.6	X	X	X	X
B. Camp	38.2	6.6	X	X	5.0
Kus'pur Pahari	11.1	X	14.2	8.3	X
S. Camp	24.8	0.0	0.0	X	X

**Table 26. PWDs not aware of Community Training Schemes**

	Tailoring NGO	Computer NGO	Adult Literacy	Women's SHG (govt)	Income gen.scheme NGO
Bhatti Mines	6.25	X	X	X	X
B. Camp	18.0	13.3	X	X	50.0
Kus'pur Pahari	66.6	X	50.0	58.3	X
Subhash Camp	51.6	3.3	11.0	X	X

It is not just the central training and credit opportunities that people are unaware of, at a community-level, people are also unaware of the various workshops and groups in existence. Even those PWDs who move around the community and

beyond do not necessarily come into contact with other PWDs, and, therefore there is little or no opportunity to share information and experiences. Sonu lives in Subhash Camp, the smallest community in the study, and goes to work as a domestic help each day in the middle-class neighbourhood nearby. She has tailoring and does some small sewing jobs for her neighbours, and would prefer to use these skills,

I want to do something with my skills but I don't know how to go about it. I did not even know that there were people like me in this community. It is only when Arvind (the community facilitator) came to my house to ask if there were any disabled people living in my house that I knew that there are other people like me living here. I didn't know that the government has made provisions for PWDs. I don't know of any benefits that disabled people get. In fact, I did not know anybody from the community before taking part in this project<sup>45</sup>.

#### *Failed Action*

As the participants in the Subhash Camp workshop had expressed a particular interest in employment, the field researcher formed an action group with nine EE participants and offered them the opportunity to take part in EE research activities related to employment and training. By accompanying the researchers and finding out more about such centres as the SEE and the NHFDC, it was hoped that participants would find a loan scheme, training opportunity or employment placement that appealed to them.

At the first meeting the participants identified the sort of work or training they would like: 3 people wanted to open a shop and 5 could already use a sewing machine and wanted to work as tailors. One participant wanted to learn computer skills but could not afford the cost of the course. One woman wanted to work and was struggling to cover household costs, and her neighbours had offered to find her a domestic job in the nearby neighbourhood, but she had turned down the offer, as she was adamant that she would not work in someone else's house. Everyone in the group saw community-based self-employment as the ideal form of employment, but no one had any ideas for businesses.

As a short-term idea to earn some extra money and to encourage the group to meet on a regular basis, the community facilitator offered to teach the group to make candles and cards to sell for the festivals of *Dussehra*<sup>46</sup> and *Diwali*<sup>47</sup>. However, no one expressed an interest.

Vijayan, wants to be self-employed and expressed an interest in running a Public Phone Booth. However, the government has not given any licences for phone

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<sup>45</sup> Since the completion of the EE fieldwork Concerned Action Now has set up a vocational training centre in Subhash camp for people with disabilities where Sonu is currently improving her skills in preparation for finding a new job.

<sup>46</sup> Dussehra is an annual festival that celebrates the point when Ram defeats and kills Ravana, demon king of Lanka

<sup>47</sup> Diwali is the festival of lights when homes are cleaned and illuminated with candles or "diyas" - earthen lamps - and new clothes are worn.

booths since 1990. The community facilitator suggested that they go to Small Scale Industries department in Okhla or Nehru Yuva Sanstha, an organisation that gives microcredit to young people. The community facilitator suggested that Vijayan look at the current businesses in the area and come up with one or two ideas that they could develop into project proposals. The community facilitator visited Vijayan after the meeting once a week over the next month to suggest ideas and try and encourage him to start up a business. However, whenever he visited Vijayan at home, Vijayan told him that he was convinced that a waged job would come up soon and, therefore, he didn't need to think about self-employment<sup>48</sup>.

The research team contacted an organisation called Disha, a garment-manufacturing unit that trains and provides job opportunities to people with disabilities. Disha offered factory positions in tailoring to 3 PWDs from Subhash Camp and also had home-based crocheting work. The community facilitator offered to accompany people to the factory and the project would cover the bus fares for the initial visit. However, on the day of the visit only one person turned up, but he never went back and continues to be unemployed. When the group discussed this later, one woman said that she could not take the bus (even though she takes the bus to work every day) and the rest of the group seemed disinterested. As the meeting progressed, it became clear that it was not disinterest that discouraged people from looking at opportunities beyond the community, but a conviction that as people living in an informal settlement and with a disability they would always be badly treated. When the group facilitator questioned this and highlighted examples of PWDs from the other three communities who had found work outside the community, the group were adamant that their status as slum dwellers and PWDs would mean that people would always look down on them.

In the end, the relationship between the community facilitator and the group broke down. The community facilitator felt frustrated that despite offering to accompany people to various places and help them to write proposals and fill in forms, the group members expected him to bring the information to them. The community facilitator believed the group were disinterested,

They're not interested in doing anything. They want everything handed to them on a plate. Some time ago some foreigners came and gave them clothes, money, enough money for one person to build his house and now they expect everyone to do the same. Even to help themselves they want me to go and find out about schemes and other benefits, they will not accompany me. I have told them to go and look for themselves and I will definitely help them if they come with me.

However, that disinterest is also tied up with a belief that they will be rejected by people outside the community due to their disability and the fact they live in a slum.

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<sup>48</sup> Vijayan found employment at a factory some months later and commutes daily by bus.

## Conclusion

It is clear that despite the range of training, credit and employment placement opportunities open to PWDs living in Delhi, PWDs living on low incomes in informal settlements are not gaining access to them. Such opportunities could clearly be of some benefit as the majority of PWDs had not received any form of vocational training and just over half of the participants are illiterate. However, having a disability clearly is not necessarily a barrier to finding employment as just over 40 per cent of the PWDs of working age have a paid employment. Furthermore, none of the EE participants who are employed had experienced wage discrimination or any other form of discrimination.

Whilst central schemes are open to unskilled PWDs and therefore are accessible to EE participants, there are a number of reasons why they are failing to attract more PWDs from informal settlements:

1. Information about the scheme does not reach the community – almost half the sample had never heard of the Special Employment Exchange, Vocational Rehabilitation Centre and Unemployment Allowance.
2. Too many individual schemes - There are many different schemes being run out of central offices all over the city – if people are unaware of the larger schemes, it is unlikely that information about smaller schemes will ever reach them.
3. Poor administration – most of the PWDs registered at the SEE have failed to find jobs, the SEE staff don't know about the unemployment allowance, the local State Bank of India staff know nothing about the loan system for PWDs
4. Lack of confidence – Subhash Camp participants were convinced that people would discriminate against them if they looked for employment outside the community
5. Lack of entrepreneurial skills – whilst there are a range of loans available, many people clearly do not have the ability to identify a viable business idea

*What can be done to overcome these obstacles to greater access?*

- Information needs to be taken to communities – NHFDC has already realised this and is planning to work more closely with NGOs that have a community presence. However, as many PWDs are unaware of what is going on in their immediate community, information needs to be actively disseminated from house-to-house. Working with a fieldworker who has a disability and lives in the community can be a cost effective way of achieving this. The Special Employment Exchange currently has no fieldworkers which is one of the reasons why it has such a low-profile amongst PWDs living in informal settlements – a mobile information centre that links up with community representatives and allows PWDs to be assessed and register for jobs in their community would be more effective.
- There should be a one-stop information centre – the Special Employment Exchange is legally required to exist and should be a central point where all

employers and PWDs seeking employment can go. The SEE could become a central information point also, where all information about training and loans is advertised. This information should then be available to communities through a mobile information centre.

- Monitoring of services provided disaggregated by skill-level and household income level of applicant – dissatisfaction with the SEE relates to the fact it fails to find jobs for PWDs with lower skills levels. However, there is currently no monitoring of the number of PWDs who successfully find short and long-term employment. Also, staff in various organisations are poorly briefed on services that are available.
- There needs to be a greater understanding that when people do not take up opportunities made available to them this does not necessarily indicate disinterest and can indicate lack of confidence to go into new work and social spaces. It is unrealistic to expect NGOs dedicated to working with PWDs to be present in every country. Also, separate NGOs for PWDs do not encourage greater integration. There has been a lot of activity in Delhi at community level to encourage women to gain skills and set up businesses as a process of empowerment. NGOs should extend the methods they have used to encourage women's participation to more actively recruit PWDs in the communities where they work. Furthermore, NGOs work in isolation even when located in the same community. They must be encouraged to share information and resources.
- Schemes offering loans to PWDs need to link up with NGOs providing short workshops on entrepreneurial skills - One of the reasons why PWDs are not applying for loans is that they do not have new ideas for businesses. Ideas that come up are normally copies of businesses people have seen in their own community and therefore, people need to have the opportunity to look at ideas beyond their community in order to be more competitive.

## CHAPTER 7: CONCLUSION

The Enabled Environments project set out to explore the reasons why people with disabilities living in poverty often fail to access the opportunities and services available to them. The project focused on three key areas: physical environment; services; home life.

The India case study has shown that large-scale physical environment initiatives aimed at the poor failed to address the needs of people with disabilities. In the area of services there has been a much greater effort to address the needs of PWDs, with a number of welfare, loan, training and employment schemes. However, poor dissemination and support for access to these services means that they have had a very limited impact on the lives of the participants in Enabled Environments.

The key issues and recommendations are summarised below:

### **Settlements and Housing**

One of the key issues raised at the workshop was the difficulty many people with disabilities face moving through their informal settlement: uncollected rubbish, uneven stony roads, and waterlogging were all barriers to the mobility of many EE participants. In theory, the current National Slum Policy should offer PWDs living in informal settlements some hope as it currently advocates in-situ upgrading rather than resettlement. However, there is a risk that upgrading will fail to benefit slum dwellers with disabilities.

The current Slum Policy makes no reference to slum dwellers with disabilities as a group requiring special attention, though it does make reference to the importance of ensuring the inclusion of women and children. By not building in barrier-free design features into the upgrading process, and recommending consultation with PWDs and their families, the current framework fails to put into practice the commitment to barrier-free environments in the Indian People with Disabilities Act.

Plans for multi-storey housing threaten to increase barriers for PWDs. In the consultation workshops, none of the participants discussed mobility problems linked to housing and almost 100 per cent of participants lived on the ground floor. A pilot upgrading project in Delhi (DUEIIP, 2001) proposes 3-4 storey structures, yet there was no information gathered on family members with disabilities in the household scoping survey.

The concept of accessibility covered by Rule 5 of the Standard Rules (United Nations, 1994) draws on the idea of space as a continuous process: the individual should be able to move from home to community to public buildings without barriers in his or her way. Plans for slum upgrading should incorporate this concept of accessibility. An important point to be made here is that when accessibility is incorporated into the original design, the additional cost will not normally exceed 0.2 per cent of the overall cost (Hobden, 2001).

## **Toilets**

Problems related to the lack of accessible toilet facilities were discussed at all the community workshops. Even in the one community that had a fully functioning toilet block, people with locomotor disabilities faced difficulties, as there are steep steps into the building and up to the first floor. The Sulabh low-cost twin-pit toilet model has been successfully replicated in numerous informal settlements around India. However, just as the National Slum Policy's aim to provide low-cost upgrading to as many slum dwellers as possible has resulted in the needs of PWDs being overlooked, Sulabh has failed to incorporate accessible design features for people with disabilities into their standard toilet blocks. The project team continues to lobby Sulabh to ensure that at least one cubicle in all Sulabh blocks has the design features recommended by the United Nations.

Donors could play a role in ensuring that accessible design features are incorporated. The toilet block constructed in Subhash Camp, one of our case study sites, was funded by the Japanese government. Japan has detailed accessibility legislation and was used as a country case study in the ESCAP accessibility guidelines (United Nations, 1995). Therefore, there is a national commitment to barrier-free environments and inclusion of PWDs. Accessibility features could have been built in as a condition of the grant.

As well as physical barriers to use, the research revealed there are also cultural barriers. The National Slum Policy argues that 'Many members of the community, especially male members, do not perceive sanitation as a clear priority need. This needs to be addressed before embarking upon the installation of sanitation.' Enabled Environments showed that rather than it just being a case of families not giving sanitation priority, families who chose to use open ground even when toilet facilities are available thought using open ground was cleaner. Sanitation awareness work with the community must include people with disabilities and respond to specific difficulties faced by people with disabilities wherever necessary.

## **Accessible Transport**

Any effort to create barrier-environments through the inclusion of appropriate design features in upgrading plans will be thwarted if public transport for those on low-incomes continues to be inaccessible. In an enabling environment, an individual would move through the community, on and off transport and into their place of work with no restrictions. The public bus is the most common mode of transport for the participants in EE and their families. However, the current design of public buses (with high footboards) means that for those who do not have full use of their legs or arms boarding a bus can either be impossible or frightening.

The report discussed the accessibility features that have been incorporated into the design of the new Delhi Metro. Whilst this is a welcome improvement, the limited coverage and higher cost of the metro means that it is unlikely to be used by people with disabilities living in low-income households. The public bus will continue to be the main mode of transport and therefore, the issue of accessibility needs to be addressed.

## **Access to Employment and Training Opportunities**

Whilst barriers in the physical environment relate to the failure of those responsible for development and planning to incorporate accessibility features, it is lack of dissemination of information that acts as a barrier to PWDs taking up employment and training opportunities aimed at them. Our research showed that most participants had a very limited knowledge of the services available and therefore were unable to benefit from them. Information needs to be brought to communities. As there is a range of services that could potentially benefit PWDs living on very low incomes, the most efficient way of disseminating this information would be as a whole rather than individual organisations promoting their own services. The Office of the Chief Commissioner for Disabilities should take responsibility for bringing this information together as part of its remit to ensure the rights of people with disabilities are recognised. The Special Employment Exchange could become a central information point also, where all information about training and loans is advertised. This information should then be available to communities through a mobile information centre.

Again, when external donors are involved in funding community economic development initiatives, they should stipulate the need to ensure the inclusion of PWDs, as has been done for women.

## **An Assessment of the Participatory Action Approach of the Project**

Following the project, Concerned Action Now has continued to support the community facilitators (CFs). Each CF submits regular reports on activities in their communities, such as the number of children with disabilities admitted to school, the names of people who have received or are in line for Disability Certificates, or a report on the training being received in the Vocational Training Centres.

Based on the project team's experiences, the CFs have prepared information sheets which cover issues such as the procedure for applying for government certificates and rail passes, or how to apply for permission to set up a Public Telephone Office (PCO). There are sheets which give a list of the names of officials who are responsible for government welfare schemes in different parts of Delhi. The CFs collect information from various government and non-governmental organisations and disseminate this to their respective communities and to CAN. CAN in turn, uses this material to update the database and answer any queries that come to the CAN Help Desk. This approach is sustainable in the long-term.

In Subhash Camp, the community facilitator, Arvind Singh, has worked closely with CAN to set up a vocational training centre which he manages and where he trains PWDs from the local community in handicrafts. Arvind has used the community networks he developed during EE to identify possible workshop participants. The project has been successful, with large orders being placed for Diwali cards and candles. The vocational centre also provides space for a homeopathic doctor who has a weekly dispensary, which Arvind promotes in the community. Arvind got interested in accessible design issues when he became involved in lobbying for accessible features for the Japanese-funded toilet block



being built in Subhash Camp. This continues to be an area of interest and he is developing a role as the key mediator between community members and municipal representatives on issues of accessibility and environmental improvement. Arvind also identifies community members who require assistive devices and works with CAN to identify donors.

Sonia Devi has worked with CAN in Kusumpur Pahari for a number of years, and is involved in facilitating women's self help groups and running a crèche facility with two other women. Sonia also established a vocational training centre with CAN's support following EE and members of the centre have earned money from selling hand-sewn handicrafts. Sonia works closely with the parents of children with disabilities to ensure the children get admission to government schools and get the benefits they are due. Like Arvind, she identifies community members who require assistive devices and works with CAN to find donors.

Kapil Kumar Aggarwal's knowledge and understanding of legal safeguards and government rules relating to people with disabilities has made him a key resource person for the Enabled Environments team. He continues to work with the members of Bhatti Mines and his own community in North Delhi, but has also established good links with the other community facilitators. As a disability rights activist, he works closely with a group of lawyers who launch public interest litigation cases.

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