

# ENABLED ENVIRONMENTS: FINAL REPORT

## Background and Objectives

Even in those countries that have introduced a range of legislative measures to support the greater inclusion of PWDs, disability and chronic poverty go hand in hand (Yeo, 2001). The project began with the hypothesis, based on our own observations in the course of working on other field research and from other studies, that despite the existence of disability legislation and service provision, people with disabilities<sup>1</sup> living on low incomes often ‘fall between the gaps’. 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.

The Enabled Environments project used a social model of disability, which understands disability to be the product of the interaction between individuals and their environment, rather than a problem of the individual in isolation (Hahn, 1986). The project identified and examined the environmental and attitudinal barriers that work against legislation and support programmes achieving the full integration of people with disabilities. Having identified these barriers, the research explored practical means of overcoming them through consultation with people with disabilities, their families, and the service providers.

The research took place in Pretoria, South Africa and New Delhi, India. Two detailed country reports were produced, which will be used as an advocacy resource by the national research teams<sup>2</sup>. This report presents highlights from the study.

The key research questions were:

- 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?
- How and why are people with disabilities excluded from the education and employment opportunities open to non-disabled members of their communities and how can greater inclusion be achieved?
- What contribution do PWDs make to their households? 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?

The project considered the implications of empirical findings for existing policies and implementation processes.

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<sup>1</sup> ‘People with disabilities’ is abbreviated to ‘PWDs’ at various points in the report.

<sup>2</sup> The country reports are available at [INSERT CARDO WEBSITE ADDRESS](#)

## Methods

### Research Approach: Working Towards Participation and Action

The project worked as far as possible with a participatory action research (PAR) approach in order that people with disabilities would be involved in generating knowledge about their own condition and how it can be changed<sup>3</sup>. This is important because a failure to use local knowledge of disability that only PWDs themselves can provide often leads to inappropriate provision and measures (Metts, 2000). 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.' 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.

### Local Sustainability and Capacity-Building

In order that the research had a greater potential to benefit the communities that took part, the researcher worked with a 'community facilitator' in each community i.e. someone local who would support the research and represent the project at a community level. The facilitators were either people with disabilities or people who had experience of working on disability issues. The facilitators carried out the surveys and participated in the workshops in each community and in the final workshop for policymakers. 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.

### Research Sites:

The research was carried out in four low-income settlements in the cities of Pretoria and New Delhi. In Delhi, all the sites were well-established informal settlements that had seen some element of basic infrastructure upgrading. In Pretoria, the four sites included a mixture of informal sites and new formal settlement developments funded under the government housing scheme. In each country, the sites were also chosen on the basis of having some community-level services in place. We also chose sites where the researchers had some previous contact either at an individual or organisational level in order to facilitate our work.

### Sampling:

In constructing our 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. We worked towards a sample of 50 PWDs in each of the four research sites in each country – a sample of 400 in total.

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<sup>3</sup> 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.

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 and from all age groups
- Included equal numbers of males and females
- 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

Working on 5-10 per cent incidence of disability, we expected to develop a larger sample from which to select participants randomly. However, in both countries, identifying PWDs who were willing or able to take part in the study proved to be more difficult than expected. In the end, we identified a sample of 200 and looked no further.

#### Sample by Disability Type:

Despite training given to the local fieldworkers on identifying different types of disability, we still ended up with a sample in both countries that over represented the most visible type of disability i.e. locomotor disability. The possible reasons for this bias in the sample are explained at length in the country reports.

**Table 1. Comparison between Enabled Environments sample and levels of disability by type in India, South Africa and the world**

Disability	India (EE)	India Census 2001 <sup>4</sup>	South Africa (EE)	South Africa Census <sup>5</sup>	UN Global <sup>6</sup>
Sight (Blind and low vision)	5.7	13.95	9.1	41	11
Hearing (Deaf/hard of hearing)	7.5	13.96	6.5	15	14
Locomotor	74.2	42.86	37.6	21	32
Mental	7.5	10.42	40.4	7	26
Not specified	0	0	0	10	13
Epilepsy	0	10.26	4.2	0	4
Leprosy Cured	0	3.43	0	0	0
Multiple	5.0	5.15	(29)	6	0

<sup>4</sup> These are not official NSSO percentages. At the time of writing this report, the NSSO had not yet analysed 2001 figures on disability incidence. These percentages are based on state totals collated by Indumati Roy on behalf of the Office of the Chief Commissioner for Persons with Disabilities.

<sup>5</sup> 1996 South African Population Census

<sup>6</sup> Cited in DAA (1995)

Speech <sup>7</sup>	0	0	2.2	0	0
Total	100	100	100	100	100

### Stages in the Research:

The range of research methods used is summarised below. The community workshops drew on community action planning method developed by (Hamdi and Goethert (1997). They were a key stage in encouraging active participation in the project. The country reports discuss the workshop approach in more detail.

**Table 2: Summary of Research Methods**

<b>Research Method</b>	<b>Description</b>
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.
Community Workshops	These workshops introduced a participatory element into the project by allowing PWDS to identify issues that were of importance to them. We then focused the research on these chosen themes.
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.
Interviews with Service Providers	EE participants drew up the questions and, wherever possible, were brought along to participate in conducting the interview.
Field visits with participants	Participants were taken to a number of places to conduct interviews, take photographs and assess accessibility for themselves.
Mobility Maps	These maps show individuals' accessibility/mobility problems in their own homes and plots. (Not a key method)
Household Survey	This gathered information on a wide range of issues including education status, employment status, income, access to services, and social life.

<sup>7</sup> The EE participants who identified speech as their main disability possibly had a hearing or mental disability that had not been diagnosed.

## **Findings**

### Housing

#### **South Africa: the housing grant recognises the specific needs of people with disabilities but there has been no attempt to make PWDs aware of the exemption**

South Africa has a housing programme that aims to provide housing, or at the very least site-and-services plots to those living on low-incomes. A housing grant is available to people who are married, cohabiting or with financial dependents. People with disabilities are exempt from this criteria and can apply for the grant. However, the Enabled Environments project discovered that none of the project participants, their families, local councillors or service providers were aware of the exemption. Across the province very few applications had been made under the exemption.

At the time of the research, housing officers at municipal level were being made aware of the exemption. Such awareness-raising needs to take place at a community level with PWDs, service providers who come into contact with PWDs, and those responsible for administering applications at a local level.

This example shows how official measures to improve access to services such as housing will not reach PWDs living in low-income communities, unless there is an attempt to disseminate the information at a community level. In the case of the South Africa example, disability grant payment points were identified as the most effective place to disseminate such information. In comparison to other locations in the community, the grants office was the place that the greatest number of participants in the study frequented.

#### **India: Urban planning for the poor that is not inclusive**

In Delhi, only participants living in a peripheral settlement threatened with eviction identified housing as a problem that affected the whole community. However, the current policy approach to informal settlements in Delhi is one of in-situ upgrading. Whilst the Slum Policy mentions children and women as specific groups that need to be included in community-led development, there is no mention of community members with disabilities. A pilot model similarly fails to recognise the need to create fully accessible settlements.

Urban development aimed at low-income households needs to work with an inclusive design that ensures universal accessibility. The cost of including access features at the design phase is far more cost-effective than introducing them later on. The Delhi example illustrates that although accessibility guidelines may exist, they may be overlooked when it comes to infrastructure for the poor. Tellingly, the new tram system in Delhi aimed at professional commuters has a number of access features aimed at PWDs.

## Toilets

### **South Africa: Mass produced toilet blocks that cannot be used by wheelchair users or adapted**

One of the advantages of moving from an informal settlement to a government housing plot is having access to a flush toilet. Site-and-services developments in the areas where EE took place included a standard toilet block made from pre-cast concrete. The narrow dimensions of the toilet block along with the standard height of the toilet meant that participants in wheelchairs and those who were unable to stand unaided were unable to use the toilet without some difficulty.

Mass-produced toilet blocks clearly keep construction costs low. However, there needs to be a mechanism that allows households containing members who have a disability to request a more accessible toilet. South Africa already has a grant that covers the cost of installing a range of adaptations including a ramp and a visual doorbell. None of the participants in the study were aware of this grant, nor in an assessment of mobility problems in the home were the aids currently covered under the grant identified as being useful. EE recommends that the cost of adaptation of the current standard toilet block be covered by the grant. Post-construction adaptation is only feasible if the toilet block is outside the house. For housing with indoor toilets, dimensions would need to be altered prior to construction. EE also recommends that the grant is broadened to cover accessibility features for those people with a sight disability or with limited upper body mobility.

### **India: Community toilet blocks are not fully accessible to PWDs**

Community toilet blocks are built without any accessible design features. In one community, a two-storey toilet and shower block meant that those with ambulatory disabilities could not access the facilities. Provision for those unable to get up the stairs could have been included on the ground floor. In another community, a new toilet block was in the design stage while the research was taking place. The EE team lobbied for inclusion of accessible design features. These included a request for 1-2 wider stalls and the installation of 1-2 western-style toilets (squat toilets cannot be used by those with an ambulatory disability). The result was the inclusion of a ramp – as none of the PWDs in the community used a wheelchair the ramp would have little impact, but required minimum disruption to the plans.

All the toilet blocks in the communities where EE took place were administered by Sulabh International and used the organisation's twin-pit toilet model. Interviews with the representatives in the Delhi office revealed that Sulabh does not include accessible design features in their toilet blocks. This shows the way in which design that responds to the needs of those living in poverty fails to include features that would allow wider access.

## Transport

### **South Africa: New accessible transport system will need to include awareness-raising at community level and consider cost**

EE did not analyse the current accessibility of transport because another DFID-funded study focusing exclusively on accessible transport had recently been completed and there are already plans in place to introduce more accessible public buses and private 'taxi'<sup>8</sup>. However, EE highlighted the lack of understanding between PWDs and taxi drivers. Project participants discussed the way in which taxi drivers would often fail to pick them up, especially in the rush hour. This means that PWDs living in peripheral communities such as those included in the study are unable to take up training and employment opportunities elsewhere in the city. Discussions with taxi drivers revealed stereotyped views of PWDs and their needs. It is clear that the upgrading of the SA transport system needs to be accompanied by sensitisation amongst drivers of the issues facing PWDs. The cost of transport was another issue mentioned by EE participants and a discount system should be considered during the overhaul of the transport system.

## Skills and Employment

**South Africa: the financial vulnerability of people with disabilities who live on low-incomes can make it more difficult for them to take advantage of training and education opportunities that are aimed at people with disabilities in general.**

Following government legislation that requires that PWDs make up at least 1 per cent of the workforce, employment and training opportunities for people with disabilities in general have increased in SA. Education for adults with disabilities has also received attention, with the paper on integrated education recommending that the model for schools be extended to the adult education sector. Despite these improvements, the majority of EE participants had limited education, had received no vocational training, were unemployed and were not seeking employment.

There needs to be much greater transparency in the disability grant system. Fear of losing the grant and being left without money can put people off job hunting. Few EE participants were aware that they could earn up to 800 Rand per month before the grant was affected.

Lack of accessible transport was another key reason why some participants could not access jobs or training courses. An employer will expect good timekeeping, yet wheelchair users said it was particularly difficult to get a taxi to pick them up during the morning rush hour. There is also an issue of cost. City centre training courses that aim to attract participants from across the city need to consider providing travel bursaries for those PWDs who come from very low-income households.

Although sheltered workshops may be considered to be an old-fashioned exclusionary form of employment that often do not pay a full wage or fail to offer sufficiently stimulating work to more employees, they are valued by many PWDs. In a volatile economy where unemployment levels are high, a low-paid job that offers social engagement without the risk of being made redundant and without affecting the

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<sup>8</sup> A 'taxi' in the South African context is a privately owned vehicle that picks up and drops off passengers along a designated route.

disability grant may seem a like a good choice. Fear of entering a formal workplace after a long period of unemployment or re-entering the formal workplace after becoming disabled can also discourage people from seeking work.

### **India: Too many services results in confusion and lack of awareness amongst PWDs.**

76 per cent of PWDs aged 10 years and over had never received any form of formal or informal vocational training. 53 per cent of adults aged 18 and above were illiterate (6 per cent of adult women). Despite this, access to training and education were not identified as key issues in any of the workshops. However, access to employment and self-employment were discussed in the workshops.

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, in the same way that the inclusion of the needs of women has been given such prominence in the last 10 years.

### **Contributions to Household**

#### **South Africa: Grant administration system puts low-income households at risk of financial crisis**

Social grants claimed by PWDs play a key role in sustaining households financially. For 25 per cent of the households in the South African sample, the disability grant was the only source of income. The disability grant was the only 'service' that everyone knew about and to which most could gain access. However, the current practice of annual review, the associated action of suspending grants without informing PWDs in a way that can be understood and the length of time taken to process reapplications can expose entire households to financial crisis.

In South Africa, PWDs play an active role in the household. 75 per cent of the sample were involved in domestic chores in some way, and a very small percentage required help in self-care activities from their family. We considered childcare to be a key area where the involvement of PWDs based at home could free other members of



the household to go out and work. However, only 11 per cent of the sample in South Africa either had main responsibility or helped out with childcare.

**India: Poor dissemination of information and a lengthy application process results in PWDs not being able to access concessions that could support them and their households.**

57 per cent of the sample aged 18 and above had no source of income. Only 39 per cent of the eligible participants had the disability certificate which allows a PWD to access a number of concessions. In one community, almost half of all participants had never heard of the certificate. As well as lack of awareness, a lengthy application process had discouraged potential applicants.

Just under 80 per cent of the participants took part in household chores to some extent. 25 per cent of the sample had sole responsibility for childcare and 25 per cent helped out with childcare.

87 per cent of the participants required no form of care from other household members.

## **Dissemination and Advocacy**

1) “transfer of skills and knowledge to 8 community facilitators”

All community facilitators (CF) developed research skills, group facilitation skills and a greater knowledge of services and how to access them. The CFs saw the experience of working with other PWDs and in other communities as being particularly valuable.

In South Africa, the CFs, along with other key participants, have formed wider networks following fieldtrips to disability-related organisations and events e.g. employment workshops, disability rights conference. One CF has gone onto university and has become the student disability rights advisor. Another CF has started a social work diploma. The third community facilitator has moved out of community-level disability issues into a provincial level advisor role and the researcher in South Africa is currently encouraging one of the EE participants to take over the community-level representation of PWDs. The fourth community facilitator was invited to represent PWDs on the main community committee and has led an initiative to ensure children with disabilities gain access to local mainstream schools.

In India, the four community facilitators have become closely linked to the disability rights NGO, CAN. They have regular meetings and disseminate service information in their communities. The NGO secured additional funding from a UK NGO to continue funding the community facilitators for an additional year. One of the community facilitators was encouraged to enter his artwork in a number of competitions and has since won an award to develop his work further.

2) “A series of community workshops leading to greater awareness of services available and way to access them”

Participatory workshops were held in all 8 communities at the beginning of the project and feedback workshops were held at the end.

As well as developing the skills of the individual community facilitators, the project also worked with wider groups of participants. In South Africa, one community set up a disability group in response to the experience of the participatory workshops. However, this group has since disbanded and in the South Africa project areas, we were unable to identify local NGOs that could continue to support the groups once the research team had withdrawn. However, the initial participatory workshops and the final feedback community workshop where participants from all four communities came together to discuss their experiences have been an opportunity to raise people's awareness of a number of issues. EE discovered that none of the participants knew about the special provision for PWDs in the housing grant system and the project has disseminated information on the grant and given support to individual applicants.

In India, the research partner, CAN, has developed a stronger relationship with two of the communities. The third community is currently threatened with eviction and it was difficult to build up an interest in disability issues in the fourth community. In one community, CAN and the local community facilitator, a trained artist, have worked in partnership to set up an employment generation workshop which provides training in crafts production and marketing. The community facilitator uses the workshop as an information point where PWDs and their families can get information on training and employment opportunities. The CF has also used the knowledge on accessible design that he gained through EE to lobby for accessibility features in a recent toilet block development. In the second community, the experience of visiting functioning Sulabh blocks in other communities has encouraged the CF to work towards getting the Sulabh blocks reopened with support from other community members and CAN.

### 3) "High-level workshops with follow-up to ensure findings are used to inform policy"

The one-day workshop held in Pretoria was attended by relevant government officials, NGO representatives, academics and the community facilitators. One of the community facilitators presented his own personal experiences of the issues that EE had researched. The workshop led to radio, newspaper and television coverage. Following the workshop, the EE research team were invited to work directly with the Dept of Housing to look at ways in which the housing grant for PWDs could be improved. The South African researcher has secured further research money to look at this issue in more depth.

The workshop in India was less successful due to limited attendance. The team have decided to develop policy briefs (see 'Publications') and use these in face-to-face discussion sessions with individual policy makers. There will also be opportunities to disseminate the findings through CAN's other awareness-raising events.

### 4) "Capacity building for local researchers"

The two local researchers have made study visits to the other research partner in order to gain a greater understanding of disability policy and practice in the international context. During their visits they made presentations on EE findings in their own countries to research and policy audiences.

## 5) Publication Plans

The team has not yet published papers from the project due to other full-time commitments. Over the next 8 months we aim to produce:

- 2-3 policy briefs in each country that can be used for advocacy purposes
- In each country, 1 article in a national journal that summarises the key national findings
- A comparative article submitted to *Disability and Society*
- An article aimed at NGOs working on disability issues submitted to *Development in Practice*
- The complete final report will be placed on the CARDO and GURU web sites at the university of Newcastle upon Tyne and can be downloaded free of charge
- Hard copies of the report will be sent to a number of relevant institutions, including:
  - DFID London, India and south Africa
  - UN Habitat
  - The World Bank
  - UNESCO
  - Relevant national and international agencies advocating on behalf of people with disabilities

## 6) Policy and Practice implications

It is our intention to develop a programme of training, workshops, seminars and good practice guidelines to embed the findings of the work in policy and practice in India and Sub-Saharan Africa. To this end we will be applying to DFID for funding to work with CAN in India and the Nuffield Commonwealth Foundation to work with CSIR in South Africa.

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