# **ENABLED ENVIRONMENTS**

# REDUCING BARRIERS FOR LOW-INCOME PEOPLE WITH DISABILITIES IN SOUTH AFRICA

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# **ACRONYMS**

APD Association of People with Disabilities

CAN Concerned Action Now

CAP Community Action Planning

CBR Community Based Rehabilitation

CSIR Centre for Scientific and Industrial Research

CWD Child with a Disability

DPSA Disabled People South Africa

EE Enabled Environments

IDP Integrated Development Plan

INDS Integrated National Disability Strategy

MEC Member of the Executive Committee

PAR Participatory Action Research

PWD Person with a Disability

RDP Reconstruction and Development Plan

SAHRC South African Human Rights Council

SSA Statistics South Africa

# **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<sup>2</sup> 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

<sup>&</sup>lt;sup>1</sup> DfID 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 authors alone.

<sup>&</sup>lt;sup>2</sup> 'People with disabilities' is abbreviated to PWDs at various points in the report.

listed in the Disability Rights Bills in South Africa and India<sup>3</sup>). However, the emphasis was placed not on identifying people through their type of disability, but on including those people 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>4</sup>

<sup>&</sup>lt;sup>3</sup> 'Leprosy-cured' also appears in the Indian Disability Rights Bill, but none of the sample reported this form of disability.

<sup>&</sup>lt;sup>4</sup> Figures relating to the incidence of disability internationally are all rough estimates as they are 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)

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). It is estimated that 100 million people worldwide have impairments which are caused by malnutrition and poor sanitation and are therefore preventable (Lee, 1999, in Yeo 2001). 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 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>5</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 Konig, 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, 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 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

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<sup>&</sup>lt;sup>5</sup> The 2002 World Development Report on Access to Services has a chapter on Health and Nutrition but has no reference to welfare services.

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 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>6</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.

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

<sup>6</sup> For more information on the Habitat Agenda, see http://www.unhabitat.org/unchs/english/hagend

- 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 question 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?

#### **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 issue:

• 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?

### 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.

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 fact that 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 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 the physical environment, especially housing.

### 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. Such economic conditions are being experienced in countries throughout the developing world, and therefore, despite cultural differences, the suggestions arising from the research are quite likely to be transferable to other countries.

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, Concerned Action Now, 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. A failure to use local knowledge of disability that only PWDs themselves can provide often leads to inappropriate provision and measures (Metts, 2000). 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.

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 the Enabled Environments project.

#### India:

Prof. Ali Baquer has worked on disability issues internationally for a numbers of years and runs Concerned Action Now (CAN)<sup>7</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>8</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 and action initiatives, detailed findings from South Africa and India have been presented in two separate reports. A shorter report of comparative highlights is also available.

The report begins with a background to disability in South Africa followed by discussions of the methodology and sample for the study. We then examine the key issues relating to physical environment that were identified by the participants. Attention is paid to the issues of education, training and employment as 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. The final section looks at access to grants, social life and services that have not been discussed in previous chapters. Generally, these issues were not considered of the greatest importance by the participants (with the exception of the administration of the disability grant). However, the survey findings did point to some aspects of social exclusion that need to be discussed.

<sup>&</sup>lt;sup>7</sup> For more information on Concerned Action Now, see http://www.indev.nic.in/can

<sup>&</sup>lt;sup>8</sup> For more information on CSIR, see http://www.csir.co.za

# **CHAPTER 2**

# COMMUNITIES AND PEOPLE WITH DISABILITIES IN THE SOUTH AFRICAN STUDY

#### Introduction

The first section provides a brief overview of the legislation that affects people with disabilities in South Africa. 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 of Disability and Legislation in South Africa

Following the end of the Apartheid era, there have been a number of notable developments in rights-based legislation and rights awareness in South Africa. Whilst disability rights may not have been at the top of the agenda in the mid-90s, there has been increasing legislation, policy and intervention aimed at enabling people with disabilities to be fully integrated into South African society. This section provides a brief overview of the extent of disability, legislation and policy, and government and non-government groups representing people with disabilities.

#### **People with Disabilities in South Africa**

There is a lack of reliable information on levels of disability in South Africa, but census data suggests levels between 5 and 7 per cent. The 1995 October Household Survey recorded a disability prevalence of approximately 5 per cent, and the 1996 Population Census recorded 6.6 per cent. These percentages change when one dissagregates by race: whilst only 3.5 per cent of the white population have a disability, 7.6 of the black population have a disability (1996 South African Population Census)<sup>9</sup>.

According to 1996 Population Census, the majority of people with disabilities have a sight-related disability (41 per cent). 21 per cent have a physical disability, and those with a hearing disability form the third largest group (15 per cent).

People with disabilities are unlikely to have a job: 99 per cent are unemployed. They are likely to be poorer that non-disabled: the 1996 census showed the average monthly income of PWDs to be R1504 compared to R2150 for the non-disabled. Black children with disabilities are particularly vulnerable with 80 per cent of them living in poverty. (Office of the Deputy President, 1997)

<sup>&</sup>lt;sup>9</sup> The 1996 Census data can be accessed via the Statistics South Africa website - http://www.statssa.gov.za/census96/HTML/CIB/Population/222.htm

More up-to-date figures from the 2001 Census were not available at the time of writing this report.

#### Rights Legislation And Policy In South Africa

There are a number a pieces of South African legislation and policy relating to people with disabilities which will be referred to throughout this paper. Each one is briefly outlined here.

South African Constitution (1996)

The Constitution outlaws any form of discrimination on any aspect of identity, including disability. It also emphasises the right to human dignity, which is particularly important in relation to disability issues since the dignity of people with disabilities is frequently compromised. The rights to a healthy and safe environment and to adequate housing are also recognised, although there is no specific reference to the access needs of people with disabilities.

Promotion of Equality and Prevention of Unfair Discrimination Act 2000, No. 4 of  $2000^{10}$ 

Section 9 of the act defines unfair discrimination on the grounds of disability as:

- (a) denying or removing from any person who has a disability, any supporting or enabling facility necessary for their functioning in society
- (b) contravening the code of practice or regulations of the South African Bureau of Standards that govern environmental accessibility
- (c) failing to eliminate obstacles that unfairly limit or restrict persons with disabilities from enjoying equal opportunities or failing to take steps to reasonably accommodate the needs of such persons

The act has far-reaching implications in relation to disability discrimination. It encompasses the ways in which all organisations relate to people with disabilities, and in the way the environment is designed and managed. It should in theory achieve the aims of the White Paper on disability (see below). However, generally, there is a lack of follow-through from the rights-based legislation through to regulation and policy and onto practice. In 2002, there were no known cases where the legislation had been used in non-compliance litigation (Venter, 2002).

<sup>&</sup>lt;sup>10</sup> The full text of the Act can be found at http://www.gov.za/acts/2000/a4-00

White Paper on an Integrated National Disability Strategy (1997)

The White Paper provides a framework for drawing up policy to achieve full integration of people with disabilities. It draws on the Standard Rules by identifying a number of key policy areas and suggests policy objectives, strategies and mechanisms for each area. The recommendations for action contained in the White Paper have been used to inform disability-related policy since 1997. Rather than discuss the White Paper in depth here, different sections of the paper are referred to relevant points in this report.

#### Representation of People with Disabilities

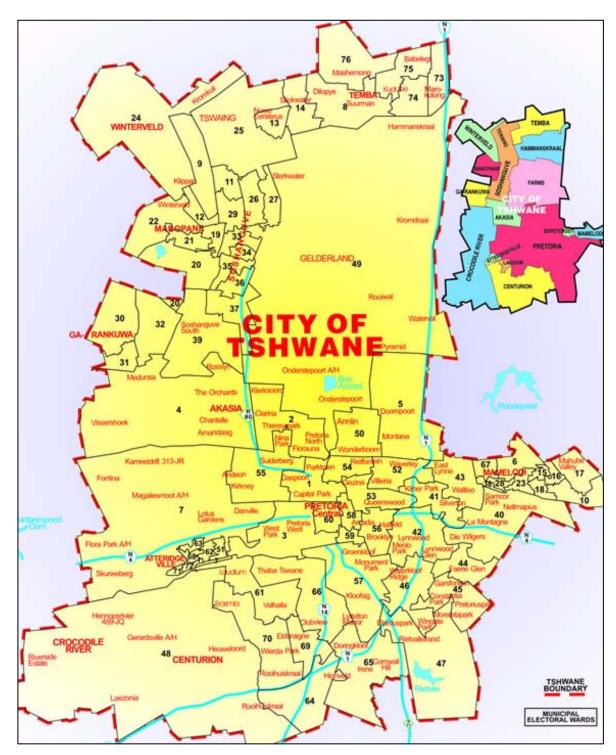
South Africa is notable for the strength and number of organisations representing people with disabilities.

The South African Federal Council on Disability is the umbrella body for all national disability NGOs. It is the national forum where all national welfare organisations, as well as national organisations of PWDs and their families, come together to negotiate and develop and common visions for the equalisation of opportunities for PWDs. Associated service/welfare organisations work with particular sectors of the disability community i.e. the deaf, the blind, the physically disabled, those with epilepsy, and those with mental health problems, the aged and those with cancer. There are then four PWD and parent organisations that concentrate on advocacy and development work aimed at empowering people with disabilities. These are Disabled People South Africa (DPSA), Disabled Children Action Group (DICAG), Down Syndrome Forum SA and the National Council of Quadriplegic Associations. Whilst service providers are part-subsidised by government, the advocacy organisations are not.

In the government, the Office on the Status of People with Disabilities is located within the Office of the President, and is responsible for ensuring the integration of disability issues across all spheres of government.

#### The Communities Studied

The four areas included in the Enabled Environments project were Stanza Bopape East, Stanza Bopape West, Saulsville and Hammanskral.



Map of Tshwane showing the areas studied

# **Selecting The Case Study Areas**

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

a) Informal Settlements Including Some Formal Housing

The project is concerned with the experiences of people who live with a disability and in poverty. Although there are no statistics showing the relationship between poverty and dwelling type, it would be fair to assume that of the 16 per cent of the

South African households who live in informal housing (Statistics South Africa, 1996) the majority live in poor households<sup>11</sup>. This assumption is reinforced by the fact that a much higher percentage of households live on low incomes: 41 per cent of households in South Africa have a monthly income below R1000 (£83.33). (Hirschowitz et al., 1997). One of the reasons why there is not a higher percentage of poor households living in informal settlements is because the government's subsidised housing programme affords some low-income households the opportunity to move onto serviced plots in newly developed formal settlements. Informal settlements located close to government-funded housing developments often serve as interim dwellings for those wanting to apply for a plot in the formal settlement area. Therefore, as well as charting the experiences of PWDs living in informal settlements, it was important to look at the experiences of those PWDs who have moved to such settlements. Three of our four case study areas cover both formal and informal settlements. Our fourth case study area includes an upgraded area that closely resembles the formal settlements found in the other three areas.

### b) A Peripheral Location Typical Of A South African City12

As can be seen from the map of Pretoria, all of the case study areas are on the peripheries of the city. In the case of the two Stanza Bopape areas and the Saulsville site, the areas represent new extensions beyond a much longer established township area (Mamelodi and Attridgeville respectively).

Hammanskral is the most peripheral of the case study areas. As a settlement located close to industrial activity with many people who commute daily to Pretoria by bus, it shares a number of characteristics with the similarly peripheral Bhatti Mines case study in the Delhi study. We felt the comparison may shed some light on the relationship between accessible transport and accessing employment opportunities.

# c) Existence Of Community-Based Services

As one of the key themes of the study was access to services, we wanted to include areas where there were general services and services aimed at people with disabilities. The presence of service providers also helped in identifying potential participants for the study. This is discussed at more length under 'Identifying the Sample'.

<sup>12</sup> There are obviously people with disabilities living in poverty residing in urban centres, and at the beginning of the project we considered including a case study area in Pretoria city centre. However, we decided that the differences in physical environment would throw up a different range of problems, and results would not be meaningful. For example, a key problem faced by people with locomotor disabilities in high-density urban areas is accessing multi-storey dwellings.

<sup>&</sup>lt;sup>11</sup> In rural areas, a further 18 per cent live in 'traditional' dwellings constructed from natural materials (Statistics South Africa, 1996).

# d) Pre-Existing Knowledge Of Community Or Good Contacts

Mark Napier had carried out research in Hammanskral in the mid-90s, and knew the area well. Both he and Justine Coulson had work in Stanza Bopape on a previous DFID-funded project. Saulsville was chosen as an example of a settlement situated close to central Pretoria.

Table 1:Case Study Area Characteristics<sup>13</sup>

ENABLED ENVIRONMENTS COMMUNITIES AT A GLANCE:				
	Stanza Bopape East & West	Saulsville	Hammanskral	
Distance from central Pretoria (approx)	30 km East	15 km West	50 km North	
Origin	Land Invasion 1990 by township homeless	Land invasion 1990 by township homeless	Land invasion by rural migrants	
Settlement Types	RDP* and informal	RDP and informal	In-situ upgrading and informal	
Number of Households	14,229	7,309	1325	
Average household size	3.66	6.16	4.99	
% of households living in shacks	50	60	80	
% of population unemployed	49	41	41	
% of households with monthly income under 12000 Rand (£1000) <sup>14</sup>	42	26	46.51	

<sup>\*</sup> New formal settlements constructed as part of the Reconstruction and Development Programme (RDP)

<sup>&</sup>lt;sup>13</sup> All statistics in this section are taken from the 1996 census, unless otherwise stated.

 $<sup>^{14}</sup>$  The Rand was particularly unstable at the time the Enabled Environments project was taking place. The currency conversion rate used throughout the study is £1 = R12 as this was the rate of exchange prior to the currency crisis. As the study only considers income within the national context, a more precise rate of conversion is unnecessary.

#### **Stanza Bopape East And West**



View from the periphery of an informal 'Phase' in Stanza Bopape.

Stanza Bopape is a large settlement<sup>15</sup> situated on the eastern periphery of Pretoria and extends beyond Mamelodi, the much longer established township. As a formal settlement, Stanza Bopape dates from the election of the new government in 1994, when the area was earmarked for government-funded housing development projects. The area is made up of 5 informal settlements, known as 'phases', and 9 formal neighbourhoods known as 'extensions'. This study covered 2 phases and 2 extensions (5/10) in Stanza Bopape West, and 5 extensions (8/11/6/10/12) in Stanza Bopape East<sup>16</sup>.

Out of the three case study areas, Stanza Bopape has the lowest average household size (3.66), the highest ratio of permanent dwellings to shacks (1:1), and the highest level of employment (61 per cent). However, these indicators of higher wealth do not translate into a higher average household income: 27 per cent of households have a monthly income of R6000 or less and a further 15 per cent earn between R6000 and R12000. These levels of income are comparable with Hammanskral.

<sup>&</sup>lt;sup>15</sup> Stanza Bopape contains 14,229 households, and is twice the size of Saulsville, which contains only 7309 households.

<sup>&</sup>lt;sup>16</sup> We had originally intended to select a fourth community. However, it became clear that we would encounter some difficulty in finding sufficient PWDs to participate in the study and the areas to be covered were large due to low-density development. In order to make the project more manageable for a single researcher, we decided that Stanza Bopape East and Stanza Bopape West should be included as the equivalent of two communities.

Stanza Bopape is well served by government and NGO-provided services, and had the widest range of services on offer of the three areas<sup>17</sup>. There are two public clinics, one of which houses a small rehabilitation centre run by a social worker, physiotherapist and nurse. This team also carries out home visits. Alongside government-run health services, there are also privately run clinics and dentists.

The area has a well-used community centre in the west that offers a library, sports, social events and training. As well as the training offered at the community centre, there are a number of other programmes offering skills training and income-generation activities. Whilst most programmes are aimed at the general population, there are three programmes aimed specifically at people with disabilities.

#### Hammanskral

Hammanskral is located 50 km north of Pretoria, and is the smallest settlement included in our study. With only 1325 households, it is less than a tenth of the size of Stanza Bopape. The previously white town of Hammanskraal was located within the borders of white South Africa, adjacent to the homeland of Bophuthatswana. Much informal settlement took place in the area because of the proximity to the homeland border and the industrial development in the area (which itself was a product of the decentralized growth programmes relating to homeland policy). The Mandela Village settlement was located on tribal land, and illegally sub-divided into irregular plots and sold by the royal family that owned the land. Other settlements in the area were sites and service projects that took place in the late 1980s and early 1990s. While services have improved over the years, as a result of the lobbying of the Councillor, the housing subsidy has not yet been granted to residents of the area. Hammanskraal has seen rolling upgrading starting around 1995 and continuing to this day. Basic water and sanitation were the first services installed, and then roads, street lighting, electricity to shacks and houses, and community buildings and a market. (Hall et al., 1996)

We originally intended to work only in Mandela Village, as a low-income subsettlement that has undergone in-situ upgrading. However, the local councillor advised us that in order to have a large enough sample we should extend our study to other sections of Hammanskral. For this reason, we also included the subsettlements Refilwe and Kanana, as well as an area known as Kekana Gardens<sup>18</sup>. All four areas began as informal settlements, but are at different stages of

<sup>17</sup> PWDs living in Saulsville have access to a similar range of services, but they are located in the adjacent formal township settlement of Attridgeville.

<sup>&</sup>lt;sup>18</sup> Kekana Gardens was originally identified as part of Hammanskral by our local informants. However, it became clear later that it falls under the responsibility of a different municipality. We decided to continue to include it as many of the residents of Kekana Gardens used the services in Hammanskral.

upgrading. 80 per cent of houses in Mandela Village and Refilwe are electrified and all plots have taps on site. Upgrading is planned for Kekana Gardens and at the time of the study, electricity infrastructure was being installed. Kanana was established only two years ago and is the newest settlement. As a result, it has the poorest services: water is available at government-managed tanks and there is no electricity. In the Hammanskral area, our sample at the time of the reconnaissance survey numbered 54. The majority of participants (29) were from Mandela Village. We also included 4 PWDs from Refilwe, 15 from Kekana Gardens and 6 from Kanana.



The lessdeveloped area of Kanana in Hammanskraal.

The Hammanskral area has the highest percentage of households living in informal dwellings; 80 per cent of households continue to live in shacks, in comparison to only 50 per cent in Stanza Bopape. The average household size is 4.99 people. 41 per cent of the population are unemployed, as in Saulsville. Household income levels are similar to those found in Stanza Bopape: 27.2 per cent of households live on R6000 (£500) or less per month, and a further 19.3 per cent live on between R6000 and 12000 (£500-1000).

One outstanding characteristic of Hammanskral is that it has a much younger population with 42 per cent of residents being of school going age in comparison to 26 per cent in Saulsville and 30.8 per cent in Stanza Bopape. Local social workers reported that one of their key problems in Hammanskral is that the high levels of adult unemployment along with the high ratio of children to adults means that many children do not attend school because their parents are unable to afford the fees and associated costs.

The majority of the population living in Hammanskral have moved there from rural farms. A social worker that had worked in Stanza Bopape and then moved to Hammanskral argued that these rural origins meant that people required greater

support. In her opinion, people in Hammanskral were much less able to demand the services they wanted, whereas the population in Stanza Bopape had more urban origins, as many had moved there from backyard shacks or sharing houses with relatives in the Mamelodi township. As a result, the population in Stanza Bopape are much more knowledgeable about services and how to access them.

Hammanskral has its own formal shopping centre that has a wide array of shops. Mandela Village, as the most developed sub settlement, has the better services. There is a clinic, créche and a community complex, which houses a large library and meeting hall. There is a local school for the Deaf, a day-care centre for the intellectually disabled, and a rehabilitation centre run as a partnership between professionals and local volunteers. There was less NGO activity in the area as a whole, both for the general population and for people with disabilities, than we found in Stanza Bopape and Saulsville.

#### Saulsville



A view of Saulsville which shows formal 'extensions' in the foreground and informal settlements located on the hillside that borders the community.

Saulsville is situated approximately 15 kilometres west of Pretoria. It is similar to Stanza Bopape in that it has developed on the edge of the township area of Attridgeville, and has a mixture of government-funded sites-and-services developments and informal settlements. The history of its formation is also similar. In 1990, people moved from Attridgeville due to overcrowding and apartheid legislation that prohibited backyard shacks and rooms and moved onto surrounding undeveloped land. The area is divided into 7 subsettlements: Jeffsville, Phomolong, Vergenoeg and Brazzaville which are informal and Extensions. 6, 7 and 8 which are government-funded developments. For this study, we worked in all four informal settlements and Extension 7. We also had two participants from Attridgeville who are deaf.

Saulsville has 7309 households, about half the number found in Stanza Bopape. It has the highest average household size of all three areas at 6.16 people per household. Unemployment is at the same level as in Hammanskraal – 41 per cent. However, the National Census figures record a smaller percentage of the population falling into the lowest income bracket: 16 per cent of households have

a monthly income of R6000 (£500) or less, and 10 per cent have a monthly income of between R6000 and 12000 (£500-1000). As the area has the smallest percentage of children of school-going age, these figures suggest that household income is greater due to the presence of a greater number of economically active adults. The ratio of shacks to permanent dwellings falls between the levels found in Attridgeville and Stanza Bopape with 40 per cent of dwellings being constructed from permanent materials.

There are clinics in Saulsville township and Extension 7, and the former also has a rehabilitation centre and an office run by the mental health society. Kalafong hospital in nearby Attridgeville provides a range of outpatient services. The area has specialist schools and a day care centre for children with disabilities, and there is a sheltered workshop for adults with disabilities. Saulsville does not have a central community centre, such as those found in Stanza Bopape and Hammanskral.

All settlements, with the exception of Vergenoeg and Brazzaville, have taps within the household. As there are too few communal taps in Brazzaville, residents are forced to buy water from other households with large storage tanks. 95 per cent of all the households in the area have electricity.

# 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 communities.

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 Pretoria study live in the communities 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 potential 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 working with people living in the researched communities to enable them to tackle their own

problems. An assessment of the project's achievements can be found in the conclusions.

**Mr Ntuli** has a locomotor disability. He is in the late sixties and runs a home-based shop with his wife. He was responsible for Stanza Bopape East, and had participated in a previous CARDO/CSIR project in Stanza Bopape.

**Bra** Cry is a wheelchair user in his mid-sixties. He became disabled around 1995/96 from sugar diabetes (both his legs are amputated). He is both a disability rights activist and heavily involved in community issues. He serves on the committees of many community organisations. For example, he is deputy chairperson of Lebuwe centre for the physically disabled, chairperson of Bophelong clinic, an ANC member in his ward, and has also served in the planning forums lobbying for the rights of PWDs. He was in charge of the Saulsville area.



The researcher and community facilitators in Pretoria. From left to right: Mr Ntuli;Gertrude Matsebe (researcher);Martina;Bra Cry; Molly.

Martina is an independent blind woman in her late forties who is well known in her community of Stanza Bopape West. She became blind at an early age and attended primary and secondary schools for the blind. She uses Braille and conducted the research using Braille transcripts of the survey and interview schedules. Although Martina was unemployed at the time of the research, she worked for a number of years in a workshop for the Blind in northwest Pretoria and then worked in the open labour market at a factory east of Johannesburg. She is currently serving as a chairperson for an organisation of blind people in Mamelodi East township that is in the process of establishing a sheltered workshop.

**Molly** is a mother of a son with a locomotor disability and at the time of research, was fighting with the local primary school to get her son admitted. She is also a

volunteer at the rehabilitation centre for PWDs at Mandisa Shiceka clinic in Hammanskraal. She is in her late thirties. Whilst Enabled Environments was taking place, she was nominated to represent PWDs on the ward committee of her area.

In South Africa, the project was known locally by a Sotho name, *A re tshwa raganeng*, which means 'We all hold hands together'.

#### THE SAMPLE

#### **Sampling Process**

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. As the workshops were key to finalising our research themes, 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 and from all age groups
- Included equal numbers of males and females<sup>19</sup>
- 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 service providers, community facilitators' knowledge of local populations, 'snowballing' and active

<sup>&</sup>lt;sup>19</sup> Despite conscious efforts to achieve a gender balance, females made up 42 per cent of the sample. The South African researcher feels this is because women tend to be busier with household chores and childcare. We are not able to prove this empirically.

recruitment by community facilitators in public areas, such as clinics, community centres and telephone kiosks.



A young girl acts as an interpreter for her grandmother who has difficulty speaking after suffering a stroke.

### **Types of Disability**

The 1995 October Household Survey reported a disability prevalence of approximately 5 per cent in South Africa<sup>20</sup>, whilst the 1996 Population Census reported a 6.6 per cent prevalence of disability. In the Enabled Environments case study area, there are a total of 22, 863 households across the four case study areas. Therefore, based on the 5 – 6.6 per cent level of incidence, there should be between 1143 and 1509 households containing a PWD across the four study areas. We had expected to be able to identify a large enough sample at the stage of the reconnaissance survey to allow us to select a sub sample of 200 PWDs, which would represent approximately 20 per cent of all households containing a PWD. However, despite concerted efforts by the researcher and the community facilitators to identify households containing PWDs through a number of approaches, we only identified an initial sample of 221 PWDs during the reconnaissance survey, which then became the sample for the project. By the time of the main survey, this had dropped to  $186^{21}$ .

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.

<sup>&</sup>lt;sup>20</sup> Source: White Paper on Integrated National Disability Strategy (1997, p.1)

<sup>&</sup>lt;sup>21</sup> Thirty-five participants left the study for a range of reasons – family crisis, death, loss of interest in the project and moving to a new area.

As can be seen from Table 3, our sample differs considerably in terms of the levels of different disabilities recorded in the 1996 Population Census. 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 2: Types of first disability across all case study areas

	Frequency	Percent
Blind	6	3.2
Low Vision	11	5.9
Deaf	8	4.3
Physical/locomotor disability	70	37.6
Intellectual disability/mental retardation <sup>22</sup>	36	19.4
Mental Illness	39	21.0
Hard of Hearing	4	2.2
Speech problem	4	2.2
Epilepsy	8	4.3
Total	186	100.0

Table 3: Comparison between Enabled Environments' sample and levels of disability by type in South Africa and the World

Disability	Enabled Environments	South Africa <sup>23</sup>	Gauteng <sup>24</sup>	UN Worldwide
Sight (Blind and low vision)	9.1	41	46.5	11
Hearing (Deaf and hard of hearing)	6.5	15	13.1	14
Physical/Locomotor	37.6	21	15.4	32
Mental	40.4	7	6.3	26
Not specified	0	10	0	13
Speech problem	2.2	0	14	0
Epilepsy	4.2	0	0	4
Multiple	29	6	5.7	0
Total	100	100	100	100

Sight Impairment

-

<sup>&</sup>lt;sup>22</sup> 'Mental retardation' was a term that the EE team felt was not appropriate. However, it continues to be a widely used and understood term and remains here only for the sake of clarity.

<sup>&</sup>lt;sup>23</sup> Source: 1996 South African Population Census

<sup>&</sup>lt;sup>24</sup> Gauteng is the province in which Pretoria is located. Source: 1996 South African Population Census Cited in Education White Paper 6, 2001, p. 14

When compared with the UN figure for global incidence, it is clear that the 1996 Census recorded a particularly high percentage of people suffering sight impairment in South Africa. The incidence of sight impairment found in the project research areas is closer to the UN average. As one of the community facilitators is blind, is active in the Blind Association and has links with people in other communities, we are confident that we identified all the blind people living in the research areas who were willing and able to take part in the study (6 in total). The questionnaire was also produced in Braille to enable greater inclusion.



Gertrude and Martina conducting fieldwork together in Stanza Bopape.

Identifying people with low vision is potentially more problematic. Officially, low vision is only classified as a disability when it cannot be corrected with glasses or by an operation (e.g. cataracts). However, for people living in poverty with no access to ophthalmic services, uncorrected low vision is clearly disabling. This may partly account for the high incidence of visual impairment recorded in the 1996 census. Our sample included 11 people who reported low vision as their main disability, and 9 others who identified low vision as a secondary disability. According to the South African National Council for the Blind, 80 per cent of cases of blindness in South Africa are preventable. 66 per cent of South Africans who are blind have cataracts (compared to a global total of 50 per cent), and a further 14 per cent have glaucoma. South Africa is participating in the worldwide Right to Sight campaign to reduce this number by raising the number of operations carried out each year.<sup>25</sup>

The age ranges of people with a visual impairment as a main disability may also offer a clue as to why the Enabled Environments study has a much lower

<sup>&</sup>lt;sup>25</sup> Information on preventable blindness in South Africa provided in a letter from the South African National Council for the Blind on the Right to Sight Campaign

incidence. The age range for people with low vision as their main disability is 62 to 86 years, with one child of 7. For participants who are blind, there are two young adults aged 27 and 19, one middle aged adult of 40, and two elderly people in their seventies. As deteriorating vision is linked to the ageing process and as the project did not record information on elderly people who were too frail, confused or ill to take part, we have excluded some elderly people with visual impairment. At the other end of the age scale, we will not have recorded information on children and young adults with sight impairment who stay in residential special schools. Although there is a new policy of integrated education in South Africa, residential schools for the blind continue to exist.

# Hearing Impairment

The researcher on the project had worked with Deaf Federation of South Africa for a number of years and could speak basic South African sign language. Therefore, we were confident we could ensure that the research project included members of the deaf community. However, despite this, we clearly underrepresented people with hearing impairment. We may have come across fewer people than expected because, as with sight impairment, there is still a model of residential special education. Also, in some cases, there was simply no way to communicate with the individual. For those people who could not sign or lip-read, we invited a family member along to workshops to ease communication. However, some people were unable to communicate even with family members and were illiterate.

#### Locomotor disability

A 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 attempts 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. Furthermore, the 21 per cent recorded in the 1996 census are a percentage of the whole population. As a low income, urban black population, the sample in our own study may be more vulnerable to locomotor disability. For people who became disabled in adulthood, the most common cause of locomotor disability is a traffic accident, followed by a stroke and the gunshots/stabbings.

#### Intellectual Impairment

The Enabled Environments sample has a particularly high percentage of people with an intellectual disability or mental illness. There were almost equal numbers of people with an intellectual disability (36) and with mental illness (39). It is likely that the prevalence of mental impairment in South Africa has been underreported in census data (Bhagwanjee and Stewart, 1999), because mental disabilities are often 'hidden'. This may be because a family does not wish to admit to having a person with such a disability in the family, or it may be because the census enumerator is not sufficiently sensitised to collecting information on

this type of disability. Also, people may be identified as 'moody', strange' or a 'slow learner', rather than as a person with a disability because conditions such as paraplegia, deafness and blindness are more commonly thought of as disabilities.

There are a number of reasons why there is such a high incidence of people with intellectual disabilities and mental illness in the Enabled Environments project. There is a high level of service provision for people with intellectual disabilities in all our case study areas. Both Saulsville and Stanza Bopape have school facilities for children with intellectual disabilities and sheltered workshops for adults, whilst Hammanskral has a rehabilitation group for people with disabilities that attracts a lot of adults with intellectual disabilities. Families may choose to move to an area or choose to stay in area due to the support services available, which would explain the higher incidence of intellectual disability. Secondly, census workers may be less likely to pick up cases of mental illness in comparison to our community facilitators who are known in the community.

# Speech Problem

A speech disability is not classified as a separate disability either by the UN or by the South Africa Census. However, in our sample 4 people identified a speech problem as their main disability, and 12 people identified it as a secondary disability. A speech problem may be related to a failure to diagnose a hearing impairment, a mental health problem that has resulted in the individual not speaking, of the effect of having suffered paralysis through a stroke.

#### Second and Third Disability

As Table 1 illustrates, our sample recorded a much higher incidence of multiple disabilities. Overall, 29 per cent of the sample reported more than one disability, in comparison to only a 6 per cent incidence of multiple disability reported in the 1996 census. 22.5 per cent had two disabilities and 6.9 per cent had three disabilities.

As the focus of the study was the person with a disability, and wherever possible we tried to speak to them directly, it is not surprising that we should have recorded a much higher incidence of multiple disabilities. The community facilitators were trained to explore the extent of each individual's disability rather than simply note down the first disability that was mentioned and move onto the next question.

Table 4: Type of second disability

	Frequency	Percent
Low Vision	7	12.7
Physical/locomotor		
disability	16	29.1
Intellectual disability	4	7.3
Mental Illness	8	14.5
Hard of Hearing	4	7.3
Speech problem	7	12.7
Epilepsy	9	16.4
Total	55	100.0

Table 5: Type of Third Disability

	Frequency	Percent
Low Vision	2	15.4
Physical/ locomotor		
disability	2	15.4
Mental Illness	2	15.4
Speech problem	5	38.5
Epilepsy	2	15.4
Total	13	100.0

# **Epilepsy**

Epilepsy is not currently recognised as a disability in South Africa. However, the incidence of epilepsy as the main disability matches the levels found by the UN. However, when we include those people who listed epilepsy as a second or third disability, over 10 per cent of our sample had epilepsy.

# **BOX 1: Some General Characteristics Of The Sample**

The sample was equally divided across the four research sites – Hammanskral (25.3 per cent); Saulsville (25.3 per cent); Stanza Bopape East (23.1 per cent); Stanza Bopape West (26.3 per cent)

*Gender:* 42 per cent of the sample was female and 58 per cent male. The UN estimates that worldwide 51 per cent of PWDs are women (DAA, 1995). The 1996 South African census reports 55.1 per cent of PWDs in South Africa are female and 44.9 per cent are male.

Age: 32 per cent of the PWDs are children (18 years and below), 52 per cent of the PWDs were adults aged between 19 and 64, and 16 per cent were elderly adults aged 65 plus.

Household Composition: 41 per cent of households included in the study were headed by women. Only 3.8 per cent of PWDs lived alone. 2.7 per cent of male PWDs lived in male-only households compared to 7 per cent of female PWDs living in women-only households.

# CHAPTER 3: RESEARCH APPROACH AND METHODS

# **Overall Approach**

As mentioned in Chapter 1, the project team were committed to encouraging the participation of PWDS in the study as much as possible. 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 is 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

EE participants drew up the questions and, wherever possible, were brought along to participate in conducting the interview.

#### 5) Field visits

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

#### 6) Mobility Maps

These maps show individuals' accessibility/mobility problems in their own homes and plots.

# 7) 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*' (p.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 the 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 (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 approximately 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 uninterested.

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.

Communication was a key consideration. Gertrude Matsebe, the researcher in South Africa, provided simultaneous sign language interpretation at two of the workshops. A colleague from CSIR, Johannes Mkhabele, provided simultaneous translation into Sotho, Zulu and Tsonga (Shangaan) at all of the workshops, depending on the languages spoken by the participants. Those participants who had problems with speech, and did not use sign language, were encouraged to bring along a member of their family to facilitate communication.

Table 6: Workshop Participants By Community and Type of Disability

Disability Type	Saulsville	Hammanskral	Stanza Bopape
Intellectual	2	6	4
Locomotor	10	4	21
Deaf	0	1	3
Blind/Low Vision	0	1	2
Epilepsy	1	0	0
Volunteers/Carers	1	4	0
Total	14	16	30

#### **Content of the Workshops**

Stage 1. Brainstorming Barriers through Individual Maps

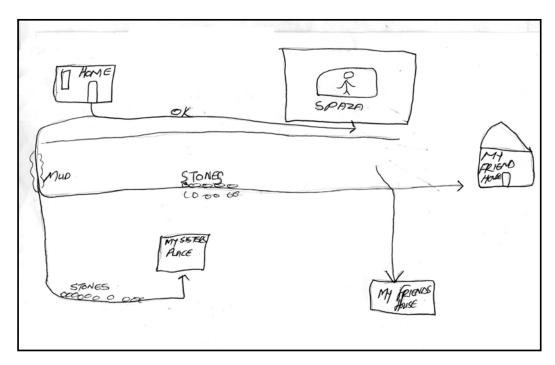
Aim: To identify places that you want to go to but cannot or find it very difficult

The first exercise involved each person drawing a map of where he or she currently goes in and around the community. The participants were encouraged to add those places that they would like to go to but could not. Having drawn the places that they visited on a regular basis (or wanted to visit), the next stage was to show any problems they faced getting there or trying to access the facility.

The exercise did not require map-drawing skills: the participants were encouraged to draw more of a 'cognitive' map. Some participants preferred to write down their ideas, whilst those people who had difficulty both drawing and writing were assisted by the community facilitators.

The purpose of this exercise was to encourage the participants to focus on the nature of their environment rather than their disability. Although a social model

of disability underpins legislation in South Africa, it became 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. This is at least partly due to the attitudes of friends, family, community and service providers. Therefore, in order for the workshop to be successful, the concept of the social model of disability was introduced through the first activity and reinforced throughout the day.



#### 'MOBILITY MAP'

As well as encouraging the participants to focus on the barriers they encountered in their daily lives, the opening activity also allowed individuals to develop their own ideas before working in groups. In the Stanza Bopape and Saulsville workshops, many of the participants had never met one another before, and it was important that the experiences of the less confident or those with communication problems were not overlooked in the group setting. The individual maps were used by the group facilitators in Stage 2 to ensure that people who were reluctant to speak had the opportunity to add their ideas and experiences.

#### Stage 2. Group Discussion of the Problems Identified

Having identified their individual problems, the plenary group split up into 3 to 4 subgroups. The plenary group was divided up in such a way that each subgroup was made up of people with a range of disabilities and included at least one person who could write. Each group had a chart with the following three columns:

Name of Problem	Why It's A Problem	For whom is it a problem
		(Type of disability)

Each group was encouraged to identify someone who could write people's responses on the chart and another person who could facilitate the discussion. Some subgroups required a lot of support from the workshop facilitators, whilst others did not.

Once in the subgroup, the facilitator asked each person in turn to mention one of the problems they had identified on their individual map. This problem was noted in the first column. The group then discussed what it was that made it a problem and whether it was a problem for people with only certain types of disability or who live in a certain area. People may have listed the same problem but for a different reason, or it may occur in a different area of the settlement.



A group at the Saulsville workshop discuss the problems they encounter in their community.

We had originally intended to work with a chart and a map of the community for this exercise. However, in the first workshop in Hammanskral, the participants found it difficult to read the map and it created too much confusion and made the exercise too long. Based on this experience, we chose not to use the community maps in the other workshops. On reflection, this was probably a mistake. It is inevitable in the process of dividing up the plenary group into subgroups that some groups will be more able than others. Therefore, the workshop format should allow for this and give groups the *option* of working with maps. The group that took part in the Stanza Bopape workshop were particularly able and dynamic and would have handled the map exercise with little difficulty.

#### Stage 3. 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 who 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.

#### Stage 4. Voting

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, the central chart was laid on a table, and each person could cast 3 votes by placing a bean on each of the three problems s/he considered of greatest importance.

Although voting was part of the initial workshop plan, it did not take place at the Hammanskral workshop. Almost all the participants were either elderly or had an intellectual disability, and by lunchtime, most were tired or distracted. The group reconvened the following day, and the workshop facilitators selected the problems that had been mentioned by the greatest number of people in their individual maps.

#### Stage 5. 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
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However, the dynamic of each workshop was different and we needed to respond to that. Therefore, in Hammanskral where there is an active group of volunteer carers that run the rehabilitation centre, the discussion focused on what the volunteers could do and whether CSIR could support them in any way. At the Saulsville workshop, there was enough interest and time to discuss what could be done in relation to all the common problems. Voting took place after the next steps were identified. At the Stanza Bopape workshop, participants decided they wanted to focus solely on the issue of access to employment, and the discussion of what could be done next used the table outline above. This group also chose to elect a committee to represent the participants and ensure the group met again, even if the research team were unavailable.



At the end of the workshop in Stanza Bopape, the group chose to vote in a committee to take their ideas forward. The photo shows the new committee members discussing the issues that came up at the workshop.

*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.

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, transport proved to be too difficult. Many areas in the informal settlements are inaccessible to vehicles and getting people in and out of cars proved to be very time consuming. Therefore, rather than including this activity in the workshop process, a number of field visits based on the problems identified were conducted following the workshops. The Stanza Bopape field visits focused on employment and are discussed in Chapter x. The Hammanskral field visits focused on accessibility in public places.

#### **Workshop Results**

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



Participants in Hammanskraal chose to end both days with a group singing session.

#### Accessibility and the Physical Environment

When designers and planners create spaces for communities, the individual who they imagine will eventually inhabit their designed space is normally someone with unrestricted mobility and movement (Paterson and Hughes, 1999). The concept of the fully mobile individual is a hegemonic discourse that dominates Western planning, and as a result, the aesthetics of design and planning lead to the development of urban landscapes that exclude people with disabilities (Imrie, 2000). The need to create environments that are accessible for all, (and thus replace the discourse of unrestricted mobility with a more inclusionary concept of heterogenous mobility), was a key focus for international guidelines that arose out of the UN Decade for Disability.

Accessibility should not focus on specific aspects of environment in isolation. The 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.

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 Box 1. It is clear that most, if not all of the people with disabilities who took part in EE experience their movement through the spaces of home, community and beyond as a disjointed or interrupted process, rather than the ideal of continuity enshrined in the Standard Rules. Although the problems identified related to the question of where PWDs found it difficult or impossible to go, the reasons for those problems were not only physical ones. Workshop participants also discussed the social and financial barriers that prevented their unrestricted movement through their physical environment. What became clear from the workshop is that physical, social and financial barriers often combine to limit accessibility.

Enabled Environments wanted to do more than simply identify the physical barriers faced by people with disabilities living in low-income areas. Each section reviews current South African policy related to the issue and considers the action points that arose out the workshops. The discussion focuses on why physical barriers exist and what could be done to remove them.

### The Domestic Environment: Considering Access And Mobility In The Home And On The Plot

Developments in technology are improving the accessibility of housing at one end of the spectrum. New high-speed digital telecommunications infrastructure means that care, health and support services can be partly provided through digital control and communication systems (Gann et al, 1999). Smart Home systems offer features such as voice-activated door enter security systems for those unable to use keys and automatic cut-outs on cookers and other household appliances for those with dementia (Dewsbury and Edge, 2001). This type of technology has been available in South Africa for some time; in 1995 an article discussed the recent development of two voice-activated homes in Johannesburg and Cape Town (Building Issue, 1995). In Wonderboom, a village complex with a fully accessible multipurpose hall, a self-help centre and 13 townhouses for quadriplegics and their families is currently being developed by the Quadriplegic Association of Gauteng North, at a cost of R14 million (Pretoria News, 17 Jan 2002). There are a number of commercial housing developments in the Gauteng Province that require that either all buildings are fully accessible or that a certain percentage of houses are built especially for people with disabilities<sup>26</sup>. However, these types of high-tech, commercial high cost interventions will clearly have little or no impact on the lives of PWDs living on very low incomes.

The workshops provided the opportunity for participants to raise a number of issues concerning their experiences of housing as PWDs living in low-income settlements. The two most commonly mentioned issues that came up in all the workshops, and will be discussed at some length here, are discrimination in the housing subsidy application process (Chapter 4) for people with disabilities and the inaccessibility or non-existence of toilet facilities (Chapter 5). There were a number of additional issues related to mobility in and around the plot that were mentioned by a smaller number of individuals and were not selected by the plenary groups as issues for further action. These include lack of grabrails in RDP housing, inability to make the house fully secure, incomplete structures and water shortages. These issues will be addressed more briefly at the end of Chapter 5.

<sup>&</sup>lt;sup>26</sup> From telephone interview with architect Christine Roos, who was working for the Cosmo city project in Randburg at the time (March, 2001).

### BOX 2: SUMMARY OF PHYSICAL ENVIRONMENT ISSUES RAISED IN COMMUNITY WORKSHOPS

#### **House and Plot**

- RDP houses have inaccessible toilets locomotor disabilities
- Lack of toilet facilities in informal settlements locomotor and visual disabilities
- PWD are discriminated against when applying for housing grant all disabilities

#### **Roads**

- Roads are uneven, muddy, rocky, unsurfaced locomotor and visual disabilities
- Crossing busy roads all disabilities (Hammanskral)
- No pavements means at risk from drivers locomotor, visual hearing disabilities
- Steep curbs at traffic lights locomotor, visual disabilities (Hammanskral)

#### **Wider Community**

- Inaccessible public toilets locomotor disabilities
- No dedicated seats for disabled at pension office (Stanza Bopape)
- Access by stairs only into key buildings e.g. bank, school, clinic locomotor disabilities
- Public phones and ATMs set too high for wheelchair users
- No sign language interpreters in any public places hospital, govt offices, church
- No local sports facilities all disabilities

#### **Transport**

- Taxi rank is too far away from the house all disabilities
- Taxi drivers refuse to pick up people with disabilities all disabilities except hearing
- Getting in and out of the taxi is difficult locomotor and visual disability
- Drivers and passengers are impatient and no one helps
- Steep, narrow steps into public bus make it difficult to get on locomotor disabilities
- Do not have money to pay the fare all disabilities
- At the train station getting onto the platform and from the platform onto the train are difficult locomotor and visual disabilities

#### **CHAPTER 4**

#### ACCESSING THE HOUSING SUBSIDY

Before considering the experiences of EE participants, it is necessary to provide some general background on housing policy in South Africa. The chapter will then go on to discuss access by PWDs to the National Housing Subsidy Scheme.

#### Housing Policy and Disability in South Africa

#### The South African National Housing Code<sup>27</sup>

As South Africa has endorsed the UN Standard Rules (Office of the Deputy President, 1997), the concepts of universal access and the need for special provision for PWDs to ensure universal access appear in key government policy documents regarding housing.

Section 26 of the South Africa Constitution states that 'Everyone has the right to have access to adequate housing' 28. The Housing Act 1997 (No. 107, 1(vi)) translates this right into policy, stating that all citizens and permanent residents should have access to '... a permanent residential structure with secure tenure' plus 'potable water, adequate sanitary facilities and domestic energy supply.' The National Housing Code (2000) contains the national housing policy and administrative guidelines as to how the housing policy is to be implemented.

The Housing Code makes specific reference to the housing needs of people with disabilities. Housing Policy rests on 8 key principles and people with disabilities are mentioned in relation to the principle of 'Skills Transfer and Economic Empowerment' where the government stresses its commitment to '... meeting special needs, such as those of the disabled'. People with disabilities are also mentioned under the principle of 'Fairness and Equality' as a group, along with women, youth, and single parent families that must be fully included in the housing process. The key principles also include the concept of choice, i.e. that individuals, families and communities must be able to exercise choice as to where they live.

However, despite this acknowledgement of an individual's right to housing, the government has faced an uphill struggle since 1994 to meet the housing needs of the population. In 1997, the Housing Department estimated that 2.2 million families were without adequate housing and due to population growth this number rises every year. The South African 1996 census found that 11.6 per cent of households lived in freestanding informal settlements, and a further 4.5 per cent

<sup>&</sup>lt;sup>27</sup> The complete National Housing Code can be found at <a href="http://www.housing.gov.za/Pages/code/">http://www.housing.gov.za/Pages/code/</a>

<sup>&</sup>lt;sup>28</sup> According to the National Housing Code 2000 (NHC 2000), the term 'adequate' refers to legal security of tenure, the availability of services, materials, facilities and infrastructure, affordability, habitability, accessibility, location and cultural adequacy.

lived in shacks in the backyards of formal (normally township) houses. Therefore, over 16 per cent of households were living in urban informal housing, and a further 18 per cent lived in traditionally constructed houses, which would be located mostly in rural areas. (Statistics South Africa, 1997)<sup>29</sup>.

Despite the commitment in the 1997 Housing Act to providing universal access to drinking water, sanitation and domestic energy, many in South Africa continue to live without these basic services. Some 12 per cent of the population did not have access to clean water in 1999. A full 30 per cent still depended on pit latrines and a further 14 per cent used bucket toilets or had no access to sanitation. In informal settlements, the situation was much worse, with a full 44 per cent using pit latrines, 12.5 per cent using buckets and 10 per cent having no access to sanitation. Although 70 per cent of households had access to electricity by 1999, (an improvement of 6 per cent over a four-year period), the percentage of households using electricity for heating and cooking had dropped. Of the 70 per cent of households with connections, only 53 per cent used it for cooking, and 48 per cent for heating. (Statistics South Africa, 2001)

In response to the large numbers of people living in inadequate housing and without services, one of the government's seven strategies to realise its housing target is the provision of subsidy assistance to disadvantaged households to assist them to gain access to housing. The outcome of the strategy is the National Housing Subsidy Scheme.

#### **National Housing Subsidy Scheme**

Any household earning less than 3500 Rand (£292) per month is eligible for some amount of subsidy. When one bears in mind that in 1996, this accounted for just over 80 per cent of households in South Africa, the importance of the subsidy scheme to the realisation of universal access to housing is clear. In the same year, over 50 per cent of families earned below R1500 a month<sup>30</sup>.

<sup>&</sup>lt;sup>29</sup> There are no figures available for the number of households living in informal housing on formal plots. Therefore, although 66 per cent of households may live on formal plots, this does not necessarily mean that these households live in formal housing.

<sup>&</sup>lt;sup>30</sup> Income analysis from the 2001 census was not available at the time of writing this report.

Table 7: National Housing Subsidy Bands from 1 April 2002

Income per month	Subsidy for immediate	Top-up, consolidation
_	ownership: Project-	subsidy (available only to
	linked, Individual,	those who have already
	Rural, and Relocation	benefited from a previous
	subsidy mechanisms	site and service state
		subsidy)
R0 – R1500	R20 300	R10 900
R1501- R2500	R12 700	R0
R2501- R3500	R7 000	R0
Old aged, disabled & indigent	R22 800	R13 400
Institutional subsidies 0 – R3500	R 20 300	

For the people living in our research areas the most common form of subsidy is the project-linked subsidy. Under this scheme, a developer identifies an area of land and a group of beneficiaries and submits their proposal to the provincial housing MEC (Member of the Executive Council) and/or the provincial housing department. If approved, the MEC agrees on the amount of subsidy to be paid and the developer enters into a contract with the individual beneficiaries. The developer submits the beneficiary's subsidy application form along with the proof of purchase to the MEC, which then checks for fraudulent subsidy claims. The MEC then has the final say on acceptance or rejection. As those living in informal settlements are often unable to afford to top up the government subsidy, developers cater their proposals to the maximum allowed for an individual application i.e. R 20 300. In this way, applicants pay no money directly to the developer.

As can be seen from Table 7, as well as being eligible for an initial subsidy towards the purchase of a serviced site, those households with a monthly income of less than 1500 rand are also eligible for what is know as a consolidation subsidy. This is to enable a beneficiary to construct a top structure on the site. The application for a consolidation grant is done as a group. The group must form a community-based organisation with representatives who will negotiate with the developer on behalf of the group. The developer could be an NGO, municipality or private contractor. The Housing Code states that 'beneficiaries should be represented within the developer body'. Prior to submitting an application, there needs to be a stakeholder consultation which will include interviews with members of the beneficiary community in order to reach a consensus on the type of construction to be put in place.

Under the new subsidy system dating from April 1 2002, beneficiaries in the lowest income bracket who do not wish to follow the People's Housing Process route (i.e. providing household labour or management contributions) are required to make a financial contribution of R2479. The aged, PWDs and indigent are not required to make this contribution.

# THE EXPERIENCE OF THE HOUSING SUBSIDY PROCESS FROM THE PERSPECTIVE OF PEOPLE WITH DISABILITIES

When people move into the shack settlements bordering the RDP housing areas in Stanza Bopape and Saulsville, the majority do so with the expectation that they will eventually be able to apply for a plot in one of the new extensions being constructed. As explained earlier, rather than dealing with random individual applications, informal settlement residents must wait until their block representative is advised by the local councillor that s/he can now put in a group application for all the residents in the block. Residents may live in the informal settlement for a number of years before being invited to apply; some of the EE participants complained of waiting 5 years or more before being invited to apply. From the time of application, residents may have to wait anything up to another 5 years. <sup>31</sup>

As none of the participants in EE lived in households with a monthly income of more than R3500, all would be eligible for the housing subsidy. 39 per cent of our sample lived in households that had already been allocated a formal plot. Of this group, 65 per cent lived in households that moved onto sites and services plots, whilst 35 per cent had moved onto a plot with some form of formal shelter provided<sup>32</sup>. 24 per cent of our sample lived in settlements that had been upgraded, and therefore services installed. Most of this group came from the Hammanskral research area, due to the history of the development of Mandela Village. 37 per cent of our sample lived in unrecognised, informal settlements, and therefore, were living in a household that was either waiting to be invited to apply for the subsidy, in the process of applying, or waiting to be allocated a site.

Although the majority (63 per cent) of our sample lived on serviced plots of some type, a larger majority (79 per cent) lived in informal housing, i.e. shacks. This highlights the fact that once allocated a sites-and-services plot, low-income households struggle to construct a formal dwelling. Of those living on a sites-and –services plot, 48.9 per cent lived in a main shack, 10.6 per cent lived in a backyard room or shack, and 40.5 per cent lived in a formal dwelling. Only a small percentage (6.5 per cent) had moved onto RDP plots with some form of prebuilt dwelling. 14.5 per cent of the sample were members of households that had built their own formal dwelling.

<sup>&</sup>lt;sup>31</sup> There are no official figures available on the length of time between application and moving onto a site. The reasons for people being on a waiting list for a longer period varies from place to place. For example, in an emergency situation, people may have to be moved from a dangerous environment and be relocated in a safe environment and therefore are allowed to 'queue jump'. As people in crisis areas are given first priority over those who may have made their application long ago, people move up the waiting list more slowly.

<sup>&</sup>lt;sup>32</sup> RDP housing projects may provide a complete structure or an unfinished structure with frame, roof and floor. The latter is referred to locally as a 'roof house'.

Table 8. Type of Dwelling in which the PWD Lives

Type of Dwelling	Frequency	Percent
Backyard Shack	16	8.6
Backyard Room	3	1.6
Main Shack	128	68.8
Main House – RDP complete	11	5.9
Main house – roof house	1	0.5
Self-built house	27	14.5
Total	186	100

### he three images show examples of complete RDP housing, roof housing and shacks in an informal settlement





Complete RDP housing

Shacks

With over 70 per cent of our sample living in informal housing and more than 35 per cent continuing to live in informal settlements, it was not surprising that housing was a key concern for many. For those living on site-and-services plots, the inability to raise sufficient funds to upgrade their shacks was a common concern. However, this is not one faced solely by people with disabilities. In a country with 37 per cent unemployment (Kane-Berman, 2000) and 41 per cent of households living on less that R1000 per month (Hirschowitz et.al., 1996?), many households moving to site-and-services plots face difficulties trying to finance the construction of a formal dwelling.<sup>33</sup>

One issue however, that did relate specifically to the participants' disabled status was discrimination within the housing subsidy application process. A number of single adult men mentioned the difficulty they faced in accessing the housing subsidy. The Housing Code states that someone is eligible for the housing subsidy, if 'He or she is married or co-habiting' or if 'He or she is single and has dependants'. As in most cases one-parent households in South Africa are headed by women, there is a popular understanding that in order to be allocated a house, a man must have a female partner. The general discussion in the workshops picked up on the fact that many men with disabilities are unmarried, and there was a suggestion that it was more difficult for them to find partners. The groups also discussed the fact that as a PWD, a man had less likelihood of finding employment and therefore had only the disability grant as income. The grant of R620 (£52) a month is insufficient to allow a man to save enough for *lobola*<sup>34</sup> and to cover the cost of maintaining a family.

Although no female participants brought up the issue of applying for their own plot/house, this should not be taken to indicate that independent home ownership is not equally important for women with disabilities. It may be that women are confident that once they start a family, they will be able to apply for a plot. However, this obviously means that those women who discover they are infertile or fail to find a partner will be forced to continue to live as adult dependants. As 57.4 per cent of the women in our study aged 18 and above lived with their children, it may be a problem that fewer women have had to confront. Of all the adult women living in RDP settlements, 36 per cent were household heads which suggests that over a third of adult women with disabilities have not experienced difficulties accessing the housing subsidy under the criteria of a 'single person with co-dependants' regardless of the disabled status.

The situation is very different for adult men with disabilities. No male PWD aged over 18 who lived with his own children lived in a household of more than five. In contrast, men without children lived in households with up to 10 members. In stark contrast with over 50 per cent of adult women with disabilities living with

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<sup>&</sup>lt;sup>33</sup> No official figures are available on how many households that move to sites-and-services plots manage to construct formal dwellings and how many remain in shacks.

<sup>&</sup>lt;sup>34</sup> South African marriage dowry paid by the groom to the bride's family. It is traditionally paid in heads of cattle.

their own children, only 5.7 per cent of adult men with disabilities aged 18 and over lived with their children. For the men in the workshops who raised this issue, their experiences of being unsuccessful in applying for a housing subsidy meant that they were forced to continue living as an adult dependant within an extended family or remain in a shack. The problems that participants mentioned in relation to living as a dependant included overcrowding, lack of privacy, misuse of disability grant by other members of the household and a lack of independence.

Alfred Sibanyoni<sup>35</sup> became a wheelchair user 15 years ago. He was working as a gardener in a Pretoria suburb and living in the grounds of the house of his employers, when he was stabbed and paralysed. His employers initially kept him on, even though he was incapable of doing any strenuous work. However, when the couple got divorced, the wife's new husband did not take to Alfred, and he found himself homeless. With no means of earning an income, and no close family (his parents died when he was young and he is not in contact with any of his siblings), he moved to Stanza Bopape to live with his niece. Whilst he was pleased to find a place to stay, he had hoped this would be temporary as he faces a number of problems living in the home of another family. Firstly, there is the issue if privacy: he shares a room with his niece's son and he feels uncomfortable when his friends come to visit him as there is nowhere they can sit and talk freely. Although Alfred currently has no interest in finding a partner (he was divorced prior to his accident and his girlfriend left him when she found out he would be permanently disabled), it would be difficult for him to have a relationship in his current living arrangement. Secondly, there is the issue of financial contribution to the household. He feels that his benefit is used to support a great number of people and therefore, gets spread very thinly. He lives in a household with three adults and three children. Other than his disability grant, there is only one other regular wage coming into the house. He feels that if he were living on his own, he would be able to keep more of his monthly disability grant and therefore benefit more from it himself. Thirdly, although his grant plays an important role in maintaining the household, there has been no attempt to modify the house or plot to his needs. The outside plot is on a slope and is covered in stones, which makes it difficult for him to use his wheelchair. Spaces within the house are too small for him to use his wheelchair, as is the toilet block, where the overall dimensions mean he cannot get inside.

It should be noted that physical overcrowding was not an issue for the majority of the sample – 61 per cent either slept in room on their own or with one other person. Only 17 per cent shared a room with three or more people at night. However, overcrowding can have a detrimental effect on the living conditions of people with disabilities<sup>36</sup>. Overcrowding may motivate an individual to leave a formal settlement in order to have greater space in an informal settlement shack.

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<sup>&</sup>lt;sup>35</sup>All names have been changed to protect the identities of the participants.

<sup>&</sup>lt;sup>36</sup> The EE mobility map case studies began to show a tendency for people with disabilities to be given the worst places to sleep. However, as we only completed a small number of mobility maps we cannot present this as an empirical finding. This requires further investigation.

Amos Baloyi is a 32-year-old wheelchair user who lives with his two adult brothers and two teenage cousins. The three-room shack in an informal settlement in the Saulsville area is in the name of his mother, who lives and works in a factory outside Johannesburg. They had originally lived in a backyard shack on his uncle's plot in a nearby formal settlement, but had decided to move to the shack due to overcrowding and in order to have a chance to apply for their own RDP plot. Amos' mother made a housing application in 1996 in her name and the family were offered a plot in 2002. This was not a straightforward process as their plot was originally given to someone else by the councillor, which was fraudulent. They will now need to wait until the development is completed. Moving to the informal settlement had a negative impact on Amos' life. Whilst living at his uncle's house, the surfaced roads and more spacious plot meant that he was more able to move around independently in his wheelchair both on the plot and in the wider community. Now, living in an informal settlement, the muddy, uneven paths that run between the plots mean that he is unable to leave the plot without the assistance of someone else, which has severely reduced his independence and the scope of his social life.

Some single men with disabilities reported having responded to the problem of not being able to apply for a disability grant by entering into 'false' relationships, either by entering into an 'arrangement' with a female friend or by setting up a relationship that they finish once the subsidy has been approved. For example, a friend of Johannes Dambuza, who is sight impaired, set up a relationship for him in order to meet the selection criteria to qualify for the housing subsidy. Once he had secured the tenure, he ended the relationship, as it was not a genuine one. Morris Baloyi also has a sight impairment and currently lives in an informal settlement in the Stanza Bopape area. He has encountered problems in securing a permanent site because as a single man without children, he does not fulfil the requirements commonly believed to be stipulated in the criteria. He has been involved in numerous relationships with the intention of enjoying the benefit of owning a house/site, but each time the site is allocated, the relationship has ended. From these examples, it would appear that the criteria in the housing subsidy application contradict the Constitution which states that everyone has a right to access to housing.

#### **Identifying the Nature of the Problem**

The findings of the workshop suggested that despite the stated commitment to the right to housing of PWDs in the national housing code, the eligibility criteria were excluding people with disabilities who had neither dependants nor partners. Therefore, it initially seemed that one of the key recommendations of EE would be a change in the criteria. However, following the workshops, a more detailed reading of the National Housing Code revealed that such a variation in the criteria does already exist.

After listing the standard criteria which requires people to be cohabiting or to have financial dependants, there is a 'disability variation' which states that,

In situations where the subsidy is being awarded to a household where a member of that household is disabled, a number of exceptions apply:

1. Disabled subsidy applicants need neither be married or cohabiting, nor have financial dependants.

Source: National Housing Code 2000

Therefore, according to the National Housing Code, people with disabilities should not be under pressure to establish relationships, no matter how fleeting, in order to have access to the subsidy. This clearly leads to the question of why this element of the National Housing Code is not being acted upon?

The findings of EE suggest it is a problem of lack of information and communication at various points in the policy implementation process.

In order to understand these shortfalls, it is necessary first of all to provide a brief outline of the current housing subsidy process. The community-level process is based on the experience of the majority of EE participants and is not necessarily the only route of application.

**National government** - National government plays the role of facilitator in the housing process. It is responsible for drawing up policy, introducing legislation, defining the subsidy process and creating an institutional framework through which policy can be realised. The national government has an annual housing budget, which is divided amongst provincial governments. Size of budget allocation to each province depends on the relative merits and the strength of motivation of the Provincial Housing Development Plan that each one submits.

**Provincial Government** - the responsibility for fulfilling the right to housing as listed in the constitution falls to the provincial government. The format for the Provincial Housing Development Plan requires information on aspects such as provincial housing shortages, environmental constraints, development opportunities, the effectiveness and efficiency of the use of subsidies etc. As well as having a key role in the monitoring and evaluation of housing policy, provincial governments are responsible for allocating the annual housing budget to each municipality. For example, in 2002/03, the housing budget for Gauteng province is R700 million. Then the province allocates the money to twelve municipalities within Gauteng, based on the population of the municipality and records of proper management of funding allocated last year. The latter is of particular significance in determining the amount to be allocated.

Responsibility for approving housing projects rests with the provincial housing MEC (Member of the Executive Council) and the provincial housing department.

Municipal Government – The municipal government must apply to the provincial government on an annual basis for budget to cover its proposed projects. Although the provincial government has responsibility for approving housing projects, they are also meant to be subject to the approval of municipalities. Municipalities should guide the location of new developments through their Integrated Development Process, which is a comprehensive multisectoral development plan for the local area.

**Contractor** – the contractor has no influence over which subsidy applications are accepted or rejected. The contractor's plans for development must be approved by the MEC based on the criteria outlined.

**Local Councillor** – Negotiates application process with contractor and MEC. As all subsidy applications come through the councillor's office, s/he may dissuade individuals from applying or veto some applications.

**Block Representatives** – sent by the councillor to collect information on each household applying. Experiences of participants in EE show that these individuals may advise household whether or not they are eligible to apply or the likelihood of success of the application.

**Individual Households** – wait to be invited to apply for subsidy by councillor/block representative

So, where do the problems lie within this model of policy implementation? The policy and budget exist, but there are two key reasons for the failure of PWDs to access the housing subsidy:

- lack of information on the policy variation
- lack of knowledge of application mechanisms

Of the 186 people with disabilities and their families, the social workers who specialise in disability issues and the local councillors who deal with the housing subsidy process on a regular basis who were all interviewed for EE, not one person knew of the disability variation in the subsidy application procedure.

A representative of Gauteng Provincial government admitted that there had been little action taken in the past to raise awareness of the disability variation. The number of subsidy applications by PWDs has risen recently, but by August 2002

only 150 applications had been approved and 250 were awaiting approval<sup>37</sup>. If one bears in mind that more than 20 per cent of the South African population either have a disability or live in a household with a person who has a disability (SAHRC, 2002, p.12) and that, according to the 1996 census, there were 314 860 households living in shacks in informal settlements and 153 503 households living in backyard shacks in Gauteng province, it is clear that there is anything up to 936,726 households that are eligible to apply for the subsidy under the disability variation.

The Gauteng government is beginning to tackle the problem. In order to increase the number of applications further, the government has set up a sub directorate to assess the effectiveness of the municipal governments' current handling of the disability variation in the subsidy application procedure. A task team has been formed to ensure that the information on the subsidy is widely disseminated. However, an interview with a training officer linked to the task force in August 2002 revealed that so far training has only been offered to housing officials at the municipal level.

Whilst this awareness raising is welcome, it is a vertical, top-down model of dissemination and as such fails to address the issue of awareness at the community level. When interviewed, the provincial training officer did not know whether there were any plans to extend training to local councillors. Yet, EE has shown that for the individual person with a disability the housing subsidy application process is experienced as a relationship between applicant, councillor and block representative. The applicant is essentially passive in the process, waiting to be invited to put in an application. For the participants in EE, their understanding of the housing subsidy is shaped by the incomplete knowledge of the block representative, whose understanding of the subsidy in turn comes from the councillor and his representatives.

As the councillor is the key point of information in the subsidy application process, it is imperative that councillors are targeted for training regarding the housing subsidy. However, it is important to bear in mind the disability rights slogan 'Nothing about us without us'. If people with disabilities have to rely on the knowledge of others in order to gain access to what they legally have a right to, the awareness-raising model in place is clearly a disempowering one. People with disabilities living in low-income households need to be made aware of the disability variation in the housing subsidy. The training process in place in Gauteng is a top-down process that will reach the people whose lives it aims to have an impact upon last of all. This top-down process could be counterbalanced with an awareness–raising campaign targeted at people with disabilities at community level. This knowledge would enable PWDs to question the actions of block representatives and councillors who are unaware of disability variation.

<sup>&</sup>lt;sup>37</sup> From an telephonic interview with a provincial government official from the Implementation and Monitoring Directorate of the Department of Housing (August 2002)

The application procedure is straightforward – an applicant submits a normal subsidy application plus a medical form completed by a doctor. Originally, any applicant with a disability who was unable to make the application through his/her councillor was permitted to take the application directly to the municipal office. However, this was changed in late 2001 and all housing applications under the PWD exemption must go through the same channels as general applications. This makes the need to raise awareness of the disability exemption among councillors and block representatives of key importance as councillors can currently refuse to put forward the housing subsidy applications of PWDs. (see Box 3)

However, any campaign to raise awareness of the disability variation needs to make the application procedure clear. When we discussed the process with some of the participants on EE they raised the following questions - Can the form be completed by any registered doctor? Is it a special form? Where should I complain if my councillor will not accept my application? Any campaign needs to allow for such questions.

## Box 3: Case Study Illustrating Problems Encountered by Single PWDs when applying for the housing subsidy

Samuel Bopape is a 25-year-old wheelchair user who became paraplegic after being shot in the street during a mugging. Despite his disability, he decided not to return to Nelspruit to live with his family, as he believed that he would become dependent and furthermore, he would no longer be able to see his young daughter who lives in the area with his ex-partner. He currently lives alone in a one-room shack in an informal settlement on the edge of an area targeted for series of RDP housing projects. His recent experience of making an application for a housing subsidy shows the stress and difficulty encountered by people with disabilities who are trying to live independent lives.

An announcement was made in his block that all the people living in his informal settlement were to be invited to make an application for a housing subsidy and thus be allocated a formal plot in a forthcoming site development. Samuel responded to an announcement like any other resident by visiting the office of his local councillor in order to register his interest. Although his daughter does not live with him permanently, he thought he needed to have dependants in order to apply. Therefore, he took his ID book and his daughter's birth certificate. The councillor informed him to bring along the ID book of the mother of his daughter (ex-girlfriend). On responding that he has separated with his ex-girlfriend, the councillor highlighted that he would not be able to register without the ID book of his ex-girlfriend.

Worried that he would lose his only opportunity for a plot after waiting for 7 years, Samuel decided that the best course of action would be to ask a female friend to assist him. His friend agreed to give him her ID book and her daughter's birth certificate. He then submitted the documents to the councillor for the second time. The councillor wanted to see the friend regardless of the fact that Samuel told him that she was working during the week and therefore was only be available at the weekend. Samuel feels there is an element of discrimination here as he knows of non-disabled men who have made housing subsidy applications

using the ID of children and partners who do not live with them, and yet they were never asked to bring their partner to see the councillor.

When Samuel and his friend visited the office; the councillor intimidated the woman by telling her that by doing Samuel this favour, she should bear in mind that she would never be able own a house in her life. Seeing that the councillor was intimidating his friend, Samuel gave up.

After a while, the staff at the councillor's office conducted house visits to register the people who wanted to apply for a subsidy. Samuel then registered using the ID book of the sister of his ex-girlfriend because the surname is similar to his daughter's. After registration, he heard other people working at the councillor's office saying that chances of submission of his form were very slim.

Samuel acknowledges that he has lied in order to secure a subsidy but feels there was no other option. When he found out about the exemption, he visited the municipal office to put in a legitimate application under the terms of the disability variation. However, he was told he must now go through his councillor. As his councillor has no knowledge of the disability exemption, Samuel does not believe that he will accept his application and is wary of going to see him.

#### The Way Forward?

The findings of EE suggest that there are of number of things that could be done to build on the Gauteng government's current approach to the problem of limited uptake of the housing subsidy by PWDs.

#### 1) Awareness Raising Campaign aimed at PWDs

In order to reach the greatest number of people, it is necessary to have a number of points of information. EE findings suggest that current ideas regarding disseminating information on the subsidy to PWDs would reach only a small percentage of participants.

Those responsible for raising awareness of the subsidy variation should not assume that PWDs are necessarily part of a wider disability community network.

One councillor from the Gauteng Province recognised that disability issues had been overlooked by councillors and community organisations in the past, but cited the greater involvement of PWDs on ward committees<sup>38</sup> as proof of the greater inclusion of PWDs<sup>39</sup>. However, whilst the representation of disability issues at community level is obviously welcome, ward committees as a point for

<sup>&</sup>lt;sup>38</sup> A ward is an area represented by a single councillor.

<sup>&</sup>lt;sup>39</sup> From an interview with a Saulsville ANC councillor (18 July, 2001)

disseminating information would have a limited impact in the communities where EE was based.

The workshops were the first point at which all EE participants in each community came together. What was evident at these gatherings was how few people with disabilities had met other people with disabilities in their communities, and how little involvement they had with community organisations. This lack of networks means that attempts to include PWDs at a community-level can sometimes be little more than tokenism. A multi-agency committee dealing with disability issues in one of the EE communities had realised that they should have someone on the committee representing the local disability community. One of the social workers attached to the rehabilitation centre suggested one of the centre's clients, a 40-year old wheelchair user, for no other reason than she knew her and she seemed like a capable person. Yet, the chosen representative knew only two of the 29 participants who attended the EE workshop, and both are wheelchair users themselves, who live near to her house. She therefore, could not be considered a representative of people with disabilities, only a representative of herself and her two friends. The findings of the survey emphasise the limited community networks of many PWDs. 76 per cent had no involvement in any form of community organisation. 26 per cent never visited friends or family within the settlement, and this figure rises to 31 per cent when asked about visits made beyond the settlement. For 31 per cent of the sample their main sphere of mobility is no further than the streets adjoining the plot. As has been previously mentioned, physical, financial and social barriers combine to limit the lives of many PWDs.

The implications of these findings for awareness-raising campaigns is that it cannot be assumed that by informing a person with a disability who has representative role information will 'snowball' through those in the community with a disability.

Relying on medical and welfare service providers to disseminate information potentially reinforces the medical model of disability.

The Gauteng task force that currently has the responsibility for raising awareness of the disability variation includes NGOs that provide services for people with special needs, and representatives from the Departments of Health and Social Services. Whilst clinics are obviously a useful place to disseminate information, it should not be assumed that health and welfare-related services reach all PWDs and therefore they should not be the only point of information regarding the subsidy within a community. Only 25 per cent of the EE sample had links with the rehabilitation centre in the community and only 25 per cent had a social worker. It is important to point out here that the most appropriate information points may differ from community to community. In Hammanskral, 40 per cent of the sample had access to either a rehabilitation centre or a social worker.

#### 2) Target those places where the majority of PWDs go.

65 per cent of the EE sample received some form of grant – a disability grant, old age pension or care dependency for carers of children with severe disabilities. This would suggest that an information campaign that involved grant distribution centres would reach a large number of PWDs.

One of the few social activities that a large number of PWDs took part on a regular basis was attending church. 71 per cent attended church at least monthly. Whilst the phenomenon of small, independent churches in South Africa may make it difficult to target all the churches in a particular community, it is clear that any awareness raising campaign should look at the possibility of reaching members of the community with disabilities through key churches.

The key point to be made about awareness-raising is that knowledge must enter the community through a number of points. This can include clinics and ward committees but cannot rely solely on these, as too many PWDS would be excluded.

#### 3) Integrated Training

The experiences of PWDs involved in EE have highlighted the need for training related to the disability variation to extend beyond municipal level housing officers. However, rather than training councillors in isolation, multi-stakeholder training could be more effective. This could include members of ward committees, health and welfare service providers, community police representatives, local community centre manager, librarian etc. Resources permitting, short training sessions based in the community would ensure a greater level of attendance and would provide the opportunity for PWDS without the money to travel to also take part.

Such sessions could also be used to raise awareness of disability in general i.e. types of disability and simple ways to make public buildings in the community more accessible to people with disabilities. PWDs living in low-income communities should be given the opportunity to talk about their own experiences at such workshops.

#### 4) Monitoring and Evaluation

The Gauteng Department of Housing currently monitors the number of housing subsidy applications made under the disability exemption. As explained above, current figures show the small numbers of people with disabilities currently making applications under exemption criteria. However, if one of the key reasons why there is not a greater number of applications is lack of awareness at community-level, any awareness raising interventions need to be accompanied by some evaluation of their success. Therefore, monitoring and evaluation should not simply focus on the number of applications.

#### **CHAPTER 5**

# ACCESSIBLE TOILETS AND OTHER HOUSING MODIFICATIONS

#### Introduction

Access to adequate sanitation is a key concern in South Africa. Despite the commitment in the 1997 Housing Act to providing universal access to sanitation, many in South Africa continue to live without this basic service. In 1999, 30 per cent of the population still depended on pit latrines and a further 14 per cent used bucket toilets or had no access to sanitation. In informal settlements the situation was much worse, with a full 44 per cent using pit latrines, 12.5 per cent using buckets and 10 per cent having no access to sanitation (Statistics South Africa, 2001)

In the EE sample, the majority of the sample (51.6 per cent) live in households for which the main toilet is an informal pit latrine. 67 per cent of households have a water tap on the plot, whilst 33 per cent rely on a community tap or water tank.

Table 9. Type of Toilet Facilities Used

Type of Toilet Facility	Percentage
Open Public Land	0.5
Formal Pit Toilet	1.1
Informal Pit Toilet	51.6
Flushing Toilet inside the house	7.0
Flushing toilet outside the house	39.8
Total	100

The lack of appropriate toilet facilities was a concern that was raised at all three workshops. The discussion centred on two key issues - 1) the problems encountered by people with locomotor and visual disabilities who live in households with informal pit toilets and 2) the inaccessibility of flush toilets built on RDP plots for wheelchair users and people who use other types of mobility device. After outlining the nature of the problems associated with toilet use in formal and informal settlements, the chapter will go on to discuss other mobility issues in the home. The final section will put forward recommendations to ensure that current subsidies available for housing modifications are better targeted to respond to the needs of PWDs, as identified by EE.

#### **Toilet Blocks on Government Plots**

It became apparent during the workshops that although a PWD may be recorded as living on a plot that has a flush toilet (and therefore be counted amongst the 56 per cent nationally who have access to adequate sanitation), this does not necessarily mean that s/he is able to use the facility.



Once plots are outlined for siteand-settlements developments, concrete toilet blocks are constructed.

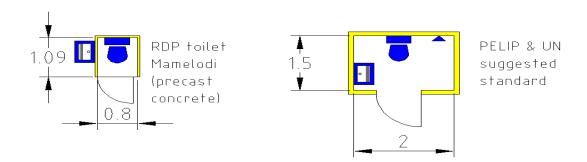
A site developer must provide serviced plots under the subsidy scheme, and image below illustrates, some developers install a toilet and a toilet block made from pre-cast concrete on each plot. In the workshops, wheelchair users reported that the doorways in these blocks are too narrow to accommodate their wheelchair, and therefore they could not use them. One man who lives in on an RDP plot in the Stanza Bopape area explained how he was forced to urinate into a bucket in the house and defecate onto newspapers. He felt even crawling to the toilet block would be preferable to this, but his paraplegic condition meant that this was not an option for him.

The standard dimensions of this toilet block are 1090 mm x 800 mm. As can be in the image below, the doorway simply is not wide enough to allow a wheelchair to enter. Nor is there extra space at the side of the toilet for an enabler, be it for a wheelchair user or the infirm.

UN recommendations for accessible toilets require a doorway with a minimum width of 900 mm. The door should open outwards and ideally 180 degrees so that it allows maximum access. The minimum dimension for the toilet block is 1700 mm x 1700 mm or 2000 mm x 1500 mm (ESCAP, 1995, pp.93-94). The dimensions are based on the minimum area required for full mobility for a wheelchair user, but also provide sufficient space for other people with impaired mobility, such as those using Zimmer frames or sticks. It is therefore appropriate to use adaptation to a wheelchair as a general guideline.

The following diagram illustrates the difference in dimensions between the RDP toilet block and the UN minimum dimensions.

#### Plans of the two types of toilet block



As well as ensuring dimensions that allow for easy movement in and out of the toilet and the presence of an enabler if required, the toilet itself needs to have a higher seat than a normal toilet. This should ideally be 450 mm (ESCAP, 1995, p.94). The toilets installed by the RDP site developers in Stanza Bopape and Saulsville are only 400 mm high.

UN guidelines also make recommendations regarding the installation of grabrails at either side of the toilet. These should be positioned at 700 mm above floor level and slightly ahead of the toilet. The space between the toilet seat and the handrail should be 150 mm.

As can be seen from photograph, the toilet blocks that have been constructed in Stanza Bopape and Saulsville are made of pre-cast concrete. This makes it more difficult for those households who wish to install grabrails to do so.

#### **Toilet Facilities in Informal Settlements**

In our case study areas, those people living in informal settlements have no formal toilet facilities, either private or communal. In these cases, households either construct an informal pit toilet or simply dig holes at random over the plot. Not surprisingly, the lack of toilet facilities is problematic for people with disabilities. Elias Mahoro is blind and lives in a one-room wooden shack on a small plot with his girlfriend in the Stanza Bopape area. At the workshop, he spoke with some embarrassment about having to dig a hole on his plot in order to defecate. He mentioned the lack of privacy and also the fact that he was dependent on his girlfriend or someone else guiding him to an appropriate spot. Those with limited mobility due to paralysis, muscular weakness or pain similarly face problems when required to use informal squat toilets.



Some shacks do not have informal pit latrines and household members may use the open land around the shack.

If the South African government is making provision for people to move to formal housing, should the lack of appropriate toilet facilities on informal plots be of concern? It is important to remember that most PWDs will live on an informal plot for a number of years before moving to an RDP site. On the issue of accessibility in slums, the United Nations offers no explicit guidelines and simply stresses that any improvement, rehabilitation and relocation programmes for slum dwellers must address the needs of people with disabilities and the elderly (ESCAP, 1995a, p.19).

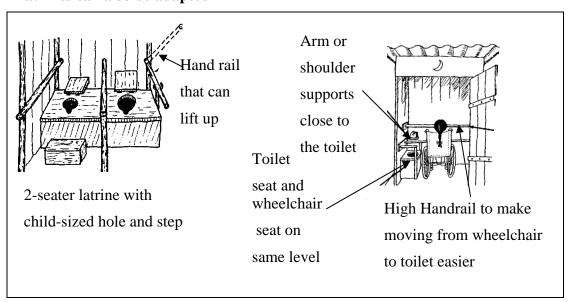
In India, the need for toilet provision in informal settlements has been addressed by the well-known NGO Sulabh, which constructs community toilet blocks with specially designed pit toilets. Such toilet blocks would probably not be appropriate in the South African context. Crime is high in South Africa and affects people differently in different areas of the city (Kruger et al., 2000, p.13). A recent workshop with general users of Stanza Bopape community facilities (Lieberman, 2002) looked at the incidence of crime and possible changes that could be made to the physical environment to make crime less likely to happen. The key findings of the workshop, not surprisingly, were that dark, enclosed or deserted public spaces were where crimes were most likely to be committed and therefore, one key recommendation was to limit the number of enclosed, secluded public spaces created in a settlement. Personal safety and the security of one's dwelling were key concerns mentioned by the PWDs who participated in the enabled environments workshops. The lack of appropriate facilities and where these do exist their proximity to vacant tracts of "left-over" land are a "hang-over" from the apartheid city. The fact that they remain undeveloped and that no one takes responsibility "ownership" of them allows those with possible criminal intent to operate freely here. Legitimate users cross these spaces at their peril and disabled users are even more vulnerable. Therefore, the construction of community toilet blocks in informal settlements, even if made fully accessible for PWDs, would be unlikely to be used by the majority of the population and more likely to become a space used by the criminally inclined for illegal activities. In South Africa, recent information highlights the correlation between sanitation

facilities and crime, especially rape and child abuse, and, therefore, communal sanitation blocks are consequently not recommended<sup>40</sup>.

In comparison to the informal settlements the project studied in Delhi, the informal settlements included in the South African case study have plots of a sufficient size that they allow for some private open space around the informal dwelling. Most households, therefore, do have the space to house an individual toilet on their plot. It is clear, however, that due to the already unmanageable financial demands of social development interventions on the government's budget, that any improvement in toilet facilities for PWDs living in informal settlements cannot realistically expected to be financed by the government at any level.

There are numerous guides to making DIY low-cost disability aids, often based on actual community experiences. A particularly comprehensive book on the rehabilitation of children with disabilities in rural areas (Werner, 1987) offers a number of low cost solutions to allow children with disabilities to use the toilet independently. Many of these would be equally applicable to an adult with a disability. As one looks at the suggestions made in Werner's book, they seem simple and obvious: a wooden frame to hold onto while one squats, a commode constructed from a chair and a tyre, a wooden grab-rail installed in a self-built latrine.

#### Latrines can also be adapted



Source: Werner, 1987

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<sup>&</sup>lt;sup>40</sup> Interview with Susan Lieberman, crime and environment specialist at Boutek, CSIR (18 March 2003).

The key question to be raised here is which organisation/community group is best placed to disseminate information on constructing more accessible toilets?

## Going beyond the Workshop Findings – Considering Access and Mobility in the Home

Access to toilet facilities was the only issue related to access and mobility around the home that was mentioned by participants in the workshop. The fact that that the participants did not mention other access problems in the home does not mean, however, that problems do not exist nor that improvements could not be made that would increase the PWD's independence.

Whilst government and non-government agencies may have adopted the social model of disability, it is important to remember that many PWDs and their families continue to understand their disability according to the medical model. It is understandable therefore, that when one starts to ask questions about problems with accessibility and mobility in certain environments, whether public or private, that the respondent will often refer to the nature of his/her disability. Both in the workshops and in the surveys<sup>41</sup>, questions that asked about problems with doing everyday activities in and around the home often elicited responses such as 'my legs don't work' or 'I can't see'. If one follows this through to think of a solution, one comes back to assistive devices that compensate for the physical shortcomings of the individual as opposed to any proposals for changing the environment to allow everyone equal levels of access, mobility and independence.

We interviewed 186 PWDs and only 34 (18 per cent) responded to the question relating to the problems they faced trying to carry out everyday chores and activities around the house. Many of these 34 identified more than one problem. 7 responses focused on the nature of the disability. Two responses related to nonspatial issues, i.e. lack of money and job discrimination. Overall dependence on others was raised by 6 of the people who responded to this question: a more detailed analysis of the respondents living spaces would be required to assess whether or not modifications to their homes and plots could result in greater dependence for these people. 7 people discussed problems related to things being too high for them to reach: not being able to hang out the washing because the line is too high; not being able to get to a storage box because it is on the top of the wardrobe and the respondent is unable to use a chair to climb up; not being able to reach things on shelves. 8 people referred to problems moving in and out of the house due to narrow doorways and/or steps. There were 5 respondents who mentioned uneven, stony or steep surfaces that were preventing them from moving around the plot or from getting off the plot. 4 people mentioned the fact they were unable to carry heavy things; this is a particular problem for PWDs living on their own with water taps outside the house. Within a traditional gender-based division of labour, men will often take responsibility for maintaining the physical structure of the house. Three male respondents felt the problems they faced were related to this sphere of responsibility. Whilst not being able to climb a ladder, mend a roof or use a hammer may not seem like a problem

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<sup>&</sup>lt;sup>41</sup> Question No. 100: What problems do you encounter doing things in and around the house and plot?

that one would experience on a regular basis, it was clearly of concern for these men. One respondent mentioned not being able to cook because she only has the use of one hand and another woman referred to not being able to mend clothes due to her impaired vision.

# The Way Forward: Recommendations for Improving Domestic Access for People with Disabilities living in Low-Income Settlements

As with the issue of applying for the housing subsidy, the South African government has already considered the problems of mobility experienced by PWDs at home and has tried to respond to those problems. People with disabilities who are eligible to apply for the housing subsidy (i.e. live in a household with a monthly income of R3500 (£292) or less), are also eligible to apply for an increase in the subsidy amount to cover housing modifications that would adapt their home to their specific needs.

Depending on the nature and severity of a beneficiary's disability, the following additional provision may be granted<sup>42</sup>:

- R 720 to provide 12 square metres of paving and a ramp at the entrance to a home;
- R 300 to provide kick plates to doors;
- R 1 100 to provide grab rails and lever action taps in bathroom; and
- R 700 to provide visual doorbell indicators. (Department of Housing, 2000)

However, our study found that none of the PWDs living on RDP sites had applied for this subsidy. As with the housing subsidy variation, the problem would seem to be one of poor advertising – none of the PWDs who participated in EE had heard of the additional subsidy available for housing modifications. Information regarding the housing modification grant could be disseminated along with information regarding the subsidy variation, and therefore the recommendations regarding dissemination that appeared at the end of the previous section apply here. Applications for the modification grant are submitted at the same time as the application for the housing subsidy. It is important to note that individuals who acquire a disability after moving onto a RDP plot are still eligible to apply

<sup>&</sup>lt;sup>42</sup> A PHDB may increase any subsidy amount by a maximum amount per disabled category to accommodate the increased costs associated with adapting a top structure to meet the needs of the disabled person. This addition to the subsidy amount is determined taking into account the nature and severity of a person's disability. Additional features necessary in a house that is to accommodate a disabled person, which may be financed by the variation, are paving and a ramp at the doorway, kick plates to doors, grab rails and lever action taps in the bathroom (enlargement of the area can be done at the expense of the rest of the house), and visual door bell indicators. (National Housing Code, Part 3, Section 2.4.2)

for the modification grant. This should be made clear in order that low-income families avoid spending money unnecessarily: the family of one EE participant had spent money on building a ramp into their RDP house when they could have applied for a grant.

As well as recommending wider dissemination of information regarding the modification grant, findings from EE suggest other ways in which the modification grant could be improved.

#### **Extending the Grant to Cover the Cost of Constructing an Accessible Toilet**

The modification grant does not cover the costs of altering an outside RDP toilet to make it accessible to people who use wheelchairs and people with other locomotor disabilities<sup>43</sup>. The diagrams show the difference between the dimensions of the RDP toilet and the dimensions of the accessible model. According to the workshop findings, having an accessible toilet is of equal, if not greater importance than the other items available under the modification grant. Therefore, we would recommend that the grant be extended to cover the cost of constructing an accessible toilet. This should cover the cost of constructing a larger block, installing a toilet with a higher seat and fitting grab rails. Some consideration would need to be given to whether or not it should include the cost of labour for those PWDs who cannot rely on the assistance of family and friends.

#### Making the Grant more Flexible

Should there be a greater flexibility in what the modification subsidy can be used for? A proscriptive list is derived more from the medical model of disability than the social model. As Baum (1997, p138) explains,

The client centred approach requires professionals to alter their behaviours from those traditionally employed in the medical model. Professionals must encourage client partnership in decision-making and enable clients to identify their needs and build on their strengths. The approach must be 'flexible and individualised'. The provider of services must respect the clients' values, goals and priorities without judging what is right and wrong.

We recognise that trying to build choice and flexibility into mass housing provision can be costly both in terms of the resources and administrative support required. However, there may be other modifications required by PWDs that have not been identified. When asked about mobility problems in the survey, almost an equal amount of respondents mentioned worktops and storage that is too high for them to reach as mentioned doorways and steps that are difficult to manouvre.

Furthermore, the current definition of those who would require the modification grant is very narrow. Under the category of 'walking' disability, the code lists those who use walking aids and those who use a wheelchair either part-time or full-time. However, someone with a locomotor disability may not use a walking

<sup>&</sup>lt;sup>43</sup> The current modification grant allows an inside bathroom to be enlarged at the expense of the rest of the house under the R1100 allowed for grab rails and lever action taps.

aid or a wheelchair, but may still require grabrails when there is a change in level. Similarly, someone whose dexterity has been reduced through arthritis may not necessarily have a 'walking' disability but would still benefit from lever action taps. (Gibberd, 2001, p.52).

### Thinking About Accessible Environments For Those With Visual Impairment

There is a tendency when thinking about accessible environments in low-income communities to think primarily of creating barrier-free environments for those with locomotor disabilities – consider the assistive devices covered by the modification subsidy. Accessibility guides aimed at the community, such as the PELIP (2000) publication also focus on ways of improving accessibility for those with a locomotor disability. A representative of the Gauteng Housing Department expressed her frustration that despite having received housing subsidy applications from 8 people with visual impairment, the department was currently unable to offer them any additional assistance as there are currently no modifications for the visually impaired covered by the modification grant. None of the people with a visual impairment who took part in EE had suggestions for the type of modifications they would find helpful, and the South African Association for the Blind would be the best group to advise on this.

There are, however, simple ways to make environments more accessible to those with visual impairment through the use of colour and lighting. A study by Project Rainbow (Bright, Cook and Harris, 1997) found that the use of contrast in colour and light (i.e. shade and non-shade), along with contrast in shape and size enabled people with a visual impairment to find their way around indoor environments. The report discovered that people with a visual impairment found the following changes allowed them to move around with greater confidence:

- 1) Ensuring a clear colour contrast between a door and a wall, between the door and the handle, and, in the case of bathrooms, between wall, floor and toilet/sink.
- 2) Ensuring a clear contrast between the floor and the wall
- 3) With floors, surfaces should be non reflective. There should be no strong shadows falling across the floor and non-uniform patterns and geometric patterns should be avoided as these all serve to confuse someone with a visual impairment.

Guidelines for accessibility at the household and community level should include a section on the needs of those with a visual impairment.

#### **Support for Instalment**

The installation of ramps, kickplates, grab rails and lever action taps are only of use to people with disabilities if installed correctly. A ramp that is too steep or does not have a sufficiently deep flat area at the top of the slope to allow the PWD

to open the door will be of little use. Similarly, accessibility guidelines for public buildings specify the measurements for the most effective positioning of grab rails. These measurements are equally applicable to a domestic setting. The provincial department of housing has officers who ensure assistive modifications claimed under the grant are properly installed. As none of the EE participants had received the modification grant, the project was not in a position to assess the effectiveness of the current system.

Whilst a one-off check by an officer is useful, successful installation in itself will not necessarily ensure use by the person with a disability. A study of the use of assistive devices in Soshanguve (a township in the Johannesburg area) (Meyer and Shipham, 1995) demonstrated that people are much more likely to use assistive devices in order to have greater independence in the home, if those devices are originally demonstrated in the individual's home environment. Therefore, although dissemination through meetings, printed materials, radio programmes etc. may raise awareness of the availability of the housing modification subsidy and application and installation procedures, it is clear that some form of individual training and support would be required in most cases. We recognise that the resources of community based rehabilitation services are already stretched to the limit. Therefore, we recommend that providing training to local people with disabilities living in the community, who could then pass the information onto others, should be considered.

#### **CHAPTER 6**

# GETTING OUT AND ABOUT: ACCESSIBILITY AND MOBILITY ISSUES IN THE WIDER COMMUNITY

Having addressed the issues linked to the house and plot that arose out of the workshops, the final section of this chapter looks at the barriers that participants identified as preventing them from travelling around the community and beyond. These can be grouped under three key themes: transport, roads and access to public buildings.

#### Transport: using taxis and buses

The White Paper recognises that the full integration of PWDs into all aspects of society can only be achieved if there is a fully accessible transport service that allows people to get to places beyond their immediate community. It also recognises that thinking of transport needs only in terms of special transport provision in order to access health related services is to reinforce the medical model of disability.

The policy objective is;

... to develop an accessible, affordable multi-modal public transport system that will meet the needs of the largest numbers of people at the lowest cost, while at the same time planning for those higher cost features which are essential to disabled people with greater mobility needs.

(Office of the Deputy President, 1997, p.32)

The National Land Transportation Transition Act 2000 requires that the planning and provision of public transport infrastructure, facilities and services fully integrate the transport needs of people with disabilities.

As a DFID-funded study recently looked at transport provision for PWDs in South Africa in depth, the Enabled Environments chose not to focus on transport. However, the experiences of the EE participants have something to add to the recommendations of larger transport study.

For those PWDs living in the four communities we studied, the main form of transport is taxis or the public bus system. Taxis are unregulated mini-buses (often VW 'combis') run by private operators. They cost more than public buses but cover a wider range of routes. Overtrading on some routes has led to violent conflicts between drivers' groups, and taxi drivers continue to have a reputation for being aggressive. Public buses are subsidised and mainly run between centres of employment and peri-urban residential areas.

Access to road transport was an issue that was raised in all of the three workshops. The main concerns can be summarised as<sup>44</sup>:

- Inability to afford regular taxi use
- Attitude of taxi drivers to PWDs
- Distances between bus/taxi stands and home or destination
- Difficulty of getting on and off transport

Discussions within the workshops and in follow-up interviews brought to light the implications of inaccessible transport for the full integration of PWDs living on low incomes into society. Emily Radebe's experiences of the way in which the inaccessibility of the taxi and the attitude of some drivers impinge upon her efforts to have some social activity beyond the home has already been discussed (see Box 4.).

For those wanting to take up the training opportunities available for PWDs in the city centre, the cost of transport can be prohibitive. Whilst special transport can be seen to be non-integrationist and encouraging dependency amongst PWDs, there may need to be a more careful consideration of the needs of PWDs who live on low incomes. One NGO that provides a professional-level computer-training course in central Pretoria insists that all participants must cover their own transport fees for the 12-week course that takes place from 9-5 Monday to Friday. To travel from Mamelodi to Pretoria city centre by taxi currently costs R5 (£0.42). Over a month, travel costs alone to participate on the course would total R200, which is a third of the monthly disability grant. When questioned about the availability of travel grants for PWDs with limited funds, the course director replied that participants must be committed and therefore, must be willing to make the necessary financial sacrifices. For those PWDs living in households that have other forms of income, it may be possible to fund such travel costs out of the monthly disability grant. However, for those households where the disability grant is the only form of regular, reliable income, covering such costs would be extremely difficult. This would suggest that for those PWDs living in peri-urban settlements, the cost of transport is something that can prevent PWDs from taking advantage of training-into-employment opportunities and thus, breaking the cycle of poverty.

The attitude of taxi drivers towards PWDs was something of which the workshop participants were particularly critical. Taxi drivers either refuse to pick up PWDs or are impatient as they are getting in and out of the taxi. The refusal of taxi

<sup>&</sup>lt;sup>44</sup> Through a series of focus groups, the CSIR transport study developed a comprehensive list of access issues faced by people with different types of disability. The issues raised by EE participants had also been raised by focus group participants.

drivers to pick up PWDs has a number of implications. For example, Musa Chilwane from Stanza Bopape has had a leg amputated and uses crutches. He often has to wait a long time until he finds a taxi driver who is willing to take him as a passenger. However, due to his disability, he finds it difficult to stand for a long time. Workshops participants told us that it is especially difficult to find a taxi driver willing to take them between 7 and 10 o'clock in the morning during the commuter rush hour. This means that PWDs are unable to take jobs in the city centre, or even attend training courses that require strict attendance, as there is no reliable form of transport available to them. A number of PWDs mentioned that one of the outcomes of the taxi drivers' attitude is that they are always late for appointments at the city centre hospitals. We went to discuss the issues raised by the EE participants with an association of taxi drivers working in the Saulsville area. A summary of the discussion is presented in Box 5.

# Box 4: Case Study Highlighting The Interaction Of Physical, Social And Financial Barriers

Emily Radebe is 78 and lives with her 34-year-old daughter and three grandchildren (ages 1, 9 and 14) in a one-room shack in an informal settlement in the Hammanskral area. Two years ago her vision deteriorated and she found it increasingly difficult to walk. She now uses a walking frame and is only able to move around the plot without help. Despite her disability, Emily continues to cook and do the washing for the entire family.

Her daughter only has occasional employment, and therefore Emily's old age pension of R620 per month is the only regular support for the entire family, including sending the two eldest children to school.

Emily has a limited social life. She never visits friends or family beyond her immediate neighbourhood, and friends and family come to visit her on average once a month. As she now finds it difficult to read and the household has no television, Emily's only source of entertainment is the radio.

One place that Emily does like to go is the luncheon club for pensioners that is held at the local community centre every week. This club provides a free hot meal for any pensioners that turn up. However, getting to the luncheon club is a problem. Firstly, in order to get to the community centre Emily needs to take a taxi. The path from her house to the main road is steep in places and rocky. It also becomes muddy from households throwing out their washing up water onto the public path, which has no drainage. She therefore needs someone to help her walk down to the main road, and if her grandchildren are at school, her daughter working and her neighbours unavailable, she has to stay at home.

Once she gets to the main road to hail a taxi, she faces other problems. The taxis are not designed to be accessible to people with disabilities and she finds it difficult to get in and out of the taxi and find space to put her walking frame. The drivers are sometimes impatient. Even if she can find someone to help her down to the road and into the taxi, another barrier to Emily getting to the club is limited finances. Some weeks there simply is not enough money to cover the 10R return fare. Once Emily gets to the community centre, she faces another barrier. Although she can get into the centre itself, the toilet at the centre has been built with stairs going into it, and therefore, it is difficult for her to use it. It is clear that Emily faces financial, social and physical barriers when she tries to make a simple trip to her local community centre

House	⇒ Taxi	i <b>⇒</b>	<b>Community Centre</b>
Physical	Physical	Physical	
	Soci	al	
	Economic		

#### BOX 5: Why Don't Taxi Drivers Pick Up PWDs?

Key points from a meeting with executive members of ASTOA (Atteridgeville/Saulsville Taxi Owners' Association)

Taxi drivers know that often PWDs are not picked up, and that there has been no effort on the side of the Taxi Owners' Association to address the problem. But no one from the community has ever raised the problem with the committee before.

The drivers' negative attitude towards PWDs might be attributable to various reasons:

- It takes a long time to pick up a PWD particularly those with a locomotor disability, as they are slow to get in a taxi, and folding up a wheelchair is time consuming
- Some passengers and drivers are scared of PWDs.
- Taxi owners expect drivers to reach a certain target at a certain time during the course of the day (the taxi industry is profit-oriented).

Some of the members felt that educating drivers on disability issues is of utmost importance; particularly if an outsider conducts training, as the drivers do not always conform to what the owners say. Others felt that there is no guarantee that the education imparted on drivers would be applied. One executive member highlighted that if there were a specific day when a group of PWDs would like to go to a certain place, taxis could be made available for this. The interviewer pointed out that this would be of little help as PWDs have different errands to run like people with no disability in their own time (e.g. even in the case of collecting grants and medication, each person is given a different appointment time).

The interviewer emphasised that PWDs are entitled to same rights and treatment like able-bodied people. One executive member stated that the association has the interest of PWDs at heart, but it is difficult to cater for them because the newer-model taxis do not have boot in which to put wheelchairs. The interviewer pointed out that she had observed that 95 per cent of their taxis are VW microbuses and the space in the boot is used to store groceries of other passengers, and is sufficient to accommodate a wheelchair.

One executive member stated that if there were a financial incentive to pick up PWDs, the taxi drivers would be more motivated to stop. The interviewer asked whom he thought could provide such incentives, but he did not have any ideas. The interviewer emphasised that they should take into consideration that the majority of the PWDs are unemployed and rely solely on their disability grant for survival.

#### **Recommendations for Improving Access to Buses and Taxis**

Getting on and off buses and taxis

There is currently only one accessible commuter bus in Gauteng Province<sup>45</sup>. PUTCO (Public Transport Company) recently invested its own money in developing an accessible bus as a part of its social responsibility policy. The bus has a wheelchair lift and space for four passengers in wheelchairs. The bus drivers have been trained by the Dept. of Social Services in assisting people with a range of disabilities. The EE participants found the bus much easier to use than the normal model, and commented on the sensitivity of the drivers. As there is only one bus like this operating in the area, its impact on the life of PWDs is currently limited. At the Enabled Environments workshop in Pretoria in September 2002, the representative of PUTCO stressed that in order to build more accessible buses, they will need government support.

The national government has plans to scrap and recapitalise the current fleet of minibuses. The proposed overhaul of the current unregulated, private taxi system includes a new vehicle design that will have access features such as ramps and low steps (Mail and Guardian Online, November 1, 2002)

Accessible transport is clearly vital if PWDs are to fully participate in social, employment and educational activities in the wider community. Therefore, the provision of more accessible public transport is an urgent need amongst PWDs on low incomes.

#### The cost of regular travel by public transport

Guatrans (Gauteng Provincial Office of Transport) currently offers concessions on municipality buses to scholars and the elderly. The cumulative cost of repeated bus journeys makes it impossible for those PWDs who live in households where the disability grant is the only regular source of income to afford to take regular bus trips. Guatrans should consider concessions for PWDs.

#### The attitude of taxi drivers

The group discussion with ASTOA members (see Box 5) highlights the key reasons why taxi drivers often refuse to pick up people with disabilities. The time taken for somebody to enter a taxi, especially when a wheelchair has to be stowed away, is seen to take up too much time and therefore reduce profit levels.

<sup>&</sup>lt;sup>45</sup> The Johannesburg Metropolitan has purchased 15 access buses (double deckers) to integrate both PWDs and able-bodied people. Although they started operating late in 2002, they operate from the city centre to the surrounding suburbs and therefore, do not go to the townships where the majority of PWDs are residing. These buses were used last year during the International Day for PWDs to transport PWDs in areas around Gauteng (including Pretoria).

Participants had also experienced impatience from passengers. The idea of being scared of people with disabilities points to the continuing misinformation and knowledge gaps that exist amongst the public.

There is also a proposal for training of the drivers of the new style taxi to include sensitivity training on disability issues (Venter, 2002, p15). Whether or not this training succeeds in overcoming the problems currently experienced by PWDs will depend very much on the nature of the training.

This issue was discussed at the workshop in Saulsville, and the following points were considered to be key to ensuring that any form of training has an impact upon taxi drivers and non-disabled passengers.

- Community-based
- Dialogue/interaction between PWDs and drivers
- Awareness raising amongst general members of public also
- Opportunity for regular dialogue between users and providers at a later stage to assess the effectiveness of training

We would argue, as for any other awareness raising or training related to disability, that PWDs who live in the local community should be involved in the process.

## **Barrier-Free Access in the Physical Environment**

#### The Nature of the Problem

The White Paper on Integrated National Disability Strategy (1997) calls for 'Barrier Free Access' and focuses on four particular aspects of the physical environment (p.30):

- 1) structural barriers in the built environment e.g. flights of stairs, inaccessible toilets and bathrooms, high kerbstones and uneven pavements
- inaccessible service points e.g. bank/shop counters, public telephones, ATMs
- 3) inaccessible entrances due to security systems e.g. turnstiles, microphone loudspeaker systems

- 4) poor town planning e.g. schools, clinics positioned at the highest points in town, narrow pavement areas
- 5) poor interior design e.g. fixed seats in restaurants, clustered rooms

In 1997, when the White Paper was published, the concept of barrier free access for PWDs was not new in South Africa. Part S of the 1990 Code of Practice for the Application of the National Building Regulations outlines facilities for PWDs inside public buildings. The 1993 Code of Practice on the Accessibility of Buildings to Disabled People outlines regulations for external built environments and should be used in conjunction with Part S. However, the White Paper of 1997 recognises that these regulations have been badly administered and monitored. The reasons for this failure are, according to the White Paper, 1) there are insufficient accessibility specialists in South Africa, 2) not enough planning specialists understand the specific details required for building an accessible environment, 3) development agencies have not developed clear policies on environmental access and 4) new public buildings are being constructed without accessible design principles being incorporated (Integrated National Disability Strategy, 1997, p.30).

The key accessibility issues raised in the workshops were:

#### Roads

- Roads are uneven, muddy, rocky, unsurfaced locomotor and visual disabilities
- Crossing busy roads all disabilities (especially in Hammanskral)
- No pavements means at risk from drivers locomotor, visual, hearing disabilities
- Steep kerbs at traffic lights locomotor, visual disabilities (Hammanskral)



An uneven road running through an informal settlement in the Saulsville area.

# **Buildings and Service Points**

- Inaccessible public toilets locomotor disabilities
- No dedicated seats for disabled at pension office (Stanza Bopape)
- Access by stairs only into key buildings e.g. bank, school, clinic, railway station locomotor disabilities
- Public phones and ATMs set too high for wheelchair users

# Peter, a wheelchair user from an informal settlement in Saulsville.

Peter visited his local general store to assess accessibility. He found that it was difficult to turn corners due to stock being kept in the aisles, and the shop owner agreed to move the stock. Products on the top shelves were difficult to reach and he could not reach products that were at the bottom of the freezer.



Notably, many of the aspects of the physical environment listed in the White Paper in 1997 are mentioned by the EE participants in workshops held in 2002, e.g. steps, toilets, curbs, pavements, service points, no suitable seating. This suggests that despite renewed efforts to create more accessible environments in 1997, there has been little done to improve accessibility in low-income peri-urban communities.

Whilst one might expect there to be muddy, uneven roads running through informal settlements, what was clear from the workshop findings was that even in new formal developments insufficient attention is given to integrating barrier-free design features. For example, Mandela Village in Hammanskral was upgraded in 1995. Yet, despite the development being so recent, the high kerbs (built to prevent flooding during the rain) have no kerb ramps built into them. This makes it difficult for wheelchair users to cross the road and potentially dangerous for those with a visual disability, as there are no guiding blocks<sup>46</sup>. At various points in the formal RDP settlements in Stanza Bopape and Saulsville, there are no payements and pedestrians are forced to walk at the side of the road. Workshop participants mentioned the fact that the roadsides may be uneven or there may be rubbish blocking their route. For someone with limited mobility, veering out into the busy road to avoid an uneven surface or obstacle is particularly dangerous. For those with visual or hearing disabilities, they may be unaware of oncoming traffic. UN guidelines stress that 'pedestrian walkways should be as far as possible from vehicular traffic' (ESCAP, 1995, p.64). At a national level, the Guidelines for Human Settlement Planning and Design (CSIR, 2000) similarly stress the need for planning to take into account pedestrian movement through a settlement.

Ideally, the workshops would have included fieldtrips to document the accessibility of each of the problem areas mentioned. However, as explained in Chapter 3, there were logistical reasons why this could not be done. Instead, a small group of EE participants made a fieldtrip in the Saulsville area to look at three key public buildings (the train station, the police station and the community centre). They were accompanied by the researcher and accessibility expert, Amanda Gibberd. Highlights from the fieldnotes are presented in Box 6.

# The Current Limitations of Planning Legislation and Guidelines

In order to understand why, despite the existence of the 1986 Section S of the National Building Regulations and the associated 1993 Code of Practice, many aspects of the built environment continue to be inaccessible to people with disabilities, Enabled Environments commissioned accessibility expert Amanda

<sup>&</sup>lt;sup>46</sup> Ideally, blocks with raised dots should be used to give warning of a drop-off or a junction. Line-type blocks are used to indicate the correct route to follow. (ESCAP, 1995, p.77)

Gibberd to write an analysis of the current legislation<sup>47</sup>. Gibberd's key findings can be summarised as follows:

# 1) Current Guidelines and Legislation Do Not Consider Access for All Types of Disability

The Guidelines for Human Settlement Planning and Design (CSIR, 2000) stresses the importance of designing settlements with the pedestrian in mind. However, consideration of the disabled pedestrian is limited to references to ramps and access for paraplegics (Chapter 5.3), consideration of wheelchair users (Chapter 5.4), and 'sloped openings in kerbs' (Chapter 8). Wheelchair users are not the only PWDs whose needs must be integrated into planning. In a country where the most common disability is sight impairment, there should be a greater consideration of people with sight disability as well as hearing disability and other forms of locomotor disability that result in the use of different assistive devices. (Gibberd, op. cit., p.32)

Part S of the *National Building Regulations* (South African Bureau of Standards, 1990) fails to consider the misuse of reflective and misleading surfaces, or the use of tonal colour and contrast, which affect people with sight impairments and people with intellectual disabilities. There is no guidance on signage or wayfinding except where it relates to facilities for wheelchair users. Therefore, the physical environment needs of people with sight, hearing and intellectual disabilities and those people with locomotor disabilities who do not use a wheelchair are overlooked. (Gibberd, op.cit, p.44)

#### 2) Incorrect and Incomplete Technical Information

The Guidelines for Human Settlement Planning and Design (CSIR, 2000) do not consider roads, pavement design or surface material adequately in relation to people with disabilities. The use of brick paving should be discouraged as the texture and patterns can be confusing for people with sight impairments and people with intellectual disabilities. The layout and placement of pedestrian crossings are very important in creating barrier-free environments but are not discussed in any depth. Ramp guidance is incomplete and stair and step guidance does not take disabled pedestrians into account (Gibberd, op. cit., p.32)

Part D of the National Building Regulations relates to public safety and argues that 'any ramp or driveway shall be so designed so that it is safe when used and is fit for the persons for which it is intended', and suggests a gradient of 1:8. Gibberd (op. cit., p.41) points out that such a gradient is too steep for wheelchair users. There is also no indication of the length of the ramp or where landings should be placed. The 1993 Code of Practice on Accessibility of Buildings to Disabled People (SABS 0246) provides more comprehensive guidelines, but there

<sup>&</sup>lt;sup>47</sup> Amanda Gibberd (2001) Legislation and Policy relating to People with Disabilities in terms of Design and Management of Housing and the External Built Environment in South Africa Available from Boutek, CSIR, Pretoria

are still 'various ambiguities, misleading guidance and areas that conflict with current research' (Gibberd, op. cit., p.46). It is not clear where the design requirements included in Part S or in SABS 0246 were taken from.

# 3) The needs of people with disabilities are not fully integrated into general planning guidelines and regulations

The Tshwane Integrated Development Plan (IDP) outlines areas of future development under the four headings of Physical, Social, Economic and Institutional. One of the themes listed in the introduction is 'accessibility', but there is definition or indication of whether this includes accessibility for people with disabilities. Projects for people with disabilities are categorised as a social issues and there is no recognition of the need to integrate the needs of PWDs into all physical planning as opposed to isolated projects. (Gibberd, op. cit., p.36)

The National Buildings Regulations has a separate section on people with disabilities, Part S, as opposed to integrating consideration for people with disabilities into the generally applicable sections<sup>48</sup>. 1993 Code of Practice on Accessibility of Buildings to Disabled People (SABS 0246) also stands alone from other planning legislation.

# 4) Legal requirement is not stringent enough to ensure that planners, architects and builders include accessible features

Under the National Building Regulations, designer and builders are under a legal obligation to meet the guidelines, unless it can be shown that the standard has been met by alternative means. However, as regulations relating to PWDs sit in a separate section the legal requirement to comply with the regulations in general does not ensure accessibility. Part S, which does relate specifically to disability, seems to come with a 'get-out clause', as it states that 'economic considerations may make it difficult to provide facilities in all buildings'. Furthermore, the guidance in Section S does not apply to dwellings and therefore, there is no requirement that designers and builders involved in constructing dwellings take note of Part S.

The status of the 1993 Code of Practice on Accessibility of Buildings to Disabled People (SABS 0246) is ambiguous. SABS 0246 was published after the National Buildings Regulations and is more comprehensive than Part S. Designers and planners refer to the National Building Regulations for legal requirements, yet the Promotion of Equality and Prevention of Unfair Discrimination Act (Clause 5(2)) makes it clear that SABS standards must not be contravened and override other conflicting laws, such as the content of Part S. (Gibberd, op. cit., p.46).

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<sup>&</sup>lt;sup>48</sup> Sections that should integrate the needs of people with disabilities include Part C: Dimensions /Part D: Public Safety/Part K: Walls/Part M: Stairways/Part N: Glazing/Part O: Lighting and Ventilation.

The South African Human Rights Commission's (SAHRC) (2000, p.28) review of built environment legislation and disability also highlighted the point that there is currently insufficient enforcement of Part S by building control officers which has resulted in the majority of public buildings in South Africa being inaccessible.

The Less Formal Township Establishment Act of 1991 was brought in to facilitate the rapid construction of low-income settlements in order to encourage development and stimulate the economy. The Act allows the local authority to give permission to the developer to bypass legislation relating to town planning and building. This act provides developers with a means of bypassing any legislation relating to barrier free environments for people with disabilities. As only 5 to 7 per cent of the population of any proposed settlement may be disabled, a planner would be able to argue that bypassing regulations would have an impact upon the lives of a small percentage of the population. The current housing policy of broad coverage as opposed to depth i.e. providing the minimum for as many people as possible, may support such an argument.

#### Recommendations

It is clear from the issues outlined above that planning legislation and guidelines in South Africa fail to fully integrate the needs of PWDs through barrier-free design requirements. National design guidelines need to be rewritten so that they include correct, up-to-date technical information and consider the comprehensive needs of all people with disabilities. In order to achieve barrier-free environments, guidelines relating to access for PWDs should be integrated into general guidelines under appropriate headings, rather than being set apart. The legal requirement to comply with accessibility guidelines needs to be made much clearer. The SAHRC report (2000) recommends that legislation must be regularly updated, strictly monitored and imposed, and the repercussions of non-compliance made much clearer.

Whilst it is hoped that the SAHRC report will finally bring about the muchneeded review of the building regulations that was initially called for in the White Paper in 1997, such a review will clearly take some time. Meanwhile, RDP settlements that fail to include barrier-free design elements will continue to be developed and PWDs on low-incomes will continue to find themselves unable to move about their communities.

As explained earlier, responsibility for approving RDP housing projects rests with the provincial housing MEC (Member of the Executive Council) and the provincial housing department. Therefore, provincial governments should take responsibility for ensuring the designs for new RDP settlements and community buildings incorporate accessibility features. The *Guidelines for Human Settlement Planning and Design* (CSIR, 2000) are currently accepted nationally as a blueprint for successful settlement design and the document has a high profile

amongst relevant professional and government sectors. Yet, as explained above, these guidelines do not currently include all aspects of barrier-free design.

Rather than waiting for changes in legislation, the EE project recommends that research be undertaken to review the guidelines with reference to RDP settlements. Such a research project would involve multi-stakeholder consultation i.e. not only with government representatives and construction professionals, but also with community members. There would need to be detailed analysis of the cost implications of incorporating barrier-free design elements. One of the main reasons given for not incorporating accessibility features is cost (and the loophole in Part S seems to support this assertion), yet 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). The project should also look at ways raising awareness of accessibility amongst low-income PWDs in order that they can begin to fight for these changes themselves.

# **BOX 6:** Edited Fieldnotes – Saulsville Accessible Environment Fieldtrip 5 February, 2002

Participants: Bra Cry Maloba (community facilitator, wheelchair user); Beauty Magolego (uses a walking frame); Buti Malepa (wheelchair user) Mirriam Sibisi (uses a walking frame plus low vision); Sammy (volunteer at Bophelong clinic); Amanda Gibberd (accessibility expert); Gertrude Matsebe (researcher)<sup>49</sup>

# 1. Saulsville Railway Station

The entrance to the ticket counters was inaccessible for those with locomotor disabilities because the access was by a steep flight of stairs (see photo x). At the top of the stairs, there is a narrow passageway: Amanda took measurements of the passage and found it was not wide enough to accommodate a wheelchair, or a person using either walking frame or crutches. Staff mentioned that few PWDs used the station: when they do, fellow commuters, friends or railway employees assist them. Amanda pointed out that whilst help for PWDs was appreciated, people were putting their own health at risk by carrying PWDs and wheelchairs.

When a train pulls into the station, there is a gap between the platform and the carriage door.

The staff member thought this was a minor issue because the gap is small, but Amanda pointed out that the front wheel of a wheelchair could get caught in the gap and endanger the life of a wheelchair user. The toilets at the station were not accessible.

#### 2. Attridgeville Police Station

Attridegeville Police Station was made accessible after Bra Cry became involved in the planning process the previous year. As only one of the field trip participants had visited the station after the changes, the group were keen to assess how successful the alterations had been.

The cells are far away from the front desk and some of the participants had problems in getting there. For instance, Beauty complained of the long distance and getting tired. Amanda highlighted that the floor surface of the corridor was accessible in that it was non-slippery, but she criticised the positioning of the poles supporting the roof as a barrier for visually impaired persons. She also highlighted that the narrowness of the passageway. She also recommended that grabrails be added to the outside walkway.

The gradient of a ramp to the cells was a rather steep: both Buti and Bra Cry needed assistance. On our way to an empty cell, we passed through cells full of

<sup>&</sup>lt;sup>49</sup> The intention had been to include people with a greater range of disabilities, but no one was available on the day.

law offenders. There is a walled toilet and shower block inside the cell. Bra Cry found he could enter the toilet with his wheelchair, but the shower was inaccessible because of the low wall around the edge.

Back at the admin/main block, we were taken to another toilet designed for PWDs. Amanda commended the architects. The following features attributed to its outstanding rating:

- ➤ Door opens outwards and does not have a key operated lock
- Door handles are easy to grip.
- ➤ Handrails are easy to reach.
- > Position of the switch is reachable.
- > Adequate manoeuvring space.
- Hand basin is reachable.

We proceeded to the charge room, where Bra Cry showed us the lower counter made specifically for PWDs who cannot stand. However, there was no seating area for a wheelchair user reporting a crime, as there was a fixed chair in the place where a wheelchair was supposed to fit.



Wheelchair users, Bra Cry and Pintius find that the platform at the railway station in Attridegville is inaccessible as there is no alternative to the steps.

# **CHAPTER 7**

# EDUCATION, TRAINING AND EMPLOYMENT

The White Paper on Integrated National Disability Strategy (Office of the Deputy President, 1997) highlights the failure of both the education system and the job market in South Africa to fully integrate people with disabilities and offer them equal opportunities. Since the publication of this document, there have been a number of policy initiatives to address these problems, including White Papers on early childhood development and inclusive education and the introduction of equal opportunities legislation that aim to facilitate access to education, training and employment by PWDs. Enabled Environments was interested in exploring the participants' experiences of exclusion in these areas and using these experiences to reflect on the potential for current policy initiatives to reach PWDs living in poverty.

#### **Education**

#### A New Inclusive Education and Training System for PWDs in South Africa

According to the 2001 White Paper on Inclusive Education and Training, the key problem with the current form of education provision for PWDs is that support for learners with disabilities has been too limited in scope. Only a small percentage of PWDs are served by special schools; under the Apartheid system black PWDs received few educational resources, the curriculum and the system overall are simply too rigid to cater to the various learning needs of the learner population resulting in a high rate of drop outs, and there has been much focus on education within schools but little thought given to other levels of learning.

Current estimates are that special schools cater for only 20 per cent of learners with disabilities, and that potentially 280,000 learners with disabilities are unaccounted for (Department of Education, 2001, p.9). In response to these problems, the Department of Education has developed a framework for creating an inclusive education and training system. This framework is based on the social model of disability and understands that 'learning disabilities arise from the education system and not the learner' (Department of Education, 2001, p.12). Under this system, there will be three types of schools: ordinary, full-service and special. Learners that require low-intensive support will receive this in 'ordinary' schools, and those requiring moderate support will receive this in 'full-service' schools. Full service schools and colleges will be equipped to provide for a full range of learning needs. Learners who require high-intensive educational support will continue to receive such support in special schools. Full-service schools will have a bias towards particular disabilities, and special schools will serve as resource centres for other educators in the area.

White Paper 6 argues that the curriculum is one of the most significant barriers to learners with disabilities. The content, the medium of instruction, teaching

methods, materials and assessment methods can all be exclusionary, and White Paper 6 calls for greater flexibility in the delivery of the curriculum.

### The Educational Experiences of PWDs in Enabled Environments

30 per cent of the Enabled Environments sample is made up of PWDs who are 18 or under. Of this group, 71.5 per cent were of school going age and were attending school, 16 per cent were of school going age and not attending and 12.5 per cent were pre-school age.

Whilst our sample of children with disabilities is very small, and peri-urban, it is important to note that the problem of exclusion of children with disabilities from school was not as great as estimated for the whole country. The Department for Education estimates that 80 per cent of children are unaccounted for within the educational system. (Gauteng is the province with the greatest share of special education provision (25 per cent) in the country.)

The Disability in Children Action Group (DICAG) of South Africa<sup>50</sup> has worked with communities to examine the problems encountered by children with disabilities (CWDs) in the education system. This section uses DICAG material to identify potential shortcomings in the integrated education model currently proposed. As there were only 7 cases in the EE sample of CWDs of school going age who were not attending, it is impossible to draw any statistical conclusions from the data set. However, the individual experiences of these 7 children do highlight some of the potential shortcomings of the current policy, and there clearly needs to be more research that looks at the educational experiences of children with disabilities.

#### Why do learners drop out or fail to enter the education system?

White Paper 6 sees the main reason for dropouts as the failure of the education system to accommodate a wide range of learner needs. The curriculum is identified as the main barrier to learning. The paper also suggests that the parents of 280 000 children with disabilities are choosing to keep their children away from school because they do not understand the value of education for children with disabilities. The suggested response is a public education campaign to inform and educate parents and a programme to support special welfare needs, including providing devices such as wheelchairs and hearing aids.

The work of DICAG has identified a broader range of reasons, and the parents of the 7 EE children outside the education system also gave reasons other than those outlined in the White Paper. DICAG agrees that the rigidity of the curriculum and the attitudes of parents play in a role in preventing CWDs access to education. Some parents resist the offer of help from DICAG because they do not want people to know that they have a disabled child for fear of victimisation, or they do

<sup>&</sup>lt;sup>50</sup> All DICAG material can be found at http://www.eenet.org.uk/parents/stories/dicag

not believe that their children are capable of benefiting from education. However, DICAG has found that parents' attitudes stem from the considerable isolation and negative social attitudes parents of CWDs face both from their communities and service providers.

The White Paper fails to identify the role of service providers as a barrier to learners with disabilities receiving a full education. According to DICAG, resistance to inclusive education has come from educators in special schools,

"Many educators in special schools have resisted the idea of inclusion. Parents who promoted and advocated in favour of inclusion were subjected to many threats and under-hand tactics. Staff in residential education referred to the concept as "preposterous"! Managers of special institutions funded by public money protested most loudly in defence of their "white elephant empires"! "

DICAG's work has revealed that children with disabilities also find it difficult to transfer from a special school to a mainstream school, if they wish to. When children with disabilities want to continue beyond Grade Seven, the curriculum is not compatible with their needs and, as a result, many children remain at home, unable to complete their education. DICAG also highlights the problem of abuse of learners in special schools, which they are currently looking at in more depth.

Two of the children in the EE sample were kept away from school because of their parents did not feel a child with a disability could thrive. However, the other examples outlined here illustrate a wider number of reasons than those identified in White Paper 6:

#### Lack of Information

One mother of a 14 year old with an intellectual disability had never heard of the special school system, and had assumed that no school would accept her son.

#### **Overprotectiveness**

The parents of one 10-year-old wheelchair user believed their son could not cope at a mainstream school and had received no support or advice concerning their son'd education.

# Dissatisfaction with Special School System

Two parents of children with intellectual disabilities, both in receipt of care dependency grants, did not send their children to school because they both felt there was no local special school that was good enough.

#### Rejection by Mainstream Education

This was a key issue raised by parents who participated in the Hammanskraal workshop. Children with disabilities were rejected by the local crèche, because parents of able-children had threatened to withdraw their children. If children with disabilities are not given access to pre-school education, their skills may be less developed than those of their peers when they start primary school.



A pre-school in Saulsville

We also found a reverse case where a child was rejected by the local special school and then maintained in a mainstream school, even though the child was not coping. After the workshop was conducted in Hammanskraal, two volunteers from the rehabilitation clinic visited a school for the Deaf to lobby for the admission of one of the children with speech problem. The school promised to admit the child in 2002 (as it was already late towards the end of the year). However, when the mother took her daughter to the school at the beginning of the year in 2002, she was refused admission because she was not categorised as Deaf. The mother then took her to the local mainstream school where her daughter was reported not to be coping 5 months after admission. She was kept at the school however, for the sake of conforming to the current Integrated Education policy.

# Money

Two children with locomotor disabilities were said not to attend because the household could not afford it. One case was an only child living with her parents, both of whom were unemployed. There was no regular income coming into the household. In the second case, a 14-year boy lived with his parents (both unemployed) and his four sisters. His eldest sister is 21 and also unemployed. Of his other three sisters, one is of pre-school age, whilst one is 9 and the other 17: these two sisters both attend school. The only income coming into the house on a regular basis is the boy's disability grant.

# **Reflections on the Integrated Education Strategy**

Enabled Environments did not focus exclusively on education and the following issues are raised as suggestions for further analysis, rather than evidence-based recommendations:

#### The Need for a Broader Public Education Campaign

The White Paper calls for a public education campaign aimed at parents of children with disabilities. However, as DICAG has pointed out, the attitudes of parents do not exist in isolation but result from attitudes and prejudices in the wider community. As the experiences of parents in Hammanskral show, even when parents want to integrate their child into mainstream education or preschool, it can be the attitude of other parents and/or teachers that cause the child to be excluded. Any public education campaign should also target the staff of community-level crèches and parents of children with no disabilities. DICAG have also found that the most effective way to raise awareness is through door-to-door contact at community-level, and therefore any leafleting or media campaign would need to be supported by community-level workers in order to ensure effectiveness.

The introduction to White Paper 6 assumes that for those children with disabilities who are not attending school the problem is one of parents' keeping them isolated from the rest of the community. However, as the comments of some of the parents of children involved in Enable Environments demonstrate, schools are not always seen as positive educative and social spaces. DICAG has also come across examples of abuse within the education system. In global studies of education, non-enrolment has been shown to be linked to the poor quality of education on offer rather than a failure of parents to value education. There is no reason to assume that parents and children with disabilities do not similarly assess the quality of the education that is available, and make rational choices about whether or not to invest scarce household resources. A public education campaign about the importance of giving children with disabilities an education may fail to reach parents who have made a decision to withdraw or not enrol their children on the basis of quality.

# Lack of Adequate Information on Children with Disabilities

White Paper 6 calculates that potentially there are 280 000 learners with disabilities who are not accounted for in the education system. The paper arrives at this figure by working out the number of learners with disabilities as a percentage of learners in the school system. The WHO estimates that in every school system between 2.2 and 2.6 per cent of learners will have a disability. In South Africa this is a maximum of 400 000 learners. The paper then subtracts the number of learners with disabilities who are accounted for in the country's 380 special schools (64 200), and thus arrive at the figure of 280 000.

Although EE's sample is very small, it does suggest that these estimates may fail to truly represent the educational experiences of children with disabilities. 71.5 per cent of children participating in EE attended school, whilst government figures estimate that 80 per cent of children with disabilities are outside the education system. Is it possible that a greater number of CWDs are currently educated within the mainstream education system than is known?<sup>51</sup>

The education system needs to systematically monitor and evaluate access to mainstream schools children with disabilities. The current White Paper seems to have been based on incomplete information. Furthermore, in order to assess the effectiveness of the Integrated Education Strategy in the future it is necessary to define the current status of children with disabilities in the mainstream system. Due to the potential financial barrier to education for children with disabilities living in poverty, any study should not automatically assume that a child with a disability is excluded because of their disability.

#### School as a Physical Environment

White Paper 6 recognises the creation of fully accessible and safe environments as key to the success of the inclusive model. Cost-benefit analysis has shown that the initial investment in creating accessible schools will benefit society at a later stage, as children with disabilities will become economically active adults. The physical environment of most ordinary schools and learning settings is not barrier free and planning for accessibility is inadequate (p. 28). As an example it cites a job creation programme by the Dept of Public Works to provide ramp access for learners on wheelchairs to schools (p. 27).

This is a rather narrow understanding of accessible environments. As discussed in chapter 5, efforts to create accessible environments often focus on wheelchair users and ramps. Colour contrast for those with low vision, use of textured surfaces for those who are blind, visual representations of sound (for example, the school bell) for those pupils who are deaf, classrooms with appropriate acoustics for those with impaired hearing, the organisation of physical spaces in such a way that they allow the free movement of those with locomotor disabilities – all of these factors and more will need to be considered under the government's commitment to inclusive environments in education.

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<sup>&</sup>lt;sup>51</sup> We discussed this issue with Department of Education officials and could not get a clear answer. The individual officials felt that the figure of 80 per cent of CWDs being outside the education system was based on out-of-date information collected before the policy of integration was introduced, and therefore incorrect. Based on personal experience, they believed that the number of CWDs in mainstream schools had increased considerably, particularly in low-income and rural communities. However, there seems to be no system in place to monitor the success of the new education policy.

#### The Cost of Education

Two of the children in EE were not attending school due to the limited financial resources of the family. Yet, the Inclusive Education Strategy does not recognise that financial barriers may be the reason why some CWDs do not attend school. In the case of one child, his parents seem to have prioritised the education of their two non-disabled children over the education of their son in a wheelchair. However, with a monthly household income of R650 and another child coming up to school age, even if his parents were convinced of the importance of educating their son, would they be able to afford to educate all their children? Talking to parents in Mamelodi, they calculated that additional school costs totalled approximately 650R per year per child.<sup>52</sup> How many more children with disabilities in South Africa are kept away from school due to limited family resources? A bursary system may be necessary to ensure that CWDs living in low-income families have the opportunity of an education. Any assessment of the success of the integration policy needs to look at the issue of household resources and access to education by CWDs. It is important to recognise that the choice of parents to not invest in the education of a child with a disability, or not to place as much importance on that child's education as that of his/her able-bodied siblings does not necessarily indicate ignorance or prejudice towards children with disabilities. For families with very limited resources, the expectation that a child with a disability is less likely to find a job after school may make non-investment in his/her education a rational economic decision (Ashton, 1999). It is the responsibility of the state to ensure that the economic decisions of the family do not result in the right of a disabled child to receive an education being denied.

# **Employment and Training For Adults with Disabilities**

A key concern raised by participants in the workshop was that of unemployment. This is not surprising as statistics show that there are relatively few job opportunities for PWDs in the open labour market: in 2001 99 per cent of people with disabilities in South Africa were unemployed (SAPA, 2001, Dec 2). Whilst discrimination based on gender and race in the workplace has decreased in the 1990s, there has been less focus on discrimination against people with disabilities (Pretoria News, 2001, December 4). This is borne out by the fact that employment opportunities for PWDs in 2001 seemed to be on a downward trend: a study of over 150 000 employees in 100 companies found that the average representation of PWDs in the workforce had declined from 1.02 per cent in 2000 to 0.93 per cent in 2001 (SAPA, 2001, Dec 2).

However, although the employment prospects for PWDs in South Africa are bleak, there have been some positive changes in the last couple of years. The government has responded to the issue of equality in the workplace for PWDs with a mixture of guidelines and legislation. In 2001, the *Code of Good Practice*:

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<sup>&</sup>lt;sup>52</sup> Uniform @ 450R; School fees @100R; Books @ 100R

Key Aspects of Disability in the Workplace was published and aimed to advise employers on how they could act upon legislation contained in the Employment Equity Act (The Star, 2001, July 24). The Employment Equity Act (55) introduced in 1998 aims to achieve equity in the workplace by eliminating unfair discrimination and implementing affirmative action measures to redress disadvantages in employment experienced by designated groups (blacks, women and PWDs). The act requires every employer with a workforce of 50 or more and turnover above a certain amount to introduce affirmative action to achieve certain levels of representation of each designated group in their workforce (February, 2001). PWDs should constitute 1 per cent of the workforce. As a result, South African employers are now actively seeking to employ people with disabilities, and unprecedented job opportunities have been created (Kinghorn, 2001). Telkom, the South African telecommunications parastatal, made a public commitment to ensuring that at least 1 per cent of its workforce would comprise people with disabilities by March 2002 (Pretoria News, 2001, December 4). The burgeoning call centre industry in South Africa has also been seen as a potential recruiter of PWDs. It is estimated that the industry will create more than 100 000 new jobs by 2004, and some training is being directed specifically at people with a range of disabilities (Cape Times, 2001, Nov 12). In response to the need of South African companies to recruit more PWDs, there has also been a growth in the number of employment agencies dealing specifically with job placements for PWDs (Fick, 2001).

Is the new optimism regarding employment opportunities for PWDs reaching those marginalised PWDs living on very low-incomes in peri-urban areas? As far as the participants of EE are concerned, the answer is 'no'. Almost all the PWDs in our study continue to be unemployed: only one participant in EE was wage employed, one other was self-employed and four participants described themselves as occasionally employed. Most importantly, there is little hope amongst the unemployed PWDs of finding a job. Whilst almost 29 per cent of the adults of working age were unemployed and looking for work, a much greater percentage (60.3 per cent) of adults were unemployed and *not* looking for work.

Rather than ascribing this seeming acceptance of unemployment to disinterest in work, it would seem to be related to a sense of hopelessness. In the workshops, many participants expressed a desire to work but felt that both wage employment and self-employment were closed to them. They questioned why, when employment was so high for the general population, would an employer choose to take on a person with a disability for an unskilled entry-level position? Another issue that was mentioned in the workshops was a fear of losing the disability grant. In the current economic climate, retrenchment is common and some participants believed that if they took a job they would automatically lose their grant. Then, if they were made redundant, it would take time for the grant application to go through and the household may have no income coming in <sup>53</sup>.

<sup>&</sup>lt;sup>53</sup> People did not know that disability grant recipients can earn up to R800 per month before they must forfeit their grant. Any initiative aimed at getting low-income PWDs into work would need

Self-employment was considered positively. The group in Stanza Bopape were particularly interested in self-employment opportunities, but they saw a number of obstacles – namely, lack of vocational skills, lack of capital to get started and the issue of security (running a business from home can increase the risk of breakins).



EE participants from Stanza Bopape visited self-employment workshops for PWDs in other communities to get some advice on how to set up their own project.

# **Training and Employment Opportunities for EE Participants**

There are currently three main types of training and employment available specifically for PWDs: sheltered workshops, employment placement schemes and training courses with end qualifications. They are not mutually exclusive and one organisation may provide a range of services.

#### Sheltered Workshops

Near to Stanza Bopape and Saulsville there are sheltered workshops specifically for PWDs, which share a number of characteristics. They survive through contracts with local companies to complete labour intensive piecework. Such work involves sorting, assembling and packing a range of goods. For example, the APD workshop in Mamelodi has a bottle- and paper-recycling contract, whilst in Saulsville, assembling and packing silk flowers is a regular contract. Both workshops have problems finding contracts in the current economic climate, and pay low nominal wages of 100 Rand per week on average. As the work is repetitive, low paid and requires little training, the majority of employees in the Mamelodi and Stanza Bopape workshops have intellectual disabilities. Despite the repetitive, low paid nature of the work, there are waiting lists to join the workshop. The workshop in Mamelodi did provide training for PWDs who wished to work more independently. A number of PWDs had received training in sewing and knitting and now worked from home. The workshop was also about to start a course in conjunction with the Department of Transport and Public Works training young adults with disabilities in bricklaying and electrical skills.



Assembling plastic flowers at a sheltered workshop near Saulsville.

As well as local sheltered workshops, the Enabled Environment participants would also be eligible to attend a central workshop such as Employment Solutions, which is located in Pretoria city centre. As a central workshop, it still suffers from the problem of finding sufficient contracts, but has a wider range of contracts, employs people with a wider range of disabilities and has a greater number of employees. There are 101 people work in the workshop, and they currently have a waiting list of 187. All applicants have very low or no qualifications. The salaries range from 100R per month to 1200 R for working on higher risk tasks or working as supervisor.

The representative of Employment Solutions (ES) pointed out that problems finding new contracts were not only due to the economic climate: some unions had resisted work being contracted out to workshops such as ES. On one occasion a company wanted to contract out some work to ES, but the union blocked this because members believed that giving work to PWDs would lead to non-disabled workers being laid off. Interestingly, when the ES representative suggested that the union should take on PWDs as members as they would count as new employees, the union did not want PWDs in their union. In the end they had to go through two days of discussion for one contract and the union secured an agreement that a union member would always be present whenever the ES contract is discussed. This example shows how discrimination against PWDs is found not only in employers but also in the very organisations that should be representing PWDs rights in the workplace.

All of the workshops so far discussed were set up and are run by non-disabled professionals who set out to help PWDs. As the participants in Stanza Bopape were interested in setting up their own employment workshop, we also visited two workshops in the Johannesburg area that were set up by and are run by PWDs themselves.

T-SHAD (the Tembisa Self-Help Association of the Disabled) was set up be four people with sight impairment in 1989. They were motivated to form their own

organisation as they found the APD workshop where they were working at that time disempowering and exploitative. They were tired of able-bodied social workers doing things for them, and felt they were caught in a cycle of very low wages with no skills development that would allow them to gain employment on the open labour market in the future. The objective of T-Shad is to empower PWDs to play a meaningful role in the community, to provide quality services and products and capacitate PWDs to take up meaningful positions in the employment sector. It has affiliated to DPSA (Disabled People of South Africa). T-Shad accommodates all disability sectors in order to provide them with an opportunity to gain insight and understanding of each other's disabilities. PWDs pay a small annual membership fee and in return receive a variety of support services (e.g. grant advice, skills training). When they are employed on contracts that bring in a profit they are paid an average monthly wage of 250 Rand.

T-Shad has a range of activities including recycling, welding, vegetable gardening, and upholstery. They had previous projects in sewing, weaving, knitting and carpentry but these failed due to poor quality. Mr Manas, the director of T-Shap believed that the reason why many workshop ventures fail is inferior quality of goods and poor marketing. The other point he highlighted for EE participants from Stanza Bopape is that it had taken over 10 years for the organisation to reach a stage where it could pay monthly wages of 250R on a regular basis.

SHAP (Self-Help Association for Paraplegics) located in Soweto is the largest, most successful workshop we visited. Set up almost 20 years ago, it is now complete self-sustaining and has an annual turnover of 2.5 million rand. As well as the usual workshop activities such as recycling and metal stripping, it has two highly successful enterprises – one producing reflective safety wear for national and international clients and the other manufacturing underground cable for mining companies. As well as income-generating workshop activities, they run an adult education programme and computer courses for disabled and non-disabled. They also have a number of social groups – a choir, a basketball team and a marathon group.



Participants from Stanza Bopape interview workers in the cable production section of SHAP in Soweto.

## **Training and Employment Placement Schemes**

As mentioned earlier, with recent changes in South African Employment law large employers must ensure at least 1 per cent of their workforce is made up of PWDs. In response to this, there are now a number of organisations that specialise in finding jobs for PWDs.

There was only one local project in the EE areas, and this was based in Stanza Bopape. Ntiro specialises in finding employment opportunities in the open labour market for young adults with intellectual disabilities, and is the only project of its kind in Gauteng Province. It seeks to provide ongoing support to 18 year olds once they can no longer attend special schools. The project provides life skills such as money management and social skills in order to increase independence. Each client has a job coach who seeks suitable employment for him or her and provides regular support to the individual once they are working. Placements have included panel beating, packing, cleaning, and manning a service counter. Wages are currently much lower than the open labour market wage (i.e. R 200-300 per month). However, as the placements are not permanent jobs, the job coaches advise against salaries over 800 R per month, as the individual would then have to forgo their disability grant. At the time of interview, there were plans to make the Ntiro service available to all PWDs regardless of disability type.

The other two training/employment placement schemes we looked at were located in Pretoria city centre. Access College runs computer-training courses for people with all types of disability, other than people who are blind (Exclusion was justified on the grounds of the high cost of specialist equipment for blind learners). Entrance is selective, and students must have passed Grade 12 or 10 and score at least 30 in the college assessment test. Those who scored 29 - 29.5points are invited to enrol on the less demanding data-capturing course. Successful students receive bursaries from the Department of Labour. After completing their training, Access College try and find work placements for their students. They have a success rate of 59 per cent, and Statistics SA has employed most of Access College's ex-students to do data processing for the information gathered during the census. The college provides no transport, and individual students have to make their own way to the college. The college spokesperson mentioned that the ability to get to work on time and pay for daily transport were necessary for any type of job, and Access College was interested in preparing PWDs for the open job market. However, as the college does not pay a bursary to students from poor households, it is unlikely that students whose disability grant supports the entire household would be able to afford to attend the course.

As well as running a sheltered workshop, Employment Solutions (ES) also runs an employment placement scheme. This is aimed at PWDs with more ability or higher qualifications. Applicants must have passed Grade 12 or 10. They submit a registration form and then wait for a placement. At the time of the interview, ES had 350 people on their books. The employer pays 10 per cent of the person's annual income to ES as an administration fee. If the placement fails after 2 months, they are provided with another employee free of charge. According to

the ES representative, some employers use the scheme because they are socially committed, whilst others need to comply with the equity act. He had noted a tendency for smaller companies to seek employees with disabilities because of social commitment and larger firms because of the equity act.

ES places mainly people with locomotor disabilities, and there had been few problems with inaccessible workplaces. Most of the job placements are as switchboard operators, access control and in telesales. The ES representative had found that employers have a limited perspective of what people with disabilities can do. He had also found that when companies request a PWD, they want to be able to see the disability – for example, putting a wheelchair user to work in reception so that everyone can see them. He referred to this as 'widow dressing', and ES had had problems trying to place people who are deaf and those with mental illness because of this. As well as wanting to comply with equity act or show social commitment, some companies want to employ PWDs because they think they are going to be cheaper. They also want to offer them jobs that no one else wants, such as cold calling in telesales. The interviewee also pointed out the fact that at the moment it seems to be white employers that are requesting white PWDs through ES, as though the transformation issue and the disability issue get split. If this is a common trend, there will be a need for extra support for nonwhite PWDs.

The biggest problems ES faced in making placements work was ensuring there were suitable transport links and overcoming communication problems that many people who are deaf encountered in the workplace. Even if a placement is found and there is adequate transport, placements can be difficult because most companies do not have employment assistance schemes where employees with disabilities who experience problems can be supported. Also, disinterest in disability issues on the part of the unions means that PWDs are at more risk of dismissal.

#### **EE Participants' Access to Training and Employment Opportunities**

There are clearly a variety of training and employment opportunities available to PWDs. Yet, virtually none of the EE participants were employed, and none were enrolled in employment placement or training schemes. Why are these increasing opportunities for PWDs not having an impact upon the lives of low-income PWDs such as those who took part in EE?

# 1) Lack of Education and Training

One of the reasons why EE participants are unable to take up the opportunities that are currently becoming available is because they are not fully prepared to do so. In order to join the Access College or Employment Solutions scheme, one needs to be educated to Grade 12. However, what was most notable in the sample is the high percentage of adults with disabilities with no or little education and no vocational training.

34.6 per cent of the adults who took part in the study had never received any formal education. Of those who had spent some time at school, 86.2 per cent dropped out whilst in high school. This is borne out by the fact that so few had completed high school qualifications. Only 5 participants (3.7 per cent of the entire sample) had completed the A-level equivalent, the 'matric', and only slightly more people (11) had successfully completed their exams for 'standard' at age 16. 44 per cent of PWDs aged 10 years and over were illiterate. The level of illiteracy is higher amongst men – 54.2 per cent of the male PWDs are illiterate and 45.8 per cent of female PWDs are illiterate.

The PWDs participating in the study had also had little or no vocational training. 93.4 per cent of the sample aged 15 years and over had received no vocational training at any point in their lives.

Unfortunately, higher-level training and employment opportunities have become available before the government has started to realise its plans for inclusive adult education and training.

#### 2) Attitudes towards Adult Education

These findings would suggest that adult education and training are the solution to filling the skills gap preventing PWDs on low-incomes from accessing job and training opportunities.

South Africa has a programme of Adult Basic Education and Training (ABET). However, the Integrated National Disability Strategy (INDS) (Office of the Deputy President, 1997) recognises that ABET fails to make any provision for the needs of adult learners with disabilities. The strategy lists access problems faced by people with communication disabilities, and those living in institutions. EE findings suggest that even if ABET offices were made fully accessible, few participants would take up the opportunities offered.

There are ABET offices located in or near the communities were EE took place, but only 1 per cent of the sample was attending ABET. The problem is not solely one of inaccessibility as the INDS suggests, but also one of lack of interest. Of the overall sample, almost 50 per cent of the sample knew about ABET, were eligible to apply but were not interested in the service. When asked, 93.4 per cent of those participants who had received no education or an interrupted education stated that they had no interest in receiving additional education.

The Integrated National Disability Strategy argues that black adults with disabilities should be a priority group in terms of improving access to education. Although further education and training is not the main focus of White Paper 6, it argues that the model proposed for inclusive education for children will be

extended to the further education sector. However, there is a key difference between child and adult education: whilst the former can be made compulsory by law, adult education cannot. Even if all the services and support of full-service schools are extended to adult education centres, will this address the problem of low levels of education amongst adults with disabilities? The experiences and responses of the participants in EE would suggest that it would not. Any programme to improve accessibility of adult education for PWDs would need to consult with PWDs to discover why adult education is of little or no interest to so many PWDs. As jobs are so few and PWDs feel they will always be overlooked in favour of non-disabled candidates, there is little motivation to dedicate one's time to adult education classes, especially when one combines this with the problems PWDs encounter trying to move around in their community. If the Department of Education is going to invest in public awareness campaigns on education for children with disabilities, it should also consider raising awareness of the value of adult education for PWDs.

#### 3) Making the Links

Let us assume that the EE participants went for adult education and training locally and were eventually sufficiently well-educated to enter a training and employment programme, such as that run by Access College or Employment Solutions. Would that be enough to ensure access to such programmes?

At one of the workshops a participant mentioned that she wanted an employment workshop close to her home. It is obviously inevitable that training and employment programmes will be centralised unless there are sufficient PWDs in particular area to make a programme sustainable. However, the participant's comment highlights the key issue of transport. For a PWD living on a very low-income in a peri-urban area, the challenge of attending Access College or Employment Solutions is both the physical inaccessibility of transport and the prohibitive cost. Without support in these areas, such programmes run the risk of only providing opportunities to PWDs that come from better-off households or live within the immediate vicinity. Unfortunately, neither organisation could give any indication of the economic status of their clients.

The other link that would have to be made is that of increasing awareness. Lack of knowledge of available services and projects is a constant theme throughout the project. Participants in EE had no knowledge of the Employment Equity Act and recent attempts by South African companies to actively recruit people with disabilities. As they had no awareness of these changes, it is possible to argue that the lack of interest in adult education relates to the fact that they can see no hope for future employment. Knowledge of these changes may motivate some PWDs to seek to return to education.

# 4) The Open Labour Market as an Alien Space

Current employment legislation and education policy assume that PWDs are trying to take up employment in the open labour market and yet are being prevented by discriminating employers and inaccessible buildings. However, lack of confidence or fear of humiliation in the workplace may also hold PWDs back, and there is currently no systematic attempt to address this.

We held a group interview with five EE participants; two of the participants had a locomotor disability, two were blind and one had schizophrenia. They were selected for the interview because they had all had experience of working in the open labour market, and were communicative and dynamic (i.e. they were likely to actively go out and seek work). We wanted to discuss their experiences of employment and their perceptions of current opportunities. An interesting point that arose from this interview was that when asked if they were offered the same salary for a job in the open job market or in a sheltered workshop which one would they chose, four of the participants said that they would chose the job in the sheltered workshop. Even if the salary were lower in the sheltered workshop, the interviewees said that they would still chose the sheltered employment over the job in the open job market. When asked why, they said that 'there would be a sense of belonging', 'they could prove to the able-bodied what they were capable of', 'they would be understood and accepted', 'they could help other PWDs' and 'they would be able to work at their own pace'.

For these PWDs, the open labour market is not currently somewhere they want to be for fear of feeling unaccepted, misunderstood, or being given work they could not cope with. The able-bodied are seen as a separate group that do not understand disability, underestimate what PWDs are capable of and often demonstrate a patronising, overly protective attitude. Therefore, even armed with suitable education and training experience, this does not mean that PWDs will feel confident enough to take advantage of the increasing employment opportunities that are open to them.

As pointed out by the representative of Employment Solutions, systematic attempts to overcome exclusion in the workplace has led to each aspect of identity (i.e. gender, disability, race) being treated in isolation. As companies monitor their progress in meeting the targets of the employment equity, they should consider intersecting identities. They should also consider monitoring rates of employment of PWDs in the workplace with additional information on economic background.

The Ntiro-model of employment support service that works closely with a low-income community should be considered for further expansion. Employment projects that actively encourage PWDs to seek employment in open labour market by building up self confidence, making PWDs aware of rights, directing individuals towards appropriate training courses, advising PWDs on how to cope with discrimination at work and supporting PWDS in early stages of employment

would help in overcoming the barriers that are preventing PWDs from low-income backgrounds from accessing new employment opportunities for PWDs.

## **CHAPTER 8**

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

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.

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. 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. The final section of this chapter considers the extent to which people with disabilities living on low-incomes participate in the social life of their family and community.

#### **Social Grants**

South Africa has a system of social welfare grants that includes a grant for people with disabilities. As recommended by the Standard Rules, this grant is intended to replace loss of earnings due to inability to work or increased difficulty in finding work. The disability grant is paid monthly to adults between the age of 18 and 60. At the age of 60, PWDs become eligible for a state pension and can no longer claim the disability grant. For the parents of children with severe disabilities, there is a care dependency grant that aims to offset the loss of wages from being unable to work. In 2002, the monthly payment for the disability grant, old age pension and care dependency grant was increased from R570 to R620.

The South African social grants system is means-tested and requires applicants to show proof of their age or that their income is below a certain level. Applicants for disability grants must also show a certificate from a district surgeon. The grants system is administered at provincial level. A number of participants in the EED project had been assessed as ineligible for the disability grant because the district surgeon considered the nature of their disability insufficiently severe to prevent them from seeking work.

Administering social grants on a large-scale is often problematic and South Africa is no exception. A report by the Human Rights Commission in 2001 revealed that of the 2.6 million people eligible for disability grants, only a mere 600 000 were receiving grants (Tabane, 2001). There are a number of reasons for this:

provincial governments do not allocate sufficient resources for grants, PWDs are put off by a sometimes corrupt applications procedure, grants may be suddenly terminated and reapplication takes time. An audit of social grants payments systems in nine provincial governments in 1999/2000 revealed six provinces overspent considerably on their budget allotted to social grants: Gauteng Province overspent by R 60 million (Streek, 2001). In 2001, the government of Limpopo province had a backlog of 164000 social grants applications that had not been processed because the government argued it did not have the money to cover the cost of so many applications (Mail and Guardian, 15 Mar 2002). Added to this is the problem of fraud. A report on social grant fraud in KwaZulu-Natal in 2001 revealed the use of stolen identify documents, fake medical reports and spurious costs being charged to bonafide applicants, such as security guards changing people to enter to claim their grants and people being charged to register their application (Bisetty, 2001).

For the participants in EE, social grants was the only service category where there was 100 per cent awareness. No one in the sample reported knowing nothing or very little about the disability grant, care dependency grant or old age pension. As seen from the table below, 62.3 per cent of the sample is in receipt of one of the three major grants for PWDs. A further 14 per cent are children who do not require a dedicated carer and therefore are not eligible for the care dependency grant. A very small percentage are working.

Table 10: PWDs' Source of Income

Grant Status	Frequency	Percentage
Disability Grant	82	44
Pension	28	15
Dependency Grant	6	3.3
Child – NA	26	14
Working	5	2.8
Adults with no income	38	20.4
Missing (DK)	1	0.5
Total	186	100

Just over 20 per cent of the sample of adults with disabilities have no source of income. This group is made up of PWDs who had applied for the DG but had been assessed as being fit to work by a surgeon (7), PWDs who are unable to apply because they do not have an ID book (6), those whose applications are under review (8), those who did not know how to apply (3) and those who gave no reason for not applying (13).

The issue of the grants application process was raised at the initial EE workshops. The main concern was that grants were being suspended unexpectedly and the PWDs found they had to start the application process all over again. One participant in Stanza Bopape reported having waited 8 months for his grant to be reviewed. During the workshops, a number of participants mentioned having their

grants stopped suddenly without warning. Other participants explained that they should have received a letter 2-3 months before the grant was coming up for renewal. For those PWDs who are literate and also able to understand formal letters, this process of renewal does not pose too many problems other than the cost and time involved in travelling to the grants office. However, for those who are illiterate, find formal language difficult to understand and do not have family or friends to help them, receiving a letter notifying them of the need to renew their grant is not an effective mode of communication. This problem occurs in other areas of South Africa. In North West Province the Department of Social Services issued people with permanent disabling conditions with 'temporary disability grants' without advising the clients of the temporary status and stopped the grants abruptly without warning when they expired (Pillai, 2001).

There are two types of grants review: administrative and medical. The medical reviews for disability and care dependency grants should be done every five years. The former is to review "only essential aspects of the general, financial and pay point information such as marital status, means test, payment contractor and pay point". This review is done annually. Temporary disability grants are not subject to review but terminate on expiry of the grant. People with temporary disabilities were not included in EE.

The sudden cancellation of grants, as experienced by EE participants, could be illegal. A grant can only be suspended as a result of a review or if the beneficiary has failed to supply requested information at the review. If the grant is suspended, the beneficiary must be given reasons in writing for the suspension, with advice of his or her right to apply for the restoration of the grant within 90 days from the date of the suspension. However, a legal ruling<sup>55</sup> stated that proper notice of an impending suspension must be communicated to a person in a manner and language they understand. As many people are illiterate or have difficulty understanding more formal language, other means of communication other than by letter should be sought. (Frye, 2001)

The importance of ensuring the review procedure does not result in the grant being terminated unnecessarily becomes clear when one considers the importance of the disability grant, care dependency grant and old age pension in maintaining households. It has already been noted that the majority of households in the study are living in poverty. Almost 70 per cent of households registered a monthly income of R1300 or less. 14 per cent of households registered no regular income at all. 26 per cent of the EE sample lived in households that rely solely on the social grant brought in by the PWD. In another 10.6 per cent of households the social grant constituted between 51 and 99 per cent of the household income. In

<sup>55</sup> Bushula NJ and others v the Permanent Secretary, Dept of Welfare, Eastern Cape provincial government, Case 774, 1999

<sup>&</sup>lt;sup>54</sup> Taken from '*Policy on the Review of all Grant Types*' (Department of Social Development, 2000), cited in Frye (2001).

just over 26 per cent of households, the social grant forms between 26 and 50 per cent of household income.

Table 11: PWDs' Financial Contribution to the Household

PWD Income as % of HH	Frequency	Percent
income		
HH with no income at all	26	14
HH with income but no PWD	38	20.3
income		
Less than 25%	11	6.0
26%-50%	43	23.1
51%-75%	14	7.4
76%-99%	6	3.2
100 %	48	26
Total	186	100

Even in those households where the social grant constitutes a smaller percentage of the household income, loss of the social grant could plunge the house into a financial crisis. With household income being so low in the sample, social grants are essential to household survival rather than additional income to benefit the person with a disability. This has been borne out in other studies. A study by Karen Charlton of University of Cape Town found that 42.6 percent of households in South Africa live in 'food poverty', i.e. they cannot afford a basic subsistence diet. Charlton reported that '...grants were doing their work to alleviate poverty in that they reached those who most needed help – but they were spread too thinly, usually going in the 'family pot' and seldom being used to support only the person for whom they were paid' (cited in Caelers, Sylvester and Gano, 2001).

If the annual review system has to remain, the findings suggest that at the very least the review system has to be made more transparent. Based on the evidence, it would seem that the existence of social grants and the initial process of application are already well understood by those living in low-income neighbourhoods, at least in urban areas. Therefore, communicating information about the review procedure, why it takes place, what it entails and the rights of the applicant should be the next stage in ensuring the system works efficiently. Communication by letter is only partly effective and grants offices should consider running information sessions on the day grants are collected, supported by accompanying leaflets. Help desks at grant processing points should also be considered. As the grant system shifts towards paying grants directly into bank accounts, alternative means of communicating the grant review process should be considered.

One option is to end the review system altogether. The system of reregistering is intended to put administrative checks in place to prevent fraud. However, Hassen (2001) argues that this approach exposes genuine grant applicants to the risk of

losing much needed income. He suggests two major changes be put in place. Firstly, that rather than reregistering every 12 months, a system of selective audits of grants recipients and the establishment of an early warning system that would highlight corruption should be put in place. Secondly, there should be a greater integration of systems so that police, district surgeon, grant officials and social services are all located in one place. This would reduce the financial cost of reregistration currently placed on PWDs living on very low incomes. Finally, he suggests redesigning the application forms which are currently 'obscure'.

The other key issues relating to social grants that were mentioned by EE participants at the initial workshops were:

- Inadequate to maintain the entire family
- Long distance to collect grant
- ATMs are unsafe

The value of grants was addressed in 2002 when recipients received an 8.7 per cent rise. Many felt this still was not sufficient. However, as provincial governments are currently struggling to cover the cost of social benefits, it is unlikely that social grants will rise substantially in the future.

The problems associated with the cost and inaccessibility of public transport for PWDs are addressed in Section 2. In an attempt to address difficulties associated with travelling to collect grants, grants can now be paid directly into bank accounts. However, only 9.7 per cent of the EE sample had a bank account and a further 24 per cent reported that they knew nothing about bank accounts, which suggests that this will not be an option that many of the sample consider. Workshop participants pointed out that ATM-use incurred a service cost, which reduces what is already a very low income, and ATMs are a common target for muggers. Furthermore, ATMs are also often set too high for people using wheelchairs or are not made accessible for people with low vision or are blind.

The other issue related to social grants that arises from the survey data is the failure of people with mental illness to access the disability grant. When disaggregated by disability type it shows that there is a disproportionate number of people with mental illness and epilepsy who are failing to access the disability grant.

Table 12: PWDs with no social grant by type of disability

Type of Disability	Frequency	Percent	As % of Sample
Locomotor	14	37.8	37.6
Intellectual	3	8.1	19.4
Deaf	2	5.4	4.3
Mental Illness	12	32.4	21
Epilepsy	3	8.1	4.3
Hard of hearing	1	2.7	2.2
OAP	2	5.4	NA
Total	37	99.9	

#### Non-Financial Contributions to the Household

We have established that PWDs make an important financial contribution to their households. EE also looked at the non-financial contributions made by PWDs. 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 13: Domestic Contribution Score

Score Range	Frequency	Per cent
0	47	25.3
1-5	39	21.0
6-10	34	18.3
11-15	32	17.2
16-20	14	7.5
20+	20	10.8
Total	186	100.0

As can be seen in Table 13, 18.2 per cent of PWDs had a contribution score of 16 and above. A further 17.2 per cent made a substantial contribution with a score between 11-15. It is the young and the old who make smaller contributions to the household. Of those PWDs who made no contribution to the household, just over 50 per cent are aged between 0 and 19 years, and 27.5 per cent are aged 60 and over.

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 helping out with childcare and thus freeing other members of the household to go out to work. This does not seem to be the case. In those households where childcare was required, only 11 per cent of PWDs had sole

responsibility for childcare. 30 per cent helped out and 59 per cent had no involvement.

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. A list of self-care activities (Qu. 69) was used to calculate a dependency score with 9 indicating a high dependency. Our findings show that the participants in EE require little support from their families – 73.1 per cent require no help with self-care activities whatsoever. Only 8 per cent of the sample scored between 6 and 9 indicating a higher level of assistance is required.

#### **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 three groups related to housing, access to transport, administrative problems with the disability grant, and training and employment, and, therefore, the report focuses on these issues. However, there were individuals at the workshop that mentioned the limited scope of their social life as a concern. Young adult male wheelchair users at the Stanza Bopape workshop discussed the fact that they felt their friends and family were overprotective and would often take them home early from social events. The fear of crime and violence in the communities where we worked was a common theme and people with disabilities were perceived to be at a greater risk of becoming victims of crime<sup>56</sup>. A number of older people discussed feelings of loneliness and isolation.

It was important to find out whether PWDs per se were experiencing limited social lives. For this reason, the survey included a section (Qu. 69) that listed 14 common social activities and asked about the frequency of the individual's involvement. The most significant findings are listed here.

and attempted to rape his then girlfriend. From casual conversations with younger male EE participants, it would seem that masculine identity is tied up with notions of being able to physically protect oneself and one's family. It was not possible within the scope of this study to explore this issue further. However, the way in which experience of a disability influences young men's identities within South African communities would be worthy of further analysis.

One young man discussed the fact that as he was now a paraplegic he felt less able to protect a girlfriend from attacks by other men. Before he had been shot, a man had broken into his shack

Table 14: Frequency of Social Activities

	Never	Daily	At least	At least	At least	At least	Total
		,	once a	once a	once in	once in	
			week	month	the last 6	the last	
					months	12	
						months	
Watches TV	52.7	41.4	5.4	0.0	0.5	0.0	100
with family							
Visits friends	25.8	34.9	30.1	6.5	2.2	0.5	100
and family in							
community							
Visited by	17.2	23.1	26.9	17.2	9.7	5.4	100
friends and	17.12	20.1	2017	17.12	<i>,</i>		100
family							
Visits	31.2	3.2	10.8	25.3	16.1	13.4	100
friend/family	31.2	3.2	10.0	20.0	10.1	13.1	100
outside							
community							
Takes part in	95.7	0.0	1.6	2.7	0.0	0.0	100
stockvels*	93.1	0.0	1.0	2.1	0.0	0.0	100
	02.2	0.0	0.5	1 / 5	0.5	1.1	100
Takes part in	83.3	0.0	0.5	14.5	0.5	1.1	100
burial clubs†				20.1	10.		100
Attends	51.1	0.5	2.7	30.1	10.2	5.4	100
Weddings,							
funerals, parties							
Attends Church,	29.6	1.6	48.4	18.8	1.1	0.5	100
temple, mosque							
Takes part in	84.9	3.8	8.6	1.6	1.1	0.0	100
sports/recreation							
Takes part in	97.3	0.5	1.1	0.5	0.5	0.0	100
running comm.							
organisations							

<sup>\*</sup> Rotating Savings schemes

Watching television is the most common social activity after attending church. As approximately 50 percent of sample did not possess a television, the fact that 52.7 per cent of the sample never watch television is unremarkable. The majority of participants in the study have regular contact with friends and family beyond the home. 61 per cent of the sample spend time at other people's houses in the community on a regular basis. 50 per cent of participants receive visitors at home at least once a week, and a further 17.2 per cent are visited at least once a month. Based on the comments made in the workshops about the inaccessibility of public transport and the prohibitive cost, the fact that over half of the sample (55.4 per cent) have travelled outside of the community to visit friends and family at least once in the last six months was higher than might be expected.

As well as strong social networks, the other key social space for people with disabilities is the church. Rule 12 of the Standard Rules stress the importance of

<sup>†</sup> Community-run saving schemes to cover burial costs

ensuring the people with disabilities are not excluded from participating in the religious life in their communities. This is clearly not a problem in the studies where EE was conducted as almost 70 per cent of the sample visited a church at least once a month.

What was notable from the findings is that other than attending church, most of the sample were not involved in any organised community activity. As can be seen from the table, over 80 per cent of the sample are not involved in any form of sport or recreation, no form of community organisation or any form of savings club.

As there had been a suggestion during the workshops that people with disabilities who are elderly may be more at risk of social isolation, we were interested to see whether or not the 60+ section of the sample were over represented amongst those who never took part in any of the social activities listed.

Table 15: Over 60s as a percentage of those PWDs who never take part in social activities

activities		
Social Activity	Never (all)	60+ as % of
		'Never'
Watches TV with family	52.7	18.4
Visits friends and family in	25.8	37.5
community		
Visited by friends and family	17.2	12.5
Visits friend/family outside	31.2	22.4
community		
Takes part in stockvels <sup>57</sup>	95.7	17.4
Takes part in burial clubs <sup>58</sup>	83.3	16.1
Attends Weddings, funerals,	51.1	21.1
parties		
Attends Church, temple, mosque	29.6	23.6
Takes part in sports/recreation	84.9	19.6
Takes part in running comm.	97.3	16.6
organisations		

16.6 per cent of the sample was made up of people 60 years and over. Therefore, any activity where people over 60 made up more than 16.6 per cent of the people who never participated was an activity where elderly people were potentially routinely excluded.

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<sup>&</sup>lt;sup>57</sup> Rotating Savings schemes

<sup>&</sup>lt;sup>58</sup> Community-run saving schemes to cover burial costs

There is no pattern of overall exclusion. The key social activities where PWDs aged 60 years and over are less likely to participate are visiting friends and family within the community, outside the community, visiting church and attending events such as weddings and funerals. This suggests that people over 60 are more home-bound than other age groups with disabilities. However, people over 60 are underrepresented amongst the section of the sample that are never visited at home. Almost half (48.4 per cent) of all PWDs aged 60 and over are visited at home by friends and family at least once a month.

There are a number of concerns to be raised here. None of the 60+ respondents ever took part in any form of recreational activity. Whilst the 60+ age group may be underrepresented amongst the section of the sample that never receives visitors, they are over-represented amongst the section of the sample that receives visitors only once or twice a year. As can be seen from the table below, people over 60 who do receive visitors are less likely than other age groups to be visited on a regular basis and are more likely to be visited infrequently.

Table 16: Over 60s visited by friends and family as a percentage of PWDs sample

Never Daily		At least	At least	At least	At least	
		once a	once a	once in the	once in a	
		week	month	last 6	year	
				months		
12.5	11.6	18.0	18.8	22.2	30.0	

#### Conclusion

This chapter has highlighted the contribution PWDs make to their households and the extent to which they participate in the life of their communities. Key points for concern are:

1) Social grants claimed by PWDs play a key role in sustaining households financially. 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.

EE supports Hassen's argument that the annual review process should be stopped and that a more appropriate method of challenging fraud that does not disadvantage bona fide applicants be found. Whilst the current review process remains in place, provincial governments should

• take a greater responsibility for ensuring that grant beneficiaries are aware of their rights and the review mechanism,

- should consider alternative means of communicating the need for review other than the current method of sending a letter
- should set maximum time periods for the processing of reapplications arising from beneficiaries' failure to apply for a review in the stipulated time
- should work with local organisations such as street committees to disseminate information about eligibility for grants as widely as possible
- 2) As well as the financial contribution made through social grants, 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.
- 3) There was no pattern of systematic social exclusion of people with disabilities. However, some PWDs are more vulnerable to social exclusion: 17.2 per cent of the sample were never visited by friends and family, and 25.8 per cent never visited others. Disaggregation by age suggests that people over 60 are at particular risk of being excluded from social networks and seeing friends and family less frequently, if at all. This raises the question of whether or not current services available are addressing the needs of PWDs. The only example of a service especially for the elderly was found in Saulsville in the form of a pensioners' luncheon club. However, as explained earlier (See Box 4), this service was inaccessible to many elderly people with locomotor disabilities because the entrance was via steps and there was no accessible toilet.

#### **CHAPTER 9**

#### 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 South African case study based in four low-income settlements in the Pretoria area has shown that even when government commitment to equality and universal access for people with disabilities is translated into policy and legislation, people with disabilities living in poverty continue to be excluded.

The key issues and recommendations are summarised below:

### **Effective Dissemination of Information**

According to the findings of this project, lack of knowledge is the main reason why people with disabilities living in poverty fail to access opportunities and services available to them. People cannot ask for what want if they do not know it exists. This group can be difficult to reach: only half of the sample live in households with a television, two thirds do not have a radio in their house, and over 80 per cent take part in no community activity on a regular basis, and very few had contact with disability NGOs. Information should not be targeted at medical service providers. This only serves to reinforce the medical model of disability and furthermore, few participants had regular contact with medical services at community level.

The project set out to identify the most common contact points between PWDs and the wider society. Grant collection points would be the best place to disseminate information as 100 per cent of the sample was aware of the grants system and less than 10 per cent did not have a grant. Visiting church was one of the most common social activities for PWDs in all communities. Targeting larger churches in low-income communities may also be a possibility.

Whilst policymakers recognise that measures aimed at low-income PWDs may not be reaching the target population, the approaches to tackling this problem seems to assume a trickle-down model of dissemination. For example, awareness-raising to ensure that more PWDs access the housing subsidy is currently aimed at municipal-level officers. As it is PWDs and their families who will be most motivated to act on this information and they rarely, if ever come in contact with municipal, housing officers, it would be more effective to introduce information at a community-level as well. Also as the key point of contact for PWDs is the local councillor and the block and ward representatives, training and information should be aimed at these groups also.

We came across examples of assumptions that people with disabilities will know other people with disabilities in communities and be linked to services. Following on from this assumption is that if one introduces information to a number of PWDs with a community, the information will passed along a network. The lack of contact with services has already been mentioned. As for networks of people with disabilities, there can be no assumption that these exist. What was notable at all the workshops was that people with disabilities who lived only a few streets away from each other had often never met. The organisation wishing to disseminate information will need to actively identify PWDs in communities where no active group or obvious meeting point exists.

Knowledge also needs to reach all people with disabilities. People with locomotor disabilities can be the easiest to reach as their disability is most visible and their impairment is less likely to affect communication. Information needs to made available in Braille and communicated through sign language. Specialists need to be consulted on the best way to reach and include people with intellectual disabilities.

A key question that came up when examining the application process for the housing subsidy: where is information held? Dissemination can be very transient – adverts, billboards, leaflets that get mislaid – and therefore there has to be a permanent information point that people can go to. Although we knew that single PWDs without dependants could apply for the housing subsidy, it was unclear where one could go if people collating application information at the local level were unaware of this particular section of the housing code. Any information needs to make procedures clear, otherwise after failing to access what they require people can be unsure where to turn next.

### RDP Settlement Developments: Extending the Right to Barrier-free Environments to the Poor

The key complaint of the project participants with mobility impairment related to the toilet design. The pre-cast concrete toilet blocks being built on RDP plots are inaccessible to wheelchair users and difficult to modify to meet the needs of those with other types of locomotor disabilities. The dimensions are simply too small to allow a wheelchair to enter and turn, or to allow a carer to enter with someone who is frail. The pre-cast concrete makes it difficult to add grabrails and there is no option of installing a higher toilet.

We recognise that in order to be cost effective, mass-housing schemes cannot respond to the needs of individuals and therefore suggest that the cost of converting an RDP standard toilet to an accessible toilet be included under the modification grant scheme.

As well as the need for accessible toilets on individual plots, more could be done to create barrier-free public spaces with RDP settlements. Although the formal

settlements where EE participants lived were relatively new developments, residents still found they had a number of inaccessible features, such as high curbs, no raised surface textures or speaking traffic lights to assist the sight impaired at crossings, no pavements alongside some busy roads.

The study has discussed the current failure of building legislation in South Africa to address the issue of universal accessibility in a comprehensive, effective way. However, even if the building legislation is updated, it is not clear whether or not planners would be able to bypass any accessibility legislation on the grounds of cost.<sup>59</sup>.

Not including accessible design features into RDP developments is shortsighted, as the cost of incorporating such features at the point of construction would be a small percentage of overall cost of the project. Rather than waiting for changes in building legislation, provincial housing departments need to develop a series of guidelines for incorporating accessibility features into RDP settlement design and look at the possibility for making such features a contractual obligation for developers. As some of the technical information currently included under the building regulations, guidelines for accessibility features should be developed in conjunction with accessibility experts. If efforts to create barrier-free spaces are mainly focused on central urban spaces, PWDs living in peripheral low-income settlements will become increasingly more excluded, relatively speaking.

# The Modification Grant: The need to consult with people with disabilities when developing services for them

As with the housing subsidy exemption, none of the EE participants had heard of the modifications grant. However, even if there were a greater awareness of the modification grant, a key question raised by EE is whether the current list of modifications is what is wanted by PWDs?

Adapting an RDP toilet is a key concern for PWDs, yet is not covered under the grant. The current categorisation of disabilities is too narrow – for example, someone with severe arthritis in their hands would not be covered by the category 'walking' disability or hearing disability, yet would potentially benefit from the installation of lever-action taps. There are currently no items in the list that would benefit those with a sight impairment, despite the fact people with a sight impairment have made applications.

<sup>&</sup>lt;sup>59</sup> The Less Formal Township Establishment Act of 1991 was brought in to facilitate the rapid construction of low-income settlements in order to encourage development and stimulate the economy. The Act allows the local authority to give permission to the developer to bypass legislation relating to town planning and building.

It is not clear who was consulted when developing the grant list as it does not seem to address the needs of the people who should be able to benefit from it. The current list covered by the modification grant should be developed through consultation with groups of people with a range of disabilities at community level to ensure it covers the types of modifications people are in most need of.

# Employment, Training and Education: Reaching PWDs living in poverty requires greater effort than reaching PWDs in general

The financial vulnerability of people with disabilities who live on low-incomes can make it more difficult for them to try out 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, job opportunities for people with disabilities have been given media coverage. Training opportunities have also increased as NGOs respond to the need for employers to find skilled PWDs. 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. What could be done to bridge this obvious gap between opportunities and people with disabilities living in low-income settlements?

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 R800 per month before the grant was affected. The fact that some grant recipients had had their grant stopped suddenly only served to reinforce the idea amongst the group that a household may suddenly lose the disability grant, and reapplication could take months

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 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.

#### Assessing the effectiveness of EE's participatory action approach

Enabled Environments used a PAR approach as far as possible, and aimed to ensure that the participants gained in some way from the research process and that the research was directly linked to influencing policy change wherever possible. This key achievements are listed here:

#### Increasing networks for PWDs.

In all of the workshops, PWDs had the opportunity to meet with other PWDs from their community whom they had never met before. Repeat meetings, field trips and focus groups all provided the opportunity for the links between PWDs to be strengthened and groups of PWDs continued to meet after the fieldwork was over. Some participants also developed links with PWDs in other communities and with service providers. The link between CSIR and the community facilitators is one that they can draw on in the future.

#### Transfer of knowledge

Participating in Enabled Environments exposed participants to a wide range of information on disability rights, disability organisations, legislation and services available. The project team is keen to develop a short booklet containing all the information EE participants found useful.

#### Development of Research Skills

The community facilitators and four additional participants were trained in survey work and interview technique. One community facilitator has gone on to represent PWDs on her ward committee. Working on Enabled Environments has provided them with work experience and a referee they can call on in the future.

#### Individual Development

One young male participant who lives alone found that his involvement in Enabled Environments encouraged him to study and become more involved in disability issues. He has signed up for a distance learning degree, works as a disability rights representative at his university, and organised a trip to the International Day for People with Disabilities celebrations for other PWDs in his community. He and another EE participant tried to establish a self-help group to develop employment opportunities, but they failed to gain enough support from other members of the community.

### Working with the Department of Housing

Following the presentation of our results that clearly show that people with disabilities are not accessing the housing benefits directed at them, members of the Department of Housing approached the Enabled Environments team to work with them on developing better policy and implementation for PWDs

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