AMAWOTI: RESPONDING TO THE NEEDS AND RIGHTS OF PEOPLE WITH DISABILITIES

by

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ABSTRACT

This study is based within the informal peri-urban community of Amawoti. The context is significant in that it is one of urban poverty, the black residents being among those who are particularly marginalised in society. The study explores the response of interest groups in this area to people with disabilities.

The concepts of community development, primary health care and community-based rehabilitation are described very briefly as a background to the study. There is also exploration of different definitions of disability (and the surrounding debates), and three prevalent approaches taken in addressing disability are described. Two themes emerge from this discussion. The first is that of addressing *both* needs *and* rights; the second is that of empowerment of people with disabilities and their integration into society.

The methodology used to explore the opinions and perceptions of interest groups was that of focus group discussions. These were run with the youth, civic members, staff of Ilimo Project, teachers, business owners, landowners and State employees. Group discussions were also held with disabled people and caregivers. In total, eleven groups were run. Within each group, five major issues were discussed:

- defining disability and its causes
- behaviour towards people with disabilities
- needs of disabled people
- rights of disabled people
- interventions to address the problems of disability

Analysis of the focus group discussions indicates that there were three predominant views of disability. The first is that disabled people are *individuals who are dependent and in need*. Appropriate responses to disability are thus conceptualised in terms of material provision. The second view is that disabled people are *individuals who do not fit into society*, by virtue of being different from others. This is addressed through integration and affirmative action programmes which promote inclusivity. The third view is that *it is society that disables*. Addressing this problem requires structural change, and the transformation of oppressive relations in society.

The study concludes by presenting a new conceptualisation of disability, which links prevention, rehabilitation and social action. The implications of this conceptualisation for community groups, organisations of disabled people, and for State service providers is explored. All of these groups may contribute to material provision, integration of disabled people into society, and the challenging of the disabling world. Finally, recommendations are made concerning State service provision, the role of professionals, the need for support of community organisations and for appropriate research on disability. Consideration of these factors in addressing the issues of poverty and disability will point towards the creation of a more integrated and inclusive society.

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This thesis is not the product of a single individual. I am indebted to many people who contributed in different ways to its formation.

Without the people of Amawoti, and members of the Amawoti Disabled People's Association, this study would have been simply a theoretical exercise. Their hope for a more just, inclusive and tolerant society has enabled me to see that disability must be addressed at a deeper level than that of charity, or even service provision. Disability in Amawoti is about poverty, and addressing it is about development and empowerment. The wide range of people who participated in the focus group discussions indicate the variety of creative responses there can be to the issue of disability. I appreciate their openness and the sharing of ideas which has enabled us all to learn more about those who are particularly oppressed in society.

I am also grateful to my supervisers for the support that they have given. Drawn together from different fields, they have provided a stimulating and challenging forum within which to pursue my interests. They took the risk of involvement with a subject - disability - which does not fit into the "box" of any discipline, and were prepared to become learners with me. I am indebted to Professor Jeff McMarthy, Dr Pam McClaren, Ms Francie Lund and Professor Rob Fincham.

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DECLARATION

I declare that this thesis is my own original work. It is being offered here for the first time.

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DISABILITY: KEY CONCEPTS AND THE SOUTH AFRICAN CONTEXT

Introduction

The period of reconstruction facing South Africa, following the end of the apartheid era, presents a great challenge to those involved in addressing social issues. The challenge includes *redistribution* of available resources, towards equity, the provision of mechanisms to ensure *participation* of structures of civil society in decision-making at all levels, and the adopting of new values of *inclusivity*.

The focus of the present study is disability in a context of urban poverty - disabled people who are poor being among the most powerless and marginalised groups in society. Other studies on disability in South Africa to date have tended to focus on disability prevalence (Disler et al 1986, McClaren et al 1987, Concha & Lorenzo 1988, Corneilje 1991). Most have been epidemiological and quantitative in nature, with the aim of providing data to build up a "disability profile" of a particular community. Each of the studies aimed to provide information that would inform the planning of health and rehabilitation services, and most were conducted by staff working from a local health centre (hospital or clinic). The present study differs from these in that:

- the focus is on recording people's *perceptions of disability*, in contrast to previous studies that sought *measurement of disability prevalence* (with disability determined by criteria established by the researchers);
- the methodology is that of focus groups, in contrast to household surveys, and as a result data emerging from the present study is more descriptive and qualitative in nature than that collected in previous studies;
- it includes exploration of interventions which community members could be involved in, and does not assume that interventions to address disability are primarily from the health and welfare sectors;

- the researcher is employed by a local disabled people's organisation which commissioned the study.

The present study has been conducted over a critical period in South African history - that of 1992 - 1994. During this time, major changes have taken place in the country, the highlight of which was the elections which led to the inauguration of Nelson Mandela as president in May 1994. This has meant transition from a Nationalist government, whose policies were based on the ideology of apartheid, to a democratically-elected Government of National Unity. This has meant a re-orientation of State provision of health and social services, as well as within its involvement in development programmes. The Reconstruction and Development Programme represents the intent of the new government to implement strategies to address the issues of poverty in the country, but the role of non-governmental organisations in this process is still under debate. While these changes represent an opportunity for the developing of creative solutions to social problems, the rapid changes occurring are a great challenge to a researcher in presenting recommendations! It is intended that the conclusions reached in this study contribute to the debate, and the continuing search for strategies and approaches to disability that promote both empowerment of people with disabilities and their full integration in the "new South Africa".

This search for appropriate responses to disability has meant exploring the key concepts of community development, primary health care and community-based rehabilitation. A very brief description of each of these concepts is given in this chapter, but they are not dealt with in depth as the intention is to sketch them out only as the parameters within which the study is located. A number of common themes emerge from these concepts, and these in turn are related to the disability rights struggle. Strategies in the fields of development, health and disability are not implemented in a vacuum and a description of the South African context is given, taking cognisance of the impact of apartheid on health and social welfare provision. The particular focus of the present study is that of an informal peri-urban community, within which there is exploration of the perceptions of different interest groups regarding disability. It is anticipated that the response of these groups to the needs and rights of people with disabilities, will have much to teach those who are working towards the building of a more inclusive society.

1.1 Community Development

The primary, narrow focus on economic growth in community development has failed to improve quality of life for the poor. This is partly due to the fact that many such programmes are designed at central level, and then imposed in a top-down approach; they tend to be authoritarian, standardised and unable to adapt to local conditions. There is often great emphasis on "results", which are measured in terms of material projects completed - an outcome which may be more in response to donors' needs than those of the community. Another problem has been that professionals are often employed as the "experts", and as a result, the conventional wisdom of traditional ways of dealing with social issues (such as disability) is overlooked or undermined. Underlying all these problems has been a fundamental flaw in community development initiatives - the *failure to challenge the unequal power relations* which themselves entrench poverty.

As a result of the failures of the past, there is a concern to "put people back into development", and to establish programmes that are more responsive to local conditions (Lund 1987). A new emphasis is being placed on issues of equity and distribution, with programmes working towards structural change and redistribution of resources at national and international levels (Wisner 1988).

If community development means the challenging of unjust power relations, it cannot be a neutral process (Wolffers & Finkenflugel 1993). It means taking the side of the poor and oppressed, actively working to strengthen the position of women, landless, disabled and other marginalised people to empower them in their struggle for a better life. Ultimately, community development is a process by which "the poor themselves define and control their own struggle" (Wisner 1988 p.26), and in so doing they become agents in creating a more just society.

1.2 Primary Health Care

Changing theories of development have in turn had an impact on other sectors such as health. Central to this has been the raising of questions about the maldistribution of health services and resources in favour of the urban elites at the expense of the poor (the "politics of inequality"). In counteracting this, equitable provision of health and other social services was seen as being part of the package that would help to conquer underdevelopment (Walt & Vaughan 1982). Parallel to this was a challenging of the medical model of health, with its "engineering/technological approach" to understanding the body and its diseases. Instead there has been emphasis on the link between disease and the socio-economic environment. There was also a growing emphasis on participation and community involvement in health. These factors (among others) led to the birth of the concept of primary health care (PHC) at Alma Ata in 1978 (WHO). This was defined as

> "essential health care based on practical, sound and socially acceptable methods and technology, made universally accessible to individuals and families in the community through their full participation and at a cost that the community and country can afford to maintain at every stage of their development, in the spirit of self-reliance and self-determination. It forms an integral part both of the country's health system, of which it is the central function and main focus, and of the overall social and economic development of the community."

In PHC, the link between health and community development is unequivocal: "there is no development without health, and no health without development" (Pikk 1991). It has been said that "*PHC is community development* through health interventions" (Coovadia 1991 p.7 my emphasis). This approach demystifies health, giving ordinary people more control over their health and lives thus challenging the power of governments and health professionals. Not surprisingly, this has been met with opposition from health "experts" who have systematically extracted the teeth of PHC to convert it, at best, to being a means for extending conventional top-down health services into underserved areas. Both selective PHC and privatisation of health have undermined and dissipated the potential radical essence of PHC (Werner 1993).

1.3 Community-Based Rehabilitation

In order to achieve change, the subjects of development should be active participants in the process. The recognition of this has had a great impact on debates about disability, for this field, like that of health, has been dominated by the medical model. Disability has been seen to be the domain of medical specialists who are most often the dominant figures in the rehabilitation team, regardless of the nature of the problem (Acton 1981). The importance of enabling disabled individuals and groups (who have for so long been traditionally led by others) to take charge of their own affairs has become a priority. This in turn has led to challenging the understanding of rehabilitation as being a product to be dispensed by professionals, to viewing it as a process in which disabled people, and their families and communities are intimately involved (O'Toole 1991). Miles (1991) refers to this as the "democratisation of rehabilitation" and it has led to the emergence of community-based rehabilitation (CBR) which is understood as occurring where

> "resources for rehabilitation are available in the community. There is large-scale transfer of knowledge about disabilities and of skills in rehabilitation to the people with disabilities, their families and members of the community. There is also community involvement in the planning, decision-making, and evaluation of the programme..." (Saunders 1990 p.4).

CBR is seen by many to be part of PHC (Loveday 1990) as both focus on prevention of disease (and resulting disability), and on rehabilitation. CBR and PHC also have in common the principles of community participation, and commitment to provision of accessible and appropriate services. While CBR and PHC do overlap to a great extent, it is recognised that the range of needs of disabled people merits an approach which links rehabilitation to the social context of the disabled person (Cornielje 1992). Thus inherent in CBR is the adoption of a multisectoral approach which links disability both with community development and with PHC.

1.4 Common themes and problems

While there are many common principles shared by community development, PHC and CBR, there are also common questions and concerns that have arisen in regard to each of them. The first of these is the way in which "community" is viewed. Many of the responses to social issues such as poverty and disability, have been based on *consensus theory*, a simplistic view of human nature which assumes that communities are homogeneous in nature and community leaders only motivated by concern for the poor (Foster 1982). This view is based on the assumption that all community members are unified in selflessly seeking the best way to respond to the needs of those who are particularly disadvantaged.

In contrast, the Marxist analysis presents a *theory of social conflict and change*, which is based on the recognition that conflict over the means of production is inherent in capitalist societies. In terms of macroeconomics, this is a system of dominant and dominated economies, where "the development of the one depends on, and creates, the underdevelopment of the other" (Sanders 1985 p.64). In microeconomic terms, the burden of poverty (and disability) may contribute to a power struggle over the limited resources available (Momm & Konig 1989).

Adopting the Marxist analysis leads to a questioning of the concept of "community" as a homogeneous unit. Instead, they are seen as being *conflictual in nature*, with the particular social, economic and political contexts having a direct influence on internal dynamics. The materialist basis of the Marxist analysis asserts that material conditions determine behaviour. This is in contrast to conventional (community development, PHC and CBR) approaches which assume that behaviour is determined by values and attitudes. The Marxist analysis thus poses the challenge for programmes to provide improvements in material conditions for poor communities (Lund 1987).

A second question common to community development, PHC and CBR is that of community participation. The top-down approach in all of the fields under discussion has meant that participation is synonymous with *compliance*, a means to improve service delivery. Underlying this view of participation is a disregard for and undermining of local culture and practices, which are replaced by "superior" practices imported from outside (Chambers 1993). A contrasting view of participation is that it is a process by which the poor work together to overcome problems and gain more control over their lives (Werner & Bower 1982). In this way participation implies a *redistribution of power* (Arnstein 1969). However, in practice, implementation of many development, health and disability programmes has led to reinforcement of unequal power relations. Professionals play a controlling role, and local people do not have the power, resources or knowledge necessary to participate meaningfully in decision-making. For example, there are very few CBR programmes run by disabled people (Miles 1992), instead the continued mystification and medicalisation of disability has enabled professionals to retain their powerful positions as "experts" in this field.

The following table illustrates various features of different approaches within the fields of community development, primary health care and community based rehabilitation:

Table 1.1 Features of different approaches

Approach:	top-down	bottom-up
View of community:	consensus	conflict
View of community participation:	compliance	empowerment
Role of professionals:	experts in control	collaborators
Aim:	improved services	social justice

1.5 The disability rights movement

The unequal power relations between people with disabilities and professionals have been challenged by the disability rights movement, and disabled people have rejected the notion that disability can be defined and controlled by professionals, without consultation and partnership with them. They reject too the societal stereotypes of disabled people as objects of charity and pity. Part of the struggle has been to *re*define disability - not as individual tragedy, but as exclusion from society. If then disability is an issue of oppression and discrimination, disabled people are united with all who are marginalised. Central to this is the need for changes of attitudes and practices, so that they become inclusive of *all* people. In this way, it is society and not disabled people that needs to be rehabilitated (Werner 1993a).

The view of disabled people as "children in need" has been challenged, and instead it is emphasised that they are "citizens with rights" (Rappaport 1981). It is the obtaining of *both* needs *and* rights, and the gaining of control over one's life that Rappaport refers to as "empowerment". Essential to this process is a changing role of professionals, from being "experts", to being "collaborators" in the struggles of disabled people. CBR is then understood as "a philosophy whereby disabled people together with committed professionals ... are working together in the struggle for human rights" (Alexandra Health Centre 1992).

1.6 South Africa: social welfare and health policies as instruments of apartheid

The policies of apartheid have "systematically oppressed, discriminated against, and curtailed and restricted the lives of millions in a society in which no one can claim to remain untouched or unblemished" (Benatar 1991 p.35). This has meant that within South Africa over the past four decades there have been many "development" policies and practices which have actively worked against the interests of poor and marginalised groups. In fact, the policies of social welfare and health have been used, not in favour of the poor, and to address injustices prevalent in society, but to reinforce unequal power relations and to entrench the ideology of apartheid. The following discussion focuses on these policies as they have been implemented specifically in the social welfare and health sectors.

1.6.1 Features of health and welfare provision under the Nationalist government

A central feature of health and social welfare policy in South Africa has been the differential expenditure on health services between races, in which a disproportionate expenditure has been on services for whites (Price 1986, McKendrick 1990, Dor et al 1993). The outcome of the racially-defined system has been divided, uncoordinated and unjust provision of health and welfare services (UND 1990). Policies based on the ideology of "separate development" have led to *fragmentation*, and *duplication* of services - factors which have serious consequences for coverage, comprehensive care, efficiency and costs. This has been compounded by the centralised and bureaucratic administration system (Dor et al 1993).

Although the Nationalist government's Department of National Health and Population Development advocated that it was committed to the principles of PHC (1992), the South African Health and Social Services Organisation (1993) pointed out that the State had a "flawed PHC model". These "flaws" included:

- the insistence of the State that communities pay for the cost of services. Immediately, this restricts the accessibility which is a pillar of the PHC approach.
- the fact that within the health budget, State expenditure on curative services far exceeded that on preventive services (Price 1986).

- State expenditure on PHC which has been scanty and restricted to clinics and day hospitals. These have a top-down approach, which is antithetical to the PHC philosophy of community empowerment (Werner 1982). Even mobile clinics (as illustrated in Photograph 1.1) tend to be top-down and disempowering for community members.
- the lack of collaboration of the State health sector with other sectors which has had a negative impact on diseases influenced by health-related factors (Dor et al 1993). This selective PHC is reinforced by a very narrow perspective of welfare which does not embrace health, housing and job creation (Action Group on Social Services 1989).

Photograph 1.1 Primary health care services for poor communities under the Nationalist government

Many of the disabilities manifesting within black communities in South Africa are preventable (Loveday 1990). If the Nationalist government had addressed the causes of violence, PHC initiatives could have had an enormous impact on the prevention, detection and early treatment of disability. Instead, the high-technology, institution-based, "curative" approach to rehabilitation has made disability the "property" of medical and paramedical professionals. The resulting treatment, based on a medical understanding of disability, with little collaboration with health-related sectors, may be inappropriate and/or irrelevant to the disabled person concerned.

Since the 1980's there has been a move by the State towards *privatisation* of health and welfare services. This means that economic apartheid is substituted for racial apartheid (Benatar 1991) which favours the rich (who have insurance coverage) at the expense of the poor (who do not). Privatisation has been severely criticised by those within the progressive health and welfare sector, not least because privatisation and the welfare of the people stand in stark contradiction to each other. Indeed, without real economic changes the health and welfare needs of the people will never be met (Yach & Edwards 1992). It is evident that because the majority of actual and potential health and welfare service recipients are economically disadvantaged, privatisation will lead to increased inaccessibility of services to those who are in greatest need (Action Group on Social Services 1989). It also places an illogically heavy burden of responsibility for their own health and welfare on individuals and families who can least afford it. In sum, the move towards privatisation in health and welfare, instead of alleviating poverty, hardship and suffering, will in the long-term further entrench inequalities between rich and poor.

1.6.2 Implications of policies for disabled people

What has been the impact of these health and welfare policies for people with disabilities in South Africa? Firstly, it is evident that the racial bias has meant that black disabled people have been disadvantaged as compared to white disabled people in terms of provision of (among others) rehabilitation, health and education services.

Secondly, the focus of medical and social work professionals (particularly those in the progressive sector) has been (and will continue to be) on improving equity of health and welfare services for the majority black population. While this emphasis on racial differences is necessary in correcting the injustices imposed by apartheid policies, it may have been made at the expense of consideration of other differences such as physical disabilities. The energy, time and resources channelled into lobbying for improved provision for those who are black has certainly not been paralleled by a lobbying for accessible services for people with disabilities.

Thirdly, the authoritarian approach taken to the provision of health and social services has been a top-down one, with no consultation with or accountability to consumers. Professionals working for disabled people in the welfare arena often cannot identify with problems of unemployment, poverty and discrimination experienced by their clients. And yet it is professionals who are responsible for articulating the problems of disability to the public at large (Nkedi 1989). Very often this leads to the perpetuation of the medical or charity approach to disability, with negative images of disabled people as those who are sick, and in need of care.

Finally, the fragmentation and duplication of health and social welfare services has also negatively affected people with disabilities. There is no comprehensive policy on disability, and often disabled people fall between different departments - such as when a person who is mentally handicapped is discharged from hospital and needs ongoing medication, counselling, a disability grant and day-care facilities (Freeman 1992). Is this a health or welfare problem? Who should take responsibility for it? There is also no comprehensive policy on home-based care of disabled people.

1.6.3 Policy recommendations

What can be done to improve health and welfare provision for *all* citizens of South Africa (regardless of race or ability)? This has been the subject of many workshops and conferences within the progressive sector over the past few years, resulting in proposals for transformation of the system. Included in the health and social welfare policy guidelines that have emerged is the view that all citizens irrespective of race, gender, religion, political affiliation or disability should have equal access to services, the sole criterion being *human need* (Action Group on Social Services 1989).

The issue then becomes finding ways of skewing the provision of services towards those that need it most (Lund 1990) and of transforming the system into "a mechanism for redistributive justice, as well as ... a platform for development" (Lund 1993 p.1). This commitment to *social justice* and the reallocation of resources to address the needs of the poor, is central to the philosophies of community development, PHC, and CBR. It means that within South Africa, the trend towards privatisation needs to be replaced by "egalitarian development" and the provision of public goods and services so that the productive capacity of the poor is increased (Coovadia 1987). It is also essential that there be *participation* of those affected by a problem in addressing it, thus ensuring that services are both appropriate and accountable to consumers (Nkedi 1989).

1.7 The focus of the present study

The present study is based in one geographical area - the informal peri-urban community of Amawoti. Residents of such areas are among the most poor and marginalised groups within cities of South Africa (Haarhof 1985).

A civic committee in Amawoti identified disabled people as a particularly vulnerable group in the area. This led to a survey of disabled people being conducted, and the subsequent election of a committee to provide the mechanism whereby disabled people, parents of disabled children and civic members could work together to address priority needs. In this way the commitment to participation and empowerment of disabled people was demonstrated, as was the understanding that disabled people are an integral part of the community.

It was then recognised that a number of influential groups in Amawoti could also be involved in addressing the needs of disabled people, and ensuring that their rights would be protected. This recognition led to the posing of the question which has been the focus of the present study:

What key resource and interest groups can be identified, so that their influence can be supplemented or challenged, as part of the process of empowerment and integration of disabled people in community life?

Answering this question has meant looking at the responses of key interest groups in Amawoti to disability, and analysing these in order to observe trends. Focus groups provided an effective mechanism (and methodology) by which various diverse interest groups could express their views, which included defining disability and its causes, the needs and rights of people with disabilities, and appropriate interventions that would improve the situation of disabled people in Amawoti. The action research method used implies that the results emerging from this study are socially useful. Indeed, it is anticipated that recommendations will be made regarding appropriate interventions for disabled people that could be facilitated at both the local community level and at regional and national policy levels.

Conclusion

Within the current debates about community development, primary health care and community-based rehabilitation, the concepts of participation and power are central. Certainly there are many obstacles - among them structures and professionalism - which prevent ordinary people from gaining more control over their health and their lives. How can this "gaining of control" be facilitated for marginalised groups such as people with disabilities who are poor? Much of the theory and practice within the field of disability has already been challenged by the disability rights movement, but within South Africa, the disabled poor have also to contend with a history of negative development practices, based on apartheid ideology. The present study, based within a poor urban black community, explores perceptions of disability, and strategies to support disabled people, proposed by different interest groups in the area. These, in turn, are related both to the wider debates about participation (and disabled people's "gaining of control"), and to the current challenge facing South Africa - that of building a more just, inclusive and tolerant society.

CHAPTER TWO:

A FRAMEWORK FOR DEFINITION OF AND APPROACHES TO DISABILITY

Introduction

In exploring issues of disability within a particular geographical community, two questions need to be addressed. The first relates to the very *definition* of the term "disability", and the debates around this. The second relates to the different *approaches or strategies* that can be taken in support of people with disabilities. These are closely related, in that definitions of disability influence the conceptualisation of responses to it.

This chapter discusses some of the factors contributing to the need to define disability, and highlights the problematic nature of this task. Two prevalent yet contrasting definitions, those of the World Health Organisation (WHO) and those of the disability rights movement, are presented with critiques. This is followed by a discussion of three different approaches taken to disability viz. the traditional approach (based on culture and religion), the medical/welfare approach, and the social approach. Concepts of empowerment and integration, as they relate to people with disabilities, are explored as part of the social approach to disability. These in turn are related to current debates about community development and community-based rehabilitation.

2.1 Defining Disability

2.1.1 Background:

(a) The need to define disability

Historically, a classification system for disability grew from the need to distinguish the "deserving poor" from the "undeserving poor" (Oliver 1990). People were defined "disabled" when they could not operate in the labour market and were therefore (legitimately) in a position of dependency. The classification process provided the setting for diagnostic medical experts to intervene in separating the infirm from others. The medicalisation of the definition and measurement of disability was thus written into social policy in the late 1920s as "a defence against scrounging" (Sainsbury 1989 p.5), and resulted in transfer of policing from legal to medical authorities (Abberley 1987). The need to assess eligibility for pensions led to the development of standard "objective" measurements of disability, by using comparisons with "normal" people of the same age or sex. This was the beginning of a process of classifying disabled people and interpreting disability in medical terms (Finkelstein 1990).

Parallel to this process have been developments within the medical and other related fields over the past century, which have changed the pattern of disease and illness by making it possible to treat a number of formerly fatal diseases. The result has been an increased population of those surviving with reduced levels of functional performance, and "the burden of illness is coming to be dominated by chronic and disabling conditions" (Wood 1980 p.377). There is thus a growing need to shift the focus within the medical field from diagnosis and causes of illness, to the *outcome* or consequence of disease i.e. the resulting disability. This means that for rehabilitation service providers, classification remains a major issue, for "a rehabilitation programme for people with disabilities requires a clear definition of who is disabled" (WHO 1994a p.1).

(b) Problems of definitions

The definition of disability is particularly significant, in that it is an expression not only of how society perceives people who are disabled, but also how it responds to them. If disability is defined in terms of individual tragedy, then disabled people will be treated as victims of circumstance. This treatment will not only be evident in day-to-day interactions within society, but will also be reflected in service provision and policies relating to disability. However, "disability" is a social construct, and thus definitions of it are invariably in contention: "They depend upon the interests, intentions and unexamined presuppositions of those with the power to define, and the ability of those so defined to resist inappropriate conceptions of their reality" (Abberley 1992 p.153).

Definitions of disability cannot be objective and transferable across cultural, socio-economic and other differences. It is a term which is "slippery and inherently unstable" (Sainsbury 1989 p.4). What constitutes disability is relative, and depends on local attitudes and physical barriers, which change from one society to another, and even from one generation to another. "A mobility or visual impairment may be more of a disability in a Western urban environment than in a village in the South where there are no buildings with stairs, no pavements with kerbs, and no newspapers to read" (Coleridge 1993 p.107).

Thus it is more important to evaluate the *social effects of disability* than to try to come to a conclusive definition of it, which in reality does not exist (Curtis & Reier, World Institute of Disability, personal communication 1993).

Indeed, concentrating too much on definitions of disability may itself be a danger, for "people with *disabilities* are also people with *abilities*" (Bowe 1990 p.4 italics indicate my emphasis). There is the need to move away from an approach of emphasising disabilities to classify individuals, "since these tend to be the direct or aggravated result of the attitude of the community itself towards persons who suffer from some real or apparent physical or mental disorder or functional problem" (Despouy 1991 p.44). Instead, there should be an emphasis on developing the capacities of the individual to the full.

Despite these difficulties, efforts have been made to define disability. Among the most prevalent definition in use is that proposed in the classification of the World Health Organisation (WHO 1980). A description of this classification is given, and this is followed by an alternative definition of disability proposed by the disability rights movement.

2.1.2 Differing definitions:

(a) World Health Organisation

(i) Definitions

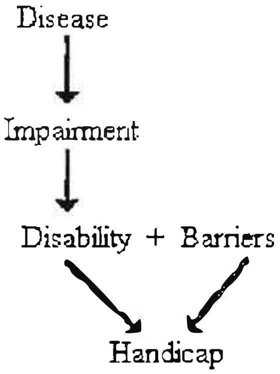
In 1980 the WHO introduced the International Classification of Impairment, Disability and Handicap (ICIDH), in which a clear distinction was made between each of these terms as follows:

impairment is any loss or abnormality of psychological, physiological or anatomical structure or function. It refers to organs of the body.

disability is any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being, this resulting from an impairment. It refers to the person.

handicap is a disadvantage for an individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, and social and cultural factors) for that individual. It refers to the interaction of the person and society.

The interaction of these concepts is as follows:



To illustrate use of these terms, an example may be helpful. Polio (disease) may result in paralysed leg muscles (impairment), which cause difficulty walking (disability). The person with difficulty walking may not get a job because potential employers believe that someone with deformed legs is not intelligent (handicap) (WHO 1994b).

It must be noted that these concepts cannot easily be translated into other languages. In Zulu, "ukukhubazeka" is used to refer to impairment, disability *and* handicap - no distinction is made between them.

(ii) Usefulness of distinctions

The value of these distinctions has been highlighted in relation to the provision of services. Identification of *impairments* is important for the planning of medical interventions, and for the provision of appliances. Establishment of *disabilities* is necessary for planning rehabilitation services which include training for daily activities, education and particular skills. Identification of *handicaps* is essential for social welfare provision, and for planning measures to remove barriers to social integration (Wood 1989, WHO 1994a).

Negatively, lack of clarification of these terms may lead to problems. For example, welfare benefits may be obtained on the basis of an impairment (e.g. absence or paralysis of a limb or degree of blindness or deafness), but educational or vocational services may be based on disabilities (WHO 1994a). This may mean that those in need of particular services, are denied access to them, because of differing assessment criteria between (health, welfare and education) sectors.

(iii) Critique of WHO definitions

While the WHO classification of impairment, disability and handicap has been widely adopted, criticisms of it have been raised by the disability rights movement. Firstly, it is argued that there is no practical difference between *impairment* and *disability*. The first indicates "loss of function" and the second "lack of ability to perform". These are seen as being virtually synonymous (Coleridge 1993).

Secondly, it is problematic that disability is viewed as a *deviation* from what is "considered normal". There is reification of the idea of normality, which is challenged by Sutherland (1981) who holds that any definition that separates people into "disabled" and "able-bodied" is unsatisfactory because it perpetuates "the myth of the normal healthy body". She maintains that every human being is more or less disabled. Even if the idea of "able-bodied normalcy" is conceded, the WHO classification ignores the situational and cultural relativity of normality (Oliver 1990).

It has been argued that the WHO classification was made in the context of the health experience, and that the terms are basically clinical (Despouy 1991). The difficulties are seen from the perspective of proposed treatment for a "patient", without recognising that the individual has to weigh up whether this treatment fits into the overall economy of their life. The medical approach thus produces definitions of disability which are partial and limited (Oliver 1990) and which do not incorporate the social and cultural aspects which are necessarily present in disability and impairment (Despouy 1991).

Another major criticism of the WHO classification is that it is based on the theory of personal tragedy, which individualises the problem of disability. A disabled person is seen as an unfortunate victim or a "tragic case" (Morris 1991). This poses problems for individual and group identity (Oliver 1990), in that people are categorised according to disease or impairment, not according to social disadvantage.

(b) The disability movement and the social model of disability

(i) Definitions

An alternative to the WHO definition, is that which sees disabled people not as "individuals with unfortunate "defects", but as *an oppressed group in society*" (Milton Keynes 1990 p.11 italics indicate my emphasis). This oppression is in relation to the rights of access to economic, political and social power which disabled people are denied. Thus disability is viewed as a problem located within society rather than within individuals who happen to have impairments (French 1993)

In rejecting the WHO definitions, the disability movement has developed two basic concepts related to the social model of disability (Oliver 1990, Coleridge 1993):

Impairment is the lack of part or all of a limb, or having a defective limb, organism or mechanism of the body.

Disability/handicap is the disadvantage or restriction of activity caused by a contemporary social organisation which takes no or little account of people who have physical impairments and thus excludes them from the mainstream of social activities.

What is at stake here is the issue of *causation*, and whereas the previous definitions were ultimately reducible to the individual and attributable to biological pathology, this definition locates the causes within society (Oliver 1990). The issue becomes the *disabling world*: "It isn't so much the disability that paralyses, but the thousandfold handicaps caused by society. It isn't that one is disabled, but that one is *turned into* a disabled person" (Boylan 1991 my emphasis).

(ii) Value of the social model

Defining disability as a form of oppression has meant that "disabled people can be regarded as a group whose members are in an inferior position to other members of society because they are disabled people" (Abberley 1987 p.7). This has certainly been a unifying concept within the disability movement; it has helped to spread the message that disabled people, whatever their impairments, share many problems, and should be regarded as one unified disadvantaged group (French 1993).

(iii) Limitations of the social model

While agreeing with the basic tenets of the social model of disability, French (1993) points out that some of the most profound problems experienced by people with certain impairments are difficult, if not impossible, to solve by social manipulation. Ultimately, "to experience disability is to experience the frailty of the human body... to deny the personal experience of disability is, in the end, to collude in our oppression" (Morris 1991 p.183). The fact that some difficulties cannot be addressed by simple changes in society, illustrates the limitation of the social model to adequately explain all experiences of disability. There is a tendency of the social model to present disability in a straightforward, uncomplicated manner, neglecting the examples that do not fit. The questions raised by French (1993) and Morris (1991) are not intended to undermine this approach, but rather to challenge those who hold it to broaden and intensify their examination of disability and deepen their knowledge to the benefit of all those who define themselves as disabled.

2.2 Approaches to Disability

In this section, there is a description of three different approaches taken to disability viz. the traditional approach, the medical/welfare approach, and the social approach. These approaches are not seen to be mutually exclusive, as there may be many overlaps between them. The broad categorisation given provides a framework for understanding different conceptualisations of approaches to disability.

2.2.1 The Traditional Approach

Among African communities "there is little if any room for the concept of *chance* in the world-view" (Buhrmann 1984 p.32). Religion and culture thus provide the construct of the traditional approach to disability. These beliefs give the framework for an ongoing search for a *cause* and for understanding the reasons for occurrence of disability in the community.

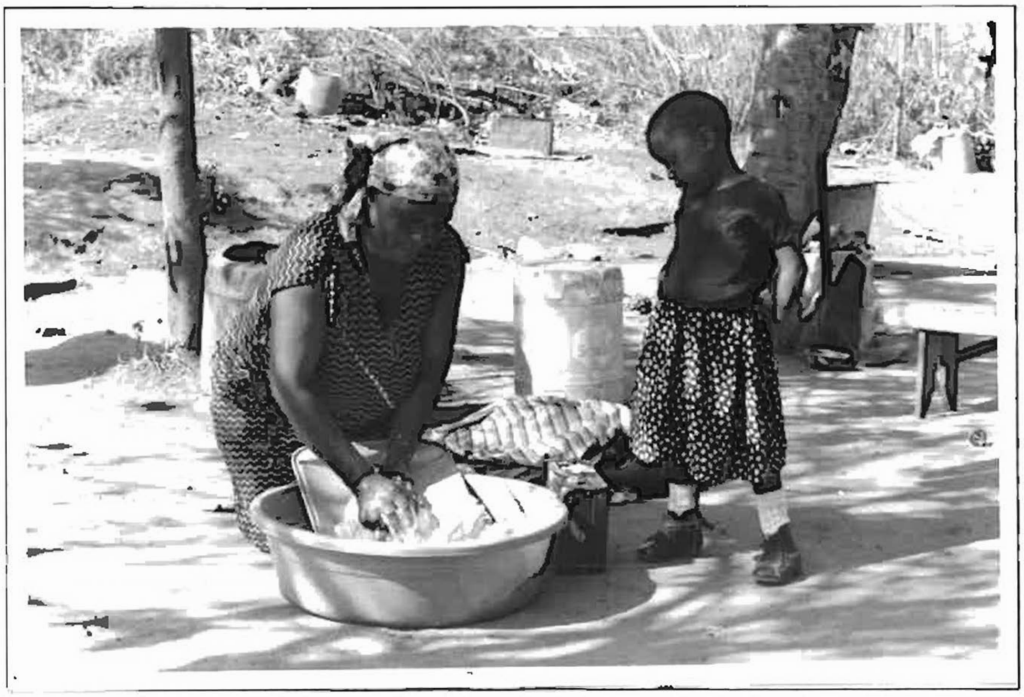
Many authors have written about ethnomedicine and causality concepts within traditional belief systems (Ngubane 1977, Bannerman et al 1983, Coleridge 1993). Suffice it to say that in many African cultures, disability is seen as a punishment, or the result of ancestral anger or retribution by divine forces. This may be as a result of:

- neglect of simple customs or requests of the ancestors, indicating a lack of respect for their needs and wishes:
- omission of a particular custom (such as the ceremony performed for the deceased head of a household to bring him back to the home as an ancestor);
- unethical behaviour of a member of the family; or
- jealousy of neighbours who have resorted to the use of witchcraft (Buhrmann 1984).

The traditional approach views disabled people as unfortunate, different and "blemished" (Coleridge 1993), disability being a punishment for their own wrong-doings, or those of family or neighbours. A family that has a child born to it with a congenital disability, is considered to be collectively punished.

What are the implications of these traditional beliefs? Firstly, disability seen as a divine curse "justifies" low esteem for disabled people and their families. Secondly, disability as a "justifiable" condition absolves the non-disabled of responsibility to provide services for people with disabilities. These beliefs may also lead to feelings of sinfulness or shame on the part of the disabled person and their family, with the disabled person being hidden away from society (Helander 1984).

In a study of beliefs and attitudes among rural disabled people in Zimbabwe (Jackson & Mupedziswa 1988) it was found that witchcraft was most commonly cited at the causal agent of disability. The second most important perceived cause was God, followed by natural causes and ancestral spirits. This study is significant in its observation that a local rehabilitation programme had had a negligible impact on the beliefs held. The authors conclude that for rehabilitation, *it may be irrelevant what beliefs people hold regarding causal agents of disability, provided they have access to rehabilitation services.* While this may indicate that traditional beliefs do not influence use of rehabilitation services, one cannot ignore the prejudices and discriminatory attitudes which may result from these beliefs. They may themselves contribute to the "disabling world".



Photograph 2.1 **A disabled child may be regarded as punishment for sins**

It is significant that in the Zulu language, different words are used to denote those people who were born disabled, and those that acquire disabilities later in life. Those born disabled (e.g. with cerebral palsy) are referred to as "isidalwa" or "one who is created". There is a sense of fatalism, where one has no control over God's creation, and it evokes emotions of sympathy. In contrast, those who acquire disabilities later in life are felt to have in some way deserved it - and so are subject to much less sympathetic attitudes.

Many derogatory terms are used to refer to them, such as "isilimi" ("fool/idiot") or "isishaywa" ("one who is hit/punished").

2.2.2 The Medical/Welfare Approach: "Cure or Care"

Inherent in the medical/welfare approach, is the perception that disabled people are sick, defective, and in need of a "cure". When medical interventions are not effective, then disabled people need to be "cared for".

(a) Features of medical/welfare approach

A cornerstone of the medical/welfare approach is the *medicalisation of disability* i.e. the view of disability as being individual pathology. Over the past century, the great strides in medical science and technology led many to believe that any dysfunction could be explained through rational scientific argument. The cause of any condition regarded as abnormal could be attributed to malfunction of a physiological system, excluding the causes that could have emerged from a social or spiritual reality. Pathology thus provided the means by which "dis"-ability could be distinguished from able-bodiedness, "ab"normality from normality (Coleridge 1993). Disability as malfunction has since grown to be seen as a specialised health problem, at the heart of which is an emphasis on clinical diagnosis. The aim of medical rehabilitation, in responding to impaired individuals, is thus to assist the individual to be "as normal as possible" (Oliver 1990).

Without doubt, the contribution of modern medicine has led to increased survival rates and prolonged life expectancy for many disabled people and even eradication of some disabling conditions. "But the issue for the late twentieth century is not one of life-expectancy but *expectation of life* and it is here that the negative and partial view prompted by the medicalisation of disability is most open to criticism" (Oliver 1990 p.48 italics mine).

Another feature of medical/welfare approach is the tendency to reduce problems of disabled people to their own *personal inadequacies* or *functional limitations*. This can be illustrated by some items from a questionnaire used in a survey on disability in Britain recently (quoted in Oliver 1990).

- Can you tell me what is wrong with you?
- What complaint causes your difficulty in holding, gripping or turning things?
- Does your scar, blemish or deformity limit your daily activities?
- Does your disability make it difficult for you to travel by bus?

These questions could just as easily be rephrased thus:

- Can you tell me what is wrong with society?
- What defects in the design of everyday equipment like jars, bottles and tins cause you difficulty in holding, gripping or turning them?
- Do other people's reaction to your scar, blemish or deformity limit your daily activities?
- Do poorly-designed buses make it difficult for someone with your disability to use them?

The issue at stake here is whether disability is determined by the *impaired individual* or by *society*, the "disabling world".

(b) Critique of the medical/welfare approach

i) Entrenchment of segregation

The prevalent approach which focuses on the personal inadequacies of people with disabilities, and has medicalised their condition, has significantly contributed to the *exclusion* of disabled people from community life. The focus has been primarily on the impairment, secondarily on the individual that bears it, and only minimally on the social and physical environment. While major achievements have been recorded in surgery, physical medicine and other interventions upon the impairment, protection of the fundamental right of people with disabilities to participate in the benefits of society cannot yet be guaranteed (Acton 1982).

The marginalisation of the disabled poor has been referred to as "a problem of secluded people; seclusion from attaining social independence and of being branded "special cases" amongst their communities" (Nyathi 1986 p.61). This exclusion is formalised by the medical profession when doctors provide the clinical labels by which persons become officially chronically sick - and signal the beginning of the process by which people with disabilities become segregated from society (Locker 1983). Thus the producing of a domain in which the professional is the expert may itself undermine the ability of the populace to integrate its own disabled members and to provide social support for them (Aptekar 1983).

ii) Dependency-creating

There are a number of ways in which dependency is created through professional medical and welfare services. The *kinds of services* available (both residential and day care) are often characterised by

- institutionalised regimes,
- failure to involve disabled people meaningfully in the running of such facilities, and
- rigidity of the routine activities.

All of these factors serve to institutionalise disabled people and create dependency (Oliver 1990). The very *professional-client relationship* may also create dependency as it "enshrines the professional in a world of exclusive and privileged knowledge and consequently entombs the [disabled] individual in a fundamentally dependent role" (Brechin & Swain 1988 quoted by Oliver 1990 p.90).

Dependency is also created through the *mindset of "charity"* in which disabled people are seen as "welfare cases" and the passive recipients of "aid". This goes beyond the individual level and has an impact at regional and even national levels, as Venkatesh (1993 p.11) states: "The provisions made by governments world-wide [for disabled people] are welfare oriented, reflecting the perception of "providing for" or "looking after"... these have succeeded in promoting an attitude of dependence".

iii) Needs-based

The medical/welfare approach is derived from the needs model of dependent people (described by Rappaport 1981). It views people as children who depend on outside professionals and "experts" both to establish needs, and to meet them. It is "Medical experts... often decide what they think disabled people need" (Milton Keynes 1990 p.7). and "precisely *because* disabled people are viewed as being "less-than-human", they have *needs* to which the more fortunate of us should minister" (Carter 1988 p.7). This view contributes to the maintaining of the existing social order within hospitals and institutions, it accepts that there are some who are less needy and more human than others (the staff), who help the rest, the very needy and the "less-than-human" (those with disabilities).

Undeniably, needs are easier to meet than their rights, as the "definition of needs can be an arbitrary, selective, one-off exercise, subject to cultural definition, relative, fragile and impermanent" (Carter 1988 p.143). Needs can be arbitrarily defined by those in power, usually non-disabled professionals. They focus on the deficiencies of people with disabilities, without taking into account their demand for human dignity and their rights. This approach denies the wholeness, depth and integrity of disabled people, and it is both patronising and disempowering.

2.2.3 The Social Approach: Empowerment and integration of disabled people

The view that disabled people are an oppressed and marginalised group in society is central to the social model of disability (Abberley 1987, French 1993). For many black disabled people in South Africa, the disadvantages of disability have been *in addition* to disadvantages imposed through legislated racial discrimination and poverty. Poverty in itself is a form of social, political and psychological disempowerment (Friedmann 1992), and powerlessness and exploitation are among the factors that perpetuate poverty (Clark 1991). Thus the disabled poor are among the most marginalised in society. Empowerment, on the other hand has been described as the "inclusion of the excluded" (Friedmann 1992 p.158). This does not imply that people with disabilities must adapt so as to fit into society - it is *not* about "normalisation", cure, or care. Instead, it is about integration, it is about removing barriers that prevent people from disabilities from exercising their right to participate in society (Coleridge 1993).

What can be done to challenge the oppression and exclusion of members of society who are defined as being "disabled"? This section describes empowerment and integration as two essential principles of addressing the issue of disability in society.

(a) Empowerment

In addition to the oppression of apartheid and poverty, disabled people have been disempowered by two major institutions of modern society - medicine and welfare: "Accordingly they become subject to the decisions of others who allocate them to clinical and administrative categories, define their needs and the most appropriate way of meeting them" (Locker 1983 p.43). Insofar as medical and welfare professionals have control of resources, the disabled person may have no choice other than to accept whatever is deemed necessary for his/her own good.

The empowerment approach has been advocated as a means by which to address some of the root causes of this oppression. Empowerment is the process by which disadvantaged - disabled - people work together to increase their control over the events that determine their lives: "The goal of empowerment is to enable communities, individuals and families to read their reality and transform that reality in order to be less dependent on outside resources, services, and regulations, and to be in control of their own destiny" (Kaseje

1991 p.3). This approach views disabled people as active subjects, in the forefront of analysing their problems, seeking solutions, and then taking the required individual and collective action. It means moving from personal understanding to group action - a process that has three major dimensions (Keiffer 1984):

- the development of a sense of self-confidence,
- the construction of a more critical understanding of the impact of social and political factors and
- the nurturing of individual and collective resources for social and political action.

Thus empowerment is *a process of becoming*, an ordered and progressive development of participatory skills and political understandings. It cannot be done *for* or *to* anyone, people can only empower themselves (Kaseje 1991).

In working towards the goal of enhancing the possibilities of disabled people to control their own lives, the medical/welfare view of disability is challenged. People with disabilities are not seen as "simply children in need, or as citizens with rights, but rather *as full human beings who have both needs and rights*" (Rappaport 1981 my emphasis). This approach shifts the base of power, so that the professional is seen not as the "expert", but rather as a "collaborator", a partner standing in solidarity with the oppressed. It means that professionals must work *with* disabled people, rather than *for* them (Finkelstein 1984). For this to be possible, there must be a genuine recognition of the capacity of community members - both disabled and non-disabled - to contribute to the definition and addressing of issues of disability. "Social problems, paradoxically, require that experts turn to non-experts in order to discover the many different, even contradictory, solutions that they use to gain control, find meaning and empower their lives" (Rappaport 1981).

The empowerment approach is an attempt to address oppressive practices and imbalances of power, and to use resources provided by the health and welfare sectors (among others) not to promote an attitude of dependence and disempowerment, but one of self-confidence and dignity (Venkatesh 1992). Such services and resources are greatly needed in poor communities - indeed they have the potential to effectively modify the impact of impairment and disability in everyday life - but ultimately the question of power needs to be addressed. "It is paternalism that often keeps welfare agencies from the insight that lack of power, not simply lack of services, drives the poverty cycle" (Lamb 1975). The empowerment approach challenges the assumption that provision of these resources *alone*, without consideration of control over them, will bring about significant changes in the quality of life of disabled people.

In summary, the empowerment approach acknowledges the needs and rights of people with disabilities. It views development as not only genuine and lasting improvement in the conditions of life and livelihood, but also as a political struggle for empowerment (Friedmann 1992).

(b) Integration

i) Defining integration

Integration has been defined as the active participation of disabled people in the mainstream of community life (Helander 1984). In drawing a contrast between programmes aimed at rehabilitation, and those aimed at integration, Davies (1989 p.10) describes the first as "all those efforts which help a disabled person to become as independent as possible". This author sees the latter as going further in that "integration programmes comprise rehabilitation as well as the *conditioning of the social and economic structures* of the community, to get them to understand and cope with the problems of disability, with a view to enabling disabled people to become a natural part of the community - fully involved in all that community's activities, services and responsibilities" (my emphasis). To achieve this, educational and training opportunities, jobs and services must be provided for people with disabilities; and at the same time public awareness must be stimulated and discriminatory attitudes (which prevent integration) challenged.

Integration must be seen as distinct from assimilation which is to deny all differences, blurring the boundaries between disability and non-disability. Abberley (1987 p.16) sees this as "devaluing and denying the authenticity of an impaired person's experience, dissolving real problems in the soup of "attitude change"". The needs of disabled children will not be met by pretending that they are not different, and do not require specific resources and services (Stubbs 1992). Sachs (1992 p.9) pursues this theme further, maintaining that people have both the right to be the same and the right to be different:

> "We are all the same - all citizens, all equal, all human beings... The right to be the same is not the duty to be identical in terms of belief, culture, values or personality, whether in the private sphere or in public life. With the right to be the same, therefore, we have the right to be different... I have been made different because I lost my arm... We are different, by birth, by accident, whatever it might be, but we want the same rights - legal, civil, political - to move in society, to be employed, and not to be discriminated against because we might have one arm instead of two arms or because we are in a wheelchair instead of able-bodied people. So we want

the right to be the same on the one hand, and the right to be ourselves on the other."

ii) Factors leading to exclusion

In its investigation of human rights in urban areas, UNESCO (1983) identified a number of factors that contribute to social exclusion of the poorest sectors of society. These can be applied specifically to people with disabilities who are poor:

- destitution - with inadequate housing, sanitation, clothing and food, disabled people existing below the poverty line are prevented from exercising rights that others enjoy. They are outside structures of society that could protect their interests (such as trade unions) and much of the disability rights movement is based in middle-class communities and formal townships.
- indifference - society turns a blind eye to the exploitation and suffering of disabled people. Injustices are seldom challenged, but become part of accepted norms of behaviour.
- intolerance - disabled people are often victims of irrational prejudice, or of pseudo-rational arguments. These may be linked to beliefs about the causes of disability, and result in a distancing and denial of communication.
- administrative practices - complex, fragmented and corrupt administrative practices may result in the exclusion of disabled people. (A problem being experienced at present in Amawoti is the objection by clerks at the pay-out points to people in wheelchairs collecting their own disability grants.)

iii) Achieving integration

"The answer to exclusion is participation" (UNESCO 1983 p.80). The answer to exclusion of disabled people is not aid - which *reinforces* their exclusion - rather, it consists of transferring them from recipients of aid to that of participants with rights and duties. People with disabilities have the right to participate fully in the life of the society to which they belong, and society needs to enable them to exercise that right (N'Kanza 1981 p.3). This means community members recognising that disabled people are contributors (Venkatesh 1992), and it means disabled people showing that they can be useful - they can help in the context of the family, they can work, they can go to school, they can make their voices heard (Helander 1981). "And it is when the disabled themselves start to make their voices heard that our societies will begin to adjust their thinking and their structures so as to meet the needs of all their members" (Shearer 1981 p.21).

A number of specific strategies can be used to promote integration and participation of disabled people in community life:

1. Changing attitudes

One of the most fundamental barriers to integration of disabled people is that of attitudes: "We cannot hope to accomplish integration without changing people's interpersonal, social, economic, and political behaviour. We cannot bring about changes of behaviour that will be genuine and lasting unless we change people's attitudes" (Acton 1982 p.148). This is done through a well-orchestrated combination of information and experience, and it is facilitated by sustained first-hand experience of interactions between people who are regarded as being disabled and others, in the natural environments of life.

Helander (1984) has suggested a long-term strategy to address prejudice against people with disabilities, which focuses on children and adolescents, who may not have acquired ingrained attitudes. This author believes that religious leaders and groups can also be highly effective in counteracting and uprooting prejudice. In addition, disabled people themselves should be prepared to speak up, as "the suppression of dignity is only made possible so long as those who should be heard remain silent" (Helander 1984 p.23).

2. Environmental accessibility

Another factor contributing to integration is the removal of environmental and architectural barriers thereby creating of "an environment of equality" (Nyathi 1988 p.62).

3. Institutional change

Particular attention must be paid to the integration of disabled children into community schools, as their isolation results in furthering negative attitudes towards them and marginalizing them in terms of their share of the community's resources. If children with disabilities are not given the opportunity for the same kind of play as non-disabled children in integrated situations, then they are being deprived of their rights. Indeed, they are being further handicapped because they will have a less developed social image that will make them less prepared for the future (Mendis 1989).

Affirmative action is required in order to facilitate integration of disabled children into community schools (WHO 1984). In this context, ""equal opportunities" means positive discrimination in favour of the most underprivileged" (UNESCO 1983 p.80). There is a need not only for legislation to enforce this principle, but also for careful preparation of parents, teachers and pupils involved in the process of making schools more inclusive.

(c) Addressing Needs *and* Rights

Earlier in this chapter the medical/welfare approach to disability was described as being *needs*-based, and the neglect of disability *rights* was highlighted. Carter (1988 p.7) holds that "the ideology that services should be based on needs rather than on rights is, perhaps the key to understanding most current services, whether in health, education or social services".

There has been much debate about the relationship between needs and rights within development and other circles (Galtung 1977, Rappaport 1981, Conyers 1982, Streeten 1984) - the "basic human needs" being one approach which has been widely adopted and implemented in a number of different forms. The aim here is to explore a few of the main issues which impact on the discussion of disability and poverty - an attempt being made to keep needs and rights in creative tension, (as recommended by Rappaport (1981)), as integral to the empowerment approach.

Galtung (1977) distinguishes between needs and rights by holding that needs are located *inside* individuals, while rights operate *between* them. This author sees the relationship between the two concepts as complex, but maintains that "the human rights approach is at its best in connection with the human needs referred to as security and freedom... The rights are the means, and the satisfaction of needs is the end" (Galtung 1977 p.258). The theme of means and ends is taken up by Friedman (1991) who highlights two approaches that can be taken in the meeting of needs. The first of these views the meeting of needs as an end in itself - clearly the position taken by Galtung. The second view is that the meeting of immediate, practical needs is a means of reaching more strategic needs. Both may result in practical improvements for communities but the latter is also aimed at "challenging the oppressive social relations", and thus furthers the process of human development. In addition, Friedman (1991) holds that the second view "has the potential to redefine basic needs as basic rights." There must be a struggle for immediate practical needs in the short term, but also a longer term struggle against oppression and exploitation, for the attainment of human rights.

Streeten (1984) identifies two basic categories of rights: the first he refers to as "negative rights", which include rights in the narrow sense (such as the right not to be tortured or murdered), civil rights, and political rights. These he sees as requiring no resources. The second category, of "positive rights", include social and economic rights - and these require substantial resources. "It is in this context that it is said that the satisfaction of basic human needs should be an integral part of positively, constructively and concretely defined "human rights"" (Streeten 1984 p.10). Streeten maintains that people are entitled to expect a fair share of the world's limited resources (in order to achieve social and economic rights) but it cannot be the right to the satisfaction of any needs, however basic, for such a right would not take into account the scarcity of available resources and the necessity of interpersonal and intertemporal choices.

Aside from the consideration of resources, UNESCO (1983 p.69) follows a similar theme to that of Streeten in pointing out that "when the prerequisites for any kind of decent human life (work, housing, education, health etc.) [social and economic needs] are not ensured, civil and political rights remain a dead letter; they are pointless." The meeting of needs is thus part of the ensuring of rights. This would seem to be the position of those who hold the "strong" or "radical" view of the basic needs approach to development (Wisner 1988). This approach goes beyond economic needs to address questions of equality and social justice. With this understanding, needs include basic consumptive goods, basic services and participation in decision-making (Conyers 1982).

Carter (1988) and Rappaport (1981) argue for an approach to social issues that combines both needs and rights. "Definitions of need alone can be arbitrary and paternalistic, unless they are based on *practices that accept the human rights of people* to equal, fair and just treatment" (Carter 1988 p.139 my emphasis). This author sees the need to address questions of power in favour of the relatively powerless - in this case people with disabilities. The significance of this is clear:

> "Human rights will not genuinely be respected... until the rights of the least significant and most deprived members of society are given precedence at all times. The practice of giving priority to the poorest of the poor is not a luxury. It is the means of guaranteeing that rights and, therefore, the dignity and humanity of all men will be truly respected... The poorest and most excluded people can teach a society the lengths to which it must go to ensure that human rights become a genuine reality for all its citizens" (UNESCO 1983 p.80).

Conclusion

This discussion has identified different definitions of disability that exist, and points out some of the strengths and limitations of each. Three different approaches to addressing disability issues have been described viz. the traditional approach, the medical/welfare approach and the social approach. In one sense this categorisation is artificial, for attitudes and practices prevailing in one approach (e.g. the belief that disability is punishment for sins), often influences attitudes and practices in another (resigning oneself to control by the health and welfare institutions).

In placing the present discussion in context (specifically that of an informal peri-urban community), the question is raised as to how these approaches to disability relate to a context of poverty. The poor are among the most powerless and exploited in society (Friedmann 1992), and those who are disabled are viewed as an oppressed and marginalised group (French 1993). What interventions would appropriately address those who live with the "fearsome combination of poverty and disability" (Acton 1983 p.79)? It is of value at this point to refer back to some of the concepts described in the first chapter.

Community-based rehabilitation (CBR) has been defined as "a strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities" (ILO, UN quoted in WHOb 1994 p.iii). This understanding clearly affirms the centrality of social integration of people with disabilities, which is a cornerstone of the social approach. In addition, this definition highlights the need for equalisation of opportunities, so that such integration is possible. If community development is understood as being a process "by which the poor themselves define and control their own struggle" (Wisner 1988 p.26) then the reference to community-based rehabilitation as being "a strategy of community development", indicates the commitment of community-based rehabilitation to the empowerment of disabled people. This was the second cornerstone of the social approach just described. Community-based rehabilitation has also been described as the "democratisation of rehabilitation" (Miles 1991). This may suggest that CBR is one method of implementing the social approach to disability in that central to it are the commitments to integration and empowerment of people with disabilities.

In working towards strategies that appropriately address issues of disability, it has been suggested that the term "rehabilitation" is inappropriate, in that it has medical connotations. It tends to be based in the medical rehabilitation paradigm, with a diagnosis-prescription model, which is inappropriate for vocational rehabilitation. Momm & Konig (ILO) propose the use of the strategy of "community integration programmes" which is seen to combine rehabilitation services with programmes geared to equalisation of opportunities and the social integration of disabled people. Another suggestion has been use of the term "community support for disabled people" (Medi, Save the Children Fund, Mozambique, personal communication 1994).

Despite differences of terminology, it is evident that certain core elements of any programme are required in order to effectively address the combined problems of poverty and disability. These are: rehabilitation, equalisation of opportunities, social integration and empowerment of people with disabilities. This may mean a combination of the three approaches described in this section. It may mean making sense of traditional beliefs about disability so that they provide identity for the disabled person, without being labelled or oppressed by it; it may mean re-orienting medical and welfare services to becoming more accessible and accountable to people with disabilities, and it may mean making the commitment to empowerment and integration which are central to the social approach.

CHAPTER THREE:

AMAWOTI: THE STUDY AREA IN ITS URBAN CONTEXT

Introduction

Situated on the southern tip of the African continent, with a population of close to 40 million people, South Africa is a country poised on the threshold of a new era. The process of negotiations between leaders of the black majority and white minority has led to the formulation of a non-racial constitution and the election of the country's first democratic government. After almost fifty years of bitter apartheid rule, the prospect of a more open and humane society seems a real, albeit demanding, possibility. There is the potential that differences of race, gender or ability will be seen as essential elements of an enriched and diverse society and not determinants of alienation and oppression.

This chapter briefly sketches the process of urbanisation as it has occurred under the Nationalist government. It has been characterised by under-provision of housing for blacks, and increased rates of urbanisation, which have contributed to the massive growth of the peri-urban informal settlements. Amawoti, the study area, is one such informal settlement. It is a place of suffering, characterised by poverty and lack of services and infrastructure, and yet it is also a place of hope. It is the people, the interest groups, and local community organisations that build the vision for a better future for this area.

3.1 National Politics: placing Amawoti in context

3.1.1 The legacy of apartheid

The official policy of apartheid was legally and politically entrenched in 1948, the year that the Afrikaner Nationalist Party was voted into power. This policy may be described as one of racial separation, legally guaranteeing white control of economic, political and cultural power (Frederikse 1990). Practically, this led to the majority of the wealth and resources of the country being in the hands of the minority of the population. It has meant inequity of resource distribution in all sectors - including health, housing and education -

and thus the denial of basic human rights to a large sector of the population. "Over several decades South Africa has earned its reputation as one of the worst violators of human rights. It has been said that every right mentioned in the Universal Declaration of Human Rights has been infringed directly or indirectly, by the implementation of apartheid and by the system of 'security legislation' introduced to preserve white political dominance and to maintain 'law and order'" (van der Westhuizen 1991 p.173). This has been the cost of apartheid, the cost of subordination of black economic, political and social needs to the interests of the mainly white minority. However, the repressive and ideological apparatuses of the National government did not operate without resistance. Lodge (1983) observes that the phases of Black opposition to apartheid occurred within key periods of economic change. It was this internal opposition, together with international pressure and severe economic problems which eventually forced the Nationalists to the negotiation table.

The decades of popular mass-based and extra-parliamentary struggle have left a significant mark on the self-understanding and culture of the people of South Africa, born out of the "collective heritage of struggle" (ANC 1994b p.3). The importance of participatory democracy, mandate, consultation and accountability are now a vital part of the culture and vocabulary of a vast sector of the population (Moosa 1989, Patel 1992). Processes of empowerment have begun to give ordinary people more and more control over aspects of their lives, as they actively seek to secure the rights that have for so long been denied them. So too people with disabilities are involved in the struggle for human rights - so too they are speaking out against past discriminatory practices and are calling for self-representation and equality of opportunities (DPSA 1993). For them, the struggle for integration, participation and liberation from discrimination has been part of the general liberation struggle (Nkedi 1989). These values and processes constitute major challenges to developing appropriate strategies and policies to address issues of disability in South Africa.

3.1.2 Urbanisation and the growth of peri-urban informal settlements

"South Africa's urbanisation strategy disregards the needs of the people: it serves the ends of a repressive regime..." (Tomlinson 1990 p.195). Indeed, for most of this century, official policy has been designed to prevent large-scale African urbanisation (Bernstein 1991), in line with apartheid policy which has seen geographical separation as the key to white domination. Such policies removed blacks from the field of white competition, and sought to contain them permanently in their own areas (Meer 1976).

Urbanisation in South Africa began on a large scale with the development of the mining industry, the engine of industrialisation, which required a large unskilled labour force (Dor 1989, Patel 1992). Coercive legislative measures in the form of taxes, the Squatters Law and the 1913 Land Act (which reserved less than 10% of the land for Africans and thus deprived peasants of their most important means of production) resulted in the movement and settlement of a substantial African population (Haarhoff 1985, Patel 1992). While compounds were provided for the mine workers, other workers initially stayed in multi-racial slums, informal shack settlements and backyard shacks on white properties. But as health conditions deteriorated in these areas, authorities feared that infectious diseases would spread to the white residents. This fear, together with an increasing militancy of African urban residents, led to a situation in which Africans were only tolerated in urban areas if their labour was required. Their status was that of "temporary sojourners" (Dor 1989).

Over the past four decades, the Nationalist government created an increasingly explicit urbanisation policy designed to affect the rate and patterns of urban growth. This was a direct outcome of the racial nature of capitalist development. A number of strategies were used to entrench this urbanisation policy (Bernstein 1991):

- homeland development and homeland urban growth
- pass-laws
- settlement and location of African people throughout South African space economy
- statutory residential segregation
- forced removal policies

A multitude of laws were based on the "myth of the *Homelands*" (or bantustans) by which the Nationalists claimed to have eliminated Africans altogether from the urban areas (Meer 1976). This was an extensive programme of social engineering, based on the allocation of Africans to different ethnic groups, thereby defining them to be citizens of different bantustans. It was intended that Africans would eventually be settled in their territorially segregated areas which would be economically and politically independent units separate from white South Africa (Dor 1989). The bantustans were part of a complex system of control over the movement of African labour: they secured a cheap labour supply, while simultaneously functioning as "dumping grounds for millions of people not 'needed' by the 'white' economy" (Price 1986 p.159). In this way, large numbers of unemployed, aged and disabled Africans, and those caring for them, were removed from 'white' areas, thus reducing the social costs to the Nationalist government.

Influx controls, together with forced repatriation to the homelands of "illegals", the removal of "black spots" from "white" South Africa, and the *removal of squatters* were other strategies used by the Nationalist government to control black urbanisation patterns. Legislation concerning acceptable health standards was used to justify removals and the Prevention of Illegal Squatting Act enabled the State to demolish structures without the obligation to provide alternative accommodation or compensation (Mabin 1991). This led to the situation where "the main State response to informal settlement by Africans was to bulldoze" (Mabin 1991 p.40). This Act made millions of South Africans vulnerable to removal. Although the more subtle strategy of "orderly urbanisation" was being advocated, it was clearly masking a racial bias regarding the rate of urbanisation.

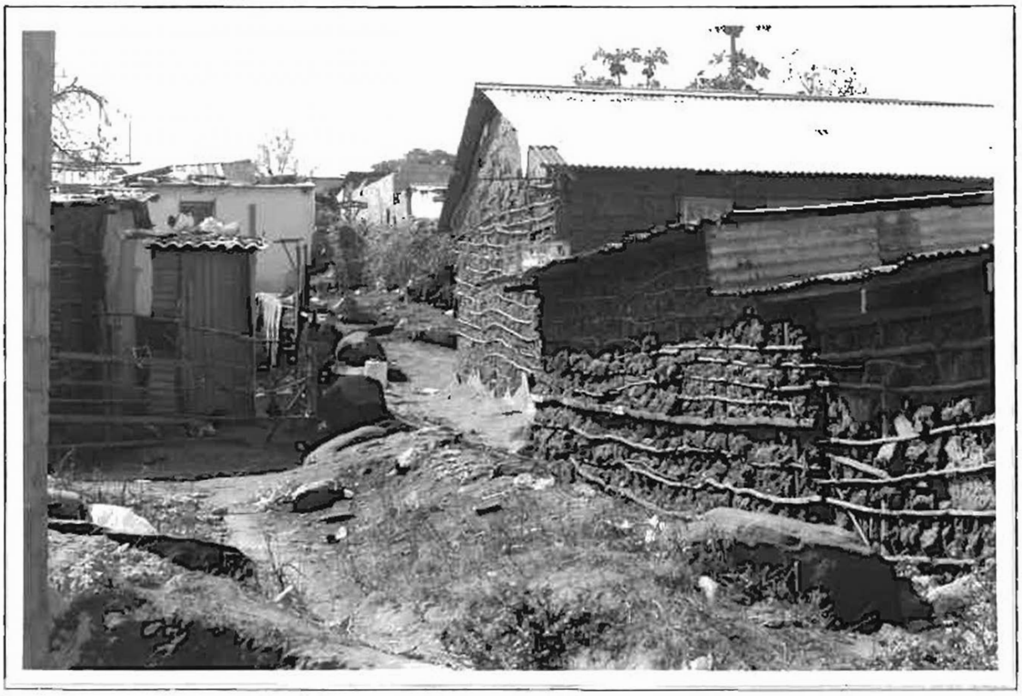
Realising that a small proportion of African workers was required in the urban areas in order to meet the needs of industry, the Nationalist government set up a massive public housing programme. These areas were very clearly demarcated on racial bases, and were designed to accommodate families removed from areas in accordance with the Group Areas Act, as well as to remove inner city slums and squatter populations to new townships in designated areas. It was during this period that most of the houses in townships such as Umlazi, KwaMashu and Chatsworth were built (Haarhoff 1985, Dor 1989).

During the 1970's, the combination of widespread resistance to apartheid policies and decline of the country's economy led the National Party to institute reform. There was a need for a more skilled and stable urban work force, both to restore capitalist profitability and to crush resistance. Black Local Authorities were introduced in the townships as an attempt to form representative government at local level - but these structures failed to win political legitimacy. The townships were expected to be financially self-sufficient, income to the local authorities coming from house rents and services, but rent boycotts and unacceptably high service charges, which residents refused to pay, were indications that this system was financially unworkable (Dor 1989).

The Regional Services Councils (RSCs) represented an attempt to address the financial weaknesses of the local government structure. This system raised income through levies on employers, which was in turn used for development in all areas of their region. To some extent, the RSCs allowed for redistribution to poorer communities, but they reinforced the continued existence of racially segregated local authorities at regional level (Dor 1989).

Influx controls were lifted in 1986, and the pass document replaced by a uniform identity document for all race groups. These factors have contributed to the rate of urbanisation increasing significantly, and now it is estimated that 60% of the country's population live in urban areas (ANC 1994b). Within the next ten years the population of the city of Durban will be close to 6 million (MRC 1991, Yach 1994). This is not an indication that the Nationalist government adequately provided the basic need for housing to black residents. Far from it, before being defeated in the 1994 elections, the National Party had handed the task of housing provision to the private sector. This strategy, while relieving the Nationalists of pressure, ultimately did not address the backlog, for they were built at a rate too slow to meet the housing needs, and sold at prices unaffordable to the majority of Africans (Dor 1989). The lack of provision of housing continues to be a factor leading to overcrowding in townships and the formation of a large peri-urban informal settlement population. In these settlements, housing is usually constructed with unconventional building materials acquired informally i.e. outside of the formal housing delivery systems (Urban Foundation 1991) as illustrated in Photograph 3.1.

Other reasons for growth of the informal settlements include the high population growth rate and increasing urbanisation rate of the black population; the shortage of formal residential sites in township areas and the prevailing low income and high unemployment levels, making formal housing unaffordable to large sections of the black population (Department of Development Aid 1990).



Photograph 3.1 **Typical forms of housing in the peri-urban informal settlements**

The massive growth of peri-urban informal settlements has demonstrated the failure of Nationalist government policy towards urbanisation over the past four decades. The rapid, unplanned urbanisation which has been occurring, has inevitably led to high population concentrations and a physical environment which is characterised by squalor and pollution. Indeed, the very living conditions of these settlements and their location indicates the failure of the economy to provide for the basic needs of a huge sector of the population (Mabin 1991). The crisis has been heightened by the fact that the phenomenon of informal settlements has taken on massive proportions: it was estimated in 1989 that close to half of the population of Durban live in shacks (Inkatha Institute 1989). In some areas authorities have lost confidence in their ability to improve the situation, particularly in regions such as KwaZulu-Natal, where there is uncertainty over who is responsible for large areas of land (Maasdorp 1976, MRC 1991).

3.1.3 Present conditions in the informal settlements

It has been proposed by that the informal peri-urban areas be conceptualised as marginalised communities, in that the dominant classes produce capital accumulation for some, and marginalisation for many, and "this marginalisation is a price that the ruling groups may be willing for the poor to pay" (Haarhoff 1985 p.84). The crisis of informal settlements is not simply about a lack of appropriate housing for the poor, it is about lack of power. Marginalisation of people in informal settlement means not only the lack of services, it means the *lack of a voice* to demand such services. Both of these factors have implications for the health and development status of people living in such areas. Socio-economic indicators of health include housing, water and sanitation, electricity, levels of unemployment, income and literacy levels (Fincham et al 1993, Yach 1994), and residents of informal settlements score low in every one.

Within the informal peri-urban areas, rates of unemployment are extremely high (Meikeljohn & Grant 1994). Of those who are employed, many work in unskilled positions as labourers or domestic workers. This is not suprising, when one notes that the education and skills profiles of residents of informal communities are far lower than those of residents of formal settlements (Urban Foundation 1991). Thus the lack of service provision (including education and employment opportunities) typical of such marginalised communities, perpetuates the poverty cycle.

It has been observed that by its nature spontaneous housing is susceptible to conflict (Urban Foundation 1991), and over the past few years informal settlements have been particularly vulnerable to violence. A key factor has been conflict between different political groups - on the one hand those associated with apartheid and its structures (including the bantustans), and on the other, those who oppose it (de Haas 1993). The violent clashes have themselves led to an increased rate of disability - for it is estimated that for every person killed in violence, three are permanently disabled (Rowland 1989) - and has also decreased the likelihood of obtaining necessary services (Lancet 1992). Many welfare agencies have withdrawn field staff from such areas due to fear of personal injury and theft of vehicles.

While many would acknowledge the devastating impact which apartheid has had on patterns of urbanisation, and the lives of the majority of people in South Africa, little attention has been paid to those people who have been most severely undermined by the social and economic policies of apartheid. "These people are the disabled people of South Africa. The deaf, the blind and mentally disabled, who as a result of their disabilities have suffered special penalties in relation to access to essential services, inaccessibility within the built environment, discrimination within the workplace and a host of other measures designed to exclude disabled people from society, rather than promote their integration" (DPSA 1992 p.1).

What is the impact of life in the informal settlements for people with disabilities? Suffice it to say that disabled people experience the same deprivation and marginalisation that other residents of such areas experience, but to a greater extent. For disabled people, it means dependency, as they may have to rely on family members or neighbours for fetching of water, washing and cooking. For disabled children, there are extremely limited education opportunities in local schools, due to physical inaccessibility and negative attitudes towards disabled scholars. For them the cycle of poverty, lack of education and unemployment and entrenched poverty and dependence becomes a reality.

Untarred roads and steep dust paths restricts the mobility of those with physical disabilities, making use of wheelchairs particularly difficult. The minimal local health services are often inaccessible, both physically and financially, for disabled people, and a visit to the provincial hospital for specialised care can prohibitively expensive if it means hiring transport to get there (for those who cannot make use of public transport). Lack of infrastructure and services in the informal communities also means that after discharge from hospital, there is no follow-up of disabled people living such areas (Lancet 1992). There are simply no road names or addresses by which to trace them!

3.1.4 The Reconstruction and Development Programme

Discussion of apartheid, urbanisation and poverty would not be complete without reference to the Reconstruction and Development Programme (RDP) proposed by the African National Congress and its Alliance as the "map" of the government of National Unity in implementing its social and economic programmes. The RDP is an "integrated, coherent socio-economic policy framework. It seeks to mobilise all our people and our country's resources toward the final eradication of apartheid and the building of a democratic, non-racial and non-sexist future" (ANC 1994b p.1). This programme aims to address poverty and deprivation and to provide tangible prospects for a better life, particularly for those who have been most oppressed and marginalised by the apartheid policies. It identifies people with disabilities and those living in informal settlements as among those who have been historically disadvantaged.

The key programmes of the RDP relate to the meeting of basic needs, developing human resources, building the economy and democratisation of the state and society - a multi-pronged strategy of addressing poverty. The provision of basic needs includes housing, health and other services. A commitment is made to building one million low-cost homes over five years (ANC 1994b). Legislation pertaining to the rights of people living in informal settlements will be developed, and the RDP emphasises the need for the provision of appropriate housing for people with disabilities.

It is recognised that provision of resources alone will not address the problems of inequality and poverty in South Africa. Thus it is envisaged that a huge investment will be made in developing opportunities for education and training for those that have been most disadvantaged in the country. There will also be a focus on building the economy, aimed at using the resources available for all the citizens of the country. This would include large-scale employment projects as well as support for the informal sector. Provision of housing, services and employment for the poor *per se* is not development. "Development is not about the delivery of goods to a passive citizenry. It is about active involvement and growing empowerment" (ANC 1994b p.5). The RDP highlights the importance of community participation in health and social service provision, and points to the need to democratise the state and society, providing mechanisms whereby structures of civil society can influence policy.

3.2 Amawoti: "Place of Suffering and Hope"

The present study is based in one particular informal peri-urban community - that of Amawoti, a sub-district of Greater Inanda. Inanda itself is a sprawling informal settlement that lies thirty kilometres north of central Durban. Due to its rapid growth, Inanda makes Durban to be the one of the fastest growing cities in the world, second only to Mexico City (Madladla & Rioga 1994).

With a population of approximately 100 000 people, Amawoti is a community marked by poverty and an associated lack of basic services. Like the rest of Inanda, Amawoti falls outside of official boundaries of the Durban City Council, and as such becomes "no person's" responsibility in terms of resource allocation.

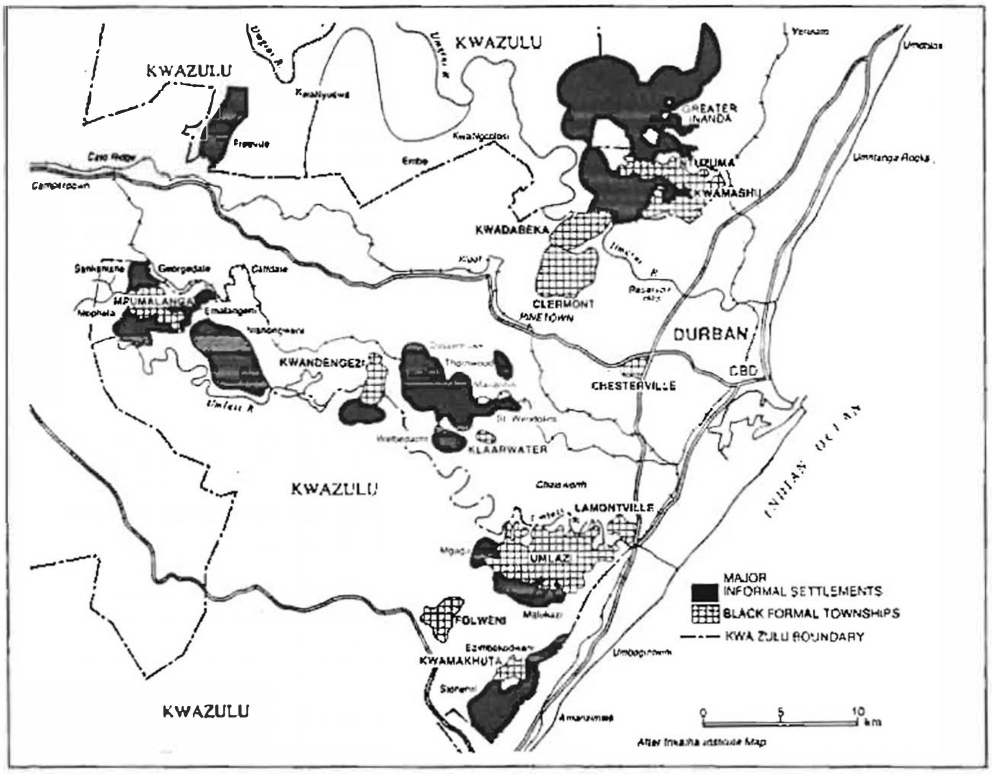


Figure 3.1 **Informal settlements in the Durban Functional Region** (Urban Foundation 1991)

3.2.1 A brief history of the area

In the early 1900's, Inanda was predominantly a sugar farming area. It abutted on one of the reserves demarcated for housing of African people, which was later incorporated into the KwaZulu 'homeland'. Although private ownership of land in the reserves was impossible, some prominent families acquired land in Inanda (prior to 1913 Land Act). In

1936, most of Inanda was excised from 'white' South Africa (the government referred to it as 'released'), and destined for eventual incorporation into KwaZulu. Since then, its official designation has been "Released Area 33".

There has been steady growth of shacklands within Amawoti and the wider Inanda area, with people making homes out of cardboard, iron sheeting, plywood, wattle and daub, or any other material available, and erecting them on the privately-owned farms. There are many different reasons documented for people choosing to live in these informal settlements (Department of Development Aid 1990). For some, there are historical, cultural or religious ties with the area. Others had no choice, as their move to Amawoti was precipitated by forced removals from Mkhumbane (Cato Manor) as part of the Nationalist government policy of separate development. Other factors include the lack of sites and accommodation, as well as the high cost of living in formal townships (such as KwaMashu and Newtown), which led many to move into Amawoti. In addition, political tensions and/or violence in other areas of Natal meant that many people fled their homes. Since 1986 Amawoti has provided refuge for a group of Amapondos from the Natal south coast (as illustrated in Photograph 3.2), while others have come from Ndewdwe and Pietermaritzburg.

Photograph 3.2 **Amapondos who were moved into Amawoti in 1985 are still living in tents**

What of the private land-owners on whose land these structures were erected? There seemed to be little opposition in Amawoti, as those owning land found the income from rent of sites more lucrative and regular than sugar, cattle or tobacco, particularly in light of the competition from the (white) Natal coastal belt agribusiness sector.

The steady growth of Amawoti and Inanda, and the transformation from a farming district to a sprawling informal settlement (with gradual merging with nearby townships), meant that these areas were being drawn more closely into the metropolitan economy, with many of residents working in the city of Durban. This growth was ignored by the Nationalist government, and there was no accompanying provision of services. People drew water from streams and collected rain in drums; those with a small plot of land grew maize or kept chickens. Some community-sponsored schools were built, but children were considered luckier if they got into township schools. Politically, Amawoti and Inanda was suspended in "released" limbo, as the settlement was dismissed as a temporary problem. Squatters were by definition impermanent - at least as far as their relation to city life went - and therefore infrastructural developments like sewerage, rubbish removal or lighting were unnecessary. In any case, people were living on private property, so the state could argue that it had no responsibility towards them" (Hughes 1985). It was only after a drought and a typhoid epidemic in the early 1980s that the Nationalist government was forced to put in water supplies.

3.2.2 Community profile: description of Amawoti

Residents of Amawoti are black, predominantly Zulu-speaking people. The area is characterised by a high density of informal housing - mostly constructed with wattle, mud, corrugated iron and packing cases. There is no piped water into homes, and hence water must be collected in 25 litre drums at a cost of 7 cents/drum. At present electricity is only supplied along the one main road, there is no water-borne sewerage, and no adequate rubbish removal system.

The living conditions in Amawoti in themselves pose serious health hazards, and are further exacerbated by the inadequate provision of health services. There is no permanent health centre in the area - it is serviced by twice-weekly mobile clinics. Educational facilities provided by the Nationalist government in Amawoti have been inadequate and poorly serviced in terms of resources. At present, there are three primary schools and one high school in the area. One of primary schools is situated at least 2km from the main tar road, making accessibility for young children very difficult. Another primary school is housed in two rows of corrugated iron huts referred to by local people as "fish tins". The single high school (which was housed in corrugated iron huts for two years) was registered in 1988 and offered matriculation classes for the first time in 1991. In early in 1994 this school moved into a new three-storey building. Prior to the 1994 national elections, the "released" nature of the Amawoti was evident from the fact that one school was administered by KwaZulu, and the other three by the Department of Education and Training. None of the community schools offer remedial classes, or are accessible for wheelchair-users.

The lack of basic services as described has ensured that the poverty cycle in Amawoti is perpetuated. Limited educational opportunities lead to a high rate of illiteracy, and limited employment opportunities. While the rate of unemployment is extremely high (local development workers estimate it as being 60%), many of those who do have work, are employed as labourers on road construction sites or sugar cane fields, or as domestic workers, often being victims of exploitation and oppression in the workplace.

Most of the finance that comes into Amawoti comes from the small percentage of residents that are employed, from the many that do temporary unskilled labour, and from disability grants and old age pension pay-outs. There are also a number of diverse businesses that have been set up in the area - these include taxis, shebeens, and communal gardens. As there are no banks in Amawoti, most saving is done through "stokvels" or through other insurance schemes such as burial clubs. Most residents buy their food in the area, and as very few people have fridges, fresh produce must be bought on a daily basis. Those who can afford to buy furniture do so from large stores in central Durban, very often on hire-purchase agreements.

A description of Amawoti would not be complete without reference to its situation within KwaZulu-Natal, a politically volatile province. This community has been subject to the on-going violence between supporters of the African National Congress and the Inkatha Freedom Party, which was fuelled by the Nationalist government. This conflict was violently resolved over a period between 1988 and 1990, after which civic structures were elected to replace those of Inkatha, and Amawoti became an ANC-dominated area. Although civic structures have been particularly active in the area over the past few years, the culture of intolerance and violence has become wide-spread. Sporadic incidents still occur - in January 1993, 13 Amawoti residents were killed as a result of a power struggle over "muti" (Weekly Mail February 5 1993) and in June 1994 four people were brutally murdered by criminals claiming to be associated with the Pan African Congress. It remains a great challenge to the local leadership to foster a spirit of tolerance, and to develop their own capacity to take an active part in processes of development of the area.

How have the residents of Amawoti made sense of their reality in the face of such suffering? Religion and spirituality form important components of life within the area. Besides the mainline denominations (which are in the main based on western models), there are numerous independent Zionist churches. While being predominantly "other worldly" and pietistic in nature, the churches nevertheless provide a source of meaning and support within a context of poverty and suffering. They provide the symbols of hope during significant events - such as weddings or funerals. Although some of the culture of residents of Amawoti has been eroded over time, many of the customs held in the past (in rural areas) have been adapted to fit into modern urban life. People hold together diverse views, for example consulting *both* "izangoma" (traditional healers) *and* hospital staff for treatment for the sick. Other rituals - such as slaughtering a cow as part of "housewarming" festivities - are observed when finance is available to do so.

3.2.3. Interest Groups present within Amawoti

The previous description of the community of Amawoti takes as given the definition of "community" as a particular locality (Heller 1989). However, at another level, it is recognised that "community" cannot be viewed as a homogeneous unit (Lund 1987) and there is the need to explore its conflictual nature. For this reason, there is description of a number of "interest groups" in the area. These groups were identified as being influence-leaders in Amawoti by members of the Amawoti Disabled People's Association.

(a) Youth

The youth are among the most politicised and organised groupings within Amawoti. Besides the large number of sports clubs, choirs and recreational groups, there are several political structures on which they are represented. These include the marshalls, the African National Congress (ANC) Youth League and the ANC Branch Executive Committee. Historically, the youth have been the prime movers for political change within Amawoti. With their energy and commitments, the youth often lobby around particular issues - such as police action - but their zeal creates the potential for intimidation of other community members who may not be committed to their cause. They are a very visible group as their actions, though often erratic and reactive, do make their impact felt on residents of Amawoti.

(b) Civic structures

The Amawoti Civic Association consists of fourteen local civic committees (each of which represents a sub-area of the settlement) and a central, co-ordinating executive committee.

Members of this central committee have defined portfolios which include health and welfare, development and education.

The civic structures were set up in 1990, as an alternative to the State-supported Inkatha councillors which has existed before that time, in an effort to secure democratic and representative community leadership. The Civic Association aims to address development issues in the area of Amawoti, and to improve the quality of life of residents. This includes lobbying for provision of services (e.g. health and education), giving legal advice and developing skills of community members through different training opportunities (Madladla & Rioga 1994).

(c) Business owners

Despite the very high rate of unemployment in Amawoti, there is a proliferation of informal businesses, and four formal grocery stores, three of which are owned by Indian businessmen. Due to the lack of electricity in homes in the area, fresh fruit and vegetables are bought daily, often from the "shack shops" and "izinqola" (wagons) at the road-side. The businesses in Amawoti, represent a source of employment and income in the area, and as such business owners are important influence-leaders.

(d) Landowners

During the apartheid era, Amawoti was one of the few areas in which Black people owned the land (it was bought before the Land Act of 1913). There are approximately 122 landowners in Amawoti, a large number of whom actually live on their property in the area. Many are elderly widows whose husbands originally purchased the land. The landowners are part of the more wealthy sector of the community, having relatively large homes and regular incomes. They form a respected group, almost an upper class. The present going rate for a site in Amawoti is R40/year and numerous "middlemen" rent sites for this amount, build a row of rooms and rent out single rooms at a cost of R20/month. In this way, landowners are not directly responsible for housing in Amawoti, they are shack farmers by virtue of renting out land on which others build.

(e) Church leaders

Most of the numerous home-based Zionist churches in Amawoti are headed by local men. As these groups cannot afford to employ leaders, ministers often have "secular" employment during the week and are involved in church activities in the evenings and at weekends. Most have not had any formal theological training, but have charismatic, preaching, healing and other gifts that benefit the church members. Ministers provide an important source of personal support during times of suffering and bereavement, but do not often speak out on political or social issues.

(f) Teachers

Most teachers at schools in Amawoti come from outside of the area - many travelling in daily from nearby townships such as Ntuzuma and KwaMashu. Thus, while identifying with the educational needs of scholars in the area, they are not themselves community members. Up to the present, there have been minimal resources at schools in Amawoti, poor classroom and sports facilities and (at one school) on-going tensions between principal and students - all of which negatively affect teachers in the area.

(g) Government services (health, welfare and security)

Being defined a "released area" Amawoti has suffered under the unco-ordinated and fragmented administrations of the Natal Provincial Administration (NPA) and KwaZulu government. (For the present discussion, focus is on the role of the NPA in responding to disabled people.) In addition to the racist bias, bureaucratic structures, a top-down approach and lack of consultation in decision-making contributed to the poor relationship and lack of accountability between government service-providers and community consumers.

3.2.4 Two community-based organisations:

Despite the poverty and harsh living conditions in Amawoti, there are signs of hope evident in the determination of people there to participate in events and processes that affect their lives. Two organisations operating in the area have been channels for this:

(a) The Ilimo Community Project

The Ilimo Project is a community-based primary health care project that has been operating in Amawoti since 1988. It began in response to the devastation caused by floods in late 1987. In dealing with the relief needs of people in the area, Ilimo staff members attempted to avoid the indiscriminate supply of "hand-outs". Instead, an effort was made to support the poorest members of the area to deal with their own crisis, through the setting up of structures to prioritise needs and ensure fair distribution of resources. This relief work soon extended beyond the crisis of the floods, and the Ilimo Project began to address the health and development needs in Amawoti caused by the poverty (Ilimo Project proposal 1993).

The term "*ilimo*" denotes community co-operation and mutual support, and it is a spirit that the Project has aimed to foster through its various activities in Amawoti. In defining itself as a health project, Ilimo sees

> "...health as a quality of life to be cared for. It includes physical, psychological, spiritual and social well-being, which needs to be promoted at individual, family and community levels. Health is not seen as a medical problem, but as a broader question of access to power. It is influenced by socio-economic and political factors, and is integrally linked to community development. Health includes the whole spectrum of promotive, preventive, curative, rehabilitative and palliative care." (Mission statement of Ilimo Project, August 1992.)

Adopting a comprehensive approach to health has meant that the Ilimo Project has been involved in a wide range of activities to promote well-being of residents of Amawoti. These have attempted to address environmental, socio-economic, and other causes of disease. To this end, the Project has been supporting the growth of *income-supplementing activities*, which include a number of production groups, involved in gardening, sewing and chicken-raising projects. There is also a building programme, at which young men from the area are taught to make cement blocks, and others to build 2-roomed block houses. Another aspect of the Project has been the *support of civic programmes*. Staff from Ilimo Project have been seconded to the Amawoti Civic Association to assist this organisation to set up different programmes which address development issues (e.g. health, education and disability).

The philosophy of the Ilimo Project is outlined by the following five principles (Philpott 1991):

(i) Identification

The first stage in approaching the community has been that of *identification* with the people, accompanying them in the struggle to survive. This process assumes a deep level of commitment, where one participates fully and becomes part of the community, embracing its struggles and joys. It has meant staff of the Project living in Amawoti, but it also has a deeper significance: it is a symbol of solidarity. This process is crucial to the establishment of relationships of equality and real partnership; it has been an important factor in the development of trust between people of different race groups and it also lessens the danger of an "us" and "them" mentality

(ii) Establishment of needs

Through the process of identification and interaction with community members, awareness is raised of particular needs. These needs are not predetermined or imposed, nor are they formulated in response to resources that may happen to be available. Establishment of needs, in partnership with community members, implies a process of "sitting, asking and listening. Sitting implies lack of hurry, patience and humility; asking implies that the outsider is the student and listening implies respect and learning" (Chambers 1983). Collection of information (in the form of research) is recognised as an important mechanism by which people are able to decipher their own needs, and make informed decisions in response.

(iii) Building community structures

Following the identification of needs, it is essential that *structures* be set up in response to particular needs. This is one channel through which community empowerment takes place - through structures which are chosen by and accountable to the community. These structures take the responsibility for particular issues, and in this way, people affected by a problem are involved in addressing it. This principle is also based on the need for accountability within community development activities - it facilitates group responsibility and collective action and it lessens the danger of individuals in the community developing power bases from which they oppress others. Structures also provide the mechanisms by which a particular group can negotiate for resources and programmes required (Philpott 1994).

(iv) Values

A conscious effort is made to nurture community-supportive *values*. This is done mainly through group Bible study and reflection, which is related directly to the community and the activities of the Project.

(v) Vision

Closely related to the nurturing of values, is the need to constantly build *vision*. This may be difficult at first within a community of poverty and oppression, where people have not had control over their own destiny, where they have not had access to decision-making powers or the freedom of choice. The setting up of community structures is seen as one way to create a channel through which a shared vision can be built, as members begin to realise the potential that they have to creatively respond and change their situation. The ultimate vision, based on community-supportive values, is social transformation.

(b) The Amawoti Disabled People's Association

In the latter part of 1990, one of the civic committees in Amawoti became increasingly concerned about the number and needs of disabled people in the area. At the time, staff of the Ilimo Project were working with the civics, and thus provided support for this committee in doing a survey of disabled people. Information was collected regarding the main problems of disabled children and adults. Feedback of this survey led to the setting up of a committee on which there was representation of disabled people, parents of disabled children and civic committee members. This group was later constituted as the Amawoti Disabled People's Association, and became a member of the national group Disabled People South Africa (DPSA).

The organisation of people with disabilities has done fund-raising for support to pursue the following aims:

- to assist disabled adults and children to meet their needs and secure their rights (e.g. to education, employment and social welfare benefits);
- to organise parents of disabled children to work together;
- to network with other organisations which support disabled people;
- to visit disabled people regularly in their homes and
- to teach people in Amawoti to live with, and respect and take care of disabled people.

Conclusion

The process of urbanisation in South Africa has been influenced by the ideology of the Nationalist government (based on apartheid and capitalist economic policies). This has led to capital accumulation for some (whites) and marginalisation for many (blacks) - evidenced through the growth of the informal peri-urban settlements. The living conditions within the informal settlements provide particular difficulties for residents with disabilities, for they are most often excluded from having access to the limited services and resources that are available.

Amawoti is a one of these peri-urban informal settlements, and description of it provides insights into the diversity of interest groups that exist within the informal areas. Despite extremely harsh living conditions, these interest groups and community organisations are indications of the determination of members of the community to be active participants in improving conditions of living in the area. An essential component of this (which is of particular concern to members of the Amawoti Disabled People's Association) is their relationship to those who have been among the most marginalised and excluded in the past - people with disabilities. Thus the question is raised: How can interest groups in Amawoti respond to the needs and rights of people with disabilities?

The answer to this question is of concern not only to local community groups, but also to State service providers, for the Government of National Unity faces the challenge of addressing issues of poverty and the problems of those who have been marginalised from society. This will mean giving particular focus to residents of the informal settlements and to the disabled poor.

CHAPTER FOUR: RESEARCH METHODOLOGY

Introduction

Data was collected for this study in two different ways. Firstly, a *document study* provided secondary data that informed the collection of the primary data. Secondly, this primary data was collected through the use of *focus groups*. The following discussion explores the social science research methodology used, and describes the philosophy on which the study was based, using the community psychology approach and paradigms of action research and "research as praxis". Thereafter the implementation of the focus group method is described and its value and limitations are identified.

4.1 Social Science Research Methodology

4.1.1 Document study

Literature on social science research methodology was used as the basis on which to plan the data collection process of this study. Initially texts consulted were very broad (Peil 1982, Bailey 1987), but once the focus group method had been selected, they became more specific. These included texts on the focus group method (Kreuger 1988, Knodel 1989), which were used to inform the planning, implementation, recording and analysis of the focus group interviews.

Literature on community psychology was particularly valuable in guiding the approach of the study, and in looking at disability as both an individual and a societal problem. Consideration of the empowerment approach described by Rappaport (1981), with the emphasis on needs and rights, directly influenced the questions included in the interview guide. This approach, and the action research paradigm (Lazarus 1987) reinforced the need for the study to produce socially relevant and useful information.

The topic of this study also meant that literature on disability research was examined. This included looking at texts that explore action and emancipatory research methods in this field - most of which are highly critical of the traditional ways of conducting research on disability, which is seen as reinforcing the alienation and oppression of people with disabilities (Abberley 1992, Oliver 1992). This literature highlighted the need to consider the social relations of research production - not only during the process of data collection, but also in terms of the outcomes of the study, and recommendations made.

Document study was also of great value in being able to place results emerging from the focus groups in Amawoti within a wider context both nationally and internationally. Documentation from the United Nations, such as the report of the Commission on Human Rights entitled "Human Rights and Disability" (Despouy 1991), and the World Programme of Action Concerning Disabled Persons (UN 1983) enabled the researcher to place the perceptions of people in Amawoti within wide international debates. In addition, literature from the disability rights movement, relating both to individuals (Finkelstein 1980, Jagoe 1987) and to groups (Disabled People South Africa 1992), provided essential secondary data.

This document study cannot be considered to be a primary method of social research in that none of the documents used was written for the purpose of the present study (Bailey 1987). They are combinations of primary methods of social research, thus providing a source of secondary data for this study, to inform the collection of the primary data through focus groups.

4.1.2 Field methods of social research

Part of the document study included exploring different field methods described in the literature. Peil (1982) identifies three broad classes of social research field methods which are considered to be primary, and these are described in relation to the present study.

(a) participant observation

Using this method, the researcher directly observes and also participates in the sense that s/he has durable social relations with those being studied. The present study could be seen to be a process of participant observation, in that the researcher is an on-going participant in the context of the study. It was within this context that focus groups were set up specifically to discuss issues of disability.

(b) enumerations and samples

This method includes both surveys and direct, repeated, countable observations. The present study did not take a *quantitative* approach to data collection and analysis. This was due to the focus of the study on *qualitative* data (exploring perceptions and opinions regarding disability), which cannot easily be quantified.

(c) informant interviewing

Interviews are commonly used to clarify findings which emerge from the use of other techniques (Maccoby & Maccoby 1954). Within this method of data collection, the distinction is made between individual and group methods, as well as between standardised and unstandardised interviews (Feuerstein 1986). Falling between these two extremes, there is a third option for the researcher - the *semistandardised* or *focus* interview, which makes use of an interview guide with a list of objectives and suggested questions, but which gives the interviewer considerable latitude within this framework (Maccoby & Maccoby 1954). In the present study, the semistandardised interview method was used in *focus groups*.

A number of researchers in the social sciences (McCarthy 1987, Kreuger 1988, Stewart & Shamdasani 1990) have described the use of focus group discussions as a valuable tool for qualitative data collection. This format of interviewing is a semi-standardised group interview method, and is a tool by which perceptions of a group of key informants can be tapped. The group members can be regarded as key informants in that they are selected because they have certain characteristics in common which relate to the topic of the focus group. Kreuger (1988 p.18) defines focus groups as being "carefully planned discussions designed to obtain perceptions on a defined area of interest in a permissive, non-threatening environment." Participants are chosen so that the focus group is relatively homogeneous with respect to characteristics that might otherwise hinder the free flow of discussion. The main purpose of this particular approach is to yield "qualitative information exposing perceptions, opinions, underlying attitudes and behaviour patterns" (Knodel 1989 p.108).

4.2 Research Paradigm

Understanding the problems of disability as having both individual and societal roots, implies a close affinity to the approach of *community psychology*, in which power is a central issue. While *action research* is aimed at being both socially useful and theoretically meaningful, *emancipatory research* goes further in making an explicit commitment to empowerment and the transformation of structural inequalities.

Community psychology has been defined as an approach that looks at "the relationship between the individual and society, and attempts to discover and work with both *the* *individual and the societal roots of the problems in living*" (Lazarus 1985 p.112 my emphasis). This author points out two essential elements of the community psychology approach viz. alienation and power. The first relates to the individual's lack of awareness of control over his/her own life and the environment, which leads to feelings of powerlessness, meaninglessness and isolation. Power, on the other hand, implies a personal sense of control over one's life, as well as social and political control of institutions of which one is a part. The development of a sense of personal power is documented as an important strategy for preventing social problems, and there is recognition of the need for increasing competence of people in solving their own problems and gaining control over the institutions that affect their lives (Lazarus 1985). Seedat & Cloete (1990) support this view and advocate an approach that draws on and affirms the value of local knowledge and experience (as opposed to dependency on professionals), generates community participation and facilitates the process of empowerment.

In exploring societal problems, action research has been described as "research done in actual context, aimed at being socially useful as well as theoretically meaningful" (Lazarus 1985 p.113). Here the researcher is an "insider" who learns and contributes, identifies with the "objects" of the research, and who helps to change things within that context. It is essential that action research findings to be fed back into the local situation and thus to contribute to immediate concerns; it represents an effort to achieve effective interplay between research and action as part of an ongoing process in a local situation (Lees 1975). Closely linked to this, accountability of the researcher to the community is of crucial importance - not only in making results available and accessible to community members, but also to ensure that the findings become socially useful. Such usefulness must go beyond the local level, as one of the critical tasks of research is "the effective communication of findings to the policy-maker and the discovery of ways and means to ensure their absorption into public decision-making" (Lees 1975 p.155). [1]

In applying these principles to the field of disability, Oliver (1992 p.102) holds that "disability research should not be seen as a set of technical, objective procedures carried out by experts, but part of the struggle by disabled people to challenge the oppression they currently experience in their daily lives". This implies a changing of the social relationships of research production such that there is a genuine partnership between researched and researcher, in a process of empowerment (Zarb 1992). Research that works towards a critique of the status quo and the building of a more just society has been termed "emancipatory research" (Oliver 1992) or "research as praxis" (Lather 1991). Its

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[1] A good example of this is that the researcher has been participating in the Rehabilitation Commission set up by the African National Congress to review rehabilitation policy and make recommendations for changes, as part of the restructuring of health policy for the future in South Africa.

purpose is to empower the oppressed to come to understand and change their own oppressive realities.

The principles of community psychology, action research and "research as praxis" are applicable to the present study for the following reasons:

1. Disability is viewed as both an individual and a societal problem.
2. Disabled people in an urban informal community are a particularly powerless segment of society. They do not have control over many of the institutions (such as those of health and welfare) that affect their lives.
3. Community development, primary health care and community-based rehabilitation all deal with issues of community empowerment and community participation.
4. The researcher has been working in the actual context for over six years, and is a closely identified with the work with disabled people in the community. The researcher recognises her position as a participant within the context being studied, in contrast to an outsider who may come into the community specifically for the purpose of gathering data.
5. Civic members in Amawoti identified disability as a problem, and have been involved in addressing it in a variety of ways.
6. The study aims to gain an understanding of the status quo in terms of attitudes and behaviour towards disabled people in Amawoti, and is committed to challenging unjust structures and practices.
7. The research is aimed at being socially useful, in being able to inform and guide the future development of the work with disabled people in Amawoti, as well as giving recommendations for policy on disability at a regional and national level.

4.3 Selection of method: Focus Group interviews

The question may arise as to why the focus group method was selected from the possible options of social research methods, and how this particular method relates to the wider paradigms of action research and "research as praxis" (Lather 1991). The following discussion highlights the appropriateness of this method in terms of the type of data that was required. There is also a description of the value of focus groups in providing a mechanism by which to identify and engage with key resource and interest groups. This engagement facilitates the process by which to access socially useful data, and at the same time highlights disability as an issue of development within the community.

4.3.1 Appropriate method for type of data required

The value of the focus group method lies in its potential to create a relaxed, non-threatening environment within which opinions and perceptions can be freely expressed. It is useful for exploring the way that particular groups of individuals think and talk about a phenomenon and for generating new and creative ideas (Stewart & Shamdasani 1990). This method is particularly appropriate for use within an informal peri-urban community where most residents have a low level of literacy, but a strong oral tradition and culture. Certainly many participants in this study would not have felt comfortable completing written questionnaires, or even doing individual interviews. The focus group, on the other hand, provides the opportunity for participants to express opinions and ideas in their own words, and within a group context. At the same time it provides checks and balances, in that the opinions of each group member is subject to criticism by other participants.

The focus group method was also an effective means by which to gather the particular type of data required - that on the "perceptions, opinions, underlying attitudes and behavioural practices" (Knodel 1989 p.108) concerning disability.

4.3.2 Identification of key resource and interest groups

Part of the process of action research and "research as praxis" has been to address the question: *What key resource and interest groups can be identified, so that their influence can be supplemented or challenged as part of the process of empowerment of disabled people and their integration into community life?* This question could be considered to be within the emancipatory research paradigm in that it addresses the issue of access to needs and protection of rights of disabled people. It identifies key groups that have specific resources and obligations, and attempts to extend their influence in favour of disabled people in a way that does not control those who are oppressed but empowers them.

There is the recognition that disability is both an individual *and* a societal problem, as described in the approach of community psychology. Disabled people are not seen simply as individuals with unfortunate defects, but as an oppressed group in society (Milton Keynes 1990), and thus disability must be addressed as a community-wide issue: "The goal must be to find a basis for mutual accommodation and to build a truly integrated attack on these problems which are *problems of society - of the members who are called disabled and of the ones who are not"* (Acton 1982 p.148 my emphasis). Focus group discussions with key resource and interest groups are part of the process of achieving the integration of disabled people within the wider community. This is done by engaging with social and economic structures (among others) in order to change them, a strategy described by Davies (1989) as "conditioning". The focus group discussions are also a means whereby information is shared with different interest groups, thus exposing them to different views about disability, and increasing the interactions between themselves and people with disabilities. The focus groups also provide a means of disabled people starting to make their voices heard, so that groups in the community begin to adjust their thinking and their structures so as to meet the needs of all (Shearer 1981).

The reference to "interest groups" recognises the conflictual nature of community. One understanding of community is that of its being "relational" (Heller 1989), and this is the view taken in the present discussion. The groups identified represent people with shared interests, roles and/or resources within the geographical locality of Amawoti.

4.3.3 Interaction at an organisational level

Each of the groups (excluding disabled people and caregivers) that was invited for the discussions was made up of people from a particular interest group in Amawoti. They were invited by the committee of the Amawoti Disabled People's Association. Thus the discussions were being held between members of groups or organisations, but they also reflected personal opinions of people within the organisations. According to Trapp (National Training & Information Centre, personal communication 1991), there are two important sources of power - money and people - but it is only when they are organised that they become powerful. In their engagement with community interest groups, members of the Amawoti Disabled People's Association recognise that these groups are sources of power. Yet their potential to positively influence the situation of disabled people in the community will not be felt until their power is organised, until it is challenged and channelled in such a way that it will facilitate the empowerment and integration of disabled people.

Members of the Amawoti Disabled People's Association identified groups that are "influence leaders" in the community. These can be viewed as groups that have the potential to change things, those with access to resources or who are in themselves resources. In the process of interaction with these groups, there was an effort to make these resources more accessible and appropriate for disabled people. The question was asked: "With your particular resources and influence, what can you do to change the situation of disabled people in the community?" This is a fairly pointed question, which adopts the social view of disability. The question was not "What difficulties does a disabled person have in making use of your resources (church/school/clinic/shop)?" The implication is that it is not just the disabled person who must adapt to society, but it is society which must make adjustments to accommodate all of its members.

Engaging at an organisational level has been critical in the building of credibility of the Amawoti Disabled People's Association as an organisation of disabled people. This has had a far-reaching impact, particularly in relation to the civic structures in Amawoti. For example, at the focus group discussion with the civics, it was suggested that a member of the Amawoti Disabled People's Association be represented on the civic executive committee. This discussion was followed by two subsequent workshops which included representatives of Ilimo Project, and civic structures, at which there was further clarification of the position of the structure representing disabled people as a component of the Amawoti Civic Association.

4.3.4 Disability is a development issue

Implicit in the methodology - that of engaging with a wide range of interest groups in Amawoti - is the view that disability impacts at all levels of community life. It is not restricted to the health arena, but is also a human rights and development issue. Addressing disability means addressing issues of access and discrimination. As a result in addition to consultation with those providing health services in Amawoti, discussions were held with groups providing education, social welfare and security services. There was also engagement with groups representing political, economic and church structures in Amawoti. Consultation with each of the focus groups (representing different interest groups) in itself helped to extend the understanding of disability as a development issue, as did explanation to each group of the other groups that participated in the study.

4.4 Research Procedure

The following flowchart illustrates the process of the research, and each of the steps (4.4.1 - 4.4.5) are described more fully in the section that follows.

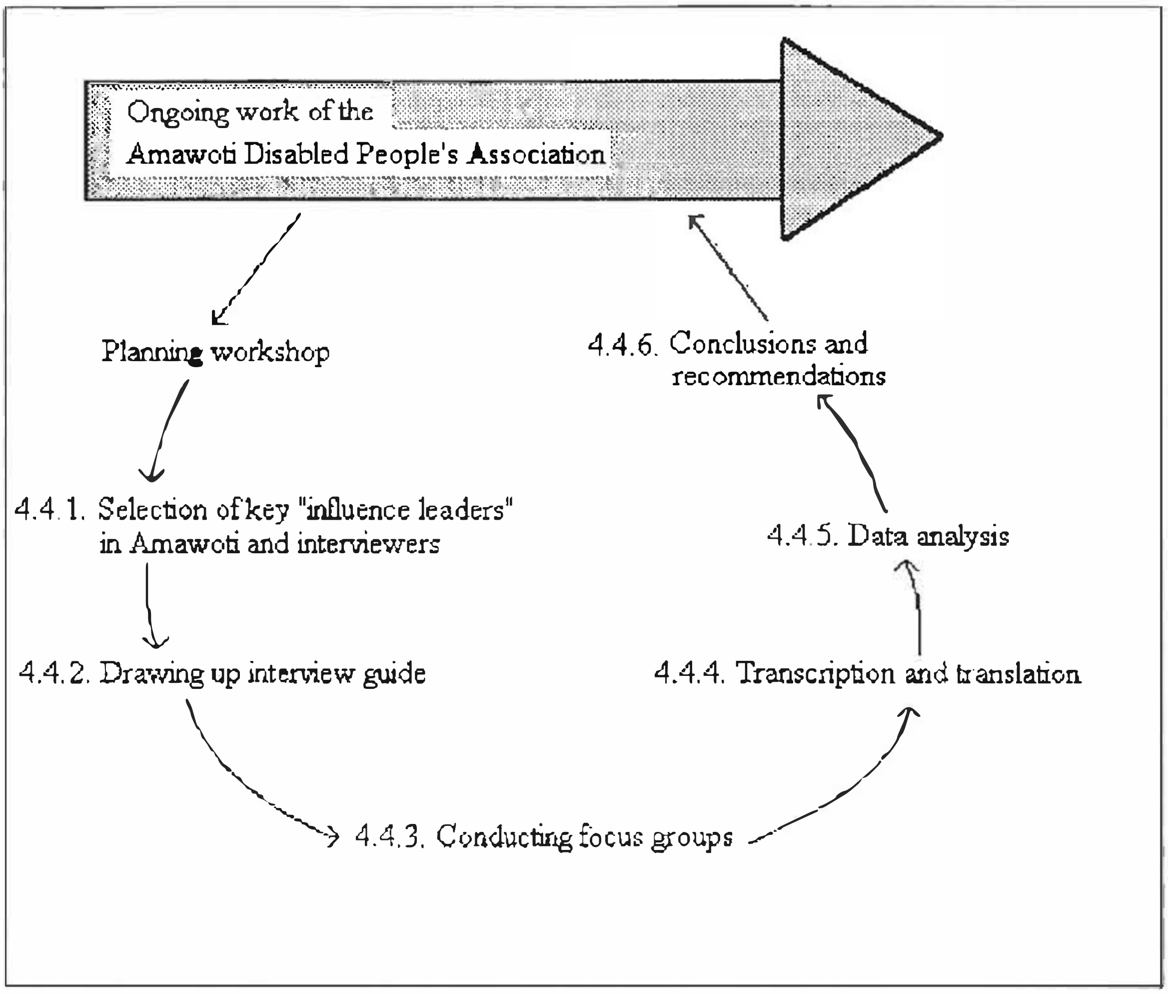


Figure 4.1 **Flowchart showing research process**

4.4.1 Selection of the sample

The identification of specific resource and interest groups was done by members of the Amawoti Disabled People's Association at a planning workshop in September 1992. Participants of this workshop included (five) disabled people, (three) parents of disabled children, (two) civic committee members and a facilitator. Participants were asked to name groups that were "influence leaders" in Amawoti. The names of all the groups which were agreed upon by all the participants were recorded. Thereafter the participants were asked to rank the groups in order of priority or of most influence. Again this was done with much discussion and debate, and the final "hierarchy" was achieved with consensus:

1. YOUTH

2. CIVIC 3. ILIMO PROJECT

4. BUSINESS OWNERS 5. LANDOWNERS

6. CHURCH LEADERS 7. TEACHERS

8. STATE SERVICE PROVIDERS (e.g. nurses, police)

Following identification of these groups, participants suggested that members of the organisation consult with members of each of these categories of "influence leaders" to discuss the issue of disability. In addition it was recommended that there be close consultation with people who had direct experience of disability in the community - disabled people themselves and caregivers. Three people were then selected to host these discussions. These were one disabled person, one civic member, and an assistant (who is the current researcher).

4.4.2 Drawing up of interview guide

An interview guide was used for each of the focus group discussions. This was finalised after the second focus group meeting and then used for each of the subsequent groups. (See Appendix 1 for focus group interview guide.) The drawing up of the interview guide was informed by the literature study done prior to the data collection. Areas covered were:

- *defining disability* being informed by the debate about definitions of disability (WHO 1980, Oliver 1990);
- *attitudes and behaviour towards people with disabilities* being informed by debates on the social understanding of disability, and the need to challenge the 'disabling world' (Oliver 1990, Abberley 1987);
- *needs and rights of people with disabilities* being informed by the needs vs. rights debate highlighted in the literature on community psychology (Rappaport 1981); and
- *practical interventions* being informed by the emphasis on action research, leading to a practical outworking (Lazarus 1985, Lather 1986).

4.4.3 Conducting the focus groups

Focus groups were run with each of the eight groups of "influence leaders" identified by the Amawoti Disabled People's Association. Due to difficulties with practical arrangements, the group of State service providers was divided into two: one focus group was run with nurses and police, and another with employees of the Natal Provincial Administration (NPA). In addition, focus group discussions were held with disabled people and caregivers. In total, eleven groups were run.

Certain procedures were adhered to in all of the focus group discussions. Firstly, introductions were made and there was explanation of the purpose of the group. Thereafter there was the setting out of the "ground rules" such as there being no right or wrong answers, and the importance of all contributions. Permission was requested from the participants to tape-record the discussion and all but one of the groups agreed. The main topics were written on newsprint as an "agenda" so that participants could see the progress of the discussion. The discussions were facilitated by the chairperson, assisted by the co-chairperson who also made brief written notes and operated the tape-recorder.

These discussions aimed to

- reveal perceptions of disability held by different "influence leaders" in Amawoti
- raise awareness of the problems of disabled people in Amawoti
- provide information on views of needs of disabled people
- provide information on views of rights of disabled people
- facilitate discussion of the role of different structures in improving the situation of disabled people (addressing both needs and rights)
- inform different structures about the work of the Amawoti Disabled People's Association.

The focus group discussions were thus both a means of data collection on disability, and an intervention in the groups that were interviewed, in raising their awareness about disability issues.

(a) Venue of the focus groups

All of the focus groups were held in the office of the Amawoti Disabled People's Association. This is a three-room building within Amawoti that is used for the activities of disabled people. Light snacks and drinks were provided both before the discussion started (while waiting for other participants to arrive) and after the discussion was completed.

(b) Constitution of the focus groups

By definition, focus groups are composed of people with similar interests, this homogeneity being determined by the purpose of the study. In this case, focus group members were made up of people from a particular category of "influence leaders" in Amawoti. The following table illustrates the composition of the focus groups, in terms of numbers of people in each and age and gender differences:

Table 4.1 Composition of the focus groups

Focus Groups:	Male	Female	12-24	25-34	35-44	46+	Total
1. Youth	5	2	5	2	-	-	7
2. Civic members	7	-	-	4	3	-	7
3. Ilimo staff	1	4	-	5	-	-	5
4. Business ownrs	3	1	-	-	3	1	4
5. Landowners	2	3	-	-	1	4	5
6. Church leaders	4	1	-	1	2	2	5
7. Teachers	-	4	-	2	2	-	4
8. Nurses&police	3	3	-	5	1	-	6
9. NPA workers	2	1	-	2	1	-	3
10. Caregivers	-	5	1	2	2	-	5
11. Disabled	4	4	1	2	2	3	8
TOTALS:	31	28	7	25	17	11	59

(c) Leadership of focus groups

The facilitators of the focus groups were carefully chosen, with respect to how s/he would be perceived by the group members, skills of group facilitation, and the aims of the study. The facilitation team included a disabled person, a civic member and an assistant (the present researcher), the first two of whom speak Zulu as a first language. Adopting the principle of research as praxis (i.e. that the research itself is a process of empowerment of disabled people), meant that the disabled person who was in the facilitation team took a very active role in the running of the focus group discussions. She was the facilitator of nine out of the eleven groups. She and the co-chairperson (the present researcher) were involved in planning and preparation for each focus group.

In all but two of the focus groups, the researcher took on the role of the co-chairperson. This role lessened the disadvantage of not having full fluency in Zulu (her first language is English) as questions were posed by the chairperson. This supportive role also minimised the perception that may have been held by some group members who did not know her that she was the "white person in charge". She assisted the chairperson by encouraging discussion from all members of the group, and by recording the discussion using a tape recorder and written notes.

4.4.4 Transcription and translation

Two of the eleven group discussions were conducted in English, and these were transcribed by the researcher. All of the other group discussions were conducted in Zulu, and the tape-recordings were transcribed by two administration staff members of the University of Natal, both of whom speak Zulu as a first language. They also translated these scripts into English. These scripts are available from the researcher.

4.4.5 Data analysis

The goal of the analysis of the focus groups was to find logic in the themes uncovered in order to better understand the characteristics (attitudes and behaviour) of the groups interviewed (Williamson et al 1982). This process implies teasing out the essential meaning of the raw data, in order to reduce, reorganise and combine it in such a way that it answers the original research question (Ely et al 1991). More specifically, content analysis implies the "objective, systematic and quantitative collection and processing of data" (Williamson et al 1982 p.278). A number of authors suggest ways of approaching the question of data analysis, and the following outline is a synthesis of several of these:

(a) Specify research problem:

The first task of analysis was to specify the research problem (Williamson et al 1982), so that this could form the base on which the analysis was done. This question was used to drive and direct the process of analysis. The major focus of the present study was:

How can the needs of disabled people within a particular locality be met, and their rights protected, in a way that is integrating and empowering for them?

A second question derives from the first, and was the emphasis of the empirical study:

What key resource and interest groups can be identified, so that their influence can be supplemented or challenged, as part of the process of empowerment and integration of disabled people in community life?

The ultimate aim of the research is thus to suggest appropriate responses (i.e. those that are empowering and integrating) by interest groups to disabled people in Amawoti. In order to achieve this, exploration was made of the groups' present understanding and perceptions of disability and behaviour towards disabled people in the community. Their views on the needs and rights of disabled people were also identified, and finally, there was discussion of interventions that they felt would improve the situation of disabled people in the area.

(b) Categorisation

Formulation of categories is an important part of data organisation (Philliber et al 1980 & Ely et al 1991), as they provide the "boxes" by which to code the content of the focus group discussions. Categories may be designed on a theoretical basis, or using a pre-existing scheme; alternatively, they may arise from and make sense of the specific data. In this process, the main tool is *comparison*. "The goal is to discern conceptual similarities, to refine the discriminative power of categories and to discover patterns" (Ely et al 1991 p.178). Thus the categories must faithfully reflect the major theoretical concepts on which the study is based (Williamson et al 1982). In developing categories for analysis it is essential that researchers make explicit their methodology and criteria to ensure validity and reliability, so that others can evaluate how the conclusions were reached. Further, these categories must be applied systematically to the data, so that personal biases may be minimised (Williamson et al 1982). Ely et al (1991) emphasise the need to ensure that categories are mutually exclusive and exhaustive - and for this reason a category of "other" is included for each topic in the present study, so that unexpected responses can be recorded.

The present researcher developed a series of categories for each of the topics covered in the interview guide. These categories emerged initially from the data, as the researcher took a particular topic and constructed a "creative pattern" of responses from the first 2-3 scripts. Responses that were similar were grouped together and then named as categories.

Once these basic categories were established, she went through all of the scripts grouping responses, and adding new categories where necessary. This process of categorisation was also informed by the literature. (For example, in defining disability, the researcher was aware of the WHO's (1980) distinction between impairment, disability and handicap.) This helped to clarify distinctions between categories that emerged from the data.

(c) Margin Coding

Once the basic categories had been established, use was made of the system of margin coding proposed by Bertrand (1992). This process entailed marking on each focus group script the different categories of responses for each topic. For example, under the topic of defining disability, all the responses indicating disability as dependence were marked.

(d) Developing a matrix

Every category and every theme arises from the fact that it exists in the data and thus can be counted (Ely et al 1991). Quantification itself may help to develop certain themes - for example the frequency of an opinion expressed may make it significant (Williamson et al 1982). Once all of the responses to a particular topic were identified in the present study, a matrix was developed, the X axis representing the different groups interviewed, and the Y axis representing the categories of responses for each topic discussed. This method gave a clear indication of the number of groups (and which ones) that had a particular opinion about a given topic. (For example, in nine out of the eleven groups interviewed, disability was defined as dependency.) A description of the categories that emerged from the focus groups around the five topics of discussion, is presented in Chapter 5.

(e) Developing themes

Once categories have been established, they are "useful in teasing out *the meaning of our findings* as we consider the supporting evidence in each category and as we determine how categories may be linked" (Ely et al 1991 p.150 my emphasis). In this process, themes as statements of meaning may emerge. The linking of categories, and interpretation of the data from the focus groups in order to give it meaning, is the topic of Chapter Six.

4.4.6 Conclusions and recommendations

Inherent in the action research and "research as praxis" model is commitment to the production of socially useful research, which includes making results available and accessible to the researched. In this case, the primary responsibility is to members of the Amawoti Disabled People's Association, who commissioned the study and have hosted it.

Although there has not as yet been formal presentation of the findings of the study, the focus group discussions have already had an impact on the on-going work of the organisation, and have informed its development. (For example, the focus group discussion with members of the Amawoti Civic Association raised awareness of the need for representation of disabled people on community structures.)

A report of the findings of the study is to be compiled as a discussion document, to be used within the Amawoti Disabled People's Association and as a tool of feedback to the participants of the focus groups. It is anticipated that this will stimulate further interest around issues of disability in Amawoti.

In addition, policy recommendations that emerge from analysis and interpretation of the focus group discussions will be submitted to a number of relevant forums. This includes those representing local, regional and national government, disabled people, and service providers in the disability field (e.g. the Rehabilitation Policy Task Group, a working commission of the National Co-ordinating Committee on Disability).

4.5 Limitations of the study

There are a number of limitations of this study that need to be considered. These will be discussed under the categories of the sample, the method and the researcher.

4.5.1 The sample

This study is based in one particular geographical location which is the informal peri-urban community of Amawoti. It could be argued that this restriction limits the generalizability of the results. However, this community is one where socio-economic profile and history are not unique. Thus it is likely that perceptions of the focus group members in Amawoti reflect those of residents and service providers of other informal peri-urban settlements.

The sample making up the focus groups was constituted by the "influence leaders" identified by members of the disabled people's organisation. This implies a process of selection and thus there may be other influential groups in the community who were not included. However, consultation with nine different groups of "influence leaders", representing political, social, economic and cultural sectors of the community, means that a wide range of different perspectives were explored. While this may not have been exhaustive, it does suggest that most of the major role-players in the community were consulted.

Approximately 40% of the participants who were invited to attend each focus group discussion, did so. While this may suggest that the respondents who did participate are those that are more open to disability issues, the success rate of attendance is fairly high, and results indicate that a broad range of opinions were expressed.

4.5.2 The focus group method

(a) Interview guide

It could be argued that the way that the questions of the interview guide were framed, and that they had the potential to perpetuate generalisations about people with disabilities. This is because the disability reigned supreme, devoid of any competing context (Wright 1980). Nowhere were class, gender, age or educational distinctions revealed and all disabled people were assumed to be a homogeneous group, who would be treated in the same way, regardless of other differences. While this generalisation is acknowledged, the process of developing a social understanding of disability requires such generalisations, for only in this way can disabled people be viewed as an oppressed group in society.

(b) Running the groups

It was not always easy (or possible) to prevent domination of the group by one group member, and some of the group discussions may reflect the views of a minority, and not the majority of participants. While this remains as one of the limitations of the focus group method, attempts were made to minimise this by an emphasis on the importance of all contributions during the introduction to the discussion. In addition, part of the brief of the co-facilitator was to encourage participation by all the group members.

(c) Data collection method

The data collection method used - that of tape-recording, transcription and translation - had limitations in that it did not allow for the translation of emotions and emphases made during the discussions. The use of a tape-recorder also created some difficulties; the recordings of two focus group discussions were barely audible due to faulty machines and interference from sounds outside of the meeting room. In addition the need for translation of scripts from Zulu to English introduced the possibility of inaccuracies occurring.

(d) Analysis

The fact that relatively few focus groups (eleven in total) were conducted in this study made it impossible do to statistical analysis of the results. The data collected was *not quantitative* in nature, and thus statistically significant differences between groups could not be shown. Thus it is not appropriate to generalise about specific population parameters based on these results. Rather, the value of this work lies in its *descriptive* nature both in the presentation of the results and in analysis of the findings. An attempt was made to minimise the subjectivity and resulting bias of the analysis by the use of a standard process of analysis for each script.

4.5.3 Researcher

The present researcher has been involved in the community of Amawoti since 1987, and has lived there since 1989. She was one of the founding members of the Amawoti Disabled People's Association, and has been working for it since its inception. She also has some fluency in the Zulu language. Despite her participation in the context of the study, it still remains that there are class, race and educational differences between herself and other participants. Such differences are not necessarily limitations in themselves, but they emphasise the importance of a mechanism of negotiation, whereby "researchers... put their knowledge and skills at the disposal of their research subjects" (Oliver 1992 p.111), towards a transformation of structural inequalities. Thus the usefulness of qualitative research techniques and the emancipatory model depends "ultimately on the integrity of the researcher and their willingness to challenge the institutions which control disability research" (Barnes 1992 p.123).

Conclusion

The methodology of this study has been rooted in the action research and emancipatory research paradigms, with disability viewed as both an individual and a societal problem. In this process the researcher is not neutral and a specific commitment was made to use her knowledge and skills to promote the empowerment of people with disabilities in Amawoti.

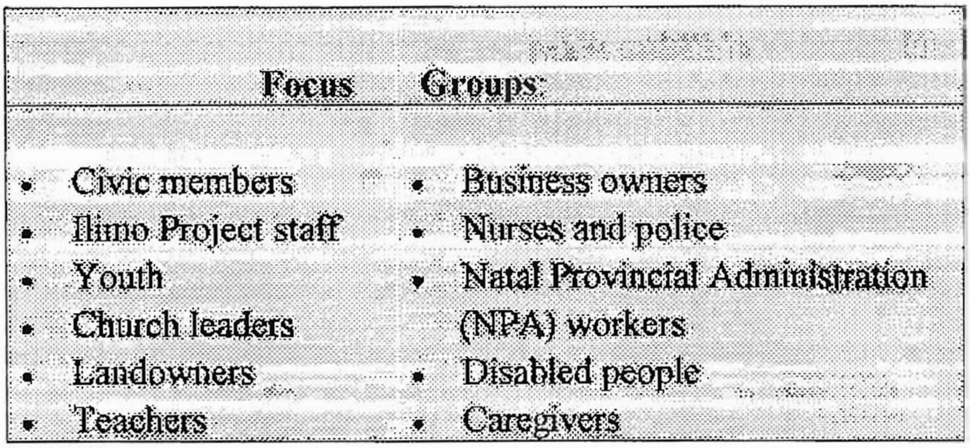
The concern of the research question is the response of interest groups in Amawoti to the needs and rights of people with disabilities. The topics explored in the focus groups expanded on this, and included definitions of disability, its causes, behaviour towards disabled people, needs and rights, and appropriate interventions. The data collection method was that of focus groups, which was felt to be most appropriate for the type of (qualitative) data required and the participants (who have a strong oral tradition). These discussions were tape-recorded, and systematically analysed, resulting in the emergence of categorisations of responses for each of the topics covered. The results of the focus groups are presented in the following chapter.

CHAPTER FIVE:

RESULTS OF THE FOCUS GROUPS AND DISCUSSION OF THE FINDINGS

Introduction

Over a period of eight months, a total of eleven focus groups were run, and each of these discussed the same questions, which were outlined in the interview guide. This chapter is a compilation of the opinions expressed in these discussions. The different groups interviewed were:



Focus Groups:

- Civic members
- Ilimo Project staff
- Youth
- Church leaders
- Landowners
- Teachers
- Business owners
- Nurses and police
- Natal Provincial Administration (NPA) workers
- Disabled people
- Caregivers

In the presentation of the results, quotations are taken from these different groups, and the following abbreviations have been used for referencing these quotations: Civic, Ilimo, Church, Business, NPA workers and Disabled. The other groups are referred to in full.

The interview guide that was used for each of these focus groups covered five key areas with regard to disability in Amawoti. These five topics constitute the five sections of this chapter. At the beginning of each section, a summary of the main findings in relation to the particular topic is given in a shaded box. Thereafter, summaries of the findings of the sub-sections are indicated by shaded paragraphs.

Content of the focus group discussions:

1. **Defining disability and its causes**
2. **Behaviour towards disabled people**
3. **Needs of disabled people**
4. **Rights of disabled people**
5. **Interventions to improve the situation of disabled people**

5.1 Defining disability and its causes

In this section an attempt is made to understand what "disability" means for people in Amawoti. There is an exploration of features and characteristics of disability which stand out for members of the focus groups and an attempt to answer the question: in what terms do they define disability? This is not looking for a conclusive definition of "disability", but rather the intention is to identify some of the key constructs by which it is perceived in Amawoti. Indeed, the debate about definitions of disability is well documented - providing the forum for different perspectives to be aired (WHO 1980, Oliver 1990). Suffice it to say that numerous definitions exist - a widely adopted one being that of the WHO, which itself has been criticised for its exclusion of social and cultural aspects which are necessarily present in disability (Despouy 1991).

The aim of the focus groups was not to create a new system by which people with impairments can be classified. Rather, it was seeking to discover the context-specific perceptions of disability, so that the organisation of disabled people in Amawoti can better strategise how to address the socially imposed restrictions, thereby developing the capacities and potential of the individual to the full. In this process a wide range of perceptions of disability were expressed, both within and between focus groups. This illustrates the multi-dimensional nature of disability, and of society's perceptions - a feature which is congruent with the literature on this field. The different opinions emerging are classified thematically.

5.1 Disability and its causes:

5.1.1 Disability is...
(a) "not functioning"
(b) "needing help"
(c) "not normal"/different

5.1.2 Disability is caused by...
(a) general factors
(b) violations of human rights
(c) cultural factors

5.1.1 Categories of understanding:

(a) Disability as "not functioning"

Among the focus groups, disability was understood as a way of "not functioning". This was seen to take different forms.

(i) Disability as "a part of the body not working well"

Nine of the focus groups described disability as *dysfunction*. There did not appear to be a gender distinction with this perception, in that in all the female-dominated and all of the male-dominated groups this view was expressed. This view of disability was also not observed to be age-specific.

In defining disability as dysfunction, focus group members held that disability "means that a certain part in the body is not working well" (Civic). Thus a disabled person is one who "has a part of the body that does not function properly" (Disabled).

One mother in the caregivers group described the dysfunction thus: "My child does not have legs. Her parts of her body are incomplete". The child she was referring to has cerebral palsy and her spasticity means that she is unable to walk. The mother was thus not literal in her statement that the child "does not have legs", but was implying that there was an absence of function. Another group (Nurses & police) expressed dysfunction of the body as the "lack of a normal physical feature". Such "features" could be speech or hearing (Caregivers). There was recognition that disability could be dysfunction of either mental or physical capacities as "a part of the body is affected... either mentally or physically" (Landowners).

The perception of disability by the focus groups as "the body not working well" is very closely paralleled to the WHO's (1980) concept of impairment, which is defined as "any loss or abnormality of psychological, physiological, or anatomical structure or function".

(ii) Disability as functional limitation

There was the perception by four of the focus groups that disability is defined in terms of *functional restrictions*. A disabled person was seen as "someone that's not functioning" (NPA workers). Of the four groups that expressed this understanding of disability, two were male-dominated, and two had equal numbers of male and female members. No age-bias was observed.

The specific disabilities of mobility and speech were highlighted in two of the groups, as a disabled person was seen to be "Someone who cannot walk" (Youth) and one who "wants to give you an answer, but he is failing to talk" (Landowners). It may only be a physical restriction such that "... s/he can think properly but it is just a certain part of his/her body that is disabled" (Business). It was recognised that the consequence of such restrictions may be dependence on others.

The difference between "a part of the body not working well" (impairment) and "a person who does not function properly" is subtle but distinct. The latter results from the restrictions imposed by the former i.e. because a part of the body is absent, or not working properly, the person's activities are restricted. For example, a person who is blind (impairment) may have difficulty with cooking (disability). The view expressed by the focus groups could be compared to the definition of disability advocated by Despouy (1991 p.24), who takes it further in anchoring disability in the arena of human rights:

> "Any person suffering from a permanent or prolonged functional disorder, whether physical or mental, which having regard to his age and social environment entails considerable disadvantages for the purpose of his family, social, educational or occupational integration, and for the effective enjoyment of his human rights, shall be considered disabled."

(iii) Disability as "something not working well in one's life"

In three focus group discussions, the opinion was expressed that everyone is more or less disabled. All but one of the groups in which this opinion was expressed were male-dominated, and most were in the 35-44 year age bracket

"I think there is nobody who is not disabled in his life. Even someone who we told ourselves is well, there is something that is not working well in his life" (Civic). Disability is there defined as "something not working well in one's life", and everyone is at a different point on the continuum. This was substantiated by the business owners' view that "If a person is poor and does not have money s/he is disabled".

The view that poverty itself is a disability was held by the church leaders, who saw it possible that "A normal person can become poor and end up being disabled".

> Mr. D: The way I see it I think disability means not to be able to do the things that you want to do.
> Mr. M: For instance like me. I enjoy visiting people but because of my disability I am not able to go.
> Facilitator: What it means is that to be disabled is not to be able to do what you wish to do? Am I disabled if I wish to go to school, but am not able to? If I do not have money to go, am I disabled?
> Mr. D: It is disability because there is something you need which you do not have: you do not have money.

The concept of dysfunction in one's life being disability was expressed by one member of the Ilimo group in relation to dysfunctional behaviour: "I always see normal people as being the ones who are disabled: those who are the parents of the children. It is always the parents who go and leave behind the disabled children." The idea of "role reversal" is an interesting one raised here: the issue may be not so much the impairment per se, but the *disabling world.*

It was observed that in the three focus groups that defined disability as "something not working well in one's life", all included members who were in the age-group 35-44 years. The emerging trend is of interest as it may suggest a conscious striving towards success and accomplishment, in which men in their thirties and forties are actively working to overcome the things that are "not working well in one's life".

(b) Disability as "needing help"

The view of disability as dependence was one that was expressed by all of the focus groups that addressed this question, with the exception of the youth. No gender bias was observed.

Within the focus groups, disability was equated with dependence. "Disabled people are being seen as people who need to be cared for in the community ...there is nothing they can do on their own" (Nurses & police). The view that disabled people are dependent was based on the assumption of *inability*: "...you know that s/he won't be able to do things" (Civic). "...s/he can't help him/herself. S/he is dependent" (Business). This dependency meant "not to be able to do the things you want to do... not to be able to go wherever you want to go because you are disabled" (Church). Disabled people confirmed this saying that they "are no longer able to do some of the things properly" (Disabled). One person from this group stated "I am not able... I end up asking another person to do it for me". "She [my disabled child] is not able to do all she would like to do herself" (Caregivers).

As a result, disabled people were seen as those who are in need of help: "It's a person who is unable to do, who needs a second hand to help" (Nurses & police). "A disabled person is a person who is unable to look after him/herself, who is unable to earn his/her livelihood, who requires others to look after him/her" (Business). "This person needs help" (NPA workers). Such "help" may be of a very practical nature: "Some people even need the support of a stick in order to walk properly" (Teachers).

One group defined disability and dependency as it related to illness: "A disabled person is like a sick person. S/he cannot help him/herself. I associate him/her with a sick person because a person with a broken leg limps, but that is for the time being. If a disabled person limps, s/he limps for the rest of his/her life... S/he is dependent" (Business).

Probably the most intense statement made with regard to the defining of disability as dependency came from the group of disabled people where the comment was made that a disabled person "is like a dead person ... it is a person who is not able to help him/herself... It is a person who wishes to help him/herself but s/he is not able to, because s/he is disabled" (Disabled). This statement seems to convey the experience in which a disabled person has minimal control over his/her environment. For example a woman with a hemiplegia who is unable to wash herself must wait until her daughter (or another member of the household) has time to fetch water, to light the stove and to assist her with washing.

It was significant that the youth did not express this opinion, and it would suggest a slight age-bias towards older age groups (25 years and older). Consideration of this trend leads one to observe that youth themselves are often dependent. Most of those that participated in the focus group live with their families, and are being supported (financially and in many other ways) by them. Perhaps, in their own situation of being dependent, the youth would not view this as being unique to disabled people. On the other hand, adults are likely to be independent themselves, and to be more aware of the consequences of dependency (e.g. costs in terms of clothing and food).

Finkelstein (1980) and Wright (1987) point out the inter-dependence of all human beings - illustrating that dependency is not unique to disabled people. The assumption that non disabled people can do anything they want, individually, without help, is simply not true. We are all dependent on a daily basis on other people and services - be it water-kiosk attendant, government clerk or store cashier. "The fact is that modern living is totally dependent upon aids and human assistance" (Finkelstein 1980 p.38). Usually, however, that is not considered "help", but as "everyday living", while the help needed by disabled people is considered as "special". These different standards often prevent the non-disabled from the recognition that "society has as much responsibility to provide a usable environment... to its disabled as to its non-disabled members" (Wright 1987 p.6).

If one accepts that *all* people need help - why is it clearly so painful for disabled people to receive it? One hint is provided by the reflections of Raucher (in Wright 1987 p.9), herself a disabled person:

> "There's good help and there's imposed help. Too often I don't decide what help I need, *you* decide what help I need; and then I'm not grateful, and then you get offended, and so it goes round."

The issue then is not that disabled people need help (as we all do), but that they remain in control of that help, saying if, when, where and how they want it.

(c) Disability as "not normal" / different

Seven of the ten focus groups expressed the view that people with disabilities are "not normal". While there appeared to be no gender distinction between groups holding this view of disability, there was a tendency for older age groups (from 25 years and older) to view disability as "differentness".

This understanding of disability implied that disabled people were rated against the standard of "able-bodied normalcy" (Finkelstein 1980): "It's a person who can't do things like other people - like a cripple who can't walk like others" (Nurses & police). Being "not normal" was used as the distinguishing criterion: a disabled person "is the one who is not normal. That is the way that you can find out whether this person is disabled or handicapped because he is not normal"

(Business). "...like not being able to hear: it is disability because a person must be able to hear" (Church).

For adults who have become disabled in later life, this "normality" was seen as the condition before the disability: "...a [disabled] person has been sick and when s/he becomes better s/he does not go back to his/her normal life" (Church). Two groups (Teachers and Landowners) focused specifically on mental handicap: "He was born normal... but now he is mentally disturbed" (Landowners) "A mentally disabled person cannot think properly like a normal person... there is no feeling to do the right thing like a normal person" (Teachers). The "right thing" is a reference to appropriate behaviour and respect of societal norms - such as eating habits, or manners towards older people.

As disabled people were viewed as being "not normal" and the non-disabled as "normal" *differences* were emphasised. "The difference is that sometimes the parts of the body are not the same or the reasoning capacity tends to differ [from the able-bodied]" (Caregivers). The "differentness" of disability was seen to create a separation between disability and so-called "normality": "What I understand by a disabled person is that s/he is not like me, although s/he has the mouth, the body, but the body does not function as a normal person" (Business). There was thus a clear distinction between those who saw themselves as able-bodied and those that they perceived to be disabled: "A person who is mentally retarded doesn't think the way you think" (Landowners).

One mother of a disabled child expressed the difference thus: "Thandi is disabled because she is different from a normal child. The other child is able to see if she is carrying water, where she should pour it. Thandi cannot differentiate. She finds it easy to do things anyhow..." (Caregivers). Another mother confirmed this view by describing her own child: "The behaviour is different from a normal human being... she is different from other children". There was some comparison with people of the same age group: "... nothing is telling the body to change and do what others of the same age group do" (Teachers). "S/he is a child and does everything like a child and never grows up" (Teachers).

Jagoe (1987 p.2), herself a disabled person, identifies some of the consequences of disabled people being defined as "different": "This reaction distances the able-bodied person from someone with a disability, often with the inherent assumption that they can't be "one of us". As soon as someone is seen as other than "one of us", different standards can then apply... People with disabilities, like people of colour, women and gay people have begun to say "hang on, those are your projections, your assumptions, your definitions of our inferiority and that these projections are convenient to maintain the power balance firmly on your side".

Do disabled people themselves feel different and "not normal"? Initially some of the definitions given of disability by disabled people defined differentness in terms of a physical feature: "To be disabled is to have a certain part of the body which is not the same as that of other people" (Disabled). "It is a person who has a different part of the body - who has a leg or an arm which is not the same as that of a normal person" (Disabled). Such differences may be compared to other physical features - such as hair colour, height or weight - which are not criteria of superiority or inferiority. Kaseje (1992) uses the term "differently abled" to refer to people with disabilities. This term conveys differentness, not as a label to make one group inferior to another, but to point to diversity that has the potential to enrich communities. Such a view has the potential to change the situation in which "A person is disabled because there is no peace in his soul, because he is different from other people" (Caregivers). Ultimately, society is responsible for defining disability: "A [disabled] person is one who is judged by the community or society wherever s/he is, as *a person who doesn't conform to the norms of that community*. It can be physical, mental or social" (Nurses & police my emphasis).

5.1.2 Perceived causes of disability

Nine of the eleven focus groups were asked about causes of disability. In the analysis of the group discussions, these causes were classified according to criteria used by the United Nations Commission on Human Rights (Despouy 1991) in its study on human rights and disability. This classification is significant in that it takes as given the *causal link between violations of human rights and disability*. These criteria are:

* general factors which do not necessarily entail violations of human rights and

* those caused directly or indirectly by violations of human rights.

(a) General factors causing disability

> Among the causes of disability in this category that were identified by the focus groups were diseases, congenital factors and accidents.

Six focus groups cited "certain *diseases* on earth" as being causes of disability. Some of the groups were more specific, in actually naming the condition, such as hypertension, which was seen to lead to strokes and the impairment of hemiplegia (Landowners). Another consequence of disease leading to disability was "amputations" (NPA workers). "Epilepsy" was also named as a cause of disability (NPA workers).

There was also a strong opinion expressed by five of the groups that "others are born with it [disability]" meaning that it is *congenital* (Church, Landowners, Youth and Caregivers). One reason for this may be: "Sometimes it happens that you fall in love with someone who is your close relative. In such cases one can give birth to a disabled child. We do have such a child in our family..." (Disabled). Thus intermarriage into the same family was seen as a cause of congenital disability.

Seven of the nine groups that addressed the question of causes of disability attributed it to motor-vehicle *accidents* (Business, Landowners, Nurses & police, Teachers, NPA workers, Youth, and Disabled). This view is confirmed by the statistics: "The National Road Safety Council estimates that in 1991, 433 569 people were involved in accidents on South Africa's roads. Of this number, 34 621 people were seriously injured and 11 [illegible]22 were killed. It is estimated that of the people who are seriously injured in vehicle accidents, most will suffer some form of disablement for the rest of their lives" (DPSA 1992 p.2).

(b) Violations of human rights causing disability

The focus group discussions also revealed causes of disability that were a direct result of violations of human rights. These included poverty, poor maternal health, neglect and violence.

Several of the focus groups (Youth, Landowners) recognised that "ubumpofu" (poverty) is itself an important cause of disability. "... poverty and too much thinking. You have no money, no food, and no place to sleep. You have no work... You are not able to feed your family because there is no job..." (Landowners). In conceptualising this view, Despouy (1991), maintains that underdevelopment and its various manifestations play a crucial role in the occurrence and intensification of disabilities. In the report of the Commission on Human Rights and Disability, a vicious cycle is identified: mass shortcomings in the provision of education, nutrition, and health care bring about an increase in the disabled population that cannot contribute to development. In this way an increasing burden is placed on the poor. The problem is presented by the UN rapporteur as a denial of the right to development, "a right whose fulfilment is considered one of the most effective means of overcoming disabilities and strengthening protection of the human rights of disabled persons" (Despouy 1991 p.37).

Three groups sited as significant the *mother's health* during pregnancy (Business, Landowners and Teachers). This too could be seen as a symptom of the conditions of poverty in Amawoti, with the accompanying inadequate and inaccessible health services. It may also be the result of "*malnutrition*" (Disabled, Landowners): "It can happen if the mother does not get healthy food whilst she is pregnant, the child will not develop properly" (Landowners).

The importance of maternal and child health in the prevention of disability is recognised both nationally (DPSA 1992) and internationally. Certainly provision of health services is a priority, for "The lack or inadequacy of medical attention during pregnancy or confinement, is according to UNICEF, one of the most powerful factors in disabilities among children" (Despouy 1991 p.38). In addition, the impact of malnutrition cannot be underestimated: "In most of the world, prenatal diseases and diseases in infancy as a result of malnutrition are cited as major causes of disability in children" (Despouy 1991 p.33).

Neglect was another factor highlighted by the focus groups (Church, Teachers, Nurses & police and Disabled). This may have both physical and emotional impacts on people, leading to disability. "Even adults do become disabled if they are not properly looked after. If you are suffering you end up becoming mad. They become affected mentally and one is able to see that the cause in such people is not being fairly treated" (Disabled). Children may also be neglected: "If you've got many children, you hardly get time to stimulate them, and play with them, and make little things with them, so the children are neglected, lying on the bed the whole day..." (Nurses & police).

The focus group of nurses & police also listed a number of social factors which they viewed as causes of disability. "Illiteracy" was viewed as one factor "because the mothers do not take care of health requirements during pregnancy... do not attend ante-natal care...". "Teenage pregnancy" also causes disability because "if a teenager is under-age, say 12-25 years, she might have problems in giving birth". "And then this over-population - people having *so* many children. If you have seven children, you don't look after them, you don't care for them. You are fed up..."

The recognition by several of the focus groups that *violence* is a cause of disability in Amawoti is hardly surprising given the present context in which South Africa is currently rated as one of the most violent countries in the world (Daily News March 15 1993). This covers a wider range of violent acts, including "bombs" (Youth). DPSA (1992 p.2), affirms this view, claiming that violence "remains a key contributing factor in causing disability. The high level of violence in our society largely results from political violence, which involves state repression, retaliatory violence and community conflict and increasing criminal violence which has escalated considerably in the last ten years. Many disabilities result from shootings, stabbings, people being thrown from moving trains, and a range of other violent acts perpetrated against people". One focus group pointed out that violence was exacerbated by alcohol abuse (Nurses & police).

(c) Cultural factors

A very significant view that emerged from all of the focus groups excluding one (NPA workers) was that causation of disability is linked to cultural factors. This was phrased in a number of different ways such as "curses/bewitchment" (Church, Landowners, Teachers), "umbhulelo" (the technique of placing harmful medicines) (Disabled), "black magic" (Nurses & police), or the consequence of "not observing the customs" (Youth and Caregivers).

Disability and bewitchment were discussed by the focus group of disabled people:

> Ms D: If you walk over something which has been poured next to the door - it works slowly and slowly. That is when you have been bewitched by someone. We call it "umbhulelo".
> Mrs M: It works slowly and slowly and you end up finding yourself disabled.
> Ms D: When you go to a hospital white people tell you that you have a stroke.

The placing of noxious substances on a particular person's pathway, or scattering them along pathways to harm passers-by leads to a condition referred to "umeqo" (Ngubane 1977). The occurrence of "umeqo", was described by the group of landowners: "There is someone who was born normal in Zambia [a sub-area of Amawoti]. He was bewitched with the Shangaans medicine. Children were playing in the house, and when the grandmother arrived, she discovered that the neck of the child was red. No one knows what was inside the bottles. This child became sick. His whole body shrunk... He stayed in hospital [but] he never became normal..." The interpretation of this event was similar to that of the group of disabled people: "It means that disability can be found in the things that you walk over which are found on the ground" (Landowners).

Disability for many people in Amawoti is also interpreted in terms of the ancestors. One woman described how she understood the cause of her own disability:

> "As you see me without a leg, it was a quarrel at home about me. I was brought up in a family that I did not belong to. My mother ran away from her marriage, and came to town. She got me when she was in love with Mr. Cele. After giving birth to me, it was heard that Mrs Ndlovu [my mother] is in town, and she has a child. She decided to hide me in her family, and went back to her house [in the rural area]. It was

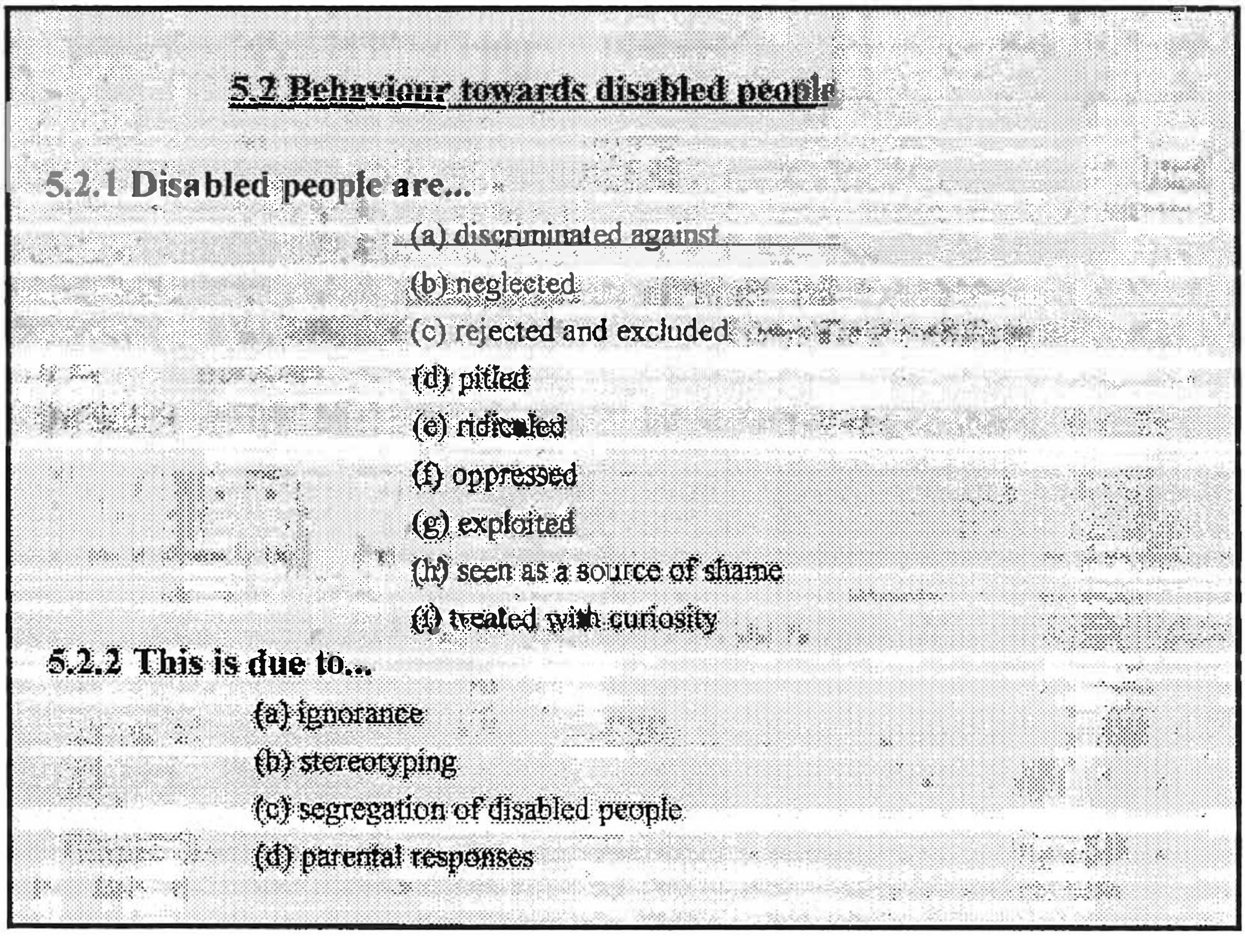
> discovered that there is a child that she got when she was in town, and it is hidden. The ancestors started quarrelling over me, and I was knocked down by a car - that happened when I was nine years old. It was said that there was a quarrel between the Ndlovu and Cele ancestors - and that was the cause of my disability" (Disabled).

Disability is also seen to be a consequence of neglect of the ancestors, and of traditions. One caregiver stated that as a child, up to the age of five, she had not been able to walk. The reason for this was that "my parents did not believe in the ancestors". However, when a goat was slaughtered in honour of the ancestors "I stood up and walked... It happened immediately after telling the ancestors that the goat was mine".

While cultural interpretations of disability may give meaning to it, they may also further perpetuate discriminatory attitudes and practices. The Harare Declaration on Legislation for Equalisation of Opportunities for Disabled People, drawn up in Zimbabwe in 1991, specifically addresses cultural factors that impact on disability and society's response to it. It states that "discrimination based on myths, cultural and religious traditions must be outlawed" (p.4).

5.2 Behaviour towards disabled people in Amawoti

Within the focus groups, there was an attempt to explore behavioural responses to disabled people, by discussion around the question "How are disabled people treated in Amawoti?" The intention was to focus on the behavioural outworking of underlying attitudes. However, it is recognised that the relationship between attitudes and behaviour is complex, and that many factors such as norms, habits, contexts and expectations also influence behaviour (Finkelstein 1980). While the problem of generalisations about disabled people as a homogeneous group is acknowledged, the intention of this section remains as the provision of a broad over-view of trends of behaviour towards disabled people in Amawoti, as observed and experienced by the focus groups included in the study.



5.2 Behaviour towards disabled people

5.2.1 Disabled people are...

(a) discriminated against
(b) neglected
(c) rejected and excluded
(d) pitied
(e) ridiculed
(f) oppressed
(g) exploited
(h) seen as a source of shame
(i) treated with curiosity

5.2.2 This is due to...

(a) ignorance
(b) stereotyping
(c) segregation of disabled people
(d) parental responses

5.2.1. Different behaviour towards disabled people

(a) Discrimination and Dehumanisation

A large majority (nine out of eleven) of the focus groups expressed the view that disabled people in Amawoti are discriminated against by able-bodied people. The Zulu word used to denote discrimination - "bandlululo" - is the same one used for "apartheid". It is significant that the two groups that did not express this view consisted of State employees. There were no age or gender distinctions observed between groups that expressed this opinion.

There was a general opinion expressed in the focus groups that "the public still discriminates against the disabled" (Civic). "Disabled people are discriminated against... They are not treated as able-bodied people in the community" (Youth). It was also seen as leading to the situation where "the community always look down upon disabled people" (Ilimo & Caregivers). This was recognised as being problematic: "Disabled people are discriminated against by the community, and we are supposed not to discriminate against them" (Civic).

The outworking of discriminatory attitudes is illustrated by one member of the focus group of caregivers: "Let us take for instance a woman who cannot walk. The falling pregnant of such a person is taken as a disgrace because of what she is. We see this person as a cripple, forgetting that her feelings are the same as our feelings. We become cross with her because she will have a problem in taking care of her child. We the community of Amawoti always tell ourselves that if you are disabled [physically] you must remain disabled and your mind is not working properly" (Caregivers).

There was general agreement in the focus groups that "the community looks down upon them [disabled people]" (Church). The group of church leaders actually used this phrase three times during their discussion. Disabled people also acknowledged that "People look down on us". Again, this has a behavioural outworking: "They are being badly treated. They do not give them their positions" (Church, Disabled). "They stay behind... They are despised, looked down upon, and seen as a disgrace" (Youth). "They are living a difficult life because people despise them" (Landowners). The teachers group observed that such attitudes become a self-fulfilling prophecy in which "a disabled person looks down upon him/herself because s/he finds him/herself not belonging to the community".

The ultimate consequence of discrimination against disabled people is that "the community does not see them as human beings... S/he is something which has no value at all" (Church). "The community see them as people who are nothing" (Landowners). The opinion that disabled people are dehumanised in Amawoti is verified by a disabled person: "Yes, it is true. We are nothing in the community".

(b) Neglect and "Taking no notice"

There was the recognition in eight of the focus groups conducted that people in Amawoti "don't take notice of the poor and disabled people".

This concept is understood as a passive process of taking no notice of, and of not caring about disabled people: "People in Amawoti do not care no matter how the situation [of a disabled person] is, no matter how needy you are" (Business). The neglect of disabled people has a behavioural outworking in that "There is no one who takes care of them" (Ilimo, Church, Teachers, Youth). In practical terms, this means "They are not washed", and symbolically "They are left at the side" (Youth).

The Civic and Teachers groups brought particular attention to the consequences of neglect on disabled children: "This child is left alone at home without being looked after by parents" (Teachers). "Even if they are sitting chatting as a group, they find themselves neglected because of being disabled" (Teachers). "When we talk of love - you as a man have a child who is disabled - when this child plays with other children they neglect him because he is born disabled. These children are supposed to get used to your child" (Civic). This comment illustrates that neglect not only has negative consequences for the (disabled) person being neglected, but also denies the one who takes no notice of him/her the opportunity of breaking down barriers and of building relationships.

Another focus group observed that disabled people "are left alone at home, ...left outside - maybe the rain comes, or the sun..." (Nurses & police). This has led to the situation where disabled people "are not doing well, they are left to waste away..." (Nurses & police). Although people in Amawoti may not be conscious of neglecting or taking no notice of disabled people, disabled people themselves acutely feel it: "No one cares about you".

It is of note that the group of caregivers (female-dominated) did not express this view. It may be due to their own acute involvement with disability, and the situation in which they did not have the option to care or not to care, it was simply expected of them as a woman in the household. It has not been possible for them to "take no notice" of the disabled relative for whom they care and around whom much of their activity is centred.

(c) Rejection, Isolation and Exclusion

Within eight of the focus groups, participants expressed the view that there was an exclusion of disabled people within community life in Amawoti. This process of exclusion appeared to be more conscious than the passive neglect described in the previous section. There were no gender differences observed between the focus groups that expressed this view.

Staff of the Ilimo Project observed that "They are not included in most of the things" and this leads to a situation in which "Disabled people always see themselves as people who are left behind".

It is of interest that most focus groups that observed this attitude towards disability, did not place the blame for it on disabled people themselves. Some felt themselves to be at fault: "We do not invite them to our meetings so as to be able to hear their views. No one asks them about how they feel about their disability. It is just quiet" (Ilimo); "They are avoided and shunned" (Youth); "Sometimes it is as if they are rejected" (Nurses & police).

Such excluding practices are not unique to Amawoti, rather "Avoidance is a behavioural response that seems to be rather typical in meetings between persons with and without disabilities" (Soder 1990 p.236). However, it is important to note that the concept of exclusion is not limited to interpersonal relationships between able-bodied and disabled people. DPSA (1992 p.6) highlights some of the environmental and societal barriers that exist:

> "Disabled people in South Africa and indeed throughout the world are confronted with a major challenge every day of their lives: To survive in an environment designed to exclude them, to identify themselves, associate and interact with a society that is committed to rejecting, isolating, discriminating against and abusing them. They hope that one day change will come, when there is a society which will come to understand and respect the dignity of all people".

The consequences of such active exclusion and rejection go beyond the individual disabled person. One mother expressed it thus: "I always watch my child when she is playing with other children... they tend to run away from her. They don't like to mix with her because she is disabled. It's easy for them to hit her. It happens anyhow, because she cannot say who has been beating her. All this affects me as a parent. I feel the pain."

(d) Pity

The view that disabled people are treated with pity was expressed by five of the focus groups. Although no age or gender distinctions were observed between groups holding this view, a class difference seems to emerge.

In some focus groups, it was felt that "the majority of people pity the disabled" (NPA workers, Landowners, Nurses & police), and "You can sympathise and feel "shame"..." (NPA workers). Those expressing this opinion were the government employees (Nurses & police and NPA workers), and the landowners. These three groups are likely to be on a higher socio-economic level than other participants of the focus group discussions - either due to education and employment (state employees) or as a result of the inheritance of land (landowners). It is thus from a position of relative power that these particular groups can look down on disabled people as "objects of pity".

The pity articulated by the group of church leaders, however, seems to have a different origin, and may be closely linked to the way that church leaders wish to be perceived in Amawoti - as "agents of charity". Certainly they would not be regarded as the more wealthy residents of the area. Their understanding of the situation of disabled people seemed to evoke a response of compassion - as one church leader put it, "... when looking at him/her you see misery and poverty, which is created by a lot of things.... You just pity him/her in such a way that it goes beyond the fact that s/he was born like that [disabled]".

The feelings of sympathy were discussed in depth in the focus group of landowners, one of whom said "It makes you feel sorry". Such feelings may evoke generous behaviour from able-bodied people: "I always give her money... because I pity her" (Landowners). Other people were perceived as not being prepared to act: "I think there's a lot of pity - as long as they [able-bodied people] don't have to do anything for them" (Nurses & police).

Within the focus group of disabled people there was ambivalence about this attitude of pity, which was recognised: "It is true - they do say "shame"". The difficulty arises in knowing how to interpret a person's actions: "a child sees me walking and limping, and he will say "oh shame"...I do not like it... It may be out of pity, or mocking, but you are affected". "I don't want a person to feel pity for me. I am very good at seeing someone who want to say "shame" and I tell him/her not to feel pity for me... I don't want people to give me 20c - I tell them that I don't want it" (Disabled).

While many studies reveal that disabled people "evoke strong feelings of sympathy and altruism" (Soder 1990 p.236), a paradox seemed to emerge between perceptions of different focus groups. On the one hand, disabled people resented being the object of pity and being looked down upon, and on the other hand, pity was seen to evoke generous donations from community members (Landowners). The business owners felt that if disabled people "want something from the next man, you must go in such a way that he feels pity for you". Thus there arises the tension between the ideal of independence and self-determination, and the need to appear "pitiful" so as to acquire donations.

(e) Ridicule

Of the four focus groups that expressed this opinion, two were female-dominated groups, one was male-dominated and one had equal representation of sexes. This may suggest that women are more sensitive to the ridicule of disabled people by community members.

Several focus groups held the view that disabled people may be the target of ridicule: "You find children making a fool of someone who is mentally retarded. They throw things at him, and do all sorts of bad things to him. This affects a disabled person because he is not free" (Caregivers).

A number of words were identified in the different focus groups as being derogatory in referring to disabled people. "Other people just call him/her a cripple" or "ingini" (person with a stump of a limb used synonymously to refer to a tree with lopped branches) (Church). Such name-calling may be deeply ingrained within a particular society where people use different terms without realising how derogatory they are. This could be seen as a facet of the "labelling approach" described by Soder (1990).

(f) Oppression

In four focus groups the view of that disabled people are an oppressed group was expressed. This oppression was seen to exist at a number of different levels - interpersonal, familial and societal. Three of the groups that expressed this view (Civic, Youth, Ilimo Project) are among the more politicised groups in Amawoti. They also represent the younger section of the community - most members of these groups being in the 12-44 age bracket. Disabled people themselves did not articulate the concept of oppression per se, but clearly expressed their experience of being on the "receiving end" of it.

There were several forms of oppression that were seen to be experienced by disabled people in Amawoti:

(i) Oppression by able-bodied people

Neglect by other people in the community was considered to be a form of oppression: "Disabled people... have been made to believe that no one takes care of them and their minds have accepted the fact that they are disabled. They find themselves oppressed" (Ilimo). Perhaps it is this oppression that makes disabled people more vulnerable to exploitation (see 5.2.7). The Youth cited as an example people who buy beers for a young man who is severely physically and mentally disabled. They saw this as exploitation - those buying the beers would expect to be paid back from the young man's disability grant, often at rates far higher than those that other members of the community would be charged.

Within the group of Ilimo Project staff, some members were prepared to take personal blame for contributing to this situation: "They are oppressed by we people who have two legs. We tell ourselves that we are not disabled. We oppress them by not taking care of them and we do not listen to their grievances. We always tell ourselves that we are important, and we do not take notice of disabled people. We see it happening when there is a party in our homes: we always start with the smartly dressed people. We do not worry ourselves even if we see a disabled person lying on the floor". This observation is affirmed by Jagoe (1987 p.3), herself a disabled person: "The barriers outside us, including the attitudes towards disability, are where our oppression lies." These attitudes are compounded by social conditions: "The most important thing that adds to the disability is the shortage of jobs for disabled people: it is the disability oppression" (Ilimo).

Although they did not articulate it as "oppression" ("ingcindezelo"), disabled people expressed some of the ways that they experienced being undermined and undervalued by other members of the community: "They do not take you as someone who is able to do an important thing in the community. You are taken as a useless thing. You are taken as someone who can never come up with useful things. You are nothing and you have a small brain".

There was also the recognition that disabled people are an oppressed group within an oppressed community: "The Amawoti area is oppressed and disabled people are more oppressed because there is no one who knows about their needs..." (Ilimo). Central to this is racial and economic oppression in that "We black people told ourselves that a lot of things are not our rights..." (Church), and "Poverty makes us believe that we are nothing" (Church). Such ingrained feelings of inadequacy and otherness have been referred to as *internalised* *oppression*, and is recognised as a major factor hindering people from asserting their rights and needs (Wright 1987).

(ii) Oppression by other disabled people

Oppression of disabled people by other disabled people was seen to be based on severity of disability: "There is what we call to be oppressed by another disabled person. There is one who has disabled legs and one who has a disabled hand. The one who has a disabled hand sees himself better than the one who has disabled legs" (Ilimo). Jagoe (1987 p.3), a disabled person herself apportions blame for divisions that exist between people with different disabilities. "Welfare, in splitting us off into different disabilities - supposedly to deal more effectively with specific problems - has in fact weakened us by denying our common barriers".

(iii) Oppression by the "elders"

Another facet of oppression was seen to be age-differences: "I see oppression because adults want to be respected and you end up not knowing what your rights are... In some cases you find an adult making high demands that one is not able to meet because he knows that he is older than you and you are not going to refuse" (Ilimo).

(iv) Gender oppression

Oppression of women by men was also observed to be present in the black community, and this was seen to have an impact on disabled people in Amawoti. "In the black culture a woman has no say to a man... it is oppression, it is a way of showing respect among the Zulus. A woman has less power than a man, and it will always be like that. A child has no power among the two people... It is a man on top, then a woman, and lastly the child... We even undermine them [disabled people] according to gender" (Ilimo).

(v) Oppression from other organisations

"When the Ilimo Project gives you points [advice], they will tell you that it is this and that. This is also oppression because your rights are in you. You are the one that must know what your needs are. No one can tell you about them. You are the one who knows" (Ilimo).

(vi) Parental oppression

"Maybe there should be training places where they teach parents of disabled children, because they are the ones who are oppressing their children. Sometimes you see a disabled child chained with a chain because he is disabled and locked inside the house whilst other children are playing. The mother doesn't care. Food will be brought to that child as if they are feeding a dog" (Ilimo).

Soder (1990 p.228) describes the "minority group perspective" in which people with disabilities are seen as an oppressed group in society, experiencing the same kind of oppression as other minority groups, such as women, or blacks in Europe. The focus is on the oppressive mechanisms and disabled people are seen as active participants in society who are capable of promoting alternative definitions of their status and situations. Adopting the conceptualisation of disabled people as an oppressed group implies the use of the social change model in relation to the struggle of disabled people, so as to challenge the oppressive and paternalistic structures prevalent in society (Curtis and Reier 1993).

(g) Exploitation

Of the three focus groups in which members felt that disabled people were exploited, two were female-dominated and one had equal representation of men and women. All were in the age group 25-44 years.

This view was expressed in different ways, initially applying to the family of the disabled person: "Sometimes for example, a mentally retarded person is getting a grant. Most probably 75% of that grant is being utilised by some members of the family, and 25% of it goes to food - clothing and that is not taken care of. So he is enjoying 25%, and the other 75% is for other kids and the family" (Nurses & police). "Children... get a disability grant, and parents enjoy the money on their own. Parents... depend on this disability grant" (Teachers). In this way the disabled person "is like a breadwinner. So it's a very hard life" (Nurses & police).

Some focus group participants felt that exploitation was also present in the wider community: "These [disabled] people are being exploited by the community. Like a person who is retarded - he or she will be pushed around to go and fetch water far away, probably for a slice of bread. This person must push a wheelbarrow to the water kiosk - and he's got to do this for the whole day. They are being exploited" (Nurses & police).

The caregivers group affirmed this view, but added to it an insight into the consequences of such exploitation. "What I have noticed about those who are mentally retarded is that they are being ill-treated. You find these people fetching water for other people without being paid. This means that this person is being made a slave because of what s/he is. They want his/her disability to be worse than what it is".

(h) Shame

Three focus groups, all female-dominated and within the 25-44 age group, expressed the opinion that disability was a source of shame and embarrassment in Amawoti.

"Most of the people in the community do not know the cause of disability and they sometimes hide their disabled children..." (Ilimo). "Other people are ashamed of having disabled people. They hide them in the house and do not give them the chance to go outside and live like other people" (Caregivers).

Goffman (1963) documents shame as being a feature of the stigmatised individual's experience within a society which has certain standards below which s/he is perceived to fall. Following Goffman's theory, for disabled people shame emerges from the individual's perceptions of his/her own disability as being a defiling thing to possess, and one that s/he can readily see him/herself as not possessing.

Two of the three groups that expressed this opinion, also articulated the view that disabled people are ridiculed by the community (5.2.5). It is likely that the experience and fear of ridicule contributed to the feelings of shame associated with disability.

It is significant that the feelings of shame associated with disability are articulated by the female-dominated focus groups. Goffman's analysis may be helpful in understanding this trend. He observes that very often a person who is related through the social structure to a stigmatised individual (in this case the disabled person) - is treated in some respects by the wider society "as one" with that individual. "Thus the loyal spouse of the mental patient, ... the parent of the cripple, the friend of the blind... are all obliged to share some of the discredit of the stigmatised person to whom they are related" (Goffman 1963 p.30). Perhaps it is this "sharing of the discredit" that is felt so keenly by the caregivers. For this and the other female-dominated groups that expressed the view that disability is a source of shame, it may indicate a greater sensitivity to some of the more emotional impacts of disability, than is evident from the male-dominated groups.

(i) Curiosity

Another view expressed in two of the focus groups was a curiosity that people have about disability: "You wonder what's wrong with him" (NPA workers). Open curiosity was seen in a negative light by one of the caregivers: "I always feel bad when I see a person standing looking [staring] at a disabled person. Sometimes if I see children in the street I take a stick and chase them away because by staring at him/her they are hurting his/her soul" (Caregivers p.2).

5.2.2 Reasons for this behaviour:

In addition to pursuing the issue of how disabled people are treated in Amawoti, the question was raised as to why negative attitudes persist and become entrenched. Some of the reasons for this is as follows:

(a) Lack of knowledge/ignorance

A major reason given for many of the dominant attitudes was that of ignorance: "Disabled people are more oppressed because there is no one who knows about their needs. Most of the people in the community do not know the cause of disability..." (Ilimo). "Looking down on each other might be caused by not knowing the needs of the [disabled] people...". "They [the people of Amawoti] do not help. The reason being that they were not taught. They do not know that a disabled person needs help. You only help the person you know. They need to be taught that a disabled person needs help" (Business).

Soder (1990) describes the "novel stimulus hypothesis" in which he asserts that, in interactions between disabled and able-bodied people, tensions emerge between the desire to explore a novel stimulus, and the fear of violating social norms. He suggests that avoidance responses from able-bodied people are not necessarily a result of devaluing the person with a disability because s/he possesses some stigma "but can be interpreted as a reaction to a novel stimulus in a specific social situation" (p.233).

Following Soder's analysis, it could be hypothesised that the ignorance of people in Amawoti about disability may be derived from the fear of violating social norms in relating to disabled people. Such fear may lead to avoidance of disabled people, which further perpetuates ignorance.

(b) Stereotypes about disability

Another factor contributing to negative attitudes towards disabled people are the stereotypes that exist about disability: "People tend to forget that their mind is not disabled. They do not think that they [disabled people] can make a valuable contribution in the community" (Ilimo). "It is like when a person gives birth to an abnormal child. The parent does not see the child as a person" (Civic).

It is clear that such attitudes towards disabled people are not unique to Amawoti, and Jagoe (1987 p.2) points out the consequences that may result from them.

> "There exist many stereotypes which have boxed disabled people into neat rather sub-human categories. These stereotypes define people with disabilities as passive, weak,

> helpless, unable to make decisions or take responsibility for themselves, overly sensitive, asexual etc. The saddest thing about stereotypes is that they have the potential to develop into self-fulfilling prophesies".

Such self-fulfilling prophesies were observed by staff of the Ilimo Project: "When a disabled person is with a normal person s/he tends to remain behind because s/he always tells him/herself that a normal person is given first preference".

The "labelling approach" has been used as a theoretical framework postulating attitudes towards disabled people as negative and prejudiced. In this perspective, which is inspired by symbolic interactionalism, disability is seen as socially created. "The negative attitude of others creates self-fulfilling prophecies where the living conditions in general and the self image of the person with the disability in particular are formed by the reactions of the environment" (Soder 1990 p.228). This approach has been greatly influenced by the work of theorists such as Goffman (1963) who conceptualised stigma as a devalued characteristic that creates negative reactions of others and tensions between the real and virtual identities of the stigmatised. This leads society to believe that the person with a stigma is "not quite human".

(c) Segregation of disabled people

The negative attitudes are entrenched by the separation between disabled people and other community members. These could be addressed by including disabled people in more community activities - a venture which would mean that "they do not look down upon each other because they are together" (Ilimo). The present system of separate schools for mentally disabled scholars which are distant from Amawoti make such integration difficult. In addition "schools in the community are already full" (Civic), a situation which means limited access for disabled children.

(d) Parental responses

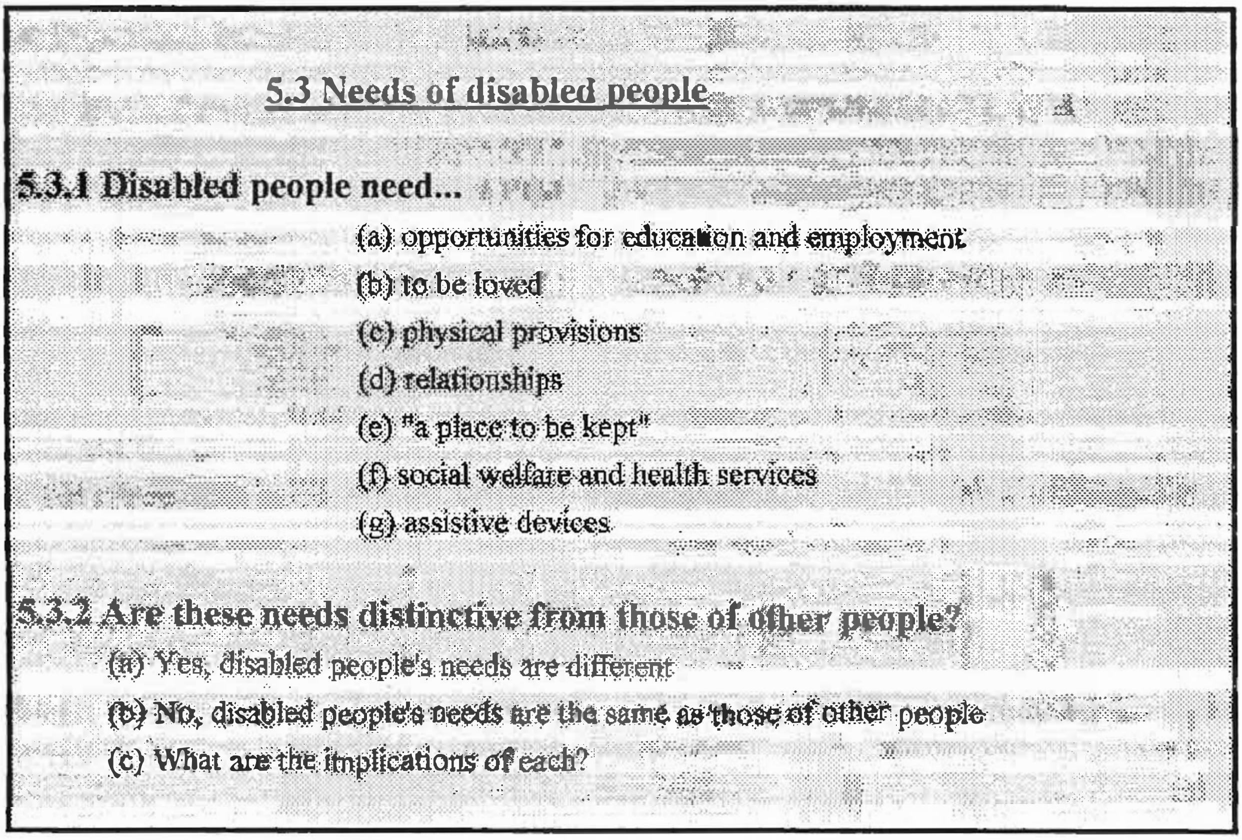
In exploring the "roots" of discrimination against disabled people, some focus group members felt that "It is very difficult for the community to accept them [disabled people] if they are discriminated against by their families" (Civic). This group also observed that "The parent does not see the [disabled] child as a person".

Such negative responses from parents may be the result of poverty: "...Some parents are poor, they do not have the means to care for the [disabled] person" (Civic). This may lead to rejection: "Some parents do not accept that [disabled] person as a gift from God" (Civic).

Lack of support and education for parents of disabled children may have tragic results: "People only know a little about how to care for a disabled child. Some people think of taking a bush knife to kill the child, because they do not know how to help him/her. The pain you feel about him/her makes you take wrong decisions" (Civic).

5.3 Needs of disabled people in Amawoti

Within the focus groups, the question was posed: "What do you think are the most important problems or needs of disabled people in Amawoti?" The responses indicated the major issues facing disabled people in the area, as perceived by focus group members. These fell into the following categories and are listed in order of most to least frequently cited across the groups.



5.3 Needs of disabled people

5.3.1 Disabled people need...

(a) opportunities for education and employment
(b) to be loved
(c) physical provisions
(d) relationships
(e) "a place to be kept"
(f) social welfare and health services
(g) assistive devices

5.3.2 Are these needs distinctive from those of other people?

(a) Yes, disabled people's needs are different
(b) No, disabled people's needs are the same as those of other people
(c) What are the implications of each?

5.3.1 Needs Identified

(a) Opportunities for education and employment

The most frequently expressed opinion was that disabled people need opportunities for constructive occupation - either schooling for children or employment for adults. The only groups that did not hold this view were the groups of the NPA workers, and the youth. This suggests a slight age bias in favour of older age groups (25-45+) for this opinion. No gender distinction was observed.

The need of disabled people for opportunities for education and employment was expressed, in different forms, by nine of the eleven focus groups interviewed. The importance of such opportunities is affirmed in a report prepared for the Convention for a Democratic South Africa (1992) by Disabled People South Africa (DPSA). Here it is pointed out that the Bill of Rights proposes that disabled people are included in programmes of affirmative action which "ensure that through education and training, financing programmes and employment, people develop and realise their natural talents and potential to the full" (DPSA 1992 p.8).

(i). Development of talents

The need for disabled people to develop their potential was articulated by several groups as it was recognised that "They've got talents that need to be exploited" (Nurses & police). There must be opportunity to nurture natural gifts and skills, so that they can be put to good use: "[Disabled people] need to be given a chance to use their talents and work in the community" (Ilimo). "They can do better - it's just that they need the opportunity" (Nurses & police). There was a general opinion expressed that the forum in which such potential could be tapped was the "community" of disabled people: "They can meet there and talk about being disabled, so that each one can show his/her talents. This shows that even if s/he is disabled, s/he can still do anything" (Civic).

(ii) Employment

The lack of employment opportunities for disabled people was highlighted: "To me the most important thing that adds to the disability is the shortage of jobs for disabled people" (Ilimo) or "unemployment" (Nurses & police). "The first problem they have is that they do not have a place to work" (Civic).

Groups saw the problem of unemployment as a direct consequence of disability. "S/he is not working because s/he is limited by his/her disability" (Church). The need for skills training was recognised: "We need to teach them to work and earn a living" (Business). "They can be taught to do things that can help to support themselves in the community" (Caregivers). "Like giving a disabled person a chance to use their hands and be allowed to work independently. Some of these people have been to school - they should be given clerical jobs in offices" (Ilimo).

The group of disabled people also discussed this issue - some members having had the painful experience of losing employment as a result of a disability in adulthood. This group identified unemployment and its resulting implications as dehumanising - "What it means is that I am no longer a human being". They noted that one should not have to lose opportunities for employment in factories or big business just because one has a disability, and there was a concern about getting access to appropriate employment opportunities: "We want disabled people to be placed where they can work". One option for this was seen as government-provided workshops.

The United Nations Commission on Human Rights and Disability (Despouy 1991) reports that internationally, unemployment is one of the main problems of disabled people. This document states that "the level of unemployment among disabled people is two or three times as high as for other persons, and in many developing countries where unemployment is very widespread, the employment prospects of disabled persons are minimal or non-existent" (p.46). This situation may lead people to resort to begging, or if they are employed, they may be forced to accept very low levels of pay.

More locally, Rowland (undated p.1) a disabled South African, makes the observation that "disabled people, perceived to be unproductive and difficult to integrate into the workforce, find themselves thrown upon the goodwill of employers and fellow workers". He argues that this is discriminatory and degrading, and advocates instead that employment of disabled people become a matter of human rights, to be secured by law. In concrete terms, Rowland proposes a quota system of employment for South Africa in which 2% of employees (in companies over 50 employees) are disabled.

(iii) Education

There was a recognition of the need to address the issue of education for disabled children. Groups realised that the existing schools do not cater adequately for disabled scholars. No schools catering specifically for disabled children exist in Amawoti so "We haven't got schools for them" (Nurses & police). Another problem recognised was that "Schools for disabled people are far away, and they end up leaving their families" (Ilimo).

Several groups recognised the need for education as applying to all children, including those with disabilities. "Disabled children can be catered for.. it is important that they get educated just like any other child" (Teachers). It was clear that this was not always easy to achieve - "The problem of a disabled child is a good education" (Business). At the same time there was the recognition that disabled children may have different needs to those of other children, and that "We need to give them... schools where they can learn... They need a school where they can be taught to use their hands" (Church). "If a disabled child cannot read or write, s/he can do something good - handwork, motor mechanics or bricklaying" (Teachers).

The United Nations World Programme of Action concerning Disabled Persons (UN 1983) stipulates that education should, as far as possible, be provided within the ordinary school system. However, there are often both attitudinal and physical (e.g. transport) barriers that prevent this from happening. (Despouy 1991). There is thus an urgent need for affirmative action in the education arena if the educational needs of disabled children are to be met.

Rowland (1986) brings attention to the educational needs of disabled adults - a dimension that was not referred to by the focus groups included in the study. He emphasises the need for life-long education, for education with a vocational emphasis, and for literacy programmes.

(iv) Occupation

In addition to the need for employment and education per se, several focus groups recognised the deep psychological need there is for constructive occupation for disabled people. "You see, if they are staying at home, their mother has left them at home, they are doing nothing" (Nurses & police). For those who are physically or mentally disabled, who are unemployed and isolated in their homes, there is often no structure to the day, nothing to get up for in the morning, no reason to dress or wash... "I decide to sleep, because there is nothing I can do" (Disabled). "What is nice is that... people who have been working, people who have been schooling... enjoy waking up early in the morning to be told they are going there. They go to work. They do what they are there for and their minds forget about disability" (Landowners). This was also recognised by the group of caregivers. "If they can be put together and have something to do, that will make them realise that there is no need to be ashamed of what they are".

(b) To Be Loved

> Another need that was noted by a large number of groups (eight out of eleven) was a psychological and emotional one.

There was the view that an important need of disabled people "is to be loved" (NPA workers).

(i) Love and care

For some of the focus group members, the concepts of love and care went hand-in-hand - "They [disabled people] cannot grow or develop because there is no one who takes care of them. They need to be loved and taken care of" (Ilimo). This love and care implies a dependency on other people in which "the most important need is to be helped whenever necessary" (NPA workers). Such love and care needed by disabled people is a far cry from the present situation in which "they lack support from the community" (Civic) and where "People don't care about them, they don't give them support and respect" (Youth).

(ii) Independence

There were, however, some focus groups that had different opinions about what a "loving response" to disabled people would be. These groups felt that disabled people not only need to be "loved and taken care of" but also need to "do things for themselves" (Ilimo). This is one way of challenging "the most important problem of the disabled people in the community [which] is oppression. They are not given their rights" (Ilimo). "A chance should be given to disabled people to sort out their own things, like applying for their pensions... They need to be taught to do things on their own, and to know their rights" (Ilimo). One element of this was the view that disabled people have the right to self-determination: "You are the one who must know what your needs are - no one can tell you about them" (Ilimo).

The notion of independence articulated by staff members of the Ilimo Project may be a reflection of the self-help ideology of a community development project. Its importance is also emphasised in the international literature on disability, as Despouy (1991 p.44) maintains that barriers and discrimination present within society create or aggravate disabilities and actually exclude people, often making them a burden to the community. "This demonstrates conclusively the importance of efforts to achieve the maximum degree of autonomy and independence for disabled persons, not only for their benefit, but for the benefit of society as a whole".

(iii) Recognition of humanity

Basic to the understanding that disabled people need love, is the recognition of their humanity: "They are human beings. They are people" (Civic). Not only do they need to be recognised as such by members of the community, but they themselves need to recognise it. "...They always see themselves as being different from other people. S/he sees him/herself as being a disabled person..." (Caregivers). Instead, "they need... to enjoy themselves and be able to see themselves as people who are the same as other people" (Church). The focus group of church leaders felt strongly that "we need to give them love". It is of note that this statement is personalised, but they go further, to state that such sentiments must be put into action. "It is nice to love each other. Besides love, we need to give them the kind of help that they need". Recognising that "the main problem is not having someone to look after him/her", the church leaders group suggested that "the community should do it like a mother... They can be able to help these people by taking care of them".

(iv) Encouragement

Another component of the psychological needs of disabled people is that of affirmation or encouragement. The teachers group gave an example of a disabled child who likes walking: "Even on the street you will hear him say we must not leave him behind... He likes to be taken out just like other people.... We as neighbours encourage him to do whatever he can do... I wish other disabled people could be seen as normal people and encouraged to do more than they think of..."

(c) Provision of basic physical needs

There was also a very clear understanding that disabled people require their basic physical needs to be met. No obvious gender or age biases were observed between the seven focus groups that recognised this as priority.

"The first problem of a disabled person is food, clothing and shelter" (Business). The civic group affirmed this and highlighted the present situation in which "Some of them do not have anything" (Civic), "- not even the food to eat" (Nurses & police). Within such poverty it is hardly surprising that personal hygiene is poor - the church leaders noted that there is a problem of "...dirtiness because s/he is not able to wash his/her clothes". Another problem observed was that "their living conditions are not good" (Church). Not only this, but homelessness of disabled people was noted: "Others do not even have a place to stay" (Caregivers).

The issue of housing was also identified by the focus group of disabled people. The main problem facing them in Amawoti "...is a home" (Disabled). It is most often lack of finance that disqualifies them from owing a home, but appropriateness and accessibility are also important factors (Rowland 1986).

In the focus groups there seemed to a recognition of Malinga's (1992 p.1) statement that "Disabled people are still the poorest of the poor, marginalised, still oppressed by malnutrition, preventable diseases, hunger and starvation..." In the context of Amawoti, disabled people could be seen as "the least advantaged of the disadvantaged groups" (Hammerman 1982 p.1).

(d) Relationships

Six focus groups highlighted the social needs of people with disabilities. There were no gender or age-biases that were observed between these groups.

(i) Personal relationships

Rowland (1986 p.4) notes that "The needs of mentally handicapped people for personal and social relationships, including sexual partnerships, are increasingly recognised". Certainly, there was an awareness of this need among some of the focus groups. One of the church leaders observed that "There is no one who spends time or visits him... There is no one who goes to him/her and plays with him/her".

Structured, organised activities may provide the forum for the establishment of such relationships as "They go to work. They do what they are there for and their mind forgets about their disability. S/he finds him/herself talking to other people... That is nice" (Landowners).

(ii) Organised action

The group of caregivers of disabled people strongly expressed the problem that "They [disabled people] are not together. They are scattered. Each of them looks at his/her own disability problem where s/he is and does not get a chance of meeting other disabled people to talk about their problems, so as to realise that they are the same as other human beings. They always see themselves as being different from other people". They identified the need for disabled people to organise themselves and act together: "If they can be put together and have something to do, that will make them realise that there is no need for them to be ashamed of what they are".

The civic group also recognised that "They need... sports... entertainment. They can meet there and talk about being disabled, so that each and every one can show his/her talents".

Goffman (1963), in his study on stigma and social identity, observes the trend of the stigmatised individual to link up with "sympathetic others" who recognise his/her humanity and normality. Such contact not only provides the opportunity to learn the "tricks of the trade" (such as coping with a disability), but also provides moral support and comfort. Such organising also provides the base for co-operative action around issues that are of concern to the stigmatised group.

(iii) Family structure

Another dimension of the social needs of disabled people that was alluded to by two of the focus groups was that of a family structure. The group of nurses and police observed the family breakdown which they saw to be typical of the peri-urban shack communities such as Amawoti. They pointed out that a symptom of this is evident in that: "Even the children - you find stranded children here".

In their understanding of this occurrence, the group of disabled people attributed family breakdown to the conditions of extreme poverty. These could become so severe that "Even the wife runs away when things are like this".

(e) "A place to be kept"

Six of the focus groups expressed the opinion that disabled people need "a place to be kept"

This view seemed to emerge from the recognition that life within the community of Amawoti is not easy for disabled people. "If you see him/her among other people in the community, you even ask whether there isn't a place where this person can be kept. S/he is... living in a place that is not suitable for him/her" (Church). "They need places where they can be looked after and taken care of" (Church). "They need a place where they can be kept, rather than being kept at home" (Business).

For some groups, there was simply the acknowledgement that such facilities do not exist, but the alluding to them suggested that if they did exist, they would solve the problems of disabled people in Amawoti. "...a [disabled] adult must stay at home. We haven't got places to take him/her to and keep him/her there for special care" (Nurses & police). "That is our problem: we have got some cripples here - but we haven't got a place to keep them... Some relatives can't go to work...because there's no place to keep them" (Nurses & police).

This appeared to be an expression of a problem or need, rather than a thought-through solution for disabled people. The group of teachers observed one disadvantage - that "Placement in places of safety may mean that the family loses the disability grant" (Teachers). There are in fact many implications of institutionalisation of disabled people, in addition to financial ones:

> "Many disabled people are kept in isolation from the rest of society in so-called special institutions. This often results in them finding it difficult to keep abreast with developments in the broader society and become socially disorientated.

> Institutionalisation of this nature does not always contribute to effective rehabilitation, in fact, permanent psychological and physical impairment sometimes results. This practice also has the effect of aggravating prejudices against disabled people in our society" (DPSA 1992 p.10).

Jagoe (1987 p.2) refers to this as the "charity/welfare" approach, in which the concept of "looking after" predominates:

> "While there is no doubt that a place which offers food, beds, some sort of activity and safety to people who have never had any, is a great advancement, they were nevertheless "dumping grounds" which served to get and keep the problem out of sight. The only reminder society had of their existence was now the more respectable, acceptable member of society, "begging" on street corners on their behalf. The tacit agreement: give us money and we'll look after them for you and keep the burden on society in manageable confined institutions. The "able-bodied" become custodians, caretakers of those too horrid, too frightening, too burdensome to contemplate."

For the group of caregivers the provision of a physical structure did not necessarily imply institutionalisation, but was symbolic of the need for disabled people to come together: "It was going to be better if they had a place to meet or a place they can be kept together and do something, because they are also human beings".

(f) Social welfare and health services

> There was a recognition by five of the focus groups that people with disabilities require access to resources of social welfare, as well as to appropriate health care services.

The group of caregivers noted that a disabled person "does not get help related to his/her disability problem". This may be due to the lack of resources and services in Amawoti: "Such people [social workers] are needed in this area" (Landowners) This focus group expected social workers to be able to assess the needs of disabled people, to assist them with food parcels and to help resolve problems of pensions.

Disability grants were also highlighted as an area of need for disabled people in Amawoti. Not only were there difficulties observed in the application for them, but also in their ongoing receipt. "Sometimes people are not paid for a number of months... And they have a problem about where to go for their review, because all reviews need to be seen by doctors" (Nurses & police). The group of disabled people also discussed the problems of disability grants - making strongly the point that the amount received is minimal, and not sufficient to live on (Disabled).

Two groups, both of government employees, (Nurses & police, and NPA workers), identified the need for medical care for disabled people. They noted that at present there is "improper medical care" (Nurses & police) but "The most important need is for care - medical care is number one" (NPA workers).

The group of nurses and police also noted the lack of accessibility and knowledge of services, such as the district surgeon. "Even if you want to refer a person, you don't know where to refer them". It is a problem of "not knowing where to send them".

It seems ironic that while the NPA workers' focus group members stated that disabled people "need to be helped whenever necessary" - resources of the Nationalist government have been both inadequate and inaccessible! The apartheid policies on health and welfare, and the inequity which the black sector of the population has had to endure has led to the situation in which the peri-urban communities have had the least access to minimal resources.

(g) Assistive devices

The assistive devices required by physically disabled people were highlighted as needs by three focus groups.

"What they need is wheelchairs and hearing aids for those who are deaf" (Civic). "There is a lack of equipment like wheelchairs and crutches" (Nurses & police). "Things like wheelchairs and crutches help them to be independent. They don't get these things because they live in Amawoti" (Ilimo).

The question of provision of these assistive devices is an important one - but needs to go beyond provision and deal with accessibility. Of what use is a wheelchair if roads and paths are not accessible? How will hearing aids be maintained if batteries are not readily available? Rowland (1986 p.4) points out that "Many disabled people are excluded from active participation in society because of doorways that are too narrow for wheelchairs; steps that cannot be mounted leading to buildings, buses, trains....; oral communication which ignores the needs of people with hearing difficulties and written information which ignores the needs of the visually disabled."

5.3.2 Distinctiveness of Needs

When discussing the needs of disabled people in the focus groups, there was also exploration of perceptions concerning the "differentness" of these needs, in comparison to able-bodied people.

Six of the ten groups that discussed the issue, felt that needs were simultaneously the same and different. Two groups indicated (only) that they were the same, and two (only) that they were different. There appeared to be a slight gender bias in that more male-dominated (3) than female-dominated (2) groups maintained that the needs of disabled people were different to those of the able-bodied. At the same time, more female-dominated (3) than male-dominated (2) groups perceived that the needs were the same.

(a) Needs are different

(i) Needs are greater

There was a perception that the needs of disabled people are different to those of the able-bodied simply because they are greater. "The needs of disabled people are greater than the needs of normal people. For example, take two children, one disabled and one normal. The disabled child needs more love than the normal child" (Ilimo). This sentiment was affirmed by the business owners group: "The disabled person needs more care and help and comfort than a normal person".

The group of disabled people felt this very strongly. "Our needs are not the same because a disabled person cannot be able to do the things done by a normal person...Your needs [as an able-bodied person] are very little". This group expressed their frustration at the difficulty of disabled people in being able to secure employment, food, housing and disability grants. There was also the recognition that disabled people in Amawoti suffer more than others in the area when there are shortages of water, as they cannot walk long distances to a neighbouring area to collect it (Ilimo).

(ii) Special care

There were some groups that felt that "Disabled people may also need special care - which is different from able-bodied people" (NPA workers, Youth). These "different needs" were identified as being "...a wheelchair, and walking sticks", and in education "some may need sign language or Braille" (Teachers).

(b) Needs are the same

The recognition that needs of disabled people are the same as able-bodied people came out of a conviction of a shared humanity: "I'll say your [as a disabled person] needs are the same as mine, because you are also a human being" (Nurses & police).

There was the recognition that some things are universal: "We all know that everybody needs help. We all have our own needs" (Ilimo). Basic needs are required by everyone (NPA workers). "Your need is money also, and I need money, so our needs are the same" (Nurses & police).

The group of caregivers felt strongly that needs were the same - they appeared to feel that if disabled people were treated differently they were being dehumanised: "They are the same because s/he needs all that I also need - like clothing or body lotions... food... money. All this means that his/her needs are the same as your needs" (Caregivers). "For example - a mentally retarded person. You find him/her dirty. That is not supposed to be happening. S/he is the same as other people. It is just that s/he is disabled. Therefore there is the need for him/her to be helped so as to look like other people" (Caregivers). These sentiments were echoed by the teachers group: "A disabled person needs to wash, eat, be clothed, be loved, be educated - and these are the needs of every person. These needs are created by God, so everyone deserves them..."

For the majority of groups, it was not possible to give a simple answer as to whether needs of disabled people are the same or different to those of the able-bodied. The Ilimo staff put it thus: "Disabled people have the same needs as normal people although there are differences here and there. A disabled person will need something to help in his disability, but their needs are the same as our needs. We all need money and clothing..."

(c) Implications of the perceptions of needs

The perceptions of the needs of disabled people, including the extent to which they are distinctive to those of the able-bodied, have important implications for the way that interventions are conceptualised. Firstly, if needs are perceived primarily as being different, it would follow that "special" schools would need to be provided to cater for disabled children. Adults would need "a place for them to be kept", apart from other members of the community. In the past, this view has led to the establishment of institutions and sheltered workshops for disabled people. Because a person with a disability "is not like me" (Business), that person has different needs (Business), s/he requires a different set of facilities and services.

Secondly, there was the perception by some focus group members that the needs of disabled and able-bodied people are the same. If this is so, the emphasis would be on improving accessibility of services that are needed by all members of the community - such as water or transport. The experience of disabled people that "The needs are the same, but it is difficult to get ours" emphasises the importance of ensuring that disabled people are integrated into community life, and that the principles of love and justice are applied without discrimination. For example, this implies that the work of the Ilimo Project as a community development project needs to address issues of development as they pertain to disabled people.

Finally, if needs of disabled and able-bodied people are simultaneously the same and different, society will need fundamentally to recognise the humanity of disabled people. This will mean catering for differences (such as use of a wheelchair), without the label of stigma. It will also mean recognition of the value of differentness in enriching society.

5.4 Rights of Disabled People

Exploration of the perceptions of the focus groups of "influence leaders" about rights of disabled people purposely followed the question raised about needs. This sequence was an attempt to counter the single-minded assumption that disabled people are "people in need." As one focus group member pointed out "disabled people also need human rights" (Teachers).

The debate on human rights in general, and disability rights in particular is very pertinent to the present political situation in South Africa. The international disability rights movement gained momentum in the early eighties with the establishment of Disabled People's International, an organisation of disabled people which was set up in opposition to the professional-dominated Rehabilitation International. In 1984 Disabled People South Africa (DPSA) was established. The disability rights movement, both local and international, is working towards the goal of equal opportunities and the full participation of disabled people in society (Jagoe 1987).

The history of the struggle for liberation for black people of South Africa is well documented, and currently the vision for a "new and democratic South Africa" is struggling to come to fruition. It is significant that the Freedom Charter, a human rights declaration, has been a key document in this process (van der Westhuizen 1991). This discussion of rights of disabled poor people living in Amawoti should be viewed within the wider struggle of the majority of the black population of South Africa to secure their rights.

The following description of perceptions of focus group members of rights of disabled people in Amawoti is not arranged in order of frequency, as previous sections have been. Rather, it is an attempt to organise some of the ideas expressed, in a way that is consistent with a framework emerging from the literature. Frequency of expression was not so much at issue here as the groups which held certain opinions. No gender differences were noted, but age differences were significant between the groups.

5.4 Rights of disabled people

5.4.1 These are...

(a) social and economic rights
(b) civil rights
(c) the right to integration
(d) the right to independent action
(e) disability rights

5.4.2 Those who should advocate for these rights are...

- others, on behalf of disabled people
- disabled people themselves

5.4.3 These rights should be secured...

- by waiting for the goodwill of others
- through pro-active campaigns

5.4.1 Various rights of disabled people

Youth asserted that disability should not be a factor excluding people from having rights: "It does not mean that because you are disabled, you no longer have rights about your life". The principle that *all* people, by virtue of their humanity, are entitled to human rights, is affirmed by the United Nations in the Declaration of the Rights of Disabled Persons (1975), which states that "Disabled persons have the inherent right to respect for their human dignity. Disabled persons, whatever the origin, nature and seriousness of their handicaps and disabilities, have the same fundamental rights as their fellow-citizens of the same age, which implies first and foremost the right to enjoy a decent life, as normal and full as possible".

Some specific rights were identified by the focus groups:

(a) Social and economic rights

Included in the recognition of social and economic rights of people with disabilities, was their right to *education*. For some of the focus groups, this implied the provision of special schools for disabled children. Whatever form this right takes, DPSA (1992 p.10&11) emphasises that:

> "The role of education in the development of the disabled child cannot be underestimated... The right to education for all cannot be reached if the educational needs of disabled children are not met. The environment should be conducive to the child's development and ensure integration.".

Secondly, the right to *employment* was identified (Landowners, Teachers, Caregivers and Disabled).

> "Disabled people have the right to economic and social security and to a decent level of living. They have the right, according to their capabilities, to secure and retain employment or to engage in a useful, productive and remunerative occupation and to join trade unions" (UN Declaration on the Rights of Disabled Person 1975).

This is one issue that has specifically been addressed in the draft Bill of Rights drawn up by the ANC (1991) which is currently under discussion. "Legislation shall provide for measures to promote the progressive opening up of employment opportunities for disabled men and women..." (Article 8).

Closely linked to this, is the right to accessible *transport* (Church), a service so important that it has been referred to as the "linchpin which enables people with disabilities to be integrated and mainstreamed into society... [it is] the key to opening up education, employment, recreation..." (quoted in Cook 1991 p.420).

The right to *social security* was also highlighted by several of the focus groups: "All disabled people should have a right to the state fund, to be provided with food, clothing, and shelter" (Business). For the groups of caregivers and disabled people, this was seen to take the form of disability grants. Disabled People South Africa recognises the difficulties that disabled people have in securing this right: "Many disabled people...have had to try and survive under conditions of extreme poverty, where services are negligible and a punitive welfare system acts to retard any form of state assistance. The struggle of disabled people in South Africa, is therefore primarily a struggle for basic human rights, particularly socio-economic rights which have been denied them for so long" (DPSA 1992 p.5).

The focus group of teachers felt that disabled people have the right to *protection*. This they saw as taking two forms: the protection by the government through the provision of appropriate services, and protection by the community from exploitation. This view is affirmed by the UN (1975), which states that "disabled people shall be protected against all exploitation, all regulations and all treatment of a discriminatory, abusive or degrading nature".

There was also the view expressed that disabled people have the right to *legal marriages* (Caregivers). Such legal recognition of a marital union needs to be accompanied by society's recognition and acceptance of it (Despouy 1991).

(b) Civil rights

The focus group of teachers expressed the opinion, that like all other people, those with disabilities have the right to vote. Certainly, this is in line with the UN's statement (1975) that "disabled persons have the same civil and political rights as other human beings". The fact that the majority of the population of South Africa has been denied the right to vote, confirms that the struggle of disabled people for human rights is part of the wider struggle against oppression in the country.

(c) The right to integration

Several of the focus groups recognised that disabled people have a right to be part of the community. However, the many barriers to this became obvious: "We are supposed not to discriminate against them - we must come together and mix with them" (Civic). "They will never get [their rights] if we despise them... We should stop using the word "cripple"" (Landowners). The landowners suggested that treating disabled and able-bodied people in the same way would help to make the former "feel free".

The Special Rapporteur of the United Nations Commission on Human Rights and Disability (1991) observed that "[disabled] persons frequently live in deplorable conditions, owing to the presence of physical and social barriers which prevent their integration and full participation in the community. As a result, millions of children and adults throughout the world are segregated and deprived of virtually all their rights, and lead a wretched, marginal life" (Despouy 1991 p.1).

One focus group felt that to ensure this integration, there should be no "special rights" for disabled people, as this would separate disabled people from the community. "You'll be saying "you're not like us", but we should judge them as equal and normal" (Nurses & police). This comment raises questions about the issue of affirmative action.

(d) The right to independent action

One focus group expressed strongly the opinion that disabled people "should be given rights to do things for themselves" (Ilimo). This implies that "they should be taught to do things on their own, and know their rights" (Ilimo). It also means that "people have the right to meet and discuss their problems, and they can go to someone who will come up with a solution if they can't resolve it" (Youth).

Staff of the Ilimo Project observed the danger that [non-disabled] people tell disabled people that their rights are "this and that. That is also oppression because your rights are in you. You are the one that must know what your needs are". This recognition, that disabled people (through organisational structures) are "experts in their own affairs", is certainly affirmed in the international arena, and has even been described as "one of the most notable features of the Decade [of Disabled Persons 1982-1992]" (Despouy 1991 p.52).

(e) "Different" Disability rights

In the discussion about disability rights, some focus groups felt that "disabled people do have rights which are not the same as normal people" (Church). For example, they have the right to special facilities where necessary (e.g. hospitals) (Youth). In addition, "there are certain privileges they should be entitled to - like ramps and buildings and transport. They must be taken as normal people" (Nurses & police).

The view that "disabled persons also have specific rights" is also held by the UN Special Rapporteur (Despouy 1991 p.18), who places such rights in context. "These rights do not appear in any formal listing but are scattered throughout a number of legal instruments, or have been recognised by the courts. In fact, what might be termed the specific rights of disabled persons are only the material and legal expression of the minimum contribution which the community or State should make towards ensuring that such persons can enjoy on an equal basis all the human rights enjoyed by individuals in general. Strictly speaking, this is not even what is known in legal terms as "positive discrimination" (affirmative action) but simply equalisation".

5.4.2 Those who should advocate for rights

Opinions between focus groups were divided as to who was responsible for lobbying and demanding rights of disabled people. One group felt that it would "be better if the community meets and talks on their behalf" (Church). "I think it is better if we talk on their behalf because to be disabled is not a nice thing. It is unfair for them to do it themselves because there are people who are there to help them" (Business). This group felt that there is a need to create a feeling of pity from the public - and in doing so, one should not be demanding: "We should talk on their behalf. They should not do it themselves... They can have their own rights if people talk on their behalf" (Landowners). This view - that perpetuation of the image of disabled people as helpless and pitiful would be most profitable to them - tended to be held by focus groups consisting of older people, in the 35-44 and 44+ age brackets.

A different opinion was held by those who felt that disabled people should speak for themselves. "They have a right to speak if something goes wrong in places of employment... They must fight for their right to be employed or educated, and to show the community that they are there" (Teachers). This indicates the need for disabled people to raise their profile, as a strategy for protection of their rights.

Disabled people themselves felt that they "need to make their needs known to the government". By doing so it "will make the government realise that there are a lot of disabled people (Caregivers), and "the government can become scared and feel pity if it sees the numbers of disabled people. They can think differently" (Disabled). While there may be some naiveté about the government's reasons for denial of rights to disabled people, and the response to demands, the principle of taking action on one's own behalf is evident. This principle one long advocated by Disabled People International in it's philosophy of activism (Rowland 1992).

DPSA (1992 p.6), in its proposal to Convention for a Democratic South Africa, outlines the fundamental rights of disabled people in a new dispensation: "the right to speak for ourselves and represent ourselves at all levels of decision-making". This would provide the forum for disabled people to advocate for their own rights and to influence decision-making in government and all sectors of society. Already this process has begun to be implemented by the work of organisations of disabled persons.

5.4.3 Action taken to secure rights

There were different views expressed about how the rights of disabled people could be secured. Some felt that demanding rights in an aggressive way (such as through a street march) would be self-defeating: "Some of the people may not like it because they are paid by the government. They are given... food parcels and clothing" (Landowners). In other words - how can we complain against the apartheid government - even the little we have may be taken away? This tended to be a view of the older age groups (of 45+ years) that participated in the focus groups.

The youth (12-24 years) expressed a very different opinion: "You will never get what you want if you don't try means of getting it. You need to do something... A disabled person should fight for his/her rights - s/he is also a person who lives on this earth, who has blood and feelings like all other people". Disabled people themselves agreed with this, "We need to ask for them [rights]".

The recognition that disabled people cannot wait on the sidelines for the goodwill of the government, or of service providers, has been a driving force in the local disability rights movement. "Already disabled people in South Africa have developed a strong movement which is aimed at ensuring the enforcement of equality legislation and the equalisation of opportunities" (DPSA 1992 p.3). This, in turn, is part of the struggle of the wider international disability rights movement to secure human rights.

5.5 Interventions to improve the situation of disabled people in Amawoti

The final question posed in the focus groups was about interventions that could improve the situation of disabled people. There were three categories that groups were asked to comment on, in terms of their roles in these interventions. These were:

- the *community* (people living in the area of Amawoti, and civic leadership structures);
- the *organisation of disabled people and their families* (Amawoti Disabled People's Association), and
- *specific groups* (those that participated in the focus groups).

5.5 [illegible]

5.5.1 The roles of residents and civic are...

(a) education of people in the area about disability
(b) provision of physical structures
(c) showing care and concern
(d) supporting the disabled people's organisation
(e) fund-raising

5.5.2 The roles of the disabled people's organisation are...

(a) raising awareness about disability
(b) providing resources

5.5.3 The roles of interest groups are...

(a) liaison with the disabled people's organisation
(b) fund-raising
(c) challenging negative attitudes towards disabled people
(d) education of people in the area about disability

5.5.1 The roles of residents and civic leaders of Amawoti:

There were no gender or age distinctions observed between the focus groups' perceptions of the following roles that could be played by residents and civic leaders in improving the situation of disabled people in Amawoti.

(a) Education

Nine of the eleven focus groups interviewed expressed the view that the community has an important role to play in education - this implies both education of community members about disability issues, and education of disabled people themselves.

(i) Education of residents of Amawoti

The role of education was recognised as being an important instrument for changing of attitudes towards disabled people in Amawoti. This awareness-raising was seen to have to be necessary in a number of different ways, both spoken and demonstrative, and its goal is the acceptance or integration by residents of the community of its members with disabilities. "...we must preach about people who are disabled , and ways we can use to help disabled people who are oppressed, so that they can say words which can be accepted by the community" (Civic).

It was felt that education was fundamentally important to changing of attitudes and behaviour towards disabled people. "I think the community needs to be taught. Once the community is educated, from there, it's going to be easy ... to accept, to feel that these [disabled] people are also human beings, and treat them like human beings, no matter how disabled a person is" (Nurses & police). Despouy (1991 p.69), in addressing the issue of discrimination and prejudices often directed against disabled people, affirms the need to "undertake and develop activities for the entire community, aimed at a genuine raising of awareness that will produce profound changes in attitude."

What "disability education" is required by people in Amawoti? Members of the focus groups expressed the need for people to know more about *disabled people* in the area. This would include knowing about their living conditions (Youth) - such as how a three-year old child with spastic quadriplegia is cared for by his/her family, or how a wheelchair user copes with housework. What is the life of a disabled person like? This approach could be seen as problem-centred learning, based on the realities of life for disabled people, and not only theoretical frameworks of knowledge. The UN Special Rapporteur on Human Rights and Disability is helpful in specifying the content of this education, which "should stress human needs, especially those that are as yet unmet, the specific rights that disabled persons should be recognised as having, and the need to respect them" (Despouy 1991 p.69).

Part of the education of community members includes addressing the question "What do we look like in relation to issues of disability?" There may be many ways of answering this question. For example, a *community meeting* could be called in which there is *discussion* about different diseases causing disability. Afterwards, people may be asked how they feel about the way disabled people are treated (Landowners). Another approach could be that residents of Amawoti work in consultation with members of the organisation of disabled people to do *research* on disability - determining the prevalence of disabilities and the geographical location of disabled people living in the area, "...in order that the community get in touch with them in the future" (Teachers). While there is the recognition that research is an important tool for collecting information, it is not done in isolation, there is accountability, and an awareness of who it is being done for, and who will benefit from it. The findings of such research are reported back in an accessible way to those that they concern, so that they may be used to inform further action.

(ii) Education of disabled people

The need for *vocational skills training* for disabled people in Amawoti was recognised (Ilimo). As unskilled labourers, disabled people cannot compete in the open labour market with able-bodied people in the area, for example as domestic workers or sugar-cane cutters. The need for appropriate skills, adapted to each disability, was emphasised (Disabled) and such skills were seen as a potential source of income (Business).

A different but essential component of education of disabled people in Amawoti is the provision of "adequate information of the means and services available for persons with disabilities and on their specific rights, in order for them to make full use of them..." (Despouy 1991 p.69). It was suggested by one focus group that the community set up committees of disabled people in sub-areas of Amawoti, which have as their responsibility "to teach disabled people about possible resources and sources of help" (Ilimo).

(iii) Education of families and caregivers

Another group whose educational needs must be addressed are the families and caregivers of disabled people. It was recognised that they too need the support of knowing the causes of different disabilities and how to manually handle specific conditions - such as a child with spastic diplegia. It was felt that as parents and families learn to cope with disability, their attitudes would change (Ilimo). Recognition of the key role that women play in the well-being of families (Shah 1992), such education would need to be geared particularly to women in the area.

Finally, there is the need for education of all members of the community, both disabled and able-bodied to stress "the objective contributions of disabled persons to the community, and the benefits, both spiritual and material, that the integration and full participation of disabled persons in social life will bring the community" (Despouy 1991 p.69).

(b) Provision of physical structures and services

Eight of the focus groups felt that the members and leadership of Amawoti should take some responsibility for the provision of physical structures and services required by disabled people.

The problem up to the present has been both a *lack of provision* of services by the Nationalist government, and a *lack of accessibility* to services that may be available in other areas adjacent to Amawoti. For example, the apartheid government discriminated against the black community in terms of expenditure on education. "When it comes to schools it is just that the government does not give us money" (Ilimo).

(i) What are the expectations?

In the discussion on interventions by people living in Amawoti, and by the leadership structures, there was more emphasis on what was needed, or lacking, than on who was responsible for providing it. For example, the group of disabled people said, "We would like the community to come together and build *workshops* ...for us", but did not discuss how an impoverished community could take responsibility for providing this or any other resources.

The dirth of *educational facilities* was recognised both in terms of crèches and schools (Youth, Disabled). In elaborating on this, it was felt that the schools provided should not only be for disabled people, but for all community members. Such a facility should provide vocational and practical training, and cater for both adults and children (Disabled). There was a recognition of the value of integration of disabled and able-bodied children in education. "You find that these children do not look down upon each other because they are together. There is no need for a lot of schools. The government should just increase the number of remedial teachers which is something that is not available to black people" (Ilimo). The need for wheelchair accessibility was also noted by this group.

Other needs highlighted were *medical services* (Disabled, Youth) and *housing* (Church). The group of caregivers felt that community members and leadership should provide a place where disabled people could meet together. However, there was no consensus on what form this should take: some felt that is should be a day care centre, while the disabled people continued to live with their families. Others felt that residential care was preferable - justifying this by saying that "there is unrest in our area. They can be kept safe if they can be kept in their own place" (Caregivers).

(ii) How can these expectations be met?

The group of caregivers suggested that *a fund or trust* be set up, which "can help towards the building of their schools or places where they can be able to meet and do something with their hands or anything they can be able to do".

(iii) The role of civics

How realistic are these expectations of the different focus groups? Is a trust fund for disabled people set up in Amawoti going to be able to cover the costs of building workshops or centres for disabled people? The group of civic members recognised that "We do not have money... but we are willing to help in all departments".

Part of the role of the leadership of Amawoti is *lobbying with government structures* outside the community. It is significant that this role was recognised by the NPA workers, themselves government employees, but not by any of the groups of community members. The state employees realised that their own ideas could not be strongly motivated within the state structures, "But to carry weight, it must come from the community... If the community has any ideas, you must let them come to the nearest authority, and then we will pass them on to a higher authority".

In the present context of South Africa, civics are playing an important role as the link between local communities and local authorities. They may be involved in developing creative responses to crises - such as that of education of disabled children. "Can we find another alternative, so that we can try to do something to help them reach those distant schools, while nearby schools are being built, because the government is not yet doing this" (Civic). In this case the role of civic structures may be to negotiate with principals of schools concerning admission policies or quota systems for disabled scholars. The issues of transport and recruitment of appropriate teachers will also need to be addressed (Civic).

(iv) Whose responsibility?

Within the focus groups the opinion was expressed that community members and leadership of Amawoti should take responsibility for provision of services for disabled people. Is this response simply a reaction to the fact that the state, up to the present, has failed to provide such services? Certainly, the civic structures admit that they do not have resources with which to provide such services, but could play a role in lobbying around issues in order to secure them. But who ultimately bears responsibility?

In the Statement on Equalisation of Opportunities issued by Disabled People International (Driedger & Enns 1987), disabled people are seen as giving direction to change aimed at their full participation in society, but "They are not necessarily responsible for ensuring that the change is in fact implemented" (p.16). This document clearly holds governments as responsible for the implementation of the World Programme of Action Concerning Disabled People (UN 1983), the aim of which is to promote effective measures for prevention of disability, rehabilitation and the realisation of the goals of "full participation" of disabled persons in social life and development, and of "equality".

> "... the principle obligation to remove obstacles impeding or hindering the integration and full participation of disabled persons lies with Governments. This means that they cannot be mere onlookers; they must act, sometimes with great vigour, and especially in difficult situations, in order to prevent marginalisation and to ensure equal opportunities is not just rhetoric but real and effective" (Despouy 1991 p.52).

(c) Showing care and concern

Six of the focus groups expressed the view that the situation of disabled people in Amawoti could be improved if residents and leadership in the area were to become more caring and helpful towards people with disabilities. It is of interest that this view was not held by disabled people themselves or by the group of caregivers that participated in the study.

(i) Caring

It was felt that community members should take an active part in providing for the needs of disabled people (Youth). This involvement may be sacrificial to those involved: "The community needs to volunteer to look after them [disabled people] without being paid" (Teachers).

Wright (1987 p.8) observes that "The first step in the demolition of prejudice is paying attention." Attentiveness and respect enable people to become aware of the needs of others. They then also begin to recognise how these needs can be addressed in a humane way - so as to bring relief to those who are suffering (Landowners).

(ii) Recognition of humanity

What could be the motivation behind such action? The African spirit of "ubuntu", or recognition of the humanity of all people, could go a long way to promote a spirit of tolerance and acceptance of disabled people within Amawoti (Nurses & police). The affirmation of a shared humanity, a concept central to culture in Amawoti, could provide the basis on which affirmative attitudes and practices towards disabled people are built.

Practically, integration of disabled people into the community could be promoted by the addressing of common needs together. For example, all people in Amawoti have the need for water: "I feel that in such needs normal and disabled people should come together and help each other" (Ilimo).

(iii) Organising

If the community is to address the issue of disability as a priority, this has to happen in a systematic, orderly way, as any other issue (such as health or education) is addressed (Youth, Business). This itself is an integrative approach, in that it addresses disability, not in separatist mode, but using the same principles that apply to other issues impacting on the community of Amawoti. For example, as there is a health committee in the area, making sure that health issues are on the agenda of community members and leadership, so there is a committee of disabled people, doing the same with disability issues.

(d) Supporting the organisation of disabled people

Four focus groups felt that an important role was to be played by community members and leaders in setting up and working with organisational structures representing disabled people.

(i) Organisational structures

Two groups (Civic & Ilimo) discussed in depth the need to set up community structures on which disabled people would be represented. One suggestion was that each sub-area of Amawoti have its own committee representing disabled people in that area. This idea was extended with the suggestion that a local civic member be included on each of these committees, so that s/he could report back to civic on the activities of the committee. Such involvement in community leadership structures was seen to be a strategy towards integration of disabled people. "At the end the disabled people will find themselves being members of the civic committee. The members of the civic committee should not always be normal people" (Ilimo).

(ii) People, not buildings

In recognising the limitations of provision of physical structures for disabled people, the group of civic members felt that there were other more important priorities: "It is not important to establish offices for disabled people all over the Amawoti area. That will not improve their future. What is important is to give them ways of developing themselves, that will help them in their problems". One way of realising this vision was to "promote people, and establish committees [of disabled people] or else of parents of disabled people - so that *there will be a movement*" (Civic).

It is significant that this observation, made at the local community level parallels a very important development at the international level, for it was the struggle for self-representation that was a factor leading to the birth of the international disability rights movement (Driedger 1989). More locally, in its recommendations to the Convention for a Democratic South Africa, DPSA (1992 p.6) affirms the right of disabled people "to speak for ourselves and represent ourselves at all levels of decision-making". In fact, this move goes beyond national borders, for "all over the world, disabled people have started to unite in organisations as advocates for their own rights to influence decision-makers in governments and in all sectors of society" (UN 1983).

(iii) Co-operative action

There was recognition of the value of community members co-operating with the organisation of disabled people for specific projects or activities. One example (Teachers) was in doing research - if the organisation wanted to gather more information about disabled people, residents in the area were likely to co-operate if they had been consulted and were involved in the outcome of the study. The issue of accountability is brought into question here - is the organisation of disabled people in Amawoti accountable to the local community, or to other disability organisations? What does it mean for an organisation of disabled people to be "community-based"?

Fairly extensive exposure to the literature has revealed a tendency for organisations of disabled people to concentrate more on building links between themselves (regionally, nationally and internationally) than on building relationships with the communities in which they are based. While both are essential, the latter has tended to be neglected. That its importance was recognised by some of the focus groups included in the study is significant, as the link between the organisation of disabled people and local community structures is seen to be a crucial part of the struggle for integration.

(e) Fund-raising

Four focus groups felt that an important intervention that could be made by the community would be raising funds to support the work of disabled people. Such support could take two forms - either directly, through donations, or by support of the businesses run by disabled people.

The caregivers also felt that setting up of a "Disability Scheme" or "Fund" would be an important contribution that could be made by the community in support of disabled people. "The community needs to form a fund so that they can be able to add where there is a shortage. When it comes to money, it is very difficult if money is not there..." (Church). Another group felt that community members could ask for donations - perhaps from big business in the area, in cash or kind (Business).

The question may be asked again: whose responsibility is it? Here it applies to the funding of organisations of disabled people. Is it realistic to expect such organisations to be self-sufficient financially? Should one work towards this goal? Is it the responsibility of local residents to support such a group? What is the role of the state? The UN Special Rapporteur on Human Rights and Disability (Despouy 1991 p.56) points out that the World Programme of Action (UN 1983) states that governments should "actively seek out and encourage in every possible way - including financial support - the development of organisations composed of, or representing disabled persons."

5.5.2 The roles of the organisation of disabled people and their families

Members of the focus groups saw the organisation of disabled people in Amawoti as having two primary roles - resource provision and awareness-raising about disability.

It is significant that this closely parallels the international disability rights movement, which sees the roles of organisations of disabled people as including "providing a voice of their own, identifying needs, expressing views on priorities, evaluating services and advocating change and public awareness" (Driedger & Enns 1987).

(a) Raising awareness about disability

(i) Changing perceptions

Part of the role of the organisation of disabled people is providing the mechanism whereby disabled people can make a positive contribution in the community. "A disabled person needs to do something in the community so that people can get used to disabled people... and not look down on us" (Disabled). People need to be recognised for their abilities and not their disabilities, to "be given a chance to do what s/he can do" (Caregivers).

Such a "contribution" to the community does not necessarily imply "high-powered" or remarkable feats performed by disabled people. Instead, it is in performing such everyday tasks as washing dishes, washing clothes and housekeeping that people begin to recognise that "disability means nothing. They are the same as other people" (Caregivers).

An important part of changing perceptions is encouraging disabled people to see themselves in a more positive way and improving their self-esteem. Central to this is the belief in oneself "s/he can do it" (Nurses & police). "We need to be able to be grateful to ourselves in the community, by being able to say that we have done this and that. That will make you happy" (Disabled). This may happen through their own achievements - and the results of their work, such as the creation of successful business enterprises. In this way, disabled people have the potential to change the community's perceptions of them.

Another facet to this is the ownership by disabled people of their own organisation. "They will know that the association is for them. Then they will do their best, and the community will have another perception of them. They will see that they are capable people - they can do something". Recognition of the unique role and contribution of disabled people in the international arena led to the conclusion that "There is no doubt that one of the most notable features of the Decade has been the leading role played by non-governmental organisations headed by disabled people, and the acknowledgement of their status as experts in their own affairs" (Despouy 1991 p.52).

(ii) Raising the profile of disabled people

In a move away from the tendency for disabled people to be "hidden" and "voiceless" it was suggested that the organisation play a role in making them more "public" (Business). By being publicly included in community events a statement will be made about disabled people as valued members of the community. An example of this is inclusion of disabled people in an Easter march held in 1992, an event organised by youth, civic and church leaders in Amawoti. People in wheelchairs accompanied other marchers along the 5 km-route of the march.

(iii) Research and monitoring

One useful tool of education and awareness-raising about the organisation of disabled people in Amawoti is research to find out information about disabled people in the area. This could provide the mechanism by which people are informed about the activities and services or the organisation. The information would be spread from there, because "...as soon as you make people aware, they will tell other people" (Teachers).

Ilimo staff suggested that awareness of disability in Amawoti could be promoted by having special days, on which education programmes were run, such as "Disability Day". Organisations of disabled people could help to organise these events. They also felt that such structures have the responsibility to liaise with the government over issues that concern them such as disability grants, perhaps even taking over the running of the system! (Ilimo).

This action research could also be a tool for monitoring the well-being of disabled people in Amawoti. This would mean visiting them in their homes, assessing living conditions, level of education, employment prospects, nutritional status etc. (Church). That such activities are seen to be carried out by organisations of disabled people is significant. For too long rehabilitation has been solely in the hands of professionals, and based in institutions. Rehabilitation services are not provided in Amawoti, and those that do exist are most often inaccessible - physically, culturally and financially.

(b) Providing resources or access to resources

Ten of the focus groups felt that an important role of organisations of disabled people should be the provision of resources and/or the provision of access to resources for disabled people. This could take a number of different forms:

(i) Advocacy

A crucial role of the organisation of disabled people is to advocate for the rights of disabled people. This may happen in many different ways - such as helping to secure a venue for small businesses (Disabled) or being instrumental in the setting up of a "centre", where social work and other resources are provided. Such a "centre" could also be a place where disabled children are taught "handwork, or craft work, singing or cooking..." (Teachers).

Organisations of disabled people have the responsibility to liaise with government groups and officials (NPA workers) and "collective advocacy" (Donald 1981) may an effective method to bring about political action. Perhaps the potential of this is recognised more by state officials themselves, than it is by community members. However, the history of the South African government's apartheid policies has made non-governmental organisations in the black community hesitant about being too closely identified with the state. On a more positive note, the Harare Declaration on Legislation for Equalisation of Opportunities for Disabled People (1991), specifically points out the role of organisations of disabled people in relation to the state. This includes participation with the state in drawing up of legislation pertaining to disabled people and acting as consultants in reviewing the impact of the legislation. This document also recommends that the government has a responsibility to make adequate resources available to organisations of disabled people.

(ii) Organising around issues

Another important role of the organisation of disabled people, closely linked to that of advocacy, was seen to be organising around different issues emerging within Amawoti. One example cited is the need for housing for disabled people in the area (Disabled), and another was education for disabled children (Church).

Such organising needs to be based on education - informing people of the situation - but must also lead to action which is empowering for disabled people. For example disabled people could also have a march "stating their needs, which will be led by them. Normal people should just accompany them and push their wheelchairs" (Ilimo).

Another element of organising around issues was seen as developing of alternatives. If one system is inadequate - another could be suggested. The organisation has an important role to play in setting up systems (Nurses & police). For example, in order to apply for, or to renew, a disability grant, disabled people are required to be examined by a district surgeon. The closest available are in Verulam (15km away) or in Durban (25km away). The only way to travel there is on public transport or to hire a vehicle, the cost of which is prohibitive. How then does a wheelchair-user get to the district surgeon? There is a need to set up a system, which is both sustainable and accountable, whereby people gain access to services that they need. By providing a channel for problems such as this to be voiced on a collective level an organisation of disabled people can play a very important role in developing creative and appropriate alternatives.

Another issue highlighted by the group of caregivers was that of hospital rates. A young child with cerebral palsy may require numerous visits to hospital for medication and physiotherapy. This requires money for transport (R10 return to Amawoti), as well as the hospital fee (R10) for each visit. In addition, the mother of the child is likely to lose a day's wages for having to take time off work to go to the hospital. At present, single care grants for disabled children are only available once the child reaches the age of three years. Until that time, the family is responsible for covering all the costs that may be incurred. Again, the organisation of disabled people could provide the forum for education on this issue and for lobbying for change in legislation, for reduction of hospital fees for disabled children, or for whatever changes the caregivers feel are necessary. Already they realise that "We are together because of the organisation" (Caregivers), but this needs to lead onto action.

Such organising around particular issues could be done in collaboration with other groups - both disabled and non-disabled groups. Donald (1981) advises the formation of coalitions where possible - for example with the elderly and with labour organisations, which may be working towards similar goals.

(iii) Fund-raising for particular projects

Some groups expressed the view that the organisation of disabled people has an important role to play in fund-raising if its activities and plans were to be implemented (Nurses & police). For example, the youth recommended that the organisation extend its activities, so as to reach disabled people throughout the area of Amawoti. They saw this happening through the building of small centres or offices in different parts of the area, a process of de-centralisation, in order to reach disabled people in all areas (Youth). In order to achieve this, and other activities, the organisation would need to become financially strong (Nurses & police). "...because there is nothing you can do if you have no money" (Caregivers).

How should funds be raised? By whom? One suggestion was that this could be done by getting donations from the community (Business). While this may be possible to a limited extent, the organisation of disabled people may also need to explore fund-raising options both locally, and within the international community. While funds from overseas donors may be used to initiate projects, a major issue is that of sustainability. It is essential that government support for organisations of disabled people, which provide essential services, becomes a reality in the near future.

(iv) Consultation

Another important point raised within the focus group discussions was the need for consultation with members of the community. They felt it to be essential to the success of any endeavour that people of the area were informed, through public "mass meetings" about the problems and plans of the organisation. A forum should also be provided whereby residents of the area could air their opinions and ideas regarding the issue of disability (Landowners).

In discussing resources, it is significant that the differences of various disabilities did not emerge. One reason for this could be that the organisation of disabled people in Amawoti caters for all disabilities. Jagoe (1987 p.3) affirms this approach and highlights the need for a "united front", combining all disabilities, which addresses common barriers of oppression and discrimination.

5.5.3 The roles of different "influence leaders"

The "influence leaders" referred to in this section are all those involved in this study, viz. Church leaders, Business-owners, Landowners, Nurses & police, Teachers, NPA workers and Youth. (See section 5.5.1 for discussion of the roles of civics, and section 5.5.2 for discussion of the roles of disabled people and caregivers.)

Despite the wide diversity between the groups that participated in the focus group discussions, some themes emerged that were common to several groups. The question posed to the groups was "What could *you* be doing to improve the situation of disabled people in Amawoti?" A response was that "We can use our influence, knowledge and services as employees of the State, and concerned with people" (Nurses & police). This group of nurses and police have a specific role that they can play as government employees, but *every group* included in this study has unique resources that can be tapped for the benefit of all members of the community.

(a) Liaison with the organisations of disabled people

Four of the eight groups that responded to this question, felt that different influence leaders have a role to play in supporting, and working together with the organisation of disabled people. The form that this would take was distinctive for each group of influence leaders:

The *youth* suggested that they could make use of their organising skills to bring together disabled people of all ages in the area. The role of the *landowners* could be to identify disabled tenants living on their land, and to refer them to local disabled people's organisation (Landowners). This group could also call a community meeting to which social workers would be invited, and at which problems of disability and possible solutions could be discussed. *Teachers* suggested that they introduce disabled scholars to the disabled people's organisation.

The group of *nurses & police* suggested a partnership between themselves as professionals and the organisation of disabled people. In this way, there could be a complementary sharing of skills and resources: This group recognised that "... You've got the statistics. So then our function in going house to house to those mentally retarded people is to try and teach them. I think [the role of the nurses & police is] to work hand-in-hand, if that is accepted". This suggestion raises the question of the role of government services in relation to community groups and organisations. There is the danger of co-option of the latter by the former. Issues of accountability and control also need to be carefully addressed, and the roles of each partner defined in detail.

(b) Fund-raising

Four of the eight groups that discussed this issue, felt that they could make a contribution to improving the situation of disabled people through fund-raising ventures. It was significant that three of these groups were male-dominated, and one had equal representation of males and females.

A number of these groups were simply making themselves available for collection of finance in different ways - for example "The *youth* should ask for donations in schools" (Youth). Similarly, the *church leaders* said that they could do fund-raising among the "known church organisations". Such collections may be helpful for a once-off project, such as a building, or an educational trip. They provide a mechanism for educating people in the area about activities of the organisation, and at the same time eliciting their support for these activities.

A slightly different, more long-term strategy for fund-raising was that *businesses* give on a regular (weekly on monthly) basis to the organisation (Business). The amount given would depend on the size of the business. Such support would be ideal for long-term, on-going activities of the organisation - such as a crèche, which businesses could support regularly, in cash or kind. This system would also provide businesses in the area with a mechanism through which to support the work of the organisation.

Why should residents of Amawoti support the organisation of disabled people in their area? A clue to this is the suggestion by the *landowners* that donations could be asked, as a type of "insurance": "We would like to ask for donations - it can be R5 or R10 - anything you have. I have a request for disabled people. We need support because *tomorrow it is you*".

(c) Changing attitudes

Three groups evidenced a deep insight into the attitudinal changes which would need to take place if the position of disabled people in society is to change significantly. They recognised too the need for this change to affect them personally - seeing that through their own change of behaviour the attitudes and practices of others in the area would change too. Again, each group had a unique contribution to make in this process.

Ilimo Project staff suggested that through affirmative practices, their project could present a new perception of disabled people to others living in Amawoti. For example, they could ask a disabled person to be the chairperson of their prestigious annual Christmas party. This would cause people from the community to comment, and ask the question "why [a disabled person]?". The answer would be "because you [disabled people] are important". This example is significant in coming from this group, which earlier had commented on their usual practices of despising and rejecting disabled people - excluding them from social affairs. It was noted that affirmative action had to happen on a number of different levels: "We must not use [only] one way of showing them that they are important" (Ilimo).

Teachers also recognised the potential role that they had to play in influencing attitudes, particularly those of their colleagues, towards disabled scholars. Positive attitudes and accepting behaviour by some teachers would encourage others to do likewise, and thus engage in practices "that can make a [disabled] child feel accepted".

The *youth* confronted their own stereotypes and prejudices and realised that these needed to be changed. "The youth should respect disabled people by not laughing at them... If you see another person laughing at a disabled person you need to talk to that person and ask him to stop laughing..."

Meyerson & Scruggs (1980) observe that environmental adaptations, improved accessibility and equal opportunities improve the conditions of life for disabled people, but they do not eliminate discrimination. The interventions being discussed by groups in terms of attitude changes need to parallel environmental changes, or else the problems of isolation and devaluing attitudes will remain in the classroom, in employment or in the community.

How can one facilitate the development of positive attitudes towards people with disabilities? In addressing this question, three focus groups identified some creative responses. Wright (1980 p.274) reflects deeply on this issue, and concludes that "positive attitudes are based on constructive views of life with a disability and to acquire those views requires being exposed to those views through information and direct experience".

(d) Education and awareness-raising about disability

Three groups identified a role that they could have as being to raise awareness about disability within Amawoti. Again, each group had a unique contribution in the way that this could be implemented. The *church leaders* were quite literal in saying that "we need to preach to people about disability. We need to tell people about the life of disabled people, so that they can be fed". This points to the pressing need to incorporate religious beliefs about disability into the world view of community members. It implies not only an understanding and interpretation of the meaning of disability, but also one's response to it.

The *teachers* also have a distinct role to play in the school setting: "Some parents bring their children to school at a later stage for example, at the age of ten years. When one asks what the problem is, they do not tell the truth, because they fear that they will be embarrassed. Sometimes the parent will blame the teachers that they fail to teach his/her child, instead of saying that because the child is disabled s/he cannot read or understand very well. Maybe the solution to this problem is to call a parents meeting and introduce the problem which the teachers come across when faced with a situation of a disabled child. Try to make parents talk to other parents if s/he has a disabled child". This illustrates the value of collective activity - which goes beyond the individual teacher/child situation to address the issue of education and integration at a community-wide level.

Another area of education identified by the group of *nurses and police* was that of prevention of disability, which could be included with health education. It is felt that such education is essential, but should not be restricted to be the prerogative of professional nurses only (with the danger of mystification of disease). Instead, disability prevention strategies should be popularised through school curricula, literacy programmes and health education through community health committees.

Conclusion

There has been description of the opinions of the focus groups as they relate to the five key topics viz. defining disability and its causes, behaviour towards disabled people, needs and rights of disabled people, and appropriate interventions. A range of views regarding *definitions of disability* were expressed by the focus groups, and cultural factors were identified as being an important cause of disability. All groups acknowledged that, on the most part, *behaviour* of community members towards people with disabilities is negative. The focus groups saw disabled people's *needs* as being diverse - including physical, social and psychological needs. However, groups differed as whether they felt the needs of disabled people were the same or different to those of the able-bodied and this has implications for the approach taken in interventions. Similarly, the focus groups saw *rights* of disabled people as being very broad, but views differed as to how these rights should be obtained. Finally, in discussing the *interventions* that could be made to improve the situation of disabled people, the focus groups indicated a range of responses, with some specific roles indicated for certain groups, while others were more general.

Discussion on the findings of the focus groups indicates that many of the opinions expressed are not unique to Amawoti. The literature reveals that they are found in other contexts, both nationally and internationally. What is unique about the focus group discussions is that all of them comprise of people either living or working in the area, and there is an opportunity to more deeply explore *why* certain groups responded as they did, in relation to the local context. There is also a need to make links and comparisons between some of the categories that have emerged from the discussion on the findings of the focus groups, thereby creating a framework for understanding and interpreting the responses of the focus groups, in order that there be applicability beyond the immediate context. This deepened analysis and interpretation will be the subject of the next chapter.

CHAPTER SIX:

INTERPRETATION OF THE RESULTS OF THE FOCUS GROUP DISCUSSIONS

Introduction

Having described the responses of the focus groups to the five themes (defining disability, behaviour towards disabled people, needs and rights, and appropriate interventions), there is a need to engage in a more analytical and interpretative process, and in this way understand *why* some groups responded as they did. Whereas the previous section linked focus group perceptions (horizontally) across themes, this chapter attempts to explore perceptions *within* particular focus groups (vertically). In this way the perceptions of a focus group regarding definitions of disability, are linked to its views of appropriate interventions.

The questions posed in the focus groups are of particular importance to those working in the fields of disability and development, these questions need to be raised in forums that seek to address disability issues. Professionals and community workers alike need to ask themselves: How do we conceptualise the issue of disability? How do we see disabled people in this particular context and society? What do we see as being the major problems faced by people with disabilities? The answers to these questions are crucial, in that they form the base on which interventions are strategised. For example, the perception of disabled people as individual victims of tragedy leads to the individual-therapy based approach, in which every effort is made to assist the disabled person to make the necessary adaptations to fit back into the society from which s/he is now excluded.

If the questions raised in the focus groups are relevant to other contexts, then it is also of value to learn from analysis of the responses of the focus groups to these questions. Indeed, such an analysis may provide the tools for understanding and evaluating responses in other contexts. This chapter highlights the significance of the particular focus groups selected for the study, and then explores the responses given by them, interpreting them in light of group- or gender-specific factors.

6.1 Significance of the groups identified

Prior to analysis of the *content* of group discussions, the significance of the groups of "influence" leaders themselves was explored around the questions

- What do these groups represent within Amawoti?
- How do their roles relate to the needs and rights of people with disabilities?

6.1.1 Representation of community structures

Davies (1989) highlights the need to condition *social* and *economic* structures of the community in order to achieve integration of disabled people. Other authors (Holland & Henriot 1980) go further in differentiating the roles of different structures within society, viz.:

- *economic structures*, which determine how society organises resources;
- *political structures*, which determine how power is organised;
- *social structures* which determines how society organises relationships;
- *cultural structures* which determines how society organises meaning.

This provided the researcher with a useful framework by which to identify the significance of the each of the focus groups.

Table 6.1 Categorisation of the focus groups

Economic structures	**Political structures:**	**Social structures:**	**Cultural structures:**
business owners	civic	teachers	church leaders
landowners	youth	nurses	disabled people
Ilimo Project	police	social workers	caregivers

The *economic structures* represented by the focus groups include the business owners, and the landowners, by virtue of their control of land in Amawoti. The Ilimo Project may also be included in this category as a community-based project which has access to resources, and aims to promote income-generating activities in the area. The *political structures* identified are those of the civic. Also, the youth in the community are a significant force in terms of participation and lobbying around particular issues of concern. At the other end of the spectrum, the group recognised the State structures as being of significance and this was represented by the security forces (South African Police). The *social structures* identified were those of education (teachers), health (nurses) and welfare (social workers).

The *cultural structures* are defined as those which "determine how society organises meaning" (Holland & Henriot 1980). It could be argued that this includes much of the *content* of the study, which looks at perceptions of disability, and how community members respond to it. However, two categories of focus groups are particularly significant in interpreting the meaning of disability - the church leaders, and those who have had personal experience of disability (those with disabilities themselves, and the caregivers). The latter are not community structures as such, but they provide valuable insights into the outworking of society's understanding of disability.

6.1.2 Responsibilities of interest groups in responding to the needs and rights of disabled people

Prior to analysis of the content of group discussions, there was also exploration of the significance of the groups selected in terms of their potential response to needs and rights of people with disabilities. The question was raised as to who is responsible for meeting the variety of needs of disabled people and for protection of their human rights. In answer to this, a useful categorisation method was provided by the literature (Conyers 1982) in which three major groupings of needs/rights are identified viz.

- basic consumption goods (e.g. food, clothing and shelter),
- basic services (e.g. health, education and clean water),
- the right to participate in making and implementing decisions which affect one's own development.

These three categories are very closely aligned to the needs of disabled people identified by Nyathi (1988), which are the need to survive (corresponding to consumptive and basic service needs), and the need to be given equal opportunities, and be integrated into society (corresponding to participation).

Table 6.2 Categorisation of the focus groups according to needs and rights, based on Conyer's approach

Basic consumption goods:	**Basic Services:**	**Participation:**
business owners (finance)	nurses (health)	civic
landowners (shelter)	social workers (welfare)	church leaders
	teachers (education)	youth
	Ilimo Project (development)	
	police (security)	

This discussion illustrated the diversity of community structures represented by the different focus groups. The roles of the different groups vary not only within the community, but in regard to their response to the needs and rights of those with disabilities. The following section explores in more detail the *content* of the discussions, highlighting different perceptions of disability that emerged and the associated responses.

6.2 Disability as the individual being dependent and "in need"

6.2.1 In need of care

There were two groups that primarily conceptualised the problem of disability as that of "needing care" - these were the group of *NPA workers*, and the group of *nurses and police*. Disabled people were seen to be those with impairments, whose bodies are "not functioning", and as a result they are dependent - they need help, and they need to be cared for by others. The problem arises when there are minimal resources and services to provide this help, or when particular needs cannot be directly matched to the particular "packages" provided by the State. (For example, when a disabled child is orphaned, who will draw the single care grant?)

These focus groups of *State employees* may define the issue of disability in terms of needing care because they themselves are in the caring business. This definition is basic to the medical model of disability viz. that disabled people are sick, and should spend their lives trying to "get better", with the assistance of medical and para-medical professionals (Oliver 1990). Disability is understood as *individual deficit or need* and it is defined in such a way that they, as the service providers of the State, are able to respond to it.

With this understanding of the problem, it comes as no suprise that interventions for disabled people are defined in terms of "what we can do for them". A wide variety of suggestions were made to this end:

- provision of a place for disabled people in Amawoti
- provision of opportunities for disabled people to develop their talents
- provision of services (e.g. transport).

The members of these focus groups also saw the need for recognition and regulation of activities of the organisation of disabled people by the State and for collaboration between members of the organisation, and State employees. These group members did not see the need for disability rights, and felt that such special privileges would lead to the further isolation of disabled people. Instead, they felt that disabled people should be accepted as normal people. This view is simplistic and contradictory, as disabled people do not at present have equal opportunities and are therefore denied much that is easily available to able-bodied people.

Some of the State employees articulated a feeling of powerlessness saying that interventions must come either from above (State policies) or below (the community). This may indicate a reluctance or difficulty of State employees in bringing about changes to the situation of disabled people, or it may simply be an expression of their own apathy. Some group members felt that it was up to the organisation of disabled people to change the way that disabled people are perceived in the community thus again shirking their own responsibility to do so. Such views may be expected from civil servants who have limited opportunities for taking responsibility or initiative or have become so settled in their ways of working that they do not wish for change.

The perceptions of the groups of State employees were very similar to those of the *church leaders* in being patronising towards (and not empowering of) disabled people. There was no mention that disabled people have been denied what is rightfully theirs; group members did not conceptualise the problem in terms of discrimination and oppression, in contrast to the Ilimo Project staff members who did. There was also no recognition of the need for the setting up or working with community structures or the self-representation of disabled people in fighting for their rights. Instead, the perceived solution was that disabled people need to be *cared for*. Thus a needs-based rather than a rights-based approach was adopted by these focus groups.

6.2.2 In need of help

The focus group of *business owners* perceived disability to mean *individual dependency*. It is of note that while they viewed disabled people as those needing help, they felt that people in the community do not help them. As a result, disabled people are neglected and excluded. This view was affirmed by the focus group of *disabled people*, who defined themselves as those who are not able to do particular things, and therefore need help. Following on this perception of the problem, interventions were seen at the level of meeting individual material needs. The business owners saw this as being primarily the responsibility of the State, with disabled people helping to raise funds where possible. The group of disabled people felt that the community should give donations to build workshops and schools for them. Business owners undertook to contribute financially in the form of tithe or a prayer, as well as to speak on behalf of disabled people.

The view of interventions that would address the problems of disabled people was shared by the *landowners*, who, appreciating the problems of individual impairment and resulting differentness, observed that disabled people are despised by others in the community. Their own response was to feel sorry for disabled people and to give them donations when possible. However, they felt that it was primarily the government (in the form of social workers) who deal with such things, and who should provide the help that is required by disabled people. The landowners offered, (as did the business owners) to talk on behalf of disabled people but felt that it was inappropriate to demand rights for them. They felt that disabled people should be grateful for whatever help they could get from their benefactor (the State), and would be out of place in making demands.

Both the business owners and the landowners view disabled people as passive recipients, as people in need of help. (The business owners who attended the focus group discussion thought that they had been called to the meeting so that a request for donations would be put to them.) This is a very narrow view of disabled people and issues of disability, which is restricted to material and physical needs. These perceptions are based on the "charity approach" to disabled people (Milton Keynes 1990). It suggests that disabled people are dependent on the (unreliable) goodwill of better-off members of the community, who ultimately will not take responsibility for them. It is significant that to some extent, disabled people have internalised such patronising attitudes, and have learnt that it *can be profitable to be an object of pity and charity*!

Both the business owners and landowners are regarded as among the most wealthy residents of Amawoti and as business-owners are often approached for donations (e.g. for bursaries and sponsorship of sports clubs), they may begin to see this as the only contribution that they can make to community groups. The focus on material needs potentially blinds them to the prejudice, discrimination and oppression of disabled people that also needs to be addressed. They are willing to speak for disabled people but the government must do the rest! The politics of these focus group members in relation to disabled people tend to be very conservative - an observation which is not suprising in view of the fact that they have more to lose by opposing the State than do others (such as the Youth or Ilimo). Moreover there seems to be a naive belief in the beneficent character of the government: certainly there is no evidence to suggest that (State) social workers hold the key to improving the situation of disabled people in Amawoti. There is minimal involvement of such professionals in this particular community, and the services they offer are predominantly institution-based.

The interventions suggested by the business owners and landowners, as well as by some disabled people, do not address the root causes of problems experienced by disabled people, instead they only address the symptoms. They are very short-term solutions that create dependency, and do not encourage development, or empowerment of disabled people. They see the solution as being the provision of the services of professionals, as being in the hands of outside "experts". Neither the business-owners nor the landowners recognise the importance of the participation of disabled people, or of the need for structural change and the transformation of society if disabled people are to have access to the same basic needs and rights as other residents of Amawoti.

6.3 Disability as the individual who does not fit into society

6.3.1 A breakdown of relationships

In the focus group of *civic members*, the problem of disability was conceptualised primarily as a breakdown of relationships, and separation from the community. It was felt that the rejection of disabled people by community members, and the consequent pain felt by the disabled people and their families led to wrong decisions being made (e.g. hiding the disabled person from the community). There were many factors which were seen to contribute to this breakdown of relationships one of which was the lack of knowledge about disability.

Solutions to this problem were articulated by the civic members as strategies to promote acceptance, inclusion and integration of disabled people in the community, which was seen to happen at an organisational level. Civic members felt it important that there be communication between the organisation of disabled people and the Amawoti Civic Association, so that:

- there could be collaboration and support between the two community organisations;
- there could be co-ordinated work around the issue of disability in different areas of Amawoti;
- the organisation of disabled people could benefit from the infrastructure provided by the civic;
- positive attitudes towards disabled people in the area could be promoted;
- the civic could hear about the needs, plans and strategies of the organisation of disabled people in Amawoti.

While the civic group recognised the importance of providing ways for disabled people to "develop" themselves they were acutely aware of their limitations in terms of financial resources. As a result, there was not much discussion about the concrete needs of disabled people. However, it was recognised that there is much that civic can do to address discrimination of disabled people in Amawoti and to promote equal opportunities for them.

It is significant that the civic structures were set up in Amawoti in 1990 to replace the government-appointed induna and councillors in an effort by residents of the area to establish more democratic and representative community structures. The civic is often referred to as "baba" (father) within Amawoti and it understands its role as being an overseer of the community, seeking the good of all its members, as a father seeks the good of all the family members. For this reason, the civic is concerned about discrimination and about those who are marginalised or excluded from society (such as people with disabilities). It attempts to be responsive to community needs - promoting partnership and collaboration. Within the civic, there is an emphasis on consultation, participation and representation, and this has coloured the way that this group conceptualises how it should go about addressing community issues (including disability).

It is evident that the civic gains power if it works well with community structures. Indeed, it would be costly for them to ignore an organisation that represents one sector of the community viz. people with disabilities. It thus has a vested interest in the suggestion that it works with the organisation of disabled people - as this would not only improve the self-image of the civic, but also its image and support within the wider community. The suggested interventions thus appear to be an optimal solution - both for the civic, and for disabled people in Amawoti.

In defining disability as individual limitation, which results in dependency of disabled people on those who are non-disabled, the perceptions of the *church leaders* were close to those of the civic members with the emphasis on the breakdown of relationships. (A difference could be noted in the church leaders' emphasis on personal relationships, rather than on those between different groups.) The church leaders maintained that the "differences" of disability (as compared against the standard of "normality") meant that disabled people are marginalised in the community. It is no surprise that this is a particular concern of the church leaders, for one would expect them to hold the view that all people are created by God and (as his children) are part of the God's family. A major emphasis within the church is on positive (loving) relationships, and it would be expected that church leaders would be concerned when factors (such as disability) cause the breakdown of these relationships.

Despite conceptualising the problem of disability in a similar way to the civic members, the interventions proposed by the *church leaders* differ greatly. Firstly, they suggest that disabled people should be removed from the community, to "a place where they can be kept". They do, however, see a role for community members in looking after disabled people, and providing practical help for them i.e. "love in action". This role also includes the community raising funds to provide resources for disabled people (such as a hostel), and speaking on their behalf. The church leaders felt that they could play a unique role in "preaching about disability", and in saying prayers for disabled people.

It is evident that the perceptions of the church leaders is based on the "charity approach" to disability (Coleridge 1993). There is the assumption that they need to think *for*, and do things *for* disabled people. Suggested interventions are thus made on the basis of the "good intentions" and "good deeds" of community members and not on the recognition that disabled people are denied their basic needs and rights. Many church leaders in Amawoti do not function within the participatory democratic mode of leadership, but tend to use a top-down, authoritarian style. It may be for this reason that this group does not see the importance of the participation of disabled people in securing their needs rather it sees it as being a disgrace if disabled people participate in marches and other acts of resistance. The emphasis is on individual adaptation, rather than on change occurring at a community-wide level, a view which may emanate from the doctrine of individual salvation. The interventions suggested by the church leaders suggest a reformist rather than a transformative approach to disability. This may be influenced by their own spirituality which tends to be pietistic and "other-worldly", and not liberatory and transformative. It then becomes a source of concern if the activities of church leaders - specifically preaching, praying and collection of funds - serve to reinforce the stereotypes of disabled people as objects of charity.

6.3.2 Not conforming to norms

The focus group of *teachers* conceptualised disability primarily as being different, of not conforming to norms. This was seen to take different forms - such as inappropriate or asocial behaviour, or not reaching particular milestones of growth by a given age. Cultural factors were seen as being a frequent cause of disability. This group also noted that disability, and the resulting exclusion from society, has a very negative effect on the self-esteem of the disabled person. This defining of disability as "differentness" was shared by some members of the focus group of disabled people who felt that they were "not the same" as able-bodied people.

Within any community, teachers play an important role in the socialisation process - teaching pupils to conform to societal norms, and preventing deviant behaviour. Rules are part of any educational institution and rules require conformity in such things as dress, code of conduct and behaviour. Thus it comes as no surprise that teachers view disabled people to be excluded from the community because they do not conform to societal norms.

The teachers were particularly concerned about mental disability and it was the impact that this had on the socialisation of the child that they found to be disturbing. They were acutely aware of those who deviate from societal norms, and who suffer the negative consequences of doing so. Thus teachers saw themselves as having to play the role of "protector", defending a disabled child against abuse, ridicule and/or exploitation from other pupils. The interventions proposed by the teachers could be seen as the provision of mechanisms which would enable disabled people to "catch up" with able-bodied people (affirmative action). This includes the provision of opportunities for disabled people for education and skills training, an intervention that was affirmed by the group of disabled people. The proposed interventions, however, suggest a non-acceptance of disabled people by the teachers, in that they see them as needing to become something other than what they are, conforming to what is "normal".

This view differs slightly from the charity approach taken by the church leaders, in that the teachers emphasised the need for disabled people to organise themselves and to fight for their own rights. It was also different from the view of disabled people as being those who are passive and in need of "care" (focus group of nurses & police); instead the teachers stressed the need for disabled people to actively develop themselves, and adapt to the environment. It is significant that the interventions proposed by the teachers did not include structural and/or institutional changes. Nowhere was it noted that schools in Amawoti are virtually inaccessible to disabled scholars and teachers, or that teachers are trained neither for early detection of disability nor for teaching of children with disabilities. This indicates that while the teachers are aware of some of the immediate, pressing problems of disability in the community, they have not given serious consideration to the long-term requirements of equalisation of opportunities in education for disabled scholars in Amawoti.

6.4 Society disables the individual

6.4.1 Disability as a form of oppression

There was one focus group - that of staff members of the *Ilimo Project* that conceptualised the problem of disability as being one of *oppression*. This was seen to encompass many forms of oppression including political, cultural, age and gender. It was seen to result in the stereotyping of disabled people, discrimination against them, and the denial of their rights. Disabled people were seen as being excluded from mainstream community life.

It is significant that this particular group conceptualised disability in this way. This may be a reflection of their experience and training, which has made staff aware of the socio-political dimensions of community work. They have been "conscientized" and are thus able to conceptualise oppression occurring at different levels within society. In addition, the Ilimo Project is explicitly committed to the poorest and most marginalised of community members, and this value makes staff more aware of groups that may be excluded.

The view of disability as being a form of oppression influenced the way that the Ilimo group conceptualised interventions. Firstly, they saw the need for the setting up of structures on which disabled people could be represented. This would provide the mechanism for organising disabled people, for educating people in the community and for changing attitudes. It would facilitate the participation of disabled people in their own organisation, and allow for self-determination. The Ilimo Project staff group also recognised the need for the group of disabled people in Amawoti to learn from and network with other groups of disabled people in the region and country. They also felt that there should be collaboration with able-bodied people, but not domination by them. Other interventions proposed by the Ilimo staff were the education of disabled people, as well as the provision of equal opportunities for them. They felt that disabled people should have a higher profile in the community, and should be integrated into community life. The group of disabled people also recognised many of these interventions to be important particularly that of raising their profile so that they become more public in the community.

The staff's suggestions for interventions could be directly linked to the Ilimo Project's philosophy: there is an emphasis on building community structures and on community participation. Disabled people are seen to be included in its activities of Ilimo as a comprehensive, integrated primary health care project (of which education is one component). It is for these reasons that staff did not primarily perceive interventions to be concrete and short-term (e.g. in the form of financial provision for disabled people), as was the case with other focus groups included in this study. Instead appropriate interventions were seen as being intangible, more long-term, aimed at addressing issues that were seen to be the causes of oppression of disabled people. Disabled people were thus not seen as objects of pity and recipients of welfare, but as an oppressed group, who have been denied their rights. It was recognised that the participation and self-representation of disabled people ("empowerment") is essential if this oppression is to be challenged.

The views held by the Ilimo Project staff could be regarded as being fairly objective, when compared to other groups that participated in the focus group discussions, in that this group had nothing to gain or lose from expressing different opinions. It appeared that no one was seeking to gain mileage from holding a particular position. This was in contrast to the civic group which would benefit directly from (the suggested intervention of) working with the structures representing disabled people.

Some of the interventions suggested by the Ilimo group were very similar to those of the *youth* - a basic assumption being that people affected by a problem should be involved in looking for solutions to that problem. The youth are known to be among the more politicised members of the community, and thus it is not suprising that they should conceptualise the issue of disability in socio-political terms. Further, the present democratic culture, with the emphasis on participation and accountability, influences their understanding of appropriate solutions. However, there seemed to be a contradiction appearing in the interventions suggested by the youth: while they saw the need for disabled people to become actively involved in demanding their rights and securing their needs, the youth suggested that the community be responsible for providing hospitals, schools and crèches for disabled people (and youth could be involved in collecting donation for this). The latter, while being unrealistic at best, does not address the root causes of discrimination against disabled people. The perceptions of the youth are based on the "charity model" of disability, which is paternalistic and ultimately leads to more separation of disabled people from the community. The youth appear to be radical in theory, but conservative in practice!

If one accepts the conceptualisation of disability as a form of oppression, there appear to be major gaps in the youth's analysis of appropriate solutions. There is no suggestion of:

- affirmative action and provision of equal opportunities for disabled people;
- partnership and collaboration of disabled people and other groups in the community or
- integration of disabled people into existing structures (e.g. schools).

6.4.2 The disabling world

The focus group of ***caregivers*** perceived disability primarily as limitation and as difference - a view which was shared by a number of other groups (Landowners, Disabled). What was unique about their perceptions, however, were the social implications of disability: namely that it leads to the exploitation of disabled people and consequently exaggerated disability. Thus, while the effect of the individual impairment was not ignored, the impact of the "disabling world" was particularly emphasised by the caregivers. This group felt that a major problem faced by disabled people was having to cope with such attitudes and behaviour in isolation and "not being together".

The personal experience of having a disabled family member meant that the caregivers felt the impact of disability very acutely. They have themselves felt the rejection, isolation and guilt associated with disability. The direct cultural interpretation of disability by the caregivers and by disabled people themselves indicates their own search to find meaning for themselves as to the causes of disability. Both groups were aware of social relations between disabled people and other community members, and the impact that this has on disabled people viz. lowering of their self-esteem.

It is significant that in the group of the caregivers, which was female-dominated , there was more awareness of psychological and emotional needs of people with disabilities than there had been in any of the other groups.

The interventions proposed by the group of caregivers were ways to address the isolation of disabled people and to "bring them together". They felt that this would enable them to share and work together on common problems, and to get specific help where necessary.

It would also provide companionship, and give the disabled people involved confidence in themselves. This view was affirmed by the group of disabled people who recognised the need to develop their own self-esteem and "to be grateful to ourselves". While the caregivers saw the need for disabled people to support themselves in the community, their perception differed from that of the teachers, which emphasised the need for disabled people to adjust to the environment. Instead, the caregivers saw their own responsibility in that "We should teach them [people in the community] that disability means nothing. They are the same as other people..."

While the caregivers did not articulate disability in the same terms as the Ilimo staff, there are clear parallels between them. The caregiver's approach appears to be primarily needs-based (the needs being the ones that the caregivers had observed), and did not emphasise the importance of rights. However, there was the recognition that attitudes and behaviour can be themselves be disabling. The caregivers' suggested interventions could be seen to supplement those of the Ilimo staff and the civic, in emphasising that interventions have to make an impact for disabled people at the psychological/emotional level, and not only at the structural level.

It is significant that two out of the four groups that perceived disability to be a societal issue were made up predominantly of women. This may indicate that women are more sensitive to issues of oppression in society. On the other hand, one of the female-dominant groups was that of the caregivers - and it may be the personal experience of disability which explains this position. Another observation is that those who hold what is arguably the most patronising perceptions of disabled people (seeing them as individuals who are dependent and in need) are those who are either among the most wealthy residents of Amawoti (Business and Landowners) or professionals (Nurses, police & NPA workers). The exception to this is the teachers - who still have an individual focus on disability (as not conforming to societal norms) - but are slightly less patronising. This may be explained either by the fact that this group was female-dominated, or by the nature of teacher-training (which is to "teach", rather than to "do for").

In terms of age-specific perceptions, it would generally seem that the groups that see disability as a societal issue are under the age of 35 years. The NPA workers, are however, an exception to this, thus suggesting that age per se is not a determining factor in perceptions of disability, as other factors (such as professional training and class) may override it.

Table 6.3 **Perceptions of the focus groups regarding disability and interventions**

Views of disability	Suggested interventions	Focus groups holding this view
1. individual dependent and in need	primarily material	
in need of help	acting on behalf of disabled people	Business owners (M) Landowners
in need of care	what "we can do for them" (service provision)	NPA workers Nurses & police
2. individual "not fitting" into society	strategies to promote acceptance & integration	
breakdown of relationships	"love in action"	Civic (M) & Church leaders (M)
not conforming to norms	protection & affirmative action	Teachers (F)
3. society disables the individual	structural change	
a form of oppression	setting up structures	Ilimo Project (F) & Youth (M)
the disabling world	organised action to promote self-esteem & solidarity	Caregivers (F)

This table summarises the different perceptions of disability and corresponding interventions as envisaged by different focus groups. Gender dominance within each group is indicated, with (M) denoting male-dominated groups, and (F) female-dominated groups. (For further details regarding the constitution of the focus groups, refer to section 4.4.3).

The reason for the absence of the focus group of disabled people from this table is that the views expressed by this group were very diverse, and could not easily be categorised in this way. It became apparent that disabled people experienced disability not only as dependence, but also as exclusion, and at the same time the range of interventions suggested by the other focus groups were seen by the disabled participants as being appropriate.

It is evident that most of the groups included in this study adopt a patronising approach to people with disabilities, considering them to be individuals with deficits, who do not fit into the community. Only a few groups see disability as being socially determined - and it is significant that those who do so are groups that either have personally experienced the reality of disability (Disabled & Caregivers), or those that have been conscientized and are politically aware and sensitive to issues of oppression (Ilimo & Youth). When looking at strategies to change perceptions of disability (from those that focus on the individual tragedy and are patronising to those that recognise society's role in determining disability) two options present themselves.

Firstly, one could expose all interest groups in the community to personal experience of disability. While it is both impossible and undesirable to inflict disability on either members of the interest groups or their families, other means of personal experience could be explored. One of these is facilitation of interaction between members of the different interest groups and people with disabilities. However, in order to make this a positive experience, it would be important that this happens in settings in which the people with disabilities are functioning in terms of their capabilities and not their inadequacies (Wright 1980).

A second option (which could supplement the first) would be to link disability with awareness-raising about other issues which lead to marginalisation in society (e.g. civic become aware of the parallels between apartheid and racial exclusion and the exclusion of people on account of their disabilities). This could be a strategy adopted in the development of a community-based disability programme.

Conclusion

Analysis of the focus group discussions had two foci. Firstly, the significance of the particular interest groups was explored, in terms of the structures that they represent in the community, and their roles in relation to the needs and rights of people with disabilities. Secondly, analysis of the responses of the different interest groups provided insights into group- and gender differences, thus making it possible to identify prevalent perceptions of disability (and reasons for them), as well as a variety of interventions. This process led to the emergence of a framework for understanding views of disability, and interventions.

This analysis has identified the impact that community structures (political, economic, social and cultural) have on people with disabilities - an observation that is often overlooked by rehabilitation professionals in their focus on the individual disabled person, removed from his/her context. Thus the question is raised as to whether these structures need to be addressed if disability is to be dealt with effectively. In addition, the framework emerging from the analysis has potential for applicability beyond the interest groups of Amawoti, for it provides a tool by which to analyse perceptions of disability and interventions in other contexts.

These insights provide valuable information for the development of community-based rehabilitation programmes, in that they make it possible to identify the perceptions of different categories of interest groups, indicating opportunities that can be maximised, and "threats" that need to be challenged. They also highlight the need for disability to be addressed at a number of different levels, which include service and material provision, promotion of social integration, and structural changes. This knowledge can guide the approaches taken at community level, as well as the formulation of policy concerning disability.

CHAPTER SEVEN:

MOVING TOWARDS A NEW CONCEPTUALISATION OF DISABILITY

Introduction

This study set out to explore the issue of disability within a context of poverty. Its purpose was to examine the perceptions and views of interest groups within one particular informal settlement, to begin to understand how members of these groups view disability and its causes and effects, and what they perceive to be appropriate interventions. The approach taken meant that discussions on disability were not restricted to the health and welfare sectors, but involved the whole range of community structures. The concepts of community development, primary health care and community-based rehabilitation have provided the tools by which to interpret and understand not only the responses to disability envisaged by interest groups in Amawoti, but also to make recommendations for appropriate interventions.

This chapter outlines the main themes that have dominated this study, some of which have emerged from discussion and analysis of the empirical data collected, and others from the literature. These have all contributed to a *new conceptualisation of disability*; the implications of this are explored. Finally, factors for consideration in policy formulation are identified.

7.1 Themes of the study

Reflecting back on the study reveals a number of themes that have emerged. Some were there, in a nebulous way, at the outset, and helped to inform the formulation of the research question. Others have emerged through the process of the study itself.

7.1.1 A community-based approach

This study has attempted to understand disability within a local community. All of the focus groups were constituted of people either living or working in Amawoti, and discussions were based around disabled people in this area. This community-based approach differs from that usually taken by health and welfare professionals, who tend to see disability as a *personal tragedy* and *individual deficit* (Werner 1993). This perception individualises the problem of disability (as do other victim-blaming theories) (Oliver 1986) and as a result professionals tend to have limited awareness of the responsibility of the wider community in determining or addressing disability.

One of the aims of the study has been to raise awareness of the social barriers that lead to discrimination and disempowerment of people with disabilities, and to emphasise the importance of community resources and facilities being accessible to and usable by all its members. Central to this is a shift away from the *family* as the primary focus of responsibility for people with disabilities (Bowe 1990) towards placing equal responsibility on a *range of groups* within the wider community. This creates the environment whereby disability and rehabilitation can be integrated into the everyday life of the family and community (Wolffers & Finkenflugel 1993). The value of this approach is based on the observation that sustainability is achieved when development initiatives (such as community-based rehabilitation) become an integral part of the lives of people in the community (Kajese 1990).

7.1.2 The link between poverty and disability

The basing of this study in an informal settlement has given insights into the situation of people with disabilities in a context of poverty. The significance of this context lies not only in the present numbers and projected growth of the populations of such settlements around cities in South Africa, but also in the understanding that such poverty itself - the living conditions and the present levels of violence in such areas - leads to an increased rate of disability.

This study has affirmed the link between disability and poverty, which has been demonstrated in the literature (Acton 1981, Loveday 1990). The extreme poverty as experienced by those living in Amawoti, is intimately bound up with disability, for "indigence, besides being in itself the most palpable expression of human exclusion and denial of all human rights, is a direct cause of disability as well as a factor that worsens both disability and discrimination against disabled persons" (Despouy 1991 p.40). Many (preventable) disabilities are caused by poverty and its associated effects; in turn, a major consequence of disability is the heavy demands made on the scarce resources available to the person and family affected, and the result is a further entrenchment of poverty. This means that "in looking at the question of disability and rehabilitation in the Third World, we need to recognise that *the biggest disability is poverty itself*" (Werner 1983 p.53 my emphasis). The lack of education, transport, finance and other resources means that disabled poor people and their families have no "safety net" that can help to support them to compensate for the loss of physical or other abilities (Lund 1994).

The problem of disablement is a critical economic and social one that requires an immediate response. Understanding that disability is an important cause and consequence of poverty, and an aspect of "underdevelopment" means that it must be addressed as a development issue (Acton 1981). Thus interventions made to prevent or minimise the effects of disability need to go beyond the individual medical approach to address issues of poverty at all levels.

7.1.3 Range of perceptions of disability

The researcher has not made the assumption that "the community" is a homogeneous group of people living in a particular locality. Instead, the research methodology adopted has facilitated the process by which "the community" was problematised into different interest groups of "influence leaders". Through this process a range of views emerged concerning definitions of disability, behaviour towards disabled people, needs and rights of disabled people, and appropriate interventions. In this way, the wide diversity of views about disability present within "the community" was demonstrated.

The results and analysis suggest that perceptions of disability are influenced by cultural beliefs, gender, age, class and exposure to people with disabilities. These perceptions in turn influence how interventions are conceptualised.

The study was not looking to obtain the "right" response to disability, but to expose the range of possible interventions. Different interest groups, by virtue of the role that they play in the community, and the resources to which they have access, can play a part in addressing disability. The interventions suggested by the focus group members ranged from material and service provision to structural change. *All* of these may be necessary. The issue is that disability is not only to be addressed by those within the health and welfare sectors, but also by a wide range of interest groups and organisations that have an impact on community life.

Insight into the perceptions of different interest groups is of value in the setting up of a community-based rehabilitation programme. It enables planners to know what resources exist and can be supplemented; indeed, the first step in community-based rehabilitation is to identify the ingenious ways in which community members are already coping with disabilities and analyse how these can be strengthened (Wolffers & Finkenflugel 1993). At the same time there needs to be recognition of those interest groups whose behaviour and attitudes towards people with disabilities needs to be challenged.

7.1.4 Questioning and raising consciousness

During the process of conducting the focus groups and analysing the results, the contradictions within different views emerged. For example the group of youth saw disability as being a social problem, but the interventions that they suggested were primarily material provision. In this way, the study enabled the researcher to gain an understanding of positions taken by different interest groups in Amawoti, providing insight into where people "are at" (and why) and the potential for them to move on from there. Such an understanding of people's perceptions, in turn, enables one to challenge the assumptions on which they are based.

The need to raise the consciousness of groups regarding their own contradictions became evident throughout this study. For example, many groups equated disability with dependency. In reality, however, *everyone*, by virtue of being human, is dependent on other people. This is not a characteristic unique to disabled people. Another false assumption made by focus group members was that disabled people are "not normal", and that they are characterised by their "different-ness". Sutherland (1981) highlights the contradiction of this view, by referring to the "myth of the normal healthy body". The baseline ("normality") against which disability was defined is thus dispelled as myth.

Discussion of "different-ness" begs the question of what constitutes "normality", and definitions of "dis"ability raise questions about defining "ability". Such questions challenge the assumptions that dominate in society, and have the potential to enable people to begin to understand their society from the position of its victims.

7.1.5 The importance of changing attitudes

This study has brought into focus the impact of negative attitudes in perpetuating the "disabling world". Attitudes of community members tended to be discriminatory and disempowering of people with disabilities, and disabled people were seen as objects of pity and charity. Many of these attitudes are based on traditional beliefs about causes of disability, associated with bewitchment, punishment for wrong-doing or neglect to perform certain cultural rituals. Often disability is equated with illness, and thus a disabled person does not need to accept any responsibility in everyday life - for s/he should be busy trying to get better (Driedger 1989).

The medical and "personal tragedy" model of disability most often adopted by professionals assumes that a disabled person's experience is determined by his/her medical or physical condition. This assumption, together with the control that the institutions of health and welfare have over disabled people, reinforces their sense of powerlessness (Morris 1991) so further disabling them.

The emphasis on *society's* disabling effects means that each individual needs to examine his/her own attitudes and behaviour towards people with disabilities. Disability is not a distant problem "out there" - it brings a personal challenge to discriminatory attitudes and behaviour.

7.1.6 Addressing needs *and* rights towards empowerment

Much of the practice in the field of disability has been based on the needs model of dependent people described by Rappaport (1981). The present study has indicated the weaknesses of this model, and its tendency to be disempowering and oppressive of people with disabilities, in that "needs" can be determined arbitrarily by professionals. In counteracting this, there is the recognition that disabled people are not so much dependent children in need as *citizens with rights*. This change of perspective is central to creating relationships of equality between disabled people, other citizens and professionals.

The debate about rights of disabled people should not be viewed in isolation. Indeed, the legacy of apartheid in South Africa is characterised by human rights abuses and the Government of National Unity faces an enormous challenge in creating a "human rights culture". This "human rights culture" needs to be actively nurtured at all levels of society, for "democracy and tolerance do not seem to be the natural human condition. It is not merely enough to remove the obstacles in the way thereof. The *recognition and protection of human rights needs to be fought for continually*, and democracy has to be treasured and practised every day" (van der Westhuizen 1991 p.183 my emphasis). This is crucial if any constitutional and legal guarantees of human rights are to be effective. This "human rights culture" needs to permeate all sectors of society. Among others, the provision of health care services "has to be based on the acceptance of the fundamental principles of human rights" (Sefularo 1993).

Notwithstanding the recognition that rights of people with disabilities are integral to the broader struggle for human rights, it has been suggested that there is a male bias to the morality of rights (Belenky 1986). The argument for this is that people operating within a rights morality - more commonly men - evoke the metaphor of "blind justice" and rely on abstract laws and universal principles to adjudicate disputes and conflicts between conflicting claims impersonally, impartially, and fairly. The author contrasts this view with that of people operating within *a morality of responsibility and care* - primarily women - who reject the strategy of blindness and impartiality. Instead, women argue for an understanding of the context for moral choice, claiming that the needs of individuals cannot always be deduced from general rules and principles and that moral choice must also be determined inductively from the particular experiences each participant brings to the situation. They believe that dialogue and exchange of views allow each individual to be understood in his or her own terms. The argument is that mutual understanding is most likely to lead to a creative consensus about how everyone's needs may be met in resolving disputes (Belenky 1986).

This perspective gives some very useful insights into the present discussion, for it points to the need for people with disabilities to be viewed within their own context (poverty being one of particular vulnerability) and on their own terms. It also affirms the social model of disability - i.e. that disability is not just an individual problem, but one that impacts on and is influenced by the wider community.

Although the adoption of explicit policies on disability and disability rights may seem like an ideal goal, such a goal is in danger of ignoring the existence of the morality of responsibility and care. Instead, "The best policies may be those which create *the enabling environment* within which the best informed choices between alternatives can be made" (Lund 1992 p.67 my emphasis). Perhaps in this way, it is possible to nurture *both* a human rights culture *and* a morality of responsibility and care.

7.1.7 The role of professionals

By virtue of being "qualified experts", and administrators of the institutions of health and welfare, professionals have the power to restrict or deny the rights of disabled people, and to adopt a needs-based approach in which they determine what disabled people need.

In contrast to this, adopting the empowerment approach to disability means that professionals become partners and "collaborators" with disabled people in their struggle against a disabling society. Those who come from privileged backgrounds have much to learn from the experience of life of the majority of (urban poor) disabled people. The empowerment approach is an attempt to address the imbalances of power, and to use resources provided by the State and welfare sector not to promote an attitude of dependence and disempowerment (Venkatesh 1992), but one of self-confidence and dignity. Resources from the health and welfare sectors (among others) are desperately needed but "the challenge is not only to provide services to meet the needs [of disabled people] but to provide them in a manner that does not create dependency and a devalued status" (Locker 1983 p.199). These resources could effectively be made available through community development initiatives that are committed to the empowerment of the poor, providing a mechanism by which professionals place their expertise at the service of disabled people. In this way, there is the potential for professionals to become agents of change, catalysts of development in which disabled people play an integral role.

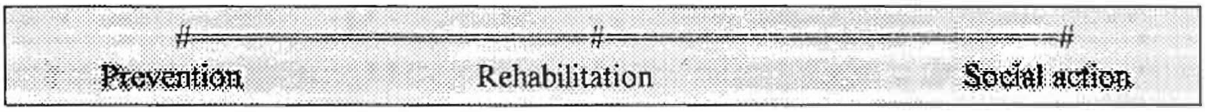
7.2 A new conceptualisation of disability

7.2.1 Describing a new conceptualisation of disability

If real progress is to be made in the field of disability, and in the lives of the disabled poor, it will be essential to adopt a new conceptualisation of disability. This will enable the breaking out of the disempowering restrictive model in which disability is viewed primarily as an "individual tragedy" and medical problem. While not denying the reality of the personal experience of disability, there needs to be a recognition that disability is not primarily a health or welfare issue. The problems of disabled people are those of *"underdevelopment" and discrimination* (Rowland 1992) and addressing disability is thus a question of development (addressing poverty, dependence and powerlessness) and of protection of human rights.

What does a changed understanding of disability mean for practitioners in the fields of development, health and disability? Firstly, there is the challenge to look beyond the medical paradigm in its definition and response to disability, and to learn from the disciplines of social science, and other areas of academic endeavour, such as community psychology and development studies. These provide valuable tools with which to explore both individual and societal problems (disability being one) and describe different approaches in addressing them. This means making the link, both conceptually and practically, between the fields of community development, primary health care and community-based rehabilitation. In addressing poverty and "underdevelopment" associated with disability, solutions lie in the fields of development and economics, just as they do in the health, education, welfare and other sectors.

Secondly, there is a need to focus not only on the *impaired individual*, but also on the *disabling world*. The struggle of disabled people has been likened to the struggle against apartheid. It is a struggle for liberation from oppression, from discrimination, from being viewed as "second-class" citizens. It is a struggle for the right to be different in the "rainbow nation". Perhaps much of the energy spent in teaching people to fit into society or to be "as normal as possible" would be better channelled into community development efforts that work for human - and disability - rights, and challenge the dis-integrative attitudes and practices towards disabled people. Unless this is done, society's attitudes and practices will continue to be disabling and excluding, even when disabled people have mastered all the physical or social skills that professionals can teach them.



Acton's (1981) schematic representation of the interaction between the various responses to disability (prevention, rehabilitation and social action) is useful in working towards this new conceptualisation. The medical approach to disability has limited the focus to the central component - *rehabilitation*. Following the argument presented earlier, *prevention* of disability means involvement in community development activities, addressing issues of poverty, powerlessness and dependence which contribute directly to disability. *Social action* means going beyond the individual-therapy centred approach, important though this is, to look at the community and society of which people with disabilities and professionals are members. It means challenging the "disabling world" which violates the rights of some of its members, and it means addressing barriers that prevent the integration of disabled people - both at policy level and through grassroots action.

Adopting a new conceptualisation of disability means addressing factors that lead to discrimination and exclusion of disabled people from society. This is a matter of justice, not of charity. By creating an *environment of equality* (Nyathi 1986) the general system of society is made accessible to all, thus empowering people with disabilities, and not segregating them from mainstream society (Bowe 1990). This cannot be dependent on the (unreliable) goodwill of members of society - there is a need for definite policies on equal opportunities, which are enforceable through legislation.

7.2.2 Role differentiation

South Africa's Government of National Unity faces a particular challenge in creating a new ethos of participatory democracy. This means developing a "listening culture", so that civil society can teach the State what society needs (Swilling 1992) and this includes appropriate ways of addressing disability issues. A new conceptualisation of disability means reviewing the roles played by different community and State groups, and exploring ways in which they can contribute to the creation of a more "enabling world". The groups identified as playing specific roles with regard to disability are community interest groups, disabled people's organisations and State structures.

(a) Community interest groups and organisations:

- Civic
- Development project
- Youth
- Business owners
- Landowners
- Church leaders

(b) Disabled people's organisations

(c) State structures

(a) The roles of community interest groups and organisations

Organisations active at community level have the potential to play important roles in addressing disability issues. Some of these are general roles, that all of them play, and others are more specific. In this discussion, the general roles will be described, and this will be followed by a description of the specific roles of different groups.

- Firstly, community organisations have a responsibility to *educate* community members about the causes and prevention of disability. This includes basic health education, as well as awareness-raising about the negative consequences of discrimination and exclusion of disabled people from the mainstream of community life. Community members also need to be informed about ways that they can challenge the "disabling world".

- Secondly, community groups can play an active role in *supporting and collaborating with local disabled people's organisations.* This may be done through combined activities in working around common issues - such as access to water, housing or education.

- Finally, community organisations have the responsibility to *promote a climate of inclusivity.* Basic to this are positive attitudes towards all people, regardless of their disabilities, and a commitment to serving all members of the community. This means provision of physical accessibility to local churches, shackshops and other public amenities, and it means inclusion of disabled young people in choirs or drama groups that may be active in the area.

In addition, there are some specific roles that the following interest groups could play in Amawoti, and each will be discussed in turn:

Photograph 7.1 Civic members in Amawoti support a disabled woman in obtaining a wheelchair

(i) Civic structures

In fulfilling their recognised role as the "father of the community", the civics have a wide range of responsibilities to disabled people as well as to other residents of Amawoti, but (as yet) they have minimal physical resources. It is their advocacy role that is crucial, as is their potential to interact with and influence a number of resource groups - including the State. Increasingly the civic structures are to play the role of "watchdog" of local government. This means that the civics bear a particular responsibility to ensure that public services, including those of health and education, are accessible to all community members. Not only do civic structures have the potential to recognise and affirm the rights of disabled people, they also can begin to set in place "appropriate and effective policies and legislation as well as accountable services... which are enforced to provide all disabled people with opportunities for the full enjoyment of all these rights" (DPSA 1993).

(ii) Ilimo Project

The concept of "*ilimo*" is one that implies community co-operation and mutual support, and it is a spirit that the Project has aimed to foster through its various activities in Amawoti. This concept should have practical implications for the relationship between able-bodied community members and those who are disabled - a relationship of mutual respect and support, not one of pity and charity. The Ilimo Project could play a crucial role in facilitating the process of building "essential alliances" in which *both* disabled people *and* other residents of Amawoti are contributors. In providing particular services, the Ilimo Project staff need to look very critically at whether such services are truly accessible to and inclusive of disabled people. This includes the building programme and the production groups. Indeed, the realisation that disabled people are among the poorest and most oppressed residents of Amawoti, should enable staff of the Ilimo Project to consider the issue of disability in all of their activities. Its very nature as a primary health care project, means that Ilimo has the responsibility to support initiatives that address the right of disabled people to health and rehabilitation (DPSA 1993).

(iii) Youth

The youth of Amawoti have little in terms of physical resources to offer disabled people. However, an invaluable resource that they do possess is their energy, their vision of the future and their history of fearless commitment to addressing issues of injustice and exploitation experienced under the Nationalist government. Should the politicisation of the youth be extended to include the understanding that disabled people are an oppressed group within Amawoti, there could be far-reaching effects, for it would mean that the struggle for human rights in which the youth have so actively participated, would be inclusive of people who are oppressed because of their disabilities.

(iv) Business owners

The business owners in Amawoti could play a role in contributing to the practical, "survival" needs of disabled people through the contributions of finance or in kind (e.g. food). However, they could go beyond this very limited ("charity") response, and provide opportunities of employment of disabled people within local business. Business owners could also make a valuable contribution by ensuring that their services are physically accessible (e.g. providing ramps up steps, and assistance onto taxis). In order to minimise the potential danger of a "charity mentality" developing, (with businesses giving to disabled people out of pity or guilt), it is important that partnerships of mutual accountability and respect are developed between the two groups. This would also protect businesses from exploitation by disabled people (and other groups in Amawoti), as numerous demands are made on them.

(v) Landowners

Landowners are important decision-makers for the future physical development of Amawoti. At present, negotiations are on-going with private development companies who are looking to buy land and provide the infrastructure for a more formal "township". As players in the development process, it is important that the landowners are aware of the diversity of needs of their tenants, including those with disabilities. Flexibility and understanding of disability issues on the part of landowners would help to ensure that disabled people secure their right to homes.

(vi) Church leaders

The greatest contribution that church leaders can make to disabled people in Amawoti is to influence positively the meaning that community members give to disability. This means addressing the cultural beliefs and interpretations of disability, to reveal the discriminatory and oppressive attitudes that they mask. It means preaching and living the message of God's concern for the most rejected, oppressed and marginalised in society. It means the acceptance of people with disabilities as members of the community, with the church being exemplary in its actions of love. The church plays an important role not only in providing "meaning" to disability, but also opportunities for disabled people to participate in community life and to be accepted for who they are, as those who are fully human and children of God.

(b) The roles of organisations of disabled people

Organisations of disabled people have a unique role to play in addressing disability issues in society - indeed, their very existence indicates a claiming of the right to self-representation (DPSA 1993), rather than being represented through health and welfare professionals. The slogan of Disabled People South Africa "nothing about us without us" indicates their determination to participate in decisions and processes that affect their lives. These organisations can play a number of diverse, yet integrated roles.

- Disabled people's organisations play a crucial role in *advocacy*. These groups provide the means by which disabled people advocate for their own rights to influence decision-makers in governments and all sectors of society (Driedger & Enns 1987).

- They can also play a role in *organising and lobbying* around particular issues which are of concern to their members. Such constituency-based organising to put pressure on the decision-makers is essential if disability is to be regarded as a priority issue in competing with other welfare needs (Lund 1994).

- Disabled people's organisations can play a crucial role as *consultants and participants* in relation to service-providers in the field of disability. By virtue of the fact that their members are consumers of health and welfare services, disabled people's organisations can give valuable input into setting priorities, and into the planning, implementation and evaluation of such services. This involvement is essential in order to ensure the accountability of service-providers.

- The membership base of a disabled people's organisation provides a mechanism for *monitoring* at community level. Regular group activities and meetings provide the means by which regular contact is kept between people with disabilities, thus allowing for addressing of problems as they arise, as well as feedback about members' successes.

- It could be argued that the most important role of disabled people's organisations is that of *changing perceptions about disability*. Collective activity, and the fostering of group identity by such organisations, can help to address the isolation of individual disabled people, and facilitate the process by which problems of exclusion and discrimination are understood as issues of power. Disabled people's organisations have the potential to challenge disempowering, patronising and dependency-creating attitudes and behaviour, and to nurture the perception of disabled people as contributors within the community.

(c) The roles of State structures

The roles of the government in responding to issues of disability are seen to be influenced by factors operating within the country and within the wider international community.

The Reconstruction and Development Programme (RDP) is the socio-economic policy framework that forms that basis for development of the "new" South Africa, under the Government of National Unity. Its key programmes relate to the meeting of basic needs, developing human resources, building the economy and democratisation of the State and society (ANC 1994b).

Internationally, the World Programme of Action Concerning Disabled Persons (WPA) was adopted at the beginning of the Decade of Disabled Persons (1983-1992). Its purpose was to promote effective measures for prevention of disability, rehabilitation and realisation of the goals of "full participation" of disabled persons in social life and development, and of "equality". This meant ensuring that disabled people have opportunities equal to those of the whole population, and an equal share in the improvement in living conditions resulting from social and economic development (UN 1983). It was recommended that governments undertake to implement the WPA, and a number of strategies for achieving this at national level were proposed:

- participation of disabled people in decision-making;
- prevention of impairment, disability and handicap;
- rehabilitation and
- equalisation of opportunities for disabled people.

Although the Decade of Disabled Persons has come to an end, the international community has not wanted to lose the gains made during this period, and in 1992 the United Nations undertook to further the implementation of the WPA to the year 2000 and beyond (UN 1992). The strategy to achieve this has been to put particular emphasis on:

- promotion of rights of persons with disabilities;
- promotion of the community-based rehabilitation approach;
- promotion of independent living;
- enhancement of economic independence and
- development of appropriate legislation.

Recently the General Assembly of the United Nations adopted the Standard Rules on the Equalisation of Opportunities for Persons with Disabilities (UN 1994), as an instrument for policy-making which would help to ensure that disabled persons, "as citizens of their societies may exercise the same rights and obligations as others" (UN 1994 p.6).

The programmes of the RDP and the goals of the WPA (both past and future) are very closely linked. Indeed, one could view the WPA as providing the guidelines by which the RDP becomes a reality for people with disabilities. Already this is starting to happen - for the National Health Plan for South Africa (ANC 1994a) specifically identifies people with disabilities as a vulnerable group in society, and makes the recommendation that community-based rehabilitation be used as the strategy to address their problems, and promote their interests.

7.3 Policy considerations

The factors outlined here as considerations in policy formulation, are not made in isolation, but recognise the broader national context of South Africa, as well as the international community.

7.3.1 Government service provision

Government service provision, within all sectors, should be based on principles of *accessibility*, *integrating disability and development* and *participation*.

(a) Accessibility

Enabling all members of society to have access to particular services means the creation of an "environment of equality" in which people with disabilities have the same access as others to available resources. This may require legislation to ensure that disabled children have access to community schools, and it may mean creating physically accessible school facilities. It may even mean flexibility in terms of age of admission. Such accessibility would enable disabled children to acquire social and academic skills, thus facilitating their social integration.

Guidelines for the creation of this "environment of equality" are provided by the Standard Rules of the Equalisation of Opportunities for Persons with Disabilities (UN 1994). Through the equalisation of opportunities and programmes of affirmative action skewed towards those that have been historically disadvantaged (the disabled poor), the government can work towards equity of service provision.

There needs to be a particular emphasis on addressing the situation (of powerlessness and dependence) of disabled people in informal settlements. This may be done through re-orientation of existing services - which include health, welfare, education, housing, security, development - so that they become accessible to this group.

(b) Integrating disability as part of development

Earlier in this study it was argued that addressing disability means addressing issues of poverty, dependence and powerlessness and the violation of rights of disabled people. Interventions should not be restricted to the health and welfare arenas - instead disability must be viewed as an issue of development. Adopting the new conceptualisation of disability in implementing the RDP would mean that disability issues are integrated into programmes to improve the quality of life of all citizens of the country. This approach, combined with a commitment to improved accessibility and equity in the provision of services, will do much to ensure the integration of people with disabilities into the mainstream of community life.

A cornerstone of development is that of provision of employment opportunities for disabled people. The creation of employment opportunities is central to the RDP, but the challenge is to ensure that these are available to people with disabilities, on a basis of equal opportunity. Since 1992 DPSA has been lobbying the African National Congress for a 2% quota system to ensure affirmative action in the workplace, but this recommendation has not yet been adopted by the State. It will be necessary for such lobbying by organisations of disabled people to continue, applying the principles of equal opportunities to all development activities that occur within the framework of the RDP.

(c) Participation

An essential task for the Government of National Unity in implementation of the RDP is to facilitate the process by which there is active involvement and growing empowerment of its citizenry (ANC 1994b). For this to be possible, there must be the provision of mechanisms for the *participation* of consumers in setting priorities, planning and implementation of programmes that affect them (Nkedi 1989, SAHSSO & PPHCN 1993). This points to the need for health, welfare and education systems (among others) that serve the people, but also involve them, systems that address the needs of the clients but at the same time empower them.

An approach which combines these three key factors - accessibility, integrating disability and development, and participation - is that of community-based rehabilitation, for "*CBR is a strategy within community development for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities*" (WHO 1994b p.iii). Community-based rehabilitation could be understood as the democratisation of rehabilitation, a strategy of empowerment of people with disabilities. The Government of National Unity, in consultation with disabled people's organisations and structures of local communities, must seek to implement this strategy as part of the RDP and in accordance with the National Health Plan for South Africa (ANC 1994a). Future policies on disability need to go beyond transfer payments (which has tended to be a focus in the past) to include laws and programs related to education, social and economic rehabilitation, and civil rights (Barnartt 1992).

7.3.2 Professionals working in the field of disability

In South Africa to date, the fields of disability and rehabilitation have been dominated by white middle-class professionals, who have been operating from the medical paradigm of disability. By virtue of having access to knowledge and resources, this group has had the power to define what disability is, as well as to strategise "appropriate" responses or interventions (Oliver 1990). For too long their race and class, and their "professionalism" have preserved their distance from the issues of disability faced by urban poor communities.

There is a need for re-orientation of professionals from theory and practice based on the medical paradigm of disability, towards the development of a more social understanding of disability. This means that training must be grounded in the concepts of community development, primary health care and community-based rehabilitation, with inputs from the fields of development studies and community psychology. The training should facilitate the process by which professionals learn to work as partners and collaborators with disabled people and community groups; *listening*, as those who were traditionally "non-experts" become the experts, charging professionals to re-think much of the theory and practice in the field of disability.

7.3.3 Creating an enabling environment for community organisations

During the decades of governance by the National Party, a large number of non-governmental organisations (NGOs) and community-based organisations (CBOs) were initiated. Many of these were attempts to "fill the gaps" in poor (mostly black) areas in which State services were inadequate or non-existent. These groups also played an important role in opposition politics within the progressive sector. In 1994, a democratic Government of National Unity (with an African National Congress majority) was elected into power, and it has made a commitment to addressing the pressing needs of the majority of people in the country through the RDP. Is there then still a need for NGOs?

Bernstein (1994) presents a very clear argument for the future of NGOs in a democratic South Africa: Firstly, they have the potential to ensure quality of services, by advocating the interests of those who have been ignored or marginalised. Secondly, NGOs can assist the State in providing for the social and physical needs of the population by harnessing community and individual energy towards this end. Thirdly, by virtue of their flexibility, NGOs have the potential to respond more creatively to local problems of poverty than do State departments. In this way, they can promote innovative policies and new approaches to social problems.

If community organisations (including those of disabled people) within the informal settlements are to perform such functions, there needs to be support for them, there needs to be *capacity-building* (ANC 1994b). Clark & Bekker (1994) propose that this be done in two ways viz. through sensitive community involvement in the development process, and through training. The latter includes organisational and institutional development, administration, and record-keeping. The RDP (ANC 1994b) suggests that the process of capacity-building be facilitated by the State, and funded through a variety of sources. In addition, the report of the Independent Study into an Enabling Environment for NGOs (Bam et al 1993) recommends that civil society be empowered by the constitution to participate in public life. While this is commendable, there must be avoidance of the danger of cooption of NGOs by the State, so that they come to be seen as an extension of the arm of the government (Kajese 1990).

7.3.4 Research on disability

It is imperative that research on disability is socially useful and conducted within the action research and emancipatory research paradigms. This needs to be done in consultation with disabled people and their organisations to ensure the research is not used an instrument of oppression. This means the researcher making explicit the commitment of the research to pursuit of equity and social justice for people with disabilities.

Out of this study, it has become evident that a number of priority issues and questions could be pursued in future research. These include:

- What is the impact of traditional beliefs about disability on community-based programmes?
- How can disability issues be addressed through the RDP and other development programmes?
- How can community-based rehabilitation be implemented at national and district levels as part of the National Health Plan for South Africa?

Towards a more integrated and inclusive society

This study has sought to explore the perceptions of members of an informal community with regard to issues of disability. The results that emerged have confirmed the existence of negative attitudes, prejudices and stereotypes of people with disabilities. The empirical data, and the literature, identified one view of disability as being an "individual tragedy" and medical problem. Another view recognised the impact of the "disabling world", which leads to the exclusion and segregation of disabled people from community life. The fact that this study was based in a context of poverty has highlighted the link between poverty and disability, and pointed to the need to address disability as an issue of development, thus addressing the associated powerlessness, dependency and violation of human rights.

The issue of disability cannot be left to the health and welfare sectors to address, for it impacts on every sector of society.

> "We must never forget that society holds a tremendous responsibility for the existence of disability in its midst. The obligation to respond is greater than that of caring for the less fortunate; it is a matter of correcting a flaw in our culture, a flaw that has denied to millions of people the human rights that we have declared for everyone" (Acton 1982 p.148).

Within South Africa, a non-racial, non-sexist, democratic government has been elected to power. There is the potential to build a society that accepts and values diversity as much as it does conformity, and to promote lives of interdependence. There needs to be nurturing of a "human rights culture" together with a morality of responsibility and care, in which "interdependence is our equality" (Doe 1992 p.48). South Africa has been referred to as the "rainbow nation" and certainly "society needs difference and colour and variety, and each human being should have the right to contribute his or her uniqueness" (Hurst 1992 p.28). The challenge is to ensure that this diversity extends to those that traditionally have been amongst the most marginalised and oppressed in society - the disabled poor. Indeed, the changes that will make a better society for disabled people to live in will make a better society for everyone to live in.

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APPENDIX: FOCUS GROUP INTERVIEW GUIDE

1. Introduction

Opening prayer
Welcome and introduction of participants
Explanation of aims of the discussion
Setting the ground rules

- all contributions welcomed
- request to use tape-recorder

2. Questions

2.1 Defining disability

(a) What is disability? What do you think of when you think of disability?
(b) How would you describe a disabled person?
(c) What are the causes of disability?

2.2 Behaviour towards disabled people in Amawoti

(a) How are disabled people treated in Amawoti?
(b) What is their situation here?

2.3 Problems and needs of disabled people

(a) What do you think are the major problems facing disabled people in Amawoti?
(b) Do you think the needs of disabled people are the same or different to those of able-bodied people?

2.4 Rights of disabled people

Do you think that disabled people have special rights?

2.5 The Amawoti Disabled People's Association

Do you know anything about this organisation?

2.6 Interventions

(a) How could people in Amawoti help to improve the situation of disabled people here?
(b) How could you improve the situation of disabled people?
(c) How could the situation of disabled people be improved by the Amawoti Disabled People's Association?

3. Explanation of the aims and activities of the Amawoti Disabled People's Association

4. Thanks and closure