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**BARRIERS EXPERIENCED BY PEOPLE WITH PERMANENT
LOCOMOTOR DISABILITIES: A CASE STUDY IN LOTUS RIVER**

Thesis submitted in fulfilment of the requirement for the degree of Doctor of
Philosophy of the Department of Social Development, Faculty of Humanities,
University of Cape Town

By:
Merle Futter

Supervised by:
Assoc Prof André Smit
Dr Lionel Louw

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A social gathering for the disability grant beneficiaries arranged by the Western Cape Project for the Physically Disabled (WCPPD) at the end of the research conducted in Lotus River. From left to right: President Thabo Mbeki, Marthinus van Schalkwyk (Premier of the Western Cape) and the researcher. Some of the recipients are seated in their wheelchairs in the foreground.

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ABSTRACT

People with physical disabilities are largely excluded from the mainstream of society by barriers that prevent their participation. This is particularly so in disadvantaged communities where the disabled are the poorest and most vulnerable of the population.

AIMS

The aims of this study were to

- determine and explore the nature and extent of the barriers confronting the disabled with permanent locomotor disabilities;
- improve their quality of life as well as that of their caregivers by providing them with wheelchairs, mobility aids, assistive devices and concrete ramps and pathways; and
- propose a model Integrated Intervention Programme that could be used in similar disadvantaged communities throughout South Africa.

METHODS

A comprehensive community profile of Lotus River, Lavender Hill, Retreat, Steenberg and Grassy Park was compiled before the research was conducted in order to provide an accurate background of the focus groups, people with disabilities and their caregivers.

A cross-sectional design using a 'multi-method' approach of both qualitative and quantitative methods of research was used.

Six focus groups were utilised to identify the barriers that confronted the disabled in their activities of daily living and a questionnaire was developed based on their findings.

Interviews were conducted with the entire population of 81 people with locomotor disabilities who lived in Lotus River. They were identified by means of the disability

grant beneficiary list of the Department of Social Services and Poverty Alleviation, snowballing and referral from community health centres.

The extent to which the barriers affected them were measured by means of a questionnaire.

Their needs for wheelchair, orthopaedic appliances and small building alterations were assessed and they were supplied with the appropriate equipment by means of funding obtained from the Department of Social Services and Poverty Alleviation and, AllPay, a private agency which paid out their disability grants. They and their caregivers were taught how to use the equipment and to maintain it. Evaluation interviews regarding the effects the equipment had had on their quality of life were conducted six months after they received it.

FINDINGS

More than 60% of the participants did not experience any problems with safety, unemployment, isolation and loneliness, domestic assistance, attitude of the community, abuse and health.

However, lack of money, transport, housing, health services, social services and accessibility were found to be substantial problems which severely affected their quality of life and ability to participate in society.

CONCLUSION

This is the first research in which the barriers of the disabled have been studied within a specific community and an effective partnership has been formed with a private company and government department to address the mobility and functional needs of the most vulnerable of the population in South Africa, namely, people with disabilities living in a disadvantaged community.

The wheelchairs, mobility aids, assistive devices and small building alterations increased the level of independence of the disabled significantly and substantially improved their and their caregivers' quality of life. For a small amount of money it was possible for them once more to take an active role in their families and to participate in social activities and events in the community.

Wheelchairs became a fundamental means of transport to attend hospital and clinic appointments to obtain essential medication to prevent deterioration in their medical conditions and further complications from developing and leading to additional disablement. They also provided a means for the disabled to personally obtain their disability grants.

Furthermore a successful recycling programme was developed and sustained by a community worker who was trained to measure, fit and teach the disabled how to use the mobility equipment. He monitored the health of the disabled and the use of the equipment and when the disabled died he was able to allocate their appliances to the next persons in need on the waiting list in the community.

An Integrated Intervention Programme developed as a result of this research is described in terms of structure and process. This programme can easily be replicated and sustained by community workers in other disadvantaged communities.

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PREFACE

As Lotus River was established during the era of 'apartheid', the conventional South African terminology for describing the races of the different people during this period was used. 'White' was used to refer to the descendants from European settlers, 'Black' for African people and 'Indian/Asian' for people of Asian descent. 'Coloured' was the term used to describe those people who were legally classified as being of mixed descent.

For convenience and simplicity 'disabled' was used in general terms and included handicap and impairment. It was used interchangeably with 'people with physical disabilities' and 'people with locomotor disabilities' as the term 'locomotor' is not a term with which lay people are familiar. Therefore, all documentation which the participants had to read referred to the term 'physically disabled' although in some cases the participants also suffered from additional mental or cognitive disabilities. The terms 'physically disabled', 'disabled people' and 'people with disabilities' are accepted by the disability rights movement of South Africa (DPSA, 2001).

The terms 'caregivers' and 'carers' were also used interchangeably.

'Participants' refer to 'people with locomotor disabilities' and/or their 'carers' where appropriate.

'Appliances' refer to wheelchairs, mobility aids and assistive devices.

The home language of the majority of the population in Lotus River was Afrikaans. Although they were all able to understand English there was a section of the population which could not speak the language. As the researcher was

able to converse, read and write fluently in both English and Afrikaans the need for an interpreter was unnecessary.

For ease of reading the results together with the related figure/table/photograph have been printed on the same page. Where necessary, a copy of the appropriate table and items of the Lotus River Questionnaire Appendix (iv) appear on the opposite page.

The researcher is a physiotherapist and not a social worker. She wished, however, to investigate disablement beyond that which the medical model offers, namely, prevalence of physical disabilities as this has been done in many studies. This is the first study in South Africa in which disablement has been researched from a social model perspective where the barriers of society confronting the disabled have been identified and investigated and an integrated intervention programme has been implemented to improve their quality of life.

CHAPTER ONE

INTRODUCTION

1.1 INTRODUCTION

Lotus River is one of the low-income suburbs in Cape Town where the vast majority of people with permanent physical disabilities receive a disability grant rather than any form of private insurance. It is typical of most of the suburbs on the Cape Flats and the problems the disabled experience are, to a greater or lesser extent, shared by the disabled living in neighbouring suburbs.

People with disabilities are largely disqualified and excluded from the mainstream of society and experience difficulty in accessing fundamental rights. Numerous studies have shown that even in developed countries such as the United Kingdom (UK) and the United States of America (USA) the disabled are markedly worse off than their non-disabled counterparts and that there is only limited public awareness of their existence and their needs (Daniels and Mickel, 2002; Little, 2002; Williamson, 1998; Lonsdale, 1990). In addition there is a strong relationship between disability and poverty (Martin et al, 1999; Smart and Smart, 1997). Poverty makes people more vulnerable to disability and disability reinforces dependency and poverty (Office of the Deputy President, 1997; Chamie, 1989).

People with disabilities are not a homogenous group. They range across different ages, genders, educational backgrounds, socio-economic groups, types and severity of disability. According to the social model of disability most people with a physical disability are handicapped primarily in the range of choices of housing, educational opportunities and facilities, employment accessibility, leisure and social activities that are available. These primary handicaps produce

secondary handicaps such as lack of access to material resources and the experience of poverty (Lonsdale, 1990; Chamie, 1989; Finkelstein, 1989).

In developed countries the literature focuses on disability prevalence and in developing countries the small amount that is available tends to involve community-based rehabilitation, but there is very little work available on the social and political problems which confront the disabled in South Africa.

Several authors have referred to the paucity of information on disability prevalence in South Africa and have called for research to be prioritised in order to provide epidemiological information (Frieg, 2000; Coetzee, 1997; Bhagwanjee and Stewart, 1999; Helander, 1993). Empirical data are important as they form the basis for planning of health and rehabilitation services and ensure effective legislation and policy implementation (Office of the Deputy President, 1997). However, disability prevalence research does not provide any information on the needs of the disabled once they have passed through the health and rehabilitation systems. On conclusion of their rehabilitation programmes the disabled return to their communities and together with their families have to cope with the challenges of the physical and social environments on their own without any support from the health system. In order to plan comprehensively for the needs of the disabled on returning to their homes and communities it is imperative to address their needs by researching and gaining an understanding of their economic, emotional, physical, intellectual, spiritual, social and political needs and priorities in their home and community environments. Unless the disabled are personally involved in these needs assessments the services will always be inadequate in scope and philosophy (Coleridge, 1993).

The South African government acknowledges that disability is a problem. The Integrated National Disability Strategy (INDS) White Paper claims that one of the yardsticks by which a society's respect for human rights is measured is by observing the status that it accords to those members of society who are

disabled. The concept of a caring society is strengthened and deepened when it is recognised that disabled people should enjoy the same rights as non-disabled people and that society has a responsibility towards the promotion of their quality of life. The INDS White Paper also acknowledges the importance of contributing to the development of disabled people by developing partnerships with them so that they are involved with the promotion of joint objectives for their advancement. It has identified key areas which need to be addressed, namely, prevention; health care; rehabilitation; public education; barrier-free access; transport; communications; development social welfare and community development; social security; housing and sport and recreation (Office of the Deputy President, 1997).

However, even though the government recognises disability as a problem, it is not perceived as a priority as it presently has to deal with essential necessities such as housing, access to land, unemployment, poverty, basic health care, electricity and clean water for the majority of the population in the country.

1.2 MOTIVATION FOR STUDY

The author has had many years of experience as a rehabilitation physiotherapist working with people with disabilities during the acute stage in hospital as well as during the chronic stage of rehabilitation in Community Health Centres (CHC) and in their homes.

There is a tendency for society to view people with disabilities as a single group, ignoring the diversity of disability and the variety of needs experienced by people with different types of disabilities. Disability needs to be understood as a social construct where it is more than just an individual problem. It has a social context in which certain meanings are attributed to having a disability. These allow social roles to have a profound effect on the life chances of the individuals, both

objectively in what is on offer for them and subjectively in terms of which they perceive themselves to be capable.

Full rehabilitation often means months of attending outpatient clinics and CHC's after the trauma or onset of illness. When the disabled have achieved their optimal level of functioning they are discharged home and into the community. Many of them are assessed as being 'fully independent' by the rehabilitation therapist albeit sometimes with assistive devices, mobility aids or the help of a caregiver.

It was during the home visits in Lotus River that the author became disillusioned with the medical model of rehabilitation where the disabled completed their time-consuming and expensive rehabilitation programmes and returned to their home environment where they were unable to perform basic activities of daily living which they were able to achieve in hospital or the outpatient physiotherapy department.

In the physiotherapy departments where rehabilitation takes place there is a large amount of uncluttered space and the floor is smooth. The doorways are wide and there are steps for the disabled to learn to ascend and descend. These have well-positioned handrails at the appropriate level for the individual. In other words, the disabled achieve their maximum function in an optimal environment.

However, once they return to their dwellings in Lotus River the environment is very different. The rooms are cluttered with furniture and the doorways are narrow and, frequently, partially blocked by furniture. The floors have ill-fitting mats with ends turned up which make the surface difficult and dangerous to traverse. Steps to the front and backdoors do not have handrails making it impossible for the disabled to negotiate them independently. The hand rails that have been built in the blocks of flats do not extend to the top and bottom steps and are situated on only one side of the flights of stairs.

Once the disabled achieve their maximal functional level in hospital or CHC and are discharged home there are no follow-up visits done to the homes by the physiotherapists and the disabled and their families are expected to adapt to the physical difficulties in their home environment by themselves. Most of them are unable to achieve this. They lose their independence by not being able to function in the challenging environment and gradually deteriorate and lose the confidence and ability to function at the level they had achieved before being discharged. Thus, once home, it is not the medical and technical aspects of rehabilitation that impact on their level of independence and quality of life, but the physical and social barriers of the environment.

Prevalence rates of disablement may be important to plan and provide services, but once the disabled leave rehabilitation they actually are faced with barriers which the medical model of rehabilitation does not address. It was for this reason that the author was motivated to research the barriers which confronted the disabled living in Lotus River. To the author's knowledge there has been no research done on the barriers experienced by the disabled themselves living in a specific geographical area of South Africa. The current study was planned in order to investigate these barriers as Katzenellenbogen et al (1997: 164) recommend that "In the absence of adequate routinely available health data, sample surveys may be the only way to investigate health issues in specific communities ...". Research is the best way of attempting to have valid and reliable information if the barriers are to be removed and the services and resources needed by the disabled are to be accurately identified. Additional research data can only help to improve the services already available and provide data for the advocates trying to improve the quality of life of the disabled.

The researcher interviewed 31 (38%) disabled women and 50 (62%) disabled men during the fieldwork period. There are parallels between disability issues and issues surrounding the role of women generally (Abu-Habib, 1997;

Coleridge, 1993; Lonsdale, 1990) and this research is, therefore, representative of both disabled women and men.

For the author the time spent in the Lotus River community was a very informative experience. It was most extraordinary and inspiring to see how the disabled and their families, often under the most desperate of circumstances, coped with their situations without any bitterness or expectations of support. Negative aspects of their living conditions, such as overcrowding, became positive factors when the disabled reported that they did not feel lonely, isolated or helpless as there were always other people in the dwelling or on the property with whom they could talk and who were willing to assist them with activities of daily living.

The information gathered by this research will be sent to the departments of housing, roads and sewerage, transport, health and welfare and to the Disabled People South Africa (DPSA) to assist them with service planning and advocacy.

1.3 AIMS OF STUDY

- To determine and explore the nature and extent of the barriers experienced by people with permanent locomotor disabilities residing in Lotus River;
- To improve the quality of life of the disabled and their carers by providing them with wheelchairs, mobility aids, assistive devices and small building alterations; and
- To develop a model Integrated Intervention Programme that could be used in similar disadvantaged communities throughout South Africa.

1.4. OBJECTIVES OF STUDY

- To conduct a community profile of the suburbs in which the research took place;
- To identify all the adults with permanent locomotor disabilities living in Lotus River;
- To identify the nature and extent of the barriers experienced by the disabled in their activities of daily living;
- To gather demographic data with respect to age, gender, family status, educational level and employment status of the people with disabilities;
- To compile a disability profile of the disabled;
- To assess the needs of the participants with regard to wheelchairs, mobility aids, assistive devices and minor building alterations;
- To provide the people with disabilities with appropriate appliances to optimise their level of independence;
- To gather data on the financial status of the participants;
- To investigate the problems the people with disabilities experienced with regard to different modes of transport;
- To gather data on the houses and living environments of the disabled;
- To compile a profile of the type and level of social support of the disabled;
- To investigate the utilisation and needs of the health services by the participants;
- To investigate the utilisation and needs of the social services by the people with disabilities and their carers;
- To determine the attitude of the community towards the people with disabilities;
- To determine the nature and extent of the environmental barriers confronting the disabled;
- To investigate the nature and extent of abuse suffered by the disabled;

- To investigate the nature and level of discrimination experienced by the people with disabilities and their parents;
- To determine the level of knowledge the participants and carers had of patients' rights and responsibilities;
- To empower the people with disabilities and their carers by informing them of patients' rights and responsibilities;
- To determine the extent of caregiver utilisation by the people with disabilities;
- To compile a burden profile of the caregiver;
- To empower the participants by providing them with information regarding the health, social and support services;
- To determine the level of knowledge the participants had of HIV/AIDS; and
- To increase their awareness and provide them with information on HIV/AIDS.

1.5 OUTLINE OF RESEARCH DESIGN AND METHODOLOGY

A cross-sectional design using a 'multi-method' approach of both qualitative and quantitative methods of research was used.

A comprehensive community profile was compiled of the suburbs in which the research was undertaken and in which the focus groups were conducted. Focus groups were utilised to identify the barriers which confronted the disabled within their communities.

The disabled with permanent physical disabilities were identified by means of the disability grant beneficiary list obtained from the Department of Social Services and Poverty Alleviation (DSSPA), referral and by snowballing. Interviews were conducted with 81 of the total disabled population of 84 to record the nature and extent to which the barriers affected them.

Wheelchairs, mobility aids and assistive devices were provided and concrete ramps and pathways were built for those in need in order to improve their quality of life.

After six months the disabled who had received these appliances and building alterations were interviewed to evaluate what effect the equipment had had on their quality of life.

1.6 ORGANISATION OF THE STUDY

In Chapter Two a literature review will be presented on various aspects of disability. The social and medical models of analysing disability will be described and the associated confusion with defining disability as a result of the different models will be discussed. Global prevalence and the prevalence rate in South Africa will be presented from an overall disability perspective as well as a locomotor perspective.

Problems which affect the disabled in their daily lives will be described in terms of employment, poverty, gender, race, discrimination, oppression, independence, self-image, abuse and powerlessness. Recent legislation and policies in South Africa, which will have an impact on these aspects when they come into effect, are listed and discussed briefly.

An outline of the rehabilitation process will be given and the lack of access to these services and assistive devices will be discussed.

A criticism of the inadequacies of disability grants under the umbrella of social assistance is provided and recommendations are given with regard to provision for the special needs of the disabled.

The caregiving role is discussed in relation to the cost-saving of government funds that occurs when caregivers are family members. The cost to the caregiver with regard to not being able to work and the stress of decreased income and increased physical work is presented in terms of general strain, isolation, disappointment and emotional involvement.

In view of the HIV/AIDS pandemic in South Africa it would have been indefensible not to make use of the opportunity of increasing the awareness of the disabled and their families about HIV/AIDS. This was a crucial aspect of their lives in Lotus River as the prevalence rate in the Western Cape increased from 8.6% in 2001 to 12.4% in 2002 (Caelers, 2003a) and the Ministry for Welfare and Population Development (1997) projected that the epidemic would grow exponentially to years 2005 and 2010 when between 18% and 27% of the total population of the country are likely to be infected. Therefore a section on HIV/AIDS prevalence and the effects it is having on our society at large is included and a broad outline of the HIV/AIDS situation in South Africa is provided with the effects it is having on the demography of the country. The effects of the disease on the increased number of orphans arising from maternal HIV/AIDS deaths, the burden on the elderly relatives of raising these orphans and the increased poverty in general are also discussed.

It was also an appropriate opportunity to empower the participants by making them aware of patient's rights and responsibilities.

In Chapter Three the methodology is described. The selection and structure of the focus groups are described. The process of identifying the disabled is explained and the measurement instruments are described in terms of appropriateness, validity and reliability. A brief description of the data gathering and statistical analysis is provided. The procedure of the entire research study is also described.

The findings of the barriers identified by the focus groups are presented in Chapter Four. The extent to which these affected the disabled in Lotus River are presented and discussed in relation to other research findings and the impact that prospective and new legislation will have on the lives of the disabled.

The methodology of an integrated intervention programme for people with physical disabilities, based on the research conducted in Lotus River, is presented in Chapter Five.

The conclusion in Chapter Six summarises the main findings of the research.

As it is essential to be familiar with the community in which research is to be conducted a detailed community profile of Lotus River and its neighbouring suburbs is provided in Appendix (xvii).

CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

In this chapter, literature regarding various aspects of physical disablement will be reviewed. The different ways in which physical impairments are perceived by the medical and social models will be discussed and disability and rehabilitation will be defined and explained in relation to these theoretical frameworks. The difficulties of establishing prevalence of disability in both South Africa and internationally will be presented followed by an overview of the disability grant (DG) process. An introduction to the concept of care-giving and the difficulties experienced by caregivers are provided followed by a brief overview of the prevalence and management of HIV/AIDS in SA. This is done in order to demonstrate the importance of educating and informing people at every available opportunity about prevention and the existing services available for the treatment of the condition.

2.2 MODELS OF DISABILITY

There is a plethora of theoretical approaches to disablement. These can be placed on a continuum with the medical model at one extreme and the social model at the other. At the one extreme disablement is considered to have its locus in the individual with the disability whereas the viewpoint at the other extreme is that disability is located in the social environment and it is that which places restrictions on the disabled person.

Because the emphasis in South Africa, has been on the medical needs of disabled people there has been a corresponding neglect of their wider social needs which has resulted in severe isolation for them and their families (Office of the Deputy President, 1997).

2.2.1 MEDICAL MODEL

In early times illness and disability were seen in terms of moral and religious issues. It was only during the twentieth century that they became redefined as a medical issue (Lonsdale, 1990; Scheer and Groce, 1988).

The medical model was constructed by medical scientists for the purpose of studying disease. It focuses on individual pathology and physical malfunctioning and is the prevailing model used in the Western world (Marks, 1997; Imrie 1997; French, 1993d; Zola, 1993). As the basic scientific discipline is that of molecular biology the norms are measurable biological values occurring at the molecular level and are independent of the social, psychological and behavioural factors that may be affecting the disabled person (Mason, 1985). The numerical values assigned to the biological measure assume much more importance than the disabled individuals themselves and the only aspects of importance are seen to be ways of curing, preventing or caring for disabled people (Marks, 1997; Harrison, 1993). Disability is seen only in terms of failure of one of the bodily systems and is perceived as a deviation from the normal (Marks, 1997; Davis, 1995; Abberley, 1993; French, 1993d).

The medical model is also used for the education of medical personnel, but no differentiation is taught between its use for scientific research and how it ought to be applied to medical practice at the intervention level (Harrison, 1993).

Although the approach to studying disease has been most successful, the fact that it has excluded related psychosocial and cultural aspects interferes with effective client care (Gleeson, 1995; Shakespeare, 1994; French, 1993d; Harrison, 1993; Scheer and Groce, 1988). It places more emphasis on technical and laboratory tests than it does on the client's subjective account. Therefore, psychological and behavioural manifestations and descriptions are not related to the biochemical deficits (Oliver, 1990; Bury, 1979).

Clinical skills of interviewing the client and analysing these reports in terms of psychological, social and cultural terms as well as in physiological and biochemical terms are underutilised (French, 1993d; Harrison, 1993). Important aspects of when clients perceive themselves as being disabled, when others perceive them as being disabled or how much the relationship between the doctor and client influences therapeutic outcomes are not considered. Even affluent people having access to health care complain that the doctors are interested only in their symptoms and not their personal and family problems. This is why medical practitioners are perceived to be cold, uncaring and impersonal centres which are used for medical research only. It has caused many doctors to question whether their qualifications are sufficiently adequate to offer quality care to their clients (Harrison, 1993).

Diseases and disabilities are a mystery to most clients and this frequently results in psychological trauma. The medical model fails to understand how disabled people are socialised into particular ways of being, of accepting their inferiority by society and behaving in ways which seemingly conform to the expectations and stereotypes which have been handed down. Because the physical and social environment remains a given in the medical theorisation of disability, there has been a tendency for disabled people to be stigmatised as the perception has developed that the body must be cured or adjusted so that it is 'normal' and fits into the environment (Imrie, 1997; Mitzoeff, 1995; Abberley, 1993; Dalley, 1992; Fallon, 1990; Lonsdale, 1990).

The professionals are seen as a group of people who work on behalf of the disabled people in order to help them overcome their problems which are perceived to arise out of their disabilities. Thus the focus is on 'normalising' the disabilities rather than accommodating them (Davis, 1995; Abberley, 1993; French, 1993d; Lonsdale, 1990; Chamie, 1989; Finkelstein, 1989). However, where there is widespread poverty and malnutrition society's standards of 'normal' functioning might become so low as to conceal the widespread disability among its citizens that starvation is causing (DPSA, 2001; Wendel, 1996).

Disabled people are marginalised and are often depicted as pitiful and tragic characters worthy only of the charity of the 'able-bodied' population. They are perceived as helpless dependants who are incapable of mastering the elementary skills essential for engaging in productive social and economic activities (Imrie, 1997; Morris, 1993c; Lonsdale, 1990; Oliver, 1990). It is expected that changes must be brought to bear on the individual rather than the environment and that the individual requires help in the form of professional medical services (Marks, 1997; Fine and Asch, 1988). This creates a sense of disempowerment in the people with disabilities (DPSA, 2001; Lonsdale, 1990).

Although the medical model is the prevailing model used in Western countries in the developing countries the WHO is only primarily concerned with instituting programmes which prevent impairments rather than focusing on fostering accommodations and social changes which bring about inclusion of disabled people (Groce, 1996; Oliver, 1990).

According to Savage and Benatar (1991) the medical model of dealing with health has proved to be ineffective in improving the level of health of South Africa as a nation.

“Finally, between Eleusis and Athens, Theseus met the brigand Procrustes who possessed a hammer, a saw and a bed. He compelled travellers to lie on the bed, and those who were too long for it he would cut down to size; those who were too short he would hammer out until they fit it exactly. He too perished at Theseus’ hand in the way he had killed his victims” (Morford and Learndon, 1996: 459).

Procrustes is an example of what disabled people perceive society wishing to do, namely fitting people into societal standards of the body normal. In the example of Procrustes there is only one type of enforcement of ‘normalcy’, namely that of height. The differences in people with disabilities are as vast as the differences in the type of social, physical and psychological handicaps they have. The differences in the types of handicap reflect conversely on the way in which society evokes its response to them, and as a result effects their responses to society.

2.2.2 SOCIAL MODEL

Proponents of the social model claim that society needs to adjust to impaired people rather than disabled people needing to adjust to their impairment (DPSA, 2001; Marks, 1997; Lonsdale, 1990). Barnes (1994: 88) defines disability from the social model perspective as “The loss or limitation of opportunities to take part in the normal life of the community on an equal level with others due to physical and social barriers”.

This perspective of disablement demands a great deal of change in the relationship between the professionals and the disabled as the social model accepts that disabled people have medical conditions which may inhibit them and may need medical treatment from time to time, but that most of the day to day problems that they have to face are caused by the fact that they live in a disabling world which is largely designed to fit able-bodied people ((DPSA, 2001; Marks, 1997). The social model is, therefore, critical of those professionals whose aim is to change the people with disabilities rather than the environment.

As opposed to the individualised approach of the medical model, the social model places disablement in a rejecting and oppressive social environment and not in an impaired or malfunctioning body. The restrictions encountered by the disabled people are not a natural consequence of their impairment, but are as a result of the social environment which fails to take account of their differences (Oliver, 1990; Longmore, 1987; Zola, 1985; Finkelstein, 1980).

The extent to which disabled people experience their impairments include the nature of the natural and built environments (Imrie, 1996; Sibley, 1996), social hierarchy (Oliver, 1996), legislation (Barnes, 1994), attitudes, images and technologies (Roulstone, 1994; Finkelstein, 1980), aesthetics (Wendell, 1996; Mirzoeff, 1995; Bogdan, 1988) and languages and culture (Davis, 1995; Shakespeare, 1994; Morrison and Finkelstein, 1993; Groce, 1985).

Many disability activists define independence as autonomy over decision-making rather than the capacity to carry out activities of daily living (French, 1993a; Morris, 1993b; Badley and Tennant, 1991) and perceive dependency as arising out of the way in which needs are met rather than the lack of intrinsic capacity (Marks, 1997; Thornhill and HoSang, 1988). For example, a wheelchair-user may need to have assistance when negotiating steps to a building, but could be independent if there were a ramp provided for access.

Rehabilitation takes place to a certain extent in hospitals and clinics, but the majority of it should take place in the home and community where the people live. If it is accepted that disability is not within the individual, but rather in the relationship between the person and his/her social environment then it is important that the focus be placed on reducing disability through changes in social policy, culture and institutional practices (Lang, 2000; Marks, 1997; Morrison and Finkelstein, 1993; Hahn, 1988) rather than concentrating on 'normalising' the individual with the disability.

Changes can only be made to the physical, social and attitudinal environment if disabled people mobilise themselves and speak for themselves as their life experiences and expertise is what is needed to ameliorate their circumstances and not the professional technical knowledge (DPSA, 2001; Lang, 2000; Leavitt, 1995; Groce, 1996; Shakespeare, 1996; Bickenbach, 1993; Department of Health, 1990).

2.3 DISABILITY

Disability is a very complex concept to explain as there are a multiplicity of definitions which describe it (Nordenfelt, 1997; Oliver, 1996; Nordenfelt, 1995; Quinn, 1995; Barnes, 1994; Verbrugge and Jette, 1994; Nagi, 1991; WHO, 1980). The descriptions and explanations depend on the theoretical framework of the models used by the authors; whether they are health workers or people with disabilities themselves (Bickenbach et al, 1999; Nordenfelt, 1997; McDowell and Newell, 1996; Oliver, 1996; Verbrugge and Jette, 1994; Lonsdale, 1990); and whether they regard it as a natural aspect of health for the majority of people at some stage of their lives (Bickenbach, et al, 1999; Marks, 1997; Badley, 1995; Halbertsma, 1989); or as a catastrophic incident as an outcome of disease (Barton, 1996; Shakespeare, 1996; Quin, 1995).

Disability is not a black or white phenomenon. It varies in types, extent and over a lifespan and should be regarded as occurring on a continuum. Types of disability vary according to age (Smart and Smart, 1997; Murray and Lopez, 1996; Comielje, 1993; Badley and Tennant, 1991) and geographical region (McLaren et al, 1987). Diseases such as poliomyelitis still occur in developing countries whereas it has been eliminated in most Western industrialised countries. It mostly affects young children and the disabilities with which they are left vary considerably from individual to individual. Msuleni joint disease is found

only in Msuleni, a rural area of KwaZulu-Natal in South Africa, and people affected by it have varying degrees of disability. In countries such as Cambodia, Angola, Mozambique and Somalia where there have been political instability and war there are large numbers of people of all ages with amputations of limbs. In developed countries the number of people with lower limb amputations increases with age and is largely due to diseases such as diabetes and peripheral vascular disease which do not affect children in this way.

According to Pope and Tarlov (1991) most people of 75 years of age would have experienced some form of limited functioning for 13 years of their lives and so it can be a natural event for most people at some point during their lives. An individual might contract Guillain-Barré syndrome at 30 years of age and be acutely ill in a hospital on life-support for a few weeks. He/she may then have to undergo an extended period of rehabilitation and may make a full recovery to return to his/her full social role. Even for those suffering from chronic illnesses such as multiple sclerosis or asthma their functional capacities are not fixed, but fluctuate from day to day and over an extended period (Marks, 1997). Thus they violate the norms of the 'sick role' by neither withdrawing totally from social activities, as an acutely ill person would, nor in recovering to 'normality' and returning to full social activities (Davis, 1995; Abberley, 1993; Oliver, 1993; Lonsdale, 1990; Brown and Rawlinson, 1972).

The functional status of many disabled people never changes and they do not 'recover' (Marks, 1997) such as persons born with spina bifida who are never able to walk.

2.3.1 DEFINITIONS

Quinn (1995: 56) defined disability as a "Physical or mental impairment that substantially limits one or more of the major life activities of an individual";

whereas other authors describe it from the point of view of physical and social barriers which negatively affect the person's opportunity of taking part in the normal life of the community (Bickenbach et al, 1999; Pope and Tarlov, 1991; Haber, 1990).

According to the WHO's International Classification of Impairment, Disability and Handicap (ICDH) "*Impairment* refers to any loss or abnormality or psychological, physiological or anatomical structure or function" (WHO, 1980: 41). The loss of structure or function is ascribed to malformation or malfunction of parts of the body or its organs such as the ability to walk or speak (Lang, 2000; Imrie, 1997; Wood and Badley, 1983). Remediation of the loss is attempted by means of medical treatment or management, for example, analgesics are prescribed to reduce backache, antibiotics are provided to control respiratory infection and physical rehabilitation would enable a person to learn to walk after a leg amputation. However, Gleeson (1995) argues that impairment can only be understood through the historical and cultural socialisation processes of a society and not through organic differences or absence.

"*Disability* is any restriction (as a result of an impairment) or lack of ability to perform an activity in the manner or within the range considered normal for a human being" (WHO, 1980:143). Disability is therefore concerned with the ability to perform activities at an appropriate level for the age and gender of the person. Consistent with the WHO definition of disability the aims of rehabilitation are to improve and to aid function (Wood and Badley, 1983) by means of exercises and assistive devices such as crutches and wheelchairs. According to the social model the inability to perform these tasks is as a result of socially imposed restrictions or discriminatory practices of society (Lang, 2000; Verbrugge and Jette, 1994; Nagi, 1991; Haber, 1990) which impinge on the family and social roles of the individual (Imrie, 1997; McDowell and Newell, 1996; Badley, 1995). In other words it is not due to the inability of the people in the immediate environment, but is due to society at large to adapt to the characteristics and

needs of individuals with impairments and disabilities (Fougeyrollas et al, 1989; Saucier et al, 1987) by reducing the demands and accommodating social and physical environmental modifications (Verbrugge and Jette, 1994; Nagi, 1991; Haber, 1990).

The third component of an alteration in function, namely, *handicap* is defined as "A disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex and social and cultural factors) for that individual" (WHO, 1980: 183). However, from the social model perspective handicap expresses the social consequences of disease or trauma (Imrie, 1997; Wood and Badley, 1983; WHO, 1980) and comprises the negative interrelationship between the disabilities of the individual and the realities of the environment and society that limit people with disabilities from exercising their rights (Fougeyrollas et al, 1989; Saucier et al, 1987). Thus it is a mismatch between the characteristics of impaired people and the characteristics of the environment which results in the individual missing social and economic opportunities in life due to the barriers of the environment (Marks; 1997; Chamie, 1989; Halbertsma, 1989). For example, deafness would not be a handicap in a community which can use signing as a means of communication (Marks, 1997; Groce, 1985) and a minor facial scar may handicap a model or beauty queen, but may not noticeably restrict another person (McDowell and Newell, 1996).

Wood and Badley (1983) contend that handicap cannot be managed in isolation by dealing with the individual's physical or mental state, but requires improving the underlying impairments and disabilities in conjunction with altering the environments in which the individuals live and increasing the resources available to them. In this way they can personally manage the problems confronting them. This requires changes in social security and welfare policies, vocational training, housing, education, transport as well as the provision of comprehensive

rehabilitation services (Lang, 2000; O'Day, 1999; Hahn, 1988; Abu-Khalil, 1997; Marks, 1997; Morris, 1993d; Wood and Badley, 1983).

The above definitions of the WHO of 'impairment', 'disability' and 'handicap' are seen to be three sequential stages where impairment refers to the parts or systems of the body that do not work, a disability describes the activities that the person cannot do and handicap refers to the social roles the person is unable to fulfill and the economic disadvantages that this causes the person (WHO, 1980). Trauma may lead to the development of a hip joint impairment which may lead respectively to a disability in walking and general mobility. The person may then be handicapped by not being able to continue in his/her choice of occupation and achieve economic independence.

Proponents of the social model of disability claim that the level of handicap is a product of both a disabled person's characteristics such as race, gender, socio-economic class, culture and environment (Smart and Smart, 1997; Shakespeare, 1994; Lonsdale, 1990) and the characteristics of the individual's environment such as public transport, accessibility of buildings, availability of services and employment opportunity (Imrie, 1996; Sibley, 1996; Oliver, 1996; Badley, 1995; Barnes, 1994; French, 1993c; Chamie, 1989). Thus the person's personal characteristics do not form part of their explanations of disablement.

There has been a great deal of criticism of the ICIDH by disability activists over many years with regard to the terms and definitions focusing on defects and non-normality and reflecting only the medical model of disability (Lang, 2000; Marks, 1997; Shakespeare and Watson, 1997; Oliver, 1996; Badley 1997; Badley, 1995). The disability rights movement have never accepted the definitions as they were developed without consultation with people with disabilities themselves and they did not sufficiently reflect the social context that prevented people with disabilities from participating as equal citizens (DPSA, 2001). The movement insisted that any classification of people with disabilities should be made in the

social context and not in the individual context. This had led to the development of a new document called the International Classification of Functioning, Disability and Health (ICIDH-2) being developed which integrates health at biological, individual and societal levels in order to achieve a universal language for functioning and restrictions (WHO, 2001).

The former ICIDH terms 'disability' and 'handicap' have been replaced by the neutral and universal terms 'activity'/'activity limitation' and 'participation'/'restriction of participation' and now fall under the umbrella term 'disability'. 'Activity limitations' are difficulties that an individual experiences in performing some actions or activities. 'Participation restrictions' are problems that an individual may have in the way or extent he/she becomes involved with life situations. 'Participation restriction' is usually seen to be an advantage, but it is culturally-based as an individual can be disadvantaged in one group of people or geographical location and not in another social group or place. The term 'impairment' has been retained and is graded according to the level of severity. Environmental (physical, social and attitudinal) and personal (gender, race, age, education, etcetera) factors influencing 'activities' have been included and focus on three levels, namely, individual, services and systems (WHO, 2001).

The researcher deemed the ICIDH-2 an inappropriate tool for this study as it is very time-consuming to administer and still focuses on the disability of the individual whereas the aim of this study was to investigate the nature and extent of the barriers experienced by the community of Lotus River.

Lack of consensus of the concept of disablement has led to different notions about a person with a disability (Pinder, 1993). A person with paraplegia is seen by a doctor to have paralysis of the legs; to a social worker it implies a certain level of independence and restriction to total independence; to a physiotherapist it means a diminished level of physical functioning; to a person with the disability it may mean that certain buildings do not have ramps for access. The

professionals perceive the paraplegia as being permanent whereas the individual with paraplegia perceives occasional difficulties when certain buildings are a problem, but others where there are ramps to be no problem. An individual with red-green colour blindness has an impairment which does not normally lead to a limitation of activity. However, if he/she wished to become a pilot it would result in a handicap (Badley, 1995).

By recognising that disabled individuals might require some form of assistance and support does not imply that they are incapable or that they are dependent on care. Attendant care assistance, walking aids, wheelchairs and other adapted equipment are means of facilitating greater independence and control over their lives (Verbrugge and Jette, 1994; French, 1993a; Lonsdale, 1990). As a person with a severe disability Hershey (1993) maintained that she was able to live independently although she had to use attendants, an electric wheelchair and a voice-activated computer for all of her basic activities of daily living.

Lang (2000) claims that the terms 'impairment', 'disability' and 'handicap' are easily confused with each other and are used interchangeably. 'Impairment' refers to physical or cognitive limitations that an individual may have, such as the ability to walk or speak; whereas 'disability' is a result of socially imposed restrictions. These restrictions are imposed on those with impairments by the discriminatory practices of society (Lang, 2000). Bickenbach et al (1999) maintains that the definition of 'impairment' is the functional limitation within the individual caused by physical, mental or sensory impairment and 'disability' as the loss of opportunity to take part in the normal life of the community due to physical and social barriers. It is the inability of the people in the immediate environment and society at large to adapt to the characteristics and needs of individuals with impairments and disabilities (Fourgeyrollas et al, 1989).

Although the WHO (1980: 41) states that "There is a distinct cleavage between disability and handicap, both conceptually and in the means for intervention ...",

in reality, the terms 'impairment', 'disability' and 'handicap' are used interchangeably (Lang, 2000) and because of this confusion when measuring health indices 'disablement' has been proposed to refer to both 'disability' and 'handicap' (McDowell and Newell, 1996).

This general lack of consensus in terminology makes it difficult to obtain accurate data and to compare research findings (Smart and Smart, 1997; Helander, 1993; Zola, 1993; Chamie, 1989). In the literature reviewed for this study no definitions of disability were found which included partial incapacity where functions could be performed with someone's assistance; the extent or severity of the disability; or the complex and fluctuating nature of many disabling conditions over the life span.

2.3.2 DISABILITY AND EMPLOYMENT

There is a large amount of literature regarding the circumstances of people with disabilities living in the United Kingdom (UK) and USA, but nothing was found regarding developing countries and only a small amount concerning people with disabilities living in SA.

Disability has been found to be influenced by low income, poverty, employment in dangerous jobs, lack of health insurance, low education attainment, lower occupational status and faulty testing/diagnostic procedures (Schneider, 1999; Coetzee, 1997; Imrie, 1997; Smart and Smart, 1997; McNeil, 1993; Yelin, 1992; Alston and Mngadi, 1992; Chamie, 1989; Thornhill and HoSang, 1988; Brisendon, 1986; Bove, 1981; Sutherland, 1981).

To be disabled is also to be disadvantaged. It means being unable to participate in the social and economic activities which most people take for granted and this

leads to a state of conditioned passivity (Lonsdale, 1990; Brisendon, 1986; Sutherland, 1981).

Rates of poverty, unemployment, domestic violence and suicide are much higher among people with disabilities than in the non-disabled population (Daniels and Mickel, 2002; Little, 2002; Schneider 1999; Williamson, 1998; Smart and Smart, 1997; Lonsdale, 1990; Brisenden, 1986; Locker, 1983; Syme and Berkman, 1981; Sutherland, 1981; Wright, 1968).

The lack of a job due to disability means not only material hardship, but also the problem of having surplus unstructured time which leads to loneliness, boredom and loss of confidence (DPSA, 2001; Mann et al 1999; Grue, 1996; Law et al, 1996; McCuaig and Frank, 1991; Wehn and Sommerschild, 1991; Lonsdale, 1990).

Disabled people in paid employment have been found to be in a better state of health, both mentally and physically than those disabled who are unemployed (Mann et al, 1999; Law et al, 1996; McCuaig and Frank, 1991; Lonsdale, 1990). However, people who have disabilities are at a serious disadvantage compared to the rest of the population in the labour market (DPSA, 2001; Martin et al, 1999; French, 1993c; Hastings 1980).

In South Africa unemployment among people with disabilities is high (Ministry for Welfare and Population Development, 1997; Coetzee, 1997). "The South African economy has not been able to supply sufficient employment opportunities for all who want to work. ... In addition, the market also makes little provision for those with special needs, such as people with disabilities" (Ministry for Welfare and Population Development, 1997: 9). According to the Western Cape Premier, 88% of people with disabilities are unemployed and recent research has indicated that the percentage of people with disabilities employed in large companies diminished from 1.02% to 0.93 % during 2002 (Van Schalkwyk,

2002). If more people with disabilities are to be employed there will need to be a fundamental shift in how they are viewed. The focus should be on abilities rather than disabilities (Van Schalkwyk, 2002; Law et al, 1996). Thus attitude is the most important component of employment of people with disabilities (Lonsdale, 1990; Hastings, 1980). Employment and the right to earn one's own living are important and neglected issues, as all too often it is incorrectly assumed that people with disabilities will not be able to work in paid employment (African National Congress (ANC), 1994; Lonsdale, 1990).

According to the DPISA (2001) more White disabled people have benefited from the provisions of the Employment Equity Act than Black disabled people, particularly in the private sector although the public sector appears to provide more equal opportunities for Black people with disabilities under the new dispensation. However, they are more likely to be appointed in lower rank positions, irrespective of their abilities or potential, than their White counterparts.

2.3.3 DISABILITY AND POVERTY

Disability has a major impact on society. It does not only affect the disabled, but also the family and the immediate community (DPISA, 2001; Office of the Deputy President, 1997; Jette, 1994; McNeil, 1993; Alston and Mngadi, 1992; Thornhill and HoSang, 1988). Unemployment contributes to poverty and without paid employment an individual has fewer social contacts, less status and most importantly, less income (Daniels and Mickel, 2002; Smart and Smart, 1997; Lonsdale, 1990). There is greater poverty in disabled households than non-disabled households (Jelsma and Maart, 2004; Martin et al, 1999; Smart and Smart, 1997).

Poor people face a greater risk of impairment or disability (Office of the Deputy President, 1997; Chamie, 1989). In addition, the birth of a disabled child, or the

occurrence of disability in a family, often places heavy demands on family morale, thrusting it deeper into poverty (Office of the Deputy President, 1997). This means not only that there is a higher proportion of disabled people amongst the very poor, but also that there is an increase in families living at the poverty level as a result of disability. It is estimated that in South Africa as many as one out of four (25%) of households are affected by disability in a household size of six persons (DPSA, 2001)

2.3.4 DISABILITY AND GENDER

Gender considerations are as pertinent to the experiences of disabled people as they are to those who are able-bodied, yet they may be overlooked because the disability may be the most obvious factor influencing social identity (Abu-Habib, 1997; Lonsdale, 1990; Ainley, 1984). Disability should be understood as actually reinforcing inequalities between men and women as there are few studies which have looked at disability and gender together yet these people are not sexless, but are individuals with different interests, economic status, aspirations and life-experiences (Lahelma et al, 1999; Abu-Habib, 1997; MacIntyre, 1993).

This failure to differentiate data according to gender occurs even on an international basis where, for example, the report published on the Information on the UNDP Human Development Health Report (1995) omitted most data on health, education and economic activity with regards to females (Ramadam, 1997). Neither did the United Nations Fourth Conference of Women held in Beijing in 1995 include consideration of disability as a 'women's issue' or integrate the views of disabled women into the conference proceedings and results. Thus the decisions reached on policy and action did not truly represent the interests of all groups of women, but only that of able-bodied women (Abu-Khalil, 1997).

Because disabled women are perceived to be dependent, passive and needy by able-bodied women the women's movement in South Africa has marginalised disabled women within the movement in order to advance a more powerful, competent and appealing female image (DPSA, 2001).

Physical, social, psychological and other disadvantages caused by disability have a strong gender dimension (Arber, 1997; DiMarco, 1996; Waxman, 1991; Lonsdale, 1990). There are illustrations of problems and challenges faced by women with disabilities in literature, but mainly from the developed world (Freeman, 1993; Hershey, 1993; Ranzoni, 1993; Stromsness, 1993; Wilmuth and Holcomb, 1993; Zirinski-Wyatt, 1993; Boylan, 1991) even though the majority of women with disabilities live in developing countries (Thomas and Thomas, 2002; DiMarco, 1996). In the literature available it is recognised that these women face a triple handicap and discrimination due to their disability, gender and developing world status (DPSA, 2001; Abu-Habib, 1997; DiMarco, 1996; Hema, 1996; Solomon, 1993; Deegan and Brooks, 1985).

The fact that there is very little written on the needs of women who are disabled is possibly due to the view that it is more acceptable for a women to become disabled because passivity, docility and dependency are more compatible with the female sex role (DPSA, 2001; Lonsdale, 1990; Brisendon, 1986; Oliver, 1986; Sutherland, 1981). Similarly the lack of paid employment may be perceived to be less traumatic for women because they are seen to rely on it less and to have an alternate role in the home as homemaker (Thomas and Thomas, 2002; Martin and Roberts, 1984; Kutner and Gray, 1981; Nathanson, 1980; Brown and Rawlinson, 1972).

Women with disabilities are more likely to be divorced or abandoned than non-disabled women (UNDP, 1995; Fine and Asch, 1988; Franklin, 1977) and are equally vulnerable to sexual abuse as other women (UNDP, 1995; Ryerson, 1981). They are also less likely to be employed, earn substantially less and are

less likely to be college educated than men with disabilities or non-disabled women (DPSA, 2001; Greenblum, 1977; O'Toole and Weeks, 1978). It is estimated that having a disability doubles an individual's likelihood of being assaulted. Because of their isolation, however, women with disabilities are likely to have less resources to turn to for help (Dreidger, 1996; Lonsdale, 1990).

With regards to men and women with disabilities getting married and having children attitudes are very different. In the Middle East it is considered that as long as the men were able to provide for their wives they were perfectly eligible for marriage and parenthood (DPSA, 2001; Abu-Habib, 1997; Ghanem, 1993); whereas family planning and reproductive services have been aimed at preventing women with disabilities from having children (DAWN, 1994; Killoran, 1994; Nolan, 1994; Waxman, 1994; Wasser et al, 1993; Waxman, 1991; Shaul et al, 1985). Mothers with disabilities frequently experience threats from government agencies to try and take custody of their children from them (DAWN, 1994; Killoran, 1994; Kocher, 1994; Wasser et al, 1993).

Women with disabilities have complained that rehabilitation programmes appear to have been designed to suit disabled men's aspirations for recovering their masculinity and sexuality and focus on getting them back into employment (Morris, 1993a; Begnum, 1992; Lonsdale, 1990) and that special rehabilitation geared towards the employment needs of women and mothers with disabilities are required (Nosek, 1997; Leavitt, 1995; Stace, 1986).

2.3.5 DISABILITY AND RACE

Disability rates for racial and ethnic minorities have been found to be disproportionately higher than those for White Americans (Smart and Smart, 1997; Hayes-Bautista, 1992; Thornhill and HoSang, 1988; US Department of Health and Human Services, 1985; Bove, 1985).

Disler et al (1986c) found that the prevalence of locomotor disability in Black residential areas was higher than in White and Coloured residential areas of Cape Town. The results of a study in Woodstock, Cape Town found that the Coloured population were more than twice as likely to be disabled than White respondents (Jelsma and Maart, 2004).

The statistics on racial differences for disability in South Africa do not accurately reflect reality due to the fact that disability rates are also influenced by age and poverty and the data on the rates of disability do not provide the levels of income associated with prevalence.

2.3.6 DISABILITY AND DISCRIMINATION

Discrimination occurs at many different levels in society ranging from hostility and aggression to patronage, exclusion and fear (Lonsdale, 1990). One of the greatest forms of discrimination which many people with disabilities experience is having lack of access (Van Schalkwyk, 2002; Barnes, 1994; Lonsdale, 1990; Fine and Asch, 1988; Hahn, 1988). Access includes transport, buildings and functions and if they are not able to have access to these physical facilities it means that they get denied equal opportunities in employment, business, recreation and public life (Van Schalkwyk, 2002; Lonsdale, 1990; Martin et al, 1999).

“Prejudice lies at the heart of the segregation which many disabled people experience” (Morris, 1993c: 101) and is therefore a major barrier to integration.

There are differences imposed on people with disabilities by the cumulative disadvantage of race and disability (Crewe, 2002; DPSA, 2001; Michilin and Juarez-Marazzo, 2001; Smart and Smart, 1997). In research in the USA it has

been found that African Americans have been even more discriminated against based upon both disability and racial discrimination (Adams, 2001; Akabas and Gates, 1997; Belgrave and Walker, 1991).

In South Africa Coloured and Black people with disabilities are more likely to experience discrimination than their White counterparts due to the 'apartheid' system in the past which was responsible for the

- unequal resource allocation to the former Black and White special schools;
- difference in curriculum in educational institutions;
- lack of transformation in educational institutions;
- lack of rehabilitation facilities and services for Black people with disabilities residing in peri-urban and rural areas; and
- inaccessibility to appropriate rehabilitation services (ANC, 1994).

2.3.7 DISABILITY AND OPPRESSION

There is a fair amount of literature regarding disability which supports the theory that people with disabilities are oppressed by non-disabled people. By being labeled or treated as "the disabled" eventually leads those so-named into a state of conditioned passivity (Swain et al, 1993; Brisenden, 1986; Sutherland, 1981). This label is an accurate description of a social minority (Oliver, 1986; Safilios-Rothschild, 1970) and it encourages feelings of solidarity and supportiveness among the group of people whose disparate physical characteristics are uniformly used to oppress them, namely, disability rights movements. These writers view disability as a particular form of social oppression in which socio-economic and political forces impinge and restrict the lives of the disabled (Stuart, 1993; Duval, 1984; Oliver, 1983).

Oppression occurs when the non-disabled group of people systematically undermines the disabled group materially and psychologically, thus invalidating the experiences of the oppressed group (Stuart, 1993; Lonsdale, 1990).

People with disabilities are frequently marginalized by 'able-bodied' members of society who consider them to be deserving of pity and sympathy and that they are dependent on others in all areas of life (DPSA, 2001; McLaren and Philpott, 1999; Clarke, 1999; Coleridge, 1993; Tenant, 1997). In this way they are reduced to their impairment (French, 1993b; Zola, 1993). This leads to discrimination if the people with disabilities internalise the myths and stereotypes about themselves (Swain et al, 1993; Safilios-Rothschild, 1970).

Much of the rejection experienced by people with disabilities is not necessarily overtly hostile, but comprises a consistently low and patronising expectation of them (Stuart et al, 1993; Gething, 1985; Roeher, 1961). This results in practical and material deprivation experiences, for example, lack of accessibility and low income (Gething, 1985; Campling, 1981).

2.3.8 DISABILITY AND SELF-IMAGE

'Body image' is a central part of self-image and consists of a person's feelings about his/her body and is partly based on how other people react to it (Mitzoeff, 1995; Knudson-Cooper, 1981). Stereotyped attitudes, particularly negative ones, influence the social expectations and self-image of the disabled (Lonsdale, 1990; Ainley, 1984; Hastings, 1980; Roeher, 1961). Rejection by the able-bodied can lead to feelings of inferiority, self-consciousness, fear, maladjustment and withdrawal (Swain et al, 1993; Gething, 1985; Ainley, 1984). This is particularly so if the person has been disabled from birth as it becomes incorporated into each stage of their development (Gething, 1985; Falvo et al, 1982; Kerr and Thompson, 1972). On the other hand, those who becomes disabled in adulthood

experience a major change in their identity and a strong sense of loss (Simon-Meyer, 1999).

Women often have to rely on their beauty and attributes such as youth and good looks to have control over their lives. But to be disabled is not regarded as attractive. The more physical appearance, according to an idealised norm of a society, is highly valued the more difficult it is to live with a physical disability (DPSA, 2001; Fallon, 1990; Lonsdale, 1990). The White Paper of the INDS acknowledges that women with disabilities in South Africa experience more discrimination than other women as they are unable to live up to the demanding ideals for womanhood imposed by society (Office of the Deputy President, 1997).

2.3.9 DISABILITY AND INDEPENDENCE

When referring to disablement independence means autonomy with regard to decision-making rather than the physical capacity to carry out routine tasks such as activities of daily living (French, 1993a; Morris, 1993b). Independence involves the physical and social environment of an individual and takes many forms such as being able to control one's life and be responsible for oneself, living independently and having the opportunity to earn a living or receiving an adequate income (Mann et al, 1999; Mann and Lane, 1995; McCuaig and Frank, 1991; Lonsdale, 1990).

It is a relative concept as society expects people to be independent, but does not provide for the extent of dependence that the disabled frequently require by relying on others in their environment (Grundy, 1999; French, 1993a; Lonsdale, 1990). By having to be very dependent on others does not allow people with disabilities to plan and take responsibility for their own lives. The personal assistance they receive from others for their activities of daily living can make them either dependent (Neistadt and Crepeau, 1998; Mann and Lane, 1995;

French, 1993a; McCuaig, and Frank, 1991) or facilitate their independence and self-determination depending on the attitudes of their helpers (Mann et al, 1999; McCuaig and Frank, 1991; Oliver, 1983).

A physical disability often involves relying on help in the form of assistive devices and appliances, housing and workplace adaptations, or personal assistance for activities of daily living (Grundy, 1999; Bain, 1998; Morris, 1993d; Lonsdale, 1990). Physical disability in itself need not impose a state of dependency on someone, but an unaccommodating and hostile environment or prejudicial attitudes will do so (Bain, 1998; Law et al, 1996; Mann and Lane, 1995; McCuaig and Frank, 1991). Independence is not only a function of individual abilities, but the interaction between those abilities and the physical and social environment (Mann et al, 1999; Bain, 1998; Lonsdale, 1990).

Children who are born disabled are sometimes given less responsibility and are often taught to be helpless (Swain, 1993; McCuaig and Frank, 1991; Bone and Meltzer, 1989). Things are done for them and continue to be done for them into adulthood. It creates dependence and depersonalises them. They are often still dependent on parents long after the age when most young people would expect to leave the parental home (McCuaig and Frank, 1991; Lonsdale, 1990; Bone and Meltzer, 1989).

People who become disabled in adulthood find that they have their adult status removed and are relegated to that of childhood with its concomitant loss of control, decision-making and opportunity to live independently (Bain, 1998; Lonsdale, 1990).

Crucial to anyone's ability to live independently is having suitable accommodation that is provided or having the financial means to provide it for oneself (Grundy, 1999; Law et al, 1996; French, 1993a; McCuaig and Frank, 1991).

Not being given a proper education not only implies a life of dependency, but ensures that people with disabilities leaving school will not be equipped to earn a living and will lack the confidence to make their own way in the world. A poor or negligible education is the most effective means of denying individuals the same life chances as anyone else (Abu-Habib, 1997).

Independence and self-determination are only possible when people are able to make choices, about how they wish to live their lives, and have the confidence, power and economic means to follow through with those choices (French, 1993a; McCuaig, and Frank, 1991).

By being able to do more physically and by the environment being made more accessible allows the person with a disability to make more decisions independently and to participate in society (Van Schalkwyk, 2002; Oliver, 1996; Helander, 1993; McCuaig and Frank, 1991).

2.3.10 DISABILITY AND ABUSE

Although people with disabilities are particularly vulnerable to abuse there was minimal literature available on the prevalence of abuse of people with disabilities in general and specifically men with disabilities.

There is no literature on prevalence of abuse of disabled children or women in South Africa and the White Paper for Social Welfare acknowledges that the real extent of child abuse and neglect is unknown as a result of under-reporting, erratic research, an uncoordinated record-keeping system, and the lack of a central register. In the Western Cape there was a dramatic increase in reported general child abuse cases. From April 2002 to March 2003 the numbers

increased from 730 to 1 258 excluding actual rape which falls into a different category (Sookha, 2004).

Sexually exploited children are particularly vulnerable (Ministry For Welfare and Population Development, 1997). Although it does not give any idea of the numbers of people concerned the DPSA (2001) alleges that there are many Black people who were certified by the courts and placed in mental institutions during the 'apartheid' era who still reside in appalling conditions and suffer physical and sexual abuse.

Studies from both Western industrialised countries and developing countries show that there is a great deal of abuse of women with disabilities.

Boukhari (1997) and Abu-Habib (1997) found that disabled girls in Asia were a target for violence and abuse both in and outside the family and McFarlane et al (2001) found that Asian women in the USA were more likely to report physical or sexual abuse than Black, White or Hispanic women with disabilities.

Studies of sexual abuse of disabled women in the USA found that only 20-30% of victims report the abuse and that 99% of the offenders were known to their victims who were often dependent on them (Yllo, 1993; Ryerson, 1981; Seattle Rape Relief, 1979). They found that the attitude of men towards disability was often one of harassment, molestation, incest and rape. If the women reported the abuse it often meant a further loss of independence and possible institutionalisation where the women could not be guaranteed protection from further abuse (Lonsdale, 1990).

Violence against women undermines their psychological and physical health. It is estimated that one in six South Africa women is battered by a male partner and many girls' first experience of sex is by force (Smith, 2004). According to the

South African Police Services, only 2,8% of rapes are reported to the police (Ministry For Welfare and Population Development, 1997).

Ryerson (1981) claims that women with disabilities in the USA were equally vulnerable to sexual abuse as other women while Curry et al (2001) and Nosek et al (2001) found that they were at an increased risk for emotional, physical and sexual abuse.

It is possible that the same situation exists with children and disabled women in SA.

2.3.11 DISABILITY AND POWERLESSNESS

Miller (1983: 3) defines powerlessness as "A perception that one's own actions will not affect an outcome".

Powerlessness may occur in chronically disabled people as a result of physical or psychological losses. The sense of lack of control may arise from the disease itself where the disabled person is no longer able to continue working, getting from place to place or carrying out basic activities of daily living independently (Swain et al, 1993).

It can also arise from experiences in the health system (Briggs, 1993; Oliver, 1993a). The disabled may not be given explanations regarding diagnostic tests or the choice of treatment alternative and may never be involved in the health team's decision-making or choice of management (Swain et al, 1993).

Once the disabled have been discharged from hospital they become part of their community and society. It is at this stage that their disabilities become obvious as they face restrictions to the opportunities that allow them to participate in their

communities. This is when they become frustrated and passive and no longer participate within their family and community (Morris, 1993e; Oliver, 1993a; Oliver and Barnes, 1993; Checkoway and Norseman, 1986). It ultimately leads to regressive behaviour, depression and anxiety and they finally become isolated from their families and communities (Barnes, 1993; Corker, 1993; Morris and Finkelstein, 1993; Stuart, 1993; Miller, 1983).

With chronic disabilities the feeling of worthlessness occurs when the disabled are no longer able to perform physical functions or fulfill their previous role within the family (Morris, 1993b). It also occurs when they perceive themselves as less competent and different from others (Miller, 1983).

Knowledge and insight about their disabilities are enabling factors for people with disabilities to control their lives (Oliver, 1993b). It allows them to participate in decision-making as they understand alternative courses of action (Barnes, 1993; French, 1993d; Swain et al, 1993). The disabled can have modifications made to their environment to allow them increased control over their activities of daily living and decision-making regarding their daily routines (Roulstone, 1994).

It is important that health personnel dealing with the disabled help them to set realistic goals in order to avoid withdrawal, depression and feelings of worthlessness if they are unable to achieve goals beyond their capabilities (Oliver, 1993b).

Self-esteem is a power resource and enables the disabled to take an active part in controlling their personal care (Mitzoeff, 1995; Oliver, 1993a; Falvo, 1983). For example, a person with a stroke will ensure that family members allow him/her to do as much as possible for himself/herself and will encourage them to assist with activities which will foster further physical improvements and function, (Falvo, 1983).

Coping with powerlessness is a major demand throughout the life of the chronically disabled, but power as a resource for living is present in all persons (Miller, 1983). Dimond (1979) and Pattison (1974) both found that the social support network provided by families helped the disabled to maintain psychological strength as a power resource.

Rehabilitation can assist in preventing the negative aspects from which the chronically disabled suffer by empowering them to function as independently as possible so that they can fulfill modified roles within their family and gain a sense of control. It is crucial for rehabilitation therapists to encourage the disabled to participate in decision-making concerning the alternatives of their management. In this way success with the rehabilitation regimen is much more likely to be achieved (Oliver, 1993b; Swain et al, 1993).

2.3.12 DISABILITY AND POLICY IN SOUTH AFRICA

A great number of White Papers and policies with regard to disablement have been introduced in South Africa since the ANC government came into power in 1994. They are very much in line with what the United Nations World Programme of Action put forward in 1982 as a major issue, namely, ".... equalisation of opportunities for people with disabilities" (Lindquist, 1995). The disability movement described this as the future structure and social mores of a future society. A future society such as this would indeed be free from oppressive structures and negative social attitudes held by society at large. This would enable disabled people to attain their legitimate status of full citizenship (Lang, 2000).

In the White Paper on an INDS (1997) it is made clear that there has to be a fundamental shift in the way in which disabled people should be viewed (Office of the Deputy President, 1997). The previous individual medical perspective should

be replaced with an approach which ensures the human rights and development of disabled people. The Western Cape Premier, in his address at an Access Conference, stated that disability should not be treated as a health and welfare issue, but rather as an issue of equal opportunity to contribute to society and to be gainfully employed (Van Schalkwyk, 2002).

The Bill of Rights in the Constitution of the Republic of South Africa (Act 108 of 1996) provides for both political and socio-economic rights for all South Africans within a framework of non-discrimination and equality. In particular it provides for the disabled by:

2.3.12.1 The right to equality which provides for equality before the law for all people and which prohibits discrimination on the basis of age and disability (Section 9);

2.3.12.2 The right of every child to family care, shelter, basic nutrition, basic health care and social services, protection from abuse, neglect ... (Section 28);

2.3.12.3 The Constitution of the Republic of South Africa (1996: 11) states that "Every person shall have the right to basic education and to equal access to education institutions". One of the strategies proposed by The White Paper for Social Welfare (1997) is that the "Children with disabilities should as far as possible be accommodated in mainstream education or attend other educational facilities where appropriate" (Ministry for Welfare and Population Development, 1997: 65).

2.3.12.4 "Every person shall have the right freely to engage in economic activity and to pursue a livelihood anywhere in South Africa" (The Constitution of the Republic of South Africa 1996: 10). In addition, the White Paper for Social Welfare recognises that, "... employment opportunities, such as workshops for the employment of people with disabilities who have no potential for or capacity

to work in the open labour market, will be developed and supported” (Ministry for Welfare and Population Development, 1997: 78).

2.3.12.5 The Employment Equity Act (Act 55 of 1998) ensures that affirmative action in employment is implemented. Section 13 of the Act states that the employer’s workforce should reflect the demographic profile of the national population and that the employer’s should “Ensure the equitable representation of suitably qualified people from designated groups in all occupational categories and levels in the workforce” (Government Gazette, 2002). People with physical disabilities fall into the ‘designated groups’.

2.3.12.6 The Promotion of Equality and Prevention of Unfair Discrimination Act (2000) outlaws unfair discrimination on grounds of disability and places a responsibility on government to take special measures to promote equality with regard to disability by providing for measures to facilitate the eradication of unfair discrimination on the grounds of disability.

The purpose of The White Paper on an INDS (Office of the Deputy President, 1997) is to facilitate the realisation of disabled South Africans’ rights to equality and dignity through full participation in a barrier-free society for all (DPSA, 2001). It provides governmental departments with guidelines that enable disabled people to:

2.3.12.7 Be as free as possible from needing permanent medical care and rehabilitation services, but having access to such whenever necessary (Office of the Deputy President, 1997: 25-26);

2.3.12.8 Exercise their rights to full citizenship and to have access to all institutions and services of the community, including education (Office of the Deputy President, 1997: 37);

2.3.12.9 Have a minimum livelihood, if appropriate by means of social benefits (Office of the Deputy President, 1997: 52);

2.3.12.10 Have as much mobility as possible, including access to buildings and means of transport (Office of the Deputy President, 1997: 30 - 34);

2.3.12.11 Play a meaningful role in society and to take part in economic, social, leisure, recreational and cultural activities (Office of the Deputy President, 1997: 55);

2.3.12.12 Provide disabled people and their families with safe shelter and dwellings of their own through equitable access to a range of options in the housing subsidy scheme (Office of the Deputy President, 1997: 54).

2.3.12.13 Provide opportunities for employment of disabled people by "... negotiating with other Government departments about increasing accessibility to training ..." (Ministry for Welfare and Population Development, 1997: 54) and "Protected employment opportunities need to run concurrently ... providing equal opportunities for people with disabilities in the open labour market" (Ministry for Welfare and Population Development, 1997: 78).

2.3.12.14 The Disability Rights Charter of South Africa (2000) Article 11 states that disabled people "shall have the right to education" and "shall be provided with equal opportunities to reach their full potential in life".

2.3.12.15 The Education White Paper 6 (2001) provides for education of disabled children by claiming that all children can learn and that the barriers to learning and exclusion should be addressed by both curriculum and institutional changes (Department of Education, 2001).

2.3.12.16 The Children's Charter state that "all children have the right to free and equal, non-racial, non-sexist and compulsory education within one department as education is a right and not a privilege" (Children's Charter of South Africa, 1996: Article 8).

2.3.12.17 "The education and training need of the disabled and other marginalised groups should be catered for as part of a process of facilitating access to facilities and to the economy, so that disadvantaged groups are seen as an asset - by themselves and by society at large" (ANC, 1994: 63).

Even though the new Constitution of the Republic of South Africa of (1996) states that people with disabilities should be able to access the same fundamental rights as any South African citizen, these rights and duties of citizenship that accrue automatically to the non-disabled population, may be granted conditionally to people with disability. For example, although education and housing might be made available to the non-disabled population who did not have them during the 'apartheid' era, in the case of the disabled this might have to wait for additional funds to be made available to provide special adaptations to their houses such as larger doorways, ramps for wheelchair-users and special transport to take children to school.

2.4 DISABILITY PREVALENCE

The prevalence of disability in any society depends on the way it has been defined and measured (Office of the Deputy President, 1997; Chamie, 1989; Lonsdale, 1990). In most of the literature on prevalence of disability there is confusion and differing concepts on 'disablement' as well as methodological and logistical variations in generating the data.

In South Africa further reasons for this unreliability are provided by the White Paper on an INDS (DPSA, 2001; Office of the Deputy President, 1997). These are the

- negative traditional attitudes towards people with disabilities;
- poor service infrastructure for people with disabilities in underdeveloped areas; and
- violence levels in certain areas at certain times which impede the collection of data and affect the overall picture.

In Western industrialised societies, there has been an increase in chronic and disabling diseases which have replaced traumatic injuries and infectious diseases as major causes of disablement (Wood and Badley, 1983; Bury, 1979). Studies done by Disler et al (1986a)(1986b)(1986c) and Concha and Lorenzo (1993) also provide evidence that trauma is not the leading cause of disability in SA. Both studies show that trauma and disease contribute approximately the same percentage to disability.

2.4.1 GLOBAL PREVALENCE RATE

The global disability prevalence rate ranges from 0.2% to 20.9% of the population (Chamie, 1989; Bejnarowicz, 1984; Patrick et al, 1981) and for moderate and severe disability it is estimated to be 5.2% varying from 7.7% for the developed regions to 4.5% for less developed regions (Clarke, 1999; Helander, 1993).

In a review of international prevalence rates Chamie (1989) found that developing countries reported lower prevalence rates. This was attributed to actual differences in disability rates and the divergent screening tests used. Developing countries in Asia and Africa used screening techniques that were impairment-specific resulting in the identification of only the most severely

affected cases of disablement; whereas developed countries used more sensitive broad-ranging disability survey screens concerning functional and activity limitation. These included aspects such as hearing, walking substantial distances, seeing small print, personal care activities or any form of work limitation. These broad-range disability questionnaires screened larger proportions of population as disabled (Zola, 1993; Chamie, 1989).

O'Toole (1987) contested the WHO prevalence rate of 10% and cited surveys in developing countries where the results were between 0.7% – 1.8% (Flinkelflugel, 1991; Chamie, 1989; Zimbabwe Red Cross, 1986).

Waidmann and Manton (1998) claim that in much of the industrialised world, available survey data point to a decrease in the disability rates amongst the elderly, but there are wide disparities in the disability measures, methodologies, and sample designs preventing comparison across data sources. However, other studies have found the reverse – that disability prevalence increases with age in every region, particularly among rural residents, and in most types of disabilities (Ayling and Cooper, 1999; Arber, 1997; Smart and Smart, 1997; Murray and Lopez, 1996; Cornielje et al, 1993; Badley and Tennant, 1991; Crimmins et al, 1989; Verbrugge, 1989a; Chamie, 1989; Hoffman et al, 1988; McLaren et al, 1987).

Most of the large-scale research done on disablement failed to disaggregate by sex the people studied. The work that does exist on women and disability has tended to consist of personal accounts or small-scale qualitative studies (Ramadan, 1997; Barnes, 1994; Briggs, 1993; Corker, 1993; French, 1993c; Morris, 1993d; Lonsdale, 1990). By a number of different measures, more women than men are likely to experience physical disability or a limiting long-standing illness. Although from birth onwards, male mortality overall is higher than female mortality, the pattern is reversed with regard to female morbidity (Arber and Cooper, 1999; Lorber, 1997; Marks, 1996; Craig, 1995; Cornielje et

al, 1993; Waldron, 1993; Lonsdale, 1990; Hoffman et al, 1988; Soldo and Agree, 1988; McLaren et al, 1987; Nathanson and Lopez, 1987). Part of the reasons for more women having disabilities with increasing age is due to their longer life expectancy, which has been increasing in recent years relative to that of men (Verbrugge, 1990b; Arber, 1997; Craig, 1995; Crimmins et al, 1989; McKinlay et al, 1989; Verbrugge, 1989a; Haavio-Mannila, 1986; Dick et al, 1978).

2.4.2 PREVALENCE RATE IN SOUTH AFRICA

There is a serious lack of reliable information about the nature and prevalence of disability in South Africa due to the different concepts of disablement and methodologies used. Different geographical areas comprising urban and rural areas as well as different age groups have been studied independently. Bhagwanjee and Stewart (1999) claimed that recent estimates of disability rates indicated a prevalence of 13% in 1995 with 5% of the population being severely disabled; a 1995 estimate put moderate to severe disability prevalence in our country between 5% and 12% of the population (Office of the Deputy President, 1997); and data from the 1996 National Census indicated that 6,6% of the total population and 3.7% of the Western Cape population were disabled at the time of the census (www.statsa.gov.za). However, DPSA (2001) cautioned that the percentages may have been an undercount, as a result of the stigma attached to certain types of disability being reported and that the real incidence of disability is probably much higher. Another important factor contributing to an undercount was that persons in various residential institutions such as prisons and old age homes were excluded from the 1996 Census.

Prevalence rates for all disabilities in South Africa range from 3% to 8,6% (Frieg, 2000; Coetzee, 1997; Concha and Lorenzo, 1993; Cornielje et al, 1993; Hoffman et al, 1988; Disler, 1986; Dick et al, 1978;). These prevalence rates are substantially lower than the 10% estimated by the WHO (1980) and WHO (1981).

From the literature available for developing countries the reason for the discrepancy in prevalence is not clear (O'Toole, 1987). However, it is possible that minor disabilities such as learning disabilities, mild mental handicap, psychiatric disabilities, mild visual and hearing disabilities were not identified in self-report surveys. Helander (1993) estimated a global prevalence rate of 5.2% for moderate to severe disabilities which is more in line with the studies done in SA, as it is possible that only the more severe disabilities were reported.

Dick et al (1978), studied an urban population with substrata from different socio-economic backgrounds and found a higher prevalence rate in the lower socio-economic substrata. This is consistent with findings in other countries (Daniels and Mickel, 2002; Little, 2002; Williamson, 1998; Smart and Smart, 1997; Futter, 1996). Cornielje et al (1993) also studied an urban population with a more heterogeneous socioeconomic population and divided substrata into housing type (Formal, Old and New areas, and Informal areas). The overall disability prevalence was found to be uniform within the substrata with similar socio-economic backgrounds. An overall disability rate of 8.5% was reported from the township of Alexandria in 1993 (Cornielje et al, 1993). The most recent study, in Mitchell's Plain, reported a crude rate of 3,8% for all disabilities (Coetzee, 1997).

2.4.3 LOCOMOTOR DISABILITY

Locomotor disability refers to an individual's physical ability to execute distinctive activities associated with moving, both himself and objects, from place to place (WHO, 1980). The prime concern of locomotor disability is walking, transversing uneven surfaces of terrain, climbing stairs, stepping over obstacles and running. It also involves changing of posture such as bending, reaching, kneeling, crouching, stooping, getting on and off a bus, transferring in and out of a car, and lifting and carrying objects from place to place (Wood and Badley, 1983).

People acquire disabling impairments because of a congenital limitation, trauma, acute illness, chronic health condition or other medical episode that has limited their ability to function independently. In South Africa there is an excessively high rate of violence and trauma-related injuries (Speciality Focus Group, 1999). Medical conditions which may frequently cause locomotor dysfunction are those affecting the neurological and musculoskeletal systems.

Locomotor disabilities fall into the ICDH's definition of 'handicap' and affect most of the aspects of handicap such as physical independence, occupation, social integration and economic self-sufficiency, but it refers mostly to aspects of mobility (Wood and Badley, 1983; WHO, 1980).

An important aspect for individuals with locomotor disability in determining their life outcome is accessing a wide range of community environments. Intervention through altering the physical environment and providing assistive devices for improved functional mobility and independence can assist with the integration of the person into society (Pain et al, 2003; Bain, 1998; Mann and Lane, 1995; Vernardakis et al, 1994; York, 1989; Lemer-Frankiel et al 1986).

2.4.4 LOCOMOTOR PREVALENCE RATE

There is not a great deal of literature on locomotor disability prevalence specifically. This is most likely because many of the studies on overall disability have included locomotor disorders and the data have not been reported discretely.

Locomotor disability prevalence has been found to be 1.02% in London for ages 16 - 64 (Patrick et al, 1981) and a study in Lambeth reported locomotor impairment prevalence of 5.1% in females and 2.5% in males (Bennett and Garrad, 1970).

The prevalence of locomotor disabilities in South Africa ranges from 1% - 2% (Coetzee, 1997; Cornielje et al, 1993; Concha and Lorenzo, 1993; Jacka et al, 1984; Disler et al 1986a, 1986b, 1986c). McLaren (1987) found it to be 8.6%, but the study was done in a rural area, Msuleni, where there was a particularly high incidence of Msuleni Joint Disease which is specific to that geographical area.

Disler et al (1986a) found that the prevalence of locomotor disability in Black residential areas (1.8%) was higher than in White (1.3%) and Coloured (1.2%) residential areas of Cape Town. The overall locomotor disability prevalence was found to be higher for females (Cornielje et al, 1993; McLaren et al, 1987), but that it did not increase with age as was found in other studies (Smart and Smart, 1997; Chamie, 1989; Cornielje et al, 1993; McLaren, 1987; Badley and Tennant, 1991).

2.5 ASSISTIVE DEVICES (AD) AND MOBILITY AIDS

An assistive device is “Any product, instrument, strategy, service and practice, used by people with disabilities and older people – specially produced or generally available – to prevent, compensate, relieve or neutralise the impairment, disability or handicap, and improve the individual’s autonomy and quality of life” (Jensen, 1999: 80).

Participation and feedback by the people with disabilities, their caregivers and families are essential in the choice of an appropriate and acceptable assistive device to ensure that it meets their requirements and that of their environment (Pain et al, 2003; Coetzee, 1997; York, 1989).

Some assistive devices assist the user to achieve an activity of daily living (Vernardakis et al, 1994) while others replace a function (Pain et al, 2003). For

example, a wheelchair replaces the function of walking and a urinary catheter replaces the need to use the toilet to pass urine. A shower chair assists the individual to wash themselves and a grab bar assists with getting in and out of a bath or on and off the toilet. Pathways assist the wheelchair-users to propel themselves over rough or uneven terrain.

Mobility refers to any movements that lead to a change in body position or geographical location (Trombly and Quintana, 1989) by the individual's own means performed with or without some form of assistance (Blouin and Bergeron, 1997). It is a basic and essential activity for quality of life of all people of all ages (Creel et al, 2001).

Mobility aids are used to increase the independent walking ability of individuals with locomotor disabilities. By enabling some of the body weight to be supported by the upper limbs they provide pain relief and, in cases of weakness of the lower limbs, assistance with weight-bearing. They also provide stability for people who have difficulties with balance and co-ordination (Pain et al, 2003; Stewart, 1983).

Wheelchairs, walking frames, crutches, walking sticks and quadruped walking aids provide varying degrees of weight relief and support during standing and walking according to the needs of the individual and the environment in which it is to be used (Pain et al, 2003; York, 1989; Jacka et al, 1984).

Assistance can also be from a helper or some form of technical aid, for example, an assistant to feed an individual whose arms are paralysed or a computer with a large monitor screen for people with visual impairments (DPSA, 2001).

The selection of the most appropriate mobility aid depends on the

- user's age, physical development, strength, comfort, body measurements and safety;

- home and landscape environment;
- daily activities and social roles of the user; and
- amount of training received (Routhier et al, 2003; Scherer, 1994; Trombly and Scott, 1989).

The social roles which need to be considered are the family relationships, beliefs and values of the individual and amount of participation in community activities (Nisbet et al, 1996).

Of all the mobility aids available wheelchairs are used the most often (Kirby, 1996) and have an important role enabling users to carry out their activities of daily living and their social roles as independently as possible (Routhier et al, 2003). However, in a study on locomotor prevalence in Mitchell's Plain, Coetzee (1997) found that walking sticks were the most commonly needed pieces of equipment.

An important aspect of the quality of life of people with locomotor disabilities is being able to access a wide range of community environments (Coetzee, 1997). Intervention by means of assistive devices and alterations of the physical environment can have a great positive influence over their the quality of life by improving their functional ability and independence (Speciality Focus Group, 1999; French, 1993a).

The assessment of the appropriate mobility aids for a disabled person needs to be conducted in their home, work, school and social environments (Kirby and MacLeod, 1996; Law et al, 1996; Davidson, 1991; Ozer, 1990). If rehabilitation has taken place in a hospital environment and no home visits have been carried out to assess the needs those prescribed may not be appropriate for assisting functioning in the individual's home and community environment (Palisano et al, 2003; Young et al 1996; York, 1989; Lemer-Frankiel et al, 1986) as most people with disabilities spend the majority of their time in their homes and communities

(McLaughlin et al, 1998; Steinbok et al, 1997; Calderon-Gonzales et al, 1994). According to the ICIDH-2 (WHO,2001: 161) "environmental factors comprise the physical, social, and attitudinal conditions that are present in an individual's life".

Jacka et al's (1984) research in Cape Town provided the following reasons for assistive devices and mobility aids of the disabled not being used:

- Individuals had no knowledge of the use of the device or they were not suitable for the environment;
- Some of disabled had progressed in their functional level and the devices were no longer suitable; and
- They required different assistive devices.

Egmond and Van den Broek (1987) cautioned against prescribing appliances when they are not functionally important to the individual as he found this to be one of the reasons for poor compliance with the use of equipment.

2.6 REHABILITATION

"Rehabilitation includes all measures aimed at reducing the impact of disability for an individual, enabling him or her to achieve independence, social integration, a better quality of life and self-actualisation. Rehabilitation includes not only the training of disabled people, but also interventions in the general systems of society, adaptations of the environment and protection of human rights" (Helander, 1993: 17). It is one of the four pillars of primary health care (Rule, 1999) and has a strong focus on disability prevention (Smart and Smart, 1997).

It is a major challenge for rehabilitation therapists to combine the goals of self-sufficiency and civil rights for disabled people as there is very little unity between the two goals (De Jong and Batavia, 1999; O'Day, 1999; Rolland, 1997; Renwick and Friefield, 1996; Greenwood, 1985). If they achieve a high level of independence there is the risk of their social benefits being lost and them and

their families becoming stigmatised and disadvantaged (Crewe et al, 2002; Crewe, 2000). Frequently disabled people are anxious about gaining too much function in case their improvement jeopardises their social support. Often a level of independence gained will be helpful to the disabled people in their activities of daily living, but it does not mean that their newly-gained level of function will enable them to return to their occupations. Thus advocacy by the therapists is required to ensure that policy provisions are changed to prevent their losses of social benefits (Crewe et al, 2002).

Rehabilitation is concerned with disabled individuals achieving their maximum potential capacity as persons within a family and the communities in which they live and work and, therefore, involves multisectoral sectors such as health, welfare, housing, cleansing, sewerage, roads and transport systems (Speciality Focus Group, 1999; Morris, 1993d; Gloag, 1985; Ben-Sira, 1981).

Rehabilitation of chronic conditions is not a short-term intervention. It may well start during a period of hospitalisation as the result of an acute condition, but continues afterwards in the home, place of work and community until the person has readjusted to a new lifestyle and has reached his/her optimal capacity (Gloag, 1985; Putterhill et al, 1984a; 1984b; Frazer, 1982).

Apart from the fact that it is the right of every vulnerable individual to receive rehabilitation (ANC, 1994), Leavitt (1992) points out that it is a means of decreasing the costs of disablement to both the individual and society in general. Unless appropriate rehabilitation is received the disabled can become an unnecessary burden to themselves, their families and the community (Schofield and Bloch, 1998; Howe et al, 1997; Allen and Mor 1997; Sharman, 1972) and the disabled themselves develop feelings of inferiority and rejection (Simon-Meyer, 1999a; Office of the Deputy President, 1997; Lonsdale, 1990). Rehabilitation optimises the individual's capacity to function physically which facilitates their

ability to be independent, take control of their lives and make their own decisions (Mann et al, 1999; Neistadt and Crepeau, 1998; Lonsdale, 1990).

Traditionally rehabilitation has taken place in hospital settings. However, hospitals no longer are able to provide adequate rehabilitation services now that the average hospital stay for clients has decreased to such an extent, life expectancy has increased and there remains a general shortage of rehabilitation therapists in most countries (Frieg, 2000; Speciality Focus Group, 1999; Hunt and Annandale, 1999; Keith, 1997; Coetzee, 1997; Condie, 1991).

Mortality and morbidity are inversely related and as the mortality rate for conditions such as stroke, spinal cord injury and brain injury declines there is an increase in disability and an increased need for rehabilitation (Speciality Focus Group, 1999). Medical and welfare services for disabled persons in developing countries cannot cope with their rehabilitation loads. According to the WHO (1981) two thirds of the world's population with disabilities are not being exposed to any rehabilitation services and it is estimated that at least 1.5% of the total population, at any given time, could benefit from rehabilitation.

Community-based rehabilitation (CBR) is a means of providing people with disabilities with appropriate and acceptable rehabilitation services particularly those living in rural areas (Frieg, 2000; Coetzee, 1997; Blaxter, 1983).

"Community-based rehabilitation is a strategy within the community for the rehabilitation, equalisation of opportunities and social integration of all people with disabilities. It is implemented through the combined efforts of disabled people themselves, their families and communities and the appropriate health, education vocational and social services" (WHO, 1981: 11). Successful community-based rehabilitation programmes are based on the principles of equality, social justice, solidarity, integration and dignity while promoting and protecting the human rights of the disabled (Helander, 1993). Thus rehabilitation services should be planned and implemented according to the needs expressed

by the people with disabilities themselves (Crishna, 1999; Stuelz, 1999; Leavitt, 1995; O'Toole and McConkey, 1995; Helander, 1993). The community-based rehabilitation strategy is strongly encouraged by the White Paper on an INDS to "... form the basis of the national disability strategy" (Office of the Deputy President, 1997: 27).

The rehabilitation practices of a society cannot be understood without making sense of its cultural beliefs and coping mechanisms. Societies develop their characteristic patterns of coping with physical disability, depending on the way disability is understood and their resources identified (Dalaal, 2002). For example, in India, disability rehabilitation is primarily considered to be a responsibility of the family. Large and extended Indian families provide essential physical, emotional and economic support to its members with disabilities where culture and traditions are viewed as strengths rather than impediments in improving the quality of life of the disabled (Dalal, 2002; Morrison and Finkelstein, 1993). However, the very poorest people such as famine victims, landless rural labourers, women-headed households and homeless persons may simply lack the means to help their disabled relatives (O'Toole and McConkey, 1995; Glendenning, 1992; Glendenning, 1989). They require help from the state and non-governmental organisations (NGO's).

The Speciality Focus Group (1999) confirms, in its discussions on Specialised Rehabilitation Centres, that in order to achieve an appropriate level of functioning within the patient's community rehabilitation needs to be within the home/community setting.

However, according to the INDS of the Provincial Administration of the Western Cape (PAWC) (1998) there are minimal community-based rehabilitation programmes in the Western Cape due to inadequate staffing, facilities and referral systems. People with disabilities have difficulty accessing the available services and the transport systems are inaccessible, inadequate and costly. In

addition the disabled are unable to be issued with mobility and assistive devices at the facilities that do exist.

2.7 SOCIAL ASSISTANCE IN SOUTH AFRICA

Most Western industrialised countries have state-controlled programmes to provide basic social security for pensions, unemployment, housing, education and health services for those who are permanently or temporarily disadvantaged. However, in developing countries where there are limited resources social assistance is restricted and does not reach all the population in need (Ahmad et al, 1991).

In South Africa the welfare system is that of the residual type of service delivery (Luiz, 1994) in that it only provides some form of assistance to those in need when the individual, family, community or economic systems can no longer cope and it is regarded as a safety net only. However, Aliber (2001; 38) describes it as being "less of a net devised to catch an unfortunate few in times of temporary distress, than a major commitment to help a large fraction of the population over a sustained period". Thus it is typical of countries at this stage of economic development and industrial transition (Van der Berg, 1992). However, the new Constitution of South Africa (1996) states that there should be no discrimination against anybody on the basis of their disability (Government Gazette No 108 of 1996) and there is new legislation regarding employment equity to ensure that there are increased opportunities for disabled persons (Government Gazette No 55 of 1998). It is important for this legislation to be enforced and that a multi-sectoral approach be put into place to ensure employment opportunities for the disabled.

People with disabilities are obliged to depend on welfare benefits in order to survive as there are barriers to obtaining employment (Oliver, 1996), but DG's

are perceived by some to discourage the disabled persons from actively seeking employment as the past policies resulted in "Passive income maintenance through grants (Hunter, 2002; Government Gazette No 1108 of 1997: 49). It is claimed that the DG's had a demotivating effect on the beneficiaries as it made them dependent on welfare (Hunter, 2002; Fraser-Moleketi, 1998).

The DG also acts as a safety net to other members of the disabled person's family and has been a source of household security for millions of the population, greatly contributing to poverty alleviation (Hunter, 2002; Office of the Deputy President, 1997; Lund, 1997; Budlender, 2000; Schneider and Marshall, 1998).

Social security programmes provided by the state are described in Appendix xvii: paragraph 25 and, included in the categories of people defined as chronically poor, are people with disabilities (Aliber, 2001).

Social assistance is not seen as the right of the individual and the services are provided selectively only and are viewed as a privilege which may be withheld (Luiz; 1994; McKendrick, 1987). In other words, presently, only the symptoms of poverty are partly being addressed, but the underlying causes have not yet been dealt with in any meaningful manner (Ministry for Welfare and Population Development, 1997; Luiz, 1994).

The White Paper on Social Welfare (Government Gazette, Notice 1108 of 1997) was developed after widespread consultation and negotiations with many stakeholders. The document emphasises that welfare programmes should optimise social functioning and it acknowledges that welfare service provision currently has a racial and urban bias. It concedes that as resources are limited the welfare expenditure can only be increased when higher economic growth is achieved in the country and that people's expectations, including those of the disabled, cannot be comprehensively met in the short term. However, the human rights activists insist that no citizen should be deprived of living above minimum

acceptable standards (National Human Rights Research and Advocacy Project, 1998).

The White Paper on Social Welfare follows the social model approach of viewing disability as the Financing Policy of the Department of Welfare is moving from a policy of providing social assistance in isolation to one where social assistance is linked to social services (Government Gazette, Notice 463 of 1999). People receiving income in the form of DG's will now be able to identify their real needs and there will be an attempt at addressing these barriers which they experience.

In 1995/96 8,7% of the national budget was allocated to the welfare budget (Ministry of Social Welfare, 1997). Social assistance was the largest expenditure in the welfare budget comprising 88% of this budget (64% was spent on old age grants (OAG's) and 24% on DG's. The same document reports that 1,6% of the total South African population received a DG. However, Dr Zola Skweyiya, the current Minister of Social Development, estimated that only 19% of persons with disabilities received government grants and acknowledged that the services for disabled people were inadequate and that 68% of disabled non-pensioners were neither receiving a grant nor any form of private insurance pension (Skweyiya, 2000; Schneider et al, 1999). The authors also report that DG's were the most commonly received grants of the remaining 32% of disabled non-pensioners who did receive a grant.

The system of social assistance is controversial. The main arguments against social assistance include the systems' reinforcement of the medical model of disability and the culture of dependency it creates (Government Gazette 1108 of 1997), while it is acknowledged that opportunities for employment are limited for persons with disabilities and that they often rely on the grants as the only means of income (Office of the Deputy President, 1997; Lund, 1997).

2.7.1 DISABILITY GRANTS (DG) IN SOUTH AFRICA

There is a lack of clear definition of disablement in the legislation which affects the inclusion criteria of the different grants (Committee of Inquiry, 2002; Kimanie, 2000). For example, the aim of the care dependency grant (CDG) is to enable permanent home care for disabled children. The CDG presently benefits only severely disabled children who live at home permanently and does not cater for the many other children with milder disabilities or those in day-care facilities. Recommendations put forward by the Committee of Inquiry (2002) were that the CDG benefits be extended to include children with moderate disabilities and those in special schools or day centres.

Adults with disabilities can apply for state assistance in the form of a DG as published in the Social Assistance Act (Government Gazettes No 59 of 1992 and No 106 of 1997) and the Regulation Gazette (Government Gazette No R 417 of 1998). The welfare office in each magisterial district administers these and other social grants on behalf of the provincial Department of Social Services. People with disabilities are eligible to apply for DG's if they are between 18 and 59 years for females and 18 and 64 years of age for males, and are not receiving another social grant.

When applying for a DG the disabled have to submit documentation as stipulated in the Act, namely, an application form (VRT-3) and medical report (Appendix i). The disabled have to prove their need on the basis of a means test and the amount awarded is calculated on a sliding scale. It takes into consideration the material means available to potential recipients in determining both whether they should receive benefits and what level of benefits they should receive (Van der Berg, 2001c). The maximum monthly amount that can be awarded is R740 and it is paid into the beneficiaries' bank accounts or they collect their payments at the Allpay payout centers in various suburbs in the Western Cape.

In a study conducted in nine of the provinces with 1 703 disabled people Schneider et al (1999) found that of all the disabled who were non-pensioners 68% were not receiving a grant of private insurance provision and that DG's were the most common type of grant for non-pensioners. They found that Coloured respondents were more likely than any other race group to receive grants of private insurance pensions. Respondents with locomotor disability (64%) were found to be more likely to have applied for a grant and they were also marginally more likely to be successful in their application. If they had more than one disability they were more likely to receive a grant than respondents with only one disability and males with a single disability were more likely to receive a grant than females with a single disability. Nearly half of the respondents claimed to have waited between three to twelve months for their DG to be issued. Disabled people who used assistive devices were significantly more likely to receive a DG than not to receive one.

During October 2002 there were 319 DG's paid out to the disabled in Lotus River (Allpay, 2002). By dividing the number of DG's awarded by the total number of disabled, according to the 1996 Census, 66% of the disabled received DG's (Central Statistical services, 1996).

Several studies have found that the main items that the disabled spend their money on are household necessities such as food and groceries and clothes (Schneider et al, 1999; Schneider and Marshall, 1998; Lund, 1997).

When people with disabilities need to be cared for at home by a family member they can apply for a grant-in-aid to relieve their financial burden as many of them have had to give up their jobs to stay at home and take on the role of caregiver (Government Gazette No R 417 of 1998). However, the amount of the grant is generally much less than what the caregiver was earning in employment and thus the level of poverty for the family is increased. The state, nevertheless, is

saving a great deal of money by not having to pay for the disabled person's care in an institution.

2.7.2 CRITICISMS OF THE SOCIAL GRANT PROCESS

From the researcher's personal experience and reading the literature available on the social grant system there appear to be problems all along the process of applying and being awarded a DG (Kimani, 2000; National Workshop on Social Assistance Policy, 2000; Schneider et al, 1999; Schneider and Marshall, 1998; Lund, 1997).

There does not appear to be a standard procedure to follow to activate the application process and there is a lack of information on the actual procedure for the disabled people which makes the application process extremely lengthy and difficult (Kimani, 2000; Schneider and Marshall, 1998). The majority of people applying for DG's have difficulty in moving independently and they have less education and are less literate. They are sent from one stage of the process to another and from one doctor to another (Kimani, 2000). There are few guidelines for assessing the extent of disability and it rests with and is awarded at the discretion of the medical officer (Kimani, 200; Lund, 1997) who frequently does not complete the forms in full or his/her handwriting is illegible making it difficult for a rational basis for either approval or denying the grant (Kimani, 2000). If an application is not successful the officials do not provide the disabled with the reasons for their applications being rejected. Nor do they give them reasons for grants suddenly having ceased (Lund, 1997). The medical model is reinforced in welfare services in South Africa as eligibility for a grant is assessed by medical practitioners only and on the basis of impairment only and not of disability or handicap (Government Gazette notice 1108 of 1997).

Although the benefit is a statutory right, recent legislation has made it a discretionary award. It is heavily biased towards a medical diagnosis and does not take into consideration the disabled person's external environment (Lund, 1997) nor the number of dependents a household may have (National Workshop on Social Assistance Policy, 2000).

The Committee of Inquiry (2002) maintains that means testing is rarely used correctly, is administratively demanding and has been reported as demeaning. The assessment test itself is highly subjective and is open to the personal interpretation of the medical officer. They recommended that eligibility should not be based on the person's 'incapacity' to work, as their lack of work is often due to the poor economic climate and prejudice in the workplace as opposed to their physical or mental inability to perform the job. Eligibility should be determined by a needs-based assessment which should replace the current means testing which is awarded on a sliding scale according to income. Van der Berg (2001c) claims that there is a conflict between private income sources and social grants and that means tests affect incentives and behavioural responses to social grants.

The Committee of Inquiry (2002) recommends that the disabled who are also poor should receive a basic income grant (BIG) as a first step in a package of benefits. This grant should meet their daily living expenses (Le Roux, 2001). Thereafter, consideration should be given to their special needs and provision should be made in the form of 'topping up' in relation to cash benefits, in-kind benefits and other essential services (Committee of Inquiry, 2002).

Several authors have recommended that research be conducted with regard to disability prevalence and potential numbers of eligible beneficiaries so that it can be possible to accurately determine the extent of coverage of social grants of the disabled (Van der Berg, 2001c; Barbeton, 2000; National Workshop on Social Assistance Policy, 2000; Schneider and Marshall, 1998).

2.8 CAREGIVING

“A caregiver is any person looking after another, resulting in the caregiver losing personal freedom” (Ayling, 1993: 780). A family carer is a person who assumes “A cardinal role in looking after a relative with a chronic illness or disability” (Schofield and Bloch, 1998: 405).

Injury or onset of disease can lead to a period of hospitalisation and rehabilitation. When discharged home the spouse, mother or immediate family members living in the same household usually takes on the role of caregiver (Miles, 2002; Abu-Habib, 1997; Dwyer and Coward, 1992; Jackson, 1992; Anderson, 1988) to carry out basic nursing skills and to assist the disabled person with activities of daily living. Once maximal function has been achieved in rehabilitation a maintenance programme must be continued at home to prevent physical deterioration and this task inevitably falls on the caregiver too (Miles and Frizell, 1990; Werner, 1989; Anderson, 1988) as no health care system is capable of providing this service on its own. This is particularly so in developing countries where there is a shortage of rehabilitation therapists. The importance of caregivers is likely to be realised even more in South Africa in the future as community-based rehabilitation is introduced to meet the rehabilitation needs of the country (National Rehabilitation Policy, 1998; Office of the Deputy President, 1997; Kay and Dunleavy, 1996).

In a study of the needs of disabled people Clayer et al (1998) found that in addition to help with activities of daily living they needed assistance for home maintenance, heavy housework and managing money and that they generally sought caregiver assistance for those activities in the informal rather than the formal sector.

The additional obligations and sacrifices the caregivers have to fulfill place a major burden on them in terms of psychological, physical and financial resources (Medeiros et al, 2000; Glendenning, 1992; Forster and Young, 1990; Schultz et al, 1990; Glendenning, 1988; Camwath and Johnson, 1987; George and Gwyther, 1986; Gilleard, 1984). Sometimes the caregiver's obligations entail being available all day and all night throughout the week (Forster and Young, 1990) and it has been found that there is a strong correlation between the number of hours spent on caring and the strain experienced (Taylor et al, 1995; Askham, 1992).

During the eighties there was a shift in the USA and UK from institutionalised care to community care which in this instance referred to family care. This has always been the norm in South Africa as there are very few day care facilities and institutions for the disabled (Petersen, 1991; Singer and Irvin, 1989). Support is provided to families in Western developed countries in the form of respite services at home, special respite care facilities, day/night respite care services and respite programs based at an institution (Elmstahl et al, 1996; Forster and Young, 1990).

The caring role in families has been assigned traditionally to women (Abu-Habib, 1997; Dwyer and Coward, 1992; Anderson, 1988). They are often the sole carers and nurturers at home in addition to being productive and doing back-breaking household chores (Begum, 1992). Many of them have to give up their employment in order to cope with their relatives (Glendenning, 1992; Glendenning, 1989; Glendenning, 1988). In South Africa carers automatically become unpaid workers who save the social service providers money and many of the women have had to give up their jobs to care for the physically disabled persons (Petersen, 1991)

Studies of caregivers of severely disabled family members have found that they face the following common challenges: (Glendenning, 1992; Forster and Young, 1990; Singer and Irvin, 1989)

- Chronic stress;
- Grief;
- Financial costs;
- Losses in financial opportunities;
- Extraordinary time demands;
- Difficulties with normal family routines;
- Marital discord;
- Absence of services; and
- Difficulties with the physical management of the disabled person.

The burden of the caregivers eventually results in a deterioration of their health and this leads to a breakdown of family functioning (Elmstahl et al, 1996; Schofield and Bloch, 1998; Anderson, 1988). The most common health problem incurred by carers is backache and painful legs brought on by lifting dependents in and out of beds, in and out of the bath and up and down steps (Petersen, 1991). There is always a high turnover over of staff in institutions caring for the severely physically disabled in the USA where the staff provide only 40 hours of caring per week (Powell and Heceimovic, 1986) compared to those of caregivers in disadvantaged areas in SA.

Research shows that women carers experience significantly higher levels of stress than men (Miller et al, 1991; Hinrichsen, 1991; Harper and Lund, 1990). Other authors (Elmstahl et al, 1996; Schulz et al, 1990) report on the frequency of depression and isolation experienced by the caregivers. They become isolated from their extended families, friends and community and have no time for themselves (Forster and Young, 1990). These problems are compounded in developing countries where there are poverty and social tensions (Petersen,

1991). Murphy et al (1997), Taylor et al (1995) and Brody et al (1987) found that being in paid employment was clearly protective, associated with fewer major health problems and a higher life satisfaction and less resentment. However, with multiple roles, working carers also reported higher overload (Murphy et al, 1997; Stull et al, 1994; Mui, 1992).

The burden of caregivers changes over time (Taylor et al, 1995) and, unexpectedly, caregivers to disabled showing the greatest improvements in activities of daily living function also reported the highest total burden and disappointment (Elmstahl et al, 1996). Generally, however, there is a consistent negative correlation between caregiver's burden and quality of life for disabled people (Elmstahl et al, 1996; Futter, 1996, Futter, 1995).

Many carers successfully adjust to the caring role over time and their perceived level of burden decreases (Leff, 1993; Parker, 1990; Twigg et al, 1990). Other writers suggest that some carers experience benefits in caring (Clifford, 1990; Motenko, 1989) although no mention is made of the financial circumstances or the amount of state support in the form of respite they received.

Schofield and Bloch (1998) recommended that more flexible employment arrangements are needed to reduce work conflict and give caregivers more options in combining paid employment and caring to reduce the financial burden and to provide a form of respite from the disabled person. Many carers need information and advice, respite and domiciliary assistance to help them maintain a tolerable quality of life while they perform a valuable social function (Thomson and Thomson, 2001; Taylor et al, 1995).

At a community level education is needed to promote the social value of caring and an awareness of the demands and impact of the caring role (Kaye and Applegate, 1990; Finley, 1989).

Taylor et al (1995) recommend that services for caregivers should target needs that are demonstrated rather than assumed and the only way of doing this is to establish and describe trends in the population relying on caregivers before unnecessary and unwanted services are provided.

2.9 HUMAN ACQUIRED IMMUNODEFICIENCY SYNDROME (HIV/AIDS) IN SOUTH AFRICA

AIDS is “The medical designation for a set of symptoms, opportunistic infections, and laboratory markers indicating that a person is in an advanced stage of HIV infection, with an impaired immune system” (Irwin et al, 2003: xxv).

A person who is HIV-positive has been infected by the virus, but has not yet developed full-blown AIDS and that is the reason that there are always far greater numbers of HIV-positive people in a population than the number of people with AIDS.

It takes an average of 10 years from the time people are infected with HIV until they develop clinical symptoms of AIDS, although some people may develop it much sooner (Irwin et al, 2003). As the immune system becomes weaker opportunistic infections in the environment cause debilitating illnesses and symptoms such as TB or pneumonia during the last two years of life (Nattrass, 2002).

HIV is spread through having unprotected sex with an infected person, sharing needles or other drug injection equipment previously used by an infected person, or receiving a transfusion of blood contaminated with HIV. The virus can also be passed from a mother to her infant before or during birth or through breast-feeding (Cadre, 2002).

In Africa the epidemiological pattern differs from that found in industrialised countries, as it is largely transmitted via heterosexual contacts rather than through homosexual contacts and drug abusers sharing needles (Stillwaggon, 2000; Caldwell et al, 1993).

It is estimated that about 40% of the deaths that occurred in South Africa in the age group 15 – 19 during 2000 were due to AIDS and that about 20% of all adult deaths in that year were due to AIDS. When this is combined with the excess deaths in childhood due to mother-to-child transmission, it is estimated that AIDS accounted for 25% of all deaths in the year 2000 and that it has become the single biggest cause of death (Dorrington et al, 2001; Whiteside and Sunter, 2000; Laubscher and Malunga, 2000).

2.9.1 PREVALENCE

AIDS is a devastating pandemic currently sweeping South Africa with far-reaching and overwhelming effects. South Africa has the world's highest AIDS caseload with an estimated 6 million of its 45 million population infected with HIV (Reuters, 2004). It is predicted that, in the absence of adequate health-care interventions, the AIDS epidemic will bring life expectancy down to nearly 40 before 2010 (Dorrington, 2000; 2001; Actuarial Society of SA, 2001). AIDS is already the single largest cause of death in South Africa and will be responsible for more than 50% of deaths by 2006.

The total population of the Western Cape in 2002 was 4,615,965. Of these 218,468 people tested HIV-positive, 13,620 were sick with AIDS, and the cumulative AIDS deaths were 20,975. There were 7,325 orphans from mothers who had died of AIDS (Dorrington et al, 2002).

As a predominantly sexually-transmitted disease HIV/AIDS attacks the age group that is sexually active, which usually involves young adults at the peak of their income-earning years who are often heads of families (Lundberg and Over, 2000). The peak prevalence occurs between the ages of 20 and 45 for men, and 15 and 30 for women with a higher HIV prevalence for women than for men (Reuters, 2004; Dorrington, 2001; Whiteside and Sunter, 2000; Laubscher and Malunga, 2000). Deaths among women aged between 20 and 49, one of the groups most at risk for contracting HIV, were up 168% over the past six years (Reuters, 2004).

There is some evidence that there is little difference in HIV prevalence between men and women who are employed suggesting that unemployed women are particularly vulnerable to HIV infection (Dorrington, 2001). HIV prevalence rates amongst the unemployed are typically 30 – 50% higher than among the employed – reflecting, in part, the large share of young people and females amongst the unemployed (BER, 2001).

Prevalence also appears to vary between skill levels and racial groups (Nattrass, 2002). Dorrington (2001) reported that those in the higher job grades have an HIV prevalence of only 2,5% to 3% compared to 11% in the lower job grades. The ASSA model predicts that HIV prevalence will peak at different times and rates for the various racial groups in the country, namely, at 3,2% for Whites in 2011, at 4,8% for Asians in 2010, at 6% for Coloureds in 2010 and at 19,5% for Africans in 2002. It predicts that the overall HIV prevalence will grow from its current level of 11% and will peak at 16,2% in 2006 involving 7,7 million people. The number of people with full-blown AIDS is predicted to rise five-fold to 880,000 in 2005 and then to 1,2 million people in 2015. The number of AIDS-related deaths will follow the trend for full-blown AIDS with a two-year lag (Nattrass, 2002).

Among pregnant women attending public health clinics for antenatal care the prevalence increased from less than 1% in 1990 to 25% in 20001 (Dept of Health, 2002).

2.9.2 DEMOGRAPHIC EFFECTS

The prevalence peaks of HIV/AIDS will have an affect on the country's demographic growth over the next few years. The Doyle Metropolitan Life demographic model predicts that the population will grow by only 1,5 million between 2000 and 2015 which is 10 million fewer than would have been the case had there not been any AIDS. The labour force will remain almost stagnant over the next 14 years as a result of the most economically-active group of people being affected the most (Nattrass, 2002; Arndt, 2000).

2.9.3 ORPHANS

The mortality rate of 20 – 40 year olds has increased as a result of AIDS and this has caused an increasing number of orphans (Arndt, 2000).

Without proper care and support these children will be vulnerable to antisocial behaviour (Cadre, 2002) and this will result in rising crime in South Africa over the next 10 to 20 years, and, as HIV/AIDS is also likely to widen income inequality this will also increase the crime rate (Fourie and Schonteich, 2001; Schonteich, 2000, 1999).

The emergence of HIV/AIDS orphans has an effect on other households in the community or extended family. The additional children strain the household income and productive capacity of the extended families who buffer some of the impact of the death of parents (Ainsworth et al, 2000).

As extended families have become overstretched by a large number of HIV/AIDS orphans it has led to the emergence of child-headed households. Increasingly, therefore, orphans are cared for by very young siblings where their elderly relatives are unable to cope or do not live in the vicinity (Cadre, 2002).

Orphans in child-headed households or extended households with limited access to education are often exposed to malnutrition (Cadre, 2002). As the labour supply shrinks and there are fewer teachers and health workers due to AIDS the lives of the orphans are even more negatively affected (Donahue, 1998).

2.9.4 SOCIAL EFFECTS

The social impact of HIV/AIDS involves increased food insecurity, decreased school access, increased burden of care, losses and shifts in community support, increased work burden on children, and social isolation (Desmond et al, 2000; Aggleton and Bertozzi, 1997).

2.9.5 EFFECTS ON ELDERLY RELATIVES

Elderly relatives frequently take over the roles of surrogate parents to the orphans and become caregivers to the adult persons with AIDS who tend to move back to their families and communities of origin (Agyarko and Kowal, 2000; Knodel et al, 2000). These additional roles impact negatively on the welfare and health of the aged relatives (Ainsworth and Dayton, 2001).

2.9.6 POVERTY

A general topic throughout the HIV/AIDS literature on Southern Africa is its relationship with poverty. Once affected by HIV/AIDS, poverty remains the primary concern of the family as HIV/AIDS flourishes in situations of poverty and, at the same time, increases the level of poverty (Cohen, 1999; Thomas et al, 1999; Costigan et al, 2000; Goudge and Govender, 2000).

With the mortality rate of 20 – 40 year olds increasing the working population has reduced. Recent estimates indicate that up to 15% of SA's economically active population was HIV-positive or suffering from AIDS in 2000. This has decreased the amount of money earned by the family and thereby reduced the disposable household income (Cadre, 2002).

For the past decade companies have decreased their reliance on unskilled labour and have moved out of economic sectors where the customer-base comprised lower-income consumers. This had led to poor households being doubly disadvantaged. Not only does this make their access to the labour market even more difficult, but the products that they purchase become scarcer and more costly (Natrass, 2002).

AIDS increases the burden of the working age population as they are required to care for the young and take over the additional responsibilities of caring for the sick (Arndt, 2000).

2.9.7 TREATMENT AND PREVENTION

Prevention of HIV/AIDS can occur in different areas of risk infection. The risk of contracting HIV through sex can be reduced by the use of male or female condoms. Transmission among intravenous drug users can be stopped by

people not sharing injection needles. A short course of antiretroviral medications given to an HIV-positive mother at the time of delivery reduces transmission of HIV from mother-to-child. Thorough techniques of collecting blood supplies from donors can almost eliminate the risk of contracting HIV through transfusions (Irwin et al, 2003).

Prevention of new HIV infections by transmission through sex and injection needles require the population to become educated about HIV/AIDS and needs to go beyond ensuring that people understand the physical mechanism of transmission and providing them with barrier devices like condoms.

In spite of many prevention efforts focusing on individual behaviour from the 1980's the spread of HIV has not decreased and has actually increased in many areas of the world. Irwin et al (2003) contend that broad-scale social and economic factors of poverty, class disparities, structural racism and gender power differentials need to be dealt with in order to decrease individuals' vulnerability to the infection.

Gender power differentials can be reduced by providing female condoms to promote female-controlled prevention. AIDS education and counselling of men need to be addressed to change male attitudes to sexual behaviour with regard to coercive sex and condom use of both male and female condoms (Irwin et al, 2003).

Drugs used to treat HIV/AIDS are known as antiretrovirals. Should adults be able to obtain treatment they have to remain on antiretrovirals for the rest of their lives. The drugs have brought down the death rates in wealthy countries and have enhanced the quality of life of those who have been able to afford and obtain treatment (Irwin et al, 2003).

There is an increasing demand for a comprehensive treatment and prevention plan, including the use of antiretrovirals, for managing the South African HIV pandemic (COSATU, 2000). The demand has its basis in human rights arguments and covenants (Heywood, 1998) especially the Bill of Rights in the South African Constitution of 1996, which guarantees the rights of life and dignity. The Constitution also puts an obligation on the state to progressively realise the right of citizens to health-care services (Constitution, 1996). If immense human suffering is to be avoided, it will be essential over the next decade to massively reduce the number of new infections and increase access to adequate health-care for the bulk of the HIV-positive population (Geffen, 2002).

In contrast to other parts of South Africa where there are developments around anti-retroviral treatments the Western Cape has agreed to take over the responsibility and budgeting for anti-retroviral drugs and laboratory costs. HIV/AIDS spending in the province will double in 2005 from R47m to R90m (Caelers, 2004a) so that anti-retrovirals for all children under 14 will be provided free (Caelers, 2004b).

2.10 SUMMARY

The medical model approach to assessing disablement is based on clinical evaluation only which does not encompass any other forms of assessment about the extent to which someone is handicapped by their disability. It does not accurately measure the extent to which a person is able or not able to perform certain activities of daily living and is oriented towards the individual and not the physical, social and attitudinal environments in which the task must be performed. It is not appropriate for assisting permanently impaired people once they have passed through the acute phase of injury or disease as it does not incorporate the social and economic aspects affecting the disabled.

The medical model promotes optimal physical independence whereas the social model focuses on accessibility of the environment and the removal of barriers.

Definitions of disability vary according to the theoretical framework of the author. Those from the medical model discuss it in terms of the individual's ability or lack thereof in performing tasks. Those using the social model as a starting point view it in terms of how the environment impacts on the capacity of the disabled person to participate within the family and community.

Racial laws in the past had a very negative influence on poverty, employment, education and housing of people living in historically disadvantaged communities. However, there are also many other aspects of life which have a destructive impact on the lives of the disabled. Discrimination and oppression still cause unemployment and poverty leaving the disabled feeling powerless and dependent.

Prevalence studies of disability, including the South African Population Census and the criteria for receiving DG's, are all based on impairment underscoring the fact that the health and welfare systems are deeply entrenched in the medical model even though the Constitution of the country views disability as a human right (Government Gazette No 108, 1996).

Rehabilitation and assistive devices are means which can assist the disabled with regard to independence, but accessibility to these services and equipment respectively are limited due to the lack of resources.

DG's do assist the disabled and their families with household expenses, but the process of acquiring them is stressful. There are no clear guidelines for the disabled to follow when applying for them and if they are rejected there are no explanations provided for the criteria on which the rejection or ceasing of grants were based.

The social assistance and safety nets do not provide sufficient coverage for all those disabled with the greatest need and the administration is bureaucratic, inefficient and demeaning to the most disadvantaged of the South African population.

Caregivers are providing an essential service to the disabled in need which is saving the social services a great deal of their budget by not having to provide institutions to care for these people. However, very few of the caregivers receive a grant-in-aid for their services and many of them have had to give up their jobs in order to care for their disabled relatives. The grant-in-aid is much less than most labouring jobs and this puts the family into a situation of worse poverty.

Since 1994 policies and legislation have been put into place which should have a positive impact on the lives of the disabled and their families in the future once there are the finances to implement them. The rapid increase in HIV infection is alarming. However, unless adequate treatment and prevention programmes are instituted in the whole of South Africa very shortly the social and economical consequences of the HIV/AIDS pandemic will be catastrophic for the country.

CHAPTER THREE

RESEARCH METHODOLOGY

3.1 INTRODUCTION

In this chapter the methodological process is described and issues pertaining to the research conducted are discussed. The reasons for having selected particular methodological choices are provided, potential sources of bias are identified and attempts at minimising these are described in the relevant sections.

The study comprised the following five processes:

3.1.1 Becoming familiar with the community; identifying a research assistant; and obtaining funding for the wheelchairs, mobility aids, assistive devices, minor building alterations and the salary of the research assistant.

Data were gathered for a community profile (Appendix xvii) of the areas from where the study population, focus groups, pilot and reliability studies were conducted. This was to ensure that the researcher was thoroughly familiar with the communities, as well as their environments, in order to develop an appropriate and accurate questionnaire to achieve the aims of the study (Pope and Mays, 2000; Chamie, 1989).

The study population was recruited from Lotus River and the focus groups, reliability and pilot studies were conducted in the neighbouring suburbs of Grassy Park, Lavender Hill, Retreat and Steenberg. This was to avoid the study population forming part of the focus groups, reliability and pilot studies.

During the time that the Community Profile was being developed a research assistant was identified by the Lotus River Community Forum. He had lived in Lotus River for 30 years and was well-known, deeply respected and trusted by the community at large; participated in all community activities; recently retired and had the time and enthusiasm to participate in the research activities.

Funding was sought and obtained from the DSSPA and a private company, Allpay, which paid out the monthly DG's to the beneficiaries. A partnership was formed between Allpay, DSSPA and the researcher who acted as the representative of the University of Cape Town. The partnership became known as the Western Cape Project for the Physically Disabled. This is in alignment with the national goals of the White Paper for Social Welfare which proposes "To promote and strengthen the partnership between the Government, the community and organisations in civil society and in the private sector who are involved with the delivery of social services" (Ministry for Social Welfare and Population Development, 1997: 12). The DSSPA provided the names of the people with permanent disabilities, the researcher investigated their needs for appliances and minor building alterations and Allpay provided the funding for the equipment.

3.1.2 Focus groups were conducted to generate the data in order to construct the questionnaire concerning the barriers.

3.1.3 The survey was conducted by administering the questionnaires to the participants. Data regarding the extent to which each of the barriers affected the disabled were recorded and their needs for mobility aids and assistive devices were identified.

3.1.4 Appliances were fitted and the disabled were taught how to use them. This required at least two visits, depending on the understanding and progress of the participants and their caregivers.

3.1.5 The evaluation interviews were conducted with the recipients of appliances six months after they had received them and building alterations had been completed in order to investigate the different ways in which this equipment had affected their quality of life.

3.2 RESEARCH DESIGN

The research was a qualitative descriptive cross-sectional design using a 'multi-method' approach of both qualitative and quantitative methods of research. Qualitative research is very useful as the first stage of quantitative research and in 'validating' or providing a different aspect on the same phenomenon (Pope and Mays, 2000; Brink, 1991). The focus groups were utilised to generate the qualitative data with which to construct the structured questionnaires which provided the quantitative data.

One of the main aims of descriptive research is to generate knowledge of a particular population as it exists in reality (Payton, 1994). This study was conducted in the natural settings, namely, at the regular venues for meetings of the pre-established focus groups and in the homes of the people with disabilities. According to Brink (1991), Pinder (1993) and Bergner (1989) the real meaning of quality of life is experienced in a natural setting and can, therefore, best be investigated in a social structure frame of reference. For that reason, a detailed community profile of Lotus River and its neighbouring suburbs was developed before the focus groups and individuals participants were interviewed.

The quantitative component of the study comprised an interviewer-administered questionnaire. A questionnaire was considered to be the most appropriate method as epidemiological information of a defined group of persons with disabilities was sought in order to achieve the aims.

Katzenellenbogen et al (1997: 164) confirms that "... Surveys are often descriptive studies which try to estimate health-related events in the community".

Data for the questionnaire were only gathered at one point in time. This is a limitation of descriptive studies as changes in the population cannot be measured. However, the study population received permanent DG's; major changes in population characteristics, for example, education level, income and housing were unlikely to have changed; and changes in the nature and extent of the barriers were not likely to have occurred over the research period. It was thus considered to be unnecessary to repeat measurements over time. However, the 48 people who received wheelchairs and assistive devices were visited monthly and finally after six months they were re-interviewed to evaluate what effects the appliances and building alterations had had on their quality of life over that period of time.

3.3 STUDY POPULATION

It was the researcher's intention that the study population include all adults with permanent locomotor disabilities living in Lotus River in October 2002. This was to avoid the bias and incorrect inferences which can occur when using a small sample size (Sacket, 1979).

The entire population of 81 was identified by the following means:

3.3.1 THE DISABILITY GRANT LIST

The names of the beneficiaries who received their DG's at the Lotus River payout point were obtained from the DSSPA. As the researcher assumed that not every person with a locomotor disability in Lotus River collected their grant payments at this specific centre she also procured the lists of beneficiaries who received their payments at Lavender Hill, Grassy Park and Retreat payout centres. The names of the Lotus River recipients were extracted and incorporated into the Lotus River beneficiary list to ensure that the entire study population were included.

The DSSPA made the medical files available to the researcher for perusal. Data on the person's address, diagnosis, medical history and notes were extracted. If the diagnosis or notes gave any indication that the person might be suffering from a form of locomotor disability he/she was included in the study population.

3.3.2 SNOWBALLING

Participants also joined the study by means of 'snowballing'. When the community became aware of the researcher's activities in their vicinity they provided additional names of relatives, friends and neighbours who had locomotor disabilities. They also notified the research assistant about housebound disabled in the community when they saw him at church or social events.

All of the additional participants either had or were already receiving DG's, but their medical files were not up to date and did not indicate, either in the diagnosis or the medical notes, that they suffered from any form of locomotor problems. One person had for many years received the grant as he had been unable to work due to uncontrollable epileptic fits. However, he had later sustained severe head injuries in a motor car accident and was unable to walk, but this had not been entered in his medical notes. Seven people had been classified as suffering from diabetes and their files did not indicate that they had subsequently had to have either one or both legs amputated. Six of the beneficiaries with hypertension only had later suffered single, double or multiple strokes and all had varying degrees of locomotor disabilities. Of the 14 participants who were recruited by snowballing, four had, for no reason, been removed from the DG list in spite of their disability status remaining unchanged. The researcher contacted the DSSPA and had their files rectified and their DG's re-instated.

The State DG is provided to people from 19 – 60 years of age for women and 19 – 65 years of age for men. Once they reach these ages the DG's are automatically converted to OAG's. Thus the only means of recruiting the people with disabilities above 60 and 65 years of age for women and men respectively was by 'snowballing' and referral.

3.3.3 REFERRAL

Physiotherapists working at the Lotus River CHC and Victoria Hospital, Wynberg referred four clients who were receiving rehabilitation services for locomotor disabilities and were receiving OAG's.

It was assumed, at the end of the research period of one year in Lotus River, that the total population of people with locomotor disabilities had been reached as there were no additional referrals from either the CHC's, hospitals or members of the community.

3.3.4 INCLUSION CRITERIA

- People over 18 years of age with any form of chronic locomotor disability which arose out of physical impairments;
- People with chronic locomotor disabilities who received a DG or OAG during October 2002; and
- Persons with locomotor disabilities who consented to the interviews.

3.3.5 EXCLUSION CRITERIA

- Persons with psychiatric disorders or intellectual impairment without physical disability. Six people were excluded on this basis;

- Elderly people without any specific physical impairment. Twelve people fitted this criterion;
- DG beneficiaries who were absent on three successive home visits by the researcher or research assistant. This situation arose with three persons; and
- DG beneficiaries who were unable to communicate verbally if no proxy respondent was available after three visits by the researcher. There were no exclusions for this criterion.

3.4 METHODS AND MEASUREMENT INSTRUMENTS

3.4.1 FOCUS GROUPS

Focus groups are group interviews which rely on interaction between the group members in order to generate data on topics of interest to the researcher (Bloor, 2001; Pope and Mays, 2000; Morgan, 1997). The significant feature of focus groups is the specific use of group interaction to produce data and insights that would be less likely to be achieved in face-to-face interviews without the interaction found in a group (Kitzinger, 2000; Morgan, 1997). Thus participants are encouraged to talk to one another, exchange accounts of incidents and to comment on each other's experiences and attitudes (Kitzinger, 2000; Pope and Mays, 2000). Focus groups have become widely used to investigate people's experiences of disease and health services as well as for market research (Kitzinger, 2000; Pope and Mays, 2000; Murray et al, 1994; Gregory and McKie, 1991).

Whilst conducting the community profile the researcher recruited six focus groups in the adjoining suburbs of Grassy Park, Lavender Hill, Retreat and Steenberg. The features and characteristics of the adjoining suburbs are similar to those of Lotus River. The neighbouring areas were selected as the researcher planned to interview the entire study population in Lotus River and,

therefore, did not wish to include any of the participants from Lotus River in the focus groups, reliability or pilot studies.

Krueger and Casey (2000) and Morgan (1997) recommend that between three and five groups be used for research purposes as a greater number of groups rarely provide meaningful new insights.

The focus groups in this study comprised seven to ten people with locomotor disabilities. Research shows that the optimal number of people in each group should be between six and ten individuals. If there are fewer than six it is difficult to initiate and maintain the discussion between the group members. With more than ten in a group is difficult to guide the discussion to ensure that everyone actively participates and has the opportunity to share their personal experiences (Krueger and Casey, 2000; Pope and Mays, 2000; Morgan, 1997). There was a good range of age groups represented from approximately 18 to 75 years of age with males and females equally represented in the younger ages and more females than males in the older social groups.

The method of focus groups was selected as it was a quick and easy way of having an exhaustive amount of data produced on the research topic (Bloor, 2001; Krueger and Casey, 2000; Morgan, 1997). It was also an efficient way of gathering information as it would have been much more time-consuming to gather the same amount of information in face-to-face interviews with the people with disabilities. The already-constituted groups of people with physical disabilities were selected as their lives involved similar problems and experiences as that of the study population. It was, therefore, relatively easy for the researcher to match the goals of the research with the data that the focus groups could produce to meet these goals (Bloor, 2001; Krueger and Casey, 2000; Morgan, 1997). Although the aims of their group meetings were specifically for social reasons the individuals continuously experienced the barriers facing them in their daily lives. From a practical point of view, by using already-constituted groups meant that the people knew one another and were accustomed to discussing matters, often of a very personal nature,

amongst themselves. It also eliminated problems with transport and venues for the meetings.

The focus groups were recruited by invitation after they had been informed of the research project and how their contributions could assist in providing the information for the questionnaire. At the beginning of each focus group meeting the researcher described the aims of the study to be conducted and explained how an interview questionnaire would be developed and constructed from the outcomes of the meetings with them.

Meeting times were arranged with the participants of the various groups who agreed to form part of the focus groups. Signed consent was obtained from each participant before the group meeting (Appendices ii and iii).

At each meeting participants sat around a table facing each other and a flip chart was placed at one end of the table so that it was clearly visible to everyone. They were welcomed and thanked for their attendance and the aims and outcomes of the study were reiterated. They were assured of confidentiality of their names and focus group names. By using brainstorming all members of each group engaged in a round-robin feedback session naming and describing precisely the problems they experienced in their daily lives. The researcher wrote these down on a flip chart in random order. As they were pre-established groups who met on a regular weekly or two-weekly basis, they all knew each other and were not hesitant or anxious about discussing their personal issues. It was not possible for them to write their contributions down on a piece of paper as some were unable to write because of their physical disabilities and others were not functionally literate.

After several round-robin cycles when all their contributions had been exhausted the researcher asked them to cluster the problems and then to rank them. She recorded the individual ranking of each person and wrote it on the flip chart. After a discussion took place on the individual rankings the overall ranking was voted on and the results tabulated.

The groups were then asked to think independently of the difficulties (items) they personally experienced with each of the problems that had been listed. Even though some of the topics discussed were very personal matters the quieter, shyer participants were motivated to contribute by the less inhibited ones due to the mutual support gained when they expressed their experiences. The researcher read out one of the problems recorded and the items were listed under each problem by means of another round-robin brainstorming session. Thereafter each item was discussed by the group to obtain clarification of meaning. The researcher recorded the statements. She then invited them to make suggestions regarding the wording of the items in their own vocabulary. The group evaluated them and voted on the wording preference which they felt best portrayed their experiences and would be simple for others in their communities to understand. There were two participants in the focus groups who were unable to speak. They, however, contributed by nodding their heads in agreement or disagreement when discussions took place and they participated in the voting. The researcher recorded the wording of the items which had been decided upon as the most suitable at reflecting the items of each problem.

The method employed to obtain the data for the questionnaire was that of a modified Nominal Group Technique (NGT). This is a technique of gathering information focusing on a single goal from a variety of people with expert knowledge and experience of a particular topic. It ensures participation across members of a group and balances the influence of individuals producing a great number of ideas (Jones and Hunter, 2000; Pope and Mays, 2000). The method was modified due to the writing difficulties of the groups. Instead of silently writing down their own thoughts the researcher had to record their thoughts and ideas on the flip-chart. The focus groups fell naturally into the class of people with expert knowledge as they were all disabled and frequently experienced the difficulties discussed in many of their activities of daily living.

Each focus group met once to identify the problems which they encountered in their daily lives. This formed Section B of the questionnaire. Three

additional sessions were required for the identification of the items listed under each of the problems (Sections C to T). They were listed randomly and exhaustively. All sessions lasted two hours.

After the data had been collected from all six groups the researcher collated the problems according to the extent that it affected the individual members. If the problem applied to one person only it was discarded as it was considered to be a specific personal problem of the individual only.

3.4.2 SURVEY

“The survey exposes the sample population to a predetermined set of questions, the answers of which can be quantified with descriptive statistics” (Payton, 1994: 96).

The advantage of surveys is that they provide population information that can be gathered relatively easily, quickly and inexpensively (Hennekens and Buring, 1987). The most common tools for survey research are questionnaires and interviews or a combination of both (Payton, 1994). They are techniques which involve collecting data from a large number of people so that a general overview of the topic can be obtained (Hicks, 1995).

The researcher conducted a survey of the disabled people living in Lotus River using a questionnaire (Appendix iv) as the data gathering instrument.

3.4.2.1 SCHEDULED INTERVIEW : QUESTIONNAIRE (Appendix iv)

The Lotus River Questionnaire (Appendix iv) was developed as the measuring tool by utilising the data gathered during the focus group sessions. A questionnaire was the most appropriate means for obtaining quantitative information on the number of people affected and the extent to which the

barriers affected the individuals (Pope and Mays, 2000). The questionnaire was completed during the interview with the participants.

Closed questions were used almost exclusively with the opportunity at the end of each section for the participants to add information which they felt was important to them, but was not included in the particular table. Closed questions offered the respondents a limited range of responses from which they were asked to choose the one that most closely fitted their answer (Veale, 1998). Response options were, as far as possible, kept standard throughout the questionnaire. These were straightforward to code and analyse. The scaled responses sought a ranking that was nominal for information on age group, level of education, sex or occupation or 'yes', 'no' and 'not applicable' responses. Ordinal responses were required where there was a degree to which a problem affected them, for example, 'no problem', 'mild problem', 'moderate problem', 'severe problem' or 'complete problem'.

The language used was simple and had been structured by the focus groups themselves to ensure that it was at the same level as and could easily be understood by the respondents. Although the entire questionnaire could have been completed by the participants as a self-report survey the researcher completed them all personally. The time provided the researcher with an opportunity of getting to know the participants well and she was able to ask pertinent questions which gave her a deeper insight into their lives within their families and within the Lotus River community. That insight would not have been gained by simply processing the data obtained by a self-report method. It also provided the participants with the opportunity of asking questions and being provided with information about the health, social services and grants available.

Items that were basic and simple to answer appeared at the beginning of the LRQ in Sections A, B and C. These included demographic information, a list of barriers and the disability profile. The few questions that might have been sensitive or embarrassing occurred towards the end of the questionnaire in Sections N, O and P (Britten, 2000; Currier, 1990) once the researcher had

established a rapport with the participants and they were comfortable about discussing their personal issues.

The questionnaire was constructed to gain information on the following aspects of the lives of the participants:

- a) Section A: demographic details.
- b) Section B: a list of the general problems experienced in their daily lives, in order of priority, as identified by the focus groups.
- c) Section C: The Stanford Health Assessment Questionnaire Scale (HAS) was used to measure the level of difficulty in performing activities of daily living. The researcher selected this scale as it had been widely used in clinical and research studies involving arthritis, general orthopaedic conditions and general disability (Milligan et al, 1993; Wolfe and Cathey, 1988; Fries et al, 1980) matching well with the locomotor disabilities of the research population in Lotus River. Its thoroughness and results were rated the highest of 16 most frequently used activities of daily living scales (McDowell and Newell, 1996; Liang et al, 1990). The Stanford Health Assessment Questionnaire Scale is broad in scope and can be completed in five to eight minutes as either a self-report or researcher-administered scale. It is a good descriptive instrument and although it is not suitable for measuring clinical change in outcome studies, that was not the intention of this study. The aim was to establish what activities of daily living the participants had difficulty in performing. It had also been shown to have good validity and reliability correlations with other scores (Hakala et al, 1994; Ramey et al, 1992; Brown et al, 1984; Fries and Young, 1982; Fries et al, 1980).

The disability profile was positioned early in the questionnaire as it provided the researcher with a greater understanding of the participants' disabilities and allowed her questioning to be more appropriate and in-depth to gain a greater insight into their lives and problems experienced. It

also allowed the opportunity to ask probing questions when she felt responses were not understood or that they did not correspond with what she observed. This minimised the possibility of obsequiousness bias.

- d) Section D: financial problems.
- e) Section E: transport problems.
- f) Section F: housing problems.
- g) Section G: employment problems.
- h) Section H: social support profile. Social health was measured by means of The Medical Outcomes Study Social Support Survey scale (MOS). It was developed as a brief self-administered indicator of social support and was intended for use in general surveys in chronically ill patients matching the study population who were permanently disabled. It is quick to complete and demonstrates that functional support is distinct from the structural aspects of support, a distinction similar to the availability and adequacy of support. The criterion validity coefficients, test-retest and item-scale correlations had been demonstrated in several studies (McDowell and Newell, 1996; Sherbourne and Stewart, 1991).
- j) Section J: utilisation of health services.
- k) Section K: utilisation of social services.
- l) Section L: attitude of community.
- m) Section M: environmental barriers.
- n) Section N: abuse.
- o) Section P: discrimination.

- p) Section Q : decision-making.
- q) Section R: disabled person's knowledge of patient's rights and responsibilities.
- r) Section S: carer profile. The Caregiver Burden Scale (CBS) was selected as the tool for measuring caregiver burden as it was developed for caregivers who had been caring for chronically disabled relatives who had both physical and cognitive disorders whereas other scales focus on dementia, Alzheimer's Disease and elderly people only (Elmstahl et al, 1996; Grafstrom et al, 1992; Vitaliano et al, 1991). It also matched the study population to a greater extent than other scales as it was developed for caregivers of people who had suffered from strokes for at least three years and the study population were all chronically disabled people of a wide range of ages. The Caregiver Burden Scale had also been shown to have good construct validity and test-retest stability in other studies (Elmstahl et al, 1996). Additional questions included in this section of the Lotus River Questionnaire were based on previous research conducted in Manenberg (Futter, 1995) and Mitchell's Plain (Coetzee, 1997).
- s) Section T: carer's knowledge of patient's rights and responsibilities.
- t) Section U: researcher's recommendations for wheelchairs, mobility aids, assistive devices and pathways and ramps to improve the quality of life of the people with disabilities and the carers.
- u) Sections were not labelled as "I" and "O" to avoid confusion with similar looking numbers in the data capturing process.

As with all questionnaires there is always the possibility of obsequiousness bias being introduced by under- or over-reporting (Sackett, 1979). However, all questions were asked in a neutral manner to minimise this effect and

responses were probed where they did not correspond with other responses. Section C was a self-report component on the level of difficulty which was incurred with activities of daily living. In the researcher's experience when dealing with people from disadvantaged backgrounds this section is mostly under-reported when compared to a physiotherapist's functional assessment or to that of a person with a disability living in a developed country.

On the other hand there may have been over-reporting in most of the sections for fear of their DG's being jeopardised. An attempt was made to minimise this fear by the research assistant reassuring them, at his initial visit, that the researcher was a physiotherapist who was not involved with the DG of the DSSPA. Over-reporting may also have occurred as the letter of introduction (Appendices v, vi and vii) stated that the needs of the people with disabilities would be investigated for wheelchairs and assistive devices. They may have over-reported their disabilities and barriers to ensure that they were given these appliances.

However, under- and over-reporting was easy to identify in two ways. Firstly, the interview provided the opportunity for the researcher to ask in-depth questions to ascertain and ensure the accuracy of their responses. Secondly, their self-reports were also validated against the researcher's findings when she performed objective functional assessments of their needs for wheelchairs and assistive devices.

Rumination bias could also have been introduced throughout the questionnaire as most of the participants were confronted with questions to which they had previously not given much consideration.

3.4.2.2 INTERVIEWS

Although the structured questionnaire was developed as a self-report survey the researcher conducted the interviews with all of the study population and administered the forms herself. In the situations where the participants were

unable to respond accurately due to cognitive problems or were unable to speak due to their physical disability a proxy was used in the presence of the person with a disability.

The reasons for the questionnaire being administered by the researcher personally were several fold:

- The educational level of the majority of participants was too low for them to read and complete it themselves;
- Some of the participants were unable to write due to their physical disabilities;
- The researcher was able to check that the participants understood the meanings of the questions or items as some of them had mental as well as physical impairments;
- It allowed the researcher the opportunity of interacting with the participants and their families and gaining a deeper insight into their lives;
- It allowed the participants an opportunity to discuss and ask questions of concern regarding the health and social services available to them. It also empowered them with regard to their rights by providing them with information about optimal utilisation of these services; and
- It provided a good opportunity for providing the participants and their families with information regarding their health problems, patient's rights and responsibilities and HIV/AIDS.

Each questionnaire took approximately two and a half hours to complete. The interviews were conducted in English or Afrikaans depending on the home language of the participants as the researcher was fluent in both of these languages. There were no Xhosa-speaking participants so there was no need to have an interpreter. The researcher made every effort to prevent leading the participants in a particular direction when responding to avoid introducing obsequious bias which Sacket (1979) states is a disadvantage of using interviews.

The researcher attempted to create an informal and friendly atmosphere so that the participants could feel at ease. She introduced herself to the participants as a physiotherapist who had for many years supervised students in the Lotus River and Retreat CHC's. This was done to alleviate any anxiety regarding the researcher's motives and their DG's and OAG's. They also felt free to discuss personal problems relating to their health as they perceived the researcher's role to be that of a 'helping' nature and this made interaction easy. Once a rapport had been established they appeared to be comfortable with discussing the more personal aspects of the questionnaire and provided far more in-depth discussion in these areas than what was required of them.

Comprehensive field notes of the home circumstances, interpersonal relationships of the family and any critical events that occurred were taken during the interviews and valuable data regarding the physical environment and social structure of Lotus River were gathered during this time.

3.4.2.3 PARTICIPANT OBSERVATION

"Observation is a technique of conducting research which involves the researcher simply observing what goes on in natural settings" (Hicks, 1995: 240).

The researcher spent one year in the community and homes of the participants whilst conducting the community profile, administering the questionnaires and assessing the needs of the disabled for wheelchairs and appliances. Those people with disabilities who required wheelchairs or assistive devices were visited again to be taught how to use them. Follow-up visits were done again four weeks later to check on their use and to ensure that they were the most appropriate for the individual's needs. Ad hoc visits were paid when the researcher was in the neighbourhood visiting other participants.

These visits allowed a great deal of time to observe and take detailed field notes of the environment; relationships and interaction between family members and between the people with disabilities and their caregivers; and critical events that were of importance and influenced the lives of the participants. The impressions and feelings gained in this way allowed a far greater understanding of their lives and environment than would have been obtained by a self-report survey.

Although reliability can be a problem when using observation on its own as a method, it can be an invaluable approach in conjunction with other data collection techniques as events can be observed in the way in which they normally occur (Pope and Mays, 2000; Hicks, 1995).

3.4.2.4 AUDIO RECORDINGS

There appears to be no universally acceptable definition of quality of life in medicine and there is no distinction between quality of life measures and methods (McDowell and Newell, 1996; Jette, 1993). Thus some of them are clinical scales, some involve measures of primary care and others are indicators of well-being (Bergner, 1989; Kottke, 1982; Jones, 1977).

In the social sciences quality of life refers to the adequacy of people's material circumstances, and to their feelings regarding those circumstances (McDowell and Newell, 1996). The intention of this research was to investigate the living environment of the disabled and how they perceived its effect on their lifestyle.

Qualitative analysis was used to obtain these data as it was not the intention to measure the amount of increased mobility/functional level, but rather to know and understand the different ways in which the equipment affected the quality of life of both the disabled and their caregivers (Brink, 1991). In other words it referred to the participants' subjective assessment of their circumstances. For this reason the researcher elected to use audio taped

interviews as a means of evaluating in which specific ways (qualities) their individual lives had been affected rather than in general categories of mobility, self-care or function as measured in the EuroQuol Quality of Life Scale or the Quality of Well-Being Scale (EuroQuol Group, 1990; Kaplan et al, 1989). According to Patton (1987) and Franklin and Thrasher (1976) participation is a valid form of programme assessment and Pinder (1993) maintains that through qualitative study, data collection and concept generation often occur simultaneously, the one complementing the other. Ben-Sira (1981) argues that if one is measuring the success of a person with disabilities reintegrating into the normal social environment, self-perception or self-conception is a more reliable indicator than a professional's judgement of functional abilities.

All participants who had received appliances and pathways and ramps were interviewed six months afterwards. Audio recordings were made of these interviews which were conducted by the research assistant from the community to minimise any bias the researcher might have introduced by being present. Participants might have felt obliged to comment positively on their circumstances since the research programme intervention. The research assistant also spoke the Afrikaans dialect used in the community for informal conversation which made the introduction of a tape recorder less threatening.

The research assistant followed a structured format of questions during the interview to ascertain how the participants' quality of life had been affected as a result of their wheelchairs and assistive devices (Appendix viii).

The audio recordings were transcribed by an official transcriber employed by the university who was fluent in both English and Afrikaans. She merely captured the recorded discussions she heard and did not make any attempt to interpret or translate them.

3.5 VALIDITY

“A valid measure is one which measures what it is intended to measure” (Grinnell, 1985: 161). Validity in qualitative methods is very dependent on the skill and competence of the evaluator because the evaluator is the instrument (Patton, 1987).

“Content validity refers to comprehensiveness, or to how adequately the sampling of questions reflects the aims of the index that were specified in the conceptual definition of its scope” (McDowell and Newell, 1996: 30). A common procedure to establish content validity is to ask patients and experts in the field to critically review the content of the scale (McDowell and Newell, 1996).

Krueger and Casey (2000) state that in qualitative research the process should ensure that the results are trustworthy. Content validity of the Lotus River Questionnaire was achieved as far as possible by using focus groups to identify the barriers and the various components of the problems which were measured in the questionnaire. This included all sections of the Lotus River Questionnaire except Section C and parts of sections H and S which comprised the Stanford Health Assessment Questionnaire, Medical Outcomes Study Social Support Survey and Caregiver Burden Scales. The members of the focus groups generated the data and by consensus agreed on the relevance and wording of the items. A physiotherapist with expertise in community physiotherapy critically reviewed the Lotus River Questionnaire once it had been constructed. As to be expected there were no alterations required to the content and wording.

Because the questionnaire comprised mostly of closed-ended questions with limited response choices it offered breadth and, therefore, one could make generalisations (Krueger and Casey, 2000). However, the researcher has reservations about the findings of this questionnaire being generalised to other communities as the focus groups generated the content and they came from communities neighbouring to Lotus River where the community profiles

were similar. The findings could, therefore, be generalised to Grassy Park, Lavender Hill, Retreat, Steenberg and other disadvantaged suburbs in South Africa. However, transferability is not possible to communities with different historical backgrounds, incomes, geographical area, housing and transport situations as the questionnaire may not necessarily “fit” other communities.

Various studies have shown the Stanford Health Questionnaire to have strong validity having correlations of 0.88 to 0.91 with other scales of performance (Hakala et al, 1994; Brown et al, 1984; Fries, 1982).

Criterion validity for the Medical Outcomes Social Support Scale has been found to show significant convergent correlation with scales of loneliness (-0.53 - -0.69), marital and family functioning (0.38 – 0.57) and mental health (0.36 – 0.45) (McDowell and Newell, 1996; Sherbourne and Stewart, 1991).

The Caregiver Burden scale has shown to have good construct validity (Elmstahl et al, 1996)

3.6 RELIABILITY

“A reliable measurement obtains the same result on repeated occasions and by independent individual’s administering the instrument” (Grinnell, 1985: 171). Reliability is concerned with error in measurement and requires consistency or stability of the measurement process across time, patients, or observers (Feinstein, 1987). In other word the measurement has to be stable, repeatable and dependable.

Although the Lotus River Questionnaire was constructed as a self-report questionnaire because some of the people with disabilities were unable to write due to their physical disabilities and the majority of the others were functionally illiterate the researcher was the only person who completed the questionnaires and thus it was not necessary to test inter-rater reliability (Hoffman, 2001).

Test-retest (intra-tester) reliability was performed by the researcher interviewing and scoring five people with disabilities from Lavender Hill. The researcher repeated the Lotus River Questionnaire with the same disabled people two weeks later. The delay of two weeks was to eliminate the risk of recall by the participants. Spearman's correlation coefficient revealed a correlation of 0.93 which demonstrates that the repeatability of the questionnaire and the data collection was conducted in a reliable manner (Hoffman, 2001; Katzenellenbogen et al, 1997).

Reliability of using the Lotus River Questionnaire with participants suffering from different medical conditions was confirmed by the researcher and an independent physiotherapist each interviewing one person with a stroke, the second who had both legs amputated and the third who had osteoarthritis. Spearman's correlation coefficient revealed a correlation of 0.99.

The Stanford Health Assessment Questionnaire has been shown to have inter-rater reliability of 0.85 and test-retest reliability after six months of 0.98 (Ramey et al, 1992; Fries et al, 1980).

The reliability for the Medical Outcomes Social Support Scale has been found to be 0.9 (internal consistency) and 0.78 for test-retest after one year (McDowell and Newell, 1996; Sherbourne and Stewart, 1991).

The Caregiver Burden Scale has been found to have internal consistency of 0.70 and test-retest reliability of 0.98 (Elmstahl et al, 1996).

3.7 PROCEDURE

3.7.1 COMMUNITY PROFILE

Data were gathered for a Community Profile to ensure the researcher was familiar with the communities in which she was going to work. Apart from

using secondary data sources for information, key leaders in the Lotus River community were identified by means of contact with the Lotus River Community Forum, librarians and school principals. They were interviewed throughout the 12 months of data collection for information and discussions regarding the community at large, its history and development, problems experienced by the community and how they dealt with them.

During the period in which the Community Profile was conducted a research assistant was identified by means of consultation with the Lotus River Community Forum.

3.7.2 FOCUS GROUPS

Six focus groups comprising seven to ten members were conducted to generate the data and construct the questionnaire. They were groups that already existed in the communities who agreed to serve as focus groups for the purposes of this study.

3.7.3 PILOT STUDY

Once the questionnaire had been constructed its validity was established by being critically reviewed by an independent physiotherapist who worked in the community to ensure that the questions were unambiguous and that everyone would be inclined to understand them in the same way (McDowell and Newell, 1996). No alterations were required to be made.

A pilot study was then conducted. Three physiotherapists each interviewed two people with disabilities who were recruited from the DG lists in Grassy Park, Lavender Hill, Retreat and Steenberg.

No alterations was found to be necessary as the focus groups themselves had decided on the wording which they felt reflected the meaning most

clearly. However, they did make suggestions regarding the layout and sequencing of the sections so that the disability profile was obtained early in the interview to make it easier to establish a rapport with the people with disabilities .

At this stage it was decided not to translate the questionnaire into Afrikaans as the researcher was fluent in English and Afrikaans and capable of translating the items should the participants have any difficulty in understanding them.

Reliability tests were performed on the Lotus River Questionnaire (Chapter Three: paragraph 3.6).

3.7.4 RECRUITMENT OF STUDY POPULATION

Letters were mailed to the study population of 84 people identified with locomotor disabilities according to the personal files of the DG beneficiaries, snowballing and by referral from health institutions (Appendix v, vi and vii).

As the researcher was aware that the majority of the beneficiaries were functionally illiterate and would probably not understand the content of the letters the research assistant visited each one of them with a copy of the letter and verbally explained the aims and objectives of the study to them. He emphasised that participation was voluntary and that they could withdraw from the study at any time without jeopardising their DG. He also assured them of confidentiality and that their personal details would not be made available to the DSSPA. None of them refused to be interviewed.

After the consent forms were signed he arranged a time for the interview with the researcher that was convenient for both the person with a disability and the caregiver (Appendix ix and x). He advised them that it would take approximately two and a half hours.

Three of the study population were not at their homes at the time arranged with the research assistant. All of them had been visited by him during the weekends and had agreed to participate in the research. However, when the researcher visited them they were not at home for three successive visits. Wishing to give them the benefit of the doubt the researcher inquired from the neighbours as to when they were likely to be at home and she was informed that they all had full-time employment. As DG beneficiaries are not permitted to earn above a certain amount of money the researcher assumed that they were hesitant about participating in the study as knowledge of their employment might jeopardise their DG's. They were, therefore, excluded from the study. Advocacy from the social work and health professionals is needed to ensure that changes are made to the Social Development and Poverty Alleviation laws that place individuals with disabilities at risk of losing their benefits and becoming further impoverished and disadvantaged should they obtain some form of employment. This needs to be done to merge the goals of self-sufficiency of rehabilitation programmes and the rights of people with disabilities with regard to employment as recommended in the Charter of Disability Rights (Disability Rights Unit of Lawyers for Human Rights, 2000).

3.7.5 IMPLEMENTATION OF THE INTERVIEWS

The study population were interviewed and the questionnaire was administered to the disabled and/or proxy and, where appropriate, the caregiver.

Physical assessments were performed on those individuals who could benefit by wheelchairs and assistive devices. Factors such as age, general physical state, physical development, body measurements, participation in community activities, environment, safety, comfort, wheelchair components and construction were considered for the optimal selection of appliances.

The participants in need of health and social services that were available, but had not been utilised by them, were provided with information and on the process of accessing them.

Once the questions regarding HIV/AIDS in the questionnaire had been completed she was able to explain the magnitude of the problem in South Africa and to discuss any aspects of concern or interest which they themselves raised. They were provided with various appropriate pamphlets on HIV/AIDS provided by the DSSPA for education of the general public (Appendix xi). They were also given the telephone number of the AIDS Helpline and advice on the nearest CHC where they could have a free HIV blood test.

3.7.6 FOLLOW-UP VISITS

Follow-up visits comprised fitting of equipment and teaching the disabled how to use their wheelchairs and assistive devices. For example, they were taught to use the brakes; transfer from a wheelchair to the bed, bath and toilet; go up and down ramps and pavement kerbs; and to propel themselves around their small homes and outdoors. Those persons who were given crutches, sticks or walking frames were taught how to stand up from a chair, walk with a good gait pattern and how to negotiate steps. This required two or more visits depending on the understanding and progress of the participants. Visits were spaced approximately one month apart to enable them and their families to have sufficient time to use and experiment with the equipment.

Participants signed forms of receipt of their appliances (Appendices xii and xiii). It was explained to them that the equipment was not a donation, but on loan to them for as long as they required it. When they no longer required it they or their relatives were to notify the research assistant. He, in turn, would arrange collection thereof and would loan it to some other needy person within the Lotus River Community. Thus a form of recycling of wheelchairs in the community was put into practice.

The researcher used the opportunity of empowering the participants with regard to managing their medical conditions optimally. For example, those suffering from hypertension were educated about the importance of taking their medication regularly to control their blood pressure and to prevent a stroke or another stroke in the case of those already suffering from one or more strokes. Another example is a family who were required to take their mother to Valkenberg Psychiatric Hospital to have her condition stabilised on medication. This had to be monitored regularly on a weekly basis over an extended period. They were unable to take her because of the high transport costs and, therefore, she was not receiving any medication and her condition was deteriorating. The researcher was able to inform them of the Dial-a-ride service offered to the disabled and educated them about the registration process and how to arrange for the bus to collect the mother and family member who was needed to escort her.

3.7.7 EVALUATION INTERVIEW

Six months after the final visit to ensure that the disabled and their families knew how to use the equipment supplied to them a final interview was conducted after the consent form had been signed (Appendix xiv).

The research assistant arranged a convenient time with the participants and conducted an interview which was audio taped. This was to investigate the different ways in which the wheelchairs and assistive devices had affected their quality of life.

3.8 DATA MANAGEMENT

Data gathered by means of the questionnaire were captured on Excel spreadsheets. They consisted of a set of demographic data (Section A) and 18 constructs (Sections B to T) each measured by a set of items associated

with the barriers of disability. The constructs and items were identified and validated by the NGT applied to representative focus groups. The services of a statistician were utilised to assist with the data analysis.

The analysis was conducted in two main steps. First each construct was evaluated by examining the mutual relationships between the items within the set. This was done by various interdependence and scaling techniques such as categorical Princals (CAT-PCA)¹ and Cronbach's Alpha test. CAT-PCA projects the items, which were treated as either or both single nominal or ordinal levels, as vectors into two or more dimensions of space (SPSSA, 2001).

The length of the vector represents its relative contribution to a dimension. Dimensions are characteristics which are grouped together by means of clusters of responses.

The angle between the vectors represents the level of association between the vectors.

When the set of items appeared one-dimensional, Cronbach's Alpha test was used as a reliability coefficient to express the internal consistency between the items.

In the second step, where required, items were rescaled by transformations invariant to the level of measurement of the items if this level was not violated. Thus all subsets were transformed into one or a few scales depending on the

¹ CAT-PCA belongs to the group of non-linear multivariate (or optimal scaling) techniques. It can be used as an alternative to log-linear models. These scaling techniques have the advantage of remaining stable when sample sizes are small or large avoiding the difficulty of interpreting the large number of parameter estimates required by log-linear models. CAT-PCA performs non-linear analyses on a set of items that may have different levels of measurement to reveal limited, but major dimensions of variation. Thus, the original set is replaced by a smaller one with as little loss of information as possible. CAT-PCA was developed by the Data Theory Scaling System Group (DTSS), Psychology Department, Faculty of Social and Behavioural Sciences, Leiden University, The Netherlands. It is part of procedures optional in SPSS, a software package for data management and statistical analysis.

underlying dimensions² of the constructs. Eigenvalues³ are given to indicate how successful the maximalisation and minimalisation criteria were. The component loadings⁴ and mutual relationships of these scales were subsequently analysed by appropriate multivariate techniques.

3.9 ETHICAL CONSIDERATIONS

3.9.1 The Research Committee of the Department of Social Development approved the research proposal for the proposed research on 30 July 2002.

3.9.2 At a meeting on the 20th August 2002 the Assistant Director of the DSSPA granted permission for the researcher to access the names and addresses of the permanent DG beneficiaries and to peruse their personal files in order to read their medical notes.

3.9.3 It was important to notify all stakeholders to inform them of the proposed research to ensure that there was no conflict of interest or activities within the health services and NGO's active in the region. Letters regarding the intended study were sent to the superintendents and physiotherapists of the Community Health Centres in Grassy Park, Lotus River and Retreat; Victoria Hospital; and the Western Cape branch of Disabled People South Africa (Appendix xv and xvi). They

² Dimension: a reduced number of variables which represents the information of a large number of variables without the loss of information. The original variables are weighted such that they correlate maximally with one dimension, but minimally with another thus creating dimensions that are not correlated. Therefore, conceptually, a dimension is labeled by the common characteristic of the variables that determined the particular dimension.

³ Eigenvalue: "a special set of scalars associated with a linear system of equations that are sometimes also known as characteristic roots" (Marcus and Minc, 1988:144). It indicates how successful the maximisation and minimalisation criteria were.

⁴ Component loadings: are the factor loadings in a factor analysis. They are weights contributing to and can be considered as the correlation with the dimension. Thus a high component loading is important in the definition of a dimension and variables with relative high component loadings on a dimension are strongly related.

were requested to notify the researcher if they required any further information or had any reservations about the proposed study.

3.9.4 DG recipients in Lotus River were sent letters in English, Afrikaans and Xhosa notifying them of the intended research; that participation was voluntary; and that all information would be treated in the strictest confidence (Appendix v, vi and vii).

3.9.5 It was made clear that participation in the focus groups was voluntary and that they could withdraw from the study at any time without having to provide any reasons and that, if they chose to do so, it would not in any way, affect their membership of the groups. As two of the groups requested that their group names also be kept confidential the researcher did not include any of the group names. Each member of the focus groups was required to complete a consent form before the meetings were conducted (Appendix ii and iii). It was also explained that the outcomes of the research would be used to inform various state departments of the extent to which the daily lives of the disabled were being negatively affected.

3.9.6 The individuals who participated in the reliability and pilot studies in Grassy Park, Lavender Hill, Retreat and Steenberg were assured of confidentiality and were required to complete consent forms before the questionnaires were administered (Appendix ix and x).

3.9.7 The people with disabilities and/or their proxies and their caregivers in Lotus River were assured of confidentiality and were required to complete consent forms in their home language before the questionnaires were administered (Appendix ix and x). There were no Xhosa speaking participants.

3.9.8 Consent forms (Appendix xiv) were signed prior to the audio recordings of the evaluation interview.

3.9.9 Regular meetings were held with the Assistant Director of the DSSPA to inform him of the progress of the research.

3.9.10 On completion of her PhD it will be necessary for the researcher to provide feedback of the findings to the Lotus River Community Forum; Departments of Health, Social Services and Poverty Alleviation, Housing, Transport, Roads and Sewerage and the DPSA.

3.10 ASSUMPTIONS

3.10.1 The responses of the participants were honest and a true reflection of their lives.

3.10.2 The entire study population would be able to be identified by means of their personal files at the DSSPA. This was not possible as the diagnoses and medical notes were not comprehensive or up to date. The entire study population (81) was eventually reached by the end of one year by including techniques of snowballing and referrals from health institutions.

3.11 WEAKNESSES OF THE STUDY

3.11.1 The paucity of information, literature and research concerning the barriers that people with disabilities experience in disadvantaged communities in developing countries. Where relevant, information gathered in other countries was used. However, the researcher was fully aware of the caution that needed to be exercised in generalising from the communities of one country to another, from one geographical area to another and from one economical area to another.

- 3.11.2 Researcher bias with the structured questionnaire had to be recognised. The subjective responses of the participants might have been what they thought was appropriate, rather than their true circumstances. However, subtle signs and intimations were followed up by in-depth questioning by the researcher which might have, to a certain extent, overcome this bias.
- 3.11.3 The data base of the DSSPA is incorrect and out of date. Seven persons who should have had their DG's converted to an OAG were still receiving a DG although they were not recorded on the system as DG recipients. However, as the researcher also obtained the study population by means of snowballing and referral it appears that the entire disabled population above 18 years of age was included. Hence the internal validity of the study should not have been compromised.

3.12 STRENGTHS OF THE STUDY

- 3.12.1 The researcher was an outsider to the community and, therefore, had no vested interest or private agenda for personal gains.
- 3.12.2 The majority of participants received four visits by the researcher which allowed her to gain greater insight into the barriers confronting them in their home environments.
- 3.12.3 By having time to establish a good rapport with the participants and their families there was sufficient time to use the opportunity available to increase their awareness of patients' rights and HIV/AIDS. Explanations were provided to their questions and they were given information leaflets supplied by the Department of Health (Appendix xi).

- 3.12.4 The researcher reported regularly to the funders who provided the wheelchairs and assistive devices. As the project was very successful in Lotus River they agreed to the researcher's request that the funding be extended to the DG beneficiaries in the adjacent suburbs of Grassy Park, Lavender Hill, Retreat and Steenberg. Before the end of the research study the project was extended to all DG beneficiaries in the entire Western Cape and is known as the Western Cape Physical Disability Project. Physiotherapists, occupational therapists, social workers and orthopaedic sisters from the region assess the disabled and send their requests to the committee for consideration and processing. To date R1,3m has been spent on wheelchairs; mobility aids; assistive devices; concrete pathways and ramps; and the research assistant's salary.
- 3.12.5 The wheelchairs and assistive devices were made and assembled by a small family-owned company which employed people with disabilities from the community in their workshop and a disabled person as an administrator in the office.
- 3.12.6 The concrete pathways and ramps from the roads to the front- and backdoors were constructed by a builder in the community who employed unemployed labourers from the community creating an opportunity for them to earn some wages albeit only temporarily for a few months and contributing to poverty alleviation.
- 3.12.7 A system of recycling of equipment has been implemented. Once the disabled have died the equipment is returned to the research assistant in Lotus River or the orthopaedic sisters, physiotherapists, occupational therapists and social workers in the various regions who initially ordered the wheelchairs. They then distribute it to recently-disabled people who have been discharged from hospital.
- 3.12.8 The researcher had regular meetings with the Assistant Director of DSSPA to inform him of the progress of the project in Lotus River and

of the extent of the barriers experienced by the disabled who did not have wheelchairs or assistive devices. When he attended one of the wheelchair handing-over ceremonies provided by the funders, he contacted the Department of Health and they agreed to take over the responsibility of providing DG beneficiaries with wheelchairs and assistive devices in the Western Cape from 2004.

3.12.9 The Western Cape Physically Disabled Project has agreed to sustain, on a long-term basis, the present system of providing wheelchairs and assistive devices to the needy who might not meet the criteria of the Department of Health in 2004.

3.12.10 As a direct result of the experience gained by the intervention phase of this research a model was developed to meet the mobility needs of the disabled. This involved identifying people with permanent physical disabilities in a specific community; assessing their mobility needs; obtaining funding to provide the necessary appliances and building alterations; educating and training a community worker; and implementing and sustaining the programme by means of a community worker. This model could easily be applied in any disadvantaged community in South Africa.

3.12.11 The research assistant was empowered by learning to assess the needs of the disabled with regards to social grants and housing alterations. He was taught the process of applying for the relevant grants and to which local authorities the disabled needed to be referred for their health and social service needs. He also learned to fit wheelchairs and appliances to meet the mobility needs of the disabled, teach the disabled and their families how to use them, and became responsible for "recycling" the equipment when the disabled died. In other words he gained the knowledge and skills to be an effective community worker responsible for conducting an integrated intervention programme for the disabled people in the Lotus River community.

3.12.12 A comprehensive community profile of Lotus River and its neighbouring suburbs was developed. It provides helpful background information for health and community workers who are new to the region (Appendix xvii).

3.12.13 A simple, but practical methodology of an integrated intervention programme for wheelchairs, orthopaedic appliances and minor building alterations was developed which can easily be implemented in any disadvantaged community in South Africa (Chapter Five).

CHAPTER FOUR

FINDINGS AND DISCUSSION

4.1 INTRODUCTION

The findings of the research are reported in this chapter. Mutual relationships between the items within each section are presented in tables or graphs followed by a discussion and, when possible, reference is made to the literature in order to demonstrate similarities and differences to other disability research findings.

In view of the vast amount of data that was collected by means of the focus groups, interviews, observations and tape recordings the findings have been presented in two parts

- The qualitative data gathered from the focus groups, in terms of the barriers identified, are presented in paragraph 4.2
- The quantitative data are presented in Sections A and B. Section A comprises the demographical data of the participants and Section B includes the extent to which the barriers affected the people with disabilities. All the items regarding each barrier are included as the researcher did not feel entitled to select information for the presentation as a shortened version might not have reflected the barriers experienced accurately. For ease of reading the headings have been presented in the exact format of the Lotus River Questionnaire (Appendix iv) and should be read in conjunction with Appendix (iv) to comprehend the presentation format and the statements to which the item numbers refer in the scoring blocks.

Although it does affect the layout presentation for convenience of the reader, as far as possible:

- the figures, tables and photographs appear on the same page as the text to which they refer;
- the legend of symbols used in graphs appear on the opposite page; and
- certain items of the questionnaire are presented on the opposite pages.

4.2 FOCUS GROUPS

The barriers identified by the six focus groups as those constituting problems in the daily lives of the people with locomotor disabilities are presented in Table (1). 'Lack of money', 'transport', 'housing', 'accessibility', 'health services' and 'social services' were perceived to be conceptually significant barriers and affected 73% to 100% of the members respectively. The remaining categories affected only 8% to 39% of the participants of the focus groups. This was confirmed by the findings of the study population in Section B, Table (5).

Table 1: Frequency of barriers identified by focus groups

Groups	Number in each group	Abuse	Poor Health	Safety	Attitude of community	Domestic assistance	Isolation/Loneliness	Unemployment	Privacy	Social Services	Health Services	Accessibility	Housing	Transport	Lack of money
1	7	0	1	2	2	2	2	1	2	5	5	4	7	6	7
2	9	0	0	1	2	3	3	4	3	7	7	9	9	9	9
3	8	0	1	2	3	3	2	4	3	6	5	6	8	8	8
4	10	2	3	3	4	3	4	3	5	8	8	9	8	9	10
5	10	2	3	2	2	2	3	4	5	7	9	8	9	10	10
6	7	0	2	2	1	2	2	2	2	4	6	7	6	6	7
Total	51	4	10	12	14	15	16	18	20	37	40	43	47	48	51
%	100	8	20	24	27	29	31	35	39	73	78	84	92	94	100

An interesting finding was that the focus groups did not identify their physical disabilities as being one of the barriers they experienced. Those participants who did rate 'poor health' as a problem usually referred to the pain which they suffered, but this was not necessarily related to their specific disability. For example, a person who had had a leg amputated seven years previously complained of pain which had developed in his shoulder over the past six months. The participants appeared to accept their disabilities as a fact of life and simply as one of the many personal characteristics they possessed which was not the most significant or important influence on their lives. Yet, for the researcher who had years of experience working in a medical model, their disabilities appeared to her to be the most dominant and important elements of them as people. The findings of other authors confirm that most disabled considered their disabilities natural and a mundane inconvenience only. They proposed that the view of the disabled is in contrast to outsiders who believe disability is the worst thing that could happen in life (Lonsdale, 1990; Gething, 1985; Weinberg and Williams, 1978). Close relatives of the disabled were also classified as insiders and if they had close contact with the disabled for many years had a less tragic, succumbing view of disability than outsiders. It is a good example of how negative attitudes and discrimination can be generated and then generalised to other characteristics of the person such as limited intellectual capacity, unemployable and the need to be pitied (McLaren and Philpott, 1999; Clarke, 1999; Smart and Smart, 1997; Gething, 1985; Lonsdale, 1990).

5.3 FINDINGS OF QUESTIONNAIRE

SECTION A. DEMOGRAPHIC DATA

There were 81 people with disabilities from Lotus River who participated in the interviews. Their demographic data, relationship to their proxy and the number of children they had are presented below.

Table 2: Relationship of disabled and their proxies

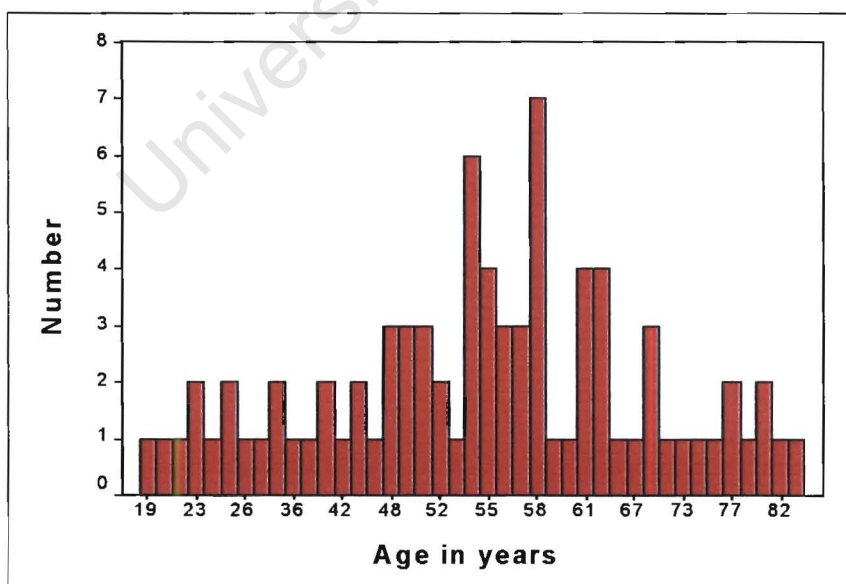
	Self	Proxy	Both	Spouse	Child	Parent	Relative	Friend
Respondents	47	3	31	14	5	5	7	3

Three of the 81 participants were unable to be interviewed independently due to their cognitive and physical disabilities and, therefore, a proxy was used to complete the questionnaires in their presence. Thirty-one interviews were done with both the participants with disabilities and a proxy who was also the carer (Table 2). In many cases it was not essential to have had a proxy, but due to the overcrowding and shortage of accommodation the proxy happened to be in the same room at the time of the interview and simply participated in the discussion when the questions were asked.

Age and gender of disabled study population

Most studies demonstrate that, generally, disability increases with age in both developing and developed countries and that there is an increase in number in most types of disabilities (Ayling, 1999; Smart and Smart, 1997; Murray and Lopez, 1996; Badley and Tennant, 1991; Chamie, 1989; Hoffman et al, 1988). Figure (1) indicates that the highest number of participants in Lotus River occurred in the younger age group of 54 – 58 years, followed by the 61 and 62 years groups and then the 48 – 50 years groups. This deviation from the general findings is not unexpected as Lotus River is a relatively new suburb which has a young age distribution (Appendix xvii: paragraph 4.6) compared to most communities which have been established for a long time. The study conducted in Mitchell's Plain, also a relatively new housing suburb with a large low-income area, confirmed a lower crude disability rate due to its younger age distribution (Coetzee, 1997).

Figure 1: Age distribution of participants with disabilities



Not only does disability vary with age, but it also differs across genders in most geographical areas. However, statistics on most disability studies frequently fail to separate, by gender, the people being studied (Ramadan, 1997). Although women are considerably more likely to experience disability than men of the same age (Arber and Cooper, 1999; Abu-Habib, 1997; Lorber, 1997; Marks, 1996; Comielje, 1993; Lonsdale, 1990; Hoffman et al, 1988; McLaren et al, 1987) the study population comprised 50 (62%) males and 31 (38%) females (Table 3).

Figure 2: Relationship between gender and age of disabled

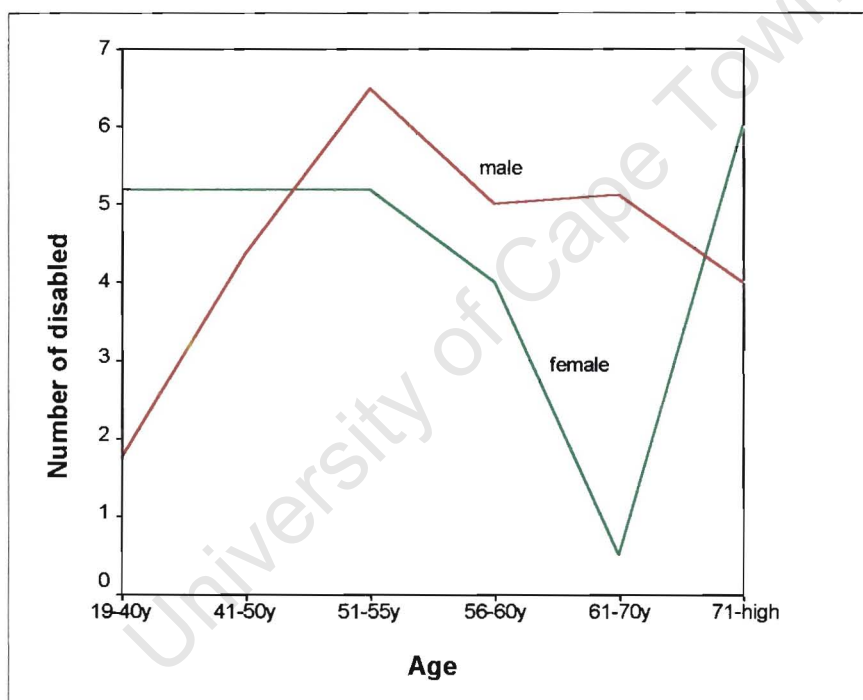


Figure (2) indicates that in Lotus River disability varied by sex across the ages, but not in the same way other studies involving age and sex have found. In the 19 - 40 age group there were more participants with disabilities amongst the females than males and this phenomenon occurred again from 71 years and upwards. The peak age of disability amongst the men was 51 - 55 years and

then it declined with increasing age. The number of females with disabilities was consistent from 19 - 55 years, declined with age at 56 - 70 years and then dramatically increased above 71 years of age. The relationship or association between gender and age groups was too small to test parametrically. A non-parametric Mann-Whitney test showed that the difference in gender was significant at $p < 0.10$ only for the age group 19 – 40 years. There were more females than males in the general population of Lotus River (Appendix xvii: Table 89) and so the disability rate is relatively much higher for males than females in the 51-70 age groups. The researcher was unable to find any reason for this as, in other studies in SA, overall locomotor disability prevalence was found to be higher for females (Cornielje, 1993; McLaren et al, 1987).

Table 3: Relationship between marital status, age and gender of disabled

Gender	Status	Age						Total
		19-40y	41-50y	51-55y	56-60y	61-70y	> 70	
Male	single	11	4	3	2		1	21
	widow		1		2		3	6
	married		1	4	5	8	2	20
	divorced		2	1				3
	total	11	8	8	9	8	6	50
Female	single	4	1	1	3			9
	widow		1		1	2	6	10
	married		1	2	2		2	7
	divorced	1	2	2				5
	total	5	5	5	6	2	8	31
Total		16	13	13	15	10	14	81

There were a greater number of married men than married women in all age groups except for the 41-50 year group where there were the same number (Table 3). This was to be expected as there were more men (50)(62%) than women (31)(38%) in the study population.

There were more widows (10) than widowers (6). This is confirmed by findings in the general population where the lifespan of males is shorter than that of females

(Hunt and Annandale, 1999; Lahelma, 1997; Grundy et al, 1996; Hart, 1989; Department of Health and Social Security, 1981).

Number of children of disabled

The number of children per age group is shown in Table (4), but only two of the participants had children after their disablement.

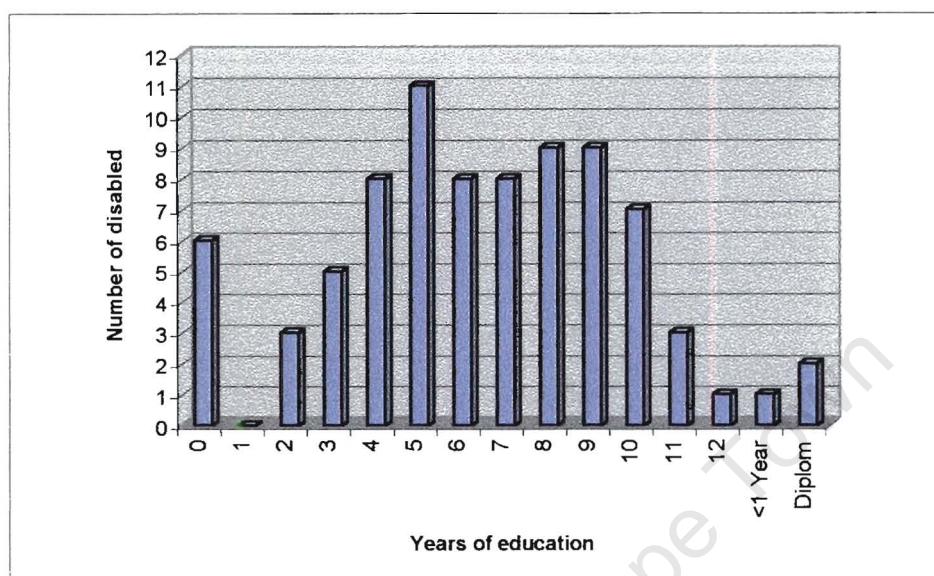
Apart from the age group 19 - 40y the children should all have been independent. However, because of the level of unemployment and housing shortage many of the children of the participants in the older groups lived with their parents and were dependent on their DG's for, at least, their food and accommodation.

Table 4: Number of children of disabled per age group

Number of Children	Age						Total
	19-40y	41-50y	51-55y	56-60y	61-70y	> 70	
0	14	2	1	5		2	24
1		1	1	2	1	4	9
2	1	3	3	2	1	1	11
3	1	3	4	1	1	2	12
4		2	1		2	2	7
5		2	1	2	2	1	8
6			1	2	2	1	6
7				1			1
8			1				1
9					1	1	2
Total	16	13	13	15	10	14	81

Educational level of disabled

Figure 3: Level of education of disabled



As presented in Figure (3) six (7%) of the participants had never attended school. Two of them could not attend the local school as they were unable to walk and had no wheelchair or transport facilities. Four of them required special schools which were not accessible to them by virtue of the fact that, during the 'apartheid' government, there were very few special facilities accessible to 'Coloured' children and they were not permitted to attend White schools.

Forty (60%) of the participants had never attended high school indicating that they had less than eight years of school education. During the time that they were growing up education was not compulsory for all children and there was not a minimum level of grade to achieve before being permitted to leave school. In the general population illiteracy in metropolitan areas is 27% and most of the existing adult education programmes are inaccessible to persons with disabilities (Ministry for Welfare and Population Development, 1997).

The lack of educational facilities for the disabled prevents mothers from seeking employment or being forced to leave employment as they have to care for their disabled children at home. This decreases family incomes and increases the level of poverty (Ministry for Welfare and Population Development, 1997).

Four percent of the participants had a senior certificate compared to the provincial figure of 18% and two (2%) percent of the participants had a diploma compared to the provincial population figure of 10% (Dickson, 2003).

Summary of demographic data

The study population comprised 50 (62%) males and 31 (38%) females. Twenty-four (30%) did not have any children and only 2 (2.5%) participants had children after their disablement.

The educational level of the participants was too low to allow them to find employment in fields which did not require physical activity as part of the job description. It was also too low to enable them to gain additional administrative or computer skills where they would not require any physical capacity to be employable.

This situation should improve gradually over the next few years by legislative changes being introduced that will affect, especially, people of colour and those with disabilities. People with disabilities "Shall have the right to education" and "Shall be provided with equal opportunities to reach their full potential in life" (Disability Rights Charter of South Africa, 2000: Article 11). The Education White Paper 6 claims that as all children can learn, the barriers to learning and exclusion should be addressed by curriculum and institutional changes (Department of Education, 2001). The Children's Charter states that "all children have the right to free and equal, non-racial, non-sexist and compulsory education

within one department as education is a right and not a privilege" (Children's Charter of South Africa, 1996: Article 8). According to the Constitution of the Republic of South Africa (1996: 11) "Every person shall have the right to basic education and to equal access to education institutions" and the ANC (1994: 63) states that "The education training needs of the people with disabilities and other marginalized groups should be catered for as part of a process of facilitating access to facilities and to the economy, so that disadvantaged groups are seen as an asset - by themselves and by society at large". One of the strategies proposed by The White Paper for Social Welfare (1997) is that the "Children with disabilities should as far as possible be accommodated in mainstream education or attend other educational facilities where appropriate" (Ministry for Welfare and Population Development, 1997: 65). The INDS (1997) states that the disabled should have access to education as a right to their full citizenship.

Had the study population become disabled during the last few years and had they been in employment at the time of their disablement it is possible that their employees might have been able to have them attend free skills training programmes run by Seta (Whole and Retail Sector Education Training Authority). However, this was not available at the time that this study was conducted.

Thus there are ample planning, white papers and charters to ensure that all disabled children have access to education in the future. However, the Western Cape Premier, Ebrahim Rasool, made no reference to the intended dates to implement any specific programmes for the educational needs of the disabled in his State of the Province Address of 28 May 2004 (Rasool, 2004).

SECTION B. BARRIERS EXPERIENCED BY THE PEOPLE WITH DISABILITIES

The extent to which the different barriers, identified by the focus groups, affected the individuals with disabilities is presented in Table (5).

Table 5: Frequencies of barriers experienced per variable (N=81)

	No problem	Mild problem	Moderate problem	Severe problem	Complete problem
B1 Lack of money	0	25	20	15	21
B2 Transport	0	26	12	15	28
B3 Housing	0	31	19	26	5
B4 Safety	67	8	1	3	2
B5 Unemployment	52	6	4	6	13
B6 Isolation and loneliness	51	11	8	7	4
B7 Privacy	70	2	2	3	4
B8 Health Services	3	21	23	22	12
B9 Social Services	9	23	23	16	10
B10 Domestic assistance	67	7	6	1	0
B11 Attitude of community	68	6	4	1	2
B12 Accessibility	35	23	13	4	6
B13 Abuse	76	2	1	1	1
B14 Health	46	14	13	2	6

Sixty percent or more of the participants experienced 'no problems' with items B4 to B7 ('safety', 'unemployment', 'isolation and loneliness' and 'privacy'), B10 ('domestic assistance'), B11 ('attitude of the community') and B14 ('health'). Ninety percent or more experienced 'no problem' with B13 ('abuse'). As can be seen in Table (5) this confirms the frequencies and percentages with which the focus groups rated the barriers they experienced (Table 1). These categories had far lower frequencies than 'lack of money', 'transport', 'housing', 'accessibility', 'social services' and 'health services'.

Safety

Although the problem list had been generated and prioritised by focus groups from the adjacent suburbs and 'safety' had been discussed at great length as one of their major barriers, more than 60% of the participants rated it as 'no problem'. In Appendix (xvii): paragraph 20 the crime statistics and gangster activities are presented and the enormity of the problem is discussed in detail. However, when discussing safety issues with the participants during the interviews it was obvious to the researcher that the majority of participants did not consider them a major problem in their lives.

Although Lotus River is a low-income suburb there are areas within the suburb itself where there is greater poverty than others. People living in the higher income areas with larger houses with no backyard shacks believed that their areas had no 'safety' problems as there were no gangsters living in the immediate vicinity. Their windows and doors had burglar bars which prevented theft and they stated that they had no problems with the gangsters in the streets.

The participants living in the poorer areas where there were smaller houses and additional backyard shacks stated that they felt safe as they were well-acquainted with the gangsters. They had grown up in the same neighbourhood with each other and they believed that they would not harm the residents. The gangsters did not, in any way, interfere with the disabled and even provided them with assistance when requested to do so. For example, when the participants required to be physically carried down the steps from the third storey of a block of flats the gangsters were very willing to do so. The only fear for personal safety the disabled had was the cross-fire during the gang wars.

They stated that an additional problem was that they could not leave their houses unattended at any time as thieves stole their movable property although this theft was not necessarily committed by gangsters, but by people who were well-

acquainted with the activities of the residents in the area. However, with the overcrowding and unemployment there were always people in the houses at all times so that they did not find safety a significant problem.

The level of crime and gangsterism has been recognised by the President and Premier of the Western Cape in their State of the Nation and Western Cape Provinces addresses respectively (Mbeki, 2004; Rasool, 2004). Police stations are to be upgraded and more police sent to hotspots. They are to be given intensive anti-gang training in order to arrest notorious drug lords within the traditional 100 days of the appointment of the new Western Cape Premier (Rasool, 2004).

Unemployment

There could be many reasons for 'unemployment' not being reported as a problem of any significance. Firstly, 17 (21%) of the study population were above retirement age and received an OAG. Secondly, according to the 1996 Census, the percentage of people who were unemployed and actively looking for employment was 15% (Central Statistical Services, 1996). However, this did not take into consideration the number of people who were unemployed, but did not report that they were looking for work. Driving through the suburb during the daytime and seeing the number of young male adults sitting on the pavements and chatting on the street corners gave the impression that the unemployment rate was significantly higher. Therefore, the fact of people being unemployed was simply accepted by the community. Thirdly, the participants who were employed prior to their injury or onset of disease all worked as unskilled labourers and, due to the nature of their physical disabilities incurred, were not able to return to the same work. Their low level of education prohibited them from obtaining employment in an administrative environment or receiving training in computer skills. They merely accepted the fact that they could not be

employed. Fourthly, they received a DG and, although minimal, it was some form of income compared to those who were unemployed and had no income at all. They perceived themselves, therefore, as being relatively well-off.

Isolation and loneliness

Due to the level of overcrowding in the homes it is easy to understand why the participants did not find 'isolation and loneliness' a major barrier. Whenever the researcher was conducting interviews there was a constant stream of family members or neighbours coming in and out of the houses. There was always an exchange of greetings, a bit of banter and local news shared with the disabled.

Privacy

It is difficult to comprehend that the participants did not find 'privacy' a substantial barrier as 43 (53%) of them, who were not married/did not have a partner, had to share a bedroom with at least one other person. In many cases where the married/partner couples did not have to share a bedroom, the sitting room and/or the kitchen served as bedrooms at night (Table 6).

Table 6: Number of people sharing a bedroom with the unmarried/single disabled person

Number of participants	1	2	3	4	5	6	7
Number of additional people in bedroom	17	11	9	4	0	1	1

Domestic assistance

'Domestic assistance' did not appear to be a problem as there were many family members sharing the houses and household chores were distributed among them.

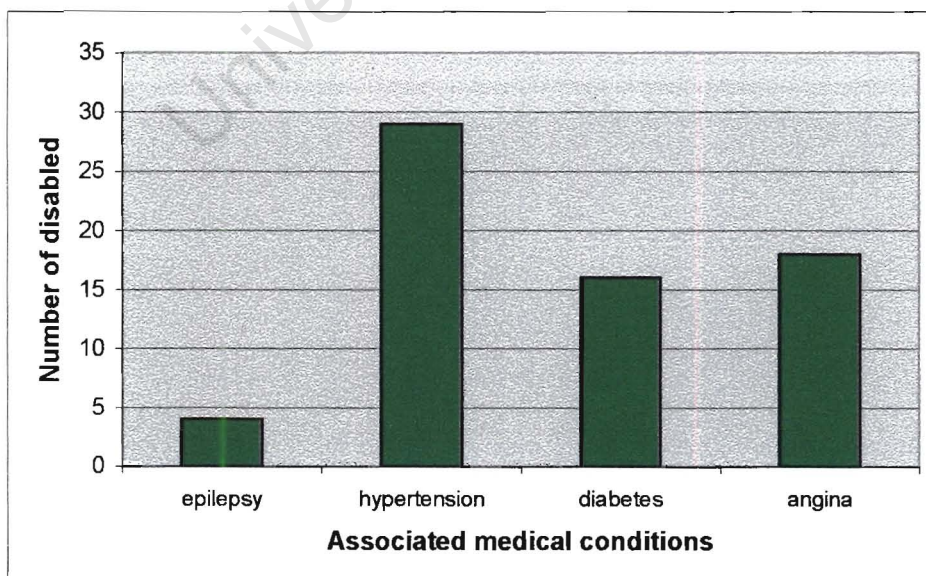
Abuse

The fact that 'abuse' was not a problem to 94% of the participants was confirmed during the interviews and home visits. Although the houses in which two of the participants with disabilities lived were dirty, untidy and unhygienic they were cared for very well. At no time during the visits over a period of one year was there any evidence of verbal, emotional or physical abuse. The families were caring about the needs of the disabled and were tolerant of their individual idiosyncrasies, likes and dislikes with regard to meal times, getting up, being put to bed and being bathed. The only complaint that two of the participants had was that their families collected their DG's and did not give it to them, but used the money for purchasing food, electricity and clothes for the whole extended family, many of whom had no form of employment and income and made no attempt to obtain employment.

Health

It is surprising that more than 60% of the participants regarded 'health' as no problem since Figure (4) demonstrates the number of people who suffered from medical conditions associated with their locomotor problems. These conditions required control by medication and, in spite of medication, frequently caused them to have further amputations of limbs, strokes or epileptic seizures. Fifty-one (62%) participants suffered from more than one of these conditions. Eight (10%) people suffered from more than two strokes and six (7%) people had both legs amputated, but on different occasions. Three (4%) of these people also had varying numbers of fingers amputated. In addition to the medical conditions from which they suffered 72 (89%) of the participants experienced some form of pain and 37 (45%) suffered moderate to severe amounts of pain (Table 14 and Figure 8). However, health is defined as "A state of complete physical, psychological and social well-being" (Blackburn, 2002: 22) and, as will be discussed in Section H, the level of social support the participants received from their relatives and friends was high and frequent and this might have overridden their physical difficulties when rating 'health' as a problem.

Figure 4: Number of disabled with associated medical conditions



Only six of the participants regarded their disabilities as problems. They had all been disabled for less than two years and were still receiving rehabilitation. It appears that they still fitted into the medical model of disability. The other participants regarded their disabilities as being part of them and, therefore, identified the barriers as being their problems. They appeared to fit into the social model of disability. It is understandable that, while the onset is recent, and the person is receiving rehabilitation they are constantly reminded of their physical disabilities, but once they leave the medical system they progress along the continuum of disability to the social model of disability.

Lack of money, transport, housing, health services, social services and accessibility

The remaining variables 'lack of money' (B1), 'transport' (B2), 'housing' (B3), 'health services' (B8), 'social services' (B9) and 'accessibility' (B12) were analysed more elaborately. As the items were too small, for ease of analysis, the categories of 'no difficulty' and 'some difficulty' were combined and recoded.

A two-dimensional categorical PRINCALS (CAT-PCA)¹ scaling test was used to examine the relevance and relationship between the variables 'lack of money' (B1), 'transport' (B2), 'housing' (B3), 'health services' (B8) and 'social services' (B9). The results are presented in Tables (7) and (8) and Figure (5). Table (7) shows that 61% of the variance was explained by the solution.

Table 7: Summary of a two-dimensional solution of the variables 'lack of money' (B1), 'transport' (B2), 'housing' (B3), 'health services' (B8) and 'health services' (B9)

Dimension	Cronbach's Alpha	Variance Accounted For	
		Total (Eigenvalue) ²	% of Variance
1	.589	1.890	37.801
2	.155	1.141	22.823
Total	.838	3.031	60.623

¹ CAT-PCA belongs to the group of non-linear multivariate (or optional scaling) techniques. It can be used as an alternative to log-linear models. These scaling techniques have the advantage of remaining stable when sample sizes are small or large avoiding the difficulty of interpreting the large number of parameter estimates required by log-linear models. CAT-CPA performs non-linear analyses on a set of items that may have different levels of measurement to reveal limited, but major dimensions of variation. Thus, the original set is replaced by a smaller one with as little loss of information as possible. CAT-PCA was developed by the Data Theory Scaling System Group (DTSS), Psychology Department, Faculty of Social and Behavioural Sciences, Leiden University, The Netherlands. It is part of a set of optional procedures in SPSS, a software package for data management and statistical analysis.

² Eigenvalue: "A special set of scalars associated with a linear system of equations that are sometimes also known as characteristic roots" (Marcus and Minc, 1988:144). It indicates how successful the maximisation and minimalisation criteria were.

Table 8: Component loadings³ and relationships of the variables 'lack of money' (B1), 'transport' (B2), 'housing' (B3), 'health services'(B8) and 'health services' (B9)

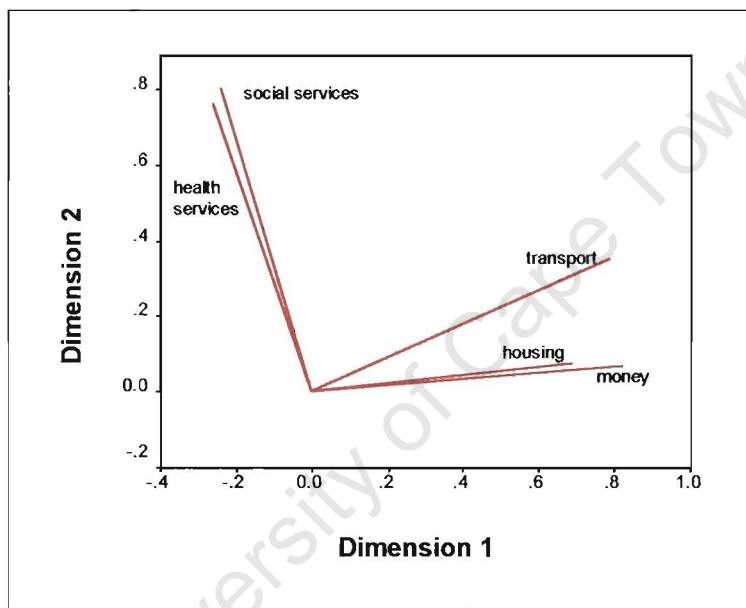
	Dimension ⁴	
	1	2
Lack of money B1	.818	.063
Transport B2	.789	.323
Housing B3	.690	.067
Health services B8	-.256	.699
Social services B9	-.237	.735

³ Component loadings: are the factor loadings in a factor analysis. They are weights contributing to and can be considered as the correlation with the dimension. Thus a high component loading is important in the definition of a dimension and variables with relative high component loadings on a dimension are strongly related.

⁴ Dimension: a reduced number of variables which represents the information of a large number of variables without the loss of information. The original variables are weighted such that they correlate maximally with one dimension, but minimally with another thus creating dimensions that are not correlated. Therefore, conceptually, a dimension is labeled by the common characteristic of the variables that determined the particular dimension.

Figure (5) shows more clearly than Table (8) that participants made a clear difference between problems with 'social and health services' and problems with 'transport', 'housing' and 'lack of money'. Thus the first dimension refers somewhat to the quality of services provided whereas the second refers to emotional and/or physical aspects of the disability.

Figure 5: Graphical representation of the component loadings and relationships of the different barriers experienced



The length of each vector represents the extent of the barrier and the angle between the vectors represents the level of association between the various barriers. For example, 'housing' was less of a problem than 'money' and 'money' and 'housing' were more related than 'money' and 'transport'. 'Health services' and 'social services' were less related to 'money' than 'housing' and 'transport'.

Summary of barriers experienced by disabled participants

The focus groups identified 14 barriers in their activities of daily living. During the interviews the disabled rated these barriers in the same order of priority as that of the focus groups, namely, lack of money, transport, housing, health services, social services, privacy, unemployment, isolation/loneliness, domestic assistance, attitude of community, safety, poor health and abuse.

All the participants lived in neighbouring disadvantaged suburbs with similar historical backgrounds; economic, political, geographical and physical environments. It is, therefore, to be expected that the disabled in all disadvantaged suburbs in South Africa experience the same barriers to a greater or lesser extent.

For example, disabled living in self-constructed dwellings in informal settlements might experience 'privacy' as a major problem; whereas in Lotus River this was less of a barrier as the majority of the disabled lived in formal council dwellings which had personal boundaries demarcated by fences or walls.

'Transport', which was rated as the second major barrier in Lotus River, might be perceived to be as large a problem to the disabled living in rural areas or disadvantaged suburbs elsewhere in South Africa.

SECTION C. DISABILITY PROFILE

This section provides a description of the disabilities that affected the participants, the extent to which they could perform activities of daily living and the relationship of their disabilities and pain which they experienced.

Table 9: Frequency of the number of years of being disabled and the cause of the disabilities

Years of being disabled	Cause of Disability				Total
	Congenital	Disease	Injury	Violence	
< 5		22	3		25
6 – 10	1	12	8	2	23
11 – 20	2	6	7	2	17
> 21	3	8	4	1	16
Total	6	48	22	5	81

Table (9) shows the distribution of participants per cause of disability and the number of years of being disabled. The number of years of being disabled were categorised as: (0 to 5 years), (6 to 10 years), (11 to 20 years) and (21 years and above).

The cause of disability was largely from disease (48, 59%) rather than as a result of injury and violence (27, 33%) which was unexpected when considering the high levels of crime and violence involving bodily harm in the community (Appendix xvii: paragraph 20). This confirms the findings of other research in SA regarding disablement (Coetzee, 1997; Concha, 1993; Disler et al, 1986a, 1986b, 1986c) and is similar to findings in Western industrialised societies where, for a long time, chronic diseases have been the main causes of disablement (Rimmer, 1999; Simon-Meyer, 1999a; Wood and Badley, 1983; Kelsey, 1982; Bury, 1979). Forty-eight (59%) of the participants had been injured or the onset of disease had occurred for 10 years or less and 33 (41%) had been disabled for 11 years or more.

Level of functional ability

Table (10) represents the frequency of the ratings of the items in the Stanford Health Assessment Questionnaire regarding the level of functional ability.

Table 10: Frequency of rating items of activities of daily living (N=81)

	No difficulty	Some difficulty	Much difficulty	Unable to do
Dressing yourself	41	13	12	15
Shampoo your hair	42	11	9	19
Stand up from chair	30	14	10	27
Get in and out of bed	43	17	10	11
Cut your own meat	51	4	5	21
Lift a glass to your mouth	65	6	5	5
Open a new milk carton	54	6	2	19
Walk outdoors on flat ground	32	14	14	21
Climb up and down five stairs	16	11	14	40
Wash and dry your body	39	16	7	19
Bath in a proper bath/shower	36	13	11	21
Get on and off the toilet	48	9	9	15
Reach for object above your head	28	6	12	35
Pick up clothing from the floor	29	7	15	30
Run errands and shop	18	13	12	38
Get in and out of a car	30	17	20	14
Do housework or gardening	18	18	12	33

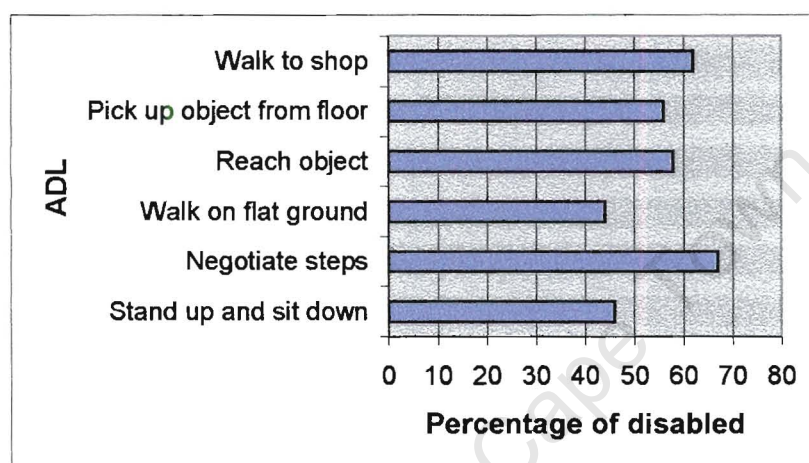
The Cronbach Alpha coefficient, based on 81 respondents and 17 items measuring 'functional disability', was 0.9593 showing a high level of consistency between the items (Table 11).

Table 11: Relative importance of the 17 items of the Health Assessment Questionnaire (HAS)

	Scale Mean If item Deleted	Scale Variance If Item Deleted	Corrected Item - Total Correlation	Alpha If Item Deleted
Dressing yourself	36.0000	231.2500	.7698	.9565
Shampoo your hair	35.9506	228.8975	.7880	.9562
Stand up from chair	35.5926	233.1944	.6489	.9586
Get in and out of bed	36.1481	231.0778	.8494	.9554
Cut your own meat	36.0617	227.9836	.7704	.9565
Lift a glass to your mouth	36.6296	241.9361	.6660	.9584
Open a new milk carton	36.1852	226.6028	.8421	.9552
Walk outdoors on flat ground	35.7160	232.7059	.6941	.9578
Climb up and down five stairs	35.0494	235.2225	.6482	.9585
Wash and dry your body	35.9383	228.8336	.8080	.9559
Bath in a proper bath/shower	35.8025	231.2105	.7213	.9573
Get on and off the toilet	36.1235	227.3096	.8738	.9548
Reach for object above your head	35.3457	230.1290	.7016	.9578
Pick up clothing from the floor	35.4444	231.3250	.6871	.9580
Run errands and shop	35.1481	232.8778	.6936	.9578
Get in and out of a car	35.7901	230.6429	.8330	.9556
Do housework or gardening	35.2716	231.4003	.7489	.9569

Certain items of the HAS were selected to demonstrate the percentage of disabled who had 'great difficulty' or were 'unable to do' the activities of daily living to show more clearly how disabled they were (Figure 6).

Figure 6: Percentage of participants unable to perform activities of daily living



The items were rescaled to one additive scale (Table 12) representing the overall level of difficulty that the participants had with their functional activities. Fourteen percent of the participants had 'some' level of difficulty with function and 41% experienced 'much' difficulty or 'total' inability with performing their basic activities of daily living.

Table 12: The ability of the study population to perform functional activities

	Frequency	Percentage	Cumulative Percentage
No problem	620	45	45
Some	195	14	59
Much	179	13	72
Unable to do	383	28	100
Total	1377	100.0	

The Functional Disability Index of the Stanford Health Assessment Questionnaire was determined by adding the highest score in each of the seven components to form a total (range 0 – 21); this was divided by seven to provide a 0 – 3 continuous score. If either devices and/or assistance was required for a component the score was determined as 2 unless the score on any of the other component question was already 3.

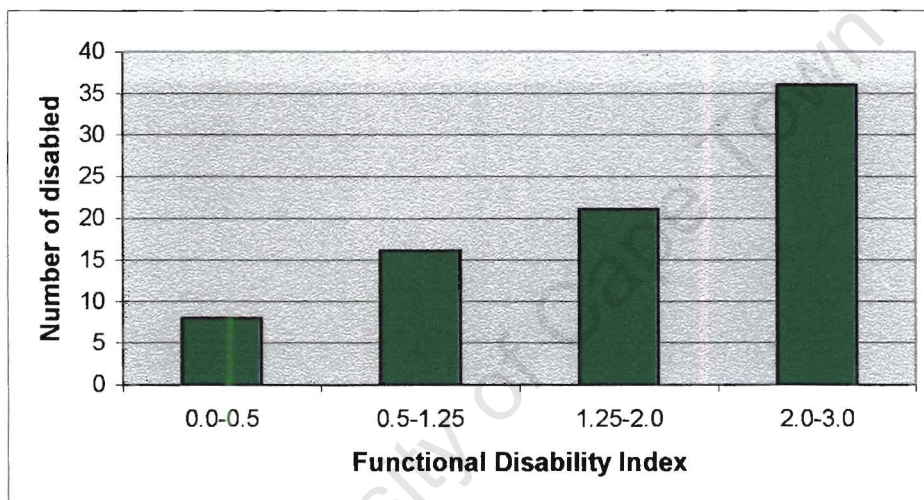
Siegert et al (1984) suggested the following interpretation of overall scores (Table 13).

Table 13: Classification of the different levels of disability

Score	Description of functional disability
0.0 - 0.5	Completely self-sufficient
0.5 - 1.25	Reasonably self-sufficient; experiences some minor and even major difficulties in activities of daily living
1.25 - 2.0	Self-sufficient, but has many major problems with activities of daily living
2.0 – 3.0	Severely handicapped

Figure (7) shows the number of participants who fitted into the different categories of functional disability according to Siegert et al's (1984) interpretation of the HAQ scores. As can be seen 57 (70%) of the participants had major problems with activities of daily living (1.25 – 2.0) and 36 (45%) were severely handicapped (2.0 – 3.0). This high level of disability was to be expected as the entire study population (81) received permanent DG's or an OAG.

Figure 7: Functional disability scores of disabled



Levels of pain

The ratings of 'pain caused by the disability over the past week' in which the survey was conducted are presented in Table (14). As the concept of pain is subjective and can fluctuate over a period of time depending on the medical condition of the disabled person, 'pain over the past week' was considered to be a representative measure.

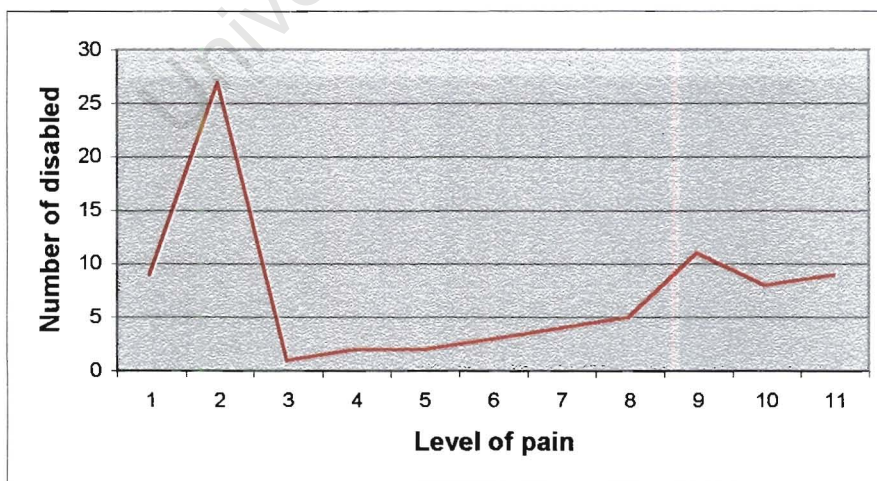
The table shows that about 37 (46%) of the respondents did not or hardly experienced pain. Another (17) 20% experienced severe pain. The remaining respondents 27 (36%) experienced between mild to moderate levels of pain.

Table 14: Levels of pain over the past week

Level of pain	Frequency	Percentage	Cumulative Percentage
0	9	11.1	11.1
1	27	33.3	44.4
2	1	1.2	45.7
3	2	2.5	48.1
4	2	2.5	50.6
5	3	3.7	54.3
6	4	4.9	59.3
7	5	6.2	65.4
8	11	13.6	79.0
9	8	9.9	88.9
10	9	11.1	100.0
Total	81	100.0	

The data in Table (14) are shown more clearly in Figure (8).

Figure 8: Levels of pain experienced over the past week



Relationship of cause of disability; length and level of functional disability; and levels of pain

Tables (15) and (16) and Figures (9) and (10) summarise the result of the disability component by presenting the relationship between the variables: 'cause' of the disability (C1), the number of 'years of disability' (C3), the overall level of functional 'disability' (C4 – C69) and levels of 'pain' (C71) caused by the disability. The relevance and the relationships of the variables were examined by a two-dimensional CAT-PCA scaling test. Table (15) shows that 68% of the variance was explained by the solution.

Table 15: Summary of a two-dimensional solution of the variables 'cause' of disability (C1), 'years' of disability (C3), level of 'disability' (C4 – C69) and level of 'pain' (C71)

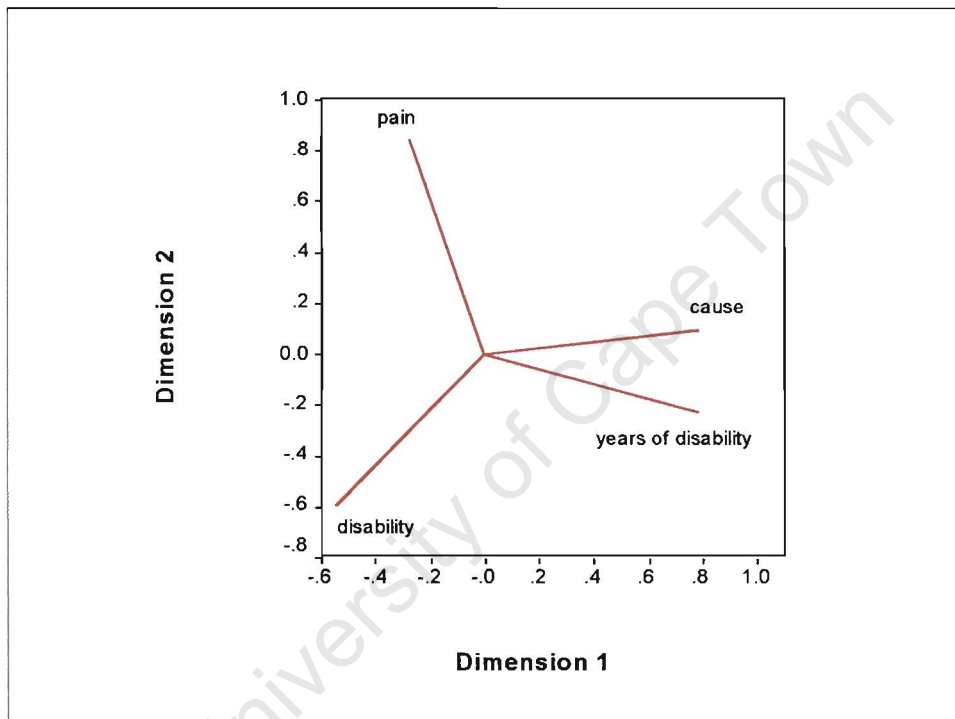
Dimension	Cronbach's Alpha	Variance Accounted For	
		Total (Eigenvalue)	% of Variance
1	.504	1.608	40.197
2	.152	1.129	28.214
Total	.846	2.736	68.410

Table 16: Component loadings of 'cause' of disability (C1), 'years' of disability (C3), level of 'disability' (C4 – C69) and level of 'pain' (C71)

	Dimension	
	1	2
Cause of disability	.791	.100
Years of disability	.786	-.228
Disability	-.542	-.598
Pain/week	-.266	.842

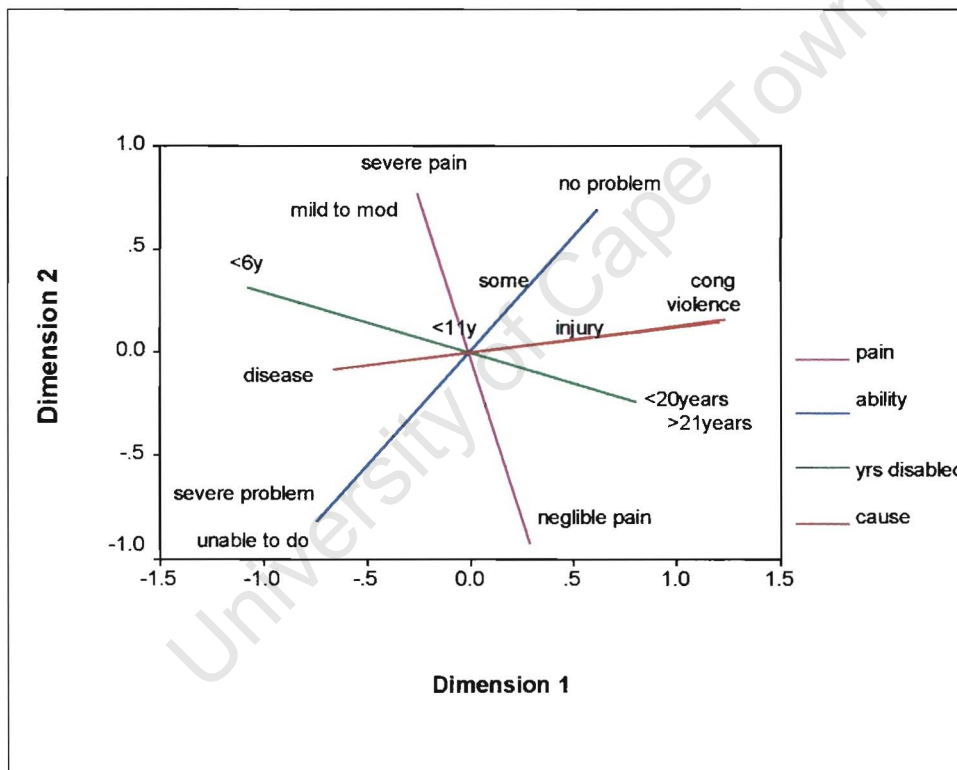
Figure (9) reveals that 'level of pain' is neither strongly related to 'disability' or to 'cause' of the disability or to the 'number of years' of having a disability. 'Disability', however, appears related to 'cause' of the disability and 'cause' of disability appears related to 'years of disability'.

Figure 9: Graphical representation of the relationships of 'cause' of disability, 'years' of disability, level of 'disability' and level of 'pain'



The relationships are more evident in the plot of the category scores (Figure 10). Participants with a disability of about 10 years or less appear to be associated with 'disease' as the cause of their disability. Participants of whom the disability is caused by a 'disease' seem to experience relatively more problems with 'disability' than those whose disabilities were caused by 'injury', 'violence' or 'congenital'.

Figure 10: Plot of the category scores and relationships of 'cause' of disability, 'years' of disability, level of 'disability' and level of 'pain'



Wheelchairs and assistive devices in possession of the disabled at the time of the first interview

As shown in Table (17) in many instances assistive devices had been obtained from relatives and friends and were not correctly adjusted to fit the participants. In other instances they were inappropriate for the disabled person's needs.

Photograph (1) shows a participant with a walking frame when what he needed was a single walking stick. Figure (11) and Table (18) demonstrate what the actual needs of the participants were and what they received after the intervention.

Table 17: Assistive devices in possession of disabled at initial interview

Assistive devices	Number	Received from hospital	Received from friends/relatives	Inappropriate for disability/house	Irreparable	Broken/repairable
Wheelchairs	24	10	14	0	8	6
Motorised wheelchair	1	0	1	0	0	0
Walking frames	9	4	5	4	3	1
Axillary crutches	6	5	1	1	4	2
Elbow crutches	4	1	3	0	0	0
Walking sticks	11	6	5	0	1	1
Tripods	1	1	0	0	1	0
Quadrupeds	2	2	0	1	0	0
Prosthesis	1	1	0	0	1	0
Orthosis	1	1	0	0	0	1
Bath board	2	2	0	0	0	0
Callipers	1	1	0	1	0	0

Photograph 1: Incorrect walking aid



It was not unusual for the researcher to be told that the wheelchairs the participants with disabilities were using had been loaned to them by a person living in the same road or by a relative living in a different suburb. In four of the instances where crutches were used they had been bought from a friend or neighbour who had recovered from a fractured leg and had sold it to the participants whose own crutches had broken beyond repair. Thus Table (17) is an immense underestimation of the needs of the disabled at the time that the initial interviews were conducted.

Eight of the wheelchairs were broken beyond repair (Table 17 and Photograph 2).

Photograph 2: Broken wheelchair with no brakes, broken crossbar, no tyres on the front castors, no hangars and no footplates



Seven participants with walking aids given to them by hospitals or clinics never used them as they were inappropriate for the level of disability or for use in the home. For example, the rooms were too small to accommodate walking frames and crutches would have been more suitable. In other situations the rooms were too small for both walking frames and crutches and the participants actually required to be taught how to walk from room to room by holding onto the furniture and doorframes in order to get around independently inside the home (Photographs 3 and 4). These findings are similar to those of Coetzee (1997) in Mitchell's Plain where she found that individuals who owned equipment had inappropriate or inadequate equipment and only 35% of all the equipment was in good order.

Photograph 3: Disabled person unable to use walking aid inside one-room dwelling



Photograph 4: Disabled with ill-fitting crutches purchased from a neighbour



Wheelchairs, mobility aids, assistive devices and pathways provided by the funders during the research project

During the interviews the participants and their carers were asked how they thought that their mobility and activities of daily living could be made easier for them (item C71). The researcher also performed a comprehensive functional assessment of the disabled and, after consultation with them, wheelchairs, mobility aids and assistive devices were prescribed and provided according to their individual needs (Figure 11 and Table 18).

The main objective when selecting this equipment was to ensure that it was the best to allow each person to attain his or her optimal physical independence in performing their daily activities and social roles.

Figure 11: Number of wheelchairs and mobility aids provided for the disabled by the funders during the research project

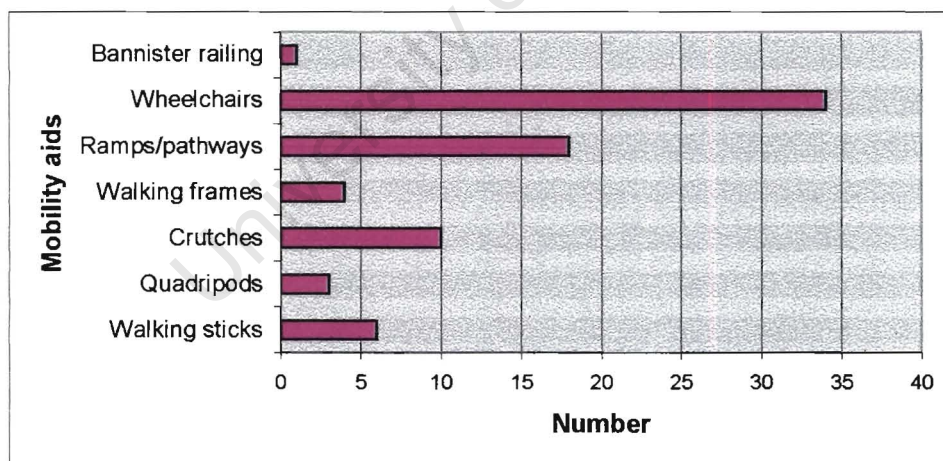


Table 18: Number of wheelchairs and assistive devices provided during the research project

Assistive devices	Number	Costs
Wheelchairs	34	R78,200
Cushions	35	R 2,250
Trays	11	R 1,100
Bath boards	18	R 3,420
Grab bars	10	R 1,710
Grocery carts	2	R 560
Kitchen aids	1	R 80
Utensil aids	2	R 150
Bedpans	1	R 100
Male urinals	1	R 35
Toilet seat raisers	1	R 200
Commodes	5	R 6,500
Ramps and pathways	18	R63,953
Total	87	R158,258

Wheelchairs were found to be the most needed mobility aid (Figure 11). This confirms the findings of other studies concerning people who have locomotor dysfunction (Kirby, 1996; Kirby and Maclaod, 1996). However, the study in Mitchell's Plain found that walking sticks were the most commonly needed pieces of equipment (Coetzee, 1997).

Only eight of the participants were able to use their wheelchairs for propulsion inside their homes due to the space limitation. The remaining 26 participants were only able to use their wheelchairs to sit outside and as a means of transport to attend clinics, DG payout centres and for social events of going to church and visiting neighbours and friends.

The participants were measured by the standard conventional methods physiotherapists use for the correct fit of wheelchairs. This included the width and length of the seat; height of the back support required; type of castors for the front wheels and type of footplates. However, in reality it was not possible to implement this. In most situations the participants preferred slightly narrower

wheelchairs so that they could be wheeled through the doorways without them having to be taken out of them and the wheelchairs having to be folded in order to take them from room to room.

Where the wheelchairs were required more for outside use and the environment was sandy, rough or uneven and the most appropriate front castors would have been of the wide type, the participants or their caregivers preferred the narrow castors so that the wheelchairs could be manoeuvred more easily inside the dwellings.

In situations where the standard practice would have been to order a wheelchair with a reclining back if the participants were not able to sit erect due to limitations of movement in their hips, it was not always possible to do this. The dwellings were too small to accommodate the additional space required for wheelchairs with reclining backs and instead additional cushions had to be provided to support their lower backs to accommodate their lack of hip movement in the smaller wheelchairs.

Thus it took some weeks after delivery to fit the participants with the most appropriate wheelchairs and assistive devices for their individual circumstances, environments and preferences (Photograph 5). In the UK, Europe and North America it is not unusual for people with disabilities to have more than one wheelchair. Some wheelchair-users have a self-propulsion chair for inside use and a motorised chair for outside use or vice versa depending on the individual's needs. Disabled people who play sport have a third wheelchair specifically for sports.

Photograph 5: Research assistant helping to carry and deliver wheelchairs and assistive devices to the disabled



Eighteen concrete pathways were built for those participants where propulsion was difficult, if not impossible, due to sandy and uneven outside surfaces (Photograph 6). Concrete ramps were also built to access the roads from the pavements and to negotiate the steps to their front and back doors (Photograph 7).

Photograph 6: Sandy and uneven ground surfaces



Photograph 7: Concrete ramp from front door and pathway leading to road



The participants and their caregivers found the bath boards to be of great assistance. Many of them who previously had to be bathed on their beds were able to use their bathrooms for the first time. The physical work of assisting the participants to transfer from the wheelchairs onto the bath boards was found to be easily managed. Thirty-four (42%) of the 81 participants required bath boards, but did not have bathrooms in their dwellings.

Commodes, bedpans and male urinals were provided for eight participants as they lived in backyard shacks and had no access to toilets at night when their landlords locked the backdoors of the main dwellings for security reasons.

Surprisingly few kitchen aids were required as there were so many relatives available to assist with the preparation of food and cooking that the participants were not required to perform any household tasks. In addition the majority of families did not have kitchen tables as their kitchens were too small and all the kitchen aids available required a table on which to be operated.

Number of visits to participants by researcher

Although the questionnaires were completed at the first visit the researcher had a great deal of more contact with the majority of participants than just one visit. As can be seen in Table (19) teaching sessions and follow-up visits were required to ensure that the equipment issued was the most appropriate and that they were able to use their wheelchairs and assistive devices competently.

Table 19: Frequency of home visits

Initial interviews	Teaching sessions	4-week follow-up	Evaluation interviews
81	213	71	71

The number of teaching sessions varied with the needs and capacity of each person. The participants and their caregivers were taught how to operate the brakes, transfer from the wheelchair to the bed or toilet and to propel themselves up and down the ramps. They were also taught how to use their assistive devices and their caregivers were taught how to assist them in their activities of daily living to allow them greater independence.

These additional visits provided the researcher with the opportunity of observing their living conditions and confirming their responses to the questionnaire.

Summary of disability profile

Fifty-six (69%) of the 81 participants had been disabled for more than five years. Fifty-seven (70%) of them had major problems with their activities of daily living and 36 (45%) were severely handicapped. Thus they were severely compromised with regards to independence and quality of life as they were unable to perform basic functional activities such as dressing, feeding, bathing, using the toilet, walking and shopping.

The cause of disability as a result of crime and violence involved 27% of the participants. The nature of causes was either as a result of assault or by the cross-fire in gang wars. This had a significant effect on their lives as they were unable to work after the injury and were obliged to become dependent on the DG as there was no fund or form of support specifically available for the needs of victims of crime. The amount of the DG was frequently insufficient to meet their special needs as a direct result of their disability, for example, incontinence sheets, bathroom alterations, bedpans, commodes, wheelchairs and assistive devices.

During the fieldwork conducted by the researcher there was no evidence of visible police patrols or attempts to harness the activities of the gang leaders in the area. However, the participants frequently reported knowledge of police involvement with the gangs and the lack of police action when they reported incidences of gang leaders bringing drugs for sale into the community.

Forty-nine percent of the participants were disabled due to preventable non-communicable diseases such as diabetes and hypertension. There is a great need for the health services to provide programmes to promote healthy life styles and changes in risky behaviour. These would include education about the harmful effects of smoking and alcohol abuse; the importance of nutritious diets to prevent obesity, hypertension Type 11 diabetes; and the necessity of exercise to reduce levels of hypertension and the maintenance of a good cardiovascular system. The participants, due to their financial constraints, consumed a large amount of potatoes and rice and very limited amounts of meat, vegetables and fruit. This was part of their difficulties in containing their obesity, hypertension and diabetes. Their financial difficulties also impacted on paying for transport to attend clinics to obtain the appropriate medication to control their diseases and to purchase meat, fruit and vegetables which were more expensive than bread, rice and potatoes.

There was a great need for wheelchairs, mobility aids, assistive devices; concrete ramps and pathways to increase the level of independence of the disabled and to reduce the physical burden of the caregivers. Forty-eight (59%) participants were in need of some form of equipment which should have been provided at the time of their discharge from hospital to enable them to participate in their family and community activities.

SECTION D. FINANCIAL

In this section the financial status of the disabled is described in terms of their DG's, OAG's, activities to supplement their income and monetary support provided by their family members.

Fifty-seven of the participants received a DG and 24 received an OAG. Twelve families received a Child Support Grant and two families received a Grant-in-Aid for caring for a disabled relative who was unable to care for themselves independently. These amounts were according to the means test and varied from person to person. According to the Ministry for Welfare and Population Development (1997) there is little understanding of the significant role played in the past by social assistance money in alleviating poverty. If the disabled participating in this research had not received the DG many of their families would have been destitute as they were totally dependent on the R740 per month received by the person with the disability.

During the 'apartheid' government the levels of DG's and OAG's were determined on racial grounds and parity in the amounts was achieved only in 1993. These grants were an essential form of social assistance in alleviating poverty, but the amounts used to be much less for Coloureds than for Whites and this contributed to the general poverty suffered by the people with disabilities in Lotus River.

Thirty-three of the participants had no other means of income and three had their disability/old age grants supplemented by their families. Forty-five supplemented their income by selling sweets and potato chips or by making and selling crafts. Ten of the participants earned an income from renting out backyard dwellings. According to the White Paper for Social Welfare the means test has penalised and demotivated people with disabilities who take up temporary forms of employment at a lower rate of payment and who have to forfeit State medical

benefits if they earn approximately R1,700 per month (Ministry for Welfare and Population Development, 1997).

Figures (12) and (13) and Table (20) show the length of time of receiving a DG or OAG; the number of people in the dwelling jointly contributing to the family income; and the relationship of the people providing financial support to the person with the disability.

Figure 12: Number of years of receiving the DG or OAG

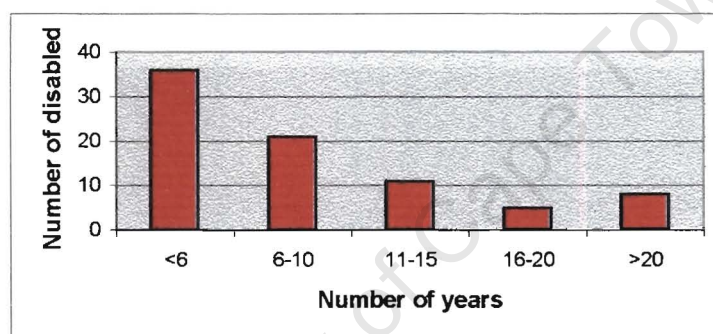
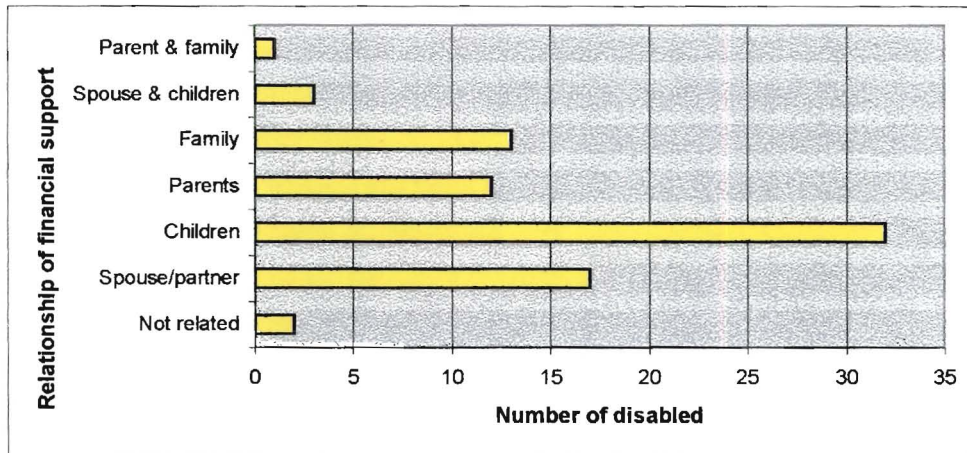


Table 20: Number of people contributing to family income

Number of people contributing	Number of disabled	%
0	20	25
1	20	25
2	29	36
3	6	7
4	2	2.5
5	0	0
6	1	1
7	2	2.5
8	1	1
Total	81	100

Figure 13: Relationship of individuals in the dwelling providing financial support

Seventeen (21%) of the participants claimed that their disability had been a financial burden to their families. The reasons they gave for feeling this burden all involved a reduced family income since their disability. Either the participants themselves were no longer able to work or else their spouses or a family member had to give up their jobs to care for them.

The focus groups identified eight items as being their monthly fixed costs for which they had to provide money from their DG's and OAG's (Table 21).

Table 21: Frequency of the ratings of the fixed costs of the disabled (N=81)

		No problem	Mild problem	Moderate problem	Severe problem	Complete problem
Food		27	21	10	8	15
Clothes		20	18	20	8	15
Rental/bond		35	13	11	8	14
Water and electricity		32	14	10	9	16
School fees	35 missed	26	3	3	6	8
Transport		6	18	24	15	18
Special needs for disabled		43	11	7	3	17
Need to be independent		40	11	8	5	17

The Cronbach Alpha coefficient, based on 81 respondents and 7 items measuring 'fixed costs' was 0.9074 suggesting a one-dimensional relationship between the items. 'School fees' (item D12) was removed because of 35 missing observations and resulting skewness. The missing observations were from participants who did not have any children or whose children were no longer at school. Thus items 'food', 'clothes', 'rental/bond' and 'water and electricity' (D8 to D11) and 'transport', 'special needs for the disabled' and 'need to be independent' (D13 to D15) were transformed¹ into a new scale variable called 'fixed costs' after recoding the rating scores (rating 3=2, 4=3, 5=3).

Table (22) shows the interrelationship between the variables 'having a disability grant/pension' (D), 'having a financial supplement' (D2), 'the number of years receiving a grant or pension' (D3) and 'management of fixed costs'. The participants who had been disabled for <6 years and >10 years show that there were approximately the same numbers who received financial supplements and those who did not receive any financial supplements. The group who had been disabled for 6 – 10 years received more financial supplements. There is no explanation for this as it was expected that those who had been recently disabled would have received more in the form of assistance from family and friends.

There was no difference in the extent of their problems experienced with 'fixed costs' whether they received financial supplements or not.

Although the entire study population of 81 received DG's or OAG's by the end of the project period this was not necessarily so at the initial interview. As it was part of the researcher's aims to ensure that the disabled were aware of their rights and that they did receive their due benefits she arranged for them to be

¹ 'Fixed costs' = [(D8+D9+D10+D11+D13+D14+D15)/7] rounded off.

taken to the Department of Social Welfare to have their benefits granted and processed.

Table 22: Contingency table with income and fixed costs

Years	Income			Fixed costs			Total
	Supplement	Grant/Pens		No Problem	Mild-Moderate	Severe	
<6y	no	grant/pens	yes	5	7	5	17
		Total		5	7	5	17
	yes	grant/pens	yes	2	4	4	10
<11y	no	grant/pens	yes	1	4		5
		Total		1	4		5
	yes	grant/pens	yes	2	1	3	6
>10y	no	grant/pens	yes	1	6	2	9
		Total		1	1		2
	yes	grant/pens	yes	3	3	4	10
Total	no	grant/pens	yes	1	2		3
		Total		4	5	4	13
	yes	grant/pens	yes	3	3	4	10
		Total		4	5	4	13
Total				24	36	21	81

The results of a two-dimensional CAT-PCA scaling test show the relevance and interrelationship between the above four variables more clearly in Tables (23) and (24). Table (23) shows that 63% of the variance was explained by the solution.

Table 23: Summary of the interrelationship between 'receiving a grant/pension (D1), 'supplement' (D2), 'years of receiving grant/pension (D3) and fixed costs

Dimension	Cronbach's Alpha	Variance Accounted For	
		Total (Eigenvalue)	% of Variance
1	.445	1.501	37.516
2	.011	1.009	25.217
Total	.802	2.509	62.733

Table 24: Component loadings and relationships of 'receiving a grant/pension (D1), 'supplement' (D2), 'years of receiving grant/pension (D3) and fixed costs

	Dimension	
	1	2
Grant/pension	-.826	-.012
Supplement	.792	-.133
Years receiving grant/pension	-.009	.967
Fixed costs	.437	.237

Figures (14) and (15) show that the 'number of years of receiving a disability grant/pension' is not evidently related to 'management of fixed costs'. 'Management of fixed costs' is related to 'disability grant' either with or without a 'supplement'.

Figure 14: Graphical presentation of the relationships of 'receiving a grant/pension (D1), 'supplement' (D2), 'years of receiving grant/pension' (D3) and 'fixed costs' plotted

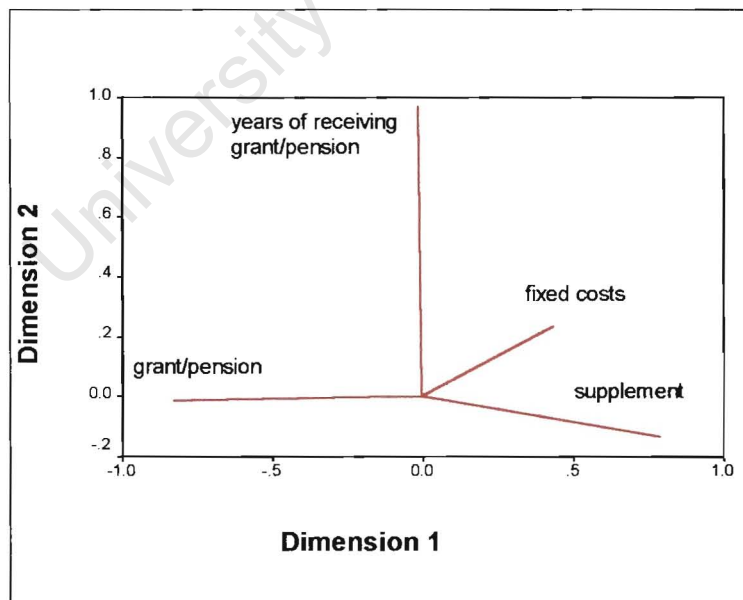
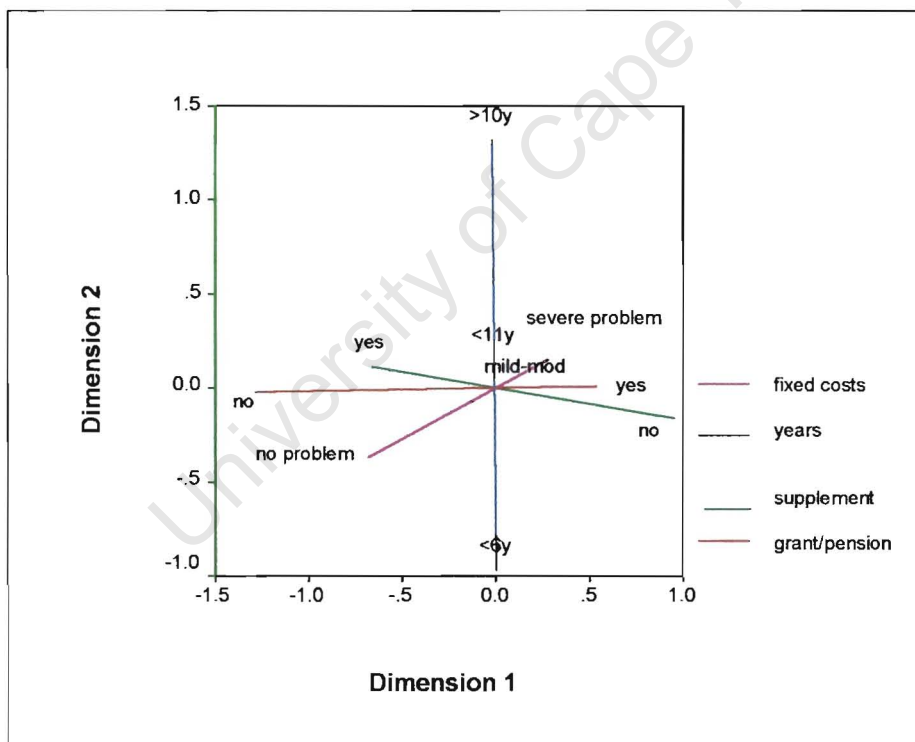


Figure (15) shows more clearly how 'disability grant or pension' is interrelated with 'supplement' and 'managing fixed costs'.

Research suggests that direct monetary assistance by ways of grants and pensions is the most important resource permitting people in need of basic needs of rent, food and transportation to live independently (Williams, 1993; Shearer, 1982) and that vocational training is only resource enhancing when the possibility of finding work is realistic (Greenwood, 1984; Williams, 1993; Shearer, 1982; Howards et al, 1980).

Figure 15: Plot of the component loadings and relationships of 'fixed costs', 'number of years', 'supplement' and 'grant/pension'



Summary of financial status of disabled

The current DG's and OAG's do not provide an adequate social security net to alleviate the poverty of the disabled. First of all, they do not reach all beneficiaries in need. Secondly, the grants frequently have to support entire extended families and are not sufficient to meet their living and transport costs or their special needs as disabled people. Forty-five (56%) of the participants had been dependent on a DG or OAG for more than five years giving an indication of the extended period of time and the level of poverty and diminished quality of life the majority had suffered.

Many of them found the costs of basic aspects of living such as food, clothes, rental, fuel and water to be major problems with which to deal on a weekly basis. This partly explains why they were unable to attend clinics to receive medical attention and medication for their special needs which impacted further on the diseases causing their disabilities. By not being able to meet all these basic costs meant that there was never any consideration given to purchasing wheelchairs and mobility aids

In the next section the various barriers associated with the different modes of transport are quantified.

SECTION E. TRANSPORT

The categories in Table (25) were not mutually exclusive and a few participants regularly used more than one mode of transport thus the totals amount to more than 81 .

Table 25: Frequency of use of different forms of transport

	For medical purposes	For shopping	For business	For recreation	For social contact	For disability pay-point	Total
None – do not leave home	8	8	8	8	8	8	48
Wheelchair	12	8	8	8	8	7	51
Own vehicle	12	7	7	7	7	6	46
Vehicle in household	4	3	3	3	3	3	19
Vehicle of family/ friend	18	8	5	11	17	9	68
Train	1	0	1	1	1	0	4
Bus	3	3	3	2	3	2	16
Taxi	17	13	12	9	9	7	67
Dial-a-ride buses	1	1	0	0	1	1	4
Walk	1	1	0	0	1	4	7
Total	77	52	47	49	58	47	330

Eight (10%) of the participants never left their homes at all. This length of time varied from six months to 12 years depending on the time since their injury or onset of disease. Three (3%) of them had never gone outside as they lived on the first, second or third storey of a block of flats. Five (6%) had left their homes to sit in the sun, but were unable to leave their properties. They were unable to use public transport, had no access to private transport and did not have access to a wheelchair. By the end of the programme all the participants were able to leave their homes and properties by means of the wheelchairs and concrete pathways provided.

At the time of the initial interviews only 18 participants had the use of functional wheelchairs although 24 had wheelchairs in their possession. However, six were broken and unable to be used. Thirty-three mentioned that they sometimes where able to borrow wheelchairs from friends on special occasions for transport such as for medical purposes and to be taken to church on Sundays.

Train

Table (26) shows the responses to the various items regarding the problems experienced by the participants when using the train. Four (4%) participants used the trains regularly and found no problems with the majority of items. Seventy-eight (96%) found all items relating to train transport to be a 'complete problem'. In other words they were not able to use the trains as a means of public transport.

Table 26: Rating frequencies regarding problems when using the train (N=81)

	No problem	Mild problem	Moderate problem	Severe problem	Complete problem
Distance from the station	2	0	0	1	78
Overhead bridges/subways	3	0	0	0	78
Train fare	1	0	1	0	79
Paying for helper too	2	0	1	0	78
No ramps at station entrance	1	0	0	0	80
Incline of ramps too steep	1	0	0	0	80
Metal pole in middle of doorway entrance	1	0	0	0	80
Gap between platform and coach floor	2	0	1	0	78
Height between platform and coach floor	3	0	0	0	78
Train staff unsympathetic and unhelpful	2	0	0	1	78
Doors close without consideration for disabled	2	0	0	0	79
Peak hours – passengers push disabled aside	2	0	0	0	79
Off peak hours – criminal elements	1	0	0	0	80
Timetables and changes of service inaccessible	3	0	0	0	78

Since the planning of the relocation of the Conradie Hospital Rehabilitation Unit to the new Western Cape Rehabilitation Centre in Mitchell's Plain the station in Mitchells' Plain has been renovated to accommodate people with disabilities so that they will be able to attend the Rehabilitation Centre by means of rail transport. However, even if the station at Mitchell's Plain proves to be most satisfactory the disabled will still not be able to utilise the trains as they will not be able to use the stations at their homes until they are also modernised to be accessible to the disabled.

Wheelchairs

There were 24 participants who claimed to have a wheelchair (item C74), but 6 of these were broken to the extent that they could not be used even for seating purposes. Thus only 18 participants had functionally intact wheelchairs. The 63 'missed' responses were those participants who either did not use a wheelchair or who did not possess one even if they needed one (Table 27).

Table 27: Rating frequencies regarding wheelchair issues (N=81)

	Missed	No problem	Mild problem	Moderate problem	Severe problem	Complete problem
Wheelchair breaks	63	5	2	2	6	3
Steps to house	63	4	2	2	7	3
Rough terrain from house to pavement	63	6	2	3	5	2
Pavement kerb steps	63	4	2	5	4	3
Rough terrain on pavements	63	5	0	6	5	2
Distance to business and social occasions	63	5	1	3	5	4
No ramps to buildings	63	2	2	3	7	4
Incline of ramps too steep	63	2	4	4	6	2
Counters in post office and shops too high	63	4	5	3	3	3
Vulnerability to criminals	63	13	2	0	1	2

Private vehicles

During the interviews the participants and their relatives spoke a great deal about the way in which people with private vehicles exploited those who needed to be taken to clinics or hospitals for medical purposes by charging the same, if not more, than the minibus taxis. However, in Table (28) the majority of participants scored Item E55 (money charged by friends) as being 'no problem' or only a 'mild problem'.

Table 28: Rating frequencies regarding issues using private vehicles (N=81)

	No problem	Mild problem	Moderate problem	Severe problem	Complete problem
Money charged by friends	51	7	8	5	10
Unavailable when needed by disabled	42	21	5	2	11
Public ignores designated parking bays	46	21	7	1	6

Bus

The majority of participants did not find the 'bus fare' (item E67) to be a major problem. The participants reported that the main difficulties with using the bus were found to be the 'distance from the bus route' and the 'steps' to board or alight the bus (Table 29).

Table 29: Rating frequencies regarding issues using the bus (N=81)

	No problem	Mild problem	Moderate problem	Severe problem	Complete problem
Distance from the bus route	5	1	0	0	75
Costs	9	15	21	21	15
Assistant also has to pay in full	4	1	12	15	49
Unable to negotiate steps to enter	4	2	2	0	73
Bus drivers impatient and do not wait for disabled to get seated	10	20	25	21	5
Bus drivers impatient and do not wait for disabled to get off	10	20	25	21	5
Bus drivers unsympathetic and do not assist disabled	17	12	16	23	13
Bus drivers rude	36	30	7	4	4
Information regarding service inaccessible	28	22	16	10	5
Vulnerability to criminal element while waiting at bus stops	20	21	19	12	9
Dial-a-ride bus service:					
Dial-a-ride too expensive	5	11	19	30	16
Unable to obtain booking with Dial-a-ride because of demand	27	26	11	10	7
Dial-a-ride unreliable	23	26	11	12	9
Information regarding Dial-a-ride inaccessible	8	8	10	30	25
Dial-a-ride drivers unsympathetic and do not assist disabled	36	30	7	4	4
Dial-a-ride drivers rude	43	19	9	5	5
Vulnerability to criminal element while waiting at Dial-a-ride stops	42	18	10	5	6
No telephone to contact Dial-a-ride	9	20	25	21	6

Although the Dial-a-ride bus service provided by the City of Cape Town is specifically for the disabled (Appendix xvii, paragraph 10) there were problems found to be associated with the service which could be remedied without a great

deal of cost. This refers to the appointment of staff who deal with the disabled. They should be people who are empathetic towards people with disabilities who are happy to be as helpful as possible to them. They should receive training in how to assist the disabled onto and off the bus safely and securely.

Minibus taxis

Table 30: Rating frequencies regarding issues using the minibus taxi (N=81)

	Missed	No problem	Mild problem	Moderate problem	Severe problem	Complete problem
Distance from the taxi route		2	0	1	1	77
Costs		1	2	2	2	74
Assistant also has to pay in full	23	0	0	0	0	58
Pay for wheelchair space	23	0	0	0	0	58
Difficulty in getting in and out		10	14	21	19	17
Drivers attitude - rude, impatient, not keen to help		8	8	10	30	25
Dangerous driving		16	20	24	8	13
Refuse to stop if they see a disabled person in a wheelchair		7	7	13	31	23

Distance from the minibus taxi routes and the taxi fares were found to be 'complete problems' to the vast majority of participants (95%) (Table 30). Costs were also a 'complete problem' to those people who used wheelchairs or who had to be accompanied by an assistant as these required additional payments (72%). 'Missed' scores were recorded for Items E93 (assistant has to pay in full) and E94 (pay for wheelchair space) as the participants did not use wheelchairs and, therefore, did not require assistants to accompany them on the taxi.

Transport is a critical problem that people with disabilities in Lotus River have to face on a daily basis and with regards to all basic aspects of living. It affects their ability to access health and social services, education facilities, employment,

social and recreational activities which are all basic human rights (Disability Rights Units of Lawyers for Human Rights, 2000).

Frequently people with disabilities are labeled as non-compliant when they do not attend clinics for medication, but this is not necessarily the case. Often it is the lack of adequate transport and the affordability which prevents them from attending their appointments.

The barriers which people with disabilities are faced with regarding transport has been recognised by several bodies since 1994, but little has been done during this time to alleviate these problems.

The INDS (1997) acknowledged that the transport services for people with disabilities were largely restricted and the needs of special categories of passengers should be identified by the responsible transport authorities and should be addressed in their passenger transport plans (Office of the Deputy President, 1997). The Integrated Provincial Disability Strategy for the Western Cape (IPDS - PAWC) provides for strategies to determine user requirements, evaluating the different modes of transport that users with special needs require, investigating fare structures that could apply and educating operators to understand and accommodate the needs of disabled people (Province of the Western Cape, 1998)

As early as 1994 the RDP recognised that "An effective publicly-owned passenger transport system must be developed, integrating road, rail and air transportation. A future policy must take into account the transport needs of disabled people" (ANC, 1994: 35).

According to the Disability Rights Charter of South Africa (2000: Article 9) the disabled "Demand that affordable and adequate transport shall be made available to all disabled people".

The Children's Charter of South Africa (1996:9) states that "All children have the right to educational facilities and transportation to such facilities should be provided to children in difficult or violent situations". Thus all children with disabilities should have transport provided to both mainstream schools and special schools.

One of the strategies proposed by The White Paper for Social Welfare (1997) is that the "Department of Welfare will negotiate with other Government departments about increasing accessibility ... transport and other core facilities within the community ..." (Ministry for Welfare and Population Development, 1997: 54).

Summary of problems experienced with the different forms of transport

Transport was rated as the next major problem in the lives of the disabled after lack of money.

All forms of transport posed different physical difficulties such as distance from the route, steps and height of platforms. Other major problems were the costs, attitudes of the transport officials and safety both in the vehicles and in the environment around the transport.

What is urgently needed is for an increased amount of policing in the transport environments. This means reinstating police on the trains and a highly visible police presence on the streets to ensure that the disabled receive some form of protection when they are waiting for transport and whilst they are travelling. Although it is not possible to have policemen in every coach it is practical to have a specific coach designated for the disabled at the beginning or end of the train which the policemen patrol regularly through the journey.

When improvements to the rail commuter system are considered it is generally for consideration of the able-bodied in the form of efficiency and safety, but there is never mention of how this could include improvements for the disabled. If there were to be a designated coach for the disabled it would also be possible for that coach to have extendible floors in the doorways which could be unfolded at each station to reduce the gap between the platform and train to make access possible and easier.

All transport officials should receive training and skills in dealing with the disabled so that they are empowered to engage empathetically and physically assist people with disabilities to access the buses, trains and taxis.

A description of the dwellings of the disabled and the extent to which each of the items affected the participants are provided in the next section.

SECTION F. HOUSING

Thirty-seven of the houses were self-constructed and 44 had been built by the Council. However, none of them were designed or built specifically for people with disabilities. Forty participants lived in houses, 31 in flats and 10 in backyard dwellings.

Forty-two (52%) of the dwellings were owned by a member of the family and 39 (48%) were rented, 29 of these from the council and 10 from the main home owner. Ownership of houses in Lotus River is 63% (Appendix xvii: paragraph 6.3) so that the percentage of participants owning houses (52%) was much lower than that of the general population confirming research findings in the UK and the USA (Little, 2002; Locker, 1983).

Five participants were boarders, 30 lived with their spouses/partners, 13 lived with their parents, 1 with a sibling, 14 with their children, 15 with relatives and 3 with friends.

Figures (16), (17) and (18) show the number of rooms per dwelling, number of people living permanently in the household and the number of people living in the main houses and backyard dwellings respectively. These figures include the people with disabilities.

Figure 16: Number of rooms per dwelling

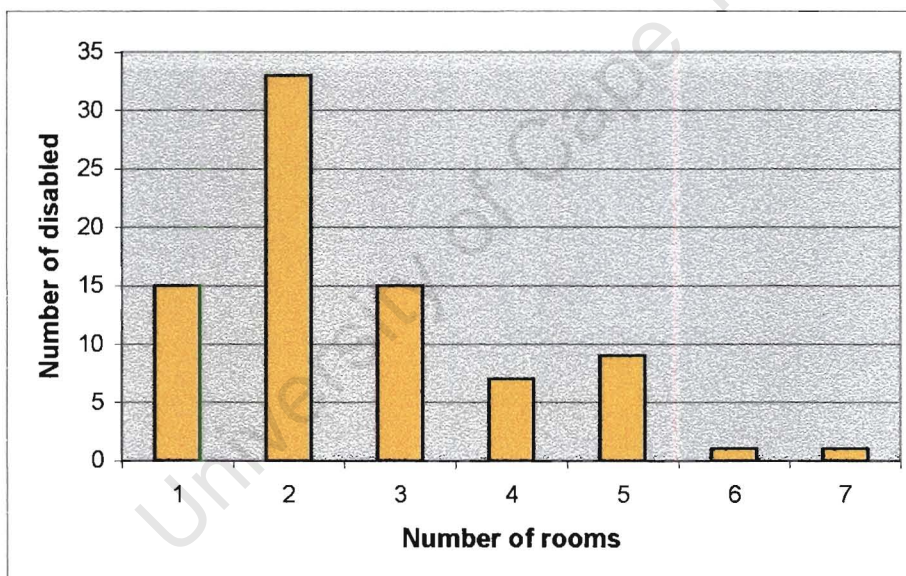


Figure 17: Number of people permanently living in household

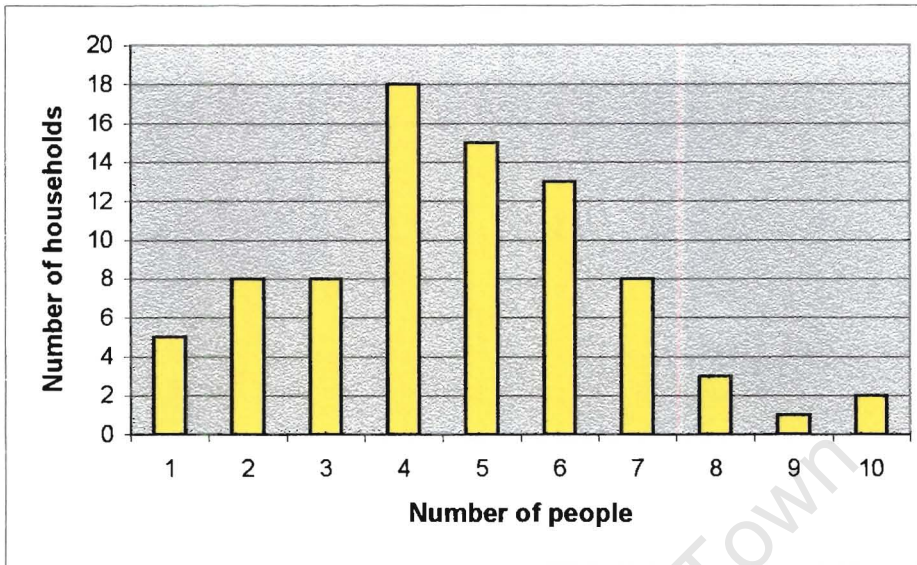


Figure 18: Number of people living in main houses and backyard shacks

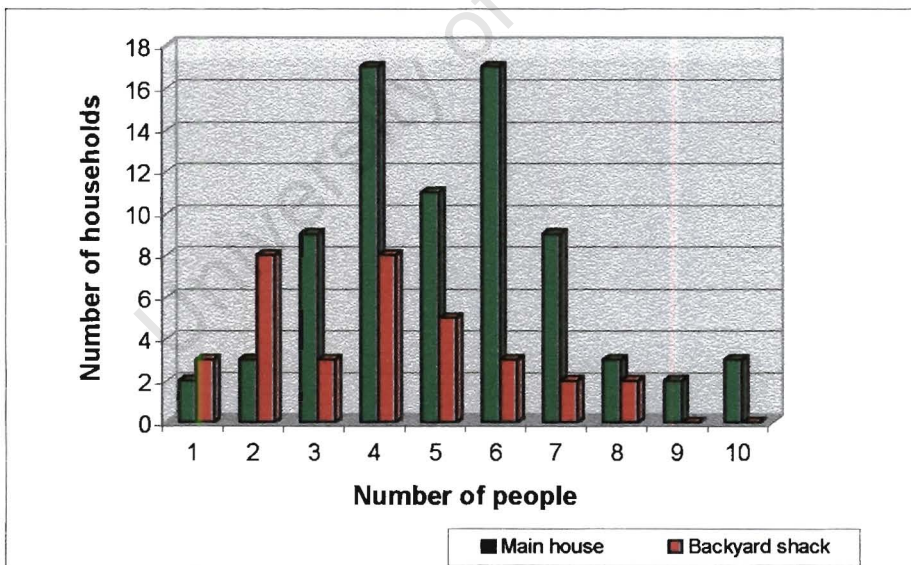


Table 31: Frequencies of ratings of housing-related problems (N=81)

	Missed	No problem	Mild problem	Moderate problem	Severe problem	Complete problem
Waiting list very long for own house	0	72	0	0	2	7
Confusion about waiting lists of South Peninsula Municipality and Ministry of Housing, PAWC	0	73	3	2	1	2
House leaks in winter	0	57	7	5	6	6
House cold in winter	0	53	10	6	4	8
House damp in winter	0	52	9	5	7	8
Cold cement floors	0	59	4	4	3	11
Leaking drain pipes	0	68	6	1	3	3
Overcrowding	0	68	2	2	2	7
No privacy	0	73	1	1	3	3
Size of rooms for walkers and w/chairs	0	55	13	4	5	4
Steps inside the dwelling	0	70	3	4	1	3
Steps outside the dwelling	0	41	14	17	5	4
No running water	0	72	5	1	1	2
No running hot water	0	59	3	8	3	8
Outside toilet	0	62	4	2	0	13
No bathroom	0	48	0	0	0	35
Bathroom too small for wheelchair	35	14	5	7	9	11
Bathroom badly designed for wheelchair	35	14	5	7	9	11
Height of bath	35	14	5	7	9	11
Height of basin	14	64	1	0	0	2
Height of toilet	0	58	0	0	1	22
Unable to use taps	0	66	2	9	2	2
Height of light switches	0	73	3	1	2	2
Height of window handles	0	75	0	2	2	2
Unable to use door handles	0	65	5	7	2	2
Rough terrain surrounding the house	0	46	10	15	5	5
House unsafe against criminals	0	68	4	5	1	3
Landlords exploit tenants by high rentals	42	29	3	3	3	1
Noise from neighbours	0	28	23	13	10	7

The items regarding housing-related problems are presented in Table (31). In items F29, F30 and F31 the 'missed' scores were from the 35 participants who rated item F28 (no bathroom) as a 'complete problem' as they did not have a bathroom and were, therefore, unable to rate the items. The 14 'missed' scores from item F32 (height of basis) refer to the 10 participants who lived in backyard shacks and did not have basins and to 4 participants who boarded in homes where they did not have access to the bathrooms of the main house.

The 42 'missed' responses of item F40 (landlords exploit tenants) were from home owners who did not have to pay rentals. The 29 participants who rented houses or flats had 'no problem', but the 10 who rented backyard dwellings all reported some level of problem with 'exploitation of rentals'.

As can be seen by the number of participants who had to share bedrooms (28 in Table 6), lived in backyard shacks (10 in Figure 18) and did not have bathrooms (35 in Table 31), many of them were living in desperate circumstances.

There are many recent charters and white papers in place regarding housing which should remedy the plight of the people with disabilities living in Lotus River and similar low-income areas, but this seems to be long in reaching fruition.

They are as follows:

a) The Disability Rights Charter of South Africa (2000: Article 8) "demands that the state shall embark on a programme aimed at ensuring adequate, accessible and affordable housing for all disabled people".

b) The Reconstruction and Development Programme (RDP) endorses the principle that ,

"..... all South Africans have a right to a secure place in which to live in peace and dignity. Housing is a human right. One of the RDP's first priorities is to provide for the homeless. As a minimum, all housing must provide protection from weather, a durable structure, and reasonable living space and privacy. A house must include sanitary facilities, storm-water drainage, a household energy supply and convenient access to clean water" (ANC, 1994: 23).

Although the backyard shacks and some of the houses provided protection from weather they did not have reasonable living space and privacy and did not have bathrooms. They had access to water only by means of the main house, but if the occupants were not at home they did not have access.

c) The Children's Charter of South Africa (1996:9) states that "All children have the right to clothing, housing and a healthy diet" and that "All children have the right to clean water, sanitation and a clean living environment".

d) The INDS (1997) maintains that disabled people should be provided with safe shelter and dwellings of their own through equitable access to housing subsidy schemes. However, it is difficult to imagine how this system will be of assistance to the research group in Lotus River as their DG of R740 per month was the only source of income. They could barely pay for the basic food, clothes and rental out of this, even with some of their family members' contributions. Their dwellings were very small and the rentals relatively low so it would be difficult for them to be granted a housing subsidy to purchase a house of their own unless it had a significant subsidy and they were not required to pay more than what they were currently paying for rent.

The responsibility for housing rests with local municipalities yet the housing office in Lotus River maintains that there are no plans for any further houses to be built (Africa, 2003) in spite of the RDP's aims of "Providing land and housing to all our people" (ANC, 1994: 14).

Developers appear to be shying away from low-cost housing following the introduction of stricter building regulations. As a result, the provincial government of the Western Cape has not been able to spend its allocated budget (R86 million) (Cape Argus, 07.10.2003) to provide housing for the homeless and the most needy in our society, namely, the disabled who have to live under extremely difficult circumstances with no end in sight.

Summary of housing of disabled

There were 10 (12%) of people with disabilities living in informal backyard shacks. These people need to be considered when the government sets aside money to provide basic shelter for people in informal settlements as, not only do they not have basic shelter, they are amongst the most vulnerable and disadvantaged of the population as they are both poor and disabled.

The formal dwellings, generally, did not provide adequate accommodation for people with disabilities. The size, number of rooms and the overcrowding compromise the wheelchair-users' independence as they were unable to propel the wheelchairs from room to room due to spatial constraints. Many of the dwellings did not have bathrooms and had outside toilets which made it difficult for them to manage their personal hygiene.

With few additional costs the council could design small houses for the disabled with wider doorways; larger bathrooms and toilets; adapted window handles, bathroom and kitchen fittings positioned at a suitable height for wheelchair-users; and ramps at the back and front entrances. These small alterations would be at minimal cost, but would allow for much greater independence and an improved quality of life of people with disabilities.

In the next section a description of the past employment status of the disabled is provided and their reasons for being unemployed at present are discussed.

SECTION G. EMPLOYMENT

Sixty-one of the participants received rehabilitation to promote independence in the home, five received rehabilitation during the acute phase of their

hospitalisation only and 15 did not receive any rehabilitation at all. They were discharged from hospital without receiving any rehabilitation and were not referred to any CHC to receive any form of therapy as an outpatient.

The RDP specifies that there should be "...integration of preventive, promotive, curative and rehabilitation services" (ANC, 1994: 45) and the Disability Rights Charter of South Africa demands that, "Health and rehabilitation services and facilities shall be effective, accessible and affordable to people with disabilities in South Africa" (Disability Rights Unit of Lawyers, 2000: Article 3). The INDS (1997) also states that rehabilitation services should be accessible whenever necessary. However, this is still not occurring in many of the CHC's in both peri-urban and rural areas as there are no therapy posts available in many of these centres and the disabled live too far from the rehabilitation facilities available in tertiary or secondary hospitals.

Only six participants received rehabilitation geared towards getting them employed. Twenty-two were beyond the age of being employed and 53 received rehabilitation, but not geared towards being employed. There has been little done with regard to training and rehabilitation to integrate disabled people into the economy. The policy has simply been one of "passive income maintenance through grants" (Ministry for Welfare and Population Development, 1997: 49).

Table 32: Contingency table regarding employment

Able to work	Marketable skills	Was	Employed		Total		
			Was	Presently			
Yes	yes	was employed	yes	Yes	1	3	4
			no	No	5	5	
			n/a		1	2	
	no	was employed	yes		2	2	
			no		3	3	
			n/a		1	1	
No	yes	was employed	yes		4	4	
			n/a		1	1	
	no	was employed	yes		39	39	
			no		17	17	
			n/a		3	3	
			Total				81

Table (32) shows the number of disabled who considered themselves able to work, had marketable skills, used to work before their disability and, at the time of the interview, were or were not employed. Only one participant out of four who considered themselves able to work, had marketable skills, used to work before their disability and, at the time of the interview, was employed.

Although (17) 21% of the participants considered themselves to be 'able to work', only one was employed at the time of the interview. This may, in part, be due to the restrictions placed on the amount of additional money DG beneficiaries are permitted to earn. It may also be due to their low level of education and the high rate of unemployment in the country. However, even in developed countries people with disabilities have always experienced disproportionately higher rates of unemployment, particularly long-term unemployment (Daniels and Mickel, 2002; Crewe, 2002; Lonsdale, 1990).

According to the Constitution of the Republic of South Africa (1996: 10) "Every person shall have the right freely to engage in economic activity and to pursue a

livelihood anywhere in South Africa". In addition, the White Paper for Social Welfare recognises the need for, "... employment opportunities, such as workshops for the employment of people with disabilities who have no potential for or capacity to work in the open labour market, will be developed and supported" (Ministry for Welfare and Population Development, 1997: 78). It also identifies the need for "... negotiating with other Government departments about increasing accessibility to training ... and other core facilities within the community ... " (Ministry for Welfare and Population Development, 1997: 54) and states that "Protected employment opportunities need to run concurrently ... equal opportunities for people with disabilities in the open labour market" (Ministry for Welfare and Population Development, 1997: 78).

The INDS (1997) maintains that the disabled people should be allowed to play a meaningful role in society and be able to take part in economic activities.

Table (33) shows the type of employment in which the participants were involved before they became disabled.

Table 33: Type of employment before becoming disabled

	Frequency	Percentage
Unemployed	31	38
Blockman	2	2.5
Builder	2	2.5
Business	1	1.2
Carpenter	2	2.5
Cleaner	3	3.7
Clerk	2	2.5
Domestic	3	3.7
Electrician	1	1.2
Factory worker	7	8.6
Farm worker	1	1.2
Gardener	3	3.7
Hawker	1	1.2
Labourer	5	6
Machinist	2	2.5
Maintenance	1	1.2
Packer	1	1.2
Painter	2	2.5
Plasterer	1	1.2
Presser	1	1.2
Printer	1	1.2
Security	1	1.2
Shop assistant	2	2.5
Skilled	2	2.5
Time-keeper	1	1.2
Truck driver	1	1.2
Watchmaker	1	1.2
Total	81	100%

Table 34: Reasons for not being able to work (N=81)

	No	Yes
Physical disability	20	61
Unable to tolerate stress	74	7
Unable to tolerate noise	76	5
Feeling under weather	77	4
Getting out of breath easily	76	5
Unable to tolerate light	80	1
Low level of education	80	1
Too old	57	24

Table (34) shows the reasons the participants reported for not being able to work and not being employed. Research studies in developed countries confirm that 75% of working age adults with disabilities are not working or are under-employed and that 25% of welfare recipients reported poor general health and emotional problems as a reason for not working (Horn, 2000; Sweeney, 2000; Crewe, 2000; Zedlewski, 1999; Stapleton et al, 1995). Crewe (2002) found that in addition to health problems 20% of people with disabilities reported a physical disability as the reason for not working.

Although only one person indicated that he/she was not able to work because of his/her 'low level of education' research findings elsewhere have found that insufficient education is a contributing factor to people with disabilities not working (Crewe, 2002).

Table (35) shows the reasons the participants gave for not being employed, but considered themselves able to work. Sixteen participants found that people did not want to employ people with disabilities. This is in direct contravention of the Bill of Rights in the Constitution of SA (1996) which prohibits any form of discrimination on the basis of disability.

Table 35: Reasons for not being employed, but able to work (N=81)

	No	Yes
Unable to find employment	65	16
Public transport inaccessible	68	13
Work buildings inaccessible	78	3
Disabled parking too far	76	5
Do not want to employ disabled	65	16
Low level of education	74	7

Lonsdale (1990) claims that the attitude of employees is the most important component of employing people with disabilities and that the focus should be on their abilities rather than disabilities. The situation in Lotus River should change with the Employment Equity Act (Act 55 of 1998) which should contribute towards more people with disabilities being employed in the future as affirmative action in employment is implemented. Section 13 of the Act states that the employer's workforce should reflect the demographic profile of the national population and that the employers should "Ensure the equitable representation of suitably qualified people from designated groups in all occupational categories and levels in the workforce" (Government Gazette, 2002). People with physical disabilities fall into the 'designated groups'.

The employment situation of people with disabilities should also be improved by the Department of Welfare's strategy for social security of people with disabilities by "Taking the lead in an employment quota ... will promote more widely an

active labour-market policy for people with disabilities through employer, employee, and welfare organisations” (Ministry for Welfare and Population Development, 1997: 53).

The White Paper for Social Welfare and Population Development (1997) makes provision for employment opportunities by stating that workshops for disabled people who cannot work in the open labour market will be developed and supported (Ministry for Welfare and Population Development, 1997).

The Promotion of Equality and Prevention of Unfair Discrimination Act of 2000 outlaws unfair discrimination on grounds of disability.

The majority of participants did not find public transport or buildings being inaccessible as being reasons for not being employed whereas research in the UK and USA show these to be significant factors (Little, 2002; Akabas, 1997; Imrie, 1996; Butler, 1995; Belgrave, 1991; Lonsdale, 1990; De Young, 1981).

During the interviews it became clear to the researcher that most of the participants who would be employed had they been living in developed countries did not consider the idea of becoming employed. This was partly because they received a DG. Due to the high levels of unemployment in their environment and the low wages generally earned there was little motivation for them to find jobs due to the nature of their disability and the fact that they were receiving a regular monthly income, albeit small. They were unable to return to jobs which involved physical work and did not have the educational skills to be employed in more sedentary forms of work. Their low levels of education did not even allow for further training to develop basic administrative skills.

In view of these findings on unemployment and the literature that supports it, there should be a conscientious effort to root out the notion that many persons

who claim physical disabilities are motivated by a desire to manipulate the system and avoid work.

The Education White Paper 6 (2001: p 5) recommends that “The education and training system should promote education for all and foster the development of inclusive and support centres of learning that would enable all learners to participate actively in the education process so that they could develop and extend their potential and participate as equal members of society” (Department of Education, 2001). When the system is indeed implemented learners will be encouraged to achieve their maximum potential and should be able to be meaningfully employed. Individuals who become disabled will be able to receive training to develop skills that will enable them to change the nature of their jobs and obtain a different form of employment.

In addition the government is at present launching an extensive public works programme to bring down the crippling unemployment rate of 40% in the country to provide work for one million unemployed people over the next five years. This should draw significant numbers of the unskilled labour who are unemployed into productive employment (Reuters, 2003). The Western Cape has also recently committed itself to reducing the unemployment level in the province by providing R17bn over three years (Johns, 2004).

Together with The Employment Equity Act (Act 55 of 1998) these programmes should assist people with disabilities in finding employment provided the criteria for receiving the DG are changed to protect disabled people who are employed from losing their state benefits (Government Gazette, 2002).

Summary of employment

In order to reduce the numbers of disabled people dependent on DG's and to empower them they need opportunities and facilities in skills development over their entire life span. This means that the disabled have to have access to education from school level through to adult basic education and training level.

When this is put into place children with disabilities will be able to achieve a level of education that prepares them for some form of employment to suit their physical and intellectual capacity. Should adults become disabled during their working life they should be able to receive further training and skills to prepare them for a different form of work appropriate to the needs of their physical capacity. The funding of this is already being provided by the government in the form of Seta learning programmes offered free to small businesses nationwide.

The nature and extent of social support received by the disabled is provided in Section H.

SECTION H. SOCIAL SUPPORT

Table (36) depicts the amount of emotional support the participants received. It shows that the majority of the respondents felt that social support was available to them 'most' to 'all of the time'. Only a few of the participants had social support available to them between 'none' to 'some of the time'.

Table 36: The Medical Outcomes Study Social Support Survey (MOS) (N=81)

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Someone to help you if you have to stay in bed	5	2	3	11	60
Someone you can count on to listen to you when you need to talk	2	2	6	14	57
Someone to give you good advice about a crisis	5	3	5	12	56
Someone to take you to the doctor if you needed it	3	3	6	8	61
Someone who shows you love and affection	3	2	5	12	59
Someone to have a good time with	5	4	10	9	53
Someone to give you information to help you understand a situation	5	0	7	11	58
Someone to confide in or talk to about yourself or your personal problems	5	0	7	10	59
Someone who hugs you	5	3	8	9	56
Someone to get together with for relaxation	4	1	10	9	57
Someone to prepare your meals if you were unable to do it yourself	2	0	2	8	69
Someone whose advice you really want	4	1	11	10	55
Someone to do things with to help you get your mind off things	3	3	9	10	56
Someone to help with your daily chores if you were sick	4	0	3	11	63
Someone to share your most private worries and fears	4	1	8	10	58
Someone to turn to for suggestions about how to deal with a personal problem	4	1	6	12	58
Someone to do something enjoyable with	5	2	6	13	55
Someone who understands your problems	5	0	7	13	56
Someone to love and make you feel wanted	3	3	8	9	58

The Cronbach Alpha coefficient based on 81 participants and 19 items measuring 'social support' was 0.973 showing a high level of internal

consistency. This allowed the multiple-item scale to be transformed into a single additive scale.

For further analysis the rating categories were recoded into three categories: 'none' to 'some' social support (1), social support 'most of the time' (2) and social support 'all of the time' (3). The result is summarised in Table (37).

Table 37: The amount of time social support was available

	Frequency	Percentage	Cumulative Percentage
Some of the time	8	9.9	9.9
Most of the time	17	21.0	30.9
All of the time	56	69.1	100.0
Total	81	100.0	

These findings are confirmed by Lonsdale's (1990) research in the UK where she found that living in extended families was helpful for people with disabilities because there was no need for them continually to explain their needs and, as the extended families provided company, it meant that the people with disabilities were never lonely. This also happened in strong supportive communities which were always willing to help and provide the disabled people with company (Lonsdale, 1990).

SOCIAL CONTACTS

- 21. How many families in your neighbourhood do you know well enough that you visit each other in your homes? H21
- 22. About how many close friends and relatives do you have? (People who you feel at ease with and can talk with about what is on your mind?) H22
- 23. During the past month about how often have friends visited you in your home?
 Every day¹ Several days a week² Once a week³ Two or 3 times during the past month⁴ Once in the past month⁵ Not at all⁶ H23
- 24. How do you feel about this number of visits?
 Happy¹ Don't mind² Would like more visits³ Would like fewer visits⁴ H25
- 25. During the past month about how often have you visited friends in their homes?
 Every day¹ Several days a week² Once a week³ Two or 3 times during the past month⁴ Once in the past month⁵ Not at all⁶ H26
- 26. How do you feel about this number of visits?
 Happy¹ Don't mind² Would like more visits³ Would like fewer visits⁴ H27
- 27. During the past month about how often did you talk with close friends or relatives on the telephone?
 Every day¹ Several days a week² Once a week³ Two or 3 times during the past month⁴ Once in the past month⁵ Not at all⁶ No telephone⁷ H28
- 28. How many social groups or organisations (church groups, clubs, parent groups) do you attend each month?
 Specify
- 29. How regularly do you attend these? Once per week¹ Once per month² Other³ Specify H29
- 30. How many social groups or organisations (church groups, clubs, parent groups) visit you each month?
 Specify
- 31. Do you know of any social or support groups that are available to you? Yes¹ No² H32
 If 'No' would you like to join a group if there is one available? Yes¹ No² H33
- 32. Do you belong to any disability groups which influence policies regarding the physically disabled? Yes¹ No² H34
- 33. Some people are happy with the amount of social contact they have. Others would like more company and some don't mind either way. How do you feel about the amount of company you have?
 Happy¹ Don't mind² Would like more company³ Would like less company⁴ H36
 Specify
- 34. Do you believe that your disability has been a social burden on your family? Yes¹ No² H38

H40

H41

H42

Extent of social contacts of disabled

The responses to the items regarding the number of social contacts are presented in Table (38). For ease of interpretation it should be read while referring to the individual items H21 to H42 of Appendix (iv) on the opposite page. For example, item H21 shows that 12 participants claimed they knew six families well enough to visit each other's homes. For item H38 there were 81 participants who claimed they did not belong to 'any disability groups which influenced policies regarding the physically disabled'.

Table 38: The frequency of items in the various categories referring to the amount of social contacts the disabled have (N=81)

	Categories						
	0	1	2	3	4	5	6
H21	23	13	8	8	7	10	12
H22	2	13	11	17	5	5	28
H23		22	10	15	10	11	13
H25		24	31	17	9		
H26		18	12	6	4	12	29
H27		21	18	20	22		
H28	15	10	7	14	9	9	17
H29	32	39	4	1	3	1	1
H31	33	40	5	3			
H32	38	35	7		1		
H34		18	63				
H36		21	60				
H38			81				
H40		48	24	9			
H42	1	24	56	0			

Legend of items on opposite page

Relationship of the number of friends visiting the disabled person and the number of visits the disabled person made

A two-dimensional CAT-PCA scaling test was used to examine the relevance and relationship between the 'number of neighbourhood visits' (H21), the 'number of

friends and relatives' (H22) and the frequencies of 'friends visiting you' (H23) and 'you visiting friends' (H26). The results are shown in Tables (39) and (40). Table (39) shows that 71% of the total variance was explained by the solution.

Table 39: Summary of a two-dimensional solution of the variables 'number of neighbourhood visits' (H21), the 'number of friends and relatives' (H22) and the frequencies of 'friends visiting you' (H23) and 'you visiting friends' (H26)

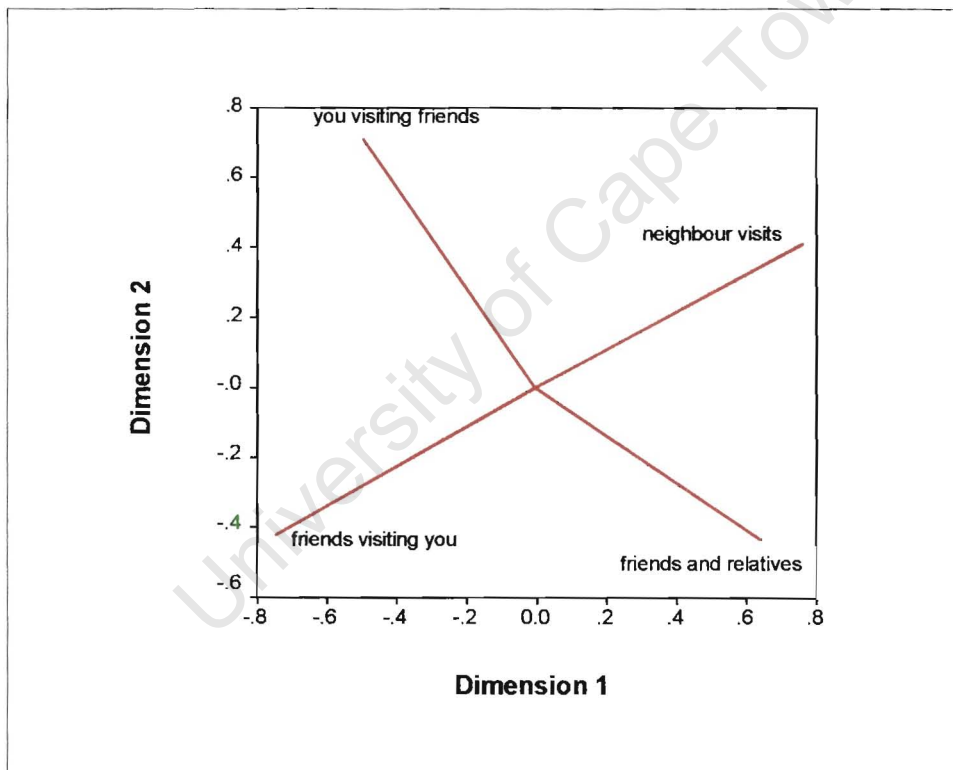
Dimension	Cronbach's Alpha	Variance Accounted For	
		Total (Eigenvalue)	% of Variance
1	.590	1.793	44.825
2	.046	1.036	25.893
	.862	2.829	70.718

Table 40: Component loadings and relationships of 'number of neighbourhood visits' (H21), the 'number of friends and relatives' (H22) and the frequencies of 'visits to you' (H23) and 'visits by you' (H26)

	Dimension	
	1	2
Neighbourhood visits	.764	.409
Number of friends and relatives	.644	-.436
Friends visiting you	-.745	-.421
You visiting friends	-.489	.708

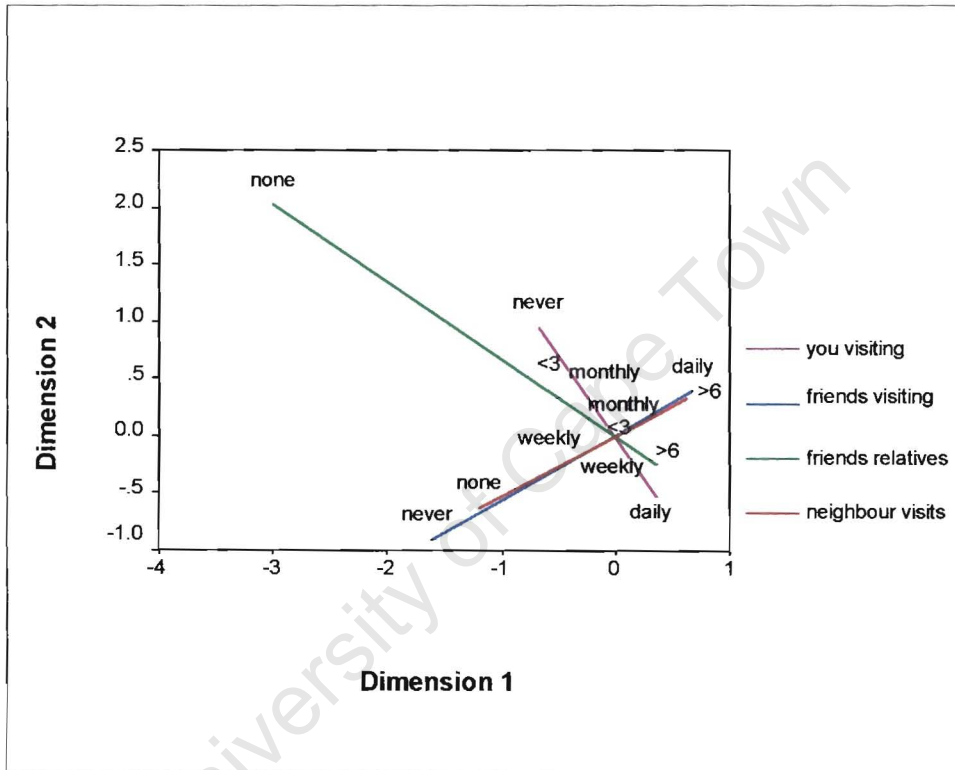
Figure (19) shows that the 'number of friends and relatives' (H22) has a stronger relationship to the 'number of friends you visit' (H26) than the 'number of friends visiting you' (H23). The 'number of friends visiting you' (H23) and the 'number of neighbourhood visits' (H21) are strongly related. This suggests that social contacts from the direct environment seem as close and frequent as with those of their own family.

Figure 19: Graphic representation of the relationship of the 'number of friends you visit' (H26), 'number of friends visiting you' (H23) and 'number of friends and relatives' (H22) and 'number of neighbourhood visits' (H21)



The plot of the category scores in Figure (20) illustrates this relationship more clearly.

Figure 20: Plot of the category scores and relationships of 'number of friends you visit' (H26), 'number of friends visiting you' (H23) and 'number of friends and relatives' (H22) and 'number of neighbourhood visits' (H21)



Aspects having a negative impact on the amount of socialization of the disabled person

The frequency of the ratings of the problems impacting on the level of socialisation of the participants are presented in Table (41).

Table 41: Frequency of the ratings per item regarding a negative impact on socialisation (N=81)

	No problem	Mild problem	Moderate problem	Severe problem	Complete problem
Your physical disability	16	12	23	6	24
Steps to your dwelling	42	13	14	5	7
Steps to your friends' dwellings	35	12	20	6	8
Steps to buildings in the community	29	15	19	7	11
Inaccessible toilets in public buildings	43	9	15	6	8
Steps to church	41	10	19	4	7
Pavement steps	34	18	16	3	10
Rough, uneven pavement surfaces	37	15	17	3	9
Transport difficulties	30	11	17	8	15
Fear of criminals	62	2	2	3	12
No money	34	11	11	6	19
Lack of social groups	66	4	3	1	7
Lack of support groups	69	2	2	2	6

Between 77% and 86% of the participants had no problem with the items 'fear of criminals' (H52), 'lack of social groups' (H54) and 'lack of support groups' (H55).

During the interviews the aspect of 'fear of criminals' was discussed in detail with the participants and their families. They stated that they were not frightened of the gangsters as they had lived as neighbours or had known them for many years and knew that they would do them no harm personally. Many of them reported that the gangsters would willingly help them push their wheelchairs through the sand or help them up and down the kerbs of the pavements.

However, when there were gang fights in the area they knew that for safety, they

had to rush indoors and stay below window height to avoid being shot in the cross-fire.

The fact that the 'lack of social groups' and 'support' groups was rated as 'no problem' by the vast majority of participants is understandable since the number of social contacts they had each day with their families and neighbours appeared to negate this need.

The relevance and relationships between the remaining items (H43 – H53) were analysed by a CAT-PCA scaling test. The results are shown in Tables (42) and (43). Table (42) shows that a two-dimensional solution explained 78% of the total variance.

Table 42: Summary of a two-dimensional solution to the variables 'physical ability' (H43), 'steps to dwelling' (H44), 'steps to friends dwelling' (H45), 'steps to buildings' (H46), 'inaccessible toilets' (H47), 'steps to church' (H48), 'pavement steps' (H49), 'pavement surfaces (H50), 'transport difficulties' (H51) and 'no money' (H53)

Dimension	Cronbach's Alpha	Variance Accounted For	
		Total (Eigenvalue)	% of Variance
1	.936	6.362	63.62
2	.349	1.458	14.58
	.969	7.821	78.21

Table 43: Component loadings and relationships of the variables H43, H44, H45, H46, H47, H48, H49, H50, H51 and H53

	Dimension	
	1	2
H43 Your physical disability	.529	.501
H44 Steps to your dwelling	.835	-.259
H45 Steps to your friends' dwellings	.862	-.167
H46 Steps to buildings in the community	.908	-.119
H47 Inaccessible toilets in public buildings	.930	-.146
H48 Steps to church	.846	-.285
H49 Pavement steps	.901	-.053
H50 Rough, uneven pavement surfaces	.918	-.089
H51 Transport difficulties	.636	.588
H53 No money	.420	.800

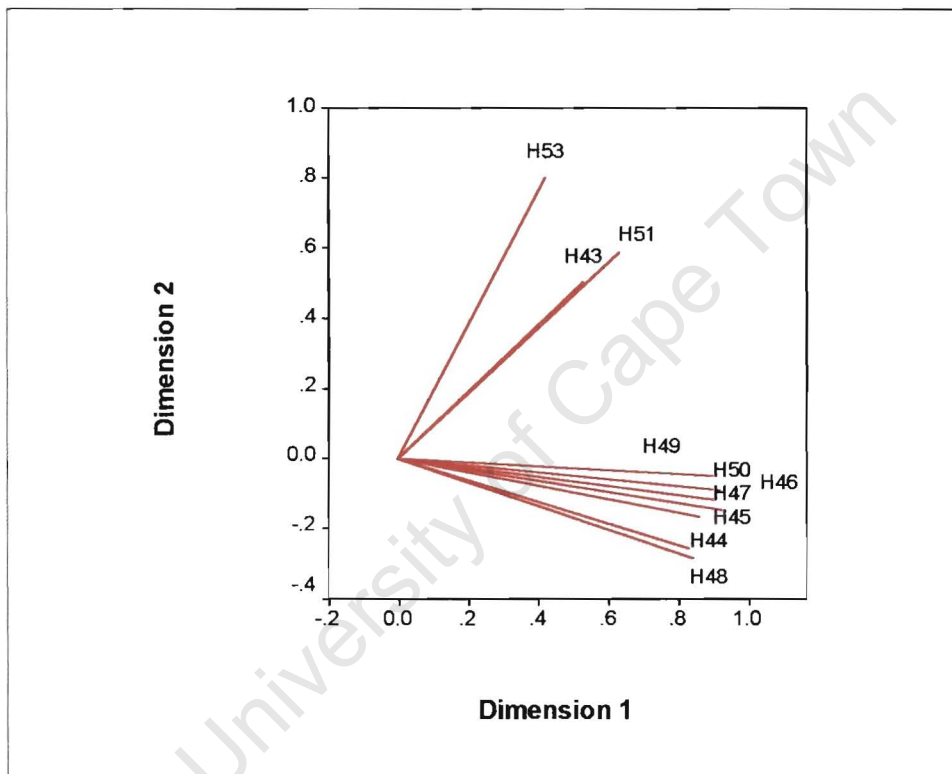
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35. Which of the following have a negative impact on the amount of your socialisation?

	No problem 1	Mild problem 2	Moderate problem 3	Severe problem 4	Complete problem 5	
Your physical disability						H43
Steps to your dwelling						H44
Steps to your friends' dwellings						H45
Steps to buildings in the community						H46
Inaccessible toilets in public buildings						H47
Steps to church						H48
Pavement steps						H49
Rough, uneven pavement surfaces						H50
Transport difficulties						H51
Fear of criminals						H52
No money						H53
Lack of social groups						H54
Lack of support groups						H55
Other: specify						H56

Figure (21) reveals that items H43 – H53 clustered into two groups. The cluster with the most items refers to issues with 'steps' in general. The other cluster consists of items H43 (physical disability), H51 (transport difficulties) and H53 (no money) and refers to issues related to 'mobility'.

Figure 21: Graphical representation of the relationships of 'physical disability' (H43), 'transport difficulties' (H51) and 'no money' (H53)



Legend of items on opposite page

Thus, two new variables were composed representing the dimensions 'problem with steps' and problems in general with 'mobility' (Table 44).

Table 44: Frequencies of the problems with the items 'steps' and 'mobility' (N=81)

	No problem	Mild problem	Moderate problem	Severe problem	Complete problem
Mobility	9	34	17	11	10
Steps	31	20	18	7	5

Figure (21) and Table (44) demonstrate that 'steps' in the general environment had a major negative impact on the socialization of the disabled; whereas 'physical disability', 'transport difficulties' and 'no money' had less of an impact.

Summary of social support of the disabled

Social support was not found to be a major problem. The disabled usually lived in overcrowded dwellings with numerous relatives and were visited frequently by neighbours, friends and relatives. Those who were sufficiently physically independent frequently visited friends and relatives in the neighbourhood.

There were, however, many barriers which had a negative impact on their level of socialisation such as steps, ground surfaces being rough and uneven, transport difficulties and the fear of criminals.

The extent to which the disabled rated the Health Services as a barrier are presented below in Section J.

SECTION J. HEALTH SERVICES

Tables (45) and (46) show the health services participants used and the frequency with which they visited these health services. It shows that 73% - 82% of the participants utilised the clinic sister, clinic doctor and received medication from the clinic on a regular basis.

Table 45: Health services regularly utilised (N=81)

	Yes	No
District sister - clinic	64	17
District sister - home	4	77
Doctor - clinic	66	15
Doctor - private	14	67
Orthopaedic aftercare sister	4	77
Secondary hospitals	34	47
Tertiary hospitals	31	50
Traditional, faith healer	0	81
Receive medication regularly	59	22

Table 46: Frequencies of utilising visiting services, if used (N=81)

	Never	Weekly	Monthly	Yearly	When needed
District sister - clinic	17	19	30	2	13
District sister - home	77	1	0	0	3
Doctor - clinic	15	6	17	10	33
Doctor - private	66	0	1	0	14
Orthopaedic aftercare sister	77	0	0	2	2
Secondary hospitals	47	1	4	5	24
Tertiary Hospitals	50	1	8	6	16

Table (47) shows that most participants had little problem with the itemised needs regarding health services. The biggest problems relating to the health services was the long waiting time, transport and distance. Sixty-six (82%), 39 (48%) and 38 (47%) respectively of the participants found these to be a 'moderate' to 'complete problem'.

Table 47: Frequencies of the ratings of problems experienced with the health services (N=81)

	No problem	Mild problem	Moderate problem	Severe problem	Complete problem
Regular visits by the district sister	62	2	10	3	4
Distance to the clinic	28	16	16	9	12
Transport to the clinic	32	11	15	8	15
Able to go to the clinic without assistance	46	7	7	5	16
No privacy	77	1	0	0	3
Staff are uncaring	74	3	2	2	0
Staff do not have enough time for you	70	6	1	3	1
Staff do not listen to what you say	72	4	3	2	0
Staff are disinterested in you as a person	75	3	1	2	0
Staff make decisions for you without fully explaining matters to you	73	6	0	2	0
The opportunity of talking to someone about your condition	75	2	0	2	2
Not having the opportunity of talking to someone about your health condition	38	4	32	5	2
Costs of health care	55	5	7	7	7
Long waiting time	6	9	22	24	20

Only items 'distance to the clinic' (J23), 'transport to the clinic' (J24), 'without assistance' (J25), 'no opportunity for talking' (J33), 'long waiting time' (J35) show a different pattern.

A three-dimensional CAT-PCA scaling test was used to examine the relevance and relationship between the items 'distance to the clinic' (J23), 'transport to the clinic' (J24), 'without assistance' (J25), 'no opportunity for talking' (J33), 'long

waiting time' (J35). The results are presented in Tables (48) and (49). Table (48) shows that 88% of the variance was explained by the solution.

Table 48: Summary of a three-dimensional solution to the variables 'distance to the clinic' (J23), 'transport to the clinic' (J24), 'without assistance' (J25), 'no opportunity for talking' (J33), 'long waiting time' (J35)

Dimension	Cronbach's Alpha	Variance Accounted For	
		Total (Eigenvalue)	% of Variance
1	.715	2.338	46.766
2	.129	1.115	22.300
3	-.037	.971	19.429
	.967	4.425	88.495

Table 49: Component loadings and relationships of the variables 'distance to the clinic' (J23), 'transport to the clinic' (J24), 'without assistance' (J25), 'no opportunity for talking' (J33), 'long waiting time' (J35)

			Dimension		
			1	2	3
Distance to clinic	J23	.916	.164	-.124	
Transport to clinic	J24	.933	.144	-.069	
Without assistance	J25	.692	.024	.556	
No opportunity talking	J33	-.371	.568	.678	
Long waiting time	J35	-.105	.862	-.427	

Table (49) shows that items 'distance to the clinic' (J23) and 'transport to the clinic' (J24) are strongly correlated with Dimension 1 and evidently refer to 'mobility' issues. Item 'able to get to the clinic independently' (J25) correlates with Dimension 1, suggesting 'accessibility' aspects as well as aspects represented by Dimension 3. These aspects are shared by aspects of items 'not having the opportunity of talking to someone about your health condition' (J33) and seem to refer to specific 'disability' demands. Item 'long waiting time' (J35) largely determines Dimension 2 and shares aspects with item 'not having the

opportunity of talking to someone about your health condition' (J33). This dimension seems to refer to some form of annoyance, frustration and/or irritation.

Summary of health services

The majority of participants had only a few problems with the health services. However, transport and the long waiting time at the clinics were substantial barriers to the majority of the disabled.

The findings of the problems experienced by the disabled with regard to the Social Services are presented in Section K.

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SECTION K. SOCIAL SERVICES

Table 50: Frequency of rating problems experienced with the Social Services (N=81)

	No problem	Mild problem	Moderate problem	Severe problem	Complete problem
Amount of the disability grant	24	14	13	16	14
Information on disability grants and pay points inaccessible	53	4	6	6	12
Pay-point for your disability grant has long queues	63	8	5	0	5
Pay-point is unsafe	61	12	5	0	3
Not having sufficient visits from a social worker	65	6	2	1	7
Not having the opportunity of talking to someone about your situation	70	4	2	3	2
Not having someone to help care for you	75	4	1	0	1
Not having someone to help with the housework and shopping	77	1	2	0	1
Transport to reach social worker	55	8	9	3	6
Transport to reach disability pay point	59	10	5	3	4
Not knowing groups that provide inter-action with other people with disabilities	62	8	7	1	3
Not knowing groups that provide interaction with non disabled people	65	8	4	1	3
Not knowing groups that provide support for your family	65	6	3	3	4
Needing training to learn an occupation	58	11	7	4	1
Needing help with setting up your own business	62	8	6	4	1

Table (50) shows that between 65% and 95% of the participants did not experience problems with the social services as indicated by the items. Only the 'amount of the disability grant' (K42) differs from the general pattern where at least 37% of the participants reported having 'severe' to 'complete problems'. This seems related to 'information on disability grants and pay points inaccessible' (K43). This relationship becomes more evident after recoding both items such that (3=2) (4=3) (5=3).

Contingency Table (51) reveals that participants experiencing problems with the 'amount of the disability grant' experienced more problems with 'access to information about the grant' (K43).

Table 51: The relationship between the amount of disability grant and the accessibility to information about grants

		Access to information about grant			Total
		No problem	Mild to moderate	Severe to complete	
Amount of grant	No problem	22	2		24
	Mild to moderate	22	2	3	27
	Severe to complete	9	6	15	30
Total		53	10	18	81

During the interviews the researcher was able to inform the participants and their caregivers about the social assistance available in the form of various grants for which she thought they were eligible according to the criteria for being awarded them. They were advised about which Social Welfare offices to approach and the process of applying for the relevant grants.

During the follow-up visits to check the wheelchairs and assistive devices she recorded the progress of their applications as presented in Table (52). The types of grants and eligibility criteria are presented in Appendix xvii: paragraph 25.

Table 52: Number of social grants applied for and awarded during the time of the research

Type of grant applied for	Number of disabled	Number of grants awarded	Number of applications being processed
Re-instatement of permanent disability grant	8	8	0
War veterans	2	1	1
Care dependency	1	1	0
Foster child	3	2	1
Child support	5	3	2
Grant in aid	7	5	2
Social relief	2	1	1
Rent relief	4	3	1
Rental indigent	2	2	0
Total	34	26	8

Re-instatement of the permanent DG was of great concern to the researcher. Eight participants had been regularly receiving a grant for two or three years when it was suddenly cut off with no warning or explanation. After letters to the relevant departments the researcher was able to advise the participants on what action to take. They first had to be reviewed by a doctor and then present themselves with the relevant medical documentation at the Wynberg offices of the Social Services Department. After this had been accomplished it took between six months to one year for the grant to be reinstated. The medical condition of the participants had not changed during the time of their temporary grant, namely, that they had had leg amputations or severe strokes so there was no reason for the severance of the grant. When the researcher approached the Department of Social Services for the number of grants paid out on a monthly basis she was told that it was highly confidential. However, she was able to obtain, from a very reliable source, that the number of beneficiaries had dropped by 10% over the year (Confidential source, 2003). This number should have

increased as there were more people being discharged from hospitals with surgical and medical conditions that warranted DG's. When queried on the length of time taken to re-instate a permanent DG the researcher was informed that it did not need to take more than 35 days (Confidential source, 2003). The only conclusion that the researcher could come to with regard to the termination of the DG's as well as the length of time for reinstatement is that it was a strategy used by the DSSPA to decrease the demands on its budget. These delays, however, had a catastrophic effect on the beneficiaries and their families. It merely increased their cycle of poverty. They had to borrow money from the loan sharks and were never able to fully repay their loans due to the interest rates charged.

For people with disabilities to present themselves for a doctor's certificate and a trip to the Wynberg Social Services offices is almost an impossibility due to their transport difficulties and the inaccessible nature of the Wynberg Social Services building. These shortcomings are acknowledged in the White Paper for Social Welfare by identification that, "Welfare services are not accessible and responsive to the needs of all people" and it has as one of its strategies, for social security for the disabled, to make the physical environment and procedures more accessible (Ministry for Welfare and Population Development, 1997: 11) and to develop "uniform, simplified and more effective assessment procedures with regard to grants for people with physical, mental and sensory disabilities" (Ministry for Welfare and Population Development, 1997: 54).

Summary of social services

The social security net is not alleviating the poverty of the most vulnerable of the population. The majority of participants found the amount of the DG as being a problem to them and that it affected their ability to meet basic food, clothing, fuel

and rental costs. It also had a major impact on their ability to paying for transport which, in turn, impacted on access to health and social services.

Although the disabled had different special needs with regards to their disabilities and different responsibilities to meet they all received the same amount of DG which was found to be inadequate by the majority of participants.

Participants were hesitant and anxious when discussing their DG or OAG, always fearing that it might be withdrawn for reasons which they were unaware of. Those that had not had their grants withdrawn at any stage did not find it a problem, but were unaware of the process that required to be followed should they have to apply for it to be reinstated. The participants who had, at some time, their DG's withdrawn did not know how to have them reinstated. In addition they found the Social Welfare offices in Wynberg to be inaccessible and the bureaucrats to be most unhelpful.

There is an urgency for social security to be addressed in order to alleviate the poverty of the disabled. It should ensure that all beneficiaries of the DG are reached and that, in the cases where disabled have children who are dependent, their DG child support grants should be provided for them until they have completed their education and become self-supporting.

SECTION L

ATTITUDE OF COMMUNITY TOWARDS YOU

1. How often do you go out in public – in the street, shopping, church, doing business, going to movies, etc
 Never¹ Seldom² Sometimes³ Often⁴ L1
2. Where do you go on a regular basis? Visit people in the area¹ Church² Shops³ Clinic⁴ L2
3. Since you became disabled have the attitude of the people in the community changed toward you?
 Yes¹ No² N/A³ L3
 If "Yes" specify L4
4. How do people in your community react to you? Friendly¹ Unfriendly² L5
5. How do people in your community react to you?
 Want to protect you¹ Ignore you² As though you are different³ Stare⁴ L6
6. How do people in your community react to you? Helpful¹ Unhelpful² Ignore you³ L7
7. How do people in your community react to you?
 Offer to help¹ Always willing to help if you ask them² Sometimes will help if you ask³
 React as if they think you do not need any help⁴
 Find excuses so they do not have to help⁵ Refuse to help⁶ L8
8. Do you prefer to stay at home because of the negative reaction of people with whom you come into contact?
 Yes¹ No² L9
9. When you are in public do you prefer to use: Crutches¹ A wheelchair² N/A³ L10
 Specify why
10. Public ignore parking bays designated for the use of disabled people
 Never¹ Seldom² Sometimes³ Often⁴ L11
11. How do you think people in the community think that you should behave as a disabled person?
 Take part in community activities just like any body else¹
 Attend but join in only some community activities²
 Attend but not join in any community activities³
 Not attend community activities at all⁴ L12

SECTION L. ATTITUDE OF COMMUNITY TOWARDS PEOPLE WITH DISABILITIES

In Table (53) various categories of events related to the attitude of the community towards disability are presented. For ease of interpretation it should be read while referring to the legend of items L1 to L11 on the opposite page. For example, item L6 shows that 75 applicants found the people in the community 'helpful', four found them 'unhelpful' and two 'ignored them'.

Table 53: The rating frequencies per item measuring attitude of community towards the disabled (N81)

	Rating frequencies					
	1	2	3	4	5	6
L1 How often do you go out in public	10	28	17	26		
L3 Change of attitude of community	17	54	10			
L5 People's reaction to disabled	80	1				
L6 People's reaction to disabled	65	10	3	3		
L7 People's reaction to disabled	75	4	2			
L8 People's reaction to disabled	8	64	7		1	2
L9 Preference for mobility aid in public	24	56	1			
L10 Public ignore parking bays	15	29	37			
L11 Community's attitude towards behaviour of disabled	28	19	29	5		
L12 Attitude of community towards you	37	8	31	5		

Items L5, L6 and L7 show the community's strong reaction of wanting to protect, help and be helpful to people with disabilities and L12 shows their positive attitude of accepting that people with disabilities should 'take part in community activities just like any body else'. Research indicates that this does not take place in all societies and that some communities are unhelpful towards, stare at, avoid, exclude or ignore people with disabilities (Abu-Habib, 1997; Boukhari, 1997; Hema, 1996; Bames, 1994; Lonsdale, 1990; Bogdan, 1988).

The Education White Paper 6 outlines how the education and training system "... must transform itself to contribute to establishing a caring and humane society"

(Department of Education, 2001: 11). By including people with disabilities in all schools and training institutions and transforming the curriculum children will be sensitised to the needs of the disabled and learn how to integrate and include them in all aspects of society.

Table (54) presents the relationship between 'how often respondents go out in public' (L1) and 'where do you go on regular basis' (L2). Overall, the most frequent places they go to are 'church' (2), 'people in area' (1) and the 'clinic' (4) respectively.

Table 54: Relationship between the frequency of 'going out in public' and 'places visited'

Appearing in public	Places visited regularly										Total
	1	1,2	1,2,3,4	1,3	2	2,3	2,3,4	2,4	3	4	
Never	2				3	1				4	10
Seldom	3				13			1	3	8	28
Sometimes	5				7			1	1	3	17
Often	10	1	3	2	8		1		1	26	
Total	20	1	3	2	31	1	1	2	5	15	81

Legend: 1 Visiting people in the area 2 Church 3 Shops 4 Clinic

SECTION L	ATTITUDE OF COMMUNITY TOWARDS YOU
------------------	--

- | | | |
|--|--|----|
| 1. How often do you go out in public – in the street, shopping, church, doing business, going to movies, etc | Never ¹ Seldom ² Sometimes ³ Often ⁴ | L1 |
|--|--|----|
- | | |
|---|----|
| 2. Where do you go on a regular basis? Visit people in the area ¹ Church ² Shops ³ Clinic ⁴ | L2 |
|---|----|
- | | | |
|---|---|----|
| 3. Since you became disabled have the attitude of the people in the community changed toward you? | Yes ¹ No ² N/A ³ | L3 |
| If "Yes" specify | | L4 |
- | | | |
|--|---|----|
| 4. How do people in your community react to you? | Friendly ¹ Unfriendly ² | L5 |
|--|---|----|
- | | | |
|--|--|----|
| 5. How do people in your community react to you? | Want to protect you ¹ Ignore you ² As though you are different ³ Stare ⁴ | L6 |
|--|--|----|
- | | | |
|--|---|----|
| 6. How do people in your community react to you? | Helpful ¹ Unhelpful ² Ignore you ³ | L7 |
|--|---|----|
- | | | |
|---|--|----|
| 7. How do people in your community react to you? | Offer to help ¹ Always willing to help if you ask them ² Sometimes will help if you ask ³ | |
| React as if they think you do not need any help ⁴ | | |
| Find excuses so they do not have to help ⁵ Refuse to help ⁶ | | L8 |
- | | | |
|--|----------------------------------|----|
| 8. Do you prefer to stay at home because of the negative reaction of people with whom you come into contact? | Yes ¹ No ² | L9 |
|--|----------------------------------|----|
- | | | |
|---|--|-----|
| 9. When you are in public do you prefer to use: | Crutches ¹ A wheelchair ² N/A ³ | L10 |
| Specify why | | |
- | | | |
|--|--|-----|
| 10. Public ignore parking bays designated for the use of disabled people | Never ¹ Seldom ² Sometimes ³ Often ⁴ | L11 |
|--|--|-----|
- | | |
|---|-----|
| 11. How do you think people in the community think that you should behave as a disabled person? | |
| Take part in community activities just like any body else ¹ | |
| Attend but join in only some community activities ² | |
| Attend but not join in any community activities ³ | |
| Not attend community activities at all ⁴ | L12 |

In Table (55) the relationship between the frequency of 'going out' (L1) and 'how people react to the participants' (L5, L6, L7 and L8) are presented.

Table 55: Relationship between frequency of 'going out' and 'how people react'

	How people react					Total
	1	2	3	5	6	
Going out	2	8				10
Never						
Seldom	4	20	3	1		28
Sometimes	2	13	2			17
Often		23	2		1	26
Total	8	64	7	1	1	81

Legend of 'people's reaction' on opposite page

University of Cape Town

In Table (56) the relationship between the frequency of 'going out' (L1) and 'preferring to stay home because of the negative reaction of people' (L9) and 'type of aids' (L10) are presented.

Table 56: Relationship between the 'type of aids' (L10) and frequency of 'going out' (L1) and 'staying home because of negative reaction' (L9)

Aids when going out	Frequency of going out	Negative reaction		Total
		Yes	No	
Crutches	Never	0	2	2
	Seldom	4	2	6
	Sometimes	2	2	4
	Often	2	1	3
	Total	8	7	15
Wheelchair	Never	3	4	7
	Seldom	4	6	10
	Sometimes	1	4	5
	Often	0	7	7
	Total	8	21	29
No mobility aids	Never	0	1	1
	Seldom	6	6	12
	Sometimes	0	8	8
	Often	2	14	16
	Total	8	29	37
Total		24	57	81

Table (57) presents the frequency of the ratings of the attitude of the community towards issues like 'intimate relationships' and 'care of children' of people with disabilities. It shows that at least 75% of the participants had no problem or only a mild problem with these items.

Table 57: Attitude of community towards participants

	No problem	Mild problem	Moderate problem	Severe problem	Complete problem
That you are somebody who should be pitied	44	17	11	5	4
That they are embarrassed by your disability	55	14	6	3	3
That you should not be able to have intimate relationships with people of the opposite sex	57	13	8	1	2
That you should not be able to get married	55	10	13	1	2
That you will not be able to look after a husband/wife/partner	56	10	11	2	2
That you will not be able to care for a house and cook	52	15	11	1	2
That you will not be able to provide for your husband/wife/partner	50	11	13	3	4
That you should not be able to have children if you want to	51	13	12	2	3
That you will not be able to care for children	49	14	12	3	3

The distribution of responses becomes more transparent when the rating categories are reduced to three by adding the scores of 'no problem' and 'mild problem' (Table 58). Research in other countries shows that many non-disabled people have negative attitudes towards people with disabilities (Abu-Habib, 1997; Boukhari, 1997; Barnes, 1994; Roulstone, 1994; Lonsdale, 1990; Chamie, 1989; Bogdan, 1988; Finkelstein, 1989).

Table 58: Attitude of community towards participants

	No – Mild problem	Moderate problem	Severe problem
That you are somebody who should be pitied	61	11	9
That they are embarrassed by your disability	69	6	6
That you should not be able to have intimate relationships with people of the opposite sex	70	8	3
That you should not be able to get married	65	13	3
That you will not be able to look after a husband/wife/partner	66	11	4
That you will not be able to care for a house and cook	67	11	3
That you will not be able to provide for your husband/wife/partner	61	13	7
That you should not be able to have children if you want to	64	12	5
That you will not be able to care for children	63	12	6

Summary of the attitude of the community towards people with disabilities

Generally the community were supportive of and helpful to the disabled. The majority of participants did not find it necessary to stay at home because of negative reactions of people to their mobility aids or disability.

The findings of the nature and extent of the physical barriers experienced by the disabled are presented in the next section.

SECTION M. ENVIRONMENTAL BARRIERS

In Table (59) the frequency of the ratings of the different categories of environmental barriers experienced by the participants are presented.

Table 59: Frequency of rating problems experienced with environmental barriers (N=81)

	No problem	Mild problem	Moderate problem	Severe problem	Complete problem
Your physical disability	13	15	23	10	20
Steps to your dwelling	42	14	15	6	4
Not enough special disabled parking bays	38	28	6	8	1
Ramps to buildings in the community	30	26	15	6	4
Incline of ramps too steep	31	33	8	4	5
Inaccessible toilets in public buildings	42	20	12	5	2
Pavement steps	37	19	15	5	5
Rough terrain on pavement surfaces	38	13	18	6	6
Shop, post office and bank counters too high	56	16	4	3	2
Entrance to shops inaccessible	60	13	5	2	1
Check-out counters at shops inaccessible	56	15	6	2	2
Public telephones too high	56	13	9	1	2
Autobanks too high	56	12	7	3	3
Transport	35	11	13	10	12
Fear of criminals	59	4	4	6	8

The reason for so many participants reporting 'no problem' with the items is that the Lotus River Questionnaire was completed at the first interview before they had been provided with wheelchairs and mobility aids. As they had not means of leaving their homes to frequent the shops, post offices or public buildings they rated these items as 'no problem'; whereas they would most likely have rated them as 'moderate' to 'complete problems' had they been using their newly-acquired wheelchairs and mobility aids.

A two-dimensional CAT-PCA scaling test was used to analyse the relevance and interrelationship between items M1 to M15. The results are presented in Tables (60) and (61). Table (60) shows that 63% of the variance was explained by the solution.

Table 60: Summary of a two-dimensional solution of the variables M1 to M15

Dimension	Cronbach's Alpha	Variance Accounted For	
		Total (Eigenvalue)	% of Variance
1	.910	6.645	44.302
2	.680	2.742	18.277
	.957	9.387	62.579

Table 61: Component loadings and relationships of variables M1 to M15

	Dimension	
	1	2
M1 Your physical disability	.356	-.277
M2 Steps to your dwelling	.626	-.547
M3 Not enough special disabled parking bays	.492	-.608
M4 Ramps to buildings in the community	.724	-.092
M5 Incline of ramps too steep	.662	-.070
M6 Inaccessible toilets in public buildings	.850	.071
M7 Pavement steps	.762	-.441
M8 Rough terrain on pavement surfaces	.698	-.396
M9 Shop, post office and bank counters too high	.877	.204
M10 Entrance to shops inaccessible	.798	.379
M11 Check-out counters at shops inaccessible	.798	.246
M12 Public telephones too high	.840	.354
M13 Autobanks too high	.608	.546
M14 Transport	.019	.642
M15 Fear of criminals	.115	.739

SECTION R

DISABLED PERSONS' KNOWLEDGE OF PATIENTS' RIGHTS AND RESPONSIBILITIES

- | | | |
|--|----------------------------------|------------------------------|
| 1. Are you aware that there is a Disability Rights Charter of South Africa which is a document which declares that all disabled people have the right to live independently in a safe environment and in a society which is free from all forms of discrimination, exploitation and abuse? | Yes ¹ No ² | <input type="checkbox"/> R1 |
| 2. Do you know that Mr. Joseph Williams works for the Unicity Disability Desk in Cape Town and that he is there specially to protect the rights of Disabled People and to monitor gender issues? | Yes ¹ No ² | <input type="checkbox"/> R2 |
| 3. Are you aware that there is a new law called the Employment Equity Act which encourages people with disabilities to get employed? | Yes ¹ No ² | <input type="checkbox"/> R3 |
| 4. Are you aware that if people with disabilities are employed their employee has the responsibility of ensuring that they receive the same benefits and development opportunities as the able-bodied employees? | Yes ¹ No ² | <input type="checkbox"/> R4 |
| 5. Are you aware that every patient has the right to: | | |
| A healthy and safe environment? | Yes ¹ No ² | <input type="checkbox"/> R5 |
| Participate in decision-making affecting your own health? | Yes ¹ No ² | <input type="checkbox"/> R6 |
| Receive emergency health care at a facility that is open regardless of whether you can pay? | Yes ¹ No ² | <input type="checkbox"/> R7 |
| Treatment and rehabilitation? | Yes ¹ No ² | <input type="checkbox"/> R8 |
| Special needs? | Yes ¹ No ² | <input type="checkbox"/> R9 |
| Counselling? | Yes ¹ No ² | <input type="checkbox"/> R10 |
| A positive attitude by health care providers? | Yes ¹ No ² | <input type="checkbox"/> R11 |
| Health information? | Yes ¹ No ² | <input type="checkbox"/> R12 |
| Know the name of the health care provider who treats you? | Yes ¹ No ² | <input type="checkbox"/> R13 |
| Confidentiality and privacy concerning your health? | Yes ¹ No ² | <input type="checkbox"/> R14 |
| Full and accurate information regarding your health? | Yes ¹ No ² | <input type="checkbox"/> R15 |
| Refusal of treatment? | Yes ¹ No ² | <input type="checkbox"/> R16 |
| Continuity of health care? | Yes ¹ No ² | <input type="checkbox"/> R17 |
| Complain about health services? | Yes ¹ No ² | <input type="checkbox"/> R18 |
| 6. Do you know that every patient has the following responsibilities? | | |
| To take care of your own health? | Yes ¹ No ² | <input type="checkbox"/> R19 |
| To care for and protect the environment? | Yes ¹ No ² | <input type="checkbox"/> R20 |
| To respect the rights of other patients and health providers? | Yes ¹ No ² | <input type="checkbox"/> R21 |
| To utilise the health care system and not abuse it? | Yes ¹ No ² | <input type="checkbox"/> R22 |
| To know your local health services and what they offer? | Yes ¹ No ² | <input type="checkbox"/> R23 |
| To provide health care providers with the relevant and accurate information for treatment and rehabilitation purposes? | Yes ¹ No ² | <input type="checkbox"/> R24 |
| To comply with the prescribed treatment and rehabilitation procedures? | Yes ¹ No ² | <input type="checkbox"/> R25 |
| To take care of health records in your possession? | Yes ¹ No ² | <input type="checkbox"/> R26 |

SECTION R

DISABLED PERSONS' KNOWLEDGE OF PATIENTS' RIGHTS AND RESPONSIBILITIES

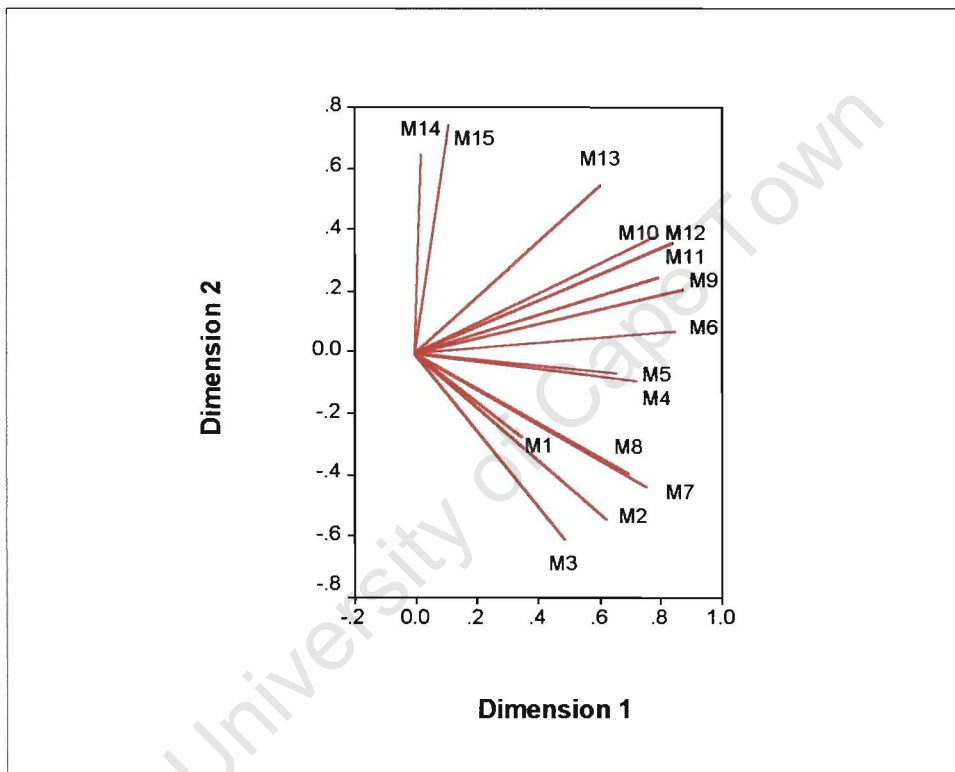
1. Are you aware that there is a Disability Rights Charter of South Africa which is a document which declares that all disabled people have the right to live independently in a safe environment and in a society which is free from all forms of discrimination, exploitation and abuse? Yes ¹ No ² R1
2. Do you know that Mr. Joseph Williams works for the Unicity Disability Desk in Cape Town and that he is there specially to protect the rights of Disabled People and to monitor gender issues? Yes ¹ No ² R2
3. Are you aware that there is a new law called the Employment Equity Act which encourages people with disabilities to get employed? Yes ¹ No ² R3
4. Are you aware that if people with disabilities are employed their employee has the responsibility of ensuring that they receive the same benefits and development opportunities as the able-bodied employees? Yes ¹ No ² R4
5. Are you aware that every patient has the right to:
- A healthy and safe environment? Yes ¹ No ² R5
 - Participate in decision-making affecting your own health? Yes ¹ No ² R6
 - Receive emergency health care at a facility that is open regardless of whether you can pay? Yes ¹ No ² R7
 - Treatment and rehabilitation? Yes ¹ No ² R8
 - Special needs? Yes ¹ No ² R9
 - Counselling? Yes ¹ No ² R10
 - A positive attitude by health care providers? Yes ¹ No ² R11
 - Health information? Yes ¹ No ² R12
 - Know the name of the health care provider who treats you? Yes ¹ No ² R13
 - Confidentiality and privacy concerning your health? Yes ¹ No ² R14
 - Full and accurate information regarding your health? Yes ¹ No ² R15
 - Refusal of treatment? Yes ¹ No ² R16
 - Continuity of health care? Yes ¹ No ² R17
 - Complain about health services? Yes ¹ No ² R18
6. Do you know that every patient has the following responsibilities?
- To take care of your own health? Yes ¹ No ² R19
 - To care for and protect the environment? Yes ¹ No ² R20
 - To respect the rights of other patients and health providers? Yes ¹ No ² R21
 - To utilise the health care system and not abuse it? Yes ¹ No ² R22
 - To know your local health services and what they offer? Yes ¹ No ² R23
 - To provide health care providers with the relevant and accurate information for treatment and rehabilitation purposes? Yes ¹ No ² R24
 - To comply with the prescribed treatment and rehabilitation procedures? Yes ¹ No ² R25
 - To take care of health records in your possession? Yes ¹ No ² R26

SECTION M	ENVIRONMENTAL BARRIERS
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	No problem 1	Mild problem 2	Moderate problem 3	Severe problem 4	Complete problem 5	
Your physical disability						M1
Steps to your dwelling						M2
Not enough special disabled parking bays						M3
Ramps to buildings in the community						M4
Incline of ramps too steep						M5
Inaccessible toilets in public buildings						M6
Pavement steps						M7
Rough terrain on pavement surfaces						M8
Shop, post office and bank counters too high						M9
Entrance to shops inaccessible						M10
Check-out counters at shops inaccessible						M11
Public telephones too high						M12
Autobanks too high						M13
Transport						M14
Fear of criminals						M15
Other: specify						M16

Figure (22) reveals three clusters of items. Items M14 and M15 represent 'safety'. Items M3, M2, M1, M7 and M8 appear to refer more to direct barriers in the participants' immediate environment; whereas the remaining items (M4, M5, M6, M9, M10, M11, M12 and M13) refer to public barriers.

Figure 22: Graphical representation of the relationships of the clusters of problems experienced with environmental barriers



Legend of items on opposite page

Three new variables, namely, 'safety', 'direct barriers' and 'public barriers' were composed from these clusters and are presented in Table (62).

Table 62: Environmental barriers classified into groups (N=81)

	No problem	Mild problem	Moderate problem	Complete problem
Safety	30	25	13	13
Direct barriers	18	35	24	4
Public barriers	45	26	7	3

Summary of environmental barriers

Safety was a barrier to the majority of participants, but they found physical barriers in their immediate environment to be even more of a problem. Barriers in the public environment were less of a problem, but was most likely rated as being less of a barrier as many of the participants were unable to leave their homes to attend community activities due to their decreased level of mobility.

The INDS (1997) claims that the disabled should have as much mobility as possible, including access to buildings and means of transport. One of the strategies of the IPDS – PAWC (1998) is to ensure adequate, dedicated budgets for rehabilitation services and assistive devices (Province of the Western Cape, 1998). However, this budget at present is so small it cannot meet the demands of even the most severely disabled people. What is more, the therapists issuing the wheelchairs and mobility aids expect the disabled to pay R100 for their wheelchairs and R20 for their crutches. Many of them from Lotus River were unable to pay this amount out of their DG and so they had to do without them.

SECTION N. ABUSE

Table 63: Frequency of ratings of various forms of abuse experienced (N=81)

		N/A	No problem	Mild problem	Moderate problem	Severe problem	Complete problem
As a disabled child	Physical abuse by other children	61	19				1
	Psychological abuse by other children	61	18	1			1
	Sexual abuse by other children	61	20				
	Physical abuse by community persons	61	19				1
	Psychological abuse by community persons	61	19				1
	Sexual abuse by community persons	61	20				
	Physical abuse by a family member	61	20				
	Psychological abuse by a family member	61	19	1			
	Sexual abuse by a family member	61	20				
	Other form of abuse	61	19	1			
As a disabled adult	Physical abuse by community persons		78	2			1
	Psychological abuse by community persons		75	3	3		
	Sexual abuse by community persons		79	2			
	Physical abuse by a family member		78	2			1
	Psychological abuse by a family member		76	1	3		1
	Sexual abuse by a family member		80	1			
	Other form of abuse		78	3			

In Table (63), the frequency of the rating of the categories of the various forms of abuse experienced by the participants are presented. Only 20 participants rated items referring to 'abuse as a disabled child' as the remaining 61 participants had become disabled after they had reached adulthood. In total seven of these 20 participants had experienced some form and extent of abuse as a child. The psychological abuse was described as teasing about their disability and the

physical abuse was bullying. However, not one participant reported any form of sexual abuse as a child.

The Constitution of the Republic of South Africa (1996: 11) states that "Every child shall have the right to security, basic nutrition and basic health services and not to be subject to neglect, abuse or child labour" and the Children's Charter of South Africa (1996: 8) claims that "All children have the right to be protected from all types of violence including: physical, emotional, verbal, psychological, sexual, state, political, gang, domestic, school township and community, street, racial, self-destructive and all other forms of violence". One of the strategies of The White Paper for Social Welfare (1997) with regard to The Family and the Life Cycle also makes provision for "The development of a comprehensive national plan for the protection of children against violence and abuse" (Ministry for Welfare and Population Development, 1997: 65).

Twenty-three out of 81 (28%) of the participants experienced some form of problem with the remaining items which referred to abuse experienced as an adult. However, there was one participant who reported a 'mild problem' with item N38 which referred to sexual abuse by a family member. Studies in the UK, USA and India show that women with disabilities are equally vulnerable to sexual abuse as other women (Lonsdale, 1990; Confederation of Indian Organisations, 1988; Fine and Asch, 1988; Ryerson, 1981) and in Lebanon research has found that women with disabilities and girls are even more vulnerable to sexual abuse (Abu-Habib, 1997; Boukhari, 1997). The White Paper for Social Welfare (1997) recognises that a strategy for violence against women needs to be "devised to counteract all forms of abuse of and violence against women ... will create a national consciousness that abuse of and violence against women is unacceptable" (Ministry for Welfare and Population Development, 1997: 74).

With the Education White Paper 6's commitment to transforming the education and training system so that it can contribute to "... to establishing a caring and

humane society” (Department of Education, 2001: 11), the types of abuse experienced by children and adults should decrease as the children become sensitised to the needs of the disabled through the new curriculum.

Table (64) identifies those participants who believed the items referring to abuse during childhood were applicable. Two participants indicated that they had experienced problems. Participant 1 had experienced ‘mild problems’ with ‘sexual abuse by other children’ (N3), ‘psychological abuse by a family member’ (N15) and ‘other form of abuse’ (N19). Participant 27 had experienced a ‘complete problem’ with ‘physical abuse by other children’ (N1), ‘sexual abuse by other children’ (N3), ‘physical abuse by community persons’ (N7) and ‘psychological abuse by community persons’ (N9).

Table 64: Severity of forms of abuse during childhood

Participant	Mild problems	Complete problem
1	N3, N15, N19	
2		
4		
5		
7		
8		
10		
12		
13		
14		
15		
17		
18		
20		
23		
24		
25		
27		N1, N3, N7, N9
28		
29		

Legend of items on opposite page

Thirteen of the participants reported that they had suffered some form of abuse as an adult (Table 65).

Table 65: Severity of different forms of abuse as an adult

Participants	Mild problems	Moderate problem	Complete problem
3			N34, N36
4		N30	
6	N30		
9	N28, N32, N34	N36	
11	N30		
12	N28		
14	N40	N36	
15	N40	N36	
16		N30	
19	N34		N28
21	N36		
22	N30, N32, N38, N40		
26		N30	

Legend of items on opposite page

Summary of abuse experienced by participants

Thirty out of 81 (37%) participants experienced some form of abuse in childhood and adulthood. As there are no reliable statistics available on the prevalence of abuse in the non-disabled population no conclusions of the extent of this problem compared to the general population can be drawn from these data.

SECTION P. DISCRIMINATION

In Table (66) the frequencies of the various items referring to discrimination are presented as 'yes' or 'no' or 'not applicable' responses. 'Not applicable' refers to the people who became disabled during adulthood only.

Table 66 : Discrimination experienced by disabled during childhood (N=81)

	Discrimination		
	N/A	Yes	No
P1 Did your family try to hide you from the community?	61	2	18
P2 Were you given the same schooling as your sisters?	61	14	6
P3 Were you given the same schooling as your brothers?	61	14	6
P4 Were you treated the same as your sisters?	61	16	4
P5 Were you treated the same as your brothers?	61	16	4

Table (66) indicates that there was discrimination experienced by two of the participants when they were children and their families tried to prevent the community from seeing them. This form of isolation is well documented (Thomas and Thomas, 2002; Abu-Habib, 1997; Hema, 1996; Deegan and Brooks, 1985; Franklin, 1977).

The fact that they did not receive the same schooling as their siblings (items P2 and P3) may be due to the fact that, during the 'apartheid' government children of colour with disabilities did not have the same accessibility to special schools and most of them were unable to attend non-disabled schools as they had no transport or their disabilities were sufficiently severe for them not to be able to cope without special assistance. However, there does not appear to have been any sexual discrimination as they rated items P4 and P5 in the same way. There is little literature from developing countries regarding discrimination in these areas apart from that found in the Middle East where it was found that girls with disabilities were more discriminated against than boys when it came to education and limited resources (Abu-Habib, 1997).

Summary of discrimination

There is some evidence that there were attempts to keep two of the disabled children out of sight of the community, but there does not appear to have been any sexual discrimination in the way in which they were treated in general.

SECTION Q. DECISION-MAKING

The frequencies of responses to three items referring to caring and decision-making are presented in Tables (67) – (69). Table (67) refers to the main person who cared for the person during childhood. Table (68) refers to the person who made the decisions about the education, medical treatment and home rules of the participants. Table (69) refers to who made the decisions regarding the participants in their adulthood.

Table 67: Main carer during childhood

	Frequency	Percent
Mother	20	100.0
Other	0	0.0
Total	20	100.0

Table 68: Decision-maker of disabled person during childhood

	Frequency	Percent
Father	5	25.0
Father and Mother	1	5.0
Mother	14	70
Total	20	100.0

Table 69: Decision-maker of disabled person as an adult

	Frequency	Percent
Self	15	75.0
Spouse	2	10.0
Father and mother	1	5.0
Mother	2	10.0
Total	20	100.0

Summary of decision-making

Although research has shown that adults with disabilities frequently do not have independence in decision-making (Abu-Habib, 1997; Lonsdale, 1990), this was not the case in Lotus River. As can be seen from Table (69), 75% of the people made their own decisions. In the situations where the 'spouse' or 'father and mother' or 'mother' made the decisions, the participants did not have the cognitive ability to make any major decisions themselves.

State how much of a problem the following have been for you as a disabled adult?

	No problem 1	Mild problem 2	Moderate problem 3	Severe problem 4	Complete problem 5	
Physical abuse by community persons						N28
Psychological abuse by community persons						N30
Sexual abuse by community persons						N32
Physical abuse by a family member						N34
Psychological abuse by a family member						N36
Sexual abuse by a family member						N38
Other form of abuse						N40

SECTION N	ABUSE
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People with disabilities are often abused sometime during their lives. This abuse can take the form of physical, emotional or psychological abuse.

State how much of a problem the following have been for you as a disabled child?

	N/A 0	No problem 1	Mild problem 2	Moderate problem 3	Severe problem 4	Complete problem 5	
Physical abuse by other children							N1
Psychological abuse by other children							N3
Sexual abuse by other children							N5
Physical abuse by community persons							N7
Psychological abuse by community persons							N9
Sexual abuse by community persons							N11
Physical abuse by a family member							N13
Psychological abuse by a family member							N15
Sexual abuse by a family member							N17
Other form of abuse							N19

More than seventy percent of them did not know about the Unicity Disability Desk in Cape Town (R2), Employment Equity Act (R3) or the benefits and development opportunities of disabled employees (R4).

Approximately 50% were not knowledgeable about patients' rights (R5 – R26) (See legend on opposite page). Although some participants responded 'yes' to the items, on further questioning they did not realise the implications of the items and the impact that they could have on their lives.

The interview provided an appropriate opportunity for the researcher to empower the participants by engaging them in discussions and providing them with an explanation of all of the items relating to their rights and responsibilities to help and encourage them to participate in decisions on health, welfare and disability policies and programmes.

Disabled persons' knowledge of HIV/AIDS

Table 71: Disabled people's knowledge of HIV/AIDS (N=81)

	Missing	Yes	No
R27 Do you know about HIV/AIDS?	9	57	15
R28 Do you know what causes HIV/AIDS?	9	48	24
R29 Does HIV+ mean that the person has the virus or does not have the virus?	9	51	21

Item R27 shows that 15 (21%) participants who were able to respond did not know anything about HIV/AIDS (Table 71). When questioned during the interview they stated that they had heard the words being mentioned on the radio or television (TV). However, they did not know anything about the disease process itself or about the extent of the pandemic in South Africa.

Twenty-four (34%) did not know how HIV/AIDS was caused and 21 (29%) thought being HIV+ was a good thing because it meant that the person did not have the HIV virus. It appears that these people associated the words HIV+ with the pictures of a healthy diet on the posters in the clinics.

Table 72: Sources from which disabled learned about HIV/AIDS

	Frequency	Percent	Cumulative Percent
1	32	39.5	39.5
1,2	3	3.7	43.2
1,2,3	2	2.5	45.7
1,2,3,4	1	1.2	46.9
1,2,3,4,5	1	1.2	48.1
1,3	4	4.9	53.1
1,3,4	1	1.2	54.3
1,3,4,5	1	1.2	55.6
1,4	1	1.2	56.8
2	13	16.0	72.8
2,3	3	3.7	76.5
2,4	2	2.5	79.0
3	1	1.2	80.2
3,4	1	1.2	81.5
3,5	1	1.2	82.7
4	1	1.2	84.0
4,5	1	1.2	85.2
5	3	3.7	88.9
Missing	9	11.1	100.0
Total	81	100.0	

Legend: 1 TV 2 Radio 3 Clinic 4 Church 5 Other

Table (72) presents the combinations of sources from which the participants claimed to have learned about HIV/AIDS. As can be seen from the table the majority of them were exposed to the information from a variety of sources.

The sources listed under 'other' were books, magazines and workshops offered by social groups.

Table 73: Frequency of obtaining information about HIV/AIDS from the different sources

Sources	Frequency
TV	46
Radio	25
Clinic	13
Church	10
Other	7

Table (73) shows the frequency of sources from which the participants obtained their information. 'TV' was rated the most frequently and 'other' in the form of books, magazines and workshops was rated the least. It was obvious to the researcher that television played a very important part in the lives of the people in Lotus River. There was a television set seen in almost every home, including the backyard shacks which had electricity supplied. As there was very little entertainment offered in the suburb most people spent their evenings watching TV and, therefore, it is not unexpected that this was from where their information on HIV/AIDS was obtained.

As the younger participants had either never attended a school or had left school more than seven years ago it is not surprising that nobody had mentioned school as a source of information under 'other'.

The Education White Paper 6 identifies the need for HIV/AIDS to be incorporated in the curriculum and the importance of mechanisms to provide teacher support in its inclusive education and training system (Department of Education, 2001). The school programmes will be aimed at increasing knowledge of HIV prevention and transmission in order to reduce HIV-related risk behaviour. For the past two years one of South Africa's well-known and popular satirists, Pieter-Dirk Uys, has toured the country visiting schools in low-income and rural areas educating the learners about HIV/AIDS in a direct, humorous and appealing way. He has also produced a video called "Survival Aids" focussing on the fears and denials

associated with the current pandemic which is being distributed to all schools (Cape Argus, 22.11.2003). At the same time, AIDS campaigner, Zackie Achmat has been calling for condoms to be made available to learners at school as at some schools the HIV infection rate was up to 30% (Caelers, 2003b). Studies have shown that while preventative educational programmes can effectively reduce risky behaviour among youths (Rotheram-Borus et al, 2001; Walters, 1999), other options like implementing outreach programmes in high-risk neighbourhoods need to be developed (Akukwe, 2001; Dryfoos, 1990). As the findings show in Table (73) this is already taking place in the clinics and churches in Lotus River. Gorgen et al (1998) and Walters (1999) recommend that peer involvement and group counselling are effective methods of addressing HIV/AIDS and sexual concerns of youths and should be accommodated in school settings.

Summary of disabled participants' knowledge of their rights and responsibilities

Generally, the participants were not aware of their rights and responsibilities.

Although 66% of the participants knew about HIV/AIDS through TV, radio, clinics, church programmes and magazines, 34% did not know how HIV/AIDS was caused. This has serious implications on the population at large as many of the people with disabilities were leading an active sexual life which means that they were unaware of the necessity of using condoms as a means of prevention.

Disabled people are frequently thought of as being asexual and are, therefore, excluded from educational programmes on HIV/AIDS. However, they actually need additional education and support with regards to the use of condoms. Some of them need to be taught how to apply a condom with one hand only while others who may not have the use of either hand need counselling on how to approach their partners to apply a condom for them. Education of the disabled in

SECTION S	CARER
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Name

- | | | | |
|---|---------------------|------------------------------------|-------------------------------------|
| 1. Gender: | Male ¹ | Female ² | S1 |
| 2. Age: | | | S2 |
| 3. Are you the major carer? | Yes ¹ | No ² | S3 |
| 4. What is your relationship to the person with the disability? | | | |
| | Spouse ¹ | Child/child-in-law ² | Sibling/sibling-in-law ³ |
| | Friend ⁵ | Other ⁶ : specify | |
| | | Parent/parent-in-law ⁴ | S4 |
| 5. Do you stay in the same household as the disabled person? | Yes ¹ | No ² | S5 |
| 6. Are you employed? | Yes ¹ | No ² | S6 |
| 7. Do you receive a "grant-in-aid" from the Social Services Department? | Yes ¹ | No ² | S7 |
| 8. For how many years have you cared for the disabled person? | | | S8 |
| 9. Did you have to leave your job specially to stay at home and care for the disabled person? | Yes ¹ | No ² | S9 |
| 10. With which of the following tasks do you assist the disabled person? | | | |

these matters is essential if the problem of reducing the incidence of HIV/AIDS in the country is to be taken seriously by the government.

Details of the caregivers with regard to their age; tasks they were required to perform for the disabled; and their level of burden are presented in Section S.

SECTION S. CAREGIVER

The frequencies of the responses to the items regarding the carers of the people with disabilities are presented in Table (74). The 36 participants listed as 'missing' were those of the participants who did not require a carer.

For ease of interpretation the table should be read while referring to the individual items S1 to S10 on the opposite page. For example, item S1 shows that the carers comprised five males and 40 females. There were 23 carers who had cared for the person with disabilities for more than six years (item S1).

Table 74: Responses of the carers of the disabled (N=81)

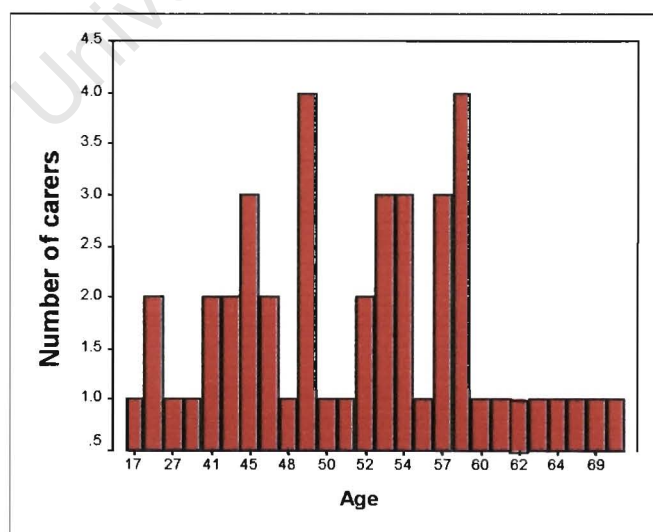
	Missing	Categories					
		1	2	3	4	5	6
S1 Gender	36	5	40				
S3 Are you the major carer?	36	39	6				
S4 Relationship to disabled person	36	20	4	7	7	3	4
S5 Do you live in the same household as the disabled?	36	34	11				
S6 Are you employed?	36	2	43				
S7 Do you receive a 'grant-in-aid'?	36	4	41				
S8 How many years have you cared for the disabled person?	36	4	8	3	2	2	3
S9 Did you leave your job to care for the disabled person?	36	13	32				

Legend of items on opposite page

As can be seen in Table (74) 13 caregivers had to leave their jobs in order to stay at home to take care of their disabled relatives. This was also found in other research on caregivers in SA (Petersen, 1991). One of the strategies proposed by The White Paper for Welfare and Population Development (1997) for social security for people with disabilities is that “Options will be explored to provide financial support for home care-givers in respect of people with disabilities. An investigation will be conducted to assess care dependency and grants-in-aid” (Ministry for Welfare and Population Development, 1997: 54) and “Options such as employment opportunities and financial support should be fully explored” (Ministry for Welfare and Population Development, 1997: 75). It recognises that “there is a shortage of day care facilities for children with disabilities, particularly after the preschool phase” (Ministry for Welfare and Population Development, 1997: 59).

Figure (23) shows the ages of the carers. The average age was 50 years and the average number of hours that they spent in caring for the disabled person was 11 hours. Twenty-four of the 45 (43%) carers were involved in caring activities for more than eight hours per day (Table 76).

Figure 23: Age distribution of the caregivers (N=45)



As shown in Table (75) the nature and frequency of the tasks with which they assisted the disabled involved a great deal of physical effort, namely, bathing; getting on and off the toilet; getting in and out of bed and their wheelchairs; and assistance with walking.

Table 75: Nature and frequency of the rating of the tasks with which the carer assisted the disabled person (N=81)

	Missing	Not at all	Seldom	Sometimes	Often	Always	Supervise only
Eating	36	20	4	3	2	12	4
Bathing/showering	36	12	2	4	2	22	3
Personal hygiene	36	15	4	3	4	17	2
Getting on and off toilet	36	22	0	4	1	17	1
Dressing	36	17	2	6	3	14	3
Getting in and out of bed	36	20	3	4	1	15	2
Getting in and out of wheelchair	36	9	4	5	5	19	3
Giving medication	36	12	3	4	3	20	3
Doing errands	36	6	1	2	6	28	2
Walking	36	9	3	4	2	26	1
Shopping	36	2	1	1	7	32	2
Housework	36	1	0	2	4	36	2
Preparing meals and cooking	36	0	1	3	3	37	1
Laundry	36	3	0	4	2	35	1
Collecting grant	36	11	1	2	1	29	1
Listening and talking	36	2	1	2	8	31	1
Other: specify	36	0	1	1	16	27	0

The number of hours spent on caring tasks is presented in Table (76). The average number of hours per day spent on caring was 11 hours.

Table 76: The number of hours per day the carers spent caring for the disabled participants

Hours	Frequency	Percent
1	3	3.7
2	4	4.9
3	2	2.5
4	3	3.7
5	4	4.9
6	2	2.5
7	1	1.2
8	2	2.5
9	1	1.2
10	2	2.5
12	3	3.7
13	1	1.2
14	1	1.2
15	1	1.2
18	4	4.9
20	1	1.2
23	1	1.2
24	9	11.1
Missing	36	44.4
Total	81	100.0

In response to the item referring to whether the 'carer had received any training' in how to care for the person with disabilities, three caregivers (almost 4%) responded 'no' and the remaining 42 (52%) responded 'yes'. Training comprised a session with a physiotherapist or occupational therapist in a hospital or clinic on how to assist the disabled persons with their activities of daily living and how to perform maintenance exercises to prevent contractures and stiffness. None of the training sessions were carried out in the home environment.

Level of caregiver burden

Table 77: Caregivers rating of level of burden (CBS) (N=45)

Items	No	Seldom	Some times	Often
General strain				
Do you find yourself facing practical problems in the care of your relative that you think are difficult to solve?	25	10	8	2
Do you think you have to take too much responsibility for your relative's welfare?	24	8	11	2
Do you sometimes feel as if you would like to run away from the entire situation you find yourself in?	18	6	18	3
Do you feel tired and worn out?	14	5	13	13
Do you feel tied down by your relative's problems?	29	3	8	5
Do you find it mentally tiring to take care of your relative?	26	3	10	6
Do you think your own health has suffered because you have been taking care of your relative?	26	5	8	6
Do you think you spend so much time with your relative that you do not have enough time for yourself?	27	6	8	4
Isolation				
Do you avoid inviting friends and acquaintances home because of your relative's problem?	32	3	8	2
Has your social life, e.g. with family and friends, been reduced?	28	2	11	4
Has your relative's problem prevented you from doing what you had planned to do in this phase of your life?	28	4	10	3
Disappointment				
Do you feel that life has treated you unfairly?	28	6	8	3
Did you expect that your life would be different from what it is at your age?	22	10	9	4
Do you feel lonely and isolated because of your relative's problem?	30	5	8	2
Do you find it physically tiring to take care of your relative?	20	5	11	9
Have you had to make financial sacrifices because you have been taking care of your relative?	24	6	6	9
Emotional involvement				
Are you sometimes ashamed or embarrassed by your relative's behaviour?	31	10	4	0
Do you ever feel hurt and angry with your relative?	29	8	7	1
Do you feel embarrassed by your relative's behaviour?	33	9	3	0
Environment				
Does the physical environment make it difficult for you to take care of your relative?	24	3	11	7
Do you worry about not taking care of your relative in the proper way?	27	5	9	4
Is there anything in the neighbourhood which makes it difficult for you to take care of your relative?	32	4	7	2

Table (77) gives the ratings of the carer on items referring to the level of burden he/she experienced.

The Cronbach Alpha coefficient based on 45 carers and 22 items measuring caregiver burden was 0.95 showing a high level of internal consistency and suggested a one-dimensional relationship between the items.

The first subset, S35 to S42 referred to 'general strain'; the second subset, S43 to S45 to 'isolation'; the third subset, S46 to S50 to 'disappointment'; the fourth subset, S51 to S53 to 'emotional involvement'; and the last subset, S54 to S56 to 'environment'. For ease of analysis these subsets were first recoded into three rating categories and then transformed into five additive scales as presented in Table (78).

Table 78: Frequency of rating aggregated caregiver burden scores (N=45)

	Caregivers' Burden		
	None	Occasionally	Often
General strain	19	15	11
Isolation	26	9	10
Disappointment	25	10	10
Emotional involvement	28	14	3
Environment	21	16	8

The relationship between these five variables and the number of hours spent looking after the person with a disability were examined further. The results are presented graphically in Figures (24) to (28) respectively.

Figure 24: Relationship between mean hours of caring and 'strain'

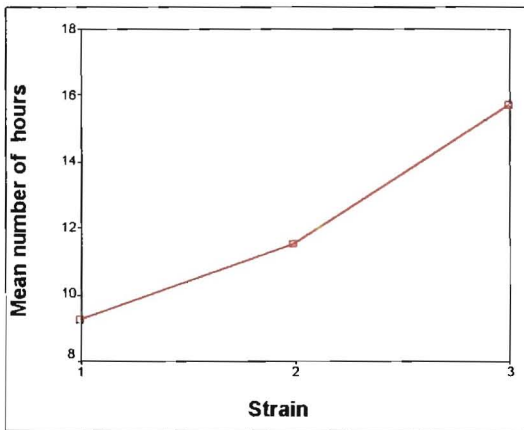


Figure 25: Relationship between mean hours of caring and 'isolation'

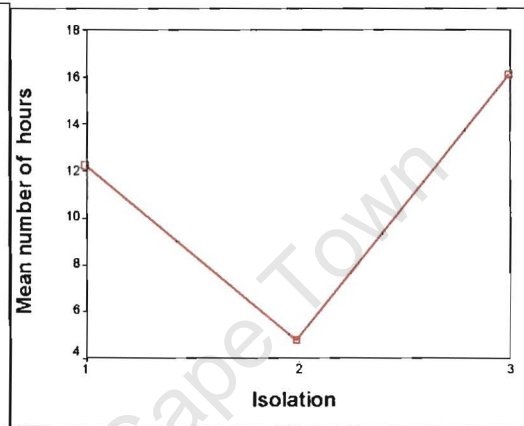


Figure 26: Relationship between mean hours of caring and 'disappointment'

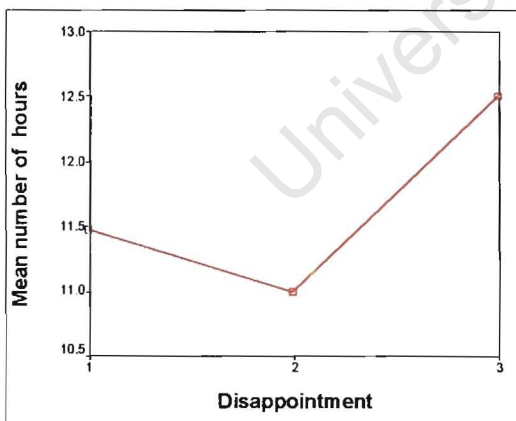


Figure 27: Relationship between mean hours of caring and 'emotional involvement'

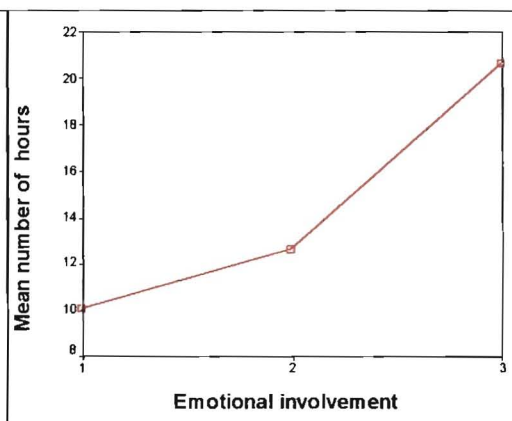
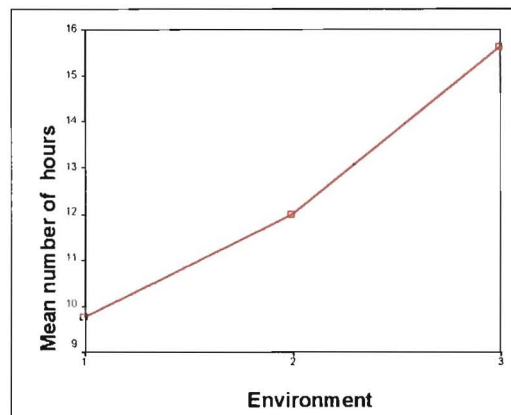


Figure 28: Relationship between mean hours of caring and 'environment'



The levels of 'strain' appear to increase with the average amount of time of looking after the person with disabilities. However, using the F-test the range was too large to reach statistical significance: $F_{(2,46)}=2.184$. The same applied to 'emotional involvement': $F_{(2,44)}=2.46$. The only variable to reach statistical significance was 'isolation': $F_{(2,44)}=5.40$. The results are presented in Tables (79) to (81). Taylor et al (1995) and Askham (1992) found that there was a strong correlation between the number of hours spent on caring and the level of strain experienced.

Table 79: Levels of 'strain' per mean number of hours of caring (N=45)

	N	Mean hours	Standard Deviation	95% Confidence Interval for Mean	
Level of strain				Lower Boundary	Upper Boundary
None	19	9.26	8.52	5.16	13.37
Occasionally	15	11.53	9.52	6.26	16.81
Often	11	15.73	4.73	12.55	18.91

MOTHER OF A CHILD WITH DISABILITIES

Do you blame yourself for the birth of your child with disabilities?

Yes ¹ No ²

Do you feel your husband/partner and his family blame you for the birth of your child with a disability?

Yes ¹ No ²

Are you blamed, shamed or stigmatised by the community because of the birth of your child with disabilities?

Yes ¹ No ²

Because you have a child with a disability do you find that your husband/partner excludes you from social activities?

Yes ¹ No ²

Because you have a child with a disability do you find that:

- your family excludes you from social activities?

Yes ¹ No ²

- the community excludes you from social activities?

Yes ¹ No ²

Table 80: Levels of 'emotional involvement' per mean number of hours of caring (N=45)

Emotional involvement	N	Mean hours	Standard Deviation	95% Confidence Interval for Mean	
				Lower Boundary	Upper Boundary
None	28	10.11	8.79	6.70	13.52
Occasionally	14	12.64	6.87	8.68	16.61
Often	3	20.67	5.77	6.32	35.01

Table 81: Levels of 'isolation' per mean number of hours of caring (N=45)

Environment	N	Mean hours	Standard Deviation	95% Confidence Interval for Mean	
				Lower Boundary	Upper Boundary
None	26	12.23	9.29	8.48	15.98
Occasionally	9	4.78	3.07	2.42	7.14
Often	10	16.10	5.00	12.52	19.68

Mother of a child with disabilities

There were only four mothers who had children born with disabilities. All the responses to items S57 to S62 (legend of items on opposite page) were rated as 'no' by the four mothers. These findings are contrary to the results of studies in other countries where it was found that mothers of children with disabilities lived in isolation and anonymity and were segregated from the community (Boylan, 1991; Lonsdale, 1990; Franklin, 1977). Sometimes this was because their disability was regarded as being contagious or inherited (Peters, 1982).

Needs of carers

In Table (82), items associated with problems that challenge the carers are presented.

Table 82: Frequency of rating items related to problems of caregiver (N=45)

	No problem	Mild problem	Moderate problem	Severe problem	Complete problem
Lack of money	10	11	6	3	15
Having nobody to assist you with caring for the disabled person	25	10	2	2	6
Having nobody to assist you with housework and shopping	24	10	6	1	4
No personal time	33	6	1	3	2
Loneliness	31	6	4	1	3

The 'lack of money' is seen to be the biggest problem by 33% of the carers whereas having 'no assistance', 'no personal time' and 'loneliness' are problematic to only a small number of them.

Summary of caregivers tasks and needs

Caregiving tasks have a major impact on the lives of the carers. Many of them had to give up their jobs in order to stay at home to care for disabled relatives. This increased their level of poverty as the Grant-in-aid which some of them received was less than their wages earned. Others had no form of income once they left their jobs.

The nature of the tasks was onerous as the average age of the carer was 50 years and the average number of hours that they spent in caring for the disabled person was 11 hours per day.

The level of burden increased with the number of hours of caring and the extent of their emotional involvement. Social isolation contributed significantly to their burden.

Mothers of children born with disabilities did not experience the same exclusion that has been found in Western countries such as blame by their husband/partner or stigmatisation by the community.

The major problem experienced by the caregivers was lack of money. Loneliness and lack of personal time were problematical to a few of the caregivers only.

SECTION T

CARERS' KNOWLEDGE OF PATIENTS' RIGHTS AND RESPONSIBILITIES

1. Are you aware that there is a Disability Rights Charter of South Africa which is a document which declares that all disabled people have the right to live independently in a safe environment and in a society which is free from all forms of discrimination, exploitation and abuse? Yes ¹ No ² R1
2. Do you know that Mr. Joseph Williams works for the Unicity Disability Desk in Cape Town and that he is there specially to protect the rights of Disabled People and to monitor gender issues? Yes ¹ No ² R2
3. Are you aware that there is a new law called the Employment Equity Act which encourages people with disabilities to get employed? Yes ¹ No ² R3
4. Are you aware that if people with disabilities are employed their employee has the responsibility of ensuring that they receive the same benefits and development opportunities as the able-bodied employees? Yes ¹ No ² R4
5. Are you aware that every patient has the right to:
- A healthy and safe environment? Yes ¹ No ² R5
 - Participate in decision-making affecting your own health? Yes ¹ No ² R6
 - Receive emergency health care at a facility that is open regardless of whether you can pay? Yes ¹ No ² R7
 - Treatment and rehabilitation? Yes ¹ No ² R8
 - Special needs? Yes ¹ No ² R9
 - Counselling? Yes ¹ No ² R10
 - A positive attitude by health care providers? Yes ¹ No ² R11
 - Health information? Yes ¹ No ² R12
 - Know the name of the health care provider who treats you? Yes ¹ No ² R13
 - Confidentiality and privacy concerning your health? Yes ¹ No ² R14
 - Full and accurate information regarding your health? Yes ¹ No ² R15
 - Refusal of treatment? Yes ¹ No ² R16
 - Continuity of health care? Yes ¹ No ² R17
 - Complain about health services? Yes ¹ No ² R18
6. Do you know that every patient has the following responsibilities?
- To take care of your own health? Yes ¹ No ² R19
 - To care for and protect the environment? Yes ¹ No ² R20
 - To respect the rights of other patients and health providers? Yes ¹ No ² R21
 - To utilise the health care system and not abuse it? Yes ¹ No ² R22
 - To know your local health services and what they offer? Yes ¹ No ² R23
 - To provide health care providers with the relevant and accurate information for treatment and rehabilitation purposes? Yes ¹ No ² R24
 - To comply with the prescribed treatment and rehabilitation procedures? Yes ¹ No ² R25
 - To take care of health records in your possession? Yes ¹ No ² R26

SECTION T. CARER'S KNOWLEDGE OF THE DISABLED PERSONS' RIGHTS AND RESPONSIBILITIES

Table (83) represents the responses of caregivers to items referring to their knowledge of various aspects of patients' rights and responsibilities .

Table 83: Caregivers knowledge of rights and responsibilities (N=45)

	Caregivers responses to items	
	Yes	No
T1	25	20
T2	5	40
T3	10	35
T4	11	34
T5	26	19
T6	24	21
T7	27	18
T8	28	17
T9	27	18
T10	28	17
T11	29	16
T12	28	17
T13	29	16
T14	28	17
T15	28	17
T16	26	19
T17	29	16
T18	29	16
T19	24	21
T20	24	21
T21	25	20
T22	23	22
T23	24	21
T24	24	21
T25	24	21
T26	25	20

Legend of items on opposite page

The responses to these items was similar to those of the disabled. More than seventy percent of them did not know about the Unicity Disability Desk in Cape

Town (R2), Employment Equity Act (R3) or the benefits and development opportunities of disabled employees (R4).

Approximately 50% were not knowledgeable about patients' rights (R5 – R26) and did not realise the implications which these items could impact on their lives.

Carers' knowledge of HIV/AIDS

Table 84: Carers' knowledge of HIV/AIDS (N=45)

	Caregivers responses to items	
	Yes	No
T27 Do you know about HIV/AIDS?	44	1
T28 Do you know what causes HIV/AIDS?	42	3
T29 Does HIV+ mean that the person has the virus or does not have the virus?	38	7

T29 again shows that there is confusion about the term HIV+ and its meaning. During discussions with the participants and carers it appears that the confusion arises from the + sign which they associate with something positive or 'good' (Table 84). Hence when they see the posters with the words 'HIV+' together with pictures of healthy foods, groups of friends talking, people holding hands depicting social relationships they perceive that HIV+ is the desired result.

Table 85: Sources from which caregivers learned about HIV/AIDS

	Frequency	Percent	Cumulative Percent
1	22	48.9	48.9
1,2	2	4.4	53.3
1,2,3	1	2.2	55.5
1,2,3,4	1	2.2	57.7
1,2,3,4,5	2	4.4	62.1
1,3	1	2.2	64.3
1,3,4,5	1	2.2	66.5
2	9	20.1	86.6
3	3	6.7	93.3
5	3	6.7	100.0
Total	45	100.0	

Legend: 1 TV 2 Radio 3 Clinic 4 Church 5 Other

Table 86: Frequency of obtaining information from the different sources

Sources	Frequency
TV	30
Radio	15
Clinic	6
Church	4
Other	6

As expected the frequency of obtaining information on HIV/AIDS from the different sources was similar to that of the people with disabilities (Tables 85 and 86). The most likely reason for 'other' being reported more for the carers than for the people with disabilities is that some of the people with disabilities had much lower levels of education than their carers and, therefore, did not read magazines or books as frequently as the carers.

Summary of carers' knowledge of disabled persons' rights and responsibilities

Generally, the participants were not aware of the disabled' rights and responsibilities.

Although their knowledge of HIV/AIDS was greater than that of the disabled there were still carers who had no knowledge of it and there was also confusion about the meaning of HIV+. Thus education programmes are still not reaching many people in the country although they have been recognised as being the most effective method of managing the disease. The approach of the Ministry for Welfare and Population Development (1997) to the management of the HIV/AIDS pandemic affecting South Africa is to provide "Appropriate and innovative education and prevention programmes as well as social services ..." (Ministry for Welfare and Population Development, 1997: 90). The RDP (1994) and the Constitution of the Republic of South Africa (1996) both provide for "Mass education programmes which involve the mass media, schools and community organizations" as a means of combating the disease (ANC, 1994).

4.4 EVALUATION OF WHEELCHAIRS, MOBILITY AIDS AND ASSISTIVE DEVICES BY THE DISABLED AND THEIR CAREGIVERS

Verbatim transcripts of the interviews conducted with the disabled and their carers six months after receiving wheelchairs and appliances are provided below. The questions they were asked by the research assistant appears in Appendix (viii).

Forty-seven of the forty-eight recipients described how their quality of life had improved. The difference that the wheelchairs, mobility aids, assistive devices and appliances made to their lives were analysed and are presented in general categories in Table (87). The categories are not mutually exclusive as the appliances frequently affected more than one category.

Table 87: Impact of appliances on the quality of life of the disabled

Category	Number of participants
Increased independence	42
Increased socialisation	31
Increased accessibility	38
Decreased level of pain	10
Increased psychological well-being	39

The responses of the 45 caregivers are presented in Table (88).

Table 88: Impact of appliances on the quality of life of the caregiver

Category	Number of participants
Decreased dependence of disabled	25
Increased time for other responsibilities	22
Happiness for well-being of the disabled	37
Personal psychological well-being	29
Decreased physical workload	21

In most instances the improvements could not be measured by scales as the level of function, socialisation, workload and general health would not have demonstrated any significant improvement. However, their words describe and reveal the precise beneficial effects the appliances had made on their quality of life. Had the content of the evaluation feedback only been categorised a great deal of qualitative information would have been lost as each participant's life was improved in a unique way that was important to them personally, according to their housing environment, family situations and physical disabilities. For this reason the transcripts are presented in full to demonstrate that, at this high level of disability experiences of one person with a disability could not be generalised to any other group of participants. For example, to one participant increased independence meant having the freedom to propel himself around his home; to a second participant it meant psychological well-being; to a third it meant relief of physical burden to her caregiver; to a fourth it means increased opportunity for socialisation; and to a fifth it meant a means of attending a clinic appointment.

Caregiver 1

What difference has this made to your daily life? "I am so grateful for the wheelchair. My mother is very heavy and I used to have to help her to move from her room to the bathroom and to the chair when she wanted to sit outside. Now my work is so much easier and I have a lot of energy to do my house work. I can push her where she wants to go now that there is a pathway. Before there was such thick sand and our backyard shack is so far from the road it was impossible to take her onto the road. Now she can go down the road to friends, to the shops and to church every Sunday. She enjoys going to church so much. It makes me happy to be able to make her happy as she was a very good mother to me when I was young".

Participant 2

Equipment received: wheelchair, cushion and tray; quadruped; grab bars for bath and toilet.

What difference has this made to your daily life? “I can go to church now and I enjoy that so very much. The minister used to come and visit me at home once every month and now I can go to church every Sunday. Now I can walk where I like when I like on my own in the house with the quadruped. I can go to the toilet on my own too because I can use the grab bars”.

Caregiver 2

What difference has this made to your daily life? “Oh, it has made a big difference because I am very busy in the house and used to have to help her to walk wherever she wanted to go. Now she can walk alone inside the house and we can take her to friends and church in the wheelchair. It has been a wonderful opportunity for us in our lives and we are so grateful to the people who gave us the wheelchair and equipment”.

Participant 3

Equipment received: wheelchair, cushion, concrete pathway and ramps.

What difference has this made to your daily life? “I am very grateful for the wheelchair because I can propel myself to my children’s homes or I can propel myself where I want to go around the house and garden. I am very grateful. Do you understand what it means to always have a wheelchair so that you can do what you want to on your own or people can just push you so easily?”.

Caregiver 3

What difference has this made to your daily life? “It has made my life much lighter and I feel so good now that she can enjoy herself more and I can push her to the clinic to see the doctor. She hasn’t been able to go to the clinic for years before she received the wheelchair because we couldn’t get her through the thick sand onto the road”.

Participant 4

Equipment received: wheelchair, cushion and wheelchair tray; concrete pathway and ramps.

What difference has this made to your daily life? “It has been a miracle. My son can push me to the Civic Center to fetch my disability grant and I can go to the shops. And I can also go and sit in the garden now instead of just staying in the shack all day long every day”.

Caregiver 4

What difference has this made to your daily life? “Thank you very much for the wheelchair. It has made my husband so happy and that makes me very happy too. Now he can go outside. He hasn’t been outside for three years since he suffered his stroke. Thank you very much. Thank you very much. The people who did this for us will be blessed by the Lord”.

Participant 5

Equipment received: wheelchair and cushion; bath board; crutches; concrete ramps and pathway.

What difference has this made to your daily life? “The wheelchair is so comfortable and I can wheel myself down the pathway onto the street and down the street to wherever I want to go. Before I received all these things I just used to sit in my backyard shack as I couldn’t walk far with my crutches as my shoulder is so painful and my one leg is off. Now my wife can push me and I can go and fetch my disability grant. I also push myself onto the pavement and just look at what the children are doing and the neighbours walking about so that I can talk to them a little bit. The wheelchair and pathway and ramps have made such a difference to my life”.

Caregiver 5

What difference has this made to your daily life? “My life is so much better because the things that I used to do for my husband he can do himself now. Its not a burden on my life because it has taken away a lot of my stress. He used to be so depressed because his shoulder used to be so painful from walking with the crutches that were too long for him and his foot used to swell so badly because all his weight had to be on the one foot only. Now he can move in his wheelchair by himself. We are so very grateful for this”.

Participant 6

Equipment received: wheelchair, cushion and wheelchair tray; bath board; concrete pathway and ramps.

What difference has this made to your daily life? “It has made a big difference. I never used to see any friends because I just had to stay inside. For four years I couldn’t move around apart from sliding on my seat (participant had both legs amputated just below the hip joint). Now my friend come and visit me to take me for walks with them to the shops and to visit the shebeens in the evenings”.

Caregiver 6

What difference has this made to your daily life? “It has made my life easier because I just have to hold the wheelchair while he climbs in and out. Before I used to have to lift him onto and from the floor onto the bed and toilet”.

Participant 7

Equipment received: wheelchair and cushion.

What difference has this made to your daily life? “It has made such a difference to my life. I live on the third storey of the flats and could never come and sit here under the tree to meet friends because I couldn’t walk far enough. Now the young men carry me down and put me into my wheelchair and push me

to this tree. Everyone meets here and we sit here all day and talk. Because I'm also blind they tell me what is going on around us and it feels so good to be part of the neighbourhood again. At the end of the month I can also go to the Civic Centre myself to fetch my disability grant".

Caregiver 7

What difference has this made to your daily life? No caregiver.

Participant 8

Equipment received: wheelchair, cushion and wheelchair tray; bath board; grab bars; quadruped.

What difference has this made to your daily life? "It makes it much easier for me to walk now. I don't need anybody to help me because of the quadruped. And the tray makes it easy for me to eat as it is close to my body and I don't have to balance the plate on my lap. The bath board is very helpful as I can sit over the bath now and wash myself without any help instead of the wife having to bring a basin of water to the bed and have to wash me herself".

Caregiver 8

What difference has this made to your daily life? "It is a great improvement and my back doesn't get sore anymore from putting him into the bath or bathing him on the bed. He doesn't get so depressed now that he knows he isn't such a nuisance to me and he can also get outside and have contact with other people every day. It is also very healthy for him to sit in the sun instead of sitting inside all day".

Participant 9

Equipment received: wheelchair, cushion and wheelchair tray; bath board; grab bars; quadruped; increase in length of banisters up four flights of stairs.

What difference has this made to your daily life? "It has made a huge difference to me. I can go and fetch my pills from the clinic and don't have to

struggle to get to the clinic or hospital. My son can just push me there and when I get there and have to wait so long the wheelchair is very comfortable to sit in. The banister alterations allow me to go up and down the steps myself without anybody having to help me and I am grateful for this independence”.

Caregiver 9

What difference has this made to your daily life? “The bath board makes bathing him very easy as I don’t have to carry him there myself. He can walk to the bathroom himself with the quadruped. I just stand by him when he is getting onto the bath board until he is safe and then he can wash himself. This has made it so much better for me and for him because he used to be embarrassed about not being independent. The sun doesn’t shine into this flat, but once more the sun is shining in our lives”.

Participant 10

Equipment received: wheelchair, cushion; bath board; walking frame; concrete pathway and ramps.

What difference has this made to your daily life? “The Lord has been very good to us. I can move around inside the house on my own now and my wife doesn’t not have to push me in the wheelchair to the road because of the pathway and ramps. She only has to push me to the clinic or to fetch my disability grant because that is quite far away. But I can manage to push myself to the church and to the shops because of the pathway and ramps”.

Caregiver 10

What difference has this made to your daily life? “It has made such a difference to his life that I will be able to get a job as a char again for a few days a week. This will help us a lot to pay for our rent and food. I have always prayed very hard for something like this to happen and now it has all taken place. I am so very grateful”.

Participant 11

Equipment received: walking sticks.

What difference has this made to your daily life? “I was walking with old sticks that I bought from a person up the road. These new ones fit me very well and the lady taught me how to use them properly so it is easier for me now”.

Caregiver 11

What difference has this made to your daily life? No caregiver.

Participant 12

Equipment received: wheelchair, cushion and wheelchair tray; bath board; grab bars.

What difference has this made to your daily life? “It makes things much easier for me. I can have my meals on the tray instead of eating off my lap and so my wife does not have to feed me any more. I can also help myself more when she gets me into the bath so that I do not have to be such a burden in her life”.

Caregiver 12

What difference has this made to your daily life? “My life is so much easier and the best thing is my husband does not feel so bad when I have to help him now because he is not so heavy when he helps himself”.

Participant 13

Equipment received: wheelchair and cushion; concrete pathway and ramps.

What difference has this made to your daily life? “This will make a big difference to me. When I became paralysed 12 years ago I was totally independent, but since my wheelchair has got old and not so strong it doesn't work very well and I haven't been able to use it outside in case it breaks and then I will have nothing. So this new wheelchair is a blessing from God and has come at just the right time so that I can again become independent and do everything

myself whenever I want to. I don't have to go through thick sand anymore and that is so much easier".

Caregiver 13

What difference has this made to your daily life? No caregiver.

Participant 14

Equipment received: bath board; grab bars; and walking sticks.

What difference has this made to your daily life? "Now I can walk on my own as far as I want to with the walking sticks as my leg doesn't pain me. Before I could only walk around the house and always had to stay at home. I can also get into the bath myself as my knee doesn't bend and now I can do it on my own."

Caregiver 14

What difference has this made to your daily life? No caregiver.

Participant 15

Equipment received: wheelchair, cushion and crutches; concrete pathway and ramps.

What difference has this made to your daily life? "I couldn't walk before and just sat inside the house. Now I can walk on my own in the house with the crutches and can go and visit my friends and family because my son can just push me in my wheelchair".

Caregiver 15

What difference has this made to your daily life? "My husband does not have to call me every few minutes to do something for him or to fetch something for him. My life is easy now because I feel free to go out whenever I want to because he is independent. I think I am going to try and find some housecleaning job to do for some money and to get me out of the house."

Participant 16

Equipment received: wheelchair, cushion; walking frame; bath board; grab bar; concrete pathway and ramps.

What difference has this made to your daily life? “My grandchild pushes me to my friends or to the shops whenever I want to go. It is like having a car. When I need to go to the clinic I don’t have to pay a taxi now or ask friends to take me because my family can just push me there. It has made such a difference to my life because I can move around freely inside the house with the walking frame and outside the house with my wheelchair”.

Caregiver 16

What difference has this made to your daily life? “I am so happy to see my mother happy going out and socializing with friends and going to church and the church activities. It is also much easier for me as I don’t have to struggle to get her into a taxi or friends’ cars and I don’t have to worry about her missing her doctor’s appointments. I pray every night to thank the Lord for providing these mercies for our family”.

Participant 17

Equipment received: wheelchair, cushion and wheelchair tray; bath board; walking frame; concrete pathway and ramps.

What difference has this made to your daily life? “I am so grateful and pleased with the people who have given me these things and taught me how to walk alone with my walking frame and my family how to push me in my wheelchair. Now I can go to church and my family can push me to the clinic when I need to see the doctor or fetch my pills”.

Caregiver 17

What difference has this made to your daily life? No caregiver.

Participant 18

Equipment received: elbow crutches.

What difference has this made to your daily life? “It has helped me a lot because now I can walk down the road to the shops or to church or to visit friends on my own because my foot does not hurt when I walk with the crutches. It will also help me a lot when I have to have my leg amputated because I already know how to use the crutches and they don’t give you crutches at the hospital”.

Caregiver 18

What difference has this made to your daily life? No caregiver.

Participant 19

Equipment received: wheelchair and cushion; concrete pathway and ramps.

What difference has this made to your daily life? Unable to respond due to cognitive impairment.

Caregiver 19

What difference has this made to your daily life? “I am able to put him into his chair and wheel him onto the pavement where he can watch the activities in the street while I carry on with my housework and cooking. Before he received the wheelchair he was always in my way because he had nothing to do and wanted my attention all the time. Now the members of the congregation also fetch him and push him to church meetings during the week and on Sundays. It is such a new way of life for both of us. Please say thank you so very, very much to the lady for making this possible”.

Participant 20

Equipment received: wheelchair and cushion; concrete pathway and ramps.

What difference has this made to your daily life? “This project in the community has been such a good one for those of us who are disabled as we have had a very hard life with our physical problems and no money to help

ourselves out of the situation. The money is always needed for food, clothing, electricity and there is nothing left over for wheelchairs. Now I feel independent even if I can't push myself all over it is nothing to ask someone else to push me as they are very willing to do it. It's just that before there was nobody who could help me to walk and, in any case, my legs could not walk further than the garden gate. We have so much to be grateful for in our lives”.

Caregiver 20

What difference has this made to your daily life? No caregiver.

Participant 21

Equipment received: wheelchair and cushion; concrete pathway and ramps.

What difference has this made to your daily life? “I can do everything myself now. I wash the floors, do the dishes, cook, wash myself in the bathroom and everything myself. The only thing I can't do is to open the curtains because I can't reach so high. But I can wheel myself to the shops and put my stuff into a packet and bring it home without anyone helping me. I feel so free now that I am independent. I only need help up the steps of the church, but here are plenty of people willing to help me once I get there.”

Caregiver 21

What difference has this made to your daily life? No caregiver.

Participant 22

Equipment received: wheelchair and cushion; concrete pathway and ramps.

What difference has this made to your daily life? “I have been given a big favour by the people who gave me this wheelchair. Now I can go out and visit friends instead of sitting inside my bedroom all the time. I have not been out of my house for four years now. It is a whole new world for me and I must say thank you very much to the people who gave me the wheelchair. I can come and go as I like now and have company during the day and fetch my own disability

grant. My wife works all day and without the wheelchair I would just sit in the bedroom all the time.”

Caregiver 22

What difference has this made to your daily life? No caregiver.

Participant 23

Equipment received: wheelchair.

What difference has this made to your daily life? “I have been up to 1st Avenue, down to 8th Avenue, the clinic, Allpay pay point and the church. I haven’t been to these places for six years. Now I feel so happy and free”.

Caregiver 23

What difference has this made to your daily life? “I carry her up and down the stairs and push the wheelchair. We go out together and that makes my life so happy”.

Participant 24

Equipment received: bath board; grab bars.

What difference has this made to your daily life? Unable to respond due to cognitive impairment.

Caregiver 24

What difference has this made to your daily life? “It has made both her life and my life so much easier. She was not able to bath before and now she can sit on the bath while I help her to wash herself. She so enjoys bathing as she hasn’t been able to use the bath for six years now. Thank you very much for helping those people who cannot afford to buy this equipment which makes such a difference to our lives.”

Participant 25

Equipment received: grab bar and bath board.

What difference has this made to your daily life? “Now I can bath myself without my wife having to be with me to help me. I can get in and out of the bath myself while I hold onto the grab bar and I can sit on the bath and pour the water over myself. It feels so good to be able to be independent with these personal things. I would just like to sat thank you very much to these people who gave us these things because they understand how difficult it is for disabled people to do these simple things themselves”.

Caregiver 25

What difference has this made to your daily life? No caregiver.

Participant 26

Equipment received: wheelchair, cushion, wheelchair tray; bath board; grab bars.

What difference has this made to your daily life? “I can eat my food on a tray by myself. Before my family always had to feed me because I couldn't sit at a table and couldn't feed myself. Now with the tray on my wheelchair I can eat and drink when I want to without having to wait for someone to feed me. I can also go to church. Someone from the congregation comes to fetch me. They carry me down the steps because we live on the fourth storey and then they push me to the church. It is lovely to be able to leave the flat and see what is happening outside and to visit people on the way home from church”.

Caregiver 26

What difference has this made to your daily life? “He can do simple things like feeding himself on his own now and can also get out of the flat and let us have time on our own without him always being here. It lets him also have a bit of a life on his own which makes us happy to know that he is happier. We all want to say thank you very much for what you are doing for the poor disabled in this community”.

Participant 27

Equipment received: wheelchair, cushion and walking frame; concrete pathway and ramps.

What difference has this made to your daily life? “I enjoy getting out and sitting in the sun”.

Caregiver 27

What difference has this made to your daily life? “It has made my life so much easier. It is a great relief. He can get up and go to the toilet with a little bit of help from me, but before he had the walking frame I had to carry him to the toilet. The wheelchair also makes it so easy to take him outside to sit on the pavement and talk to the neighbours. It is a long time since he has been able to do that and it has made it so much easier for me being able to push him instead of carrying him”.

Participant 28

Equipment received: wheelchair, cushion, grab bar and bath board; concrete pathway and ramps.

What difference has this made to your daily life? “ For two years since my legs were amputated I have been crawling on my hands and knees (Photograph 8) around the house because I was not given a wheelchair when I was discharged from the hospital. I had to wash myself on my bed and my wife had to help lift me onto and off the bed and sofa. Now I can use the wheelchair in the house and in the garden and push myself to church and the shops. I can get onto the toilet and onto the bath from the wheelchair myself so I am totally independent now. It makes me feel so free and happy. I just thank the Lord every day for this miracle that has happened to me”.

Photograph 8: Participant having to move by crawling on hands and knees



Caregiver 28

What difference has this made to your daily life? “My husband is totally independent now and I don’t have to help him with anything. I used to find it very heavy to lift him onto the toilet and onto the sofa, but now he can do everything himself”.

Participant 29

Equipment received: jar opener; bath board; eating utensils; shopping cart; walking stick.

What difference has this made to your daily life? “I can go and do my shopping myself now because I don’t have to carry a heavy packet any more so I don’t suffer such pain when my arthritis attacks are bad. The walking stick and shopping cart have really made a big difference to my life. I can also open jars and use a fork and knife easily without any pain. It used to be very bad before.”

Caregiver 29 No caregiver.

Participant 30

Equipment received: wheelchair and cushion.

What difference has this made to your daily life? Unable to respond due to cognitive impairment.

Caregiver 30

What difference has this made to your daily life? "It really hasn't made any difference to my husband or my life at all. I cannot lift him into the wheelchair on my own. Its only when the family come to visit on Sundays that I can get help to put him into the chair so that he can sit outside. In any case they used to do that when they came on a Sunday so it hasn't made any difference to us at all".

Participant 31

Equipment received: wheelchair and special cushion.

What difference has this made to your daily life? "it has made a great deal of difference. I had my last wheelchair for 30 years, but it was so broken last year that I could not repair it anymore. Since then I have had to stay on my bed as I am paralysed from the waist downwards and depend on a wheelchair. I had been to Conradie Hospital and the clinic, but they were unable to help me get a new wheelchair and I couldn't afford to buy a new one on my disability grant as I have to pay for food and rent. Now with this new wheelchair and special cushion my life is back to normal and I am very grateful as I didn't see any way out of my predicament".

Caregiver 31

What difference has this made to your daily life? No caregiver.

Participant 32

Equipment received: wheelchair and cushion; bath board; eating utensils.

What difference has this made to your daily life? “the eating utensils have help me a lot as I can eat by myself now. Since my fingers were amputated my family has had to feed me, but now I can do that myself. I can also move around on my own in the house in my new wheelchair as the other one was too big to manage. It has helped me to be independent which is very important to me”.

Caregiver 32

What difference has this made to your daily life? “The wheelchair is much easier for me to manage. I can fold it up myself and put it into the car when he needs to be taken to the clinic”.

Participant 33

Equipment received: walking sticks.

What difference has this made to your daily life? “I can walk without any pain and I can also walk as far as I want to go”.

Caregiver 33

What difference has this made to your daily life? No caregiver.

Participant 34

Equipment received: wheelchair and cushion; bath board; elbow crutches.

What difference has this made to your daily life? “It means that I can go where I like and do things for myself. I can walk inside the house with the crutches and can bath myself using the bath board. I can even go on outings now which I couldn't do before because it was so difficult and painful to move. I even went to the beach with the family”.

Caregiver 34

What difference has this made to your daily life? “I am so grateful because my husband is so happy and it has made my life much easier not having to bath

him. It is also easy to take him to the doctor now. I just push him in his chair. Before I had to try and get someone with a car to take us to the clinic. Our community has really been blessed with all these wheelchairs”.

Participant 35

Equipment received: wheelchair, cushion; bath board; quadruped.

What difference has this made to your daily life? “I was given a quadruped by the hospital, but I couldn’t use it because it was too heavy. This new quadruped is light and I can walk around in the house. The wheelchair is a blessing because I can now go outside and be wheeled to church or to the shops or just to visit friends which I couldn’t do before”.

Caregiver 35

What difference has this made to your daily life? “It has made my work much lighter and I am happy because my husband is so much happier”.

Participant 36

Equipment received: male urinal, bedpan, toilet seat raiser; wheelchair and cushion.

What difference has this made to your daily life? “It has made such a difference. I can do my own toileting now and it is not so embarrassing to always have to ask my daughter to help me. I can sit in the wheelchair and she can take me out whenever she can get a car”.

Caregiver 36

What difference has this made to your daily life? “It has made a huge difference. Everything is so much easier and my father can do all his personal things on his own now without having to ask me. He is so much happier and that makes all of his family so happy to see this”.

Participant 37

Equipment received: wheelchair, cushion and wheelchair tray; concrete pathway and ramps.

What difference has this made to your daily life? “This little wagon and pathway has made such an improvement to my life. I appreciate it so much. I feel just as if I’ve been given a drivers license. Please say thank you to the people who gave it to us. They couldn’t have done anything better for us disabled living in such a poor community. Especially for us who live in backyard shacks. It is fantastic. They didn’t just talk they did something excellent about our situation. The Lord will bless them”.

Caregiver 37

What difference has this made to your daily life? “I am very happy to see my wife being able to be taken out. She is so happy and it has improved our lives so much. We can go out together now to church and to visit family and friends. Before we just had to stay at home or I had to go out on my own and leave her alone in the shack. I am so very grateful”.

Participant 38

Equipment received: bath board, grab bars; grocery cart, kitchen aids.

What difference has this made to your daily life? “It has made my shopping and cooking very much easier and I don’t get so much pain when I am working in the kitchen or doing the shopping”.

Caregiver 38

What difference has this made to your daily life? No caregiver.

Participant 39

Equipment received: walking sticks.

What difference has this made to your daily life? “I can walk around as far as I want to and I don’t get any pain now. Before, I just used to be able to walk in the house and hold onto the furniture”.

Caregiver 39

What difference has this made to your daily life? No caregiver.

Participant 40

Equipment received: wheelchair and cushion.

What difference has this made to your daily life? “It is so nice to have a new wheelchair. My old one was broken and I just had to sit in it. Now I am free again and can go outside and even go to church”.

Caregiver 40

What difference has this made to your daily life? “He can push himself around the house now and I can take him to the clinic for his pills and to collect his pension himself from All pay”.

Participant 41

Equipment received: wheelchair, cushion and wheelchair tray; commode; concrete pathway and ramps.

What difference has this made to your daily life? “It has been like a miracle. We don’t have a bathroom or toilet in this backyard shack and my life has been very, very difficult for me for my personal cleanliness. Now that I have a commode it is so wonderful and so much easier. And the wheelchair and ramp and pathway makes it easy for me to go out to the shops and to collect my disability grant and to go to church. And I do love to go to church so much”.

Caregiver 41

What difference has this made to your daily life? “It is so much better and so much easier for me to deal with my wife in all personal ways. I am also happy to see her so happy when she can go out of the house to meet with other people”.

Participant 42

Equipment received: wheelchair and cushion; commode; crutches .

What difference has this made to your daily life? “I used to get so lonely being on my own and now I walk by myself to my friends next door and my family can also take me out with them to the beach and to church and to other members of our family who live elsewhere”.

Caregiver 42

What difference has this made to your daily life? “I am very pleased that my daughter can go out with us now instead of having to leave her at home because it was so difficult for her to walk. It is also much easier for me now that she can use a commode at night as it was a long way to the main house and I struggled to take her there to use the toilet”.

Participant 43

Equipment received: wheelchair and cushion; commode.

What difference has this made to your daily life? “ I used to glide along the floor on my seat because both my legs are off. Now I have new feet and I feel like I have a Mercedes Benz because my wheelchair is so beautiful and I can go everywhere on my own when I need to. I don't need anyone else to help me. When I use the commode I can get onto it myself from the wheelchair and that makes it much more pleasant for me not to have to bother anybody to help me to go to the toilet”.

Caregiver 43

What difference has this made to your daily life? “He is so independent now and also so happy. That makes my life so much easier”.

Participant 44

Equipment received: wheelchair cushion and walking stick.

What difference has this made to your daily life? "I can walk around the house on my own now with the walking stick. I can also walk to the church and to my neighbours without waiting for someone to help me".

Caregiver 44

What difference has this made to your daily life? No caregiver.

Participant 45

Equipment received: crutches; commode.

What difference has this made to your daily life? "I can walk on my own without falling and I can use the commode instead of someone having to put me onto the toilet inside the main house. Those things have made a big difference to my life and I thank the Lord for what he has blessed me with".

Caregiver 45

What difference has this made to your daily life? "It makes it easier for me if he can walk on his own instead of hanging onto my arm. And I don't have to lift him onto the toilet which used to be such hard work for me"

Participant 46

Equipment received: crutches.

What difference has this made to your daily life? "I don't get so much pain when I walk with the crutches so I can walk wherever I want to. If I don't have crutches I must just stay in the house and sit down all day. Now I can visit people, go to church, go anywhere I want to".

Caregiver 46

What difference has this made to your daily life? No caregiver.

Participant 47

Equipment received: crutches; commode.

What difference has this made to your daily life? "I used to get very tired and sore in my legs when I walked with a stick. The crutches are much better and I can walk everywhere with my wife when she goes to the shops or to visit friends or neighbours".

Caregiver 47

What difference has this made to your daily life? No caregiver.

Participant 48

Equipment received: crutches.

What difference has this made to your daily life? "I cannot describe how much better it has made my life. I want to go to Day Care, but if I don't have crutches I can't get there because we have no transport. I used to have to stay at home alone all day. Now I can walk down the street to the end of the block to the Day Care and spend the time with the other people there talking and knitting or whatever they do. Praise be to God".

Caregiver 48

What difference has this made to your daily life? "It makes me very happy to know that she is being cared for during the day because I have to go to work as we do not have enough money for me to stay at home to look after her".

Summary of the participants' evaluation of their wheelchairs, mobility aids, assistive devices and concrete ramps and pathways.

Apart from one participant the disabled and caregivers all commented on the positive ways in which their lives had been impacted by the equipment provided through the research project. It is interesting to note that the small activities which they were able to accomplish with the appliances made a significant

difference to their lives and that each participant found his/her life to be affected in a different, but important way to them as individuals. However, it was not possible to measure the improvement in their quality of life on any scale as it was so small.

As can be seen from the comments made by the participants the church plays an extremely important role in their lives. Socio-medical researchers confirm that aspects of religiosity such as support from fellow worshippers and an enhanced emotional state have an impact on health and well-being (Levin, 1996).

Mobility is a basic and necessary activity for the quality of life of all people at any age (Creel et al, 2001). The majority of the participants with disabilities commented on how much their newfound freedom and independence meant to them. The ability to be mobile, albeit by means of a wheelchair and someone to push them, and to take part in social activities within the community contributed significantly to improving the quality of life of both the participants and their caregivers. From this low base it could be argued that the appliances and minor building alterations were an essential aspect of their lives without which their quality of life was severely compromised.

Wheelchairs also served an important function as a means of transport to the CHC's and hospitals to attend clinics regularly and obtain essential medication to control their chronic medical problems.

4.5 RESEARCH ASSISTANT

The role of the research assistant was developed as the research programme was conducted. Not only did he trace and make contact with the participants for the first interview he shadowed the researcher and was taught to:

- measure the disabled for their appliances;
- adjust and fit the appliances;
- teach the participants how to use and care for their wheelchairs and assistive devices;
- monitor the use of the wheelchairs and walking aids and recycle them when the disabled died;
- educate the participants about the services of Dial-a-ride;
- advise participants regarding the process of having DG's reinstated, apply for grant-in-aid and child grants;
- document the visits he made to the disabled;
- record the appliances given to new beneficiaries as part of the recycling programme; and
- contact the housing department to make recommendations for handrails and ensure that the names of the disabled became a priority on the waiting lists.

4.6 SUMMARY OF FINDINGS

It was imperative to obtain funding before the research was undertaken to avoid raising the expectations of the participants without any hope of them being met. This frequently happens when surveys are conducted. They often involve obtaining data about needs without any planning to include some form of intervention to alleviate the needs of the individuals participating in the survey.

The role of the research assistant was pivotal in implementing the improvement of the participants' quality of life.

The focus groups were used to compile a relevant questionnaire for a larger sample of people with disabilities. They identified 14 barriers which affected their

activities of daily living and generated the exhaustive list of factors (items) which contributed to each barrier.

The extent to which the participants rated their problems experienced confirmed that of the findings of the focus groups. More than sixty percent of the participants with participants experienced no problems with safety, unemployment, isolation and loneliness, domestic assistance, attitude of the community, abuse and health.

Lack of money, transport, housing, health services, social services and accessibility were found to be a problem to the majority of people. These aspects fit into the category of basic needs such as shelter, food, health care and income security as defined by the Constitution of the Republic of South Africa (1996) and the White Paper for Social Welfare (Ministry for Welfare and Population Development, 1997). The barriers they experience with accessibility and transport are aspects which the Disability Rights Charter of South Africa (2000) demand attention.

Thus the lives of the people with physical disabilities and their caregivers living in Lotus River are very difficult without the basic necessities of life being available to them.

An evaluation by the participants of the wheelchairs and assistive devices described the significant impact they made on their lives with regards to their independence, socialisation, accessibility, pain, workload and psychological well-being.

The participants, on the whole, did not have a good idea of their rights and responsibilities as patients and the majority of people with disabilities did not know what caused HIV/AIDS. They also thought that being HIV+ meant that the person did not have the infection.

The Constitution of South Africa and the various White Papers and Charters make references to the barriers people with disabilities experience and strategies which are to be implemented to alleviate these difficulties and to improve their quality of life. However, none of these have yet positively affected the lives of the people with disabilities in Lotus River.

A methodology of an integrated intervention programme is presented in the next chapter.

University of Cape Town

CHAPTER FIVE

METHODOLOGY OF AN INTEGRATED INTERVENTION PROGRAMME FOR PEOPLE WITH PHYSICAL DISABILITIES

5.1 INTRODUCTION

As a direct result of the fieldwork of this study and the experience gained during the implementation of the wheelchair and appliance component of the project the researcher developed the methodology presented in Figures (29) and (30) in this chapter as a guide for any person wishing to introduce a similar programme in a disadvantaged community in South Africa where the disabled are in need of wheelchairs and assistive devices to overcome the barriers with which they have to deal in their activities of daily living.

By obtaining a small amount of funding the quality of life of people with physical disabilities and their carers can be improved considerably by the provision of mobility aids and assistive devices. It is also a means of poverty alleviation by offering employment opportunities to people with disabilities, unemployed individuals and small business enterprises in the community in which the programme is being conducted. These would involve the community worker; disabled or unemployed able-bodied people who can make simple wooden appliances; and builders who construct rails, ramps and pathways.

The methodology utilises a public-private partnership to enhance the capacity of addressing the inequities with which the disabled are confronted in their daily activities of living. This is in line with the recently-announced government and provincial planning to deal with development and poverty alleviation as

mentioned in their State of the Nation and Western Cape State of the Province addresses respectively (Mbeki, 2004; Rasool, 2004).

The aims of the programme are to:

- improve the quality of life of the physically disabled and their carers by providing wheelchairs, mobility aids, assistive devices and minor building alterations to those in need; and
- reduce the level of poverty by providing employment to physically disabled people and unemployed individuals in the community.

5.2 STAGE 1: PLANNING OF THE PROGRAMME (Figure 29)

5.2.1 PROGRAMME INITIATOR (Figure 29: block 2)

The program initiator could be a rehabilitation therapist, social worker, orthopaedic nursing sister or any health worker involved in dealing with the welfare and development of the disabled who is aware of the barriers in their activities of daily living when they are discharged home from hospital or clinic.

His/her tasks in the planning stage of the programme include:

- notifying the Directors of the Department of Health and DSSPA of the intention to conduct the programme to ensure that there is no conflict of interest or activities in the region;
- obtaining funding;
- obtaining permission from the local DSSPA to use names from the disability grant beneficiary lists from the payout agency;
- perusal of personal files of the disabled at the local Department of Social Welfare;
- identifying an appropriate community worker;

- educating and training a community worker; and
- forming an integrated programme committee.

5.2.2 FUNDING (Figure 29: block 1)

Potential donors for the funding of the project are the companies which supply wheelchairs and assistive devices and the private agencies which pay out the monthly disability grants. In this study the suppliers were not asked for direct funding, but they provided it indirectly in the form of a 15% discount on all wheelchairs and appliances purchased in bulk orders of ten and more. The researcher negotiated the financial deal with them at the start of the project as a means of augmenting and stretching the funding received.

The managing director of the grant payout agency for the Western Cape, AllPay, was approached and he provided the funding for all the wheelchairs, mobility aids, assistive devices; minor building alterations; and the salary, transport and telephone costs of the community worker. They agreed to contribute approximately R40,000 per month towards the project. Depending on the wheelchair specifications, nature of the other equipment and the hours that the community worker had completed this occasionally amounted to R2,000 to R3,000 more per month. The money contributed by AllPay came from a fund to which they contributed 10c for each disability grant payment made to a beneficiary per month. The remainder of this fund was used to upgrade community centres and halls which they used in the various communities as their monthly payment centres.

Although this agency is specific to the Western Cape each province has its own independent grant payout agency which could be approached for funding for a programme in the respective region.

A work of caution is required regarding accepting imported wheelchairs from overseas donors. The wheelchairs need thorough investigation as, generally, they have been manufactured for use in developed countries where they do not need to be as sturdy as those used in the environment in South Africa. A trial run was given to three donated wheelchairs which broke after one month's use on the rough terrain in Lotus River. They were not able to be repaired for further outdoor use and had to be given to an institution where they were utilized only for transporting residents to and from bedrooms and dining rooms.

The managing director or nominee of the funders should be on the committee which administers the programme.

5.2.3 DEPARTMENT OF SOCIAL SERVICES AND POVERTY ALLEVIATION (DSSPA) (Figure 29: block 3)

The most comprehensive list of people with disabilities can be acquired from the DSSPA of the relevant province. Permission has first to be obtained from the Assistant Director as the information is confidential. The most up-to-date disability grant list can then be obtained electronically from the payout agency for each specific pay point within the community in which the project is to be conducted.

The personal files can be perused at the local Social Welfare Department and the medical diagnosis and notes can be read. The names of those disabled with any diagnoses such as stroke, amputation, arthritis, paraplegia or multiple sclerosis which may have an element of physical disability are noted for inclusion in the programme.

The Assistant Director or his/her nominee should be on the programme committee.

5.2.4 FORMATION OF THE COMMITTEE (Figure 29: block 4)

After funding has been obtained and permission granted by the DSSPA for access to the names of the beneficiary list, an interim committee should be formed. This should comprise a representative each of the DSSPA, funding agency and a rehabilitation therapist who works at a Community Health Centre in the region in which the project is conducted. The programme initiator should chair the interim committee until the programme is functioning smoothly. A chairperson should then be elected by the committee members to serve for a term of a year.

After the committee has selected and appointed the community worker he/she should also serve as a committee member (Figure 29: block 7).

These meetings should take place on a monthly basis so that the activities of each stage of the implementation phase can be thoroughly monitored to ensure accountability. The tasks and responsibilities of the committee are to:

- Select and appoint a community worker;
- Keep comprehensive records of the beneficiaries and of the appliances they receive;
- Approve recommendations of the community worker and rehabilitation therapist with regard to appliances and building alterations;
- Approve quotes and tenders from appliance suppliers and building contractors;
- Approve payments on completion of building alterations and receipt of appliances;
- Ensure that there is no duplication of orders; and
- Approve the monthly worksheets and payments of the community worker.

5.2.5 COMMUNITY WORKER (Figure 29: block 5)

A community worker can be nominated by approaching the local Community Forum, church leaders and NGO's operating in the community to identify a suitable person. The person recommended should be:

- Interested in and be empathetic towards people with disabilities;
- A long-term resident of the area;
- Involved in a variety of community development projects in the area;
- A key leader;
- Good with interpersonal skills;
- Reliable;
- Able to document and keep records of stock and personal worksheets;
- Retired or unemployed; and
- Motivated to learn.

Formal interviews should be conducted by the committee before the nominee is selected and appointed.

The community worker should be employed on an hourly rate. He/she should keep a worksheet of the dates, names of disabled visited, hours worked and the taxi fares or miles travelled if he/she uses his/her own vehicle. This information is checked monthly by the committee before referring it to the funders for payment.

Once appointed the DSSPA committee member should educate the community worker about the eligibility criteria and process of applying for a disability grant, old age grant, care dependency grant, social relief grant, rent relief, rental

indigent grant, grant-in-aid; child support grant and exemption for paying school fees. He/she should also provide the community worker with

- the contact names of the officials of the Housing, Roads and Sewerage Department to whom he will need to refer the disabled or their families;
- The procedure for referral to the Housing Department if the disabled person is in
 - rented accommodation from the Council and needs to be transferred from a flat on the first or second floor of a block of flats to the ground floor;
 - a backyard shack and needs to be placed at the top of the waiting list for a house; and
- the procedure for applying to Dial-a-ride to transport the disabled to clinics and the Social Welfare offices.

The community worker should be given a supply of application forms for the respective grants and should assist the applicants in completing them if it is discovered that they are not receiving the grants for which they are eligible.

Should they not have transport of their own he/she should teach them how to apply for the Dial-a-ride bus service and assist the disabled or their carers to telephone the service and make an appointment to be taken to the Social Welfare offices or the hospital or clinic. This is to ensure that the disabled and their families are receiving the social grants and health services to which they are entitled.

The community worker should keep detailed records of the dates of the visits to each disabled person, to which services they were referred; appliances received and building alterations completed; and the status of the disabled and their appliances at follow-up visits.

5.2.6 IDENTIFICATION OF PEOPLE WITH DISABILITIES (Figure 29: block 6)

Apart from the names of the disability grant beneficiaries obtained from the DSSPA (paragraph 5.2.3 above) letters should be sent to physiotherapists, occupational therapists, social workers and orthopaedic nursing sisters at all the Community Health Centres and hospitals servicing the area. They should be informed of the programme and requested to refer all their clients with wheelchair and appliance needs, who have not been supplied with them by the hospital or Community Health Centre, to the community worker.

A list of wheelchairs, mobility aids and assistive devices available on the market; their specifications; and their specific benefits to the disabled should be included. Many health workers in rural areas do not have access to agency representatives and are, therefore, not aware of the stock available on the market.

As the programme progresses the list of names will increase by means of snowballing when neighbours, friends and relatives of disabled in need become aware of the programme and refer their relatives to the community worker themselves.

5.3 STAGE 2: IMPLEMENTATION OF PROGRAMME (Figure 30)

Figure (30): Block 1: The initial visits by the community worker will be accompanied by the rehabilitation therapist and serve as a training programme to familiarise him/her with the format of conducting a home assessment.

This would include gathering information regarding:

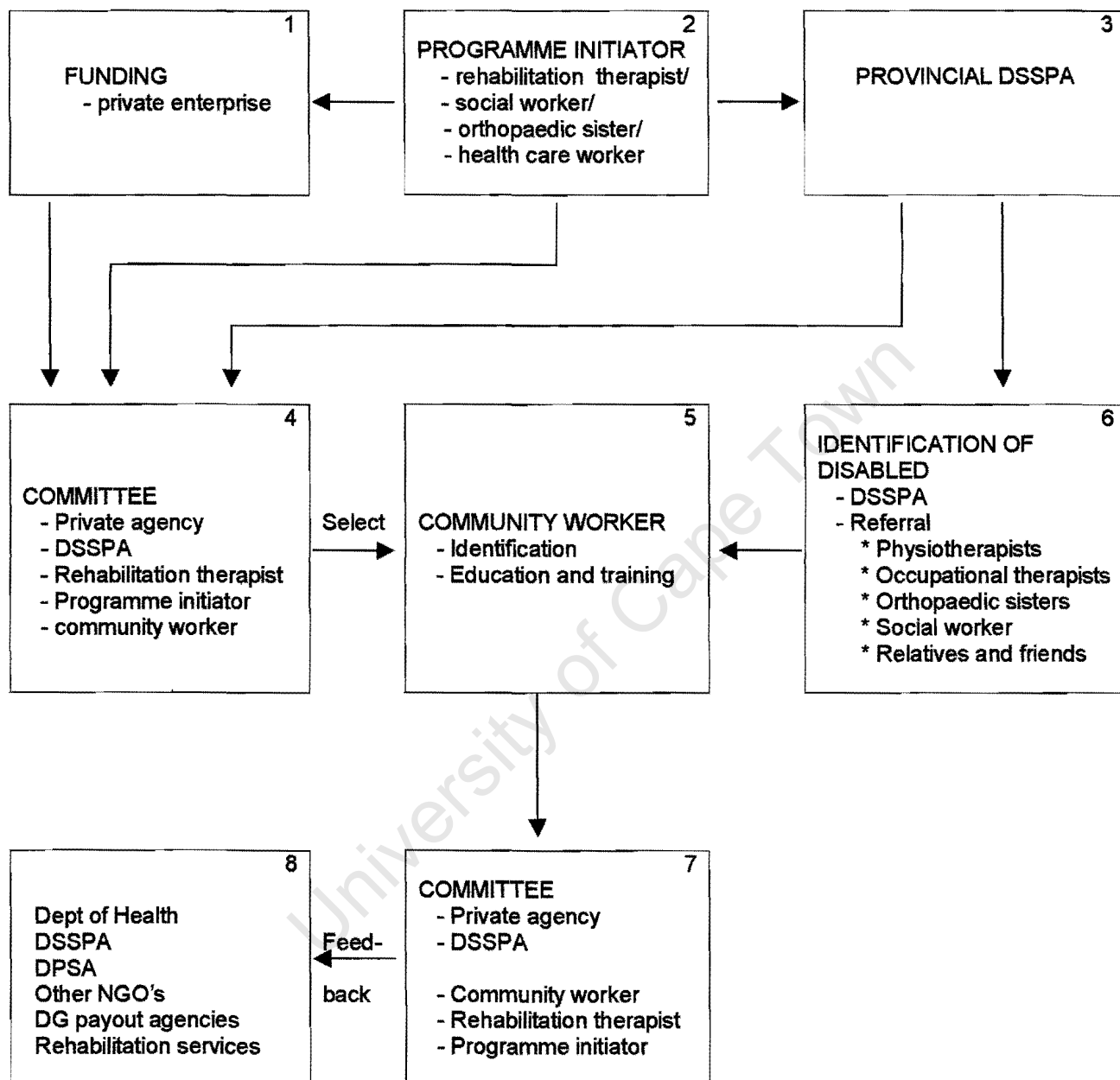
- Client's name and identity number;

- Client's level of physical function;
- An assessment of the ownership, size and composition of the dwelling; space available; and the condition of the external environment;
- An assessment of the wheelchair, mobility aids and assistive devices that the disabled need to cope with their activities of daily living as independently as possible and to reduce the physical load of their carers;
- How to measure the disabled for the correct size of wheelchair and appliances required;
- Assessment of the minor building construction required to enable ease of access to the house and pavement;
- Access from the pavement to the road;
- A review of the social grants which the disabled and families are receiving; and
- Identification of the social grants for which the disabled and their families are eligible, but are not receiving and for which they should make application.

The community worker should do home visits and assessments independently once he/she is competent in performing the tasks and has the confidence to work independently.

He/she should inform the disabled and their carers of their rights to apply for specific social grants and assists them with completing the relevant forms. He/she should explain the procedure to follow and the format of obtaining transport by means of Dial-a-ride buses.

Figure 29: Planning of programme



The above section focuses on the structure of the programme. The next section describes the structure which is presented diagrammatically in Figure (30).

Figure 30: Implementation of programme

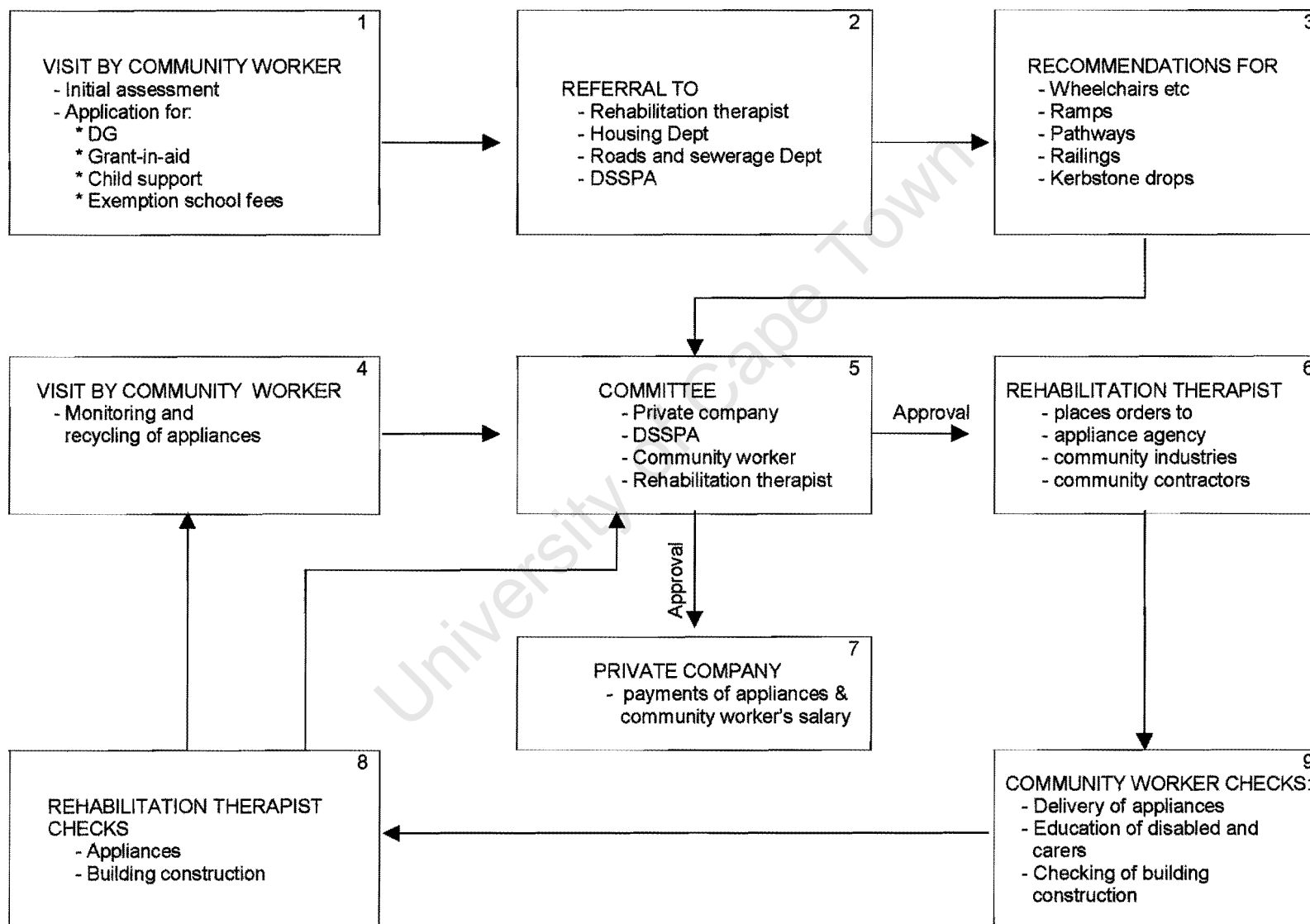


Figure (30): block 2: After the initial assessment the community worker refers the disabled person or his/her family to the relevant representatives for assessment such as the rehabilitation therapist for a wheelchair or other appliances; housing department official for their names to be placed on a preferential housing waiting list; and roads and sewerage department for kerbstone drops for the pavement. He/she arranges for small building contractors living in the community to measure the ramps and pathways that the rehabilitation therapist has recommended and to provide quotes for the construction thereof.

Figure (30): block 3: The recommendations and quotations from the rehabilitation therapist and community worker for the wheelchairs, appliances, and building alterations are sent to the Committee (Figure (30): Block 5).

Figure (30): block 6: After the quotations have been discussed and approved the rehabilitation therapist places the orders for wheelchairs and special appliances with the suppliers. Simple aids such as bath boards and wheelchair trays are ordered with measurement specifications through small wood manufacturing businesses or backyard industries in the community. Orders for pathways and ramps are given to local building contractors who employ local unemployed people for these specific jobs. Preference should be given to companies which employ people with disabilities. Utilising disabled or unemployed able-bodied people from the community is a means of reducing the level of poverty.

Figure (30): block 9: On completion of the building alterations the community worker inspects the work done to ensure that the specifications of the quotes have been met. He/she checks the appliances when they have been delivered, adjusts them for size to the disabled and teaches them how to use and care for them.

Figure (30): block 8: The community worker notifies the rehabilitation worker who does a follow-up visit to the disabled and verifies that the appliances are appropriate for the person with the disability, that he/she is able to use it correctly and that the building alterations are satisfactorily constructed. The disabled person signs the acceptance form stating that the appliances have been received in good order, that they know that they are on loan only and that they will return them to the community worker when they no longer require them. It is made clear to the families that they cannot be sold when the disabled no longer have use for them.

Figure (30): block 5: After the rehabilitation therapist has reported back to the committee on the condition of the equipment and building alterations the invoices are sent to the funders who pay the relevant suppliers and builders (Block 6).

Figure (30): block 4: The community worker continues to visit the disabled on a regular monthly basis to ensure that the appliances are being used and, if not, he/she gives it to the next person on the waiting list for the specific appliance. He/she gives regular feedback on the movement of appliances to the committee so that it has accurate records of the beneficiaries. In this way duplication of orders going to the same people, and perhaps being sold for financial gain, are prevented.

Once the disabled is able to use his/her appliances with confidence the community worker investigates their social activities. If the person is a wheelchair-user the he/she notes which shops, churches/mosques, post offices and entertainment centres the disabled frequents. He/she visits these places and investigates how accessible they are for a wheelchair. He/she makes suggestions to the shop managers with regard to ramps that need to be provided or payout tills that require a wider aisle to accommodate wheelchairs. By approaching the people in the community about the barriers which the disabled

meet they become sensitised and empathetic to the needs of the disabled and are more likely ensure that their staff go out of their way to assist them when they frequent their facility.

5.4 SYSTEM TO AVOID CORRUPTION

A programme such as this proposed methodology is open to a great deal of corruption and mismanagement of funds. For this reason:

- All quotes and transactions have to be authorised by the committee;
- When recommendations are provided to the committee by the rehabilitation therapist and building contractors each name must be accompanied by the identity number of the disabled person to avoid duplication of equipment being ordered. The funders also check the names and identity numbers of the orders before payments are made;
- The community worker does monthly visits to check on the equipment to ensure that they are being used by the people to whom they were supplied and that, once the disabled person no longer requires them, they are given to the next person on the waiting list;
- Payments are made by the funders only once they have received authorisation by the committee to ensure that equipment is not ordered for personal purposes.

5.5 CONCLUSION

The proposed methodology describes a programme to improve the quality of life of disabled people while reducing the level of poverty by providing employment to people from the community. This is very much in line with the State of the Nation and Western Cape State of the Province addresses by President Mbeki and Premier Rasool respectively. They advise effective and purposeful partnerships between state and public enterprises in order to eradicate poverty and improve the quality of life of all people by ensuring that the relevant services reach everybody (Mbeki, 2004; Rasool, 2004).

It provides a means of ensuring that the disabled do not slip through the safety net and do receive the social grants and health services to which they are entitled. By having a community worker responsible for the overall care of the disabled once they have been discharged from hospitals and community health centres, it allows for an integrated approach of addressing their barriers. In this way they become part of the community's responsibility and can once more gain independence with their activities of daily living and can participate in social activities within their families and communities.

By developing a programme as suggested by the methodology, disablement is regarded from the social model frame of reference. It regards society for being responsible for the barriers of disabled people as it does not ensure that the environment is disabled-friendly. This is in contrast to the medical model which views the barriers of the disabled as arising from the person's physical disability and that this should be cured by medical management and that it is not a matter for which society is responsible. However, it does not have any answers for the people who do not make a full recovery in spite of all the medical treatment they have received. As it does not consider factors other than medical management the disabled are unable to participate optimally within their families and

communities becoming isolated, lonely and part of the cycle of poverty. In the proposed methodology many departments become responsible for the quality of life of the disabled by dealing with their respective aspects of the community. The disabled are no longer perceived to be the responsibility of the health system where only their medical problems are managed and they are left to struggle with their lives on their own.

In order to reach the larger community of disabled people the proposed Integrated Intervention Programme needs to be disseminated to NGO's such as DPISA, rehabilitation therapists in state health care services and the agencies who issue the DG's in the other provinces. It would be simple for any of these service planners to initiate the programme in any similarly disadvantaged community and would be a means of improving their quality of life at a relatively small cost.

The major findings and implications of the study will be presented in the conclusions in Chapter Six.

CHAPTER SIX

CONCLUSIONS

There has been a large amount of research published on disablement in the United Kingdom, Europe, United States of America, Australia and Canada. The literature contains data on prevalence as well as a great deal on successful strategies of approaching the barriers confronting the disabled in their living, working and social environments.

Although there have been a few studies of the prevalence rates of physical disability in various communities in South Africa no research has been conducted on the barriers of disablement. This research was the first to study disability from a social model framework, namely, the aspects of society which impact negatively on the disabled by excluding them from their roles within their families, communities and society at large. Studies to date have been based on the medical model which views the individual's disability as the cause of exclusion from society.

The research set out to identify and explore the nature and extent of the barriers experienced by people with permanent locomotor disabilities who resided in Lotus River. It also aimed to improve the quality of life of the disabled and their carers by providing them with their individual needs of mobility aids and assistive devices.

A comprehensive community profile developed prior to the interviews with the participants was indispensable for the researcher to become knowledgeable about the history of the suburbs, demographic features, socio-economic situation of the population, physical environment, housing, nature and level of crime, community facilities and services offered. This provided important information

about the community with regard to the historical events which had influenced its development and the environmental conditions which affected the lives of the disabled and their families at the time of the research.

It was also essential to be fully acquainted with the community and its structures before approaching the Lotus River Community Forum to identify a suitable research assistant from the community. The tasks and responsibilities undertaken by him were crucial to enhancing the quality of life of the participants. It was vital that he was a key leader, well-known, respected, reliable, eager to become involved, had the time available and lived in the community itself. Without these attributes it would have been difficult to contact the entire population of disabled participants and to gain their trust in obtaining confidential details of their disabilities and financial status. He was also pivotal in sustaining the wheelchair and assistive devices project after the research had been completed.

Using focus groups from the neighbouring suburbs was an effective and efficient means of developing a comprehensive and accurate questionnaire of the nature and extent of the barriers experienced by the disabled participants living in Lotus River. By being disabled themselves they were well-acquainted with the barriers in their activities of daily living and were able to provide an exhaustive list of factors associated with each barrier. Lack of money, transport, housing, accessibility, health services and social services were found to be the most significant barriers affecting their lives.

It was critical for this research to have been conducted in the homes of the participants. It provided an excellent opportunity to observe the conditions under which they were living so that the researcher was able to elicit questions which gave her a deeper insight into the barriers which confronted them. She was able to assess more precisely the appliances that they required and the type of wheelchairs that were the most appropriate for each individual's needs and which

could provide the most mobility in the confined space available in their dwellings. This could not be achieved from a hospital or clinic as the housing situation could not be evaluated accurately.

The amount of the disability grant is insufficient for the disabled to provide for their families and to meet their additional special needs related to their individual disabilities. They did not know how to access social grants to which they were entitled and generally felt insecure about their disability grants being removed.

The disability grant is a cause of a great deal of hardship to the disabled and their families both in terms of allocation and inaccessibility of information. It is awarded on the basis of the medical condition of the disabled only and not on the commitments that the person has with regard to the number of people that need to be supported by the grant. This leads to increased poverty and suffering as the disabled do not have sufficient money left after paying for rent, fuel, food, clothing and transport to pay for their special needs.

The amount of the grant-in-aid also impacted negatively on the family when the caregiver had to leave his/her employment to care for the disabled relative as it was only a portion of what they received when they were working. The Integrated National Disability Strategy (1997) claims that the disabled have a minimum livelihood provided by means of social benefits. However, this is not possible on R740 per month with their living expenses and social responsibilities towards their families and they become further involved in the cycle of poverty.

The desperate situation of the finances of the disabled impacted on all aspects of their lives. They had difficulties in meeting costs of their most basic food, clothing, fuel, education and housing rental requirements. They were unable to afford transport fares which meant they were unable to attend essential clinics for medication. This in turn led to further deterioration in their medical conditions and the development of further preventable disablement and poor health.

Participants who endeavoured to improve their financial situation and who considered themselves able to work found that they could not find employment because of discrimination and people did not want to employ people with disabilities. They also found that public transport to and from work was inaccessible.

This is the first time that an inventory of all the factors contributing to housing, transport and accessibility barriers have been documented and data have been collected on the extent to which each of the factors affected the research population of disabled people. The factors identified are unique to South Africa and modifications of housing and transport that are appropriate for conditions in the developed world are not necessarily appropriate for conditions here. Therefore, to import buses and apply structural designs of train coaches utilised overseas are not suitable for the purposes of the disabled living here. The majority of the disabled in this research would have been supplied with motorised wheelchairs had they lived in developed countries. The transport system in South Africa needs totally different modifications for access to the disabled.

If the disabled are to be enabled to go from point A to point B the structural modifications identified to improve the transport system in Lotus River involve a great deal of funds and co-ordination of the planning of the entire transport system. However, skills development of the drivers is immediately attainable by means of education and training programmes to sensitise them to the needs of the disabled. This alone would make the transport system immediately more user-friendly and accessible to many of the disabled with milder disabilities.

The lack of safety on transport made the disabled vulnerable to criminal elements. It is imperative for trains to have adequate policing, not only for the disabled, but for the non-disabled too so that there is an atmosphere of security

and trust. The disabled who require assistance would then feel safe to have this provided by the passengers without the fear of advantage being taken of them.

Many of the disabilities resulting from disease were avoidable and their prevalence could have been reduced had the participants been aware of their means of prevention. For example, they were not aware of the importance of a nutritious balanced diet and special dietary requirements to control their diseases of hypertension and diabetes. Health promotion is an essential component of school education and there should be far greater awareness created by health awareness programmes in the Community Health Centre's and the media.

Although 27,33% of the participants had been disabled as a result of violence, this is not a true reflection of the level of violence in Lotus River as can be seen in Appendix xvii: paragraph 20. Many of the victims of violence in the area were killed or, due to the severity of their assaults, died after a period of time as a direct result of their injuries. There is an urgent need for an increase in the number of policemen patrolling the area. The Grassy Park police precinct covers Grassy Park, Ottery and Lotus River which is a large area and, therefore, policing has a low visibility in the communities. What is urgently needed are ad hoc patrols done on a daily basis in the areas in which the shebeens are active and where the drug lords operate. Increased policing will enable the drug lords to be arrested and removed from the community reducing their influence on the youth and making it a safer living environment.

There was a great need for mobility equipment and assistive devices to optimise the participants' independence. Wheelchairs were found to be the most needed mobility aid. This was not unforeseen in view of the problems the disabled had with the public transport and private taxi systems. The participants found their increased independence gained from their had improved their quality of life significantly.

The caregivers, the majority of whom were family members, reported that their physical load had decreased and they were able to take their disabled relatives to church, visit friends and attend clinic appointments since receiving their wheelchairs. This is the first time that the disabled in a community have had their needs assessed and addressed by the provision of mobility aids and assistive devices to improve their quality of life by facilitating their independence.

As mentioned previously in the literature review, disability activists claim that independence involves autonomy over decision-making rather than the capacity to carry out activities of daily living (French, 1993a; Morris, 1993b; Badley and Tennant, 1991). However, the participants reported that their increased level of physical independence had contributed greatly to their quality of life by having the freedom to move around the environment on their own and at a time they wished to do so. Several authors confirm that freedom of movement from place to place is a basic and essential activity for quality of life (Creel et al, 2001; Special Focus Group, 1999; French 1993).

Functional independence was a means of overcoming their feeling of powerlessness. They were able to take more control over their lives by making basic decisions. For example, they were able to propel themselves to the bathroom to bathe themselves when it suited them. They did not have to ask for assistance and then wait for a convenient time for the carer to assist them.

Once the disabled had completed their rehabilitation programmes and had left the health system per se they did not perceive their physical disabilities as impairments, but accepted their disabilities as a fact of life and attributed the problems they experienced to the environmental barriers.

At present rehabilitation is provided within a medical model framework where disability is perceived to have its locus in the individual. As soon as the disabled have completed their rehabilitation programme and are considered to have

reached their optimal level of functional independence they are discharged from the health system and are expected to cope and function in their homes and communities on their own without any form of social service support. However, according to the social model that is precisely where and when their 'rehabilitation' should start. This is when they need alterations to their houses and environments, accessible transport, skills and training and suitable employment to be obtained. Thus their needs at this stage are not health-related. They should become the responsibility of the departments of social services, housing, transport, roads and sewerage, labour and education as it is in these areas that they and their families experience barriers rather than with their physical disabilities (Chapter Five).

The level of poverty in Lotus River was reduced by the intervention of the research programme. It is an example how public-private partnerships can be developed to utilise the collective capacities to address the inequities in our country. By having regular meetings with the partnership representatives the Department of Social Services and Poverty Alleviation became aware of the level of need of the disabled and took the matter up with the Department of Health (provincial) who agreed to take over the responsibility of supplying mobility aids and assistive devices to the disabled in the Western Cape. This is to be implemented from 2005 and will mean that the disabled in need should be supplied with these appliances at the time of or soon after discharge from hospital or clinic so that they will be able to continue participating in their family and community and will not be excluded by being confined to their bedrooms or houses.

The housing conditions contributed significantly to the hardships endured by the disabled and their caregivers. Generally there was overcrowding and the rooms were too small to accommodate wheelchairs or walking aids. All of the problems experienced with housing demonstrates that the housing of many of the disabled

do not meet the basic criteria of what a "house" requires in order to comply with the RDP definition (ANC, 1994).

When new housing is provided for disadvantaged communities there is never consideration given to a percentage of the homes being designated for the disabled and that they are constructed with minor adaptations to meet their mobility requirements. There are people with disabilities living in informal housing settlements who are the most vulnerable of our population as they are amongst the poorest and most needy. Those living in backyard shacks in Lotus River fall into this category. The difficulties identified by the disabled are specific to housing of disadvantaged communities in South Africa and this is the first time that the deficiencies have been identified by the disabled residents themselves. Modifications and recommended designs of housing from developed countries would not be suitable for the conditions here and would be very expensive to introduce. However, modifications such as open-plan kitchen and living rooms and wide doorways from the living room leading directly into the bathroom and bedroom of the disabled would cost the same to build as the present designs of sub-economic housing. Modifications to bathroom and kitchen taps and light switches would mean some additional cost, but would make a significant difference to the independence of the disabled.

The disabled were, on the whole, satisfied with their health services. However, the long waiting time to be seen by the health workers and the distance to reach the services were significant problems particularly so for the disabled who did not have wheelchairs at the beginning of the study. They found standing in the queues to be exhausting and, frequently, these people suffered from a great deal of pain and could not attend the clinics as regularly as they were required to do due to the pain. These problems were alleviated to a large extent once they were able to use the wheelchairs provided by the research programme.

Results of the extent to which environmental barriers were found to be problematical were inconclusive as the ratings were done at the initial interview before the participants had received their wheelchairs. Many of them were unable to leave their dwellings or properties without being physically carried and, therefore, rated the items as 'no problem' as they were never confronted with barriers such as 'ramps to buildings in the community' or 'check-out counters at shops inaccessible'.

As there are many similar disadvantaged communities in South Africa it is to be expected that the disabled in those communities experience the same barriers in their daily lives. For this reason the methodology for an integrated intervention programme, based on this research, was provided in Chapter Five so that similar programmes for wheelchairs and assistive devices can be initiated elsewhere in the country. This programme will advance the care of the disabled in South Africa considerably.

With all the funds that it will require no one expects that the facilities and resources that the disabled need can be met overnight. However planned change efforts are essential if their basic rights are to be met and their quality of life is to improve. To date none of the legislation, policies and white papers regarding people with disabilities have been implemented in Lotus River and this is six years down the line from the time they were legislated by the relevant government departments.

The original data provided in this research by 132 people with disabilities identifying and quantifying their difficulties associated with each barrier will benefit the Departments of Transport and Housing when they plan upgrading of the transport system and housing developments. A small amount of money invested in these for the specific needs of the disabled will improve their quality of life significantly.

The learning from the study provides two conceptual models, one focused on structure and the other on process, which together go to make up an Integrated Intervention Programme which proved to be a successful means of improving the quality of life of the disabled. It incorporated health workers providing services at state institutions, the private agency responsible for DG payments, the DSSPA and a community worker.

The author recommends that future research is conducted on the proposed programme to evaluate:

- The cost benefit analysis of the social care economics. This would include the costs of the equipment and community worker to manage the programme; and the benefits of having carers and people with disabilities returning to employment outside the home;
- Employment benefits that could be achieved by the increased mobility and independence gained by the wheelchairs and assistive devices;
- Implications for the hospital/community services interface by having community workers living and implementing the programme at grassroots level;
- Specific issues based on culture, gender, age, rurality that occur in various communities;
- The benefits which the programme provides for the main carers;
- The level of functional independence and autonomy of decision-making that the programme creates.

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PROVINCIAL ADMINISTRATION: WESTERN CAPE
DEPARTMENT OF SOCIAL SERVICES

VRT-3

MEDICAL REPORT: APPLICATION FOR/REVIEW OF SOCIAL GRANTS FOR DISABLED
PERSONS AND WAR VETERANS

N.B. This report may be signed only by a District Surgeon or a Government Medical Officer

Official Office and Date Stamp

Name Address

Identity No.

Date of Birth Qualifications Occupation

Present complaints and disablement

Clinical diagnosis

Full details of the nature, degree and duration of the present disablements (where applicable the blood pressure, the mental age, the frequency and types of fits, the visual defect according to Snellen's optotypes, should be furnished).

Review : is review necessary? Yes/No Month Year

Does the person receive treatment? State result and prognosis

If the person has recently undergone hospital or other treatment, a copy of the hospital/specialist's report should be furnished, if possible.

Place

Date DISTRICT SURGEON/GOVERNMENT MEDICAL OFFICER

Official Stamp

FOR THE USE OF THE DIRECTOR-GENERAL: SOCIAL SERVICES ONLY

Classification by the Pension Medical Officer

Official Stamp

FOCUS GROUP INFORMATION AND CONSENT FORM**PROBLEMS EXPERIENCED BY PEOPLE WITH LOCOMOTOR DISABILITIES LIVING IN****LOTUS RIVER****STATEMENT BY PARTICIPANT**

I, the undersigned, living at (address) confirm that:

1. I have been invited to participate in the above research project which has been initiated through the University of Cape Town.

2.1 It has been explained to me that the objective of this study is to:

- Identify the different problems experienced by people with permanent physical disabilities
- Explore all factors that contribute to the problems experienced.

2.2 It has been explained to me that I will be part of a focus group which meets to discuss the above topic.

2.3 I am aware that this is a once-off procedure that will be implemented in 2003 at a time convenient to me.

3.1 It has been explained that all information will be handled confidentially. Information may be used for a thesis, publications in scientific journals and presentations at professional congresses, but names and focus group names will not be used.

3.2 It has been explained that findings from this study regarding the needs of people associated with physical disabilities will be brought to the attention of the Health and Social Welfare authorities.

4. I have been informed that I may refuse to participate in this project and that I may stop participating at any stage, and that such refusal or stoppage will not in any way negatively influence my future membership with my social group.

5. The information above has been explained to me by in English/Afrikaans and that I am proficient in that language and that my questions have been answered satisfactorily.

6. I have not been forced to consent to my participation in this project and that I realise that I may withdraw at any time without penalty.

7. Participation in this project will not lead to additional costs for myself and that I will not benefit from it financially.

I HEREBY DECLARE THAT I WILL VOLUNTARILY PARTICIPATE IN THE ABOVE FOCUS GROUP AS PART OF A RESEARCH PROJECT ON LOCOMOTOR DISABILITY

Signed at (address) on 2003

.....
Participant's signature

.....
Witness

IMPORTANT INFORMATION

Dear Participant

Thank you for your participation in this study. Should you have any questions during the duration of this study regarding:

1. problems as a result of the research, or
2. questions regarding information about the project

please contact me at the following telephone number: 406-6402
083-697-9118

**Mrs M J Futter
Senior Lecturer**

University of Cape Town

INLIGTING OMTRENT FOKUS GROEP EN TOESTEMMINGSVORM
PROBLEME WAT PERSONE MET PERMANENTE FISIESE GESTREMDHEDE ONDERVIND
EN IN LOTUS RIVIER WOON

VERKLARING DEUR VERTEENWOORDIGER

Ek, tans van (adres)
 bevestig dat:

1. Ek is genooi om deel te neem aan die bogenoemde navorsings projek deur die Universiteit van Kaapstad.
- 2.1 Dit is aan my verduidelik dat die doelwitte van die studie is om:
 - Die verskillende probleme wat persone met permanente fisiese gestremdhede ondervind te identifiseer
 - Al die faktore wat bydra tot hierdie probleme te ondersoek.
- 2.2 Dit is aan my verduidelik dat ek deel van n' fokus groep sal wees wat ontmoet om die bogenoemde te bespreek.
- 2.3 Ek is bewus daarvan dat dit 'n eenmalige prosedure sal wees in 2003 op 'n tyd wat vir my gerieflik is.
- 3.1 Dit is aan my verduidelik dat alle inligting vertroulik hanteer sal word. Die inligting mag wel gebruik word vir 'n tesis, publikasie in wetenskaplike tydskrifte en die aanbied van professionele lesings, maar dat geen name en name van fokus groepe gebruik sal word nie.
- 3.2 Dit is aan my verduidelik dat die bevindings van die ondersoek omtrent die behoeftes van mense met permanente fisiese gestremdhede aan die beamptes van Maatskaplike en Gesondheids dienste bekend sal word.
4. Ek is ingelig dat ek mag weier om aan die projek deel te neem en ook ter enige tyd tydens die projek mag onttrek sonder dat dit my enigsins negatief sal beïnvloed in die toekoms.
5. Bogenoemde inligting is aan my verduidelik/vertaal deur in Afrikaans/Engels. Dit is 'n taal wat ek goed verstaan en praat en al my vrae is in hierdie taal volledig en bevredigend beantwoord.
6. Ek is nie gedwing om aan die ondersoek deel te neem nie en is bewus daarvan dat ek ten enige tyd mag onttrek sonder enige benadeling van my regte.
7. Deelname aan die projek sal geen finansiële koste vir my meebring nie en ek besef dat ek geen finansiële voordeel sal ontvang uit deelname nie.

HIERMEE VERKLAAR EK DAT EK VRYWILLIG AAN DIE BOGENOEMDE PROJEK DEELNEEM

Geteken te (plek) op 2003

.....
Geteken deelnemer.....
Getuie**BELANGRIKE INLIGTING**

Beste Deelnemer

Dankie vir u deelname aan die studie. Indien u enige vrae het tydens die duur van die studie omtrent:

1. probleme as gevolg van die navorsing, of
2. inligting rondom die navorsingsprojek

kontak my gerus by die volgende telefoonnommers: 406-6402
083-697-9118**Me M J Futter**
Universiteit van Kaapstad

University of Cape Town

PEOPLE WITH LOCOMOTOR DISABILITIES AND THEIR CARERS LIVING IN LOTUS RIVER

QUESTIONNAIRE

SECTION A DEMOGRAPHIC DATA

Family name: First name:

Address:

Telephone:

1. Gender: Male¹ Female² A1
2. Respondent: Self¹ Proxy² Both³ A2
3. Relationship of proxy to person with disability: Spouse¹ Child² Parent³ Relative⁴
Other⁵: specify A3
4. Age of disabled person at time of interview: A4
5. Family status: Single¹ Widowed² Married/Partner³
Divorced⁴ A5
6. How many children do you have: A6

Educational level

7. Did you go to a special school for disabled children? Yes¹ No² N/A³ A7
8. Highest grade reached at school: A8
9. Diploma or technical training (one year or more): Yes¹ No² A9
10. Short formal courses (less than a year): specify Yes¹ No² A10
11. In-service training: specify Yes¹ No² A11
12. Informal training: specify Yes¹ No² A12
13. Other: specify Yes¹ No² A13
14. Why did you leave school/college?
Lack of money¹ Lack of interest² School did not go further³
No accessible school⁴ No transport⁴ To help mother with housework⁵
To help support the family⁶ Other⁷: specify A14

SECTION B PROBLEMS EXPERIENCED

The following problems affect many people with disabilities living in this area. How much does each of them affect you?

	No problem 1	Mild problem 2	Moderate problem 3	Severe problem 4	Complete problem 5	
1. Lack of money						B1
2. Transport						B2
3. Housing						B3
4. Safety						B4
5. Unemployment						B5
6. Isolation and loneliness						B6
7. Privacy						B7
8. Health Services						B8
9. Social Services						B9

	No problem 1	Mild problem 2	Moderate problem 3	Severe problem 4	Complete problem 5	
10. Domestic assistance						B10
11. Attitude of the community						B11
12. Accessibility						B12
13. Abuse						B13
14. Health						B14
15. Other: specify						B15

SECTION C	DISABILITY PROFILE
------------------	---------------------------

1. Cause of disability: Congenital¹ Disease² Injury³ Violence⁴
2. Medical condition or brief description of disability:
3. For how many years have you been disabled:

C1
C2
C3

HEALTH ASSESSMENT QUESTIONNAIRE (HAQ)

In this section we are interested in learning how your disability affects your ability to function in daily life and why you are unable to do certain functions. Please feel free to add any comments at the end of this section.

- ♦ Please check the one response which best describes your abilities over the past week:

(Circle one number on each line)

	Without any difficulty	With some difficulty	With much difficulty	Unable to do	
DRESSING & GROOMING					
Are you able to:					
Dress yourself including tying your shoelaces and doing your buttons?	0	1	2	3	C4
Shampoo your hair?	0	1	2	3	C6
GETTING UP					
Are you able to:					
Stand up from an armless chair?	0	1	2	3	C13
Get in and out of bed?	0	1	2	3	C15
EATING					
Are you able to:					
Cut your own meat?	0	1	2	3	C22
Lift a full cup or glass to your mouth?	0	1	2	3	C24
Open a new milk carton?	0	1	2	3	C26
WALKING					
Are you able to:					
Walk outdoors on flat ground?	0	1	2	3	C33
Climb up and down five stairs?	0	1	2	3	C35

37. Please check any Aids or Devices that you usually use for any of the above activities:

_____1 Walking stick
_____2 Walker

_____6 Devices Used for Dressing (button hook, zipper pull, long-handled shoe horn, etc)

_____3 Crutches _____7 Built Up or Special Utensils
 _____4 Wheelchair _____8 Special or Built Up Chair
 _____5 Other (specify) _____9

38. Please check any categories for which you usually need help from another person:

_____1 Dressing & Grooming _____3 Eating
 _____2 Getting up _____4 Walking

• Please check the one response which best describes your abilities over the past week:

(Circle one number on each line)

	Without any difficulty	With some difficulty	With much difficulty	Unable to do	
HYGIENE					
Are you able to:					
Wash and dry your entire body?	0	1	2	3	C42
Bath in a proper bath/shower?	0	1	2	3	C44
Get on and off the toilet?	0	1	2	3	C46
REACH					
Are you able to:					
Reach and get down a 2.5 kg object such as a bag of sugar from just above your head?	0	1	2	3	C53
Bend down to pick up clothing from the floor?	0	1	2	3	C55
ACTIVITIES					
Are you able to:					
Run errands and shop?	0	1	2	3	C62
Get in and out of a car?	0	1	2	3	C64
Do chores such as housework or gardening?	0	1	2	3	C66

68. Please check any Aids or Devices that you usually use for any of the above activities:

_____1 Raised Toilet Seat _____4 Bathtub Bar
 _____2 Bathtub Seat _____5 Long-handled Appliances for Reach
 _____3 Jar Opener (for jars previously opened) _____6 Long-handled Appliances in Bathroom
 _____7 Other (specify) _____

69. Please check any categories for which you usually need help from another person:

_____1 Hygiene _____3 Gripping and Opening Things
 _____2 Reach _____4 Errands and Chores

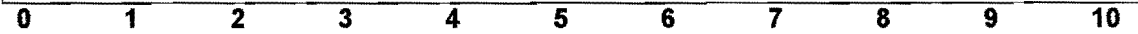
We are also interested in learning whether or not you are affected by pain because of your disability.

70. How much pain have you had because of your disability over the past week?

NO PAIN

VERY SEVERE PAIN

Place a mark on the line to indicate the severity of the pain



C71

Comments of disabled person

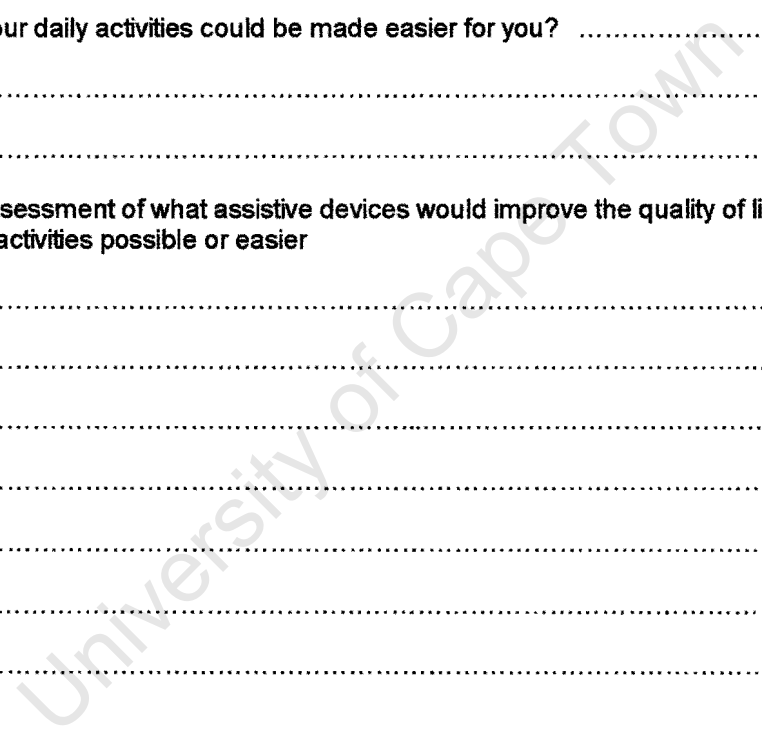
71. How do you think your daily activities could be made easier for you?

72. Physiotherapist's assessment of what assistive devices would improve the quality of life of the disabled person by making daily activities possible or easier

.....

C72

Comments



ASSISTIVE DEVICES

Which of the following assistive devices do you have in the house? (Must be seen or accounted for and filled in on the list below)

KEY FOR FREQUENCY OF USE
 1. Daily
 2. 2 – 3 times per week
 3. Once per week
 4. Once per month
 5. Irregularly
 6. Never

KEY FOR STATE OF REPAIR
 1. Good
 2. Functional
 3. Repairable
 4. Irreparable

KEY FOR NOT BEING USED OPTIMALLY
 1. Inappropriate for house
 2. Inappropriate for disability
 3. In need of repair
 4. In need of replacement
 5. More suitable assistive device available

Assistive device	Where received	When	Frequency of use (see key)	State of repair (see key)	Reason(s) for not being used (see key)
Wheelchair	C73	C74	C75	C76	C77
Motorised wheelchair	C78	C79	C80	C81	C82
Walking frame	C83	C84	C85	C86	C87
Axillary Crutches	C88	C89	C90	C91	C92
Elbow crutches	C93	C94	C95	C96	C97
Walking sticks	C98	C99	C100	C101	C102
Tripods	C103	C104	C105	C106	C107
Quadrupeds	C108	C109	C110	C111	C112
Prosthesis	C113	C114	C115	C116	C117
Orthosis	C118	C119	C120	C121	C122
Bath board	C123	C124	C125	C126	C127
Dressing devices	C128	C129	C130	C131	C132
Callipers	C133	C134	C135	C136	C137
Other: specify	C138	C139	C140	C141	C142

Comments and recommendations

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SECTION D	FINANCIAL
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1. Do you receive a disability grant or an Old Age pension? Yes¹ No²
 If 'Yes' explain in your own words, why you need to receive a disability grant
2. How do you supplement your disability grant or Old Age pension? Family¹ No other income²
 Other³: specify
3. For how many years have you received a Disability Grant and/or Old Age pension?
4. How many in the dwelling jointly contribute to the family income?
5. How are they related to you? Spouse/partner¹ Children² Parents³ Family⁴ Other⁵
6. Do you or your family get rent from rental of rooms or a backyard shack? Yes¹ No²
7. Do you believe that your disability has been a financial burden on your family? Yes¹ No²
 If 'Yes' specify in which way

D1

D2

D3

D4

D5

D6

D7

Financial problems affect many people with disabilities living in this area. How much does each of the following affect you?

Money to pay for	No problem 1	Mild problem 2	Moderate problem 3	Severe problem 4	Complete problem 5	
Food						D8
Clothes						D9
Rental/bond						D10
Water and fuel						D11
School fees						D12
Transport						D13
Special needs for the disabled						D14
The need to be independent						D15
Other: specify						D16

SECTION E	TRANSPORT
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Which form of transport do you use regularly?

	For medical purposes 1	For shopping 2	For busi- ness 3	For recreation 4	For social contact 5	For disability pay-point 6	
None - do not leave home							E1
Wheelchair							E2
Own vehicle							E3
Vehicle in the household							E4
Vehicle of family or friend							E5
Train							E6
Bus							E7
Taxi							E8
Dial-a-ride							E9
Other: specify							E10

If 'None' specify why you do not use any transport

TRAIN

What problems do you experience with the train?

	No problem 1	Mild problem 2	Moderate problem 3	Severe problem 4	Complete problem 5	
Distance from the station						E17
Overhead bridges/subways						E18
Train fare						E19
Paying for helper too						E20
No ramps at station entrance						E21
Incline of ramps too steep						E22
Metal pole in middle of door entrances						E23
Gap between platform and coach floor						E24
Height between platform and coach floor						E25
Train drivers and ticket inspectors unsympathetic and unhelpful						E26
Doors close without consideration of disabled people						E27
Peak hours - passengers push disabled people aside so that they can get in first						E28
Off peak hours – criminal elements take advantage of disabled people						E29
Information regarding timetables and changes of service inaccessible						E30
Other: specify						E31

WHEELCHAIR (This section to be completed by wheelchair users only)

What problems do you experience when using your wheelchair as a form of transport?

	No problem 1	Mild problem 2	Moderate problem 3	Severe problem 4	Complete problem 5	
Wheelchair breaks						E38
Steps to house						E39
Rough terrain from house to pavement						E40
Pavement kerb step						E41
Rough terrain on pavements						E42
Distance to businesses and social occasions						E43
No ramps to buildings						E44
Incline of ramps too steep						E45
Counters in post office and shops too high						E46
Vulnerability to criminals						E47
Other: specify						E48

PRIVATE VEHICLES

What problems do you experience with the vehicle of your family or friends?

	No problem 1	Mild problem 2	Moderate problem 3	Severe problem 4	Complete problem 5	
Money charged by friends						E55
Unavailable when needed by disabled						E56
Public ignores designated parking bays for disabled						E57
Other: specify						E58

BUS

What problems do you experience with the bus?

	No problem 1	Mild problem 2	Moderate problem 3	Severe problem 4	Complete problem 5	
Distance from the bus route						E66
Costs						E67
Assistant also has to pay in full						E68
Unable to negotiate steps to enter						E70
Bus drivers impatient and do not wait for disabled to get seated						E71
Bus drivers impatient and do not wait for disabled to get off						E72
Bus drivers unsympathetic and do not assist disabled						E73
Bus drivers rude						E74
Information regarding service inaccessible						E75
Vulnerability to criminal element while waiting at bus stops						E76
Dial-a-ride too expensive						E77
Unable to obtain booking with Dial-a-ride because of demand						E78
Dial-a-ride unreliable						E79
Information regarding Dial-a-ride inaccessible						E80
Bus drivers unsympathetic and do not assist disabled						E81
Bus drivers rude						E82
Vulnerability to criminal element while waiting at Dial-a-ride stops						E83
No telephone to contact Dial-a-ride						E84
Other: specify						E85

TAXI

What problems do you experience with the taxis?

	No problem 1	Mild problem 2	Moderate problem 3	Severe problem 4	Complete problem 5	
Distance from the taxi route						E91
Costs						E92
Assistant also has to pay in full						E93
Pay for wheelchair space						E94
Difficulty in getting in and out						E95
Drivers attitude - rude, impatient, not keen to help						E96
Dangerous driving						E97
Refuse to stop if they see a disabled person in a wheelchair						E98
Other: specify						E99

SECTION F**HOUSING**

1. Is the dwelling	self-constructed ¹	built by the council ²	F1		
2. Type of dwelling:	house ¹	flat ²	backyard shack ³	F2	
3. Do you or a family member:	own your home ¹	rent the home ²	F3		
4. Do you live with:	as a boarder ¹	legal or common law spouse ²	parents ³	F4	
	siblings ⁴	children ⁵	relatives ⁶	friends ⁷	F5
5. How many rooms does the dwelling have?			F6		
6. How many people permanently live in the household?:			F10		
8. In total, how many people live in the:			F11		
main house					
backyard shack					

The following housing problems affect many people with disabilities living in this area. How much does each of them affect you?

	No problem 1	Mild problem 2	Moderate problem 3	Severe problem 4	Complete problem 5	
Waiting list very long for own house						F13
Confusion about waiting lists of South Peninsula Municipality and Ministry of Housing, PAWC						F14
House leaks in winter						F15
House cold in winter						F16
House damp in winter						F17
Cold cement floors						F18
Leaking drain pipes						F19
Overcrowding						F20
No privacy						F21
Size of rooms for walkers and w/chairs						F22
Steps inside the dwelling						F23

Steps outside the dwelling					F24
No running water					F25
No running hot water					F26
Outside toilet					F27
No bathroom					F28
Bathroom too small for wheelchair					F29
Bathroom badly designed for wheelchair					F30
Height of bath					F31
Height of basin					F32
Height of toilet					F33
Unable to use taps					F34
Height of light switches					F35
Height of window handles					F36
Unable to use door handles					F37
Rough terrain surrounding the house					F38
House unsafe against criminals					F39
Landlords exploit tenants by high rentals					F40
Noise from neighbours					F41
Other: specify					F42

SECTION G**EMPLOYMENT**

1. Were you employed before you became disabled?	Yes ¹	No ²	N/A ³	G1
If 'Yes' what type of work did you do?				
2. Was your rehabilitation geared towards:	Yes ¹	No ²	No rehab ³	G2
Getting you independent in the house	Yes ¹	No ²	N/A ³	G3
Getting you employed	Yes ¹	No ²		G4
3. Are you presently employed?	Yes ¹	No ²		G5
If 'Yes' what type of work do you do?				
4. Employment sector:	Formal sector ¹	Protected workshop ²	Informal workshop ³	G6
	Other ⁴ : specify			G7
5. Does this support you:	Completely ¹	More than half ²	Less than half ³	Not at all ⁴
6. If you are presently unemployed do you have any marketable skills?	Yes ¹	No ²		G8
7. If 'Yes' specify				G9
8. In your opinion are you able to work?	Yes ¹	No ²		G10
If 'No' tick the appropriate blocks below as to why you are not employed:				
Physical disability				G11
Tolerating stress				G12
Tolerating noise				G13
Feeling under the weather				G14
Getting out of breath easily				G15
Tolerating light				G16
Level of education				G17
Age				G18
Other: specify				G19

If 'Yes' tick the appropriate blocks below as to why you are not employed:

- Unable to find employment
- Public transport inaccessible
- Work buildings inaccessible
- Disabled parking bays not close to place of work
- Employees do not want to employ disabled people
- Level of education
- Other: specify

G20
G21
G22
G23
G24
G25
G26

SECTION H SOCIAL SUPPORT

THE MEDICAL OUTCOMES STUDY SOCIAL SUPPORT SURVEY (MOS)

People sometimes look to others for companionship assistance, or other types of support. How often is each of the following kinds of support available to you if you need it?

(Circle one number on each line)

	None of the time	A little of the time	Some of the time	Most of the time	All of the time	
Someone to help you if you have to stay in bed	1	2	3	4	5	H2
Someone you can count on to listen to you when you need to talk	1	2	3	4	5	H3
Someone to give you good advice about a crisis	1	2	3	4	5	H4
Someone to take you to the doctor if you needed it	1	2	3	4	5	H5
Someone who shows you love and affection	1	2	3	4	5	H6
Someone to have a good time with	1	2	3	4	5	H7
Someone to give you information to help you understand a situation	1	2	3	4	5	H8
Someone to confide in or talk to about yourself or you personal problems	1	2	3	4	5	H8
Someone who hugs you	1	2	3	4	5	H10
Someone to get together with for relaxation	1	2	3	4	5	H11
Someone to prepare your meals if you were unable to do it yourself	1	2	3	4	5	H12
Someone whose advice you really want	1	2	3	4	5	H13
Someone to do things with to help you get you mind off things	1	2	3	4	5	H14
Someone to help with your daily chores if you were sick	1	2	3	4	5	H15
Someone to share your most private worries and fears	1	2	3	4	5	H16
Someone to turn to for suggestions about how to deal with a personal problem	1	2	3	4	5	H17
Someone to do something enjoyable with	1	2	3	4	5	H18
Someone who understands your problems	1	2	3	4	5	H19
Someone to love and make you feel wanted	1	2	3	4	5	H20

Additional comments

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SOCIAL CONTACTS

21. How many families in your neighbourhood do you know well enough that you visit each other in your homes? H21
22. About how many close friends and relatives do you have? (People who you feel at ease with and can talk with about what is on your mind?) H22
23. During the past month about how often have friends visited you in your home?
 Every day¹ Several days a week² Once a week³ Two or 3 times during the past month⁴ Once in the past month⁵ Not at all⁶ H23
24. How do you feel about this number of visits?
 Happy¹ Don't mind² Would like more visits³ Would like fewer visits⁴ H25
25. During the past month about how often have you visited friends in their homes?
 Every day¹ Several days a week² Once a week³ Two or 3 times during the past month⁴ Once in the past month⁵ Not at all⁶ H26
26. How do you feel about this number of visits?
 Happy¹ Don't mind² Would like more visits³ Would like fewer visits⁴ H27
27. During the past month about how often did you talk with close friends or relatives on the telephone?
 Every day¹ Several days a week² Once a week³ Two or 3 times during the past month⁴ Once in the past month⁵ Not at all⁶ No telephone⁷ H28
28. How many social groups or organisations (church groups, clubs, parent groups) do you attend each month?
 Specify
29. How regularly do you attend these? Once per week¹ Once per month² Other³ Specify H29
30. How many social groups or organisations (church groups, clubs, parent groups) visit you each month?
 Specify
31. Do you know of any social or support groups that are available to you? Yes¹ No²
 If 'No' would you like to join a group if there is one available? Yes¹ No² H30
32. Do you belong to any disability groups which influence policies regarding the physically disabled? Yes¹ No² H31
33. Some people are happy with the amount of social contact they have. Others would like more company and some don't mind either way. How do you feel about the amount of company you have?
 Happy¹ Don't mind² Would like more company³ Would like less company⁴
 Specify
34. Do you believe that your disability has been a social burden on your family? Yes¹ No² H32
- H33
- H34
- H36
- H38
- H40
- H41
- H42

35. Which of the following have a negative impact on the amount of your socialisation?

	No problem 1	Mild problem 2	Moderate problem 3	Severe problem 4	Complete problem 5	
Your physical disability						H43
Steps to your dwelling						H44
Steps to your friends' dwellings						H45
Steps to buildings in the community						H46
Inaccessible toilets in public buildings						H47
Steps to church						H48
Pavement steps						H49
Rough, uneven pavement surfaces						H50
Transport difficulties						H51
Fear of criminals						H52
No money						H53
Lack of social groups						H54
Lack of support groups						H55
Other: specify						H56

SECTION J

HEALTH SERVICES

PRESENT UTILISATION OF HEALTH SERVICES

Which health services do you use regularly?

- | | | | |
|---|------------------|-----------------|--|
| 1. District sister at the clinic | Yes ¹ | No ² | |
| How regularly: Weekly ¹ Monthly ² Annually ³ When necessary ⁴ | | | |
| 2. District sister visiting your home | Yes ¹ | No ² | |
| How regularly: Weekly ¹ Monthly ² Annually ³ When necessary ⁴ | | | |
| 3. Doctor at the clinic | Yes ¹ | No ² | |
| How regularly: Weekly ¹ Monthly ² Annually ³ When necessary ⁴ | | | |
| 4. Private doctor | Yes ¹ | No ² | |
| How regularly: Weekly ¹ Monthly ² Annually ³ When necessary ⁴ | | | |
| 5. Orthopaedic aftercare sister | Yes ¹ | No ² | |
| How regularly: Weekly ¹ Monthly ² Annually ³ When necessary ⁴ | | | |
| 6. Victoria, Somerset Hospitals, etc (Secondary Hospitals) | Yes ¹ | No ² | |
| How regularly: Weekly ¹ Monthly ² Annually ³ When necessary ⁴ | | | |
| 7. Groote Schuur, Tygerberg, Red Cross Hospitals | Yes ¹ | No ² | |
| How regularly: Weekly ¹ Monthly ² Annually ³ When necessary ⁴ | | | |
| 8. Traditional Healer, Faith Healer | Yes ¹ | No ² | |
| How regularly: Weekly ¹ Monthly ² Annually ³ When necessary ⁴ | | | |
| 9. Do you receive medication regularly? | Yes ¹ | No ² | |
| 10. From which institution(s)? | | | |
| 11. Are there any other health services that are important to meet your needs that are not listed above? | Yes ¹ | No ² | |
| If 'Yes' specify | | | |

J1
J2
J3
J4
J5
J6
J7
J8
J9
J10
J11
J12
J13
J14
J15
J16
J17
J18
J20
J21

NEEDS WITH REGARD TO THE HEALTH SERVICES

How great a problem are the following aspects to you, personally?

	No problem 1	Mild problem 2	Moderate problem 3	Severe problem 4	Complete problem 5	
Regular visits by the district sister						J22
Distance to the clinic						J23
Transport to the clinic						J24
Able to go to the clinic without somebody to assist you						J25
No privacy						J26
Staff are uncaring						J27
Staff do not have enough time for you						J28
Staff do not listen to what you say						J29
Staff are disinterested in you as a person						J30
Staff make decisions for you without fully explaining matters to you						J31
The opportunity of talking to someone about your condition						J32
Not having the opportunity of talking to someone about your health condition						J33
Costs of health care						J34
Long waiting time						J35
Other: specify						J36

SECTION K SOCIAL SERVICES

How important are these problems to you?

	No problem 1	Mild problem 2	Moderate problem 3	Severe problem 4	Complete problem 5	
Amount of the disability grant						K42
Information on disability grants and pay grants inaccessible						K43
Pay-point for your disability grant has long queues						K44
Pay-point is unsafe						K45
Not having sufficient visits from a social worker						K46
Not having the opportunity of talking to someone about your situation						K47
Not having someone to help care for you						K48
Not having someone to help with the housework and shopping						K49
Transport to reach social worker						K50
Transport to reach disability pay point						K51
Not knowing groups that provide inter-action with other people with disabilities						K52

Not knowing groups that provide interaction with non disabled people						K53
Not knowing groups that provide support for your family						K54
Needing training to learn an occupation						K55
Needing help with setting up your own business						K56
Other: specify						K57

Would you like to know more about all the relevant services that are available to people with disabilities that may be of benefit to you? Yes ¹ No ² K58

Disabled person informed of the following services, contact people and telephone numbers:

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SECTION L ATTITUDE OF COMMUNITY TOWARDS YOU

1. How often do you go out in public – in the street, shopping, church, doing business, going to movies, etc Never ¹ Seldom ² Sometimes ³ Often ⁴ L1
2. Where do you go on a regular basis? Visit people in the area ¹ Church ² Shops ³ Clinic ⁴ L2
3. Since you became disabled have the attitude of the people in the community changed toward you? Yes ¹ No ² N/A ³ L3
 If "Yes" specify L4
4. How do people in your community react to you? Friendly ¹ Unfriendly ² L5
5. How do people in your community react to you? Want to protect you ¹ Ignore you ² As though you are different ³ Stare ⁴ L6
6. How do people in your community react to you? Helpful ¹ Unhelpful ² Ignore you ³ L7
7. How do people in your community react to you? Offer to help ¹ Always willing to help if you ask them ² Sometimes will help if you ask ³ React as if they think you do not need any help ⁴ Find excuses so they do not have to help ⁵ Refuse to help ⁶ L8
8. Do you prefer to stay at home because of the negative reaction of people with whom you come into contact? Yes ¹ No ² L9
9. When you are in public do you prefer to use: Crutches ¹ A wheelchair ² N/A ³ L10
 Specify why
10. Public ignore parking bays designated for the use of disabled people Never ¹ Seldom ² Sometimes ³ Often ⁴ L11
11. How do you think people in the community think that you should behave as a disabled person? Take part in community activities just like any body else ¹ Attend but join in only some community activities ² Attend but not join in any community activities ³ Not attend community activities at all ⁴ L12

12. What are the attitudes of the community towards you with regard to the following:

	No problem 1	Mild problem 2	Moderate problem 3	Severe problem 4	Complete problem 5	
That you are somebody who should be pitied						L13
That they are embarrassed by your disability						L14
That you should not be able to have intimate relationships with people of the opposite sex						L15
That you should not be able to get married						L16
That you will not be able to look after a husband/wife/partner						L17
That you will not be able to care for a house and cook						L18
That you will not be able to provide for your husband/wife/partner						L19
That you should not be able to have children if you want to						L20
That you will not be able to care for children						L21
Other: specify						L22

13. Which of the following do you think would help to increase the community's awareness of people with physical disabilities?

(Place a tick next to the blocks)

Teaching children at school about disability						L28
Making disabled people more visible by making it easier for them to access public buildings						L30
Making special attempts to include disabled people in all community functions						L31
Regular features on disability in the local newspaper						L32
Regular programmes on the radio on disability						L33
Regular programmes on TV to highlight the difficulties experienced by disabled people						L34
Disabled people joining social groups in the community						L35
Recreational activities that include disabled people						L36
Other: specify						L37

SECTION M

ENVIRONMENTAL BARRIERS

	No problem 1	Mild problem 2	Moderate problem 3	Severe problem 4	Complete problem 5	
Your physical disability						M1
Steps to your dwelling						M2
Not enough special disabled parking bays						M3
Ramps to buildings in the community						M4
Incline of ramps too steep						M5

Inaccessible toilets in public buildings						M6
Pavement steps						M7
Rough terrain on pavement surfaces						M8
Shop, post office and bank counters too high						M9
Entrance to shops inaccessible						M10
Check-out counters at shops inaccessible						M11
Public telephones too high						M12
Autobanks too high						M13
Transport						M14
Fear of criminals						M15
Other: specify						M16

SECTION N**ABUSE**

People with disabilities are often abused sometime during their lives. This abuse can take the form of physical, emotional or psychological abuse.

State how much of a problem the following have been for you as a disabled child?

	N/A 0	No problem 1	Mild problem 2	Moderate problem 3	Severe problem 4	Complete problem 5	
Physical abuse by other children							N1
Psychological abuse by other children							N3
Sexual abuse by other children							N5
Physical abuse by community persons							N7
Psychological abuse by community persons							N9
Sexual abuse by community persons							N11
Physical abuse by a family member							N13
Psychological abuse by a family member							N15
Sexual abuse by a family member							N17
Other form of abuse							N19

State how much of a problem the following have been for you as a disabled adult?

	No problem 1	Mild problem 2	Moderate problem 3	Severe problem 4	Complete problem 5	
Physical abuse by community persons						N28
Psychological abuse by community persons						N30
Sexual abuse by community persons						N32

	No problem 1	Mild problem 2	Moderate problem 3	Severe problem 4	Complete problem 5	
Physical abuse by a family member						N34
Psychological abuse by a family member						N36
Sexual abuse by a family member						N38
Other form of abuse						N40

SECTION P	DISCRIMINATION
------------------	-----------------------

1. When you were growing up did your family try and hide you from the community? Yes¹ No²
2. When you were growing up were you given the same schooling as your able-bodied sisters? Yes¹ No²
3. When you were growing up were you given the same schooling as your able-bodied brothers? Yes¹ No²
4. When you were growing up did your parents treat you the same as your able-bodied sisters? Yes¹ No²
5. When you were growing up did your parents treat you the same as your able-bodied brothers? Yes¹ No²

Comments

.....

.....

SECTION Q	DECISION-MAKING
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1. Who cared for you mostly when you were a child?
Father¹ Mother² Other³: specify
2. Who made all the decisions about your education, medical treatment and rules about going out with friends and what time to come home?
Father¹ Mother² Other³: specify
3. Who makes all the decisions about your life now that you are an adult?
Self¹ Spouse² Father² Mother³ Other⁴: specify
If not "Self" is the person your carer? Yes¹ No²

Comments

.....

.....

SECTION R	DISABLED PERSONS' KNOWLEDGE OF PATIENTS' RIGHTS AND RESPONSIBILITIES
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- | | | | |
|--|------------------|-----------------|----------------------------------|
| 1. Are you aware that there is a Disability Rights Charter of South Africa which is a document which declares that all disabled people have the right to live independently in a safe environment and in a society which is free from all forms of discrimination, exploitation and abuse? | Yes ¹ | No ² | <input type="text" value="R1"/> |
| 2. Do you know that Mr. Joseph Williams works for the Unicity Disability Desk in Cape Town and that he is there specially to protect the rights of Disabled People and to monitor gender issues? | Yes ¹ | No ² | <input type="text" value="R2"/> |
| 3. Are you aware that there is a new law called the Employment Equity Act which encourages people with disabilities to get employed? | Yes ¹ | No ² | <input type="text" value="R3"/> |
| 4. Are you aware that if people with disabilities are employed their employee has the responsibility of ensuring that they receive the same benefits and development opportunities as the able-bodied employees? | Yes ¹ | No ² | <input type="text" value="R4"/> |
| 5. Are you aware that every patient has the right to: | | | |
| A healthy and safe environment? | Yes ¹ | No ² | <input type="text" value="R5"/> |
| Participate in decision-making affecting your own health? | Yes ¹ | No ² | <input type="text" value="R6"/> |
| Receive emergency health care at a facility that is open regardless of whether you can pay? | Yes ¹ | No ² | <input type="text" value="R7"/> |
| Treatment and rehabilitation? | Yes ¹ | No ² | <input type="text" value="R8"/> |
| Special needs? | Yes ¹ | No ² | <input type="text" value="R9"/> |
| Counselling? | Yes ¹ | No ² | <input type="text" value="R10"/> |
| A positive attitude by health care providers? | Yes ¹ | No ² | <input type="text" value="R11"/> |
| Health information? | Yes ¹ | No ² | <input type="text" value="R12"/> |
| Know the name of the health care provider who treats you? | Yes ¹ | No ² | <input type="text" value="R13"/> |
| Confidentiality and privacy concerning your health? | Yes ¹ | No ² | <input type="text" value="R14"/> |
| Full and accurate information regarding your health? | Yes ¹ | No ² | <input type="text" value="R15"/> |
| Refusal of treatment? | Yes ¹ | No ² | <input type="text" value="R16"/> |
| Continuity of health care? | Yes ¹ | No ² | <input type="text" value="R17"/> |
| Complain about health services? | Yes ¹ | No ² | <input type="text" value="R18"/> |
| 6. Do you know that every patient has the following responsibilities? | | | |
| To take care of your own health? | Yes ¹ | No ² | <input type="text" value="R19"/> |
| To care for and protect the environment? | Yes ¹ | No ² | <input type="text" value="R20"/> |
| To respect the rights of other patients and health providers? | Yes ¹ | No ² | <input type="text" value="R21"/> |
| To utilise the health care system and not abuse it? | Yes ¹ | No ² | <input type="text" value="R22"/> |
| To know your local health services and what they offer? | Yes ¹ | No ² | <input type="text" value="R23"/> |
| To provide health care providers with the relevant and accurate information for treatment and rehabilitation purposes? | Yes ¹ | No ² | <input type="text" value="R24"/> |
| To comply with the prescribed treatment and rehabilitation procedures? | Yes ¹ | No ² | <input type="text" value="R25"/> |
| To take care of health records in your possession? | Yes ¹ | No ² | <input type="text" value="R26"/> |

DISABLED PEOPLES' KNOWLEDGE OF HIV/AIDS

- | | | | |
|---|------------------|-----------------|----------------------------------|
| 1. Do you know about HIV/AIDS? | Yes ¹ | No ² | <input type="text" value="R27"/> |
| 2. Do you know what causes HIV/AIDS?
Explain to me, briefly what causes HIV/AIDS | Yes ¹ | No ² | <input type="text" value="R28"/> |

11. Were you ever taught how to care for the disabled person?

Yes ¹ No ²

S33

If "Yes", by whom, where, and when?

.....

.....

.....

12. How many hours per day do you spend looking after the person with a disability?

S34

CAREGIVER BURDEN SCALE (CBS)♦ Please check the one response which best describes your feelings over the past week:

(Tick one block on each line)

	Not at all 1	Seldom 2	Some- Times 3	Often 4	
GENERAL STRAIN					
Do you find yourself facing practical problems in the care of your relative that you think are difficult to solve?	1	2	3	4	S35
Do you think you have to take too much responsibility for your relative's welfare?	1	2	3	4	S36
Do you sometimes feel as if you would like to run away from the entire situation you find yourself in?	1	2	3	4	S37
Do you feel tired and worn out?	1	2	3	4	S38
Do you feel tied down by your relative's problems?	1	2	3	4	S39
Do you find it mentally tiring to take care of your relative?	1	2	3	4	S40
Do you think your own health has suffered because you have been taking care of your relative?	1	2	3	4	S41
Do you think you spend so much time with your relative that you do not have enough time for yourself?	1	2	3	4	S42
ISOLATION					
Do you avoid inviting friends and acquaintances home because of your relative's problem?	1	2	3	4	S43
Has your social life, e.g. with family and friends, been reduced?	1	2	3	4	S44
Has your relative's problem prevented you from doing what you had planned to do in this phase of your life?	1	2	3	4	S45
DISAPPOINTMENT					
Do you feel that life has treated you unfairly?	1	2	3	4	S46
Did you expect that your life would be different from what it is at your age?	1	2	3	4	S47
Do you feel lonely and isolated because of your relative's problem?	1	2	3	4	S48

	Not at all 1	Seldom 2	Some- Times 3	Often 4	
Do you find it physically tiring to take care of your relative?	1	2	3	4	S49
Have you had to make financial sacrifices because you have been taking care of your relative?	1	2	3	4	S50
EMOTIONAL INVOLVEMENT					
Are you sometimes ashamed or embarrassed by your relative's behaviour?	1	2	3	4	S51
Do you ever feel hurt and angry with your relative?	1	2	3	4	S52
Do you feel embarrassed by your relative's behaviour?	1	2	3	4	S53
ENVIRONMENT					
Does the physical environment make it difficult for you to take care of your relative?	1	2	3	4	S54
Do you worry about not taking care of your relative in the proper way?	1	2	3	4	S55
Is there anything in the neighbourhood which makes it difficult for you to take care of your relative?	1	2	3	4	S56

MOTHER OF A CHILD WITH DISABILITIES

Do you blame yourself for the birth of your child with disabilities?	Yes ¹	No ²	S57
Do you feel your husband/partner and his family blame you for the birth of your child with a disability?	Yes ¹	No ²	S58
Are you blamed, shamed or stigmatised by the community because of the birth of your child with disabilities?	Yes ¹	No ²	S59
Because you have a child with a disability do you find that your husband/partner excludes you from social activities?	Yes ¹	No ²	S60
Because you have a child with a disability do you find that:			
- your family excludes you from social activities?	Yes ¹	No ²	S61
- the community excludes you from social activities?	Yes ¹	No ²	S62

NEEDS OF CARER

How important are these problems to you?

	No problem 1	Mild problem 2	Moderate problem 3	Severe problem 4	Complete problem 5	
Lack of money						S63
Having nobody to assist you with caring for the disabled person						S64
Having nobody to assist you with housework and shopping						S65
No personal time						S66
Loneliness						S67
Other: specify						S68

SECTION T	CARERS' KNOWLEDGE OF PATIENTS' RIGHTS AND RESPONSIBILITIES
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- | | | |
|--|----------------------------------|----------------------------------|
| 1. Are you aware that there is a Disability Rights Charter of South Africa which is a document which declares that all disabled people have the right to live independently in a safe environment and in a society which is free from all forms of discrimination, exploitation and abuse? | Yes ¹ No ² | <input type="text" value="T1"/> |
| 2. Do you know that Mr. Joseph Williams works for the Unicity Disability Desk in Cape Town and that he is there specially to protect the rights of Disabled People and to monitor gender issues? | Yes ¹ No ² | <input type="text" value="T2"/> |
| 3. Are you aware that there is a new law called the Employment Equity Act which encourages people with disabilities to get employed? | Yes ¹ No ² | <input type="text" value="T3"/> |
| 4. Are you aware that if people with disabilities are employed their employee has the responsibility of ensuring that they receive the same benefits and development opportunities as the able-bodied employees? | Yes ¹ No ² | <input type="text" value="T4"/> |
| 5. Are you aware that every patient has the right to: | | |
| A healthy and safe environment? | Yes ¹ No ² | <input type="text" value="T5"/> |
| Participate in decision-making affecting your own health? | Yes ¹ No ² | <input type="text" value="T6"/> |
| Receive emergency health care at a facility that is open regardless of whether you can pay? | Yes ¹ No ² | <input type="text" value="T7"/> |
| Treatment and rehabilitation? | Yes ¹ No ² | <input type="text" value="T8"/> |
| Special needs? | Yes ¹ No ² | <input type="text" value="T9"/> |
| Counselling? | Yes ¹ No ² | <input type="text" value="T10"/> |
| A positive attitude by health care providers? | Yes ¹ No ² | <input type="text" value="T11"/> |
| Health information? | Yes ¹ No ² | <input type="text" value="T12"/> |
| Know the name of the health care provider who treats you? | Yes ¹ No ² | <input type="text" value="T13"/> |
| Confidentiality and privacy concerning your health? | Yes ¹ No ² | <input type="text" value="T14"/> |
| Full and accurate information regarding your health? | Yes ¹ No ² | <input type="text" value="T15"/> |
| Refusal of treatment? | Yes ¹ No ² | <input type="text" value="T16"/> |
| Continuity of health care? | Yes ¹ No ² | <input type="text" value="T17"/> |
| Complain about health services? | Yes ¹ No ² | <input type="text" value="T18"/> |
| 6. Do you know that every patient has the following responsibilities? | | |
| To take care of his/her own health? | Yes ¹ No ² | <input type="text" value="T19"/> |
| To care for and protect the environment? | Yes ¹ No ² | <input type="text" value="T20"/> |
| To respect the rights of other patients and health providers? | Yes ¹ No ² | <input type="text" value="T21"/> |
| To utilise the health care system and not abuse it? | Yes ¹ No ² | <input type="text" value="T22"/> |
| To know your local health services and what they offer? | Yes ¹ No ² | <input type="text" value="T23"/> |
| To provide health care providers with the relevant and accurate information for treatment and rehabilitation purposes? | Yes ¹ No ² | <input type="text" value="T24"/> |
| To comply with the prescribed treatment and rehabilitation procedures? | Yes ¹ No ² | <input type="text" value="T25"/> |
| To take care of health records in their possession? | Yes ¹ No ² | <input type="text" value="T26"/> |

CAREGIVERS' KNOWLEDGE OF HIV/AIDS

1. Do you know about HIV/AIDS? Yes¹ No² T27
2. Do you know what causes HIV/AIDS? Yes¹ No² T28
 Explain to me, briefly, what causes HIV/AIDS
3. When a person is HIV+ does that mean that the person:
Has the HIV virus¹ Does not have the HIV virus² T29
4. Where did you learn about HIV/AIDS?
TV¹ Radio² Clinic³ Church⁴ Other⁵ specify T30

M J Futter
 11 November 2002

University of Cape Town

Dear Sir/Madam

**PROJECT FOR PEOPLE WITH PHYSICAL DISABILITIES RECEIVING A PERMANENT
DISABILITY GRANT IN LOTUS RIVER**

The Department of Social Services and Poverty Alleviation, ALLPAY Western Cape and the Department of Social Development and Division of Physiotherapy, University of Cape Town are setting up a joint project for people with physical disabilities receiving a Permanent Disability Grant and living in Retreat, Steenberg, Lotus River, Lavender Hill and Grassy Park.

The aim of the project is to investigate how you and your carers manage your daily lives, what problems you experience and in which small ways your activities of daily living can be helped.

The objectives are to:

- make you aware of your rights as a person with a disability
- make you aware of the health, social and support services that are available to you
- find out from you what services you need to improve the quality of your life.

In order to study these aspects from the grass-roots level Mrs M J Futter, a physiotherapist, or a PAYALL representative will shortly be paying you a visit to explain the project to you and offering you the opportunity of participating in it. This should take place from approximately 1 October 2002.

There is a possibility that, after your situation has been fully assessed, minor alterations could be made to your home or that you could be provided with small assistive devices to allow you to be more independent with activities of eating, dressing, bathing, using the toilet, moving around the house and walking.

All information will be treated in absolute confidence. Your name and address will not be made available for any other use and you will be able to stop participating in the project at any stage. Participation, refusal or stoppage will not in any way negatively affect your grant.

Yours sincerely

H DE GRASS

Director: Social Security
Department of Social Services
And Poverty Alleviation

A DE JONGH

Provincial Manager
ALLPAY Western Cape

M J FUTTER

Division of Physiotherapy
University of Cape Town

Geagte Meneer/Mevrou/Mejuffrou

**PROJEK TEN OPSIGTE VAN PERSONE MET FISIESE GESTREMDHEDE WAT 'n
PERMANENTE ONGESKIKTHEIDSTOELAAG ONTVANG EN IN LOTUS RIVIER WOON**

Die Departement van Maatskaplike Dienste en Armoedeverligting, ALLPAY Weskaap en die Departement van Maatskaplike Ontwikkeling en Fisioterapie Afdeling van die Universiteit van Kaapstad beplan 'n gesamentlike projek vir persone met fisiese gestremdhede wat 'n permanente ongeskiktheidstoelaag ontvang en in Retreat, Steenberg, Lotus River, Lavender Hill en Grassy Park areas woon.

Die doel van die projek is om ondersoek in te stel oor hoe u en u versorgers daaglikse oor die weg kom, watter probleme u ondervind en op watter geringe wyse u daaglikse aktiwiteite ondersteun kan word.

Die doelwitte is om:

- U bewus te maak van u regte as 'n persoon met 'n gestremdheid;
- U bewus te maak van gesondheids-, maatskaplike- en ondersteunings-dienste wat beskikbaar is; en
- Vas te stel watter dienste benodig word om u lewenskwaliteit te verbeter.

Ten einde voormelde aspekte op grondvlak te bestudeer, sal Mev. M.J. Futter, 'n fisioterapeut, of 'n ALLPAY verteenwoordiger u kortliks besoek om die projek aan u te verduidelik en om u die geleentheid te gee om aan die projek deel te neem. Hierdie besoeke sal vanaf November 2002 plaasvind.

Nadat u omstandighede ten volle evalueer is, bestaan daar 'n moontlikheid dat klein veranderinge aan u woonplek gemaak kan word of dat u van 'n klein hulpmiddel voorsien kan word. Dit sal u daartoe instaat stel om meer onafhanklik te wees met aktiwiteite soos eet van maaltye, aantrek, was en bad, gebruik van die toiletgeriewe, beweging rondom u woonplek en loop.

U inligting sal met die strengste vertroulikheid hanteer word. U naam en adres sal nie beskikbaar gemaak word vir enige ander gebruik nie en u sal die reg hê om u deelname aan die projek ter enige tyd te beëindig. Sou u verkies om nie aan die projek deel te neem nie, sal dit nie die betaling van u toelaag in enige wyse negatief geaffekteer nie.

Die uwe

Me MJ FUTTER
FISIOTERAPIE AFDELING
UNIVERSITEIT VAN
KAAPSTAD

Me V PETERSEN
HOOF VAN DIE DEPARTEMENT
MAATSKAPLIKE DIENSTE EN
ARMOEDEVERLIGTING

Mnr A DE JONGH
PROVINCIALE
BESTUURDER
ALLPAY WESKAAP

Mhlekezzi/Nkosikazi othandekayo,

**IPROJEKTI YABANTU ABAKHUBAZEKILEYO ABAFUMANA INKAMNKAM ESISIGXINA
- LOTUS RIVIER**

ISebe leeNkonzo zeNtlalo, i-ALLPAY neSebe loPhuhliso loLuntu neCandelo lokuNyanga uMzimba ngokuThambisa (Physiotherapy) leDyunivesithi yaseKapa ziqulunqa iprojekti edibeneyo yabantu abakhubazekileyo abahlala kwimimandla yaseRetreat, eSteenberg, eLotus Rive, eLavender Hill naseGrassy Park ngokwasemzimbeni abafumana iNkamnkam esisigxina.

Injongo yale projekthi kukuphanda ukuba wena nabantu abakugcinayo nibulawula njani ubomi benu bemihla ngemihla, ngxaki zini eninamava azo nokuba ningancedwa njani kwimisebenzi yenu yemihla ngemihla.

Iinjongo:

- kukukuqondisa amalungelo akho njengomntu okhubazekileyo,
- kukukwenza ukuba ube nonxibelelwano nabanye abahlangana nobunzima obufana nobu bakho namaqela okuxhasa angasekwa ukuba nifuna njalo,
- kukukuqondisa ngeenkonzo zempilo, zasekuhlaleni ezifumanekayo,
- nokuseka iinkonzo enizifunayo ukuphucula ubulunga bobomi benu.

Ukuze kufundwe ezi mbonakalo/nkangeleko kumgangatho osezantsi wokuphila, uMnu M.J. Futter, onguMnyangi woMzimba ngokuThambisa (Physiotherapist), okanye ummeli we-ALLPAY uza kunityelela kungekudala ukuchaza iprojekthi aze aninike amathuba okokuba nithathe inxaxheba kuyo. Olu tyelelo luya kwenzeka kufuphi nomhla woku-1 ku-Okthobha wonyaka wama-2002.

Kusenokwenzeka ukuba emva kokuba imeko yakho ihloliwe, iinguqulo ezincinci zingenziwa kwikhaya lakho okanye ungabonelelwa ngamacebo okukuncedisa. Oku kungakuvumela ukuba uzityele, uzinxibise, uzihlambe, uziyele kwindlu yangasese, uzula-zule apha endlwini uhamba-hambe naphandle.

Lonke ulwazi lwakho luya kuphathwa ngendlela efihlakeleyo. Igama nedilesi yakho azisoze zifumaneke ukuba zisetyenziswe nokuba kungoluphi na uhlobo kwaye uya kuba nelungelo lokuyeka ukuthatha inxaxheba nokuba kunini kule projekthi. Uhlawulo lwakho lwenkamnkam alusoze luchaphazeleke ngokuphuthileyo ukuba ukhetha ukungayithathi inxaxheba kule projekthi.

Owenu ngenene,

NKSKZ. M.J. FUTTER

ICANDELO LONYANGO LOMZIMBA NGOKUTHAMBISA
KWIDYUNIVESITHI YASEKAPA

MNU. A. DE JONGH

IMANEJALA YEPHONDO: ALLPAY WESTERN CAPE

NKSKZ. V. PETERSON

INTLOKO KWISEBE LEENKONZO ZENTLALO
NONCIPHISO LWENDLALA

LOTUS RIVER PROJECT FOR PEOPLE WITH PHYSICAL DISABILITIES**EVALUATION OF QUALITY OF LIFE SINCE RECEIVING WHEELCHAIRS AND
ASSISTIVE DEVICES****INTERVIEWS AND AUDIO RECORDINGS CONDUCTED BY MR V CARELSE, RESEARCH ASSISTANT****A. PERSON WITH DISABILITY**

1. Please state your name.
2. What assistive devices did you receive from the Lotus River Wheelchair Project?
3. In which way(s) has it affected your life?

B. CAREGIVER

4. Please state your name.
5. What assistive devices did your disabled relative receive from the Lotus River Wheelchair Project?
6. In which way(s) has it affected your life

PARTICIPANT INFORMATION AND CONSENT FORM

PROBLEMS EXPERIENCED BY PEOPLE WITH PERMANENT PHYSICAL DISABILITIES LIVING IN LOTUS RIVER

STATEMENT BY OR IN LIEU OF PARTICIPANT

I, the undersigned, living at (address) confirm that:

1. I have been invited to participate in the above mentioned research project which is initiated through the University of Cape Town.

2.1 It has been explained to me that the objectives of this study are to:

- collect demographic data with respect to age, family status, living arrangements and employment status of people with permanent physical disabilities
- explore the experiences of people with permanent physical disabilities and their carers
- investigate the felt needs of people with permanent physical disabilities and their carers
- explore the attitudes of the Lotus River community towards people with physical disabilities
- make you aware of the health, social and support services that are available to you
- find out from you what wheelchairs, mobility aids and assistive devices you require to allow you to be more independent with eating, bathing, using the toilet, moving around the house and walking.

2.2 It has been explained to me that an interview concerning my personal experience with disability will be conducted with me.

2.3 I am aware that this is a once-off procedure that will be implemented in 2003 at a time convenient for me.

3.1 It has been explained that all information will be handled confidentially. Information may be used for a thesis, a publication in scientific journals and presentation at professional congresses, but names will not be used.

3.2 It has been explained that findings from this study regarding the needs of people associated with physical disabilities will be brought to the attention of the Health and Social Welfare authorities.

4. It has been explained that I may have full access to information concerning myself that has been gathered in this study.

5. I have been informed that I may refuse to participate in this project and that I may stop participating at any stage, and that such refusal or stoppage will not in any way negatively influence my future treatment.

6. The information above has been explained to me by in English/Afrikaans/Xhosa* and that I am proficient in that language/it has been translated to me by to my satisfaction and that my questions have been answered satisfactorily.

7. I have not been forced to consent to my participation in this project and that I realise that I may stop at any time without penalty.

8. Participation in this project will not lead to additional costs for myself and that I will not benefit from it financially.

I HEREBY DECLARE THAT I WILL VOLUNTARILY PARTICIPATE IN THE ABOVE PROJECT

Signed at (address) on 2003

.....
Participant's/representative's signature

.....
Witness

IMPORTANT INFORMATION

Dear Participant

Thank you for your participation in this study. Should you have any questions during the duration of this study regarding:

1. problems as a result of the research, or
2. questions regarding information about the project

please contact me at the following telephone number: 406-6402
083-697-9118

Mrs M J Futter
Senior Lecturer

INLIGTING OMTRENT DEELNAME EN TOESTEMMINGSVORM**BENODIGHEDE VAN PERSONE MET PERMANENTE FISIESE GESTREMDHEDE IN
LOTUS RIVIER****VERKLARING DEUR DEELNEMER OF SY/HAAR VERTEENWOORDIGER**

Ek, tans van (adres)
bevestig dat:

1. Ek is genooi om deel te neem aan die bogenoemde navorsings projek deur die Universiteit van Kaapstad.
- 2.1 Dit is aan my verduidelik dat die doelwitte van die studie die volgende is:
 - Versameling van demografiese inligting ten opsigte van ouderdom, familie, woongeriewe en diens status van inwoners met permanente fisiese gestremdhede
 - Inligting te versamel omtrent die ondervinding van persone met permanente fisiese gestremdhede en hulle opsigters
 - Onderzoek in te stel omtrent die behoeftes van persone met permanente fisiese gestremdhede en hulle opsigters
 - Onderzoek in te stel omtrent die gemeenskap van Lotus Rivier se houding teenoor persone met permanente fisiese gestremdhede
 - U bewus te maak van u regte as 'n persoon met 'n gestremdheid
 - U bewus te maak van gesondheids-, maatskaplike- en ondersteunings-dienste wat beskikbaar is
 - Vas te stel watter dienste benodig word om u lewenskwaliteit te verbeter
 - Vas te stel watter rystoele en hulpmiddels u benodig om u daartoe instaat te stel om meer onafhanklik te wees met aktiwiteite soos eet van maaltye, aantrek, was en bad, gebruik van die toiletgeriewe, beweging rondom u woonplek en loop.
- 2.2 Dit is aan my verduidelik dat 'n onderhoud met my gehou sal word insake my persoonlike ondervinding met gestremdheid.
- 2.3 Ek is bewus daarvan dat dit 'n eenmalige prosedure sal wees in 2003 op 'n tyd wat vir my gerieflik is.
- 3.1 Dit is aan my verduidelik dat alle inligting vertroulik hanteer sal word. Die inligting mag wel gebruik word vir 'n tesis, publikasie in wetenskaplike tydskrifte en die aanbied van professionele lesings, maar dat geen name gebruik sal word nie.
- 3.2 Dit is aan my verduidelik dat die bevindings van die ondersoek omtrent die behoeftes van mense met permanente fisiese gestremdhede aan die beamptes van Maatskaplik en Gesondheid bekend sal word.
4. Dit is aan my verduidelik dat ek volle toegang sal hê tot alle inligting omtrent myself wat ek in hierdie studie openbaar gemaak het.
5. Ek is ingelig dat ek mag weier om aan die projek deel te neem en ook ter enige tyd tydens die projek mag onttrek sonder dat dit my enigszins negatief sal beïnvloed in die toekoms.

6. Bogenoemde inligting is aan my verduidelik/vertaal deur
in Afrikaans/Engels/Xhosa. Dit is 'n taal wat ek goed verstaan en praat en al my vrae is in hierdie taal volledig en bevredigend beantwoord.
7. Ek is nie gedwing om aan die ondersoek deel te neem nie en is bewus daarvan dat ek ten enige tyd mag onttrek sonder enige benadeling van my regte.
8. Deelname aan die projek sal geen finansiële koste vir my meebring nie en ek beseft dat ek geen finansiële voordeel sal ontvang uit deelname nie.

HIERMEE VERKLAAR EK DAT EK VRYWILLIG AAN DIE BOGENOEMDE PROJEK DEELNEEM

Geteken te (plek) op 2003

.....
Geteken deelnemer/Verteenwoordiger

.....
Getuie

BELANGRIKE INLIGTING

Beste Deelnemer

Dankie vir u deelname aan die studie. Indien u enige vrae het tydens die duur van die studie omtrent:

1. probleme as gevolg van die navorsing, of
2. inligting rondom die navorsingsprojek

kontak my gerus by die volgende telefoonnommers: 406-6402
083-697-9118

Me M J Futter
Universiteit van Kaapstad

Key points about HIV/AIDS

AFRIKAANS	Steutelpunte oor HIV/VIGS	A
ISIXHOSA	Imiba engundoqo nge-HIV/AIDS	X
SETSWANA	Dintlha tse di bothokwa ka ga AIDS/HIV	T



AIDS HELPLINE
☎ 0800-012-322

If you have any questions about HIV/AIDS you can phone the free 24-hour AIDS Helpline at **0800-012-322**.



As u enige vrae oor HIV/VIGS het, kan u die gratis 24-uur VIGS hulplyn skakel op **0800-012-322**.

Ukuba unayo nayiphina imibuzo nge HIV/AIDS, ungafowunela inombolo yasimahla yoNcedo ye-AIDS efumaneka iiyure ezingama 24 ethi **0800-012-322**.

Fa o nale dipotso ka HIV/AIDS o ka leletsa mogala mo go *Helpline* ya AIDS ya diura di le 24 e e sa duelelweng kwa go **0800-012-322**.

There are a number of other leaflets in this series that give more information about AIDS.



Daar is 'n aantal ander pamflette in hierdie reeks wat meer inligting verskaf oor VIGS verwante kwessies.

Kukho nezinye iincwadana ezininzi kolu luhlu ezinika inkcazelo ebanzi ngemibandela ephathelelene ne-AIDS.

Go nale dipapetsana tse di mmalwa mo serising eno tse di nang le tshedimosetso ka ga AIDS.

There is no cure for AIDS, but many people infected with HIV live long healthy lives.

They do this by taking care of their health, keeping fit, getting treatment when they are sick, eating correct foods, reducing stress and practicing safer sex.



Daar is geen geneesmiddel vir VIGS nie, maar baie mense leef lank en gesond met HIV.

Hulle kan dit doen deur na hul gesondheid om te sien, fiks te bly, behandeling te kry as hulle siek is, die regte kos te eet, stres te verminder en veiliger seks te hê.

Akukho yeza lokunyanga i-AIDS, kodwa abantu abaninzi abosuleleke yi-AIDS baphila impilo entle ixesha elide.

Oku bakwenza ngokukhathalela impilo yabo, ngokuzigcina bephile qethe emzimbeni, ngokufumana unyango xa begula, ngokutya ukutya okulungileyo, ngokuthibaza nokunciphisa unxunguphalo nangokulalana ngokukhuselekileyo.

Ga go kōkō e e fodisang AIDS, fela batho ba bantsi ba ba tshhwaetsegileng ka HIV ba tshela maphelo a maleele a a ntseng sentle a a tletseng.

Ba dira se ka go tlhokomela matshelo a bona, go nna ba itekanetse, go bona kōkō fa ba lwala, go ja djo tse di nonofileng, go se tshwenyegye thata le go dira thobalano e e sireletsegileng.



AIDS is a disease that affects millions of South Africans. It is caused by a virus called HIV that slowly weakens a person's ability to fight off other diseases.

VIGS is 'n siekte wat miljoene Suid-Afrikaners raak. Dit word veroorsaak deur 'n virus wat as HIV bekendstaan, wat stadigaan 'n mens se vermoë om ander siektes te beveg, albreek.

I-AIDS sisifo esichaphazela iimiliyoni zabantu baseMzantsi Afrika. Ibangelwa yintsholongwane (yivayirasi) ebizwa ngokuba yi-HIV, yona evikiva neqoba amandla omntu okulwa ezinye izifo.

AIDS ke bolwetse jo bo amang dimilione tsa batho ba Aferika Borwa. E bakiwa ke virase ya HIV e e koafatsang mmele wa motho mme e dire gore mmele o seka wa kgona go lwantsha malwetse a mangwe.

HIV is spread from one person to another:

- by having unprotected sex with an infected person
- through contact with infected blood
- from an infected mother to her unborn or newborn baby (but only some babies born to infected mothers become infected with HIV).



You cannot be infected with HIV in other ways. For example, if a person with HIV coughs, he/she cannot pass on the virus. If you hug or touch a person with HIV you cannot get HIV.

HIV word van mens tot mens versprei deur:

- onbeskermd seks met iemand wat die infeksie het
- kontak met besmette bloed
- oordrag van 'n moeder met die infeksie aan haar ongebore of pasgebore baba (maar net sommige baba's van besmette moeders word gebore met die infeksie).

Jy kan nie op ander maniere besmet word met HIV nie. As iemand met HIV hoes, kan hy of sy byvoorbeeld nie die infeksie oordra nie. As jy iemand met HIV omhels of aanraak, kan jy nie met HIV besmet word nie.

I-HIV igqithiseleka komnye umntu iye komnye:

- ngokulalana (ngokwabelana ngesondo) okungakhuselekanga nomntu owosuleleke sesi sifo
- ngokudibana negazi elosulelekileyo
- ngumama owosulelekileyo kusana olungekazalwa okanye kusana olusandulukuzalwa (kodwa ke ziintsana ezithile ezizelwe ngoomama abosulelekileyo ezithi zosuleleke yi-HIV).

Awunakosuleleka yi-HIV ngezinye iindlela. Umzekelo, ukuba umntu one-HIV uyakhohlela, akanakuyigqithisa le vayirasi. Ukuba wonga okanye ubamba umntu one-HIV awunakosuleleka yi-HIV.

HIV e fetelela go tloga go motho mongwe go ya go yo mongwe:

- ka go dira thobalano e e sa sirelediwang
- ka go kopana le madi a a tshwaeditsweng ke HIV
- go tloga go mmê go ya go ngwana yo o fa mpeng kana yo mošwa (fela ga se bana botlhe ba ba belegileng ke bommê ba ba tshwaeditsweng ba ba tshwaetsegang ke HIV).

O ka se tshwaetse ke HIV ka ditsela tse dingwe. Go nea sekao, fa motho yo a nang le HIV a othola, a ka se go tsenye virase e. Fa o ka kgoma kgotsa wa aka motho yo a nang le HIV o ka se tshwaetsege.

Most people who are infected with HIV do not know they are infected, and you cannot tell if a person is infected just by looking at them.

It takes many years for the signs of HIV infection to show up. This is usually when a person becomes ill from other diseases.



Die meeste mense wat met HIV besmet is, weet dit nie, en jy kan nie op die oog af sien of iemand besmet is nie.

Dit vat baie jare voordat die tekens van HIV infeksie na vore tree. Dis gewoonlik as iemand siek word van iets anders en nie gou kan gesond word nie.

Abantu abaninzi abosuleleke yi-HIV abazazi ukuba bosulelekile, kwaye awungeke utsho ukuba umntu one-HIV ngokumjonga nje.

Iimpawu zokosuleleka yi-HIV zithatha iminyaka emininzi ukubonakala. Oku kudla ngokwenzeka xa umntu egula zezinye izifo kwaye engabingcono lula.

Batho ba le bantsi ba ba nang le HIV ga ba itse fa ba tshwaetsegile, mme o ka se ka wa kgona go bona gore motho o nale yona ka go mo leba.

Go tsaa mengwaga e le mentsi gore ditshupo tsa HIV di bonagale. Se, gantsi se direga fa motho yo a lwala a tshwere ke malwetse mangwe mme a sa nne botoka ka bonako.

ALLPAY WESTERN CAPE

UNIVERSITY OF CAPE TOWN: DIVISION OF PHYSIOTHERAPY

DEPARTMENT OF SOCIAL SERVICES AND POVERTY ALLEVIATION

Project for people with physical disabilities receiving a permanent disability grant living in

Lotus River

I hereby declare that I have received the following assistive device(s)



Signature

Signed at (place)

.....
Date

.....
Witness

These assistive devices have been loaned to you by the above-named organisations for your use for as long as you require them. As soon as you no longer require the assistive device(s) please contact Mr V Carelse immediately (tel no 703-3797) to fetch the assistive devices so that they can be given to other disabled people to use.

ALLPAY WESKAAP**UNIVERSITEIT VAN KAAPSTAD: DEPARTEMENT VAN FISIOTERAPIE****DEPARTEMENT VAN MAATSKAPLIKE DIENSTE EN ARMOEDEVERLIGTING****Project ten opsigte van persone met fisiese gestremdhede wat 'n permanente ongeschiktheidstoelaag ontvang in Lotus Rivier**

Hiermee verklaar ek dat ek die volgende hulpmiddel(s) ontvang het:

Handtekening

Geteken te (plek)

.....
Datum

.....
Geteken deelnemer/Vertenwoordiger

Hierdie hulpmiddels is deur die bogoneemde aan U geleen so lank soos U dit nodig het. Sodra U die hulpmiddel(s) nie meer nodig het nie kontak onmiddellik asseblief vir Mnr V Carelse (tel no 703-3797) om die hulpmiddels te haal sodat dit vir ander persone met gestremdhede kan gegee word.

LOTUS RIVER PROJECT FOR PEOPLE WITH PHYSICAL DISABILITIES

EVALUATION INTERVIEW

This interview is entirely voluntary and you are not obliged to participate in it. If you wish to withdraw at any stage such refusal will not in any way negatively affect your future ownership and use of your wheelchair and assistive devices.

I HEREBY DECLARE THAT I AGREE TO HAVE AN AUDIO TAPE RECORDING OF AN INTERVIEW WITH MR V CARELSE REGARDING THE WHEELCHAIR AND ASSISTIVE DEVICES I HAVE RECEIVED FROM THE LOTUS RIVER PROJECT

Signed at (address) on 2003

.....
Participant's/representative's signature

.....
Witness

EVALUERINGS ONDERHOUD

Hierdie onderhoud is vrywillig en u is onder geen verpligting om deel te neem nie. In geval u nie verder wil deel neem nie, sal hierdie besluit geen negatiewe invloed op die gebruik van u rystoel en hulpmiddels hê nie.

EK STEM IN DAT 'N ONDERHOUD MET MR V CARELSE OPGENEEM KAN WORD OP 'N BANDOPNEMER. HIERDIE ONDERHOUD HOU VERBAND MET DIE RYSTOEL EN HULPMIDDLES WAT EK ONTVANG HET VAN DIE LOTUS RIVIER PROJEK.

Geteken te (plek) op 2003

.....
Geteken deelnemer/Verteenwoordiger

.....
Getuie

1 November 2002

The Medical Superintendent
Victoria Hospital
Wynberg
7800

Dear Dr Eick

**PROJECT FOR PERSONS WITH LOCOMOTOR DISABILITIES RECEIVING A PERMANENT
DISABILITY GRANT**

The Department of Social Services and Poverty Alleviation, Allpay Western Cape and the Department of Social Development and Division of Physiotherapy of the University of Cape Town are planning a joint project for persons with locomotor disabilities receiving a permanent disability grant and living in Lotus River.

The objectives are to:

- collect demographic data with respect to age, family status, living arrangements and employment status of people with permanent disability
- explore the daily living experiences of people with disabilities and their carers
- investigate the felt needs of people with disabilities and their carers
- explore the experiences of the people with disability with regard to the attitudes of other people in the community towards them
- identify the strategies developed by these people for coping with their situations
- make people with disabilities aware of the health, social and support services available to them
- investigate their individual needs with regard to wheelchairs, mobility aids and assistive devices.

After the functional limitations of the disabled persons have been assessed and it is found that their independence and quality of life will be improved by means of assistive devices or small alterations to their homes these will be provided for them.

When the project has been completed in Lotus River it will be extended to Retreat, Grassy Park, Lavender Hill and Steenberg and also to other areas like Worcester and Beaufort West.

I plan to start conducting these assessments from mid November 2002.

Should you have any comments and/or questions about the proposed project I can be contacted at any of the following numbers:

(021) 406-6402 (UCT); (021) 794-3858 (home); 083 697 9118 (cell).

Yours sincerely

M J Futter
Senior Lecturer

22 October 2002

Ms Bridget van der Merwe
Cape Town Association for the Physically Disabled
P O Box 12982
MOWBRAY
7705

Fax: 637 1257

Dear Bridget

LOTUS RIVER PROJECT – PEOPLE WITH LOCOMOTOR DISABILITIES

I would like to notify you of my research project in Lotus River which will be conducted from November 2002 to December 2003. This project is a joint project with the Department of Social Services and Poverty Alleviation, ALLPAY Western Cape and University of Cape Town and for which funding has been obtained.

All Permanent Disability Grant beneficiaries with locomotor disabilities living in Lotus River will be visited in their homes. Their functional abilities will be assessed and those in need of assistive devices or small alterations to their homes will be provided with them. This will include temporary or permanent ramps, new wheelchairs or repairs to existing wheelchairs, supply of crutches, walking sticks, eating, kitchen and bathroom assistive devices.

Once the project has been completed in Lotus River it will be extended to Grassy Park, Steenberg, Lavender Hill and Retreat.

Should you have any consumers who could be assisted by this project please do not hesitate to contact me with their needs or for me to assess their needs in their homes. My contact numbers will be 406-6402 or preferably 083 697 9118.

It would be very helpful if you would forward me a list of your consumers so that I am aware of the assistance they are already receiving from you.

Yours sincerely

M J Futter
Senior Lecturer

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University of Cape Town

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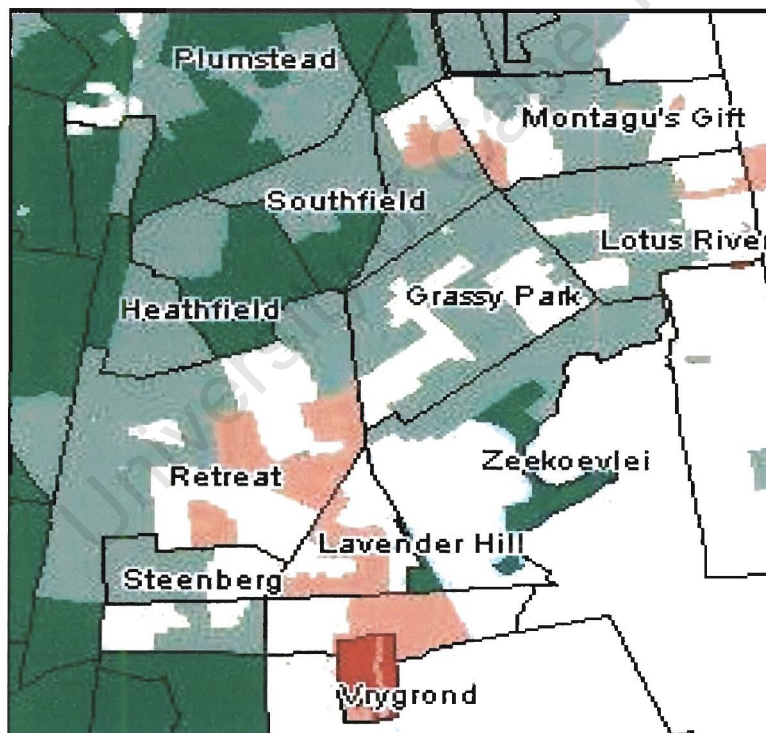
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COMMUNITY PROFILE OF LOTUS RIVER AND ITS NEIGHBOURING SUBURBS

1 INTRODUCTION

If a community project is to be successful it is extremely important for the researcher to be familiar with the community itself as well as its environment. Thus a community profile of Lotus River and its neighbouring suburbs was conducted before the research was conducted. It is presented below.

Figure 31: Lotus River and surrounding suburbs



"A community is a unique living entity and, like its people, it continuously changes physically and psychologically. It is also in a continuous relationship with its own individuals, its environment and other communities" (Swanepoel, 1989: 11).

Lotus River, a low-income suburb on the Cape Flats, is situated 23 kilometres from Cape Town railway station via the M5 and Eastern Boulevard main road routes.

Its boundary roads are Klip Road on the north, Lake Road on the west, Ninth Ave on the south and Strandfontein Road on the east. These roads are the boundary roads of Montagu's Gift, Grassy Park, Pelican Park and Phumlani, and Schaapkraal suburbs respectively (Figure 31).

In order to gain more insight into the barriers people with physical disabilities experience in Lotus River it is important to understand the historical background and the physical environment of the people in the community. An overview of the community profile will be presented with certain sections, for example, education, housing and crime covered in greater detail as these aspects have a major effect on the lives of the disabled and their families.

Because the vast majority of the community is comprised of Coloured persons a brief historical overview of Coloured people in South Africa will be included and will be followed by the more recent history of Lotus River itself.

2 HISTORICAL BACKGROUND OF THE COLOURED PEOPLE

The Coloured people are an indigenous product of the mixed unions between the early White settlers, local Hottentots, slaves and the African inhabitants of the sixteenth and seventeenth centuries in South Africa. During the seventeenth century marriages between White men and baptised Non-White women were permitted and had full social acceptance and religious support. Legitimate

children of these marriages were "..... simply absorbed into the predominantly White community" (MacCrone, 1951: 3).

Coloureds also had their origins from the marriages between men slaves and Hottentot women and secondly from the illicit relationships which occurred between White men and Hottentot women as a result of the shortage of White women experienced at that time (Lever, 1980).

Early legislation during that period ensured that there was no discrimination between people of different colours and races. The Cape Colony Ordinance No 50 of 1828 gave full citizenship to free persons of colour (Marais, 1939) and after the emancipation of the slaves in 1834, when Municipal Ordinance No 9 of 1836 came into effect for the election of Municipal Boards, no colour restrictions were imposed on either the voters or the electorates. However, there was a property qualification (Van der Ross, 1975) which did result in only property owners forming part of the electorate. When the Cape received Representative Government in 1853 all persons of colour received the same rights of franchise as did White citizens (Van der Ross, 1975).

During the eighteenth century it was extremely difficult for slaves to become emancipated and, according to MacCrone (1951), the concept started to develop that "Slavery was the proper condition of the black races". This was the beginning of racial discrimination where a pigmented skin came to be associated with an inferior status in the community and it was the foundation on which the 'apartheid' system was based (Lever, 1980).

The movement of the Coloured people with the Trekkers meant that by the end of the 19th century they were scattered over the entire Republic of South Africa and South West Africa and it was at the end of this century that Coloured political organisations started for the first time. The Afrikaner League, a Coloured political organisation, was first formed in 1883 (Van der Ross, 1975).

Non-white voters of the Cape lost their right of direct representation in parliament in 1909, but as compensation they were allowed direct representation in Provincial Councils.

Talk of segregation started in the 1930's when the United Party Government was in power with General Smuts as its leader. Various discussions took place with regard to separate residential areas, marriages, churches, sport, trade unions, political organisations, higher education and entertainment (Van der Ross, 1975).

When the Nationalist Party came into power in May 1948 they removed the Coloured people from the common roll of voters in 1956 by introducing the Separate Representation of Voters Amendment Act (Act No 30 of 1956) (Van der Ross, 1975). Many areas of segregation were legislated for by discriminatory laws introduced to ensure that the Whites did not live or mix socially with Blacks, Coloureds and Indians. The Population Registration Act (Act No 30 of 1950) required people to be identified and registered from birth as belonging to White, Black, Indian or Coloured groups.

This classification system of racial groups permitted the following laws to be implemented and regulated: The Prohibition of Mixed Marriages Act (Act No 55 of 1949) prohibiting marriages between Whites and members of other racial groups; the Immorality Act (Act No 5 of 1950) prohibiting extra-marital intercourse between Whites and Blacks, Coloureds and Indians; the Group Areas Act No 41 of 1950 declaring certain areas for exclusive use of one particular racial group. It became compulsory for people to live in an area designated for their classification group and prohibited them from acquiring immovable property or businesses in racial areas to which they did not belong;

These laws resulted in many of the Coloured people feeling unwanted, politically divided amongst themselves, disillusioned and bitter (Lever, 1980). They felt that they did not belong to any particular group of people. Brindley (1976) considered these negative attitudes to be the prime cause of the personal despair of the Coloureds; even more than that caused by their demographic and socio-economic problems.

The Commission of Enquiry (1976) into Matters Relating to the 'Coloured Population Group' explained the lack of an identity and positive self-image in a large proportion of the Coloured population as a result of the following factors (Theron, 1981; Fitzgerald, 1980):

(a) In terms of the Population Registration Act (Act 30 of 1950) the word 'Coloured' had a negative connotation as this Act defined a 'Coloured' as a person who was not classifiable as White or Black and who did not form part of the Chinese, Indian or other Asiatic groups. The name 'Coloured' was defined by the White population group. It was not based on the Coloured peoples' perception of themselves of sharing their own language, religious beliefs, values, habits or traditions.

(b) Even though they were culturally White the 'apartheid' system excluded the Coloureds from the White social order. This social segregation was more detrimental to the Coloureds than to the Blacks and Asians because the Blacks and Asians largely had their own cultures to which only a few aspects of White culture had been added (James, 1996; Mostert et al, 1987), but this was not the situation with the Coloureds who shared the White culture.

(c) The Coloureds' identity became confused because they were frequently not accepted by either Whites or Blacks and yet they were descendants of both groups. With the migration of other nationalities to South Africa Coloureds eventually comprised seven sub-groups, namely, Cape Coloured, Griqua, Malay,

Indian, Chinese, other Asiatic and Other Coloured. With the Population Registration Amendment Act (Act No. 64 of 1967) a child was classified as Coloured if both parents were classified 'Coloured' or if one parent was White and the other Coloured or Black. The other sub-groups of Malay, Indian and Chinese were not equated (Sewpaul, 1999).

(d) Cohesive and orderly communities were forcibly moved to new areas without consideration of the factors that had been the essence of their cohesion. Extended families and families comprising different generations had lived in the same street as their friends for generations. They had attended the same church and done their shopping at the local corner shop where the shopkeepers had also come from a family line and knew all their clientele. Although the housing frequently was far from ideal and there was gross overcrowding everybody knew each others' family business and problems and they provided a strong support system to each other in times of need. When these people were forcibly removed to new areas on the Cape Flats they were separated from each other and lost the support system of family and friends to which they had been so accustomed (Erasmus, 2001).

(e) The classification into White and Coloured of many residential areas changed several times during the 'apartheid' years. This led to a great deal of anxiety and apprehension as sometimes people lived in areas to which they conformed as far as colour was concerned as it was classified as Coloured, but at other times they felt as though they did not belong as the same area had been changed to a White residential area and they knew that sooner or later they would be forced to leave their homes (James, 1996).

(f) The Group Areas Act (Act 41 of 195) resulted in disparate standards whereby the Coloureds received inferior housing, education, health care, transport, social services, public safety and security. These factors had a

negative effect on family life as well as community life in general (Erasmus, 2001).

(g) People were removed from residences in areas of their choice where facilities had been close at hand. They were placed in new areas with inferior housing, higher rentals, limited facilities and inaccessible and expensive transport. This led to them becoming isolated from their extended families, friends and social networks (James, 1995; Platsky and Walker, 1985).

(h) When families were forced to leave properties they owned in White areas they suffered financial loss as they were not paid out the true market value of the properties. However, many Whites made significant financial profits in these transactions (Van der Horst and Reid, 1981).

(i) Coloured persons frequently were removed to unpleasant, flat, windy and sandy geographic environments which were isolated from their working and social environments and which made access to shopping and health care facilities very difficult. They had been accustomed to living in leafy suburbs of Constantia, Claremont, District Six and Kirstenbosch which were close to the mountain and, therefore, had attractive environments and views. They were also close to shopping, schooling and business facilities (Erasmus, 2001).

(j) The lack of essential community facilities, such as schools, community centres, post offices, libraries, public telephones and police often remained for several years after moving into their dwellings in the new council housing schemes (Erasmus, 2001; James, 1995).

(k) The above factors caused a vicious circle of poverty from which most Coloureds were unable to escape. The distance from work meant additional transport costs, their rental was often higher than what they had been paying in their original homes and the cost of food was higher as they had to shop from

small corner shops as they lived too far from the supermarkets. Schooling was more expensive due to the transport costs. All these financial increases resulted in many wives having to find employment too in order to boost the family income. There was no support system for the children who were often left unattended after school. There was no one to supervise their homework or activities and they frequently dropped out of school prematurely or joined gangs and became involved in drug abuse. Due to the lack of parental supervision and lack of entertainment and sports facilities teenage pregnancy became an enormous problem (Erasmus, 2001; James, 1996; James, 1995).

3 HISTORY OF LOTUS RIVER

Lotus River was named after the land area between the Great and Little Lotus Rivers which used to be called Lotus River Estate (Grobicki, 2001).

The area was officially classified as 'agricultural smallholdings' and was inhabited for generations by White, Black and Coloured people who raised poultry and grew vegetables, fruit and flowers. Much of the land was owned by White and Coloured residents, but the Blacks had to rent property and dwellings as the Black Land Act (Act No 27 of 1913) prohibited them from owning land outside designated reserves (Truth and Reconciliation Commission Report Volume One, 1998). Although the people were poor they were proud property owners who built wood-and-iron dwellings which they kept in good condition. Land and dwellings were also rented by Whites and Coloureds who did not own property (Le Roux, 2003; Stemmet, 2003; Engelbrecht, 2002).

During the Great Depression from 1929 to 1933 many workers from as far as the Transkei came to live in Lotus River, Retreat and Grassy Park. People migrated from the rural areas to the cities for survival as they were struggling to make a

living in the rural areas due to the drought, animal diseases and the unequal distribution of land and livestock (Le Roux, 2003; Stemmet, 2003; Elias, 1983).

Lotus River was a close-knit community where everybody knew everybody else and they treated each other with respect and affection. Due to the diverse socio-cultural networks developed by living together in the same community many of the workers, shopkeepers and children were able to speak both Afrikaans and Xhosa (Le Roux, 2003; Stemmet, 2003; Davids, 2002).

From 1924 laws were introduced which had a drastic effect on the people living in the area. They enforced the tenure and occupation of Lotus River to certain population groups. Firstly, the Pact Government Civilised Labour Policy of 1924 gave White workers preference with respect to employment opportunities and Coloured and Black workers were denied jobs or were retrenched (Davids, 2003; Van der Horst and Reid, 1981).

Secondly, the movement of Blacks was restrained by the Proclamation Act (Act 231 of 1932) and even further restricted by the Influx Control Act (Act 46 of 1937). This forced many of the Blacks to live in the bushes around Lotus River where they escaped and were beyond the control of the council (Stemmet, 2003; Van der Horst and Reid, 1981).

Thirdly, the Urban Areas Act (Act of 1938) prohibited Blacks from owning property in Lotus River (Fitzgerald, 1980). In spite of these restrictive laws Cape Town was still considered to be the least racially segregated region in South Africa before the institutionalisation of 'apartheid'.

The development of Lotus River as a residential area started from 1935 in the northern area of the suburb where houses were built in Steenbok, Eland, Duiker, Gembok, First, Second and Third Avenues. At this time property was still owned by Whites and Coloureds (Curry, 1995). Many of these houses are still

occupied by residents, but none of them appear to be descendants of the original house-owners.

Although racial segregation had been practised in South Africa since the country was first settled, the Group Areas Act (Act 41 of 1950) was the first act to regulate by law, on a uniform and country-wide basis, an administrative system instituting separate residential and business areas for the use of the four major racial groups, namely, Blacks, Whites, Coloureds and Asiatics (Sinclair, 1986). Thus resettlement of disqualified people living in White areas was enforced. The 1950 Act was 'upgraded' and 'improved' in 1957 and 1966 (Elias, 1983). Section 20 of the Groups Areas Act No 77 of 1957 declared that the area defined as Lotus River would be an area zoned and reserved for the occupation of and ownership by members of the 'Coloured' population group (Grobicki, 2001). The Whites and Blacks, therefore, were forced to leave the area. Those who owned property were forced to sell it and those who rented land and dwellings had to find accommodation in residential areas proclaimed as 'White' or 'Black' respectively (Grobicki, 2001).

In order to deal with the enormous housing shortage that existed in Cape Town, the long waiting lists for housing in the Western Cape and to accommodate Proclamation 43 of 1966, the Council purchased the land of the Whites and Blacks and also much of what was owned by some Coloured property owners (Grobicki, 2001). The Council constructed a housing scheme in Lotus River. The National Housing Commission required 50% of these dwellings to be made available to the families forcibly removed under the Groups Areas Act of 1957. Economic houses, sub-economic semi-detached houses and three- and four-storey blocks of walk-up flats comprising twelve and sixteen units were built. The houses and flats comprised one, two or three bedrooms. The flats had bathrooms, kitchens and living rooms, but the sub-economic houses did not have bathrooms and had outside toilets. Many of them still have only one room and a

kitchen with an outside toilet. The sub-economic flats were built around Fourth, Fifth and Sixth avenues (Le Roux, 2003; Stemmet, 2003; Liebenberg, 2002).

Some of the Coloured people living in Constantia, Diep River and Claremont, which had been zoned 'White' were forcibly removed and resettled in the council dwellings in Lotus River. Even though they were diverse societies they had well developed networks of economic and social relationships in their original suburbs. They had to sell their houses through the government as private interracial sales were not permitted. They simply had to accept the prices offered to them by the government which meant they usually suffered significant financial losses and some Whites profited greatly (Khan, 2002; Van der Horst and Reid, 1981; Fitzgerald, 1980).

If the people earned above R800 they were eligible to purchase a house which was situated in the areas north of Fourth Avenue. Those who earned less than that were placed in the sub-economic houses and flats (Le Roux, 2003; Stemmet, 2003; Carelse, 2002).

Most of the people who were moved to Lotus River did not want to leave their original established communities in the leafy suburbs of Constantia, Diep River and Claremont where they were close to facilities like churches, schools, community halls and recreational facilities frequently built on their own initiative and with their own hands (Khan, 2002; Van der Horst and Reid, 1981). Lotus River was isolated and far from a railway station, buses, post office, library, public telephones, police station, schools, doctors and shops. The people had to walk far distances to catch buses which were irregular and infrequent (Jacobs, 2002; Davids, 2002).

When people moved to Lotus River many of the dwelling units had still not been completed. Although they had hot and cold running water laid on many of them did not have electricity for many weeks or months. The roads were unmade and could not be negotiated by cars as they were so sandy. Pavements had not yet

been constructed and there was no street lighting. As there was no sewerage system residents had to use outhouses and a bucket system. Eventually the residents paid for the sewerage and plumbing installations themselves (Le Roux, 2003; Geland, 2002; Smith, 2002).

The area had a drainage problem as it is low-lying and the water table was high. Because there were no stormwater drains the roads were waterlogged in the winter. This led to the development of a mass of pot-holes, muddy pools and gullies dug by spinning wheels of cars which regularly got stuck in the soft clay (Valcarcel, 2002).

There were no trees and the open spaces which were meant to be play parks were used for dumping rubbish as there was no refuse collection. This gave the area a dismal and neglected appearance (Liebenberg, 2003; Dollie, 2002; Seafort, 2002)

The early residents of Lotus River had to make enormous personal sacrifices to adjust and adapt to their new living environment. The houses lacked variety and there was indiscriminate mixing of sub-economic and economic houses (Van der Horst and Reid, 1981). Because it was so isolated and far from everywhere the monthly expenditure on travelling to and from work, school and shops absorbed a great deal of their income (Van der Horst and Reid, 1981; Fitzgerald, 1980).

As there was no form of entertainment many men started to gamble as a means of passing their free time. Shebeens were started from many homes, not only as a form of income, but also to provide a place for socialisation and entertainment. However, in spite of this, most people living in the area felt that it was safe to walk around alone during both day and night (Le Roux, 2003, Stemmet, 2003; Carelse, 2002; Davids, 2002).

Even though the residents had been uprooted from their original homes and had simply been moved into areas they had not had any choice of selecting they soon started to build a new community spirit under difficult circumstances. They had originated from different geographical areas, but their backgrounds were similar and the lack of transport and amenities meant that they were forced to get to know and understand each other. They were helpful and supportive of one another, for example, residents with cars would transport those who were sick to the doctors and hospitals when necessary. They would also do shopping for those who lived in the neighbourhood (Stemmet, 2003; Engelbrecht, 2002; Smith, 2002; Curry, 1995).

The Cape Town City Council (CTCC) was responsible for constructing and managing the housing schemes in the Cape Flats area. It collected the rental, rates, water and electricity payments. It was responsible for the general maintenance of the housing units, building and maintenance of the roads and sewerage system, and removal of refuse.

The Lotus River Ratepayers Association was formed in 1969 and it liaised directly with the management committee of the CTCC to bring about improvements to the housing and living conditions (Carelse, 2002; Curry, 1995).

In 1984 the government added separate chambers for Coloured representatives to the previously all-White parliament. This was known as the tri-cameral government, but it was not supported by the community. People were mobilised to boycott the elections and in this way expressed their opposition to the system. They no longer recognised the local management committees as their representatives as they perceived them to be 'puppet' bodies of the government (Carelse, 2002; Curry, 1995).

In September 1992, the community mobilised itself and withheld rates and rents from the Regional Services Council after they had failed to heed calls from

residents, over several years, for the upgrading of amenities in the area. They also demanded that the intended 8.2% rates increase be scrapped. The rates and rents which were withheld were placed in a special trust fund (Koopman, 1993; Adams, 1992; Scott, 1992).

A moderate amount of improvement took place in Lotus River from 1980. Many council homes were purchased by the tenants for a nominal sum of money. Houses were painted, enlarged and renovated and boundary walls were built by the home owners. In 1994 the canal and many of the roads were upgraded and new stormwater drains were installed (Scott, 1994).

With the land reform policy of the present government it is possible that many of the people who had been forcibly removed from their original homes will be given the opportunity of returning to Constantia, Kirstenbosch, Claremont and Diep River. However, many of them feel that they have made a new home and friends in the Lotus River community and they are happy to continue living there (Le Roux, 2003; Stemmet, 2003; Carelse, 2002). They have lived in Lotus River for more than thirty-five years. Some of them have even been in the same dwellings for the entire time and feel it is their home (Stemmet, 2003; Engelbrecht, 2002; Liebenberg, 2002).

The Coloured community of Lotus River was disenfranchised and had to endure enormous hardships over the years as a result of the 'apartheid' policy during the Nationalist Party government rule. Ironically, once the Coloureds were included in the voting population for the first democratic election in 1994 and the first African National Congress (ANC) government election in 1998, the Nationalist Party received a majority of votes in the Lotus River constituency.

4 DEMOGRAPHIC PROFILE

Unless otherwise stated the data for this section of the community profile have been obtained from the 1991 and 1996 population censuses as well as a post-enumeration survey to estimate the number of people who were missed in the census enumeration (Central Statistical Services, 1991 and 1996). The census data were adjusted to compensate for the estimated 10.6% undercount (Urban Policy Unit, 1998).

As the census relies on self-reporting by individuals completing the census questionnaire, there might be some degree of reporting error. People living in the main house often did not include the number of people renting backyard dwellings for fear of reprisals from the Cape Metropolitan Council (CMC). Notwithstanding the limitations of the census data they remains the most comprehensive source for information at local level.

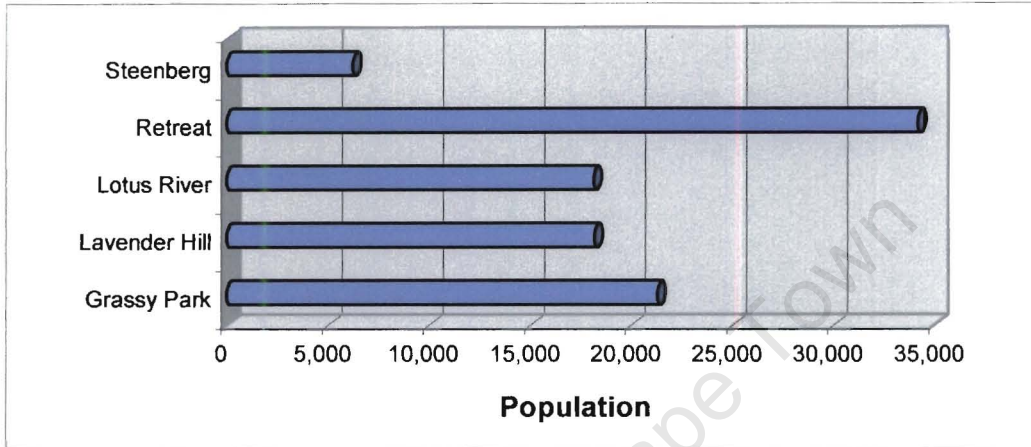
Whilst for most areas in South Africa the overall profile would not change significantly, for some areas significant changes in the size of the population and/or its characteristics will have taken place since October, 1996. In the suburbs described below there has not been any major increase in building or housing in the last few years so the population is most probably largely unchanged. However, there is ongoing construction of backyard dwellings to cope with the housing shortage and this could mean a small increase in population since the census was conducted.

Data in this chapter will include relevant information regarding the adjoining suburbs of Grassy Park, Lavender Hill, Retreat and Steenberg for the sake of comparison with the living environment of Lotus River as the focus groups, pilot and reliability studies were conducted in these adjoining suburbs.

Detailed tables will be provided with certain aspects being depicted by graphs for easy interpretation of the relevant data.

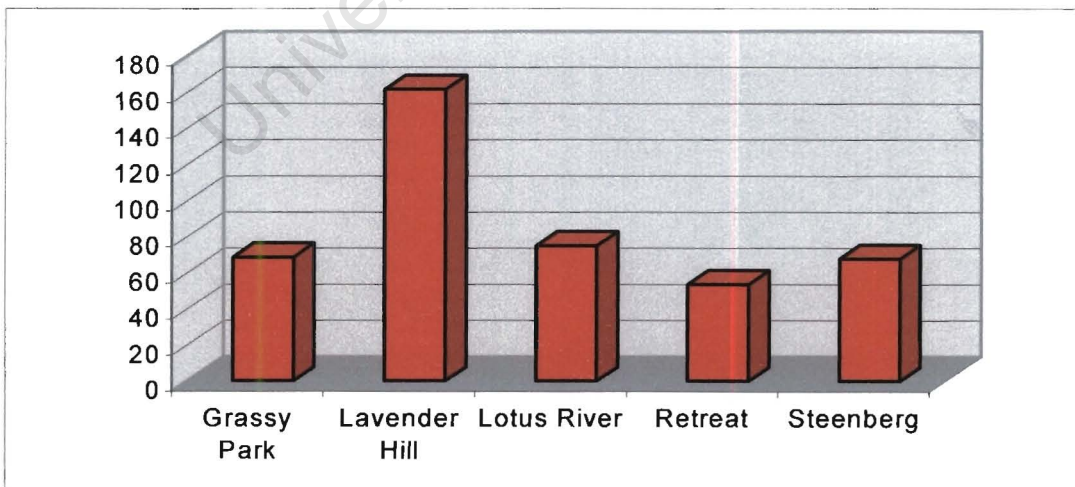
4.1 SIZE OF POPULATION

Figure 32: Size of population



4.2 POPULATION DENSITY

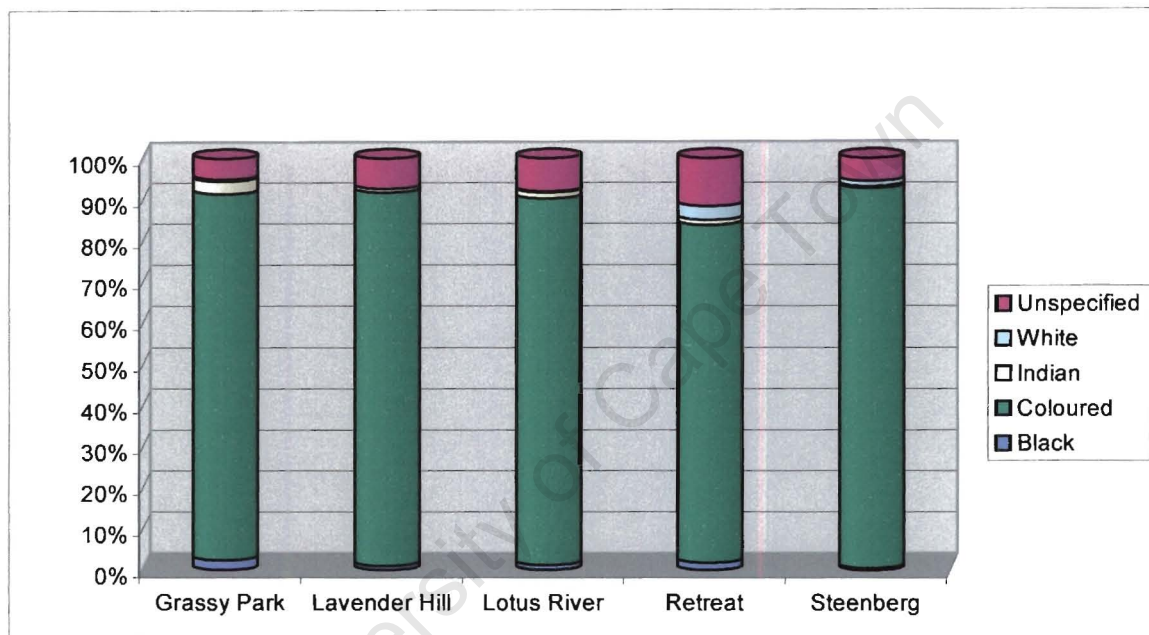
Figure 33: Population density



Grassy Park, Lavender Hill, Lotus River, Retreat and Steenberg have a population density of 69, 161,75, 54, and 68 people per hectare respectively (Figure 33).

4.3 POPULATION BY ETHNIC GROUP

Figure 34: Population by ethnic group



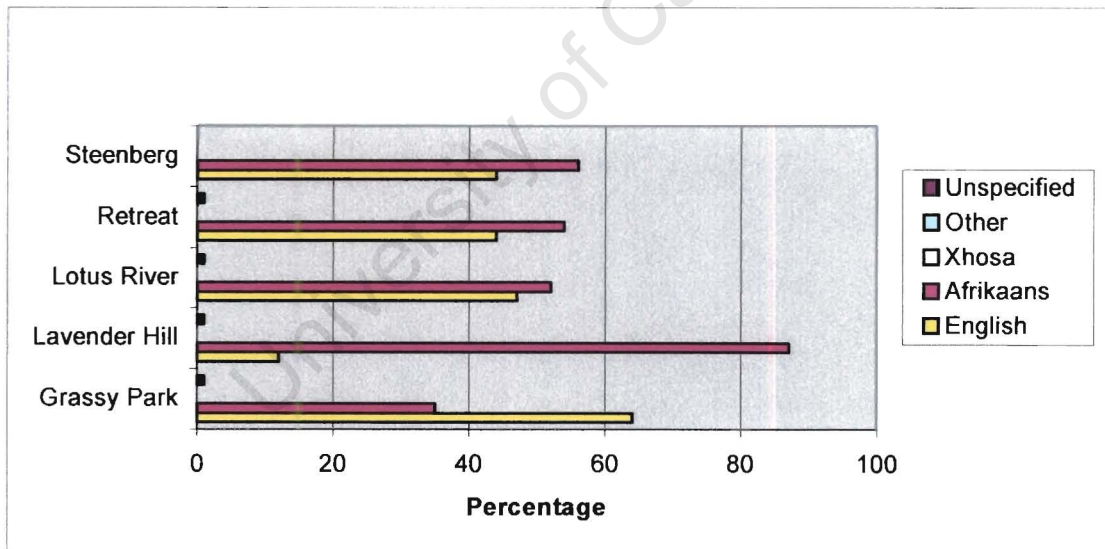
The vast majority of people living in these suburbs are Coloureds (Figure 34). There has been little migration of Coloureds from these areas (Dorrington, 2000) or Whites and Blacks to these areas since the repeal of the Group Areas Act in 1991. One of the reasons for this is the enormous housing shortages that still exist in all these areas.

4.4 HOME LANGUAGE

Grassy Park is the only suburb where the home language of the majority of people is English. Afrikaans is the predominant home language in the other suburbs although there is also a significant amount of English as the home language. Lavender Hill is the only suburb where few people have English as their home language. However, it is not unusual to find parents using Afrikaans between them and English when they speak with their children (Figure 35).

There are people whose home language is Xhosa living in all the suburbs, but it is minimal. In Grassy Park there are 85, Lavender Hill 29, Lotus River 14 and Retreat 92 individuals. Steenberg has no people whose home language is Xhosa.

Figure 35: Home language



4.5 POPULATION BY GENDER (Table 89)

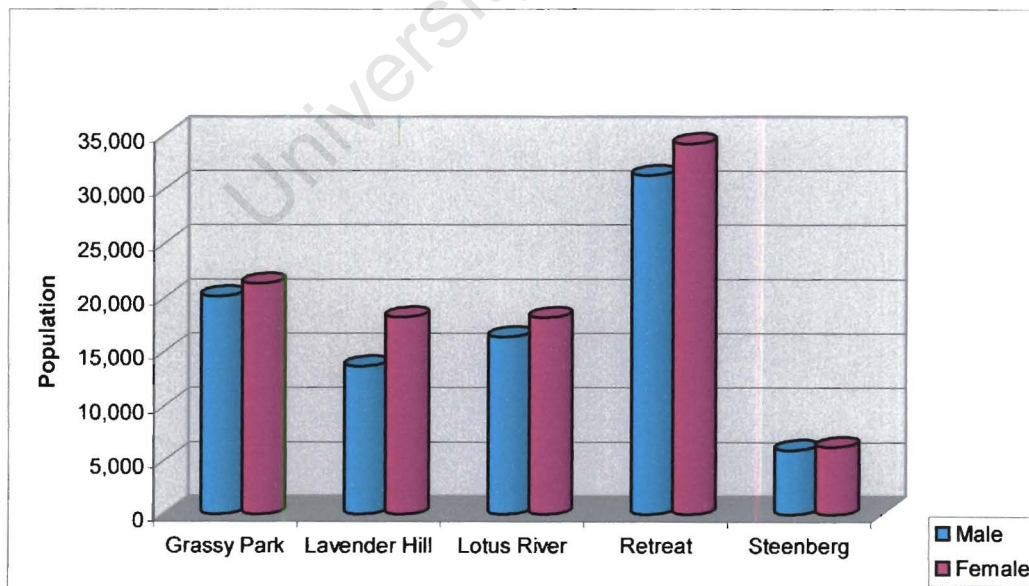
Table 89: Population by gender

Suburb	1996		1996		Total
	Male	%	Female	%	
Grassy Park	10,110	48	11,173	52	21,283
Lavender Hill	8,705	48	9,467	52	18,172
Lotus River	8,775	48	9,348	52	18,123
Retreat	16,316	48	17,860	52	34,176
Steenberg	2,971	48	3,258	52	6,229

Dorrington (2000) claims that overall the male to female ratio of the 1996 Census suggests an undercount of males relative to that of the females of some 2%.

This is particularly so in the age range of 20 – 65 years. There is also a misstatement of exaggeration in the 60 – 64 age group of males and 55 – 59 age group in females. Apparently this was in order to claim the OAP which comes into effect for females at 60 years of age and for males at 65 years of age (Dorrington, 2000).

Figure 36: Population growth between Census 1991 - 1996

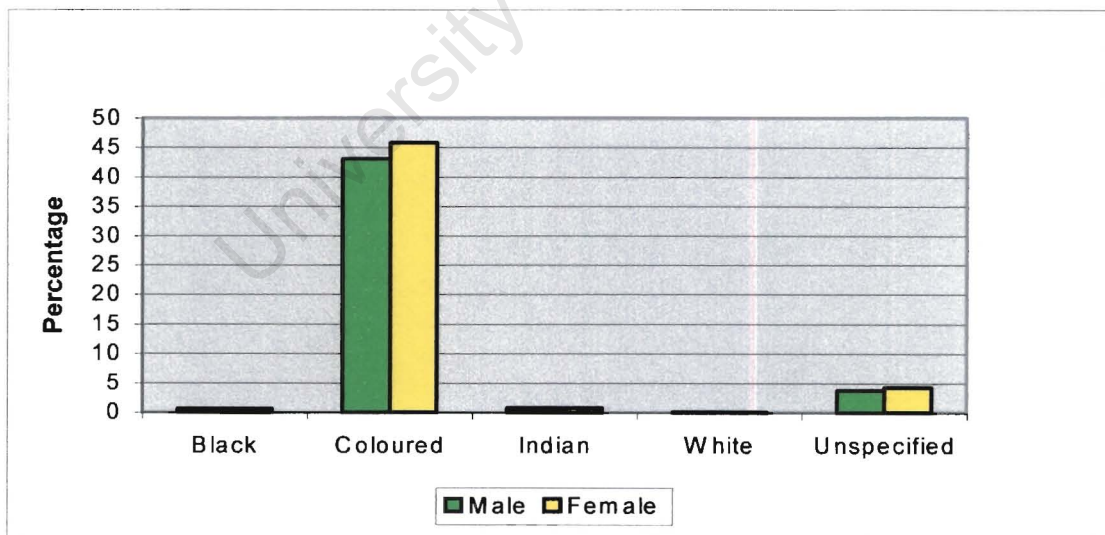


There has been growth in both male and female categories in all of the suburbs between the 1991 and 1996 Censuses (Figure 36). Grassy Park, Lavender Hill, Lotus River, Retreat and Steenberg generally grew by 5.85%, 33.07%, 10.7%, 9.38% and 4.89% respectively.

Due to the present HIV/AIDS pandemic the life expectancy of the Coloured and Black population is expected to drop from approximately 65 years to 55 years in the Coloured population and from approximately 55 years to 40 years in the Black population (Dorrington, 2002).

The male/female ratio in the Black and White ethnic groups is equal, but in the Coloured and unspecified groups the females outnumber the males. Figure (37) clearly depicts these aspects of the population of Lotus River, but they occur to the same extent in Grassy Park, Lavender Hill, Retreat and Steenberg.

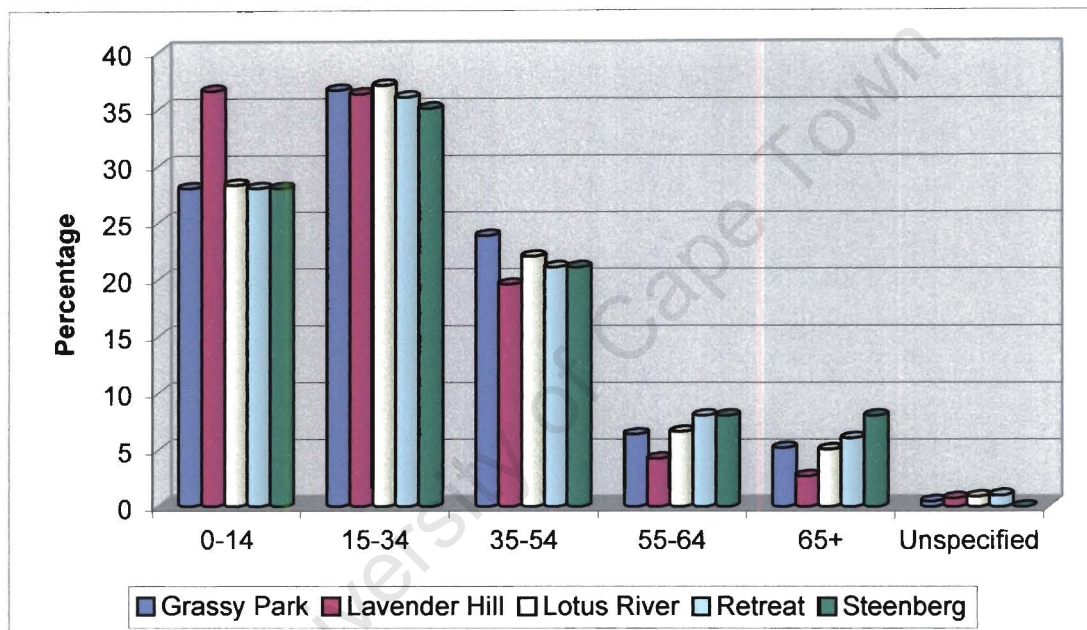
Figure 37: Lotus River by gender and ethnic group



4.6 AGE DISTRIBUTION

The highest number of people in Grassy Park, Lotus River, Retreat and Steenberg is in the 15 – 34 age group whereas Lavender Hill it is in the 0 – 14 category. Grassy Park, Lotus River, Retreat and Steenberg each have 28% of their population under the age of 15 years whereas Lavender Hill has 37% below 15 years of age (Figure 38).

Figure 38: Age distribution of suburbs



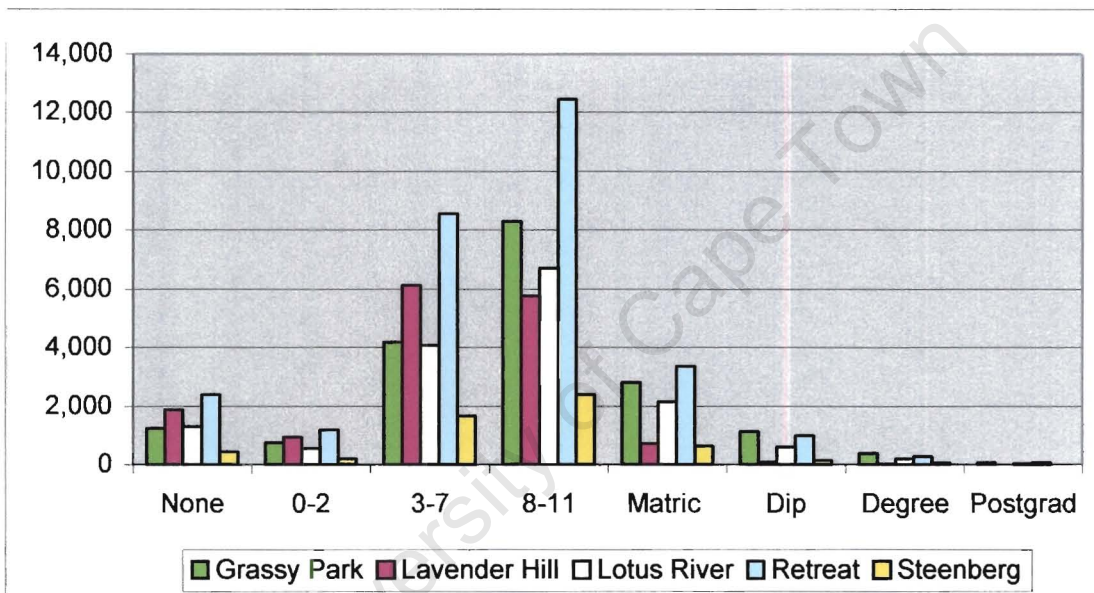
Although the percentage of people in the 65 + age group is small, namely, 5%, 3%, 5%, 6% and 8% respectively for Grassy Park, Lavender Hill, Lotus River, Retreat and Steenberg this age group has a greater degree of dependency as it is the most affected by disabling illnesses (Smart and Smart, 1997; Murray and Lopez, 1996; Cornielje, 1993; Badley and Tennant, 1991). It is to be expected that Steenberg would have a higher percentage of older people as it was established at the same time as Retreat, but did not have any housing estates

developed under the Group Areas Act and the original stable population has gradually been growing older.

4.7 EDUCATION LEVEL

The statistics in Figure (39) include the entire population, namely, learners presently at school as well as those individuals who have left school.

Figure 39: Level of education



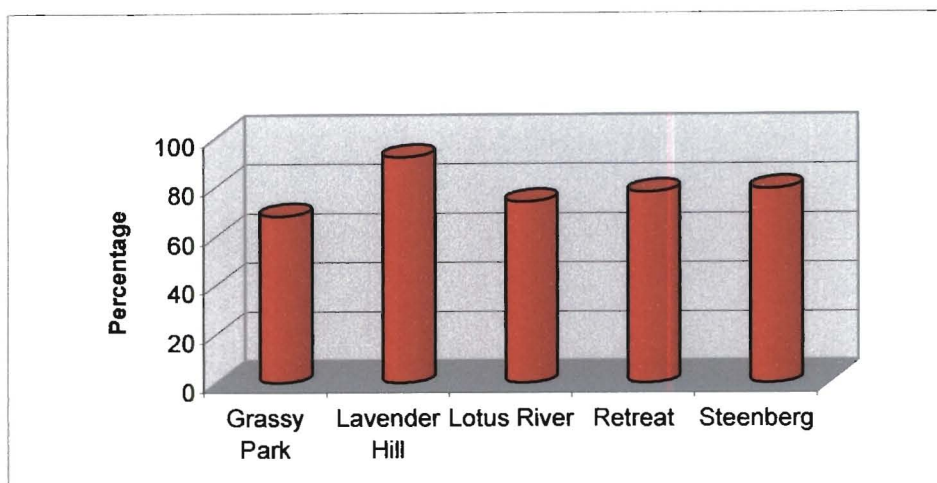
The male/female ratio for categories of 'No Education' and 'Grade 0 – Grade 2' are very similar in all the suburbs except for Steenberg, namely, that there are more males than females (Table 90). From 'Grade 3' to 'Matric' there are more females than males in each category. These two aspects can be explained by the fact that they reflect the male/female ratio in the general population.

Table 90: Level of education by gender

Grades	Grassy		Park		Lavender Hill		Lotus River		Retreat		Steenberg	
	M	F	M	F	M	F	M	F	M	F	M	F
None	570	673	989	868	649	644	1,181	1,206	210	226		
0 – 2	379	370	502	430	282	273	613	580	92	100		
3 – 7	1,818	2,369	2,801	3,315	1,928	2,139	3,823	4,725	771	892		
8 – 11	3,968	4,326	2,677	3,088	3,129	3,578	5,900	6,543	1,151	1,238		
Matric	1,342	1,473	315	391	1,052	1,091	1,589	1,782	303	343		
Diploma	558	575	35	50	315	287	506	485	74	74		
Degree	184	200	12	10	112	98	148	123	29	27		
Postgrad	51	24	0	0	21	18	58	16	3	1		

The school principals claim that another reason for this is that, at high school level, the boys are more influenced by gang activities than the girls and, if they join a gang, tend to drop out of school earlier (Carelse, 2002; Liebenberg, 2002).

During visits to the homes in Lotus River the researcher noted that there was severe overcrowding in almost all of the dwellings. Some dwellings with one room and a kitchen were being shared by five to seven people, others with two bedrooms, living room, kitchen and bathroom accommodated nine people. None of these homes had any books, there was no space for a table at which the children could do school homework and there was constant movement of people in and out of the rooms making it almost impossible for the children to do their homework and progress academically. Many families have both parents who work and it is difficult for them to take an active interest in their children's education and progress. Their main concern is generating income to pay for their basic needs of food and clothes, rental, electricity, transport and school fees.

Figure 40: Adults (18+) without a Matriculation level of education

Almost half of the children who enroll in Grade 1 do not matriculate; with large numbers leaving after Grade 8 (Johns, 2004).

Children who do achieve their matrics under these circumstances must have an exceptional ability to concentrate, persevere, and be determined to succeed as they have very little in the way of role modelling as is demonstrated by the high percentage of adults without a matriculation level of education Figure (40).

4.8 OCCUPATION

The most common occupations for all the suburbs are in craft and related trades, elementary occupations and clerks.

Unemployment, generally, is a serious problem in South Africa due to its severe economic, social and psychological costs (Ministry for Welfare and Population Development, 1997; ANC, 1994; Wilson and Ramphela, 1989). Unlike other Western countries such as Canada, the UK and the USA, there is no

comprehensive welfare or social security net in South Africa to assist families once unemployment benefits cease.

Figure 41: Percentage of unskilled labour force

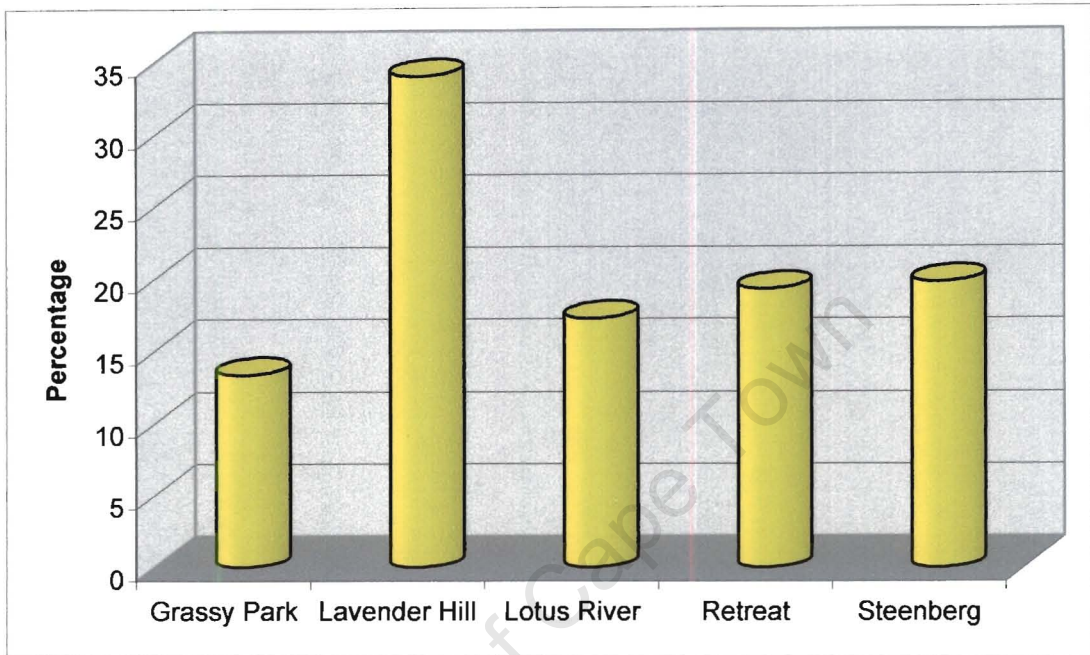
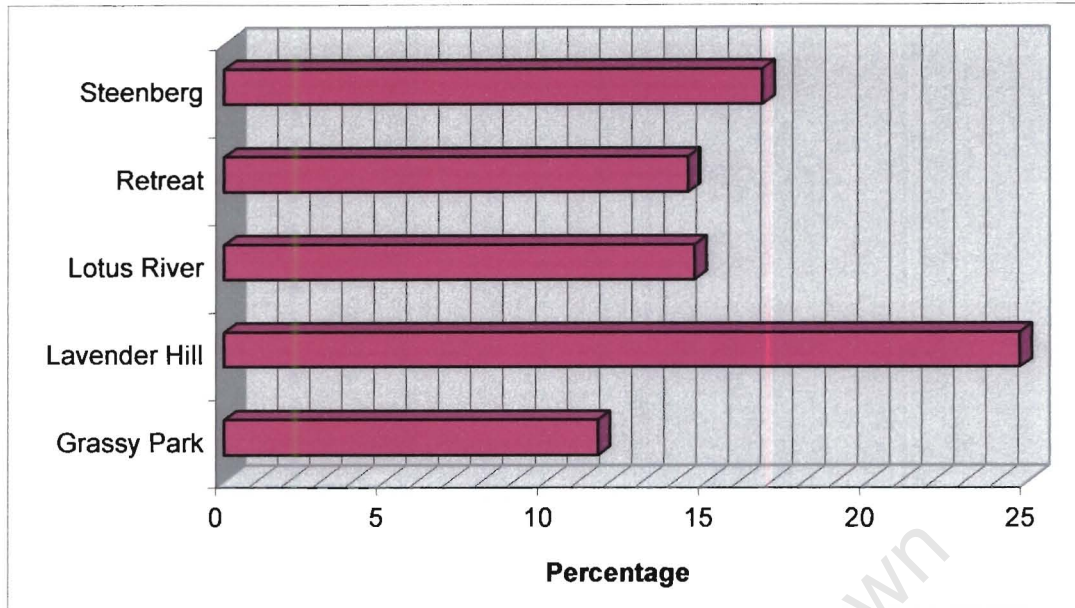


Figure (42) demonstrates the percentage of people who are unemployed and actively looking for work. Analysts believe the official figures are not accurate and that the correct unemployment figure for the country is 40% (Reuters, 2003; Wilson and Ramphela, 1989). As the suburbs in this research are considered to be low-income areas with a fairly high rate of unemployment the percentages in Figure (42), obtained from the 1996 census, are most probably inaccurate as they appear to be very low. This is most likely due to the census capturing only people who were unemployed and actively looking for work. When driving through these suburbs during the daytime one is struck by the number of young males sitting in groups at the street corners.

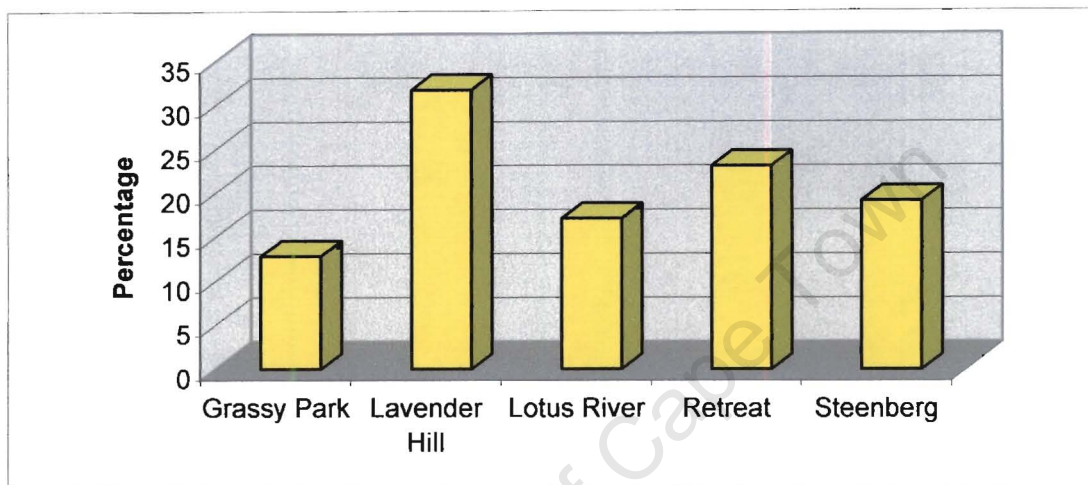
Figure 42: Unemployment

4.9 INCOME

The widespread poverty of the Coloured people can be partially attributed to the inequalities in economic and social opportunities which existed prior to 1994. A major cause of such poverty are low wages. Other contributing causes are lack of education, lack of specific training and skills and lack of adequate knowledge of budgeting (Wilson and Ramphele, 1989; Lever, 1980).

The percentage of households earning less than R12,000 per annum is presented in Figure (43). Income is calculated according to gross annual wages and salaries and includes pensions, grants, subsidies and any other fringe benefits.

Figure 43: Percentage of households earning less than R12,000 per annum



5 SOCIO-ECONOMIC STATUS

The Urban Policy Unit of the Cape Town Administration extracted information from the 1996 Census in order to develop social indicators relating to socio-economic status of the communities of the Cape Metropolitan Area to identify areas of greatest need. This was done in order to provide some insight into the quality of life experienced although it is acknowledged that it portrays only some aspects of living conditions and not the whole and that appropriate responses to problems must take a much wider range of issues into account (Urban Policy Unit, 1998).

An important measure of quality of life is socio-economic status which refers to income, education and occupational status. Income was measured by the percentage of households earning less than R12,000 per annum as this figure approximates the Household Subsistence Level for urban areas for 1996 as calculated by the Institute for Planning Research, University of Port Elizabeth. With regard to educational level a matriculation education is increasingly regarded as the minimum level for post-school training. The indicator of population that was unemployed represents the number of adults who were unemployed, but were actively seeking work as a percentage of all adults available for work. It excluded those not seeking work, such as homemakers, students and retired people. The indicator of occupational status used was the number of people employed in elementary/unskilled occupations as a percentage of all employed (Urban Policy Unit, 1998).

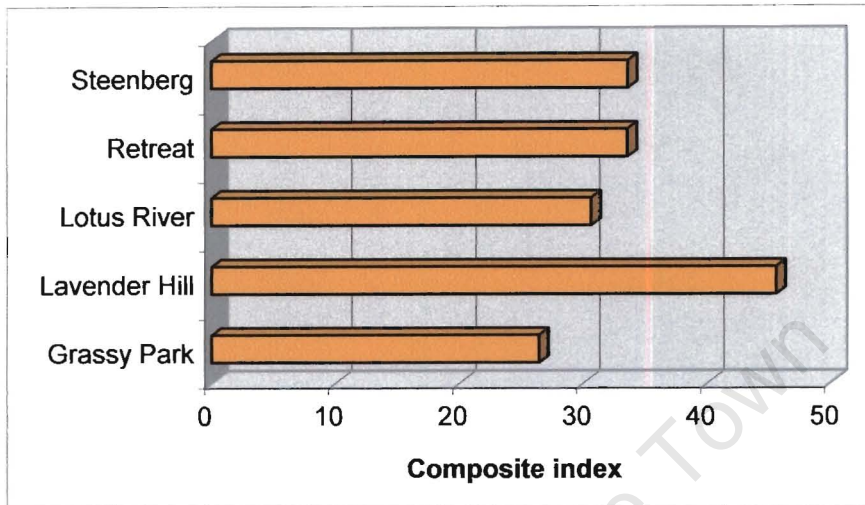
These indicators were combined into a composite indicator by calculating the arithmetical average of the four indicators. It is a measure of deprivation. The higher the index the worse off the area is considered to be. The indicators are presented in Table (91).

Table 91: Indicators of socio-economic status

	% Adults (18+) with Highest Qualification <Matric	% of Economically Active Unemployed	% Households Earning <R12,000 PA	% of Labour Force in Unskilled Occupations	Composite Index
Grassy Park	67.95	11.58	12.80	13.34	26.42
Lavender Hill	91.77	24.75	31.67	34.00	45.55
Lotus River	73.62	14.64	17.06	17.21	30.63
Retreat	77.53	14.44	23.04	19.23	33.56
Steenberg	78.91	16.72	19.06	19.71	33.60

Although relatively crude, this composite indicator provides a useful basis for comparison across the metropolitan area (Figure 44).

Figure 44: Comparison of composite indicators across the suburbs



6 HOUSING

“A house”, according to the Reconstruction and Development Programme (RDP) policy, “must provide protection from weather (four walls, a floor and a roof), be a durable structure, provide reasonable living space, sanitary facilities, storm-water drainage and a household energy supply, access to clean water and the land must be located in a suitable location geologically, environmentally and economically” (ANC, 1994: 23-24).

The housing in these suburbs comprises mostly of high-density sub-economic row houses, maisonettes and blocks of flats. There are a number of houses on separate stands, but the majority are semi-detached houses, maisonettes, flats or shacks built in backyards (Photographs 9, 10 and 11).

Photograph 9: Blocks of flats



Photograph 10: Semi-detached houses



Photograph 11: Backyard shacks of semi-detached house accommodating four families

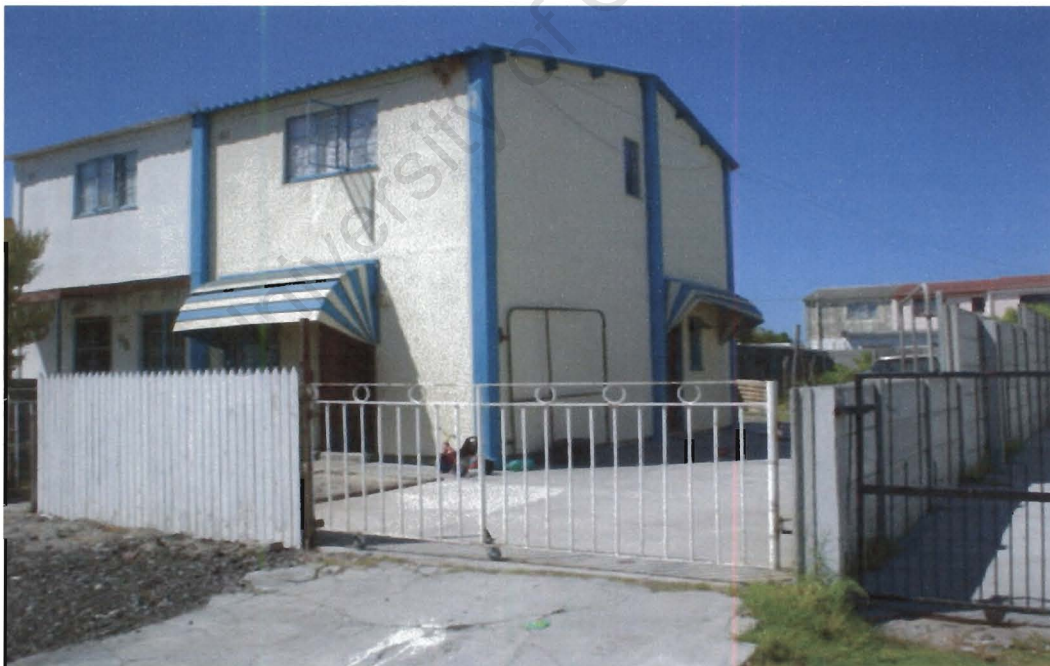


The sub-economic houses vary with regard to size and appearance. Many of the residents who have bought their houses from the council have upgraded them and have made varying attempts at vegetable and flower gardens (Photographs 12 and 13). However, many of the dwellings the researcher visited still did not have bathrooms.

Photograph 12: Renovated house with garden. The house still does not have a bathroom



Photograph 13: Renovated duplex



The blocks of flats are arranged in rows which form courts that share outdoor washing lines and floodlights. There are playing areas for the children in the courtyards and they are provided with jungle gyms on concrete surfaces (Photograph 14).

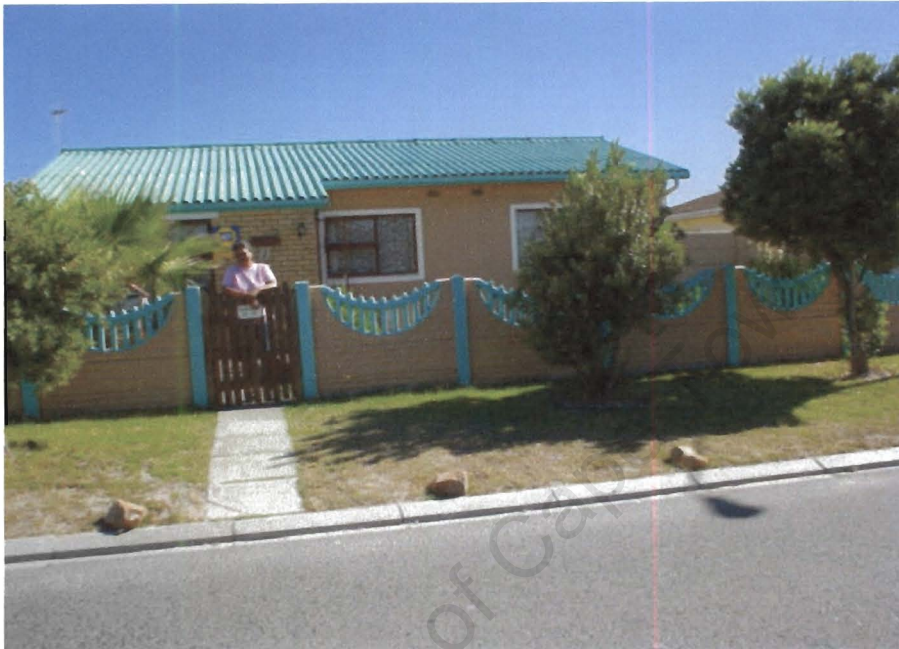
Photograph 14: Play areas for the children including jungle gym



The flats are all rented from the South Peninsula Administration (SPA), but at present there are discussions underway regarding the possibility of the tenants purchasing their flats by means of sectional title (Boltman, 2002). Tenants in the three-bedroom blocks of flats pay higher rentals and are considered to be the 'elite' flat dwellers. They do not have any complaints about their accommodation. However, residents in the smaller flats complain a great deal about the noise from neighbours. This is either from teenagers who play loud music throughout the day and until late at night or from neighbours who abuse alcohol which results in domestic arguments.

There are a small number of well-maintained owner-built houses of medium to large sizes in all the suburbs although this is minimal in Lavender Hill (Photograph 15).

Photograph 15: Owner-built well-maintained home



The percentage of households living in informal dwellings in Grassy Park, Lavender Hill, Lotus River, Retreat and Steenberg are 1.85%, 4.79%, 6.08%, 5.37% and 4.59% respectively.

Housing for senior citizens is provided in Lotus River Place and House Morea in Lotus River. The Douglas Murray Memorial Home is located in Retreat and Mandolin Place is a self-catering complex in Steenberg.

There are parks situated throughout Lotus River. They do not have any trees and the grass is poorly maintained making their appearance very barren. Litter is

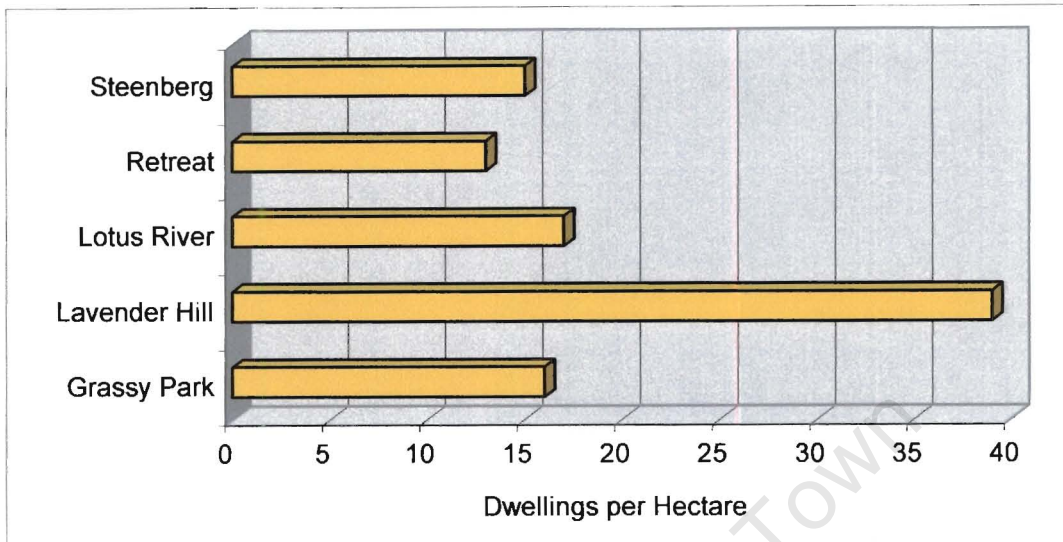
frequently blown onto the boundary fences of the parks and this remains there for weeks, if not months, before it is removed by the council (Photograph 16).

Photograph 16: Park with slides and swings for children to play



6.1 DENSITY

Figure 45: Housing density



6.2 LEVEL OF OVERCROWDING

It is difficult to estimate the level of overcrowding that exists in these areas as the 1996 Census captured only the dwellings per hectare (Figure 45) and the total number of rooms per dwelling which included bedrooms, living rooms, kitchens and bathrooms. By dividing the number of people per suburb by the number of rooms per household it can only be incorrectly and very conservatively estimated that the number of people per room is as presented in Table (92). It is not possible to subtract two rooms, namely, the bathroom and kitchen, from the number of rooms per household as, firstly, many of the sub-economic dwellings do not have bathrooms. Secondly the table from the 1996 Census is presented in columns of the number of rooms per household. These columns are titled as "0", "1" and "2" rooms, etc, and it is not logical to subtract two rooms (kitchen and bathroom) from these columns in an attempt to get a more realistic number of people per room.

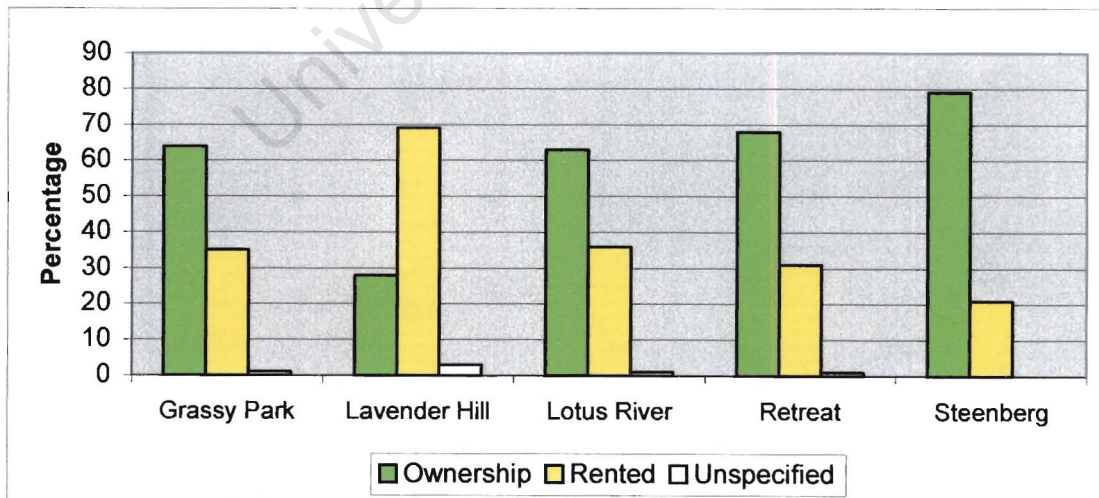
Table 92: Number of persons per room

	Population	Number of dwellings	Number of rooms	Persons per household	Persons per room
Grassy Park	21,283	5,009	22,821	4.25	0.93
Lavender Hill	18,172	3,774	13,398	4.81	1.35
Lotus River	18,123	3,931	16,398	4.61	1.11
Retreat	34,176	8,102	31,701	4.36	1.08
Steenberg	6,229	1,338	5,645	4.65	1.10

Table (92) reflects that Lavender Hill is again the most disadvantaged suburb by being the most crowded and Grassy Park as being the suburb which is least disadvantaged with the least number of persons per room.

The SPA has no plans for further houses to be built in Lotus River, but there is a private building development planned for 3,000 new economic homes in the southern area of Zeekoe Road for families whose joint incomes are more than R4,000 per month (Boltman, 2002).

6.3 DWELLING OWNERSHIP

Figure 46: Ownership of dwellings

Steenberg is the only suburb that did not have housing estates established at the time of the Group Areas Act. During the 1970's and early 1980's the majority of dwellings were rented from the CTCC. Apart from Lavender Hill, most dwellings are now privately owned, many tenants having purchased their homes from the CTCC from 1980 when they became available for purchase at nominal rates (Figure 46).

Because people with disabilities are the most disadvantaged with regard to economics, employment, housing and income (Ayling, 1999; Coetzee, 1997; Smart and Smart, 1997; McNeil, 1993; Alston and Mngadi, 1992; Yelin, 1992; Lonsdale, 1990; Locker, 1983) many of them renting council houses have been unable to afford to purchase them, even at nominal rates. Some of the disabled have had to rent backyard shacks from the owner or tenant of the main house. Most of these people have been on the Housing Waiting List for fourteen years (Liebenberg, 2003; Olivier, 2003; Simpson, 2002). Although they may be close to the top of the waiting list, because there is a great shortage of homes they have to wait until a house becomes vacant as new houses are not being built. However, in reality, when tenants move out and a house does become vacant the tenants do not notify the Housing Office and simply hand over their dwellings to their relatives in need. The persons who have become disabled since living in flats on the second, third and fourth floors are in the same situation. In order for them to move to the ground floor they have to wait for one of these to become vacant and this does not occur as the flat passes on to a relative or friend without the Housing Office being notified. In addition, the Housing Office often puts the onus onto the people with a disability by recommending that they find a tenant from the ground floor who is willing to exchange flats with them, but this does not happen for obvious reasons. It is more inconvenient living upstairs, particularly on the third and fourth floors as there are no lifts/elevators.

The Housing Office has a waiting list of 22,000 households requiring homes (Africa, 2003).

Lotus River is not a mobile suburb. Ninety percent of the research participants had lived in Lotus River, either from the time they were forcibly removed from Constantia, Diep River or Claremont or from the time they were born. The majority had lived in the same dwelling from the time they had come to Lotus River, namely, up to 33 years. Due to the long housing waiting lists and the economic situation of the people very few had changed dwellings once they married and had their own families. It was very common to find three generations living under one roof as the children simply continued to live with their parents once they married and had their own children. Many tenants accommodated their children and their families in backyard shacks.

6.4 WATER AND SANITATION

Almost all the households have piped water in the dwellings, but there are still a few who only have access to water on the site or have to use a public tap. These are the informal backyard dwellings.

Although the majority of households have flush or chemical toilets there are residents who still have to use pit or bucket latrines. Not having access to a flush toilet is a major problem to many of the people with physical disabilities who live in backyard shacks. By the nature of their medical condition they need to use a latrine frequently and, in many cases, it is extremely difficult, if not physically impossible, for them to use a pit or bucket latrine.

Although the 1996 Census provides the following statistics regarding households with flush toilets (Table 93) it does not provide any information on whether these toilets are inside or outside the house.

Neither are there any statistics provided on the number of households with and without bathrooms.

Both of these aspects have a significant effect on the lives of people with disabilities and their carers. The researcher visited many dwellings where the toilets were outside and where they had no bathrooms at all.

Table 93: Households with flush toilets

	% Households with flush toilets
Grassy Park	98.46
Lavender Hill	97.23
Lotus River	97.83
Retreat	96.68
Steenberg	97.46

6.5 ELECTRICITY

The large majority of householders use electricity for fuel for which they pay before use by means of a card. Purchasing electricity is easily accessible to all residents as they can do so at many service stations and local corner-shops.

A small number of households still use gas cylinders, paraffin or candles as a means of lighting.

This is still the cause of most of the fires in the homes as a result of candles falling over and setting light to inflammable material. Physical burns are frequently treated at the CHC's and Red Cross Memorial Children's Hospital

which have been the result of gas cylinders exploding. Children also get poisoned by drinking paraffin from bottles which are left lying around in the houses.

7 REFUSE REMOVAL

Refuse removal takes place once a week by the council. Although the council is also responsible for cleaning the streets there is sometimes a great deal of litter lying around in the alleys between the rows of houses as a result of garbage being dumped by residents. During the two-year period the researcher spent working in the area these alleys were never once cleared by the council (Photograph 17).

Generally the land immediately around the houses have little litter lying around.

Photograph 17: Litter in alley between semi-economic row houses



8 ROADS AND PAVEMENTS

Road access to all the suburbs is good as they are all major roads which are in good condition and are well maintained.

Most of the roads within the suburbs have tarred surfaces, but they are generally in bad condition with gravel bedding appearing through potholes. The painted lines and road signs have not been maintained and are no longer visible making it dangerous for both cars and pedestrians as drivers new to the area are not alerted to stop at the stop streets. Many of the street names have been removed or vandalised to such an extent one is unable to read the name as the sign is either broken or it has been changed and points in the wrong direction.

During winter pools of water form in the potholes and along the sides of the roads as many of them do not have stormwater drains or else they are badly maintained and are not effective (Photograph 18).

Photograph 18: Blocked and non-existent stormwater drains



The pavements are of sand or gravel and are rough and uneven. There are kerbstone drops only at sites where the tenants have a car which makes it difficult for wheelchair-users to access the road. During the winter the pavements become flooded and large pools of mud form on them. It is particularly problematical for wheelchair-users as they are unable to push themselves through the thick sand to reach the roads where the surfaces are adequate for them to propel themselves to their destinations (Photograph 19).

Photograph 19: Sandy pavements with no kerbstone drops

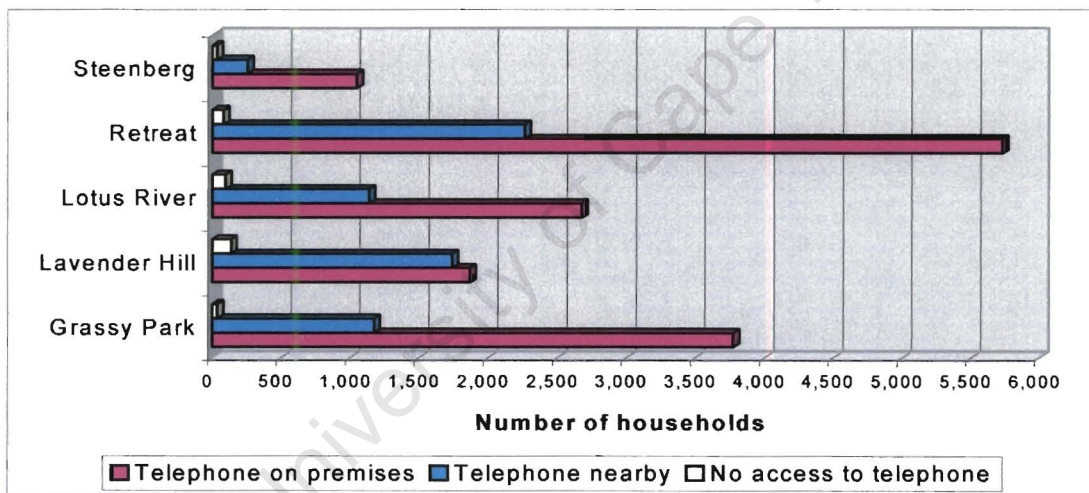


Most of the streets have lights, but these are inadequate in many areas because they are too weak and too far apart and the lamps are frequently broken by vandals.

9 ACCESS TO TELEPHONES

As can be seen in Figure (47) there are a large number of households which only have access to a telephone nearby, but not on the premises. This affects the poorer part of the population more and, as people with disabilities are often the most disadvantaged in a community (Ayling, 1999; Coetzee, 1997; Smart and Smart, 1997; McNeil, 1993; Alston and Mngadi, 1992; Yelin, 1992; Lonsdale, 1990; Locker, 1983), this affects their ability to make appointments with the social workers, specialist clinics and Dial-a-ride for transport (Jaftha, 2003; Reiners, 2003; Williams, 2003; Lottering, 2002; Simpson, 2002).

Figure 47: Access to telephones



10 TRANSPORT

The Minister of Transport of the Western Cape, Ms Tasneem Essop provided the following summary of the local transport situation: "Public transport is a key determinant in the quality of life of many South Africans. We are not providing a good service to the people of the Western Cape. The present situation is

unacceptable and unsustainable. Our public transport system needs to provide commuters with an efficient, reliable and safe service. We cannot continue to condone the high levels of crime that take place on trains and at transport interchanges and minibus taxi ranks – last year 34 people were murdered on trains in Cape Town and five women were raped – and these are the reported ones. Women and children also have important safety requirements and we need to begin to meet the needs of these groupings far better than we do at present. Violence is also a character of the system. Commuters are not safe, but violence has also been used as a means to resolve differences within the sector. There are also many forgotten commuter groups who have special needs and requirements that public transport must meet. How does it service disabled members of our community who have important constitutional rights to participate in the economy? Public transport plays an important role in human society in allowing those that are trapped in dormitory townships to access these leisure and recreation facilities” (Essop, 2002).

Due to the lack of local employment opportunities and the fact that the industrial areas are some distance away from the majority of people residents are very dependent on public transport as few of them own vehicles.

There is a train service direct to Cape Town provided from Steenberg and Retreat Stations, but this means that residents from Grassy Park, Lotus River and Lavender Hill have to catch a bus or minibus taxi to reach the station before being able to use a train. The trains are extremely overcrowded and people even travel by hanging outside the doors of the coaches which frequently results in horrific accidents causing death or severe injury and disability.

Buses run along the main routes from Mitchell's Plain via Lavender Hill, Lotus River and Grassy Park to Wynberg. There are no direct bus routes between Grassy Park, Lavender Hill, Lotus River and major areas of employment, namely,

Retreat and Ottery industrial areas. Overcrowding is also a problem on the buses.

Minibus taxis provide the best form of transport as they travel directly to the industrial areas. This seems to be the most sought after mode of transport as the rates are cheaper than those of the buses and trains and the people reach their destinations much faster. However, as they are privately owned and the drivers are paid on a commission basis there is gross overcrowding and the drivers travel at dangerous speeds, frequently being involved in accidents.

The resettlement suburbs have resulted in the situation where the monthly expenditure on travelling to and from work absorbs a large part of the residents' income. The residents claim that this is the highest single cost item for many of the workers. This not only decreases their effective purchasing power, but also prevents the unemployed from travelling to the industrial areas in search of employment (Petre, 1987).

There are no figures quoting vehicle ownership available. Many of the residents owning vehicles are frequently called upon by people with disabilities to transport them to the CHC's to attend hospital appointments, clinics or to fetch their medication, but the rates they charge are high and out of reach of the majority of the disabled.

Transport problems sometimes can have an extremely deleterious effect on people requiring chronic medications. For example, one of the participants who had suffered a stroke due to hypertension was required to attend the clinic regularly to fetch her medication to keep her blood pressure within safe limits. Due to the severity of her physical disability she was unable to use a bus and the clinic was not on a bus route. She could not walk to the minibus taxi route as she was not capable of walking independently nor could she afford the minibus taxi fare to the clinic as it meant a private minibus taxi fare as the clinic was not on

the minibus taxi route. None of her family or friends possessed vehicles and she could not afford to pay the amount demanded by the neighbours who owned cars. She remained without medication for two months and then suffered a second severe stroke, again due to hypertension. In her hospital file the notes from the clinic doctor stated that the person was “non-compliant” with regards to her medication as she had not attended the clinic regularly to fetch her medication.

“Dial-a-ride” is a service provided by wheelchair-friendly minibuses which operate throughout the Cape metropolitan area from 6am to 7pm Mondays to Fridays. It is aimed specifically at people with physical disabilities who, as a result of their disability, are unable to make use of current forms of public transport. The service is subsidised by the City of Cape Town. People with physical and visual disabilities are required to register for its kerb-to-kerb service and have to book telephonically. Bookings are accepted on a first-come-first-served basis and priority is given to people to get to and from work. Trips to hospitals and clinics are restricted to off-peak periods. Fares vary from R4 to R16 per trip depending on the number of service zones travelled.

Although this service appears ideal for people with disabilities, in reality most people in Lotus River had strong reservations about the service as they did not all have access to a telephone and they found the booking clerk to be rude and unhelpful. Clients are also expected to book transport 24 hours ahead of time. This does not make it practical for people with disabilities who might get ill and require medical attention the same day (Davids, 2003; Engelbrecht, 2002; Geland, 2002; Seafort, 2002). The same complaints have been leveled at the service by users from other suburbs (Gophe, 2004; Phillimore, 2004).

11 SCHOOLS

Table 94: Number of schools in suburbs

	Primary School	High School	Crèche /Preprimary
Grassy Park	5	3	15
Lavender Hill	3	2	13
Lotus River	6	1	5
Retreat	10	3	8
Steenberg	1	1	5

All the primary and high schools are state schools and the pre-primary schools are privately owned (Table 94). Before 1994 the education system was under control of the Department of Education and Culture within the House of Representatives. The system was generally regarded as being inferior to that of the Whites under the jurisdiction of the House of Assembly. For many years there were inadequate teaching facilities and many of the teachers were unqualified or under-qualified. There was a severe lack of sporting and extramural facilities, classrooms were overcrowded and the syllabus, as laid down by the 'apartheid' system, was restricted. This legacy is still evident in that there is always a shortage of books and teaching and learning materials. Compared to the schools in the White areas the exteriors of the buildings are drab and poorly maintained and the surrounding grounds are stark with no trees, gardens or constructed sports fields (Liebenberg, 2002) (Photograph 20).

The majority of the schools offer tuition in both English and Afrikaans. Although there are no tertiary institutions in this area the Cape Flats Development Association (CAFDA) and the New World Foundation (NWF), two NGO's, offer training courses in sewing, bakery, catering, gardening, computer literacy, business management and workplace skills.

Photograph 20: Drab school buildings and bare playing fields

The primary schools have approximately 600 learners at each school. They are dispersed throughout Lotus River and accessible so that the majority of children are able to walk to and from school wherever they live. However, some parents prefer to send their children to schools which are not necessarily the closest to their homes and they have to use a bus or minibus taxi.

There are double the number of primary schools than high schools although the high schools do not necessarily have higher numbers of learners. The reason for this appears to be that, once the children reach high school, many parents prefer to send them to high schools in higher income suburbs as they feel they are superior to the ones in Lotus River and that their children will receive a better education. This attitude probably stems from the time that the original Secondary and High Schools were in a bad state of repair due to vandalism. Windows were broken and children had to sit in classrooms which were draughty and most of the facilities were broken beyond repair (Kassan, 1990).

Approximately 60% of the children at the schools come from families who are unable to afford the school fees as both parents are unemployed. As a result there is a shortage of studying materials and learners have to compete for the books available (Liebenberg, 2002).

In order to deal with the shortage of educational material the governing bodies of the schools have to try and raise the funds to cover the costs (Liebenberg, 2002).

The lack of security personnel at the schools is a cause of concern to many parents. Gangsters often target learners at school to involve them in dealing in or selling drugs. Sometimes gangsters come onto the school premises to attack their victims or to wage battles with other gangs (Van der Merwe, 2002; Mtyala, 2002).

The schools have dealt with the problem in different ways. Some have security fences surrounding the property and the gates are locked during school hours to prevent the gangsters from gaining access. Other schools have parents acting as security personnel and they guard the property during school hours. Sirens are also used to call the children into the safety of the classrooms when gangsters come into the vicinity. Schools which have neither fencing or security personnel send the children home when the gangster activity takes place in the vicinity (Mtyala, 2002). The children in most of the schools have been taught to lie flat on the floor on command from the teacher or sounds of gunfire to avoid being struck by bullets in the cross-fire of gang fights.

Children complain that they worry about the gangs because they have to walk to and from school through the area where the gangsters meet. They complain that they cannot play outside or visit their friends safely (Williams, 2003; Simpson, 2002; Smith, 2002; Von Gussling, 2002;).

Vandalisation of school property and theft of learning material is a constant problem at all the schools.

12 LIBRARY

Grassy Park, Retreat and Lotus River each have their own libraries which also serve Steenberg and Lavender Hill. The libraries are community-centred and attract a great number of children during the school term as they use the books for their school assignments. However, the libraries are very quiet during the school holiday periods (Langenveldt, 2002).

Burglaries are commonplace in all the libraries as criminals break in and attempt to take money from the photocopiers. In order to do this they usually vandalise the machines beyond repair. In the past 18 months the fax machines, refrigerator, two computers, four scanners, television monitor, video recorder, printer, laminator, R15,000 worth of videos, compact discs, audio cassettes and televisions have been stolen from the Lotus River library alone (Southern Mail, 2003; Langenveldt, 2002).

13 POST OFFICES

There is a post office in each of the suburbs which offer full services. The postmen do daily rounds of mail delivery to all the houses and flats.

14 FIRE PROTECTION

The area is served by the Ottery and Wynberg Fire Stations. No figures are available to show the incidence of fire in the area, but it is considered to be a

“high risk” zone due to the high density housing, overcrowding in the dwelling units and the fact that some residents still use paraffin and gas as fuel.

15 COMMUNITY NEWSPAPERS

The Independent Community Newspaper that is circulated through Grassy Park, Lavender Hill, Lotus River, and Steenberg is called *The Southern Mail*. The newspaper is printed weekly and is delivered free of charge to all houses keeping the residents informed of current activities and events in their communities.

16 EMPLOYMENT

Retreat, Elfindale, Ottery and Hanover Park are major industrial areas which are all close to the suburbs and are easily accessible by bus or minibus taxi.

Some of the people are employed by the Housing Office, schools and local shops within Lotus River.

There are a number of doctors, dentists and physiotherapists in private practice who practice from their homes or small shopping centres within the different areas.

No details are available about the informal sector, consisting of trade stalls, hawkers, shebeens, repair shops and small home industries although they can be seen actively working and trading from their houses or from door-to-door with their wares of fruit, vegetables, fish, fabric and clothing.

The majority of people, however, travel much longer distances to their places of employment such as the city Central Business District, Epping Industria and Paarden Island industrial areas.

17 RECREATIONAL FACILITIES

Grassy Park has a Sports and Recreation Council that organises grassroots level projects aimed at all codes of sport by both formal and informal associations.

The council has members in Grassy Park, Lavender Hill, Steenberg and Lotus River. It both manages and maintains sport and recreational facilities in partnership with the local authority. Indoor sports include table tennis, volleyball, badminton and Fut-bal-de-dalo. Outdoor sports offered are cricket, tennis, baseball, basketball and netball.

The Southern Suburbs Football Association, affiliated to South Africa Football Association Western Province, runs 11 soccer clubs with membership at junior and senior levels.

Grassy Park has three community centres, namely, a civic centre, sport and recreation centre and the Zeekoevlei community centre.

Rondevlei nature reserve, situated in Grassy Park, is well-known and is visited by many tourists. It provides an invaluable service to all schools in and around the area with regard to environmental issues and collections of indigenous plants and birds.

Steenberg has one tennis court and four netball courts, two rugby/soccer fields and a swimming pool.

Lavender Hill has two open fields used for soccer and netball. There is also a netball court with a clubhouse/change room facility. The community makes use of Allenby Drive and Rondevlei Sports grounds in Retreat, Rooikrans Avenue Sports Grounds and 'green space' in Grassy Park for various sporting activities.

Halls in Lavender Hill include the Civic centre, SPA Community Halls and CAFDA's Mary Attlee Centre.

Retreat has the Protea Club and the Uniting Reformed Church Hall. It also has a public swimming pool, community and civic centres and a sports field and club.

Lotus River has four netball courts, 17 soccer fields and one cricket pitch. There are also two community centres and one multi-purpose center in the area.

18 PLACES OF WORSHIP

Religion plays an important part in the lives of the people in the area. Many of the people with disabilities expressed their need for attending church services on Sundays or mosques on Fridays as a priority rather than any other need. People who are unable to walk are fetched from their homes and taken to church/mosque by car by members of the congregation. This frequently entails physically carrying the person with a disability down and up the stairs from and to the fourth floor of the block of flats.

The church leaders regularly visit the homes of people with disabilities. The disabled look forward to these visits and they are highly appreciated.

The area is well represented by churches and mosques dispersed throughout the suburbs (Table 95).

Table 95: Places of worship

	Churches	Mosques
Grassy Park	19	1
Lavender Hill	8	2
Lotus River	6	3
Retreat	31	2
Steenberg	6	0

19 COMMERCIAL ACTIVITIES

The formal business areas are located in Prince George Drive, Victoria Road, Fifth Avenue, Klip Road, Buck Road, Retreat Road, Military Road and Retreat Main Road. They comprise motor service stations, hardware stores, estate agents, cafés, butchers, liquor stores, chemists, furniture stores and small supermarkets. Most of the food stores are of the small “corner-shop” variety, which offer only a narrow range of goods. They are easily accessible to the residents, but are very expensive and the majority of people travel to Ottery, Tokai or Kenilworth to shop at the large supermarkets which are less expensive.

There are doctors, dentists and physiotherapists who conduct their private practices from small shopping centres or from their homes scattered around the residential areas.

Grassy Park is the only area to have two banks which offer limited services only. This is a problem to many of the residents as they would like their pensions or DG's to be paid directly into bank accounts instead of having to collect their money from the payout centres. This is partly due to fear that they may be mugged en route from the payout centres, but also to avoid the loan sharks who wait outside the payout centres to collect any money that they are owed. Because of the high interest rate they charge the borrowers never get freed from paying off their debts as most of their grants are taken from them as soon as they

are paid and they have to borrow more money immediately to be able to get through the next month (Olivier, 2003; Carelse, 2002, Jacobs, 2002).

The informal sector consists of street vendors and door-to-door dealers who distribute fruit, vegetables, fish and a wide range of non-durable consumable goods. There are also shebeens situated in the houses or backyard shacks which sell alcohol and drugs.

20 CRIME

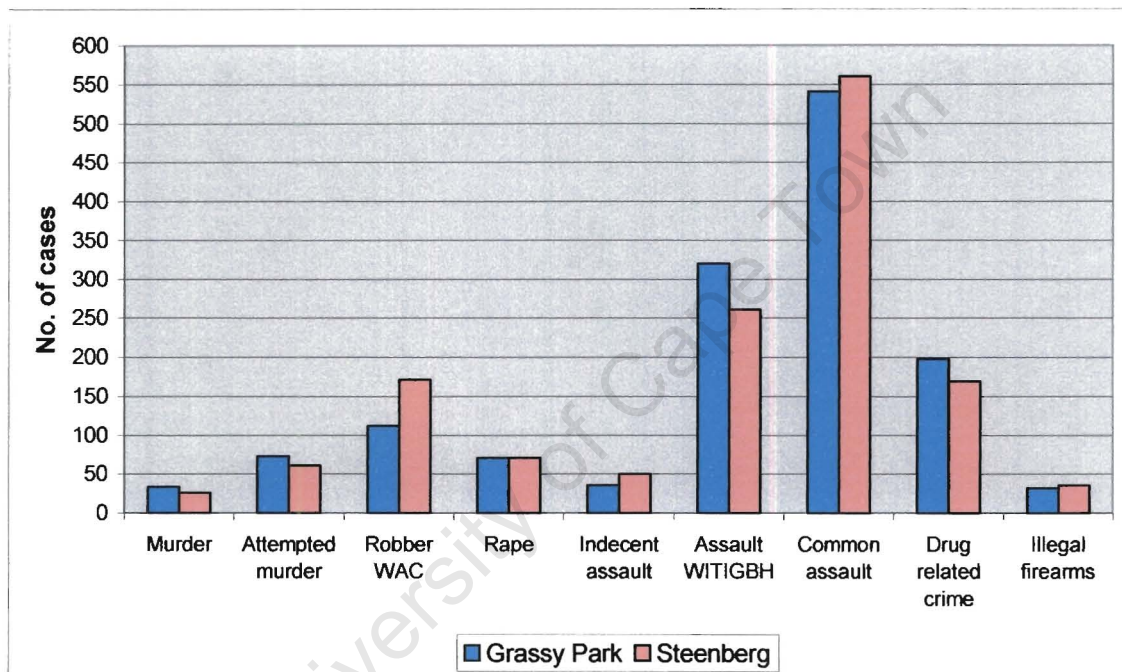
Grassy Park and Lotus River are grouped together in the Grassy Park police precinct and Lavender Hill, Retreat and Steenberg fall under the Steenberg police precinct. The police take a community policing approach to their work which means that the communities and police take a shared responsibility in an attempt to make the communities safer, more peaceful and liveable places. To this extent volunteers from within the communities substitute for the police for certain shifts and assist them with other shifts where needed (Brooks, 2002; Goss, 2002; Pienaar, 2002). Their duties involve desk work to free the policemen so that they can patrol the communities.

Both police stations have two vehicles in which to patrol their entire precincts. The Crime Prevention Units and Trauma Units also work from the police stations. They are staffed by the National Institution for Crime Prevention and Rehabilitation of Offenders (NICRO) and the Community Policing Forum and deal largely with rape and counselling for abused women and children counselling.

The suburbs on the Cape Flats manifest the negative consequences of oppression which include high levels of interpersonal violence, substance abuse, crime and gangsterism (Gilbert, 1997). According to the White Paper for Social

Welfare (1997), substance abuse is recognised as one of the greatest health and social problems in South Africa and has wide-ranging consequences, which include physical debilitation, violence in families and trauma. Alcohol remains the most popularly abused drug and it is estimated that approximately 5,8% of the South African population over the age of 15 is dependent on alcohol (Ministry of Welfare and Population Development, 1997).

Figure 48: Crimes involving bodily harm in 2001



The Western Cape has the highest gang-related violence in South Africa and Lavender Hill has the highest incidence in the Western Cape (Norman, 2003; Goss, 2002; Rhodie, 2002; Gilbert, 1997) (Figure 48). There are many active gangs in all of these areas and gang warfare occurs frequently, often involving innocent members of the community in the crossfire as firearms and zip-guns are used. The fights appear to stem from a territorial battle over the lucrative drug trade (Cape Argus, 09.12.1993). Newspaper reports over the years cite

numerous incidents of gang murders and cross-fire killings. Twelve people were killed in crossfire in one week (Cape Argus, 28.02.1994) and in March 2003 five children were killed in separate incidents within one week (Cape Argus, 17.03.2003). Several of the participants in this research were disabled as a result of injuries sustained during the cross-fire between gangs.

The chief areas of gangster crime is the localities where identification of individuals is difficult. These are where the street lighting is poor, near open fields, in the alleys between houses and in the courtyards formed by the blocks of flats (Goss, 2002; Rhodie, 2002).

From 1990 the violence, crime rate and gangsterism has increased a great deal in the Cape Flats (Cape Argus 09.12.1993; Athlone News 23.06.1993; Cape Argus 15.06.1993; Cape Times 25.07.1992; Athlone News, 14.08.91).

Gang violence is the major cause of violent death in these areas, especially amongst the youth. Robbery often includes scholars being targeted by criminals. Daytime burglaries occur in the houses where the residents are away at work and are perpetrated by unemployed individuals living in the area who do not have any form of social support in the form of extended family. Those that occur at night are perpetrated by gangsters living in the area who know the activities of their neighbours. Property-related crimes, for example, malicious damage to property are closely associated with alcohol and drug abuse and in most cases the perpetrators are friends or family members of the complainants. (Goss, 2002; Rhodie, 2002;).

Offenders are either small unorganised groups who steal anything for quick cash sales or larger well organised syndicates who steal items of great value for distribution to dealers in second hand goods.

There has been a decrease in murder, attempted murder and common assault in these two police precincts during 2000, 2001 and 2002. This can be attributed to the dedication of the police, the implementation of crime prevention programmes and the cooperation between the community, community policing forums and the police (Goss, 2002; Rhodie, 2002).

However, during the same period burglary, rape and assault with grievous body harm, malicious damage to property and motor vehicle theft have increased.

Many of the assaults occur during robberies, gang fights and domestic violence. In domestic settings it is mostly in the form of women and child abuse and usually involves alcohol and/or drug abuse.

Drug merchants live all over the suburbs and often buy food for struggling neighbours, pay rentals for those people who are in arrears and generally provide loans to those in need. These benign acts of benevolence, however, is part of a process of engendering fear and terror in the community. Shebeens flourish and are often open day and night. It is frequently after closing at night that the criminal element become active: women are raped and robbery and assaults take place (Cape Argus 07.01.2003).

Occasionally the police have been implicated in the drug and gang activities. The police at Grassy Park Police Station were found to run a soccer club which received 'donations' from druglords and gang leaders. Gangsters were seen to be wearing police-issue bulletproof vests and firing government-issue R4 assault rifles during gang conflicts (Cape Argus 10.10.2002). In a new initiative to eliminate police corruption, Resolution 7/2002 has been passed whereby a police member who has worked at one station for more than ten years has to move to another station in a different geographical area (Cape Argus, 07.03.2003).

Various attempts have been made over the years to safeguard the community. A Commuter Watch to make public transport safer was established in Grassy Park in conjunction with the Grassy Park police, the Grassy Park and Lotus River Taxi Association and the Grassy Park Neighbourhood Watch Association (Scott, 1993).

Neighbourhood Watches have been established in many areas, but have often not been maintained as members of the community are hesitant in becoming involved in reporting gangster activity or providing evidence in court cases for fear of victimisation. Their motto has been to observe and not to get involved as in many situations when they have become involved their members or family members have been stabbed or shot to death (Southgate, 2002).

The Safer Cities Program is run in Lavender Hill to facilitate development strategies that enhance community safety through environmental planning and design. This is done largely by means of community participation.

In 2001 a telephone answering service was established by the Lotus River Crime Watch. This permits the identities of people reporting criminal activities to the police to be kept confidential. When they use this line their homes are not visited by police for statements nor do they have to appear in court and this prevents the criminals from knowing who has reported them. The Crime Watch has had an excellent response and co-operation from the Grassy Park Police Station and Flying Squad (Carelse, 2002; Scott, 1991).

Eight members of the Lotus River Community Forum met with the gang leaders of the two gangs on either side of Fifth Avenue and discussed with them the effects their activities had on children in the community and how their lives were impoverished by having parents as gangsters. The researcher is unsure whether this had any direct effect or not, but the level of gangster activity in Lotus River subsequently decreased significantly for a period following this meeting. It,

however, increased again and two gangsters were killed and five critically injured in one fight on 25th February, 2003.

Youth Leaders Against Crime are youth groups that have been established in the two police precincts by Inspector Smith at the Grassy Park Police Station in order to make the youth aware of substance abuse and the repercussions of being involved with gangs and criminal elements.

The South African Council of Drug and Alcohol Abuse provides a service at the Lotus River CHC.

Spades and Pakes and the Sunshine Youth Group are organisations which provide entertainment and activities for the youth in an attempt to keep them active and away from the influence of the gangs.

The Crime Prevention Unit runs regular patrols through the various areas in an attempt to control drug distribution and the operation of shebeens.

The Crime Prevention Forum consists of 20 people representing various organisations and institutions in the area such as the Baptist and Methodist churches, Lavender Hill Civic Centre, CAFDA, NWF and a chairperson from each of the 13 Neighbourhood Watches. They meet monthly to discuss problems and possible solutions regarding crime in the area.

In January 2003 the City Police deployed 70 City Police officers in Ottery, Wetton, Lavender Hill, Grassy Park, Lotus River, Retreat and Steenberg. Their main functions were to prevent crime, assault and burglary. These municipal police work closely with the South African Police Services' Unit which focuses on combating gang-related crime.

During the data collection phase of this research there were waves of gang warfare. To start with it was quiet during the day and there was only sporadic activity at night, but this did not last long. Following the release of several prominent gangsters from prison the level of activity rose as they tried to settle old scores with rivals and to retake their turf. Two of the gangsters who used to be most helpful to the researcher when she distributed equipment to the disabled were killed and another three of their gang were critically injured in a fight during the time the research was being conducted (Cape Argus, 27.03.2003).

21 DISABILITY PREVALENCE

The disability figures of the Census were obtained by means of self-reporting and thus the data have a great deal of variability in the interpretation of the meaning of disability. People with physical disabilities, for example, a leg length discrepancy sufficiently large enough to make them walk with a noticeable limp, may not have classified themselves as having a physical disability as they are able to perform daily functional activities like walking. People who were unable to read may not have reported a visual impairment as they were able to see well enough for their activities of daily living.

Data on disability prevalence in the suburbs have been presented in detail as there are discrepancies between male/female and age/disability ratios compared to those of international prevalence studies.

As is shown in Tables (96), (97), (98), (99) and (100) there were more males than females in the 0 – 19 age groups of the total population in Lavender Hill, Lotus River, Retreat and Steenberg. As can be expected there are more males with physical disabilities than females in these areas except for Steenberg where there are more females with physical disabilities. Grassy Park had more females than males in this age group and more females with physical disabilities.

Table 96: Disability profile of Grassy Park

Age Group	Sight	Hearing	Physical	Mental	Multiple	Total	Total population
0-19							
M	16	8	5	9	1	39	3,869
F	17	8	10	7	1	43	3,918
20-59							
M	49	16	82	51	4	202	5,510
F	55	17	62	33	1	168	6,161
60+							
M	14	8	22	4	7	55	657
F	35	27	14	1	7	84	1,008
Total	186	84	195	105	21	591	

Table 97: Disability profile of Lavender Hill

Age Group	Sight	Hearing	Physical	Mental	Multiple	Total	Total population
0-19							
M	10	6	35	23	1	75	4,249
F	9	3	19	12	2	45	4,155
20-59							
M	46	28	162	71	7	314	4,044
F	48	27	128	35	12	250	4,772
60+							
M	19	7	46	2	6	80	350
F	27	10	33	2	10	82	478
Total	159	81	423	145	38	846	

Table 98: Disability profile of Lotus River

Age Group	Sight	Hearing	Physical	Mental	Multiple	Total	Total population
0-19							
M	5	11	13	6	0	35	3,503
F	12	12	5	10	0	39	3,291
20-59							
M	29	10	67	31	4	141	4,583
F	30	17	43	20	4	114	5,109
60+							
M	18	20	17	2	5	62	510
F	26	20	23	6	15	90	813
Total	120	90	168	75	28	481	

Table 99: Disability profile of Retreat

Age Group	Sight	Hearing	Physical	Mental	Multiple	Total	Total population
0-19							
M	22	16	26	21	3	88	6,312
F	30	5	11	13	4	63	6,141
20-59							
M	100	43	185	83	15	426	8,428
F	121	49	146	45	14	375	9,479
60+							
M	60	42	60	11	35	208	1,312
F	103	63	81	8	35	290	1,963
Total	436	218	509	181	106	1,450	

Table 100: Disability profile of Steenberg

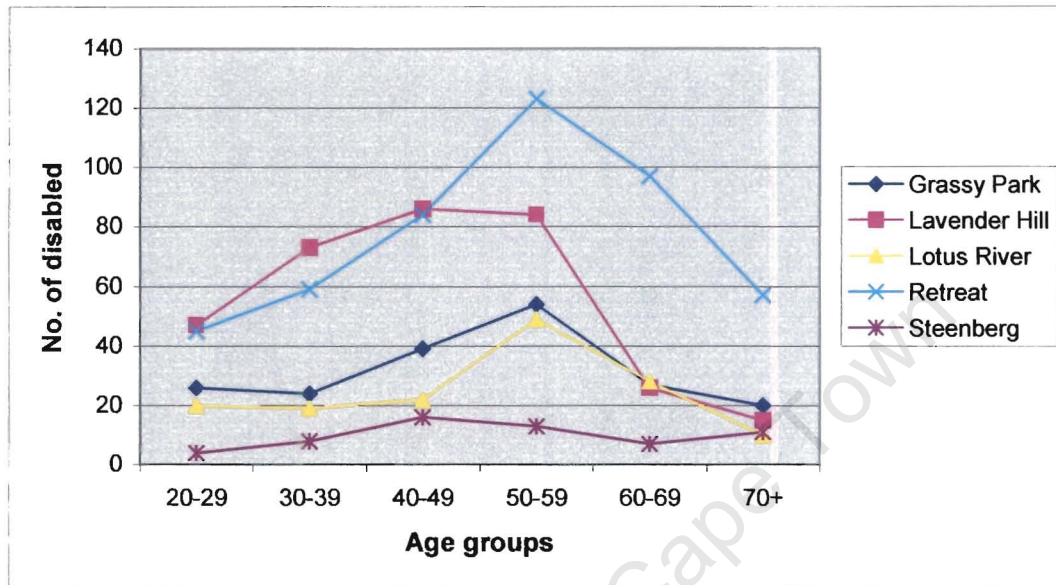
Age Group	Sight	Hearing	Physical	Mental	Multiple	Total	Total population
0-19							
M	5	2	5	3	0	15	1,148
F	2	1	6	1	0	10	1,111
20-59							
M	10	2	23	22	2	59	1,535
F	16	9	18	4	3	50	1,660
60+							
M	6	6	14	2	1	29	263
F	7	7	9	2	3	28	423
Total	46	27	75	34	9	191	

Contrary to international findings (Arber and Cooper, 1999; Lahelma et al, 1999; Lorber, 1997; Marks, 1996; Cornielje et al, 1993; Lonsdale, 1990; McLaren et al, 1987) there were more males with physical disabilities in the 20 – 59 age group in all the suburbs in spite of their being more females than males in the general population in that age group (Tables 96 – 100).

In the 60+ age group, once more there were more females than males in all the areas, but Lotus River and Retreat were the only areas which had more females with physical disabilities. Grassy Park, Lavender Hill and Steenberg had more

males with physical disabilities. The researcher is unable to give any medical reasons for this phenomenon.

Figure 49: Disability by age group in the various suburbs



According to international findings disability increases with age (Ayling, 1999; Smart and Smart, 1997; Murrery and Lopez, 1996; Cornielje, 1993; Badley and Tennant, 1991; Hoffman et al, 1988). In the suburbs under investigation, this was true until 59 years of age even though the majority of the population fell into the 15 – 34 age group, but then it dropped significantly in the older age groups from 60+ years of age where there were low numbers in the general population (Figure 49).

22 GOVERNMENT SOCIAL SERVICES

The Steenberg and Retreat Community Centres provide a vast array of social services to the community in the form of recreation, education and skills training to enhance self-reliance.

There are pre-schools for children in the mornings and in the afternoons games such as volleyball and basketball, arts and crafts are available for school-going children in order to keep them off the streets to prevent them from becoming members of gangs and/or turning to substance abuse. Scholars also receive help with school homework.

A Job Creation programme teaches unemployed women basic skills like knitting and sewing.

There are also activities provided for senior citizens enabling them to lead more sociable lives.

23 NON-GOVERNMENT ORGANISATIONS (NGO's)

23.1 CAPE FLATS DEVELOPMENT ASSOCIATION (CAFDA)

CAFDA is situated in Grassy Park and serves the surrounding areas of Retreat, Lotus River and Steenberg.

It has a small section of housing for particularly needy families.

The centre itself is large and offers premises for a crèche, people with disabilities, seminars, religious meetings, conferences and office space. It

provides education and social opportunities for children, youths, adults and senior citizens.

Social problems currently being dealt with as a means of empowering the people are violence, teenage pregnancy, child abuse, rape, HIV/AIDS and substance abuse. These programmes are also conducted during school holidays so that the youth can be involved too. A family centre offers help in terms of family planning and counselling for various types of domestic violence.

Advanced skills training courses such as sewing, woodwork, domestic work, baking and computer literacy are taught so that the community members can lead more productive lives.

Cultural awareness is promoted through dance, drama and music programmes.

Recreational activities offered include hiking, table tennis, volley ball, martial arts and swimming.

23.2 NEW WORLD FOUNDATION (NWF)

It is a multi-purpose community centre situated in Lavender Hill providing a wide range of services to the community and those of Steenberg and Lotus River.

NWF aims to address social problems within the community, namely, unemployment, overcrowding, crime, violence and substance abuse. It frequently collaborates with schools, churches, police and NGO's to offer training programmes.

An educare centre is run for pre-school children where they are educated and cared for by a team of ten local pre-school teachers.

An early childhood intervention project has been instituted, whereby psychologists counsel school children with behavioural problems. Their rehabilitation programme also involves parents and teachers.

Opportunities for the youth are provided through programmes in the school holidays as well as regular youth groups. Scholars can take part in activities such as chess, creative classes, games and workshops. Cultural activities include a youth choir, theatre projects, dance and modeling groups, relationship workshops, discussion groups in which topics such as sexuality and HIV/AIDS are covered.

A women's centre offers training, counselling and support to women and workshops on women's health and life skills are conducted from time to time.

The Wellness group has weekly meetings to provide support for those people with mental health problems.

Training programmes such as three-month workplace skills courses includes basic computer literacy, accountancy and communication. Life skills, homecare and first aid courses are available at minimum costs to the community.

NWF also runs small businesses, for example, NWF take-aways which are used to generate funds while teaching entrepreneurial skills (Egypt, 2002).

23.3 LEAGUE OF THE FRIENDS OF THE BLIND (LOFOB)

LOFOB is an organisation which aims to allow blind people to become fully independent and valuable members of society. It provides education of home management and specific life skills required by people with visual impairments. These are reading and writing in Braille, typing and walking with a cane.

4.23.4 NATIONAL INSTITUTE FOR CRIME PREVENTION AND REINTEGRATION OF OFFENDERS (NICRO)

This organisation is involved with crime prevention and providing offenders with rehabilitation programmes. It attempts to integrate the activities of various welfare and state departments to provide a multi-disciplinary approach to crime prevention and offender rehabilitation and aims to secure the welfare of both victims and arrested persons and their dependents.

NICRO processes and investigates prisoners' and ex-offenders' requests for assistance with maintenance grants for their families and arranges inter-prison transfers if family members are unable to travel in order to visit them. It also provides an employment searching programme.

NICRO is represented at the community police forums. It is involved with crime prevention awareness programmes in schools with a focus on youth development. It investigates educational opportunities with regard to child abuse, domestic violence and battered women. It also provides a youth empowerment scheme for young offenders who are referred from the juvenile magistrate's courts.

23.5 CAPE PENINSULA ORGANISATION OF THE AGED (CPOA)

The CPOA is based in Victoria Road, Grassy Park and offers recreational activities such as dominoes, cards, craftwork and croquet to senior citizens.

23.6 CAPE MENTAL HEALTH SOCIETY

The Cape Mental Health Society provides services to mentally handicapped and mentally ill residents. Field social workers from the society work closely with the psychiatric clinics. Those involved in the area do mainly home visits and provide family and individual counselling and conduct assessments. They deal largely with individuals affected by sexual abuse, battered women and substance abuse.

The society also runs a Protective Workshop in Retreat for people with mental conditions which prevent them from working in the open market.

23.7 MAMA'S SOCIAL SERVICES

This group of volunteers is very active in Lotus River providing a Development Centre for the elderly and for those on welfare. They also provide home-based care and nutrition for those in need. An advice office assists people with disabilities and those suffering from abuse. They also assist people to obtain maintenance money they are owed.

23.8 ST LUKE'S HOSPICE

Staff from St Luke's Hospice provide home visits to terminally ill people. They have a consultation room in 4th Avenue where people who are not bedridden can attend to receive counselling and medication.

23.9 HOME-BASED CARERS

Compassion in Action is a group of women from the Baptist Church who make themselves available to assist people with disabilities and the aged living in the area. The members receive training in health care by courses in nutrition, first aid, primary health care, basic rehabilitation skills and terminal care devised by the Department of Health. They visit those in need on a weekly basis and wash them and educate the family about nutrition and the care of their relatives. The relatives pay what they can afford for these visits.

People in need of their services are referred from the Lotus River CHC or they are able to apply directly to the Baptist Church.

24 HEALTH SERVICES

The health services of the suburbs are under the authority of the SPA.

Grassy Park, Lavender Hill, Lotus River and Retreat have CHC's which provide the following services:

- Antenatal care
- Family planning
- Baby clinic
- TB clinic
- AIDS testing and counselling
- Immunisations
- Health education
- Nutritional clinics

Grassy Park, Lotus River and Retreat provide the following additional services in their CHC's:

- Pharmacy
- Psychiatric clinic
- Physiotherapy
- Occupational therapy
- Social work
- Dentistry
- Radiography
- Orthopaedic workshop
- Chronic diseases

Retreat CHC offers a 24-hour service for trauma and obstetrics.

Referrals from the CHC's are sent to Victoria Hospital, Wynberg or Groote Schuur Hospital, Observatory for further investigation and care or to specialist and tertiary clinics.

The DP Marais Hospital in Retreat provides hospitalisation for people in need of TB care.

Medical staff at the clinics and CHC's are frequently traumatised by the gang fights in the various neighbourhoods. When they get hurt the gangsters enter the clinics for medical care which frightens the staff and people waiting to see health officials as they fear the rival gangs will follow and start fighting in the clinic. Health care officials have frequently been struck by stray bullets (Cape Argus, 22.02. 2002).

25 SOCIAL SERVICES AVAILABLE NATIONALLY

Social assistance in the form of grants are available in the form of:

25.1 OLD AGE GRANT

This is provided for males of 65 years or older and females of 60 years or older provided the spouses comply with the means test and they are not in receipt of another social grant. The value of this was increased to R740.00 per month at the end of 2003.

25.2 DISABILITY GRANT.

People with disabilities between the ages of 18 and 59 years for females and 18 to 64 years of age for males, who are not receiving another social grant are eligible to apply for a disability grant to the value of R740.00 per month.

25.3 WAR VETERANS GRANT.

Applicants must be 60 years and over or must be disabled and have fought in the Second World War or the Korean War. Their spouses must meet the requirement for the means test and they must not be in receipt of another social grant.

25.4 CARE DEPENDENCY GRANT.

This grant is available for children between 1 and 18 years of age who have a medical report confirming a permanent disability and who meet the requirements of the means test.

25.5 FOSTER CHILD GRANT.

The foster child must pass the means test and there must be a court order indicating foster care status.

25.6 CHILD SUPPORT GRANT.

Applicants must be the primary care giver of the child concerned and meet the requirements of the means test. This grant is available to children aged under seven years of age and the value is R160.00 per month.

25.7 GRANT-IN-AID.

This grant in aid is an additional grant awarded to persons who are already receiving one of the above grants and who are unable to care for themselves, but require a carer to assist them with activities of daily living.

25.8 SOCIAL RELIEF GRANT.

This is a temporary form of assistance intended for persons in such dire material need that they are unable to meet their or their families' most basic needs. This is awarded to people who are awaiting permanent aid and are medically unfit to undertake remunerative work for a period of less than 6 months provided they are not a member of a household that is already receiving social assistance. Social Relief of Distress is issued monthly for a maximum period of three months.

25.9 RENT RELIEF POLICY.

When residents are unable to meet their rental payments, and to avoid them being evicted, the government has put a rent relief policy into operation whereby the residents are able to repay their rental debts over a period of time which is negotiated between the Housing Office and the tenants. The monthly amount they have to pay towards their arrears is between R5 and R10

25.10 GOVERNMENT HOUSING SUBSIDY.

The government provides a housing subsidy of R18,000 for basic houses which have been constructed for people who have been living in informal settlements.

25.11 RENTAL INDIGENT GRANT.

For households living in council rental housing whose total household income is R800.00 per month or less are entitled to a rental indigent grant. Their rentals vary from as little as R10 per month and the amount that they pay is calculated by housing and finance staff.

26 SUMMARY

The profile provides an overview of the living conditions in Lotus River where the research participants lived and Grassy Park, Lavender Hill, Retreat and Steenberg where the focus groups lived. These conditions are typical of that of the low-income suburbs dominated by a local authority housing scheme.

The housing scheme comprises inadequate small dwellings accommodating large extended families. The situation is deteriorating annually and falling short of the goals of the original RDP projections. Since 1994 over one million subsidised houses have been delivered, but this has not even kept up with the backlog of houses in urban areas (Cavalieri and Madden, 2002). This is precisely the situation in Lotus River where no additional housing is being planned and, as a result, the area is becoming more and more overcrowded and inadequate backyard dwellings are mushrooming in an attempt to accommodate the natural increase in population when adult children have their own families.

Apart from housing, particular dissatisfaction is caused by the present standard of basic amenities such as roads, pavements, recreational facilities, open areas, playgrounds, parks, large chain supermarket facilities and full bank services.

The housing shortage, low levels of education and income and high unemployment rate are a result and cause of increasing poverty within the

suburbs. This poverty is, in turn, reflected in extreme overcrowding, rental arrears, high crime rates and substance abuse.

However, in spite of all the social problems that exist the community has shown considerable social awareness and commitment by the attempts at combating crime, by its own drug awareness programmes and efforts at negotiations with the police in order to create a safer environment in which to live and raise children.

This is the environment in which people with disabilities were living during the time the research was conducted.

Although findings of previous studies have indicated that the Coloured people are bitter (Lever, 1980), lack a positive self-image (Western, 1996; Finnegan, 1987; Fitzgerald, 1980) and sense of cohesion (Futter, 1995; Theron, 1981) this was not found to be the case in Lotus River.

There was always talk of the improvements that had taken place and that were being planned. For example, the Lotus River Community Forum was arranging for trees to be planted on the pavements and for the tenants of the houses to take responsibility for watering and caring for the trees in front of their houses. The residents spoke with pride of the length of time they had lived in Lotus River. This was from both people who had been living there before it was declared a Coloured housing estate and from people who had been relocated there after having been forcibly removed from Constantia, Diep River and Claremont.

When trying to locate people with disabilities their neighbours were fully aware of their whereabouts and activities and would happily take and reliably pass on telephonic messages. One caregiver was found to have been raising a neighbour's child from a few days after birth to seven years of age without any remuneration from the mother nor with the assistance of a social grant. The

caregiver had felt concerned that the baby was not being cared for properly as the mother was an alcoholic.

A member of one of the churches Women's Groups arranged for her group to make covers for all the cushions supplied with the wheelchairs to people with disabilities during the research. This entailed purchasing special waterproof material for those people who were incontinent in addition to the fabric for the cover. Likewise neighbours who had the necessary skills and tools would install the grab bars in the bathrooms for those people with disabilities who received these assistive devices.

People with disabilities living on the third and fourth floor of blocks of flats were willingly carried up and down the staircases by young men from the neighbourhood when they went to church on Sundays and when they needed to attend clinics.

Three men with severe disabilities who lived in adjacent blocks of flats received wheelchairs as part of the research project. Thereafter, they were carried downstairs daily and wheeled to a central position under a tree where they able to socialise with each other. The tenant on the ground floor close by to where they sat provided them with tea each morning and sandwiches at lunchtime.

GLOSSARY OF ABBREVIATIONS AND TERMS

AIDS: human acquired immunodeficiency syndrome.

Analgesic: medication to relieve pain.

AD: assistive devices. Equipment used by people with physical disabilities and older people to assist them with their activities of daily living to optimise their independence and improve their quality of life.

ADL (activities of daily living): refer to functional activities such as walking, feeding, dressing, bathing, climbing stairs.

ANC: African National Congress.

Appliance: a piece of orthopaedic equipment which assists disabled people to move independently.

ASSA: Actuarial Society of South Africa.

Asthma : is a condition marked by recurrent attacks of wheezing, coughing and a feeling of "tightness" of the chest.

Assistive devices: equipment used by people with physical disabilities and older people to assist them with their activities of daily living to optimise their independence and improve their quality of life.

Axillary crutch: long-length crutch which fits under the armpit. One or two axillary crutches can be used depending on the extent of assistance required.

Barriers: disabling physical environments and social restrictions which prevent people with disabilities from controlling their own lives and participating in the community.

Bath board: a flat piece of wood which fits over the bath on which disabled can sit in order to bath themselves.

Burden: the emotional, physical, social and financial stress experienced by caregivers as a result of caring for a disabled person.

CAFDA: Cape Flats Development Association (formerly Cape Flats Distress Association).

Calipers: metal bars on either side of the leg which support the body weight when there is a degree of paralysis of the lower limb muscles.

CAT-PCA: categorical Princals: a non-linear multivariate scaling technique developed by the Data Theory Scaling System Group (DTSS), Psychology Department, Faculty of Social and Behavioural Sciences, Leiden University, The Netherlands.

CBR: community-based rehabilitation.

CBS: caregiver burden scale.

CDG: care dependency grant.

Cerebral palsy: a condition affecting the muscle tone of the body and which may or may not be associated with intellectual, hearing or visual impairment.

CHC: Community Health Centre.

Chronic disability: a long-term or permanent disability.

CMC: Cape Metropolitan Council.

Component loadings: are the factor loadings in a factor analysis. They are weights contributing to, and can be considered as the correlation with, the dimension. Thus a high component loading is important in the definition of a dimension and variables with relative high component loadings on a dimension are strongly related.

Contractures: shortening of the soft tissues over a joint when the joint has not been put through its full range of movement for a period of time.

COSATU: Congress of South African Trade Unions.

CTCC: Cape Town City Council.

Demography: age, sex, occupation, education, marital status of a population.

DG: disability grant.

DH: Department of Health - provincial.

Diabetes: a metabolic disorder and consequent disturbance of the normal insulin function which results in an excessive level of sugar in the blood. Complications of diabetes frequently result in amputations, blindness and heart conditions.

Dimension: a reduced number of variables which represents the information of a large number of variables without the loss of information. The original variables are weighted such that they correlate maximally with one dimension, but

minimally with another thus creating dimensions that are not correlated.

Therefore, conceptually, a dimension is labelled by the common characteristic of the variables that determine the particular dimension.

Disability: “any restriction or lack of ability to perform an activity in the manner or within the range considered normal for a human being” (WHO, 1980: 143).

Disablement: umbrella term for disability and handicap.

DPSA: Disabled People South Africa.

DSSPA: Department of Social Services and Poverty Alleviation.

Economic self-sufficiency: the ability of individuals to sustain socioeconomic activity and independence by virtue of labour or exploitation of material possessions such as natural resources, livestock or crops (Badley, 1995).

Eigenvalue: “a special set of scalars associated with a linear system of equations that are sometimes also known as characteristic roots” (Marcus and Minc, 1988:144). It indicates how successful the maximisation and minimalisation criteria were.

Elbow crutches: short-length assistive devices for walking which fit around the elbow. One or two elbow crutches can be used depending on the extent of assistance required.

Environment: includes the physical, social and attitudinal environment in which people live and conduct their lives.

Epilepsy: a seizure is an episode caused by a sudden disturbance in the brain.

Focus group: group interviews which rely on interaction of the members to generate data of interest to the researcher.

Functional ability: refers to the individual's capacity to perform daily activities of living such as dressing, feeding and walking.

Guillain-Barré syndrome: a viral infection which results in paralysis, some of which may be permanent.

Handicap: "a disadvantage for a given individual, resulting from an impairment or a disability that limits the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for that individual" (WHO, 1980: 183).

HAQ: Health Assessment Questionnaire.

HIV: human acquired immunodeficiency virus.

Hypertension: high blood pressure.

ICIDH: International classification of impairment, disability and handicap.

Impairment: "any loss or abnormality of psychological, physiological or anatomical structure or function" (WHO, 1980: 41).

INDS: white paper for an Integrated National Disability Strategy.

IPDS: Integrated Provincial Disability Strategy for the Western Cape.

Locomotor disability: refers to an individual's ability to move himself/herself both physically and objects, from place to place (Wood and Badley, 1983).

LRQ: Lotus River Questionnaire.

Mobility: refers to any body movements that lead to a change in position or location by one's own means performed with or without technical assistance (Routhier et al, 2003).

Morbidity: the ratio of illness amongst a group of people.

MOS: the Medical Outcomes Study Social Support Survey.

Msuleni joint disease: a disabling joint disease specific to the Msuleni region in Kwazulu/Natal, South Africa.

Multiple sclerosis: a progressive nervous disorder which leads to increasing physical incapacity of the person.

Musculoskeletal: pertaining to the muscles and bones.

NGO: non-governmental organisation.

NGT: nominal group technique.

NICRO: National Institute for Crime Prevention and Reintegration of Offenders.

NWF: New World Foundation.

Occupation: the ability of individuals to occupy time in a way that is customary to their age, sex and culture, including following an occupation such as tilling the soil; running a household or raising children; or carrying out physical activities such as play and recreation (Badley, 1995).

OAG: old age grant.

Orthosis: an individually-fitted orthopaedic appliance which supports a part of the body.

Osteoarthritis: an inflammatory condition of joints causing pain, stiffness and weakness.

PAWC: Provincial Administration of the Western Cape.

Peripheral vascular disease: a deteriorating condition of the circulation in the legs which sometimes necessitates amputation.

Physical independence: the ability of individuals to maintain an effective independent existence in regard to the more immediate needs of their bodies, including feeding and personal hygiene (Badley, 1995).

Poliomyelitis: a viral disease which can lead to paralysis.

Pneumonia: infection of the lung.

Prosthesis: an artificial limb.

Quadruped: a four-footed assistive walking device held in the hand to provide support or assist balance. One or two quadrupeds can be used depending on the extent of assistance required by the individual.

Quality of life: “the objective and subjective dimensions of an individual’s ability to function in, and derive satisfaction from, a variety of social roles in the presence of impaired health status” (Jette, 1993: 528).

RDP: Reconstruction and Development Programme.

Rehabilitation: “includes all measures aimed at reducing the impact of disability for an individual, enabling him or her to achieve independence, social integration, a better quality of life and self-actualisation” (Helander, 1993: 17).

SAMRC: South African Medical Research Council.

Shebeen: unlicensed drinking houses where people meet to socialise and buy alcohol and, frequently, drugs.

Social barriers: disabling physical environments and social restrictions which prevent people with disabilities from controlling their own lives and participating in the community.

Social integration: the ability of individuals to participate in and maintain social relationships with others (Badley, 1995).

SPA: Southern Peninsula Administration.

Spina bifida: a congenital defect of the spine causing paralysis of the legs.

Stroke: paralysis of one arm and a leg on the same side of the body following an insult to the brain.

TB: tuberculosis.

Tripod: a three-footed walking device held in the hand to provide support or assist with balance. One or two tripods can be used depending on the extent of assistance required.

TV: television.

UK: United Kingdom.

UNDP: United Nations Disability Programme.

USA: United States of America.

Walking frame: an assistive device which provides maximum support for weight and balance.