

**DISABILITY PROFILES AND NEEDS OF DISABILITY GRANT
RECIPIENTS IN KLEINMOND, WESTERN CAPE, SOUTH AFRICA**

ANNETTE FRIEG



**Assignment presented in partial fulfilment of the requirements
for the degree of Master of Philosophy (Rehabilitation) at the
University of Stellenbosch**

Study leader: Ms JA Hendry

December 2000

Declaration

I, the undersigned, hereby declare that the work contained in this research assignment is my own original work and that I have not previously in its entirety or in part submitted it at any university for a degree.

Signature: ...

Date:

ABSTRACT

The South African National Census (1996) reports a disability prevalence of 6,6% in South Africa. In November 1999 the government paid out 635 881 temporary or permanent disability grants. Legislation is in place to allow the Department of Social Services to administer the grants. For this study demographic information of disability grant recipients in a semi-rural area was sought in order to improve understanding of disability and to assist in service delivery. The study was executed in Kleinmond, a coastal town in the Western Cape with a population of 3 918, where 189 people reported a disability during the 1996 census.

Objective

The objective of this study was to determine the disability profile, caregiver utilization and needs of disability grant recipients in Kleinmond, Western Cape, South Africa.

METHODS

A descriptive survey was the study design of choice. The study population consisted of recipients of a permanent disability grant who collected their grants at the Kleinmond Post Office in June 1999.

In order to capture the necessary information, a questionnaire was developed based on the disability catalogue of the International Classification of Impairment, Disability and Handicap (ICIDH) of the World Health Organisation. Pilot studies were conducted and the researcher interviewed 29 grantees during the main study in Kleinmond in June/July 1999. Repeatability of the questionnaire was tested. Ninety six percent of the responses were the same on the second visit to four randomly selected grantees. Data was analysed with the statistical software package STATISTICA.

RESULTS

The response rate was 90% (29/32). The mean age of the mainly male grantees was 42 years (range: 18 – 64). Most grantees were single, but the majority stayed with someone else. Ninety three percent (27/29) were unemployed while 69% (20/29) felt they were able to work. Most grantees took regular medication and the majority accessed health services at the primary level local clinic. Twenty five grantees

(86% or 25/29) reported multiple disabilities, while one person did not fit into any of the categories. The most common disability category was situational disability (82% or 24/29). Nineteen persons with disabilities (66% or 19/29) relied on help which was mainly given by the parents. Assistance was needed with activities such as collecting the disability grant, shopping and managing money. With regard to needs of grantees, most found it important to have the clinic closer to their homes (52% or 15/29), to increase the amount of the disability grant (76% or 22/29) and to raise awareness of disability in the community (69% or 20/29).

CONCLUSION

Most disability grant recipients in this study reported problems in many of the seven disability categories of the ICDH, i.e. multiple disabilities. This is consistent with the assumption that only severely disabled people qualify for a permanent disability grant in South Africa. This might explain why the majority of the grantees utilized a caregiver for some tasks. Needs with regard to health and social services of this defined group of persons with disabilities in Kleinmond will be brought to the attention of the authorities, who are planning a new community centre and clinic.

ABSTRAK

Volgens die Nasionale Sensus opname van 1996 is die prevalensie van ongeskiktheid in Suid-Afrika 6.6%. Bevindinge dui aan dat 635 881 individue 'n ongeskiktheidstoelaag ontvang. Hierdie toelae word volgens wetgewing deur die Departement van Maatskaplike Dienste ge-administreer. In hierdie studie is demografiese inligting van individue wat 'n ongeskiktheidstoelaag ontvang ingesamel in 'n poging om insig in gestremdheid en dienslewering aan gestremdes te verbeter. Die studiepopulasie het bestaan uit individue wat 'n ongeskiktheidstoelaag in die Wes-Kaapse kusedorp Kleinmond ontvang. Kleinmond het 'n populasie van 3 918 waarvan 189 individue ongeskik is volgens die 1996 sensus.

DOEL

Die doel van die studie was om 'n ongeskikheidsprofiel van individue in Kleinmond te bepaal, asook te evalueer of hulle versorgers benodig het en om hulle behoeftes te bepaal.

METODOLOGIE

Daar is gebruik gemaak van 'n beskrywende studie. Die studiepopulasie het bestaan uit alle individue woonagtig in Kleinmond wat 'n permanente ongeskiktheidstoelaag ontvang het en dit by die poskantoor afgehaal het.

Data is deur middel van 'n vraelys ingesamel. Die vraelys is gebaseer op die ongeskiktheids katalogus van die Internasionale Klassifikasie van Gebrek, Ongeskiktheid en Gestremdheid (ICIDH) van die Wêreld Gesondheidsorganisasie. Die vraelys is getoets deur middel van loodsstudies. Die betroubaarheid van die vraelys is ook getoets deur tydens die navorsing dieselfde vrae tydens 'n tweede besoek aan vier kandidate te stel. Hierdie vier individue is ewekansig geselekteer en 96% van die response het ooreen gestem met die van die eerste besoek.

Data is verkry van 29 individue gedurende Junie/Julie 1999. Data analise is met behulp van STATISTICA, 'n statistiese sagteware pakket, gedoen.

RESULTATE

Die responskoers was 90% (29/32). Die meerderheid van die studiepopulasie was manlik met 'n gemiddelde ouderdom van 42 jaar (rykwydte: 18 – 64). Individue was meerendeels ongetroud en het wonings met ander persone gedeel. Uit die studiepopulasie was 93% (27/29) individue werkloos. Van hierdie groep het 69% (20/29) egter gevoel dat hulle wel een of ander vorm van arbeid kan verrig. Bykans alle individue uit die studiepopulasie het gereeld medikasie gebruik. Die plaaslike primêre gesondheids kliniek is deur die meeste individue benut vir gesondheidssorg. Meeste individue (86% of 25/29) het meer as een ongeskiktheid gehad en een persoon het nie in enige van die kategorieë ingepas nie. Die ongeskiktheid wat die mees algemeenste voorgekom het was situasie-gebonde ongeskiktheid (82% of 24/29). Hulp is hoofsaaklik deur ouers verskaf en 66% individue (19/29) het van hulp gebruik gemaak. Hierdie hulp was meestal nodig met aktiwiteite soos die afhaal van die ongeskiktheidstoelaag, die doen van inkopies en die bestuur van persoonlike finansies.

Die studiepopulasie het 3 groot behoeftes uitgespreek naamlik 'n kliniek nader aan hulle wonings (52% of 15/29), 'n verhoging in die ongeskiktheidstoelaag (76% of 22/29) en 'n groter bewustheid van ongeskiktheid in die gemeenskap (69% of 20/29).

Samevatting

Baie van die individue uit die studiepopulasie het ongeskikthede in meer as een van die ongeskiktheidskategorieë aangedui. Hierdie bevinding is in ooreenstemming met die aanname dat in Suid-Afrika slegs individue met erge ongeskiktheid 'n ongeskiktheidstoelaag ontvang. Dit kan moontlik ook verklaar waarom die meerderheid van die populasie versorgers benodig het vir die uitvoer van sekere take.

Die behoeftes van hierdie studiepopulasie sal onder die aandag van die plaaslike owerheid, wat tans besig is met die beplanning van 'n nuwe gemeenskapsentrum en kliniek, gebring word.

CONTENTS

	page
ABSTRACT	i
ACKNOWLEDGEMENTS	v
LIST OF TABLES	vi
LIST OF FIGURES	vii
CHAPTER 1: INTRODUCTION	1
1.1 Introduction	1
1.2 The problems	3
CHAPTER 2: LITERATURE REVIEW	6
2 Aspects related to disability, rehabilitation and social assistance	6
2.1 Disability	6
2.1.1 Defining disability	6
2.1.2 The medical versus the social model	9
2.1.2.1 Prejudice and disability	10
2.1.2.2 Demands and needs of persons with disabilities	12
2.1.2.3 Description of the development of rehabilitation services	13
2.2 Disability prevalence	17
2.3 Social assistance in South Africa	22
2.3.1 Disability grants in South Africa	24
2.3.1.1 Legislation and procedures regarding disability grants	24
2.3.1.2 Controversies regarding social assistance	26
2.4 Care-giving	29
2.5 Conclusion	32

CHAPTER 3: METHODOLOGY	33
3.1 Objective	33
3.2 Aims	33
3.3 Study design	34
3.4 Geographical area	35
3.5 Study population	36
3.5.1 Inclusion criteria	37
3.5.2 Exclusion criteria	37
3.6 Measurement	37
3.6.1 Data capturing	38
3.6.2 Measuring instrument	38
3.6.3 Development of the measurement instrument	41
3.6.3.1 Draft questionnaire	41
3.6.3.2 Pilot studies	41
3.6.4 Implementation of field work and data capturing	42
3.6.5 Reliability	43
3.6.5.1 Repeatability of the questionnaire	44
3.6.6 Statistical procedures	45
3.7 Ethical considerations	46
3.8 Assumptions	48
CHAPTER 4: RESULTS AND DISCUSSION	50
4.1 Respondents	50
4.1.1 Respondents interviewed	52
4.1.2 Relationship between proxy and grantee	53
4.2 Demography	53
4.2.1 Age	53
4.2.2 Gender	55
4.2.3 Home language	56

4.2.4	Marital status and living arrangements	56
4.3	Disability profile	58
4.3.1	Number of years subjects received a disability grant	58
4.3.2	Disability categories reported by the grantees	59
4.3.3	Disabilities reported in each category	62
4.3.3.1	Situational disabilities	62
4.3.3.2	Communication disabilities	64
4.3.3.3	Behavioural disabilities	65
4.3.3.4	Body disposition disabilities	66
4.3.3.5	Locomotor disabilities	67
4.3.3.6	Personal care and dexterity disabilities	68
4.3.4	Conclusion regarding the disability profile	70
4.4	Employment	71
4.5	Utilization of health services	74
4.6	Permanent use of assistive devices	76
4.7	Caregiver utilization	78
4.7.1	Relationship between caregiver utilization and respondent interviewed	79
4.7.2	Activities for which a caregiver was utilized	80
4.7.3	Relationship between disability score and caregiver utilization	81
4.8	Reported needs of respondents with regard to social and health services and the Kleinmond community	85
4.8.1	Social services	86
4.8.2	Health services	89
4.8.3	Kleinmond community	92
4.9	Limitations of the study	94
4.10	Conclusion	96

CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS	97
5.1 Conclusions	97
5.2 Recommendations	100
5.2.1 Service planning	100
5.2.2 Future studies	101
REFERENCES	104
ADDENDA	
1 Application for/review of social grants for disabled persons and war veterans	112
2 Questionnaire	115
- English	116
- Afrikaans	128
3 Letter to Regional Director: Health; Boland Overberg Region	138
4 Participant information and consent form	141
- English	142
- Afrikaans	145
- isiXhosa	148
5 Letter to Chief Director: Social Services; Province of the Western Cape	150
6 Letter to stakeholders	153

ACKNOWLEDGEMENTS

I should like to thank the following groups and individuals for their contributions:

- The disability grant recipients in Kleinmond for welcoming me in their homes and consenting to the interviews,
- Ms JA Hendry, my study leader, for her unstinting support and encouragement,
- Mrs F Little for her statistical advice and friendly assistance throughout the process,
- Professor S Green for her valuable input during the final stages of this project,
- My colleagues at the Department of Physiotherapy at the University of Cape Town for their encouragement,
- The officials at the Department of Social Security who assisted me in planning this study,
- Mrs S Visagie and Mrs R Fisher-Jeffes for their help with the translations,
- My family and friends for their sense of humour and their patience.

LIST OF TABLES

	page
1.1 Disability profile in the Western Cape according to the 1996 Census	19
4.1 Proxy's relationship to the grantee	53
4.2 Marital status	56
4.3 Living arrangements	57
4.4 Number of years for which subjects had received a disability grant	58
4.5 Number of cases in specific disability categories	60
4.6 Reported difficulties in the situational disability category	63
4.7 Reported difficulties in the communication disability category	64
4.8 Reported difficulties in the behavioural disability category	65
4.9 Reported difficulties in the body disposition disability category	66
4.10 Reported difficulties in the locomotor disability category	67
4.11 Reported difficulties in the personal care disability category	68
4.12 Reported difficulties in the dexterity disability category	69
4.13 Employment status versus grantees' perception of ability to work	71
4.14 Relationship between respondent and ability to look after self	79
4.15 Relationship between total disability score and grantees' ability to look after self	82
4.16 Relationship between type of disability and ability to look after self	83
4.17 Needs with regard to social services	86
4.18 Needs with regard to health services	89
4.19 Needs with regard to the Kleinmond community	92

LIST OF FIGURES

	page
4.1 Respondents interviewed	52
4.2 Age distribution	54
4.3 Gender distribution	55
4.4 Average score per disability category	61
4.5 Utilization of health services	74
4.6 Percentage of participants requiring assistance with specific tasks	80

CHAPTER 1

1.1 INTRODUCTION

The research agenda for South Africa should, according to Bhagwanjee and Stewart (1999), prioritise epidemiology of disability, determinants of risk factors, service provision, ignorance, misconceptions and negative attitudes, and the socio-economic context of disability. One shortcoming of the current South African health arena is the paucity of epidemiological information. Health and social services can only be planned and executed appropriately when based on, amongst others, epidemiological information about communities and the description and extent of any problems they may face. In view of diminishing resources for public spending, and the redistribution of remaining available resources, as well as the welcome shift in developing countries towards community - based rehabilitation (CBR), the researcher wanted to establish the health care and social needs expressed by recipients of disability grants. This epidemiological information is believed to be the basis of research in the disability field and in service provision (Bhagwanjee and Stewart, 1999; Helander 1993).

Katzenellenbogen, Joubert and Abdool Karim (1997) stated that "in the absence of adequate routinely available health data, sample surveys may be the only way to investigate health issues in specific communities ..." (p 164). This quotation from a widely used manual on epidemiology in South Africa, and the researcher's experience as a physiotherapist in the public sector, stimulated an interest in obtaining information in order to be able to learn about a defined group of persons with disabilities. In view of this, the objective of this study was to collect demographic data and to determine the disability profile, care giver utilization and perceived health and social needs of a group of persons with disabilities.

Knowledge of the prevalence of disability in South Africa may be useful in order to appreciate one aspect of disability research. Detailed reference to the prevalence will be made in chapter 2.2. Statistics South Africa, formerly Central Statistical Services (CSS), collects and publishes extensive

information regarding South Africa and the country's population. Data from the 1996 National Census indicated that a total of 2 657 714 people or 6,6% of the population in South Africa were disabled in 1996 (www.statsa.gov.za). In the Western Cape 145 438 persons or 3,7% of the population were found to be disabled. However, Statistics South Africa cautions that percentages may be an undercount, as there might be a stigma attached to certain types of disability. Another important factor contributing to an undercount is that persons in institutions were excluded from the latter prevalence survey.

For this study, demographic and other descriptive information about the recipients of disability grants in Kleinmond, a small town on the Western Cape coast, was sought. This geographical area was chosen as the local authorities were planning a new community centre, likely to also house the local clinic. Kleinmond is a coastal town which in 1996 had a population of 3918 (Statistics South Africa, 1999). The permanent residents are, amongst others, fishermen, labourers, pensioners from a variety of provinces, employees of local government and owners or employees of small businesses. It is a popular sea resort frequented by holidaymakers on weekends and during the summer season. According to the 1996 Census 189 people in Kleinmond were disabled (Statistics South Africa, 1999). This would indicate a local disability prevalence of 4,8%.

Aside from figures on disability prevalence, there is little additional epidemiological information about persons with disabilities. However, a number of persons with disabilities seem to be reliant on financial assistance. This assistance may be provided mainly by the Department of Social Security and is governed by legislation (Governments Gazettes No 59 of 1992, No 106 of 1997 and No R 417 of 1998). Correspondence with the Deputy Director, Department of Social Security indicated that in November 1999 a total of 635 881 people in South Africa received a disability grant from the government. The figure anticipated for the Western Cape was 90 676. The Department of Social Services does not differentiate between temporary and permanent grants and there seems to be no epidemiological information about persons receiving a disability grant or their perceived needs.

1.2 THE PROBLEMS

The South African government monthly spends millions of Rands towards payment of the 635 881 disability grants to citizens the law finds to be deserving (Governments Gazettes No 59 of 1992, No 106 of 1997 and No R 417 of 1998). These figures on disability grants do not reveal the kinds of disabilities with which grantees present. The researcher was particularly interested in establishing disabilities prevalent in persons who receive a permanent disability grant. Her close contact as a physiotherapist in the public health sector with persons with disabilities has prompted a number of questions about the quality of her clients' lives and the State's role in social assistance to these persons. It was particularly unclear which clients with disabilities would be successful in their application for a permanent disability grant. The requirements in the Social Assistance Acts (Government Gazette No 59 of 1992 and No 106 of 1997) and the Regulation Gazette (Government Gazette No R 417 of 1998) merely indicated that persons who have a disability that is confirmed by a medical officer whilst completing the relevant application form VRT-3 and that renders them unfit for work, may qualify for a disability grant, depending on their income (Addendum 1). It had been assumed that only clients with severe and/or multiple disabilities and very limited income qualified for social assistance. Having no clarity in the matter, it became increasingly difficult to counsel clients attending physiotherapy services in the public health sector in terms of their eligibility for social assistance. While studying for a post-graduate qualification in rehabilitation another problem with regard to disability grants was identified by the researcher. The phrase "disability grant" suggests that the persons' disabilities were assessed. However, it appeared, and the application form for disability grants implied, that grants are denied or granted on the basis of impairments rather than disabilities or handicaps. Owing to this discrepancy the researcher wanted to establish the presenting disabilities of a group of grantees.

While working as a physiotherapist with clients with neurological disorders in an acute hospital setting, the researcher found it disturbing to witness that

these clients were discharged very soon after the onset of their illness or disability into the care of the family and other caregivers. An important aspect of the duties of a physiotherapist is caregiver training and education. This is often done on an individual basis. However, it is in line with the principles of CBR and should be more cost effective, to train groups of caregivers. In order to be able to train caregivers effectively, it is essential to establish for which tasks a group of persons with disabilities rely on their caregivers.

The researcher has over the past ten years only been able to witness the challenges persons with disabilities face while in acute hospital settings and in a tertiary outpatient department. When learning and teaching about disability issues, it is essential to develop a broader understanding of the lives persons with disabilities lead. This study provided an opportunity to gain insights into other aspects of living with a disability and to meet persons with disabilities in their own environment.

The Disability Rights Charter of South Africa reflects the fundamental demand by persons with disabilities to be consulted in matters affecting them (Disability Unit of Lawyers for Human Rights, 1993). The local authorities of the town of Kleinmond are currently planning the development of a community centre (Hangklip - Kleinmond bulletin August 1998, March 1999, December 1998 and personal communication with the Town Clerk on 9.9.98). Findings from this study will therefore be brought to the attention of the local and regional health and social service authorities. The results should assist in the planning and optimal utilisation of the proposed community centre as they reflect the perceived needs of a subsection of the town's disabled community.

To the researcher's knowledge there is no epidemiological research in South Africa regarding demographic information, disability profiles and perceived needs of persons receiving disability grants. There is also a paucity of information regarding the disability status or the needs of persons with disabilities who reside in a semi-rural area in South Africa. The current study was planned in order to address some of the problems discussed above and to provisionally develop an instrument that would capture the necessary

information. Should this instrument be found to be reliable, user friendly and able to capture the information in order to reach the objective of this study, it could be used in different geographical areas for the same purpose. In this manner greater numbers of subjects can be assessed and wider inferences made for service planning and delivery.

CHAPTER 2: LITERATURE REVIEW

2 ASPECTS RELATED TO DISABILITY, REHABILITATION AND SOCIAL ASSISTANCE

Disability and rehabilitation, specifically community-based rehabilitation (CBR), will be defined and aspects related to these concepts examined. Reference is made to the South African context. Various attempts to establish prevalence of disability internationally and in South Africa are presented in order to gain an understanding of the extent of disability. Current issues facing social assistance and the legal process of disability grant application in South Africa are then discussed, followed by an introduction to the concept of care-giving.

2.1 DISABILITY

2.1.1 DEFINING DISABILITY

Disability has a major impact on society and is recognised in the United States of America (USA) as a legitimate topic of scientific enquiry (Jette, 1994, a & b). Disability is thought to be influenced by factors such as low income and poverty, employment in dangerous jobs, lack of health insurance, low educational attainment and faulty testing/diagnostic procedures (Smart and Smart, 1997). Helander (1993) noted that "disability is not a well-defined condition, and there are many terminological and conceptual differences" (p 21). Jette (1994a) supported this by expressing his concern about the terminology of disablement continuing to generate confusion and argument across and within disciplines. It is therefore not surprising that the literature presents many definitions of disablement (Nordenfelt, 1997; Oliver, 1996; Nordenfelt, 1995; Nagi, as quoted in Verbrugge and Jette, 1994; Verbrugge and Jette, 1994; WHO, 1980). The World Health Organisation (WHO) has consequently embarked on a process to re-define disability (WHO, 1999). The most commonly used definition however, is one of the WHO's classifications for application to various aspects of health. Within this

International Classification of Impairment, Disability and Handicap (ICIDH), disability is defined as follows:

“In the context of health experience, a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.”

(WHO, 1980, p 28)

The ICIDH was developed in 1980 to define the consequences of disease in order to:

- provide a “conceptual scheme”,
- “offer a classification scheme for these different planes of the consequences of disease”, and
- “propose a theoretical framework within which to inter-relate impairment, disability and handicap”.

(Badley, 1993, p 161)

The ICIDH thus allows the user to differentiate between disability, impairment and handicap in order to capture these different domains of human functioning in relation to health. While an impairment refers to a deviation from the biomedical status of an individual, a disability describes the activities that an individual is unable to perform. A handicap on the other hand, relates to the roles a person has on a societal level and any disadvantages the person experiences in the fulfilment of these roles (WHO, 1980). Consequently, two persons with the same impairments do not necessarily experience the same disabilities or handicaps.

Over the years the ICIDH has been criticised by disability activists and academics in the disability field (Marks, 1997; Shakespeare and Watson, 1997; Badley, 1993; Oliver 1996; Badley, 1987). The strongest criticism is that the terms and definitions of the ICIDH are perceived as being individualistic and negative, i.e. focusing on defects and non-normality, and solely representing the medical model of disability. Another argument is that the ICIDH institutionalises disablement (Badley, 1987). Consequently, the

WHO is currently revising the document and the beta-2 draft of the ICIDH-2 has been published.

This new document strives to realise a synthesis of health at biological, individual and societal levels in order to provide a coherent view of these different dimensions of health, thereby attempting to facilitate the use of a universal language for functioning and disablement (WHO, 1998). What was referred to as disability in the past is now named an "activity limitation". An "activity" is defined as "the performance of a task or action by an individual", and "activity limitations" as "difficulties an individual may have in the performance of activities" (WHO, 1999, p 18). The ICIDH-2 describes impairments as significant deviations or losses in body function or structure. The third dimension, i.e. that of participation restrictions, refers to the individual's problems regarding the manner or extent of involvement in life situations.

At a workshop on the ICIDH-2 in Durban in May 2000, it was established that only one researcher in South Africa is currently making use of this new instrument (ICIDH-2, unpublished proceedings).

Due to the lack of familiarity with the new Beta-2 version, the researcher therefore utilized the disability catalogue of the original ICIDH as the basis of the questionnaire for the present study. The catalogue provides nine disability categories, i.e. behavioural, communication, personal care, locomotor, body dispositions, dexterity, situational, particular skill and other. Each category, except the latter two, is sub-divided into sub-categories of specific activities and thus two more numbers are attached in order to allow for three digit coding. The various activities are described and inclusion and exclusion criteria are stipulated. Supplementary gradings are added to enable the user to grade the severity and prognosis or outlook of the disabilities found, and includes suggested intervention. Further reference to the ICIDH disability catalogue is made in section 3.6.2 where the methodology of the present study is explained.

2.1.2 THE MEDICAL MODEL VERSUS THE SOCIAL MODEL

Criticism of the International Classification of Impairment, Disability and Handicap (ICIDH) has been mainly based on the fact that it represents the so-called “medical model” of disability, while a paradigm shift towards a “social model” is being demanded by disability activists and researchers. This section outlines differences between the two models, followed by a discussion of the consequences in these differences. These include prejudice against persons with disabilities, demands and needs of persons with disabilities and the development of rehabilitation strategies.

Marks (1997) argued that the ICIDH represents the medical model, as it “focuses on individual pathology and attempts to find ways of preventing, curing or (failing these) caring for disabled people” (p 86). Swain, Finkelstein, French and Oliver (1993) support this critique. They state that disability within the medical model is seen as a medical problem, resulting in non-normality of an individual. Consequently, the medical professional is placed in a position of power, controlling the lives of persons with disabilities. The medical model is an individualistic model which institutionalises disability. According to Coleridge (1993) this model is still dominant in the Western World. He concludes that the model is also prevalent in many developing countries, as training in these countries tends to follow Western models. Furthermore, disability projects in developing countries that are funded by Western countries are often run by medically orientated professionals and delivered within the construct of the medical model.

In the past decade, persons with disabilities have started to resent the power and control of professionals. This is highlighted by Coleridge (1993), who argues that people in the disability movement perceive rehabilitation professionals as controlling their lives. This, in turn, is seen as a primary cause of oppression of persons with disabilities. Oliver (1996), himself disabled, maintains that disability is a long-term social state, and as such neither medically treatable nor curable. He rejects professionals considering themselves to be experts and society bestowing on them the status of experts

on disability. While impairment is the main factor contributing to disability within the medical model, it is seen as only one of many factors in the social model. Marks (1997) echoes this viewpoint and states that disability is not located “in an impaired or malfunctioning body, but in an excluding and oppressive social environment” (p 88). The focus in the social model is therefore societal, rather than individual, with more attention given to priorities identified by persons with disabilities.

In order to be able to implement the planning of services within a social model of disability, it is imperative to address the demands of persons with disabilities, by having an understanding of their perceived needs and priorities. The next section explores prejudice towards persons with disabilities in order to conceptualise their call for a paradigm shift towards a social model, while section 2.1.2.2 clarifies their most pressing demands. In section 2.1.2.3 consequences of this paradigm shift for rehabilitation services are discussed.

2.1.2.1 Prejudice and disability

The Concise Oxford Dictionary (1992) defines prejudice as “a preconceived opinion” (p 940). According to Coleridge (1993), prejudice is clearly evident in the manner in which society views persons with disabilities. “Disability is perceived by able bodied people as a tragedy, a loss, or a deficiency; these powerful negatives elicit either fear, pity, or admiration, depending on how the disabled person ‘copes’” (Coleridge, 1993, p 27). Tennant (1997) reiterates that people feel uneasy in close proximity to persons with disabilities, while Helander (1993) reports that the most common beliefs regarding disability are skewed and therefore introduce prejudice.

Cultural convictions influence how the general public views disability and acts towards persons with disabilities. National policies, in turn, are informed by what society believes to be important and acceptable and may therefore

reflect prejudice. "Prejudice lies at the heart of the segregation which many disabled people experience" (Swain *et al*, 1993, p 101) and is therefore a major barrier to integration.

Oliver (1996) further supports these view points and criticises that the applications of standards of normality to persons with disabilities, who either collectively or individually "reject the prescriptions of the 'normalising' society" (p 36). He refers to Shakespeare who in 1992 argued that the causes of disability are discrimination and prejudice. Coleridge (1993) echoes this and states that persons with disabilities become disabled by the social attitudes they encounter on a daily basis. He believes, however, that these can, in most instances, be changed. Swain *et al* (1993) express their concern about the effect that these negative social attitudes have on the manner in which persons with disabilities view themselves. They summarise that the undermining messages lead to the internalisation of society's values into the lives of persons with disabilities, i.e. the person with a disability sees him- or herself in the same negative light.

Helander (1993) argues that persons with disabilities may respond in the following three ways when faced with prejudice, i.e. resignation, reform or rebellion. It was out of rebellion and the wish to reform the medical paradigm that organisations representing persons with disabilities became increasingly outspoken against prejudice and demanded self-representation in matters concerning them. The most well known organisation is Disabled Peoples International (DPI) who have contributed significantly to the international debate and changes in international policy. Many countries have national organisations of equal importance with the stance and ability to raise awareness on disability matters. In South Africa the organisation Disabled People South Africa (DPSA) was aligned with the liberation struggle. It is now considered to be the main representative body of persons with disabilities and has been actively involved in the discussions leading to the drafting of various White Papers, most notably the White Paper on an Integrated Disability Strategy (Mbeki, 1997) and the White Paper on Social Welfare (Government Gazette, No 1108 of 1997).

2.1.2.2 Demands and needs of persons with disabilities

When determining the needs of persons with disabilities, Helander (1993) differentiates between felt needs, expressed needs and assessed needs. Within the medical model the needs of persons with disabilities are often assessed in institutions, schools, or the working population. None of these locations are representative of all persons with disabilities (Helander 1993). The actual expressed and felt needs are therefore often neglected. Oliver (1996) argues that services for persons with disabilities should meet self-defined needs and that others have no right to define or decide on their behalf. It becomes clear that the overriding demand of persons with disabilities is their right to self-representation within the social model of disability.

Demands of persons with disabilities include the protection and promotion of basic human rights and the right of choice underlying true democracies. Post-Apartheid South Africa has had a new constitution since 1996. Chapter 2 of the Constitution represents the Bill of Rights. The right to equality states that "everyone is equal before the law and has the right to equal protection and benefit of the law" (Government Gazette, No. 108 of 1996, S 9(1)). Sections 9(3) and (4) highlight some sectors of society that should be particularly protected. These sub-sections specify that no one may be unfairly discriminated against on the grounds of, amongst others, disability. This places everyone, including the state, under a positive duty to promote the rights of persons with disabilities and under a negative duty to protect these rights. As South Africa enjoys constitutional supremacy, these and all the other bills of rights are binding on everyone (Government Gazette, No. 108 of 1996, S2).

The Disability Rights Charter of South Africa reflects demands from persons with disabilities (Mbeki, 1997). The first two articles of the Charter re-inforce their demands for non-discrimination and self-representation and informs all other articles of the Charter (Disability Unit of Lawyers for Human Rights, 1993). Both the White Paper on an Integrated National Disability Strategy

(1997) and the Integrated Provincial Disability Strategy for the Western Cape (draft document, 1999) recommend that power should be shifted from the professional to persons with disabilities including their representative organisations. This again reinforces the proposed change in health care delivery away from the medical model, in which the professional made the choices while the client was merely considered a recipient of services.

The development of rehabilitation services from within the construct of the medical perspective to the social perspective is discussed in the next section. As the community-based rehabilitation (CBR) initiative aims to implement services which address the needs and demands of persons with disabilities, that strategy is explained in detail.

2.1.2.3 Description of the development of rehabilitation services

The concepts of disability and rehabilitation are closely linked. In view of this, the evolution of rehabilitation is described in this section and special reference is made to community-based rehabilitation (CBR).

In the United Nations Development Programme (UNDP) publication "Prejudice and Dignity", Helander (1993) describes the development of rehabilitation services and the evolution of the term "rehabilitation" as follows: In the late 19th century persons with disabilities were looked after in institutions, sometimes for many years. During and after World War II the incidence of disability increased dramatically and rehabilitation became a recognised medical speciality. Specialist institutions developed in the industrialised countries with specialist services being delivered by large multi-disciplinary teams. The scope of rehabilitation was extended to persons with various chronic diseases with treatment often necessitating the use of expensive equipment.

Helander (1993) argues that the developing nations were unable to provide these institutionalised services to reach all citizens in need. The need for rehabilitation in developing countries, and therefore also in South Africa, was, and still is, enormous in view of wide spread poverty. Poverty results in poor educational opportunities, insufficient sanitation and many poverty related diseases and disabilities. Helander (1993) offers many reasons for insufficient rehabilitation services in developing countries such as the high cost of services and the paucity of specialist personnel, who in turn, felt that their services were ineffective. The few rehabilitation services that existed were mainly provided in urban areas and reached a small proportion of those in need.

This scenario and an increase in political awareness and democratisation in many countries, including South Africa, led to the development of community-based rehabilitation (CBR), a strategy to address the needs of all persons with disabilities. Helander (1993) has written extensively on CBR and defines it as follows:

“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 and protection of human rights.

Protection of human rights is an obligation for the authorities of each country, for communities and for every citizen. Disabled people shall have the same rights as others, and there must be no exceptions. ...”

(Helander, 1993, p 17)

CBR is thus seen as an approach within primary health care to enhance service delivery for all in need and to ensure equalisation of opportunities while promoting and protecting the human rights of disabled people (Helander, 1993). Crishna (1999) agrees and adds that the goals of CBR also include the demystification of the rehabilitation process and the intention to

give responsibility back to the individual, the family and the community. CBR is therefore understood as a process of social change.

It can be seen from the above that rehabilitation has evolved over the years from focusing on the individual's disabilities, to recognising physical barriers in the environment. It addresses unequal opportunities for persons with disabilities, while focusing on the protection and promotion of human rights. The CBR strategy is strongly encouraged in the National Rehabilitation Policy (1998) and in the White Paper on an Integrated National Disability Strategy to "form the basis of the national disability strategy" (Mbeki, 1997, p 27) for South Africa.

Advocates for disability rights (Mbeki, 1997; Rolland, 1997; Saetersdal, 1997; Pretorius, 1995) and proponents of community-based rehabilitation (CBR) (Crishna, 1999; Stuelz, 1999; National Rehabilitation Policy, 1998; Leavitt, 1995; O'Toole and McConkey, 1995; ILO, UNESCO & WHO, 1994; Helander, 1993) stress the fact that rehabilitation services should be planned and implemented according to the needs expressed by persons with disabilities. For this reason, responsibility also lies with service providers and educators within the fields of, amongst others, health and welfare, to establish those needs and to facilitate communication. Kay and Dunleavy (1996) also emphasise that "...if people with disabilities and their families are to be empowered by the CBR initiative, they must be allowed to take leadership ... Professionals and administrators should be cautious not to impose their agenda..." (p 121). This emphasises that the locus of power in CBR should be with persons with disabilities.

As discussed, CBR was established in the developing countries as a result of, amongst others, scarce resources and as an acknowledgement of a paradigm shift in health care delivery from the medical to the social model. Within this model both rehabilitation and disability are seen as multi-faceted issues. Helander demonstrates this clearly when expanding the definition of CBR:

"... .Special attention may be needed to ensure the following: access to health and social services; to educational and work opportunities; to

housing, transportation and to buildings; to information; to cultural and social life including sports and recreational facilities; to representation and full political involvement in all matters of concern to them.”

(Helander, 1993, p 17)

The United Nations Standard Rules On The Equalisation Of Opportunities For Persons With Disabilities confirms this definition and acknowledges that “disability involves all spheres of society and therefore it is necessary to use a comprehensive approach” (Lindquist, 1995, p 7). Post-apartheid South Africa, being an United Nations member state, follows this international trend. South Africa will endorse this document when addressing the country’s challenges in planning and delivery of social services (Government Gazette, notice 1108 of 1997). Stuelz (1999) emphasises that rehabilitation must focus on situations faced by persons with disabilities on a daily basis, such as health, education, vocational training and income generation. He concludes by stating that meeting the needs of persons with disabilities, their families, communities and beyond is fundamental when aiming to accomplish an effective CBR project.

The National Rehabilitation Policy (1998) and the White Paper for Social Welfare (1997) also suggest inter-sectoral collaboration as the optimal strategy for addressing national rehabilitation and welfare issues respectively. It is proposed that the Office on the Status of Disabled Persons, currently situated in the Office of the President, should co-ordinate and monitor collaboration and rehabilitation issues. An inter-sectoral approach is also reflected in one of the principles of the Integrated Provincial Disability Strategy for the Western Cape (1999) which states that “the multi-faceted nature of disability should be addressed by inter-sectoral co-ordination between relevant government departments” (p 3). Partnerships between all stakeholders, including persons with disabilities, government line functions and non-governmental organisations are emphasised.

2.2 DISABILITY PREVALENCE

Definitions of disabilities and consequences of different definitions have been introduced in the previous sections. Lack of consistency in the use and interpretation of terminology, restraining definitions of disability and divergent research methodologies result in under-estimations and –reporting of disability (Smart and Smart, 1997). In this section, various attempts to measure prevalence of disability in South Africa will be presented.

In the article about vision and imperatives for disability research in South Africa, Bhagwanjee and Stewart (1999) express concern about the paucity of epidemiological research on disability. They attribute this to a historical shortcoming in this country of not integrating disability into government statistical processes. Furthermore they maintain that available statistics are biased towards “obvious’ disabilities such as physical and medical disabilities” (p 15), as will be seen from the census figures, which are explored later in this section. Stuelz (1999) however does not support the collection of disability prevalence statistics and asserts that disability registers in developed countries are perceived as the first step in the segregation process of persons with disabilities. This viewpoint supports the criticisms of the medical model of disability, which stigmatise persons with disabilities. However, planning of any services should be based on population data, and therefore appropriate, meaningful statistics on disability prevalence and incidence should be readily available.

The global disability prevalence rate for moderate and severe disability is estimated to be 5,2% varying from 7,7% for the developed regions to 4,5% for less developed regions (Helander, 1993). However, disability prevalence increases with age in every region, and in most types of disabilities (Murray and Lopez, 1996).

A few studies have been undertaken to establish prevalence of disability in South Africa in urban areas. Disler, Jacka, Sayed, Rip, Hurford and Collins (1986) found that the prevalence of locomotor disability in black residential

areas (18,3/1000) was higher than in white (13/1000) and coloured (11,2/1000) residential areas of Cape Town. An overall disability rate of 85/1000 has been reported from the township of Alexandra in 1993 (Cornieltjie, Ferrinho, Coetzee and Reinach 1993). The most recent study, in Mitchell's Plain, Cape Town, reported a crude rate of 3,8% for all disabilities and a 2,7% locomotor prevalence rate for adults in that area (Coetzee, 1997). As different methodologies, age groups and definitions of disability have been used, these vastly different rates and percentages cannot really be compared. It is of concern, that disability research lacks uniformity and consensus, as it would be difficult to use such diverse findings as the basis for service planning and/or delivery.

Information regarding disability prevalence in South African rural areas is however scarce and includes mainly locomotor disability. Concha and Lorenzo (1993) report an overall disability rate of 4,6% in Gazankulu, while McLaren, Gear, Irwig and Smit (1987) found 5,2% of their study population in rural KwaZulu Natal to be motor impaired. Although relevant for the respective geographical areas and periods during which the above studies took place, these findings are not valid for the entire country. Their relevance to this study is further limited by the fact that very different definitions of disablement, often also including impairments, were utilized by the different researchers. Katzenellenbogen, Joubert, Rendall and Coetzee (1995) highlight other methodological difficulties in establishing prevalence data. These include sampling strategies, misinterpretations of the ICIDH and validation of the disablement status. Although possibly influenced by similar shortcomings, the most recent national data on disability prevalence are the findings from the 1996 National Census.

Much of government planning around disability and rehabilitation issues is based on the recent census despite the fact that these figures excluded people in institutions such as prisons, boarding school facilities, and hospitals, to name but a few. This exclusion may have led to an undercount in terms of disability prevalence as a number of persons with disabilities may have been

in hospitals or special schools as a result of their disability and consequently could not be counted.

It was found that 6,6% of the total South African population and 4% of the Western Cape population reported a disability at the time of the census (www.statssa.gov.za). It should be noted that none of the disability categories used in the census were based on the ICIDH disability categories, but were rather impairment based. Disability prevalence in the various disability categories in the Western Cape, as captured during the 1996 census, is presented in Table 1.1. The majority of persons with disabilities, both in the Western Cape and nationally, reported sight disabilities. Only 4% of the disabled population in the Western Cape had more than one disability, representing the smallest group (national: 5,8%).

Table 1.1: Disability profile in the Western Cape according to the 1996 National Census

Type of disability	Count	Percentage
Sight disability	40 603	28%
Physical disability	35 051	24%
Unspecified disability	30 174	21%
Hearing disability	18 965	13%
Mental disability	14 146	10%
More than one disability	6 499	4%
Total disabled population	145 438	100%

(www.statssa.gov.za)

In order to understand the situation in terms of disability prevalence in the geographical area of the present study, the census data for the Kleinmond area was requested from Statistics South Africa. The following findings are quoted (Statistics South Africa, 1999): In 1996, Kleinmond had a population of

3 918. A total of 189 persons reported being disabled. This indicates a point prevalence of 4,8%, which is higher than the provincial percentage, but lower than the national disability prevalence. The largest sub-group, in contrast to both the national and provincial findings, reported a physical disability (37% or 70/189), whereas only 2% (4/189) reported multiple disabilities. Thus a similar high proportion of physical disabilities was anticipated in the present study.

Despite the data derived from the 1996 Census, the National Department of Health commissioned a national prevalence disability survey in 1997. The Community Agency for Social Enquiry (C.A.S.E.) study established a national prevalence rate of 5,9%, which was even lower than the Census figure of 6,6% (Schneider, Claasens, Kimmie, Morgan, Naicker, Roberts and McLaren, 1999). For this cross-sectional survey the sample was stratified according to race, province, rural and metropolitan areas, with proportionate representation according to population density. Cluster sampling was used and 10 000 households were set out to be visited. In each household the senior woman was interviewed utilizing a structured questionnaire. The study also included qualitative research on the experience of being disabled. Overall, this study too appears to be biased, as the definition of "moderate to severe disability", as used by the researchers, seems vague, and more particularly as proxy reports were used for nearly half of the respondents (Schneider *et al*, 1999). Proxy reporting may lead to unacceptable disease bias, underlying cause bias and obsequiousness bias. Sample subjects were lost (only 9260 households visited instead of 10 000). Neyman bias may also have influenced the results as persons who had a permanent disability which was fatal, would have been excluded. Similarly, disability of short duration would also have been missed, again resulting in a possible undercount. However, despite its shortcomings, this study provides the most recent data on prevalence of disability in South Africa.

Self-reported or proxy-reported disability is most frequently used in prevalence surveys. The present study also captured information on self-reported disability. This approach is justified, as Wijlhuizen and Ooijendijk

(1999) examined the agreement between self-evaluation and observation of performance when measuring disability. They found high sensitivity of a self-evaluation WHO disability questionnaire for persons that can be objectively regarded as disabled, but they found the specificity to be low. In the present study it was more important to ensure high sensitivity, as persons receiving a disability grant should, by definition, have presented with some kind of disability.

With regard to proxy-reporting, a longitudinal study by Knapp and Hewison (1999) found that clients and their carers did not agree on the extent of limitations in activities of daily living after stroke and this may lead to bias. In contrast, Schofield, Murphy, Nankervis, Singh, Herrman and Bloch (1997) report high correlation between carers and care recipients' opinions regarding the care recipients' disabilities and dependencies. In view of these conflicting reports above, it can be concluded that proxy reporting may lead to either under- or over-reporting in disability research. Hence these possibilities should be taken into account when planning, executing and analysing the data of such studies. For the present study it was anticipated that the proxies would also be the likely caregivers and as such have sufficient knowledge of the grantees, in turn yielding the results valid.

2.3 SOCIAL ASSISTANCE IN SOUTH AFRICA

Ahmad, Dreze, Hills and Sen (1991) report that most developed countries have government-operated or –supported programmes to provide all or the most basic social security. This includes unemployment benefits, pensions, education and health services. Mechanisms, administration and level of support vary, but there seems to be considerable assistance for those who endure deprivation or adversity (Ahmad *et al*, 1991). The authors argue that the situation in developing countries is different. Resources in these countries are often acutely lacking and as a result social assistance in those countries rarely provides for all in need.

It is reasonable to place South Africa between the developed and the developing countries, as this country represents features and aspects similar to both extremes. Luiz (1994) argues that the South African welfare system is residual rather than universal. All citizens have the right to easy access to state services and support within the costly universal system. Assistance in a residual system however, is only provided when “the normal structures of supply break down” and the individual has no support from family, community or the economic structures (p 330). Thus support by the state is “seen as a privilege which may be withheld” (p 330). The previous government strived to decrease state welfare services by encouraging privatisation of such services. Luiz (1994) predicts that the welfare sector in the new South Africa will be challenged politically and economically in post-apartheid South Africa in order to meet the immediate need of the population. He warns, however, that underlying causes of poverty should not be ignored and that by only dealing with the symptoms, welfare might be used as a “band-aid” (p 332).

Patel (1992) argues that colonialism and apartheid have shaped and influenced the nature, form and context of this country’s social welfare policies. She explains that social security programmes consist mainly of non-contributory social pensions and of maintenance, disability, foster care and single care grants. The latter refers to assistance for those persons caring for persons with disabilities. She is critical of these state programmes and

maintains that people are penalised when unable to cope and that the majority of citizens are excluded from accessing benefits while policies at the same time merely distinguish “between the worthy and the unworthy poor” (p 40). Social welfare policies however, are supposed to be equitably distributed and to ensure adequate economic and social protection during times of hardship. Luiz (1994) agrees and states that government has a duty to recognise its obligation by providing a service which is efficient, adequate and empowering. He maintains that the role of the state proceeds beyond this duty by not only dealing with the symptoms of poverty, but also attempting to identify and counteract the causes of poverty.

The restructuring of social welfare policies is therefore one of the many pressing challenges of post-apartheid South Africa. The White Paper on Social Welfare (Government Gazette, Notice 1108 of 1997) is the result of widespread negotiations with many stakeholders. This policy document emphasises that welfare programmes should promote optimal social functioning. The same publication reiterates that welfare service provision has both a racial and urban bias. It is well known that South Africa’s welfare system was founded on racial inequity, resulting in social disintegration and consequent social problems. At the same time the document acknowledges that resources are limited, and that welfare expenditure can only be increased when higher economic growth is achieved. People’s expectations, including of persons with disabilities, cannot therefore be fully met in the short term. The demands on the state are enormous and human rights activists demand that no citizen should be deprived from living above minimum acceptable standards (National Human Rights Research and Advocacy Project, 1998).

The Financing Policy of the Department of Welfare envisages a shift “from social assistance separated from social services, to financing social services which are linked to social assistance” (Government Gazette, Notice 463 of 1999, p 19). An example is given to highlight this shift in assistance: while a child support grant is currently being paid in isolation this will be expanded by adding developmental welfare service delivery. A similar approach is envisaged for people receiving other grants such as a disability grant. This

would provide persons with disabilities not only with some income in the form of a disability grant, but should ideally identify their real needs and address those accordingly. This strategy would enable persons with disabilities to develop their abilities by addressing the barriers they face, and supports the social model approach, as previously discussed (section 2.1.2).

According to the White Paper on Social Welfare (1997) 8,7% of the 1995/96 consolidated national budget were allocated to the welfare budget. Social assistance was the largest expenditure in the country's welfare budget, making up 88% of that budget (60% of the welfare budget were allocated to grants for the elderly, while 24% were allocated to disability grants). Social assistance grants are poverty alleviation mechanisms and statutory benefits. The same document reports that 1,6% of the total South African population receive a disability grant, presumably both permanent and temporary grants. Reference to numbers of disability grants paid nationally, provincially and in the geographical area of the present study is made in section 2.3.1.

2.3.1 Disability grants in South Africa

2.3.1.1 Legislation and procedures regarding disability grants

At present, legislation in South Africa provides state assistance for persons with disabilities 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 Department of Social Services, i.e. the welfare offices for each magisterial district, administer these and other social grants.

Persons with disabilities may apply for a disability grant by submitting the accompanying documentation as stipulated in the Act. An application form (VRT-3) is attached to this report (Addendum 1). Disability grants may be awarded on a temporary or permanent basis. The welfare offices do not,

however, have information on the presenting disabilities of the recipients. A person who wishes to be eligible for a social grant must prove his or her need on the basis of a means test. Assistance is given at a very basic level. Currently payment of maximally R 520,- per month is made either at the Post Offices or to a bank account. The amount that may be granted is dependent on the means test and is paid on a sliding scale. A person applying for a disability grant should be unable to work owing to his or her disability (Government Gazette No 417 of 1998).

Correspondence with the Deputy Director: Social Security in October 1999 indicated that in November 1999 a total of 635 881 people in South Africa and 90 676 in the Western Cape were to receive a temporary or permanent disability grant from the government. If percentages are calculated by dividing the above figures by the respective total number of persons with disabilities as identified during the 1996 National Census, the following emerges: 24% and 62% of the persons with disabilities received a disability grant nationally and in the Western Cape respectively. The large discrepancy between the national and provincial percentages cannot be explained by the researcher. They may indicate unreliable census figures and/or irregularities within the data system of the Department of Social Security. They may also point to different interpretations of the legislation in the various provinces and districts. Referring to the present study, communication with the Western Cape Provincial Department of Social Services revealed that only thirty (30) permanent disability grants were paid at the Kleinmond Post Office in June 1999. This indicates that 16% (30/189) of the disabled population received such a grant. This figure for Kleinmond is even lower than the national figure of 24%, but may in part be explained by only including permanent grantees into the calculation, whereas both permanent and temporary grants were included in the national and provincial figures.

In contrast to these census figures, the current Minister for Welfare, Population and Development, Dr Zola Skweyiya, estimates that only 19% of persons with disabilities receive government grants and acknowledges that services for persons with disabilities are inadequate (Welfare Update, 2000).

In comparison, the previously mentioned C.A.S.E. study established that 68% of disabled non-pensioners were neither receiving a grant nor a private insurance pension (Schneider *et al*, 1999). The authors also report that disability grants were the most commonly received grants of those remaining 32% of disabled non-pensioners that did receive a grant.

The South African government, on occasion, relieves the financial burden of carers of persons with disabilities. Should a person who is rewarded a social grant require full-time attendance by another person as a consequence of his or her physical or mental condition, an application for a "grant-in-aid" for the caregiver may be made (Government Gazette No R 417 of 1998). The Deputy Director: Social Security indicated that in November 1999 a total of 8 893 grants-in-aid were paid out nationally (1,4% of all national disability grants) and 4140 (4,6% of all provincial disability grants) in the Western Cape (personal communication, 28.10.1999). These figures only refer to recipients of a "grant-in-aid" who care for disabled adults. While nearly half of the national "grants-in aid" are apparently paid out to persons residing in the Western Cape, there is large discrepancy between the percentages nationally and this province. This discrepancy may indicate a more lenient approach of the authorities in the Western Cape, but may also have a number of other explanations, such as flawed record keeping, and clearly warrants further investigation.

2.3.1.2 Controversies surrounding social assistance

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 (Mbeki, 1997).

Oliver (1996) suggests that many welfare states have failed persons with disabilities as “welfare provision has compounded rather than alleviated discrimination” (p 76). In his opinion persons with disabilities are forced to depend on welfare benefits in order to survive, as there are barriers to other forms of income, e.g. employment. Likewise, the White Paper on an Integrated National Disability Strategy states that the approximately 30% of persons with disabilities who received a disability grant in 1993 often had to support entire families with the grant (Mbeki, 1997). Widespread poverty in South Africa leads to this scenario. Oliver (1998) argues that dependency on welfare services excludes persons from society, and thus increases the dependency culture. In his criticism of the medical model of disability, he further debates that provision of services is dominated by employed professionals who act in their own interest rather than meeting the needs of persons with disabilities. He does not agree that doctors should be in a position to decide access for persons with disabilities to, amongst others, welfare services (Oliver 1998). The medical model is also reinforced in welfare delivery in South Africa in that eligibility for a disability grant is mainly assessed by medical practitioners and on the basis of impairment, again reinforcing the medical model (Government Gazette, notice 1108 of 1997).

Disability grants are perceived to discourage persons with disabilities from seeking employment, as they supposedly readily rely on the grants. It is further acknowledged that past policies have resulted “in passive income maintenance through grants” (Government Gazette , no 1108 of 1997, p 49). The Cape Times reported on 4.12.98 that the then Minister of Welfare and Population, Mrs Fraser-Moleketi said that disability grants had a demotivating effect on persons with disabilities and made them dependant on welfare. It was, however, acknowledged that opportunities for persons with disabilities on the open labour market were limited. The White Paper for Social Welfare (1997) re-iterates that the means test, on the basis of which the maximum amount of a disability grant is calculated, “has penalised and demotivated people who have private savings or who ... work” (Government Gazette, notice 1108 of 1997, p 49). The White Paper on an Integrated National

Disability Strategy quotes a study in which it was estimated that only 0.26% of persons with disabilities were employed in the open labour market in South Africa in 1985 (Mbeki, 1997). The more recent C.A.S.E. study reported that 88% of persons with disabilities who were older than 15 years of age were economically inactive (Schneider *et al*, 1999). This is markedly higher than the already staggering unemployment rates of 34% and 18% in South Africa and in the Western Cape respectively (www.statssa.gov.za). It is emphasised in the new Constitution of South Africa that there should be no discrimination against anybody on the basis of their disability (Government Gazette, No. 108 of 1996). New legislation regarding labour and employment equity is now in place in order to ensure increased opportunities for persons with disabilities (Government Gazette No. 55 of 1998). While it is important that this legislation is enforced, a multi-sectoral approach must be adopted in order to ensure employment opportunities for persons with disabilities.

The current Minister of Welfare, Population and Development recently initiated a National Consultative Process (NCP) in order to establish shortcomings of the welfare system (Welfare Update, 2000). He found that the "social assistance and safety nets do not provide coverage to those in greatest need and its administration requires drastic change" (p 5). Reid and Giddy (1998) also report that, while working as physicians in rural South Africa, they encountered an inefficient, fraudulent social security system, leaving persons clearly eligible for a disability grant facing bureaucratic difficulties, leading to extensive delays in the processing of disability grant applications. It is commonly accepted that the current welfare system and particularly the social assistance system has led to abuse and the White Paper for Social Welfare envisages re-registering beneficiaries and integrating this data with the National Social Grants Register (Government Gazette, notice 1108 of 1997). It was interesting to note that during the fieldwork of the present study a number of grantees indicated that they anticipated a re-registration process.

2.4 CARE-GIVING

There is a wealth of literature about aspects of care-giving. Most articles are emerging in the gerontological literature, i.e. referring to caregiver utilisation by the elderly. Consequently, it is of limited appropriateness to the present study, as, due to the legal requirement of grantees having to convert their disability grant into old age pensions at that age, the oldest subject in this study population was 65 years old.

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, p 405). The world-wide paradigm shift in health care delivery has resulted in efforts to change the emphasis from institution to home-based care. This is of particular relevance to the South African context, where, owing to a paucity of institutions, especially in rural areas, the role of the carer or family member of a dependant person with disabilities has always been an important one. Their importance is likely to be increasingly recognised as CBR is introduced to meet rehabilitation needs in developing countries such as South Africa (National Rehabilitation Policy, 1998; Mbeki, 1997; Kay and Dunleyvy, 1996; Helander, 1993). Schofield and Bloch (1998) feel strongly that health professionals' awareness about carers and their needs should be raised. This is also of particular significance to South Africa in order to allow the professionals to address these needs within a primary health care system. Taylor, Ford and Dunbar (1995) feel that services for the carers should target needs that are demonstrated rather than assumed. One of the fundamental aspects on which to evaluate needs of the caregiver is to establish and describe trends in the population relying on caregivers in the first instance.

Although different aspects of caregiver involvement and dependency have been dealt with in the literature, very little is known regarding prevalence of care-giving or the aspects for which persons with disabilities require assistance. When establishing prevalence of care-giving, Howe, Schofield and Herrman (1997) compared studies in Australia, the United Kingdom and British Columbia respectively. They report consistency of prevalence

estimates across the investigated communities (120 – 175 households per 1000 are involved in some sort of care-giving and about 50 per 1000 involved in primary, more intense care-giving). Subsequently, Schofield, Murphy, Nankervis, Singh, Herrman and Bloch (1997) have published the results of one of the Australian prevalence studies. They established that more than half of the carers were adult children caring for their parents while a quarter of the spouses took care of their partners and another quarter included parents caring for their children. However, in contrast to the present study in Kleinmond, the Australian study included the entire age range of care recipients. Most parent carers in the latter study stayed in the same household as the care recipients, whereas children staying with their care recipient single parents were as common as those living apart from their single parents.

Another team of researchers found that persons who reported disabilities relied on assistance for home maintenance, heavy housework and managing money (Clayer, Bookless, Air and McFarlane, 1998). Assistance was sought in the informal rather than the formal sector. Of those persons having reported a disability, 26% had a positive psychiatric disorder of which 43% needed assistance for a minimum of one activity of daily living.

Allen and Mor (1997) report the prevalence of unmet needs of persons with disabilities for assistance in activities of daily living (ADL) to be ranging from 4% for eating to 23% for transferring. They also established that the unmet needs for transportation and household tasks is more prevalent in 18-64 year old Americans than in those 65 years and older.

There is hardly any data on caregiver reliance of persons with disabilities in South Africa. Schneider *et al* (1999) refer to a large number of persons with disabilities interviewed in the C.A.S.E. study reporting a substantial decrease of severity of disability when an assistive device or personal assistance was provided. Unfortunately the summary report does not include the data underlying the C.A.S.E. researchers' statement. Hence, inferences cannot be made.

In an investigation of the outcome of common mental disorders in Harare, Patel, Todd, Winston, Gwanzura, Simunyu, Acuda and Mann (1998) found a strong association between permanence of disability and caregiver reliance. However, the authors admit that they were unable to establish any confounding variables, such as HIV or other physical illness.

Coetzee (1997) developed a questionnaire in order to establish disablement of persons with locomotor disabilities in Mitchell's Plain, South Africa. She measured to what extent persons who had identified locomotor disabilities were able to manage their lives in terms of mobility and physical independence, occupation, social integration and economic self-sufficiency. The extent of independence was ranked on a 7 point scale from "independent" to "not able", while it was also established which factors contributed to dependence. She reported that severity of disabilities led to an increase in handicaps, especially self-care handicaps.

The Department of Community Health at the University of Cape Town published a number of articles in 1984 based on their follow-up studies of patients admitted to an acute hospital. Again, these studies examined persons with locomotor disabilities only. It was reported that most persons post-stroke were dependent on assistance for washing, dressing and feeding but 53% could use the toilet independently (Jacka, Disler, Sayed, Hoffman and Watermeyer, 1984), while their carers experienced more emotional than financial problems (Putterhill, Disler, Jacka, Hoffman and Watermeyer, 1984).

A number of useful screening questionnaires have been developed to establish caregiver burden (Elmstahl, Malmberg and Annerstedt, 1996; Robinson, 1983). However, discussions on various attempts to measure the strain of care-giving and consequences thereof are beyond the scope of this study, as assessment of these were not included in the aims of the study.

2.5 CONCLUSION

It is evident from reviewing the literature that different definitions of disablement have led to confusion and disagreement amongst researchers and activists. These differences seem to be major factor contributing to the discrepancies in measurement of prevalence of disability as reported in the literature. Various attempts to quantify the extent of disability were also reviewed. It is a matter of concern that many practices continue to use an impairment focused approach, the most notable of these being the National Census and the processing of disability grant applications in South Africa.

World-wide there has generally been a paradigm shift from the medical to the social model of disability and rehabilitation. However, the examples cited above illustrate that South Africa is still strongly entrenched within a medical model paradigm despite disability being seen as a human rights issue.

The reviewed literature reinforced the principle that persons with disabilities should be allowed every opportunity to express their needs and expectations in matters concerning them, and in the present study every effort was made to afford persons with disabilities that opportunity.

It is also clear from the literature that the International Classification of Impairments, Disabilities and Handicaps (ICIDH) is an internationally used, standardized tool, frequently utilized in disability research. The disability catalogue of this classification instrument therefore informed the development of the questionnaire in the present study, which had the aim of establishing a disability profile of a defined population (disability grant recipients).

CHAPTER 3: METHODOLOGY

In order to obtain answers to the problems stated in the introduction of this report and to contribute to Bhagwanjee and Stewart's (1999) call for epidemiological research in the disability field, a study describing the disability profile of a defined group of persons with disabilities was planned. In this chapter methodological issues pertaining to the study are discussed. Reasons for having made particular methodological choices are given. Reference to potential sources of bias and attempts on how to minimise this is made under each sub-heading, where appropriate.

3.1 OBJECTIVE

To determine the disability profile, caregiver utilization and social and health needs of disability grant recipients residing in Kleinmond, Western Cape, South Africa.

3.2 AIMS

- a) To collect demographic data with respect to age, gender, family status, living arrangements and employment status of disability grant recipients in Kleinmond, Western Cape, South Africa.
- b) To establish present utilisation of health services by the grantees.
- c) To establish permanent use of assistive devices by the grantees.
- d) To establish a disability profile in disability grant recipients residing in Kleinmond (based on the ICDH).
- e) To establish the proportion of caregiver utilization amongst the grantees.
- f) To identify perceived needs as related to health and social services and the Kleinmond community, as expressed by the grantees.

3.3 STUDY DESIGN

A descriptive survey was the study design of choice. This was considered to be the most appropriate choice as epidemiological information of a defined group of persons with disabilities was sought in order to achieve the above aims. Katzenellenbogen *et al* (1997) suggested that "... surveys are often descriptive studies which try to estimate health-related events in the community" (p 164). The advantage of surveys is that they provide population information that can be gathered relatively easily, quickly and inexpensively. This information is often sought before embarking on larger analytical studies (Hennekens and Buring, 1987). A major limitation of this study design, in comparison to analytical studies, is that it does not involve control groups. However, the present study was purposefully planned as a descriptive study and not as an intervention study. Very little was known about the study population and hence it was deemed appropriate to describe the population before being able to formulate hypotheses for possible further investigations. Consequently, findings from this study only allow for the establishment of trends as the data provides information, but no reasons for relationships. Data was only gathered at one point in time. This is a limitation of descriptive studies, one as changes in the population cannot be measured. However, as the subjects in this study population received permanent disability grants, major changes in population characteristics were not anticipated. It was thus considered to be unnecessary to repeat measurements over time. (The results of this study support the initial notion that grantees were disabled, received a disability grant and utilized caregiver assistance for a number of years.)

3.4 GEOGRAPHICAL AREA

The coastal town of Kleinmond is situated in the Boland/Overberg region in the Western Cape, one of the nine provinces in the Republic of South Africa. As discussed in the introduction, Kleinmond had a population of 3918 in 1996 (Statistics South Africa, 1999).

Reasons for having chosen this particular area for the study are given in chapters one and two above. As only a few health services exist in the Kleinmond area and a community centre with a clinic is currently being planned, it was hoped that findings from this study would be of benefit to the planners. The literature lacks disability studies of this kind in the South African semi-rural population. Some studies have recently dealt with prevalence of disability in urban areas (Coetzee, 1997; Katzenellenbogen *et al*, 1995; Concha, 1993). Concha and Lorenzo (1993) and McLaren *et al* (1987) investigated disability prevalence in rural areas. However, a defined group of persons with disabilities in a semi-rural area has not, to date, been investigated.

Another aspect that was considered when planning this survey was the researcher's ability to converse, read and write in English and Afrikaans. Afrikaans was assumed to be the home language of the majority of the population of Kleinmond. This was an important consideration especially in view of financial constraints where the cost of employing an interpreter for the fieldwork can be prohibitive. Moreover, the researcher could reside in the area during the time of the study, thereby reducing further expenses and facilitating the logistics of implementing the study. Being in full-time employment necessitated careful deliberations by the researcher about the allocation of time and resources.

3.5 STUDY POPULATION

The study population was defined as all 32 recipients of a permanent disability grant who collected their grant at the Kleinmond Post Office in June 1999.

The original protocol for this study indicated that all recipients of a permanent disability grant in Kleinmond would be included in the study. However, a change from the protocol was necessary, as the Department of Social Services was only able to access the residential addresses of grantees in a defined area when payment of the grant was made at the Post Office. Discussions with the Department of Social Security revealed that a negligibly small number of people may have had their grants paid into their bank accounts. Residential details of these grantees however, could not be given. It is possible that a select sub-section of the recipients of a permanent disability grant were therefore included in this study, leading to potential bias. The persons that have a bank account and receive a disability grant may be different from those who do not have a bank account and collect their grants at the Post Office. This is particularly problematic in the case of assessing employment status. Keeping a bank account is expensive and some sections of the population, especially the unemployed, cannot afford it. It may therefore have been that the group studied showed a higher unemployment status.

Sackett (1979) argued that the wrong sample size may lead to bias and therefore inferences from a small number of subjects should be made cautiously. As the study population was smaller than originally anticipated, sampling was not necessary and every effort was made to visit the entire study population in order to reduce wrong sample size bias.

The study population can therefore be regarded as representative of persons with disabilities who resided in a semi-rural area in the Boland/Overberg region and received social assistance, especially in view of the Department of Social Security's statement that only very few grantees have their grants paid into their bank accounts.

3.5.1 Inclusion criteria

All recipients of a permanent disability grant who collected their grant at the Kleinmond Post Office in June 1999 and who consented to the interviews were included in this study.

3.5.2 Exclusion criteria

Grantees that were absent on three successive occasions were excluded from the study. Any grantee that was found to be unable to communicate verbally was excluded when no proxy respondent was available after three visits.

The final study population consisted of 29 respondents. Twenty seven (27) of the 30 grantees whose names and addresses were supplied by the Department of Social Security were located and consented to the interview. One person had passed away, one had moved away from Kleinmond and the address of a third was incomplete and the subject could not be traced. Two persons heard of the study and were waiting for their disability grants to be converted into old age pensions. In June 1999, however, they still collected a disability grant at the Post Office. These two persons were also included in the study.

3.6 MEASUREMENT

This section outlines details of the measuring instrument and the development thereof during the pilot studies. Methods of data capturing and the actual fieldwork of the main study are given. Aspects relating to reliability and statistical procedures are discussed. Reference to potential sources of bias

and the efforts made to reduce these bias' is made in each sub-section where appropriate.

3.6.1 Data capturing

Data was captured during face-to-face interviews with the subjects. The respondents were either the grantees or their proxies or both. Advantages of face-to-face interviews include the possibility of a higher response rate, when compared to mailed questionnaires. It also allows the fieldworker to immediately clarify any questions the respondents may have. The disadvantage is that obsequiousness bias may be introduced when the respondents attempt to alter their answer in the direction they perceive the interviewer to expect (Sackett, 1979). Every effort was made during the study to prevent leading the respondents in a particular direction when answering the questions. Details of the field work of the main study are given in 3.6.4. below.

3.6.2 Measuring instrument

A questionnaire, developed by the researcher, was used as the measuring instrument for this study. The final questionnaire comprised of eight sections to capture demographic information, utilisation of health services and assistive devices, a disability profile, caregiver utilization and perceived needs of disability grant recipients regarding health and social services (Addendum 2).

Sections A, B and C of the questionnaire were intended to gather information about home language, respondent, employment status and other demographic data. Nominal categorical variables were used except for age, which was measured on a continuous scale.

Section D dealt with the grantees' utilisation of health services and permanent use of assistive devices at the time of the study. Nominal categorical

variables were employed. The various items on the respective lists were developed on the basis of the researcher's experience in the public health field and findings from the pilot study. The nominal response categories to the list of assistive devices were given three options: "yes", "no" and "not applicable". This was necessary in order to capture information about the need for assistive devices. If a person needed and used a device, he or she would answer in the affirmative. If the person needed a device, but had none, he or she would score "no", whereas if he or she did not need that device, "not applicable" would be recorded.

The original World Health Organisation's International Classification of Impairment, Disability and Handicap (ICIDH) informed the development of Section E (WHO, 1980) (see literature review). This international classification was chosen due to relatively clear activity descriptions and as it was expected that results could be readily compared with other studies. At the time of planning the study, the ICIDH-2 was not yet readily available in South Africa (the beta-2 draft for fieldwork was only published in 1999 (WHO, 1999)).

In the ICIDH disabilities are sub divided into nine categories, each in turn containing descriptions of various activities, i.e. behaviour, communication, personal care, locomotor, body disposition, dexterity, situational, particular skill and other. This allows for research and coding in a uniform manner. For this study nominal variables, i.e. dichotomous yes/no responses, were considered to be the most appropriate in order to establish whether a person had a problem with an activity. Sackett (1979) argued that some measures are unable to detect clinically significant differences, which may lead to insensitive measure bias. However, the aim of this study was not to establish the extent of severity of problems encountered, but only whether or not grantees had difficulty with an activity. For this reason the ICIDH chapter on coding and grading of the severity of disability was not utilised. In the case of questions which might not have been applicable to a respondent, e.g. "able to care for your children" or "using a phone", a third response option ("not applicable") was utilised.

In section E, should a person have been unable to perform a task without using an assistive device but have experienced no problems performing the task with an assistive device, he or she would score “no” for that task in section E if he or she possessed such a functioning aid. An example would be the case where a person was unable to read without spectacles, but could read with the spectacles in his possession.

It must be noted that the questionnaire was intended to capture information as supplied by the grantees. For section E this meant that only self-reported disability was recorded. It may be argued that direct observation of the grantees performing the various activities would have reduced bias. This was not possible for two reasons. Firstly there were financial and time constraints and secondly the researcher, a physiotherapist, lacked the ability to objectively assess certain activities, particularly in the behavioural and situational categories.

Information regarding caregiver utilization was captured in section F. The initial question established whether or not a grantee was able to look after him or herself. If the answer to this was negative, questions regarding aspects of caregiver utilisation, such as particular activities with which assistance was needed and information regarding the caregiver, were asked. These questions were based, amongst others, on previous research by Coetzee (1997) and following discussions with persons with disabilities who were known to the researcher. Simple yes/no answers, i.e. categorical binary variables, were provided. Only question 117 was measured on an ordinal scale. The fact that self-reported caregiver utilisation was captured may have led to bias, as the grantees could have over-reported dependence in order to re-inforce the severity of their disability and subsequently their need for social assistance. On the other hand, the researcher wanted to establish what the grantees own opinion about their disability experience and caregiver utilisation was, especially in view of the demands of persons with disabilities with respect to self-representation (Oliver, 1996).

Sections G, H and I were designed to establish the grantees' perceived needs regarding health services, social services and the community respectively. It was considered appropriate to capture this information on five point Lickert scales, i.e. ordinal scales. The Lickert scales enabled respondents to indicate the degree of importance they attached to their expressed needs. Respondents were also given an opportunity to voice perceived needs that were not included in the questionnaire. Sections G, H and I were particularly vulnerable to obsequiousness bias as subjects could have systematically over – or under-reported needs in order to satisfy the perceived desire of the investigator (Sackett, 1979). Rumination bias may also have weakened the measuring instrument in sections G, H and I as subjects could have been confronted with issues they had not previously considered to such an extent. These potential sources of bias were minimised by the interviewer consistently striving to ask the questions in a neutral manner, only adding explanations when the question was not entirely understood and allowing the respondents sufficient time to answer each question. The respondents were also re-assured that they could answer "uncertain" if they felt they did not have sufficient insight regarding a particular topic or question.

3.6.3 Development of the measurement instrument

3.6.3.1 Draft questionnaire

A draft questionnaire in English, based on the disability literature and discussions with persons with disabilities, was developed. The statistician and senior occupational- and physiotherapists were then consulted for comment.

3.6.3.2 Pilot studies

The draft questionnaire was administered to four English speaking disability grant recipients attending Groote Schuur Hospital. Information regarding the

clarity of the questions was invited from these persons and their suggestions were incorporated during revision of the questionnaire.

Permission to conduct a pilot study in the Caledon/Overberg area was sought and granted by the Regional Director of Health of the Boland/Overberg region (Addendum 3). It was considered reasonable to assume that the characteristics of the pilot population were similar to those of the main study population. Kleinmond and Caledon both fall under the same region (Boland/Overberg). The population demographics are similar in respect of language, race and socio-economic status. The orthopaedic after-care nursing sister in Caledon and her colleague involved in service delivery in the field of mental health were contacted and asked for names and addresses of persons with disabilities who would be willing to participate in the study. Six disability grant recipients were visited and interviewed in April 1999. Further shortcomings of the questionnaire were identified and the necessary changes made. The questionnaire was then discussed with the statistician, adjusted accordingly and later translated into Afrikaans by the researcher. Two senior physiotherapists proficient in both languages and the disability field were consulted and the final Afrikaans version was agreed upon. The final questionnaires were then printed in both languages (Addendum 2).

3.6.4 Implementation of field work and data capturing

The researcher resided in Kleinmond for three weeks during the end of June to the middle of July 1999. All grantees were visited at their residential addresses, as provided by the Department of Social Security. If the subject had moved from that address the neighbours were asked to assist in locating the new residence.

The objectives of the study were explained in the grantees' home language and informed consent sought from either the grantees and/or their proxies (Addendum 4). Interviews were then conducted with the grantees and /or

their proxies. Persons that were absent were visited, if necessary, on three different occasions. If they were still absent on the third occasion they were excluded from the study. The interviews were conducted in English or Afrikaans, depending on the interviewee's choice. Should a person have requested to be interviewed in a language other than English or Afrikaans, an interpreter would have been employed. This was however not necessary. The fact that grantees may have been over-reporting disability and caregiver reliance in fear of the disability grant being taken away, could potentially have led to bias. Every effort was made to assure participants that findings would be handled confidentially and that the researcher had not been sent by the Department of Welfare, but rather acted in her personal capacity. This was thought to limit potential obsequiousness bias (Sackett, 1979).

3.6.5 Reliability

The researcher, who is fluent in English and Afrikaans, conducted all interviews in order to maximize inter-rater reliability in such a small study population. No translator was necessary as all subjects were fluent in either English or Afrikaans. This also contributed positively towards reliability.

In order to decrease subject variation in the study population, all participants were visited after 8h00 in the morning and before sunset. Minimum rest periods of half an hour between interviews and an hour for lunch were observed in order to reduce biological variation and fatigue of the interviewer. All interviews, with one exception, were conducted on weekdays. This person had other engagements during the week and only agreed to be interviewed on a Saturday morning.

The majority of questions in the questionnaire were closed-ended. However, it was deemed acceptable for the interviewer to probe if participants did not understand the question. This was particularly true for sections G, H and I of the questionnaire. These sections dealt with the respondents' perceived

needs regarding health and social services and the Kleinmond community, and the concept of the Lickert scales was not always clear to the participants. However, Lickert scales were used in order to improve the repeatability of the questionnaire. The alternative of utilizing an open-ended questionnaire to capture this information was discarded in order to facilitate the data analysis of this quantitative study.

Coding was done on an English version of the questionnaire to ease data recording. Data was checked and entered into the computer daily. This was important to allow follow-up while still in the field, should data be found to be missing. Re-visits for this reason were found to be unnecessary, indicating that data was complete and accurate.

3.6.5.1 Repeatability of questionnaire

In order to check the repeatability of the questionnaire, four cases were randomly selected and interviewed for a second time. Of all responses of the four people that were re-visited, 96% were the same at both interviews. Most of the discrepancies appeared in the importance ratings of the Lickert scales in sections G, H and I, where the repeatability was 87%. That means that 87% of the responses for the four people were the same for both interviews. Most of these discrepancies were small, for example “very important” and “important” might have been chosen respectively at the two visits.

There was little variation between measures, attesting to a strong likelihood that data was collected in a reliable manner, i.e. the repeatability of the questionnaire and the manner of data collection were very good (Katzenellenbogen *et al*, 1997). This in turn contributes to the internal validity of the present study.

3.6.6 Statistical procedures

The data was cleaned and analysed with the statistical software package STATISTICA (version 5.1). The services of a statistician were utilised to assist with the data analysis.

After data collection, the data needed some manipulation to form measurement scores for analysis and comparisons. Details are described below.

Most responses were categorical and these were summarised using frequency and percentage frequency distributions (percentages were rounded). Many of these distributions were illustrated using histograms and pie charts. In select cases, the relationship between two variables was examined. When these were two binary variables, the joint responses were summarised in a 2x2 contingency table and the relationship was tested using either the Chi-square or the Fisher's Exact 2-tailed test.

Many categories allowed for multiple responses, i.e. categories were not mutually exclusive. These data were also summarised using frequency distributions and percentage frequency distributions. However, the percentages were based on the 29 respondents who chose each specific answer. Due to the multiple responses, i.e. a respondent could choose more than one answer, the sum of these percentages exceeded 100, e.g. Tables 4.5 – 4.12: Number of cases in specific disability categories.

To summarise the type of disability, disability scores were calculated. These scores were the total number of "yes" responses for each disability category. A total disability score was derived for each category by adding all the "yes" answers over all the disability categories divided by the numbers of questions making up that category. To illustrate this, the calculation for the category "locomotor disability" is explained: a total of 63 "yes" answers were given in that category. This figure was then divided by eleven (11), the number of questions in the "locomotor" category. The calculated figure ($63/11 = 5.73$)

gives a standardized score for this category, which can be interpreted as the average number of positive responses per question in the particular disability category. This division was necessary to adjust for the different numbers of questions in each category. The composition of each disability category was examined by looking at the percentage of the total category score that came from each specific problem. (Here the total category score was the denominator.)

When establishing the relationship between degree and type of disability and caregiver utilization, a disability score was calculated (within each category and overall) for each respondent, again adding the number of "yes" answers for each person. These scores were then summarised within the three caregiver dependency groups using medians and interquartile ranges (i.e. the mid 50% of the data range). Due to the non-normality of the data, these medians were compared using the non-parametric Kruskal-Wallis test. This test is the nonparametric equivalent of the one-way Analysis of Variance, but it is based on ranked values rather than means. It tests the hypothesis that the three caregiver dependency groups have the same median scores for the degree of disability.

For all statistical comparisons, p-values, rounded to four decimal points, are quoted to indicate level of significance (one p-value was so small that five decimal points are given). The value of $p < 0.05$ was interpreted as highly significant, and $p < 0.10$ as worth noting (especially due to the small sample size). Anything larger than 0.10 was not regarded as statistically significant.

3.7 ETHICAL CONSIDERATIONS

The Research Committee C of the Medical Faculty of the University of Stellenbosch accepted the research protocol for the proposed research (reference number 99/016). The Chief Director of the Department of Social Services was informed about the study and granted permission to access

addresses of those grantees that collected a permanent disability grant at the Kleinmond Post Office (Addendum 5).

It was considered imperative to identify as many stakeholders as possible in order to inform them of the proposed study. Stakeholders included provincial and non-governmental service providers, local authorities in the Kleinmond/Overberg area and the Western Cape branch of Disabled People South Africa (DPSA). The Disability Rights Charter of South Africa demands self-representation of disabled people on matters concerning themselves (Disability Unit of Lawyers for Human Rights, 1993). The aims of the study were to gather data from disabled persons and it would have been considered unethical to omit inviting DPSA to comment on the proposed study. Provincial departments, i.e. branches of health and social services, non-governmental organisations (NGOs) and local authorities concerned with disability matters were informed about the study and their comment was invited. These stakeholders were informed of the study by means of a letter (Addendum 6). No responses were received from these stakeholders, but the Department of Health of the Boland/Overberg region indicated that they wanted to be informed of the findings of the study.

All participants (grantees and/or proxies) of the pilot and main studies were informed in detail of the study and its aims in their home language and invited to ask questions regarding the study. Confidentiality was assured and interviews were only conducted once the consent form had been signed (Addendum 4). The consent forms were also available in English, Afrikaans and isiXhosa.

Another ethical consideration was the need to provide feedback regarding the study to stakeholders. The researcher is of the opinion that it will be imperative to bring the findings of the study to the attention of the authorities, i.e. Kleinmond Municipality and Health and Social Services in the Boland/Overberg region.

3.8 ASSUMPTIONS

Some assumptions were made by the researcher prior to embarking on this study. The most important of these is that, as a physiotherapist, the researcher based the questionnaire on her experience of locomotor and neuro-muscular impairment and the resulting disabilities. As a consequence, those persons with disabilities that were consulted when developing the protocol and questionnaire for this study, had mainly locomotor disabilities and impairments. This assumption underlies the section on assistive devices and is supported by a previous study by Coetzee (1997), who reported a high proportion of Mitchell's Plain residents with locomotor disabilities to be in need of assistive devices. However, during the pilot study a special effort was made to include persons with mental and psychological impairments as subjects. It was further assumed that the population in which the pilot study was conducted (Botrivier/Caledon) had similar characteristics to the population in Kleinmond.

Another conjecture was the belief that only persons with multiple disabilities qualified for a permanent disability grant. In this regard, it is also important to note that, with her limited understanding of mental impairment, the researcher assumed that people suffering from these impairments were most likely to present with situational, behavioural and communication disabilities.

It was deemed reasonable to believe that persons who received a disability grant belonged to lower socio-economic classes. This opinion was supported by the literature about social assistance and disability in South Africa. It was inferred that grantees therefore made use of health and social services provided by the public sector.

The fundamental assumption, on which the organisation of the study was based, was the understanding that addresses of any grantee could be accessed through the Department of Social Services after permission had been granted and that the department's data would be accurate. This proved

to be a fallacy, which prompted a departure from the originally planned study population.

CHAPTER 4: RESULTS AND DISCUSSION

The findings of the study are reported in this chapter, followed by a discussion of the results. Findings are related to each other, when appropriate, and reference is made to the literature in order to link the outcome of this study to other disability research.

In order to have an understanding of the demographic characteristics of the study population, these are reported first, followed by the presentation of the main aspect of the study, the disability profile. Employment status, utilization of health services and the use of assistive devices by the grantees is given next and related to the disability profile, where possible. Similarly, grantees' utilization of caregivers is reported in view of other findings. Perceived needs of the respondents with respect to health and social services and the Kleinmond community are discussed last, as interpretation of the perceived needs may be easier, once the demographic details and the disability profile of the study population is known.

4.1 RESPONDENTS

The Department of Social Security supplied the names and addresses of 32 grantees who collected their permanent disability grant at the Kleinmond Post Office in June 1999. A total of 29 of these persons with disabilities were interviewed for this study. This 90% response rate (29/32) can be considered adequate for a study of this nature. The study population was sufficiently represented to ensure that the results are valid for this group of disability grant recipients.

Data from the 1996 National Census indicated that 189 people in Kleinmond were disabled (Statistics South Africa, 1999). This means that 17% (32/189)

of the persons with disabilities received a permanent disability grant at the Kleinmond Post Office in June 1999, which is markedly lower than the percentage for the Western Cape (62%) and lower than, but closer to, the national figure of 24%. [These percentages were calculated by dividing the total number of disability grants paid in November 1999 by the total number of persons with disabilities as reported in the National Census 1996 respectively.]

The reason for this discrepancy could be that this study dealt only with persons receiving permanent disability grants whereas the figures supplied by the Deputy Director: Social Security, on which the national and provincial calculations are based, included both permanent and temporary disability grants paid out in November 1999. Mbeki (1997) stated that in 1993 a total of 30% of persons with disabilities received a disability grant. Presumably this figure also refers to both permanent and temporary disability grants.

Another factor which may have contributed to the finding that such a small percentage of persons with disabilities in Kleinmond appear to be receiving disability grants, may be the many retired people living in Kleinmond and surrounding areas. Although disability prevalence increases with age (Murray and Lopez, 1996), women older than 59 years and men older than 64 years are no longer eligible for disability grants, receiving instead old age pensions. Other contributing factors may include persons having their grant paid directly into their bank accounts and flawed record-keeping at the Department of Social Security. The latter is indicative in the two persons who were still waiting to have their disability grant converted into old age pensions.

4.1.1 Respondents interviewed:

The pie chart in Figure 4.1 displays whether the grantee, a proxy or both were interviewed. Grantees contributed to 72% (21/29) of all interviews.

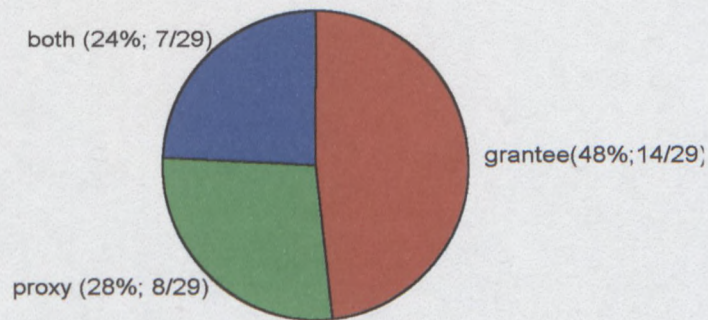


Figure 4.1: Respondents interviewed

In 48% (14/29) of cases the grantees only were interviewed, while both the grantee and a proxy were interviewed in 24% (7/29) instances. This means that for 72% (21/29) of the interviews the grantees had direct input. In only 8 of the 29 cases (28%) was it impossible to interview the grantee, not because they were absent, but as a result of an inability to contribute meaningfully to the interview due to the disability. Although proxy reporting may lead to bias (Sackett, 1979), it can be argued that in these cases the proxies had an intimate knowledge of the person with disabilities and their needs, and could contribute meaningfully to the study. While Schofield *et al* (1997) agree that carer reports are valid, Knapp and Hewison (1999) reported the opposite. Every effort was made in the present study to interview the grantees themselves.

4.1.2 Relationship between proxy and grantee:

Table 4.1 below illustrates that the relationship of the proxy respondents to the grantee was mainly parent to child. (The 14 cases in which the grantees only responded are excluded.)

Table 4.1: Proxy's relationship to the grantee

	Spouse	Child	Parent	Other	Total
Proxy only interviewed	1	0	6	1	8
Both proxy and grantee interviewed	2	1	4	0	7
Total	3	1	10	1	15

In the eight instances where the respondent was the proxy only, the relationship of the proxy to the grantee was predominantly that of parent (75% or 6/8). When both the proxy and the grantee responded, the proxy was still, in most instances, the parent (57% or 4/7). This can be explained by the fact that the majority of caregivers in this study were parents (see section 4.7).

4.2 DEMOGRAPHY

4.2.1 Age

The largest age category was 30 – 40 years (10/29 or 34% of subjects), while only one person was between 10 and 20 years of age. The mean age of the grantees was 42.5 years (SD 13.68). The range and median age can be seen in Figure 4.2.

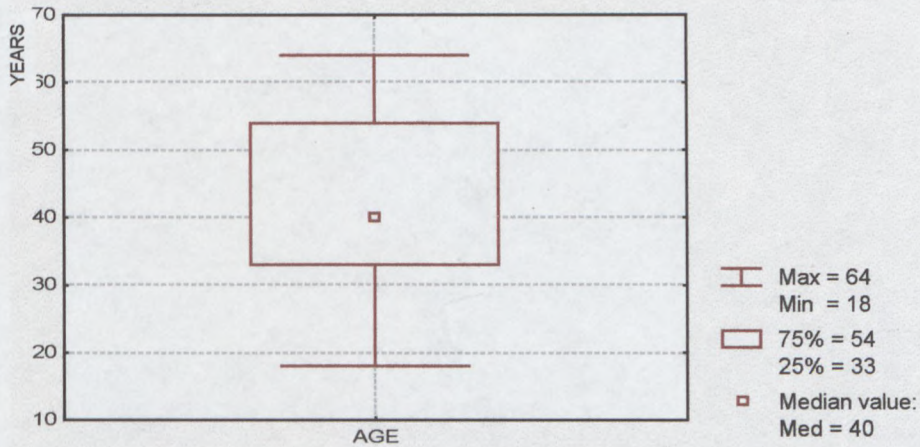


Figure 4.2: Age distribution

The ages of the grantees were nearly equally distributed with a mean of 42 years and a median of 40 years (Rosner, 1986). This indicated that no outliers skewed this result. Most grantees were younger than the average age. The minimum and maximum ages of 18 and 64 years respectively can be explained by legislation with regard to social assistance (Government Gazette No R 417 of 1998). Persons with disabilities are only eligible for a disability grant from the age of 18 years and the grant is converted into an old age pension when they reach the age of 60 or 65 for women and men respectively.

In order to allow for comparisons, the mean age of the entire 18 to 65 year old Kleinmond population was calculated on the basis of the information of the 1996 National Census (Statistics South Africa, 1999). The mean age of this sub-section of the population is 52 years. This figure can only be cautiously compared to the study population, as it includes men and women up to 65 years of age, whereas only men over 60 are eligible for a disability grant. As a result, this calculation may have resulted in a slightly higher mean age. However, it can still be concluded, that the mean age of the study population appeared to be markedly younger than that of the general 18 – 65 year old population of Kleinmond as determined during the census.

4.2.2 Gender

Figure 4.3 shows the gender distribution of the study population, clearly illustrating a higher proportion of men to women.

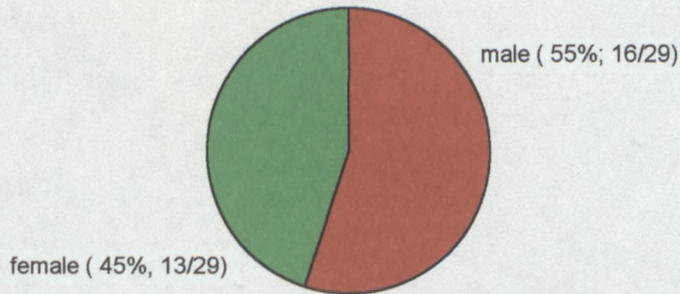


Figure 4.3: Gender distribution

The gender distribution of the total population in Kleinmond was 50% males and 50% females according to the National Census (Statistics South Africa, 1999). Although more women than men were found to be disabled nationwide (www.statssa.gov.za), this was not the case for the disability grant recipients of this study, where 55% were men and 45% were women. This finding, however, closely reflects the National Census figures, where it was reported that in the Kleinmond community 58% (110/189) of persons with disabilities were male and 42% (79/189) were female.

4.2.3 Home language

As can be expected in the geographical area where the study was undertaken, 25 subjects (86%) were Afrikaans speaking, while 3 spoke English. One person's home language was isiSuthu, but as he was fluent in Afrikaans, the interview was conducted in this language.

4.2.4 Marital status and living arrangements

Although most grantees (17/29 or 59%) were single, the majority (93% or 27/29) did not live alone. Table 4.2 shows the marital status of the respondents (including common law marriages), while Table 4.3 summarises whether subjects were staying on their own or not.

Table 4.2: Marital status

Marital status	Count	Percentage
Single	17	59%
Married	9	31%
Divorced	3	10%
Total	29	100%

The questionnaire did not allow for speculations on whether the subjects were single by choice or any other reasons.

Table 4.3: Living arrangements

Living arrangements	Count	Percentage
Not living alone	27	93%
Living alone	2	7%
Total	29	100%

The majority (90% or 26/29) of grantees lived in a house, two persons stayed in a flat and one in a shack. When looking at access to the homes, it was found that most homes (66% or 19/29) had more than one step for access, 28% (8/29) had one step and 6% (2/29) had no steps. In contrast, there were no steps inside 80% (23/29) of the dwellings, while 14% (4/29) had more than one step inside. Only 17% (5/29) of the residents had to use their toilet outside of their home.

Although most subjects were single, the majority (93% or 27/29) of disability grant recipients did not live alone. This may be explained by the fact that the majority of subjects in this study population (66% or 19/29) relied on a caregiver to some extent (see section 4.7). Furthermore, legislation stipulates that a person only qualifies for a permanent disability grant when the examining doctor and officials of the Department of Welfare consider the disability sufficiently severe (Government Gazette No 417 of 1998). The severity of the disability or the fact that a person has multiple disabilities might contribute to the fact that a grantee is unable to live alone or chooses to live with someone else who can assist with some tasks. Although this study did not establish severity or degree of disability, it was found that the majority of the grantees (86% or 25/29) reported multiple disabilities, i.e. problems with activities in more than one disability category (see section 4.3). This in turn may explain why the majority of persons did not stay alone and utilized the assistance of caregivers.

4.3 DISABILITY PROFILE

4.3.1 Number of years subjects received a disability grant:

Many grantees had been disabled since birth (31% or 9/29). Table 4.4 displays the number of years for which subjects had received a disability grant.

Table 4.4: Number of years for which subjects had received a disability grant

Years subjects received a disability grant	Number of cases	Percentage of cases
0 - 5 years	14	48%
6 – 10 years	6	21%
11 – 15 years	2	7%
16 – 20 years	5	17%
21 – 25 years	0	0%
> 25 years	2	7%
Total	29	100%

Nearly half of the subjects had only received a disability grant for the last 0-5 years. This may substantiate the comment in the White Paper on Social Welfare about a substantial increase of the welfare budget for social security since 1994 (Government Gazette No 1108 of 1997). On the other hand, 24% of the grantees (7/29) had received a disability grant for more than 15 years. Although the present study only investigated a small population, the magnitude of the state's financial responsibility to persons with disabilities over an extended period of time seems to be enormous. Seeking alternative solutions to social assistance may therefore be strongly warranted.

4.3.2 Disability categories reported by grantees:

As discussed in chapters 2.1.1 and 3.6.2, the categories used in the questionnaire were based on an international WHO classification, the International Classification of Impairments, Disabilities and Handicaps (WHO, 1980).

The first question in section E was open ended. It allowed for the grantees to describe in their own words why they received a disability grant. Multiple reasons could be given. The reason given most frequently (76% or 22/29) was "inability to work". Grantees often added that the disability grant was their only source of income (10% or 3/29) and/or that they were unable to take care of themselves (17% or 5/29). Some subjects (28% or 8/29) explained the kind of impairment they had, e.g. schizophrenia, weakness of a limb or back pain.

For the remainder of the questions assessing the disability profile of the respondents, multiple responses were possible. When respondents answered "yes" to one or more of the questions in each disability category, they were counted as having a disability in that category. Only three persons had just one type of disability (all of them a situational disability). One person did not fit into any category, as he or she answered "no" to all questions in section E, and the remaining 25 respondents (86% or 25/29) reported multiple disabilities, i.e. they reported problems with activities in more than one category. A summary of the disability profile of this study population is displayed in Table 4.5.

It was found that most persons had situational disabilities (82% or 24/29), while only 34% (10/29) reported personal care disabilities. In spite of 55% (16/29) of the grantees having a locomotor disability, only a few had problems with personal care or dexterity (10/29 or 34%).

Table 4.5: Number of cases in specific disability categories

Disability category	Number of cases	Percentage of cases (n=29)
Situational	24	82%
Communication	20	69%
Body disposition	18	62%
Behavioural	17	59%
Locomotor	16	55%
Dexterity	11	38%
Personal care	10	34%

Table 4.5 above displays an overall summary of the disability categories. However, these percentages indicate only how many of the grantees reported one or more problems in each category. Each category however, was comprised of a different number of questions. The disability profile for the sample was further summarised by calculating a standardised score for each category that reflected the average number of positive responses per item in each disability category. These average scores are illustrated in Figure 4.4. This histogram clearly illustrates that, on average, most subjects reported problems with activities in the situational disability category, while activities posing the least problems for the grantees were in the dexterity and personal care categories.

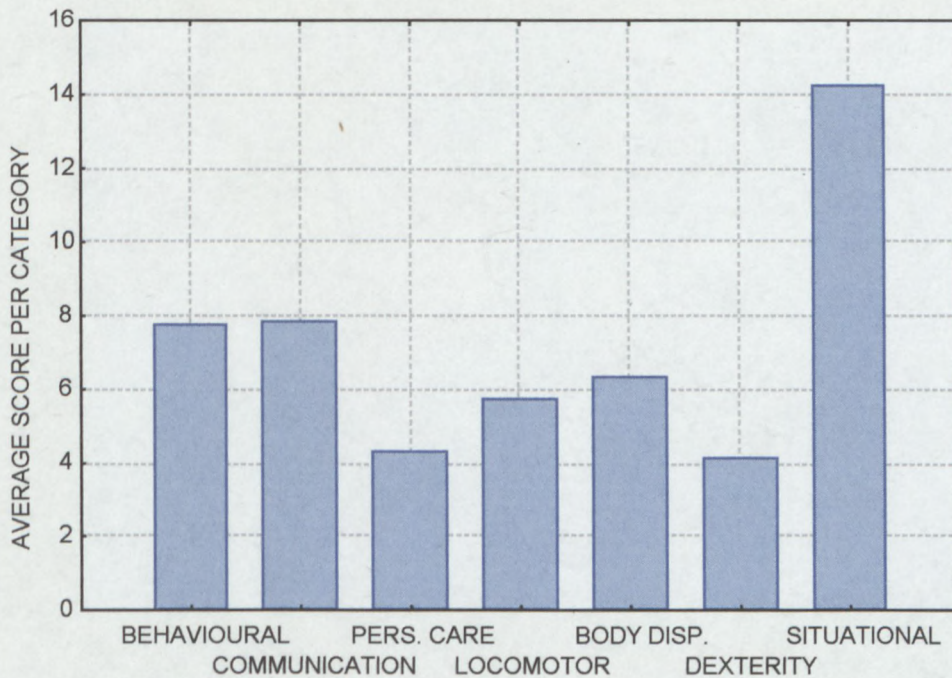


Figure 4.4: Average score per disability category

The most important result of this section is that 25 of the 29 grantees interviewed (86%), reported multiple disabilities, indicating that they had problems in more than one of the disability categories suggested by the ICDH (WHO, 1980). This is in marked contrast to the figures on disability established in the 1996 National Census, where only 4% (6499/145 538) reported more than one disability (www.statssa.gov.za). Although the disability categories utilized for the census were not based on the ICDH, it could cautiously be hypothesised that a person only qualifies for a disability grant in South Africa when the disabilities are extensive.

An unexpected finding was that one person did not fit into any disability category, i.e. that person did not have any of the problems listed on the questionnaire. This person also did not report anything under "other" at the

end of the disability catalogue, but indicated in the open ended question 44 that he or she received a disability grant for a “nervous condition” (“*senutoestand*”). There may be three explanations for this finding. It is possible that either this person’s condition was medically well under control or that he or she did not have a disability and should not have received a disability grant. It can also be suggested that the questionnaire did not succeed in identifying all possible disabilities.

4.3.3 Disabilities reported in each category:

The composition of each disability category was analysed by looking at the percentage of positive responses for the category that were associated with each item, i.e. activity, in that category. The various elements are illustrated in Tables 4.6 to 4.12. The five activities most often reported to be problematic are given in order of priority for each category. The number of positive responses, and the percentages (rounded off) for both the category score and the respondents are given. The remaining disabilities for each category are summarised under “other”, at the same time indicating the number of other items.

4.3.3.1 Situational disabilities:

The disability most commonly reported was situational disability (24/29 or 82%). Three persons had problems in this category only (see section 4.3 above). Situational disabilities refer to activities that are only considered challenging in particular circumstances, such as stressful situations, weather sensitivity or difficulty tolerating light or noise (WHO, 1980). Difficulties in

these activities may well influence a person's employability, ability to hold down a job or learn a new skill, which in turn may explain the high unemployment rate of this study population (see section 4.4 below).

Table 4.6: Reported difficulties in the situational disability category

Disability	Positive responses	Percentage of category score (n=70)	Percentage of respondents (n=29)
Tolerating stress	20	28%	69%
Tolerating noise	15	21%	52%
Feeling under the weather	15	21%	52%
Getting out of breath easily	13	19%	45%
Tolerating light	8	11%	28%

Most grantees reported one or more situational disabilities. Of the "yes" answers in that category 28% (20/70) referred to an inability to tolerate stress, which was found to be problematic for 69% (20/29) of all grantees.

4.3.3.2 Communication disabilities:

Table 4.7: Reported difficulties in the communication disability category

Disability	Positive responses	Percentage of category score (n=47)	Percentage of respondents (n=29)
Reading	12	26%	41%
Writing	11	23%	38%
Seeing	9	19%	31%
Talking	8	17%	28%
Understanding	5	11%	17%
Other (1 item)	2	4%	7%

Many grantees reported having problems with reading and writing. It was not established whether or not the respondents were illiterate. The "other" item refers to the activity of talking, which was difficult for only two persons (7% or 2/29).

The questionnaire did not determine whether a person who was unable to read had ever learned to read or write, i.e. was illiterate. As more subjects reported inabilities to read (41% or 12/29) and write (38% or 11/29) than an inability to see (31% or 9/29), this could be possible, indicating that a variable option "not applicable" would have been useful for both these activities.

4.3.3.3 Behavioural disabilities:

Table 4.8: Reported difficulties in the behavioural disability category

Disability	Positive responses	Percentage of category score (n=70)	Percentage of respondents (n=29)
Learning a new skill	14	20%	48%
Knowing what day it is	12	17%	41%
Making decisions about self	11	16%	38%
Keeping self safe	10	14%	34%
Neglecting own appearance	9	13%	31%
Other (4 items)	14	20%	48%

Many grantees had problems learning new skills (48% or 14/29) and knowing what day it is (41% or 12/29). The “other” items included appropriate behaviour and interacting with other people (17% or 5/29 respectively) and the abilities to keep one’s self safe and to recognise the people around one, which 2 subjects respectively found difficult (7% or 2/29).

Most of the behavioural disabilities reported may explain why the majority of the respondents were also unemployed and reliant on a caregiver, as command of these activities is pivotal for independent living. The positive association between behavioural disability score and ability to look after self was highly significant ($p=.0004$), confirming this deduction (see Table 4.16).

4.3.3.4 Body disposition disabilities:

Table 4.9: Reported difficulties in the body disposition disability category

Disability	Positive responses	Percentage of category score (n=57)	Percentage of respondents (n=29)
Preparing own meal	12	21%	41%
Cleaning own home	11	19%	38%
Washing own laundry	11	19%	38%
Shopping	10	18%	34%
Pick objects from floor	6	11%	21%
Other (4 items)	7	12%	24%

A number of grantees had difficulties in maintenance abilities such as preparing meals and keeping their home and clothes clean. Difficulties in these activities may necessitate caregiver assistance on a regular basis. The "other" items refer to reaching for objects above one's head (14% or 4/29), maintaining a standing (7% or 2/29) or sitting position (3% or 1/29) and the ability to care for own children (0% or 0/29). The majority of the grantees (86% or 25/29) however found the latter question inapplicable, indicating that they either had no children, or that their children did not need caring for.

Many subjects reported difficulties preparing meals (21% or 12/57 "yes" responses), doing the laundry (19% or 11/57 "yes" responses) and cleaning their homes (19% or 11/57 "yes" responses). This could be related to the fact that the majority of the respondents in this study were men, who traditionally are not very involved in household chores, or that the problems they

experienced in this category could be related to difficulties in activities in the dexterity, behavioural or situational categories. These relationships were not further analysed, as it was beyond the scope of this report. However, persons who are not independent in these activities can be considered likely to rely on a caregiver as demonstrated by the highly significant relationship between these two variables in this study population ($p=.0009$) (see table 4.16).

4.3.3.5 Locomotor disabilities:

Table 4.10: Reported difficulties in the locomotor disability category

Disability	Positive responses	Percentage of category score (n=63)	Percentage of respondents (n=29)
Running	16	26%	55%
Descending >5 steps	9	14%	31%
Ascending >5 steps	9	14%	31%
Descending 2-5 steps	5	8%	17%
Ascending 2-5 steps	5	8%	17%
Other (6 items)	19	30%	66%

The majority of the grantees (55% or 16/29) were unable to run. All abilities in this and the other categories are reflected irrespective of whether assistive devices are utilized for the activities or not. "Other" activities in the locomotor category included ascending or descending one step (14% or 4/29 respectively) and getting around outside the house (17% or 5/29). Only 7% of the respondents (2/29) reported difficulties getting around inside the house, getting out of bed or into their mode of transport.

In this category the percentage of grantees reporting difficulties with activities increased as the activities became increasingly complex. Only a few persons

reported finding it difficult moving inside the house (3% or 2/63 “yes” responses) and getting out of bed (3% or 2/63 “yes” responses). In contrast, more persons had difficulty with intricate activities such as walking up or down more than 5 stairs (14% or 9/63 “yes responses) and running (25% or 16/63 “yes” responses).

4.3.3.6 Personal care and dexterity disabilities:

Table 4.11: Reported difficulties in the personal care disability category

Disability	Positive responses	Percentage of category score (n=26)	Percentage of respondents (n=29)
Washing self	9	35%	31%
Dressing self	6	23%	21%
Shaving self	4	15%	14%
Controlling stools	3	11%	10%
Controlling urine	2	8%	7%
Other (1 item)	2	8%	7%

Very few persons with disabilities had activity limitations in the personal care category. Only 7% (2/29) were incontinent of urine or faeces (10% or 3/29), while 31% (9/29) were unable to wash themselves.

Table 4.12: Reported difficulties in the dexterity disability category

Disability	Positive responses	Percentage of category score (n=25)	Percentage of respondents (n=29)
Using a telephone	8	32%	28%
Manipulating small objects	5	20%	17%
Opening taps	4	16%	14%
Using taps	4	16%	14%
Gripping with hands	3	12%	10%
Other (1 item)	1	4%	3%

Although few grantees reported having problems with dexterity activities, 28% of all respondents (8/29) could not use a telephone. This might not necessarily have been related to real issues of dexterity, but could also be explained by respondents either finding this activity stressful or as a result of many grantees reporting behavioural disabilities. However, these associations were not statistically analysed. No subject found the activity of using a telephone to be inapplicable.

Problems related to personal care and dexterity disabilities as denoted by the grantees may all have contributed to their utilization of caregivers. This was indeed true as ability to look after self and disability scores in these categories were associated ($p < .1$) (see Table 4.16).

Although 55% (16/29) of the subjects reported having locomotor disabilities, only a few had problems with activities in the personal care (34% or 10/29) and dexterity categories (38% or 11/29). The ICDH catalogue attributes locomotor disabilities mainly to lower limb impairments, whereas upper limb function is included for the latter two categories. Many of the highly prevalent neuro-musculoskeletal impairments, such as stroke, limit activities of both

upper and lower limbs, and therefore this discrepancy of the findings was not anticipated.

4.3.4 Conclusion regarding the disability profile

It is extremely difficult to relate the results regarding the disability profile to findings from other South African studies, as the latter are not based entirely on the ICDH disability catalogue, but rather on the different concepts of impairment, disability and handicap (www.statssa.gov.za; Schneider *et al*, 1999; Coetzee, 1997; Concha and Lorenzo, 1993; Cornieljie *et al*, 1993; McLaren *et al*, 1987; Disler *et al*, 1986).

Results from the National Census show that 2,7% of the South African population had a sight disability in 1996, whereas 0,4% had multiple disabilities (www.statssa.gov.za). In Kleinmond the 189 persons with disabilities reported the following disability categories during the Census: sight: 23 (12%); hearing: 32 (17%); physical: 70 (37%); mental: 22 (12%); multiple: 4 (2%); not specified: 38 (20%) (Statistics South Africa, 1999). It must be considered that the census figures refer to all age groups and not only the 18 – 64 year olds, as in this study. As can be seen, very different disability categories were used in the census and all other disability prevalence studies known to the researcher and discussed in chapter 2.2. As these were not based on the ICDH catalogue, comparisons are impossible and meaningless. This can be highlighted by the fact, that in this study 86% of the subjects reported multiple disabilities, in contrast to National Census findings of 2% for Kleinmond and 4% for the entire Western Cape. Neither the census nor this study measured severity of disability whereas the C.A.S.E. study (Schneider *et al*, 1999) was confined to assessing the prevalence of “moderate to severe disability” only.

4.4 EMPLOYMENT

At the time of the interview the majority of the grantees (93% or 27/29) were unemployed, while 69% (20/29) of all subjects felt that they were unable to work. This indicated that only 7% (2/29) were actually employed although 31% (9/29) believed they were able to work. This finding must be seen in relation to the disability profile found in this study (see section 4.3 above). Many grantees reported situational (82% or 24/29) and communication (69% or 20/29) disabilities and this may explain the high unemployment rate, as did the finding that most grantees reported multiple disabilities (86% or 25/29).

No statistically significant relationship between previous and present employment was detected. Most grantees (55% or 16/29) were unemployed prior to having received their disability grant.

When analysing the relationship between the subjects' perceptions of their ability to work and present employment, the following was found: a higher percentage of respondents who believed they were able to work were employed at the time of the interview compared to those who believed they were not able to work (20/29 or 69%), of whom none were employed at the time of the interviews. Table 4.13 displays that relationship (Fisher exact two-tailed test: $p = .0887$). However, the numbers of subjects are too small to make valid deductions.

Table 4.13: Employment status versus grantees' perception of ability to work

Perception	Unemployed	Employed	Total
Unable to work	20	0	20
Able to work	7	2	9
Total	27	2	29

The very high unemployment rate in this study (93% or 27/29) correlates with other findings in this regard. Mbeki (1997) stated that only 0.26% of disabled people were employed in South Africa in 1993. The White Paper for Social Welfare (1997) reports that unemployment amongst persons with disabilities who are able to work is high (Government Gazette, notice 1108 of 1997). This is thought to be the result of "low levels of skill and training among the majority of people with disabilities" (p 76). The present study did not, either objectively or subjectively, establish whether grantees were unemployed as a result of their disability, prejudice of possible employers or other societal barriers, the economic situation in Kleinmond, the grantees' level of skill or education or other possible contributing factors. It was however subsequently determined whether the grantees felt they were able to work. Although statistically only marginally significant ($p=0.0887$), it was interesting to find that a higher percentage of respondents who believed they were able to work were actually employed in June 1999 (2/9 or 22%) compared to none of those who believed they were not able to work. Nevertheless, as only 7% (2/29) of grantees were employed, inferences, such as whether or not perceptions affect aspects such as employability, cannot be made from the data. However, many grantees reported situational disabilities such as difficulty tolerating stress and noise, and behavioural disabilities such as learning new skills, all of which may negatively influence employability and training.

Referring to employment, it must be taken into consideration that disability grants are paid on the basis of a sliding scale depending on the monthly income of the grantee (compare section 2.3.1). This means, for example, that a person receiving the maximum grant of R 520,- may only earn a further R 320,- (personal communication Department of Social Services, January 2000). If he or she earns more than this amount, the disability grant is forfeited. This is likely to influence the motivation of grant recipients in seeking employment. Furthermore, the unemployment rates are 34% and 18% for South Africa and the Western Cape respectively (www.statssa.gov.za). It is difficult to find employment in this country and the fact that one is disabled may make this an even bigger challenge.

Present legislation only entitles persons who are declared permanently or temporarily disabled by a medical practitioner, and who are incapable of entering the labour market, to receive a disability grant (Government Gazette No R 417 of 1998). Hence, by definition, a person receiving a disability grant should be unemployable. The high unemployment rate in this study population could therefore have been predicted. However, appropriate skill training, education and the removal of attitudinal and environmental barriers are necessary to improve the present situation for grantees in order to enable them to find employment and become self-sufficient. The White Paper on an Integrated National Disability Strategy (Mbeki, 1997) outlines three policy objectives in order to achieve this: a) the discrepancy in terms of employment between persons with and without disabilities must be reduced; b) employment options for persons with disabilities must be broadened or created; c) integration of persons with disabilities in the labour market must be improved. An inter-sectoral approach to reach these objectives is strongly recommended in this document and also in the Integrated Provincial Disability Strategy of the Western Cape (1999) and in the National Rehabilitation Policy (1998). Furthermore, the new labour law, specifically the Employment Equity Act, addresses this disadvantage for persons with disabilities (Government Gazette No 55 of 1998).

In hindsight, question 12 of the questionnaire, which determined whether subjects were employed before receiving a grant, should have been phrased differently. Informal discussions with the Kleinmond and other grantees indicated that many waited a considerable time for the application of their grants to be processed. Therefore the question "Were you employed prior to having become disabled?" might have produced more valid and meaningful data.

4.5 UTILIZATION OF HEALTH SERVICES

Grantees were requested to indicate their present utilisation of health services. Figure 4.5 shows that most subjects accessed the public health service and regularly received medication (90% or 26/29), while nobody consulted a traditional healer. The service used by the majority (86% or 25/29) was the local clinic, staffed by district nursing sisters. A considerable number of grantees (41% or 12/29) also reported that they consulted private doctors. Only two (7% or 2/29) persons were visited at home by the district sisters (one of those on a regular basis), while 76% of the grantees (22/29) paid regular visits to health services. Services infrequently used were the tertiary hospitals in Cape Town and the community-based orthopaedic sister. The latter is to be expected as most recipients had situational and not primarily locomotor disabilities (see section 4.3 above).

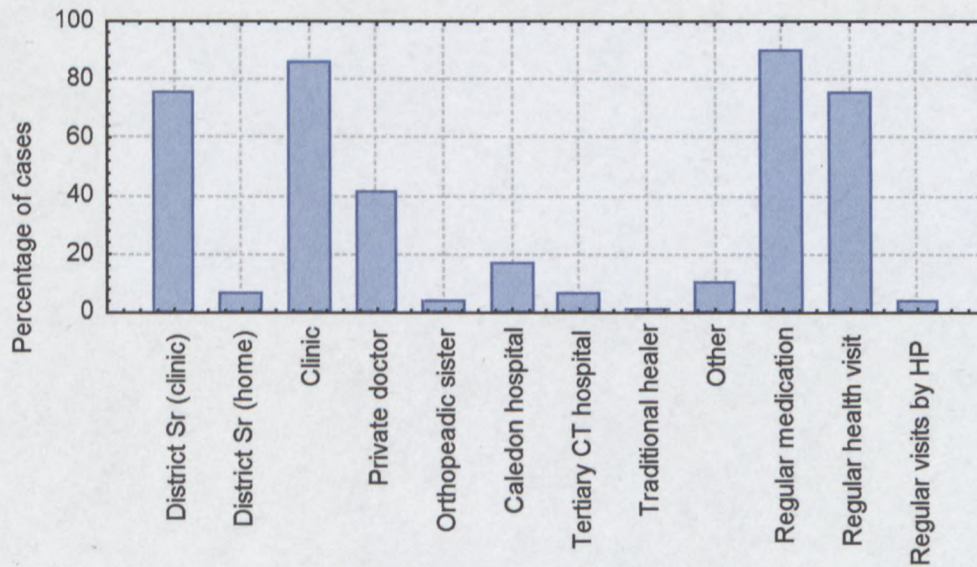


Figure 4.5: Utilization of health services: percentage of respondents using each service (multiple responses possible)

Only three grantees (10% or 3/29) indicated that they made use of health services not listed in the questionnaire, these being a pharmacy, Valkenberg Hospital in Cape Town and a dentist.

The majority of the grantees (86% or 25/29) accessed the health services at the local clinic, where 76% (22/29) were attended to by the nursing sister. This finding was in agreement with the assumption that grantees would primarily make use of health services provided by the public sector due to their limited financial resources.

The most important finding of this section is that 90% of the grantees (26/29) received regular medication. This could possibly be related to the fact that many grantees had behavioural and situational disabilities. The majority of these disabilities are likely to be associated with a psychological impairment, which, in turn, may be well controlled by taking regular medication (Paykel and Jenkins, 1994). Informal discussions with the grantees and the sisters at the clinic confirmed this supposition, but the questionnaire did not allow for such inferences.

The researcher did not expect to find that twelve (12/29 or 41%) grantees reported occasionally consulting a private doctor. The income of disability grant recipients is limited, as it is based on the means test, which stipulates that grantees may only acquire the maximum income of R 840,- (R 520,- being the maximum amount of disability grant plus R 320,- , being the maximum amount extra earnings permitted) (personal communication Department of Social Security, 2000). On this basis, it had been assumed that grantees were neither likely to have medical aid benefits nor that they were in a financial position to afford the more expensive private consultations. The questionnaire did not make provision for establishing reasons the grantees may have had for choosing to consult private practitioners.

During data collection it was predicted that few or none of the subjects consulted traditional healers, as most persons who were interviewed were observed to belong to the coloured and white population groups, whereas

traditionally the black population in South Africa consult sangomas. When developing the questionnaire it was not known how many persons from which population groups would receive a disability grant and hence this question was added.

4.6 PERMANENT USE OF ASSISTIVE DEVICES

As discussed in section 3.8 of this report, the researcher had made the assumption that many disability grant recipients would have locomotor impairments and would therefore utilise assistive devices related to movement dysfunction. The results indicated that only a few grantees used these aids. This must be seen in relation to the disability profile established in this study as problems with locomotion, dexterity and personal care were reported least frequently (refer to section 4.3). Whereas persons reporting disabilities in these, and the communication categories, are most likely to utilize the assistive devices listed in the questionnaire, seven of the twelve assistive devices listed were inapplicable to the grantees in this study.

Four people wore glasses, two made use of wheelchairs and one person walked with crutches. However, seven people indicated that they needed glasses, but had none. This can be related to the fact that 31% (9/29) of the grantees reported difficulties with the activity of seeing and 41% (12/29) with the activity of reading. Literacy was not established, and therefore it is unclear whether individuals in the latter group were unable to read due to the fact that they had never learnt to read, or whether they had a visual impairment.

Other assistive devices reported to be necessary, but not available to the grantees included: one stick for the blind and two prostheses.

The section on assistive devices thus did not reveal any meaningful information other than the fact that seven persons (24% or 7/29) indicated a need for glasses and that four persons (14% or 4/29) wore glasses. To the researcher's knowledge there are no public ophthalmology services in Kleinmond. Cornielje *et al* (1993) report that the development of affordable optometric services should be a priority in Alexandra, South Africa, as they found a high rate of visual disabilities in that area. The unavailability of such services in Kleinmond disadvantaged those grantees who indicated a need for glasses and the two persons who indicated the need for an eye specialist in section G of the questionnaire. Similarly, two grantees (7% or 2/29) reported that they needed a prosthesis. Prosthetic services are also not available in Kleinmond and persons with amputations who rely on public health services depend on referrals to the appropriate services in Cape Town.

When drawing up the questionnaire, a higher percentage of locomotor disability was anticipated. This assumption was based on the researcher's experience as a physiotherapist and the figures on disability prevalence established during the 1996 National Census. Statistics South Africa reported 24% (35 051/145 538) of the disabled population in the Western Cape having had physical disabilities at the time of the census (www.statssa.gov.za). Due to the fact that the majority of the grantees in this study reported situational disabilities (82% or 24/29), assistive devices were inconsequential, as can be inferred from the finding that seven of the twelve listed assistive devices were considered to be "not applicable" by all grantees. To the researcher's knowledge there are no meaningful assistive devices in order to improve the quality of life of persons with situational disabilities.

4.7 CAREGIVER UTILIZATION

Only ten respondents (34% or 10/29) were always able to look after themselves, while 66% (19/29) were of the opinion that they needed assistance. This may explain why 93% (27/29) of the subjects did not live on their own (see Table 4.3).

Of the subjects needing help, 63% (12/19) could on occasion take care of themselves while 37% (7/19) could never look after themselves. The majority of grantees who utilized a caregiver (68% or 13/19) reported caregiver assistance for the same number of years as they reported to have been disabled.

In 47% (9/19) of this adult study population in need of assistance, the parents of the persons with disabilities provided that assistance, which disputed the findings of Schofield *et al* (1997), who found that most carers were adult children caring for their parents. However, the care recipients in their study included all age groups, which in turn may account for this variation, as disability prevalence increases with age.

It was established earlier in this report that the proxies answering the questionnaire in this study were mainly parents of the grantees (Table 4.1). This may now be explained as parents were also the main caregivers in this study (other caregivers or assistants included spouses (26% or 5/19) and children of grantees (16% or 3/19)). The fact that parents were the main caregivers in the present study may pose problems for the future of the grantees in the event of the parents becoming ill or dying.

The majority of caregivers (90% or 17/19) stayed in the same household as the grantee. Schofield *et al* (1997) also report that persons with disabilities who relied on a parent carer stayed with their parents. The present study did not establish whether the carer lived in the household of the grantee or vice versa, but only whether or not they stayed in the same dwelling.

Most caregivers were not employed elsewhere (68% or 13/19). It was not determined whether the caregivers were unemployed as a result of their role as caregivers or for other reasons. Only 11% (2/19) of the caregivers received a "grant-in-aid" from the state.

4.7.1 Relationship between caregiver utilization and respondent interviewed:

The relationship between the respondent interviewed and the degree of caregiver utilization, which is presented in Table 4.14, was statistically highly significant (Pearson Chi-square: $p = .00003$). This may be a result of the majority of this study population (86% or 25/29) having reported multiple disabilities.

Table 4.14: Relationship between respondent and the three degrees of self-care ability

Respondent	Always able to look after self	Sometimes able to look after self	Never able to look after self	Total
Self	8	6	0	14
Proxy	0	1	7	8
Both	2	5	0	7
Total	10	12	7	29

It could be concluded that the degree of caregiver utilization was much higher in those grantees for whom a proxy answered the questions during the interview, compared to those where both the grantee and the proxy responded, and even more so compared to those when the grantee only was

the respondent ($p=00003$). Unacceptable disease bias, underlying cause bias and obsequiousness bias could have contributed to such a significant finding, but, as stated before, the proxies were likely to have an intimate knowledge of the dependant grantees and their needs. This was also ascertained by Schofield *et al* (1997), who deduced from their data that there was a high correlation between carer opinion of disability and dependency, and blind ratings from health professionals, hence validating the carer ratings.

4.7.2 Activities for which a caregiver was utilized:

A summary of the particular tasks for which the persons with disabilities required assistance, is presented in the histogram in Figure 4.6. Multiple responses were permitted.

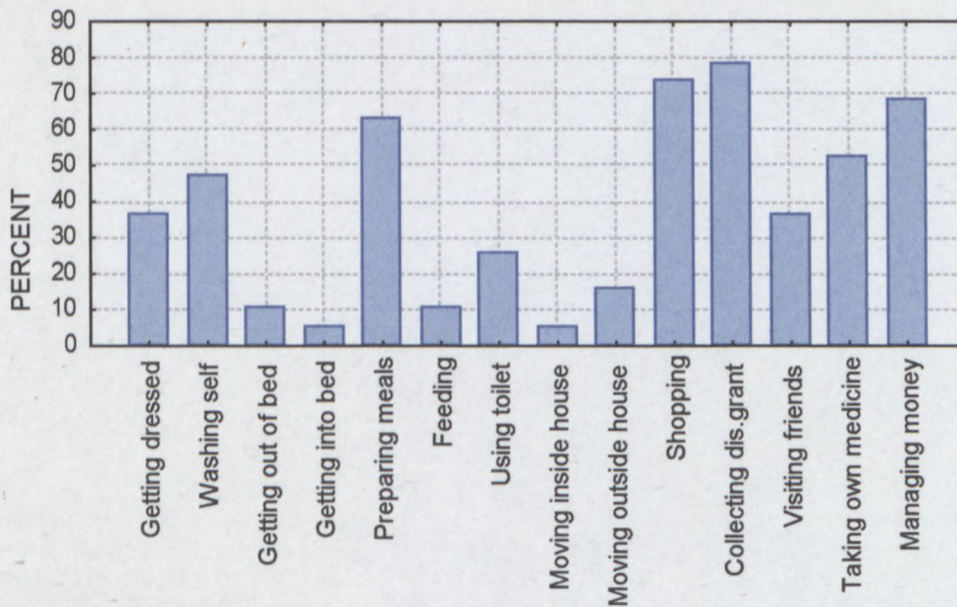


Figure 4.6: Percentage of participants requiring assistance with specific tasks (n=19)

The majority reported utilization of a caregiver for the following tasks: collecting their disability grant (79% or 15/19), shopping (73% or 14/19), managing own money (68% or 13/19) and preparation of meals (63% or 12/19). Only one person (5 % or 1/19) needed assistance getting into bed, while two persons (11% or 2/19) needed assistance getting out of bed. This parallels the findings in section 4.3 (Disability profile), in which only 7% or 2/29 of the entire sample report having a limitation of the activity "getting out of bed", while 34% or 10/29 reported having difficulty shopping and 41% (12/29) difficulty preparing their own meals. Furthermore, managing money, collecting the grant and shopping are likely to require similar competencies and hence these findings complement each other. When asked about use of health services, 90% (26/29) of the grantees stated that they received regular medication, while 52% (10/19) indicated in the present section that they needed assistance in taking their medication.

4.7.3 Relationship between disability score and caregiver utilization:

When looking at possible relationships between disability and caregiver utilization, the total disability score, i.e. all "yes" answers in the disability categories, for each grantee was added and a summary was made of the self-care ability scores. As the data was non-parametric, the Kruskal-Wallis test was used to assess whether or not there was a relationship between these two variables. Medians and interquartile ranges, i.e. the middle 50% of values, are also reported. This summary for the entire section E, i.e. the medians of the total disability score compared with the summaries of the three categories of question 98, ability to look after self is displayed in table 4.15.

Table 4.15: Relationship between total disability score and grantees' ability to look after self (Kruskal-Wallis: $p = .0001$)

Ability to look after self	Median disability score	Interquartile range
Always	6.5	5.0 – 10.0
Sometimes	12.5	10.0 – 15.0
Never	25.0	20.0 – 29.0
All groups	12.0	8.0 – 16.0

There was a strong relationship ($p = .0001$) between the total disability score and the ability to look after self, indicating that a person who reported more disabilities was less likely to be in the position to look after him- or herself. This could be anticipated, as persons who reported more disabilities might have also been more likely to need assistance in the performance of activities as listed in section F of the questionnaire. This significant finding therefore reflects a high degree of reliability of the questionnaire.

Each disability category was then analysed in order to establish whether or not there were differences in the above relationship in the various disability categories. The summary is presented in table 4.16. Medians and interquartile ranges are again reported, as are the p -values for the Kruskal – Wallis tests. The results are highly significant ($p < .05$) for the behavioural, body disposition and communication categories and marginally significant ($p < .1$) for the dexterity and personal care categories. There was no relationship in the two remaining categories (locomotor and situational disabilities).

Table 4.16: The relationship between type of disability and ability to look after self

Category		Ability to look after self			P value
		always	sometimes	never	
Behavioural	Median	0.0	2.5	5.0	.0004
	IQ - range	0.0 – 0.0	0.0 – 5.0	5.0 – 5.0	
Body disposition	Median	2.0	4.0	6.0	.0009
	IQ - range	2.0 – 2.0	3.0 – 4.5	6.0 – 6.0	
Communication	Median	0.0	1.0	3.0	.0039
	IQ - range	0.0 – 2.0	.0 – 1.5	3.0 – 3.0	
Dexterity	Median	0.0	0.0	3.0	.0059
	IQ - range	0.0 – 0.0	0.0 – 1.0	1.0 – 3.0	
Personal care	Median	0.0	3.0	3.0	.0070
	IQ - range	0.0 – 3.0	.5 – 3.0	3.0 – 6.0	
Locomotor	Median	1.0	0.0	0.0	.1485
	IQ - range	0.0 – 1.0	0.0 – 1.0	0.0 – 1.0	
Situational	Median	2.0	3.0	3.0	.5203
	IQ - range	1.0 – 3.0	1.0 – 4.0	1.0 – 4.0	

The relationship between the median disability score and grantees' ability to look after one's self were highly significant in the behavioural and body disposition categories. This was not surprising, as most grantees reported needing assistance with activities such as collecting the grant, shopping, managing money and preparing meals. These activities were also reported to

be problematic in the behavioural and body disposition disability categories (Tables 4.8 and 4.9 respectively).

Activities such as collecting a grant at the Post Office, shopping, taking medication or managing finances necessitate the command of activities in the communication category. As 59% (17/29) reported having communication disabilities (Table 4.7), the high significance of the above relationship was also not unexpected.

At the same time, it could be explained that the relationship was not significant in persons who reported situational disabilities, as these disabilities are often reasonably well managed with medication, which in turn enables the person to lead a more independent life (Paykel and Jenkins, 1994).

There was clearly no significant association between locomotor disability and ability to look after one's self. Grantees with locomotor disabilities in this study were more independent, in contrast to Coetzee's finding (1997) that locomotor disability led to a decrease in independence. Jacka *et al* (1984) also do not support the finding of the present study, as they reported that most subjects with locomotor disabilities relied on assistance for activities of daily living. However, the fact that the term "locomotor disability" was defined differently in each study may well have contributed to these different findings. This in turn reinforces the need for consistent use of definitions in disability research.

4.8 REPORTED NEEDS OF RESPONDENTS WITH REGARD TO SOCIAL AND HEALTH SERVICES AND THE KLEINMOND COMMUNITY

The literature indicates that the overriding demand of persons with disabilities is their right to self-representation in matters concerning them (Oliver, 1996; Disability Unit of Lawyers for Human Rights, 1993; Helander, 1993). It was therefore considered important to include all the results related to section G, H and I of the questionnaire in this report, as these sections reflect the opinions of persons with disabilities regarding their needs. Establishing the latter is thought to be the cornerstone of community-based rehabilitation (CBR) and disability research and should therefore be reported in detail.

Tables 4.17 to 4.19 are ranked in order of perceived importance of the questionnaire items to the grantees. Percentages (rounded off) are given in brackets. The results are related to other findings, where possible, and discussed.

4.8.1 Social services:

Table 4.17: Needs with regards to social services

	Very important	Important	Uncertain	Not important	Not at all important
Increase in amount of disability grant	22 (76%)	4 (14%)	3 (10%)	0 (0%)	0 (0%)
Groups that provide support for your family	13 (45%)	6 (21%)	1 (3%)	0 (0%)	9 (31%)
Groups that provide interaction with other disabled people	10 (35%)	7 (24%)	1 (3%)	2 (7%)	9 (31%)
Training to learn an occupation	10 (34%)	0 (0%)	2 (7%)	1 (3%)	16 (55%)
Visit of a social worker	8 (28%)	4 (14%)	2 (7%)	2 (7%)	13 (45%)
Help with setting up your own business	7 (24%)	1 (3%)	3 (10%)	3 (10%)	15 (52%)
Transport to collect your disability grant	6 (21%)	2 (7%)	1 (3%)	3 (10%)	17 (59%)
Groups that provide interaction with non disabled people	6 (21%)	5 (17%)	4 (14%)	1 (3%)	13 (45%)
Transport to reach recreational facilities	4 (14%)	2 (7%)	3 (10%)	1 (3%)	19 (66%)
Transport to do your shopping	3 (10%)	3 (10%)	1 (3%)	2 (7%)	20 (69%)
Home help	1 (3%)	0 (0%)	1 (3%)	2 (7%)	25 (86%)
The provision of a more accessible house	1 (3%)	0 (0%)	3 (10%)	5 (17%)	20 (69%)

For this section five subjects (17% or 5/29) responded that they also had needs that were not listed. These aspects included more continuity of social

services (1 person), free telephone services for people with visual disabilities (1 person), an increase in the amount of the "grant-in-aid" (1 person), availability of residential facilities (1 person) and help with the setting up of self help groups for relatives (1 person).

With regard to identifying grantees' needs in respect of social services (Table 4.17), the questionnaire appears to have been more meaningful than the section on perceived health needs (Table 4.18). Of the 29 subjects, 22 (76%) considered an increase in the amount of the disability grant to be very important while no subject responded that this was "not important at all". This clearly highlights that the recipients of a disability grant in this study found the disability grant to be insufficient. While persons with disabilities, notably Oliver (1996), argue that welfare provision increases dependency and excludes persons with disabilities from society, it is acknowledged that in South Africa many of their families rely on this financial support (Mbeki, 1997). This is even more important in view of the finding of the C.A.S.E. study, in which 88% of persons with disabilities were economically inactive (Schneider *et al*, 1999). Mbeki (1997) reports that, even when the maximum amount is paid, a disability grant is still below the household subsistence level and that often entire families depend on the grant as their only income. In the present study it was found that 93% (27/29) of the grantees were unemployed, many of them relying entirely on the grant for survival, and thus justifying the strongly expressed need for an increase in the disability grant. A number of respondents indicated that they would appreciate a visit by a social worker, possibly compounding the notion of addressing economic hardship.

Opinions were divided on the issue of whether groups that provide interaction with other persons with disabilities, were needed. Ten persons (34% or 10/29) found this to be a very important need, whereas nine (31% or 9/29) felt it was not important at all. However, 66% (19/29) expressed a need for support groups for family members. This was another clear indication of a possible shortcoming of the service that could be addressed when implementing the proposed community centre. This would facilitate self-

representation of persons with disabilities and their families, which is also demanded in the Disability Rights Charter for South Africa (Disability Unit of Lawyers for Human Rights, 1993). Needs driven services in turn are supported by the National Rehabilitation Policy document (1998).

Another aspect about which grantees had similar opinions, concerned home help. Twenty five (25/29 or 86%) of the respondents felt that it was not necessary at all for social services to provide home help. This does not imply that grantees did not need help, but only that social services were not considered to be the providers of such help. It may indicate that the grantees were content with the assistance they received from their caregivers or, in the case of proxy reporting, that the proxies, who were also assumed to be the caregivers, felt that they coped adequately on their own.

All other aspects that were listed on the questionnaire were not considered to be important in meeting the needs of the grantees. This may indicate a limitation of the measuring instrument due to unsuitable wording of the various questions, making it difficult for the respondents to provide further insights. However, in view of 93% (27/29) of the grantees having been unemployed and 31% (9/29) having indicated that they were able to work, it was surprising to find that the majority felt it was not important to receive training to learn an occupation or to be helped to set up a business. This could possibly be explained by the fact that 48% (14/29) of the grantees reported finding it difficult to learn a new skill when reporting behavioural disabilities. It was however not tested whether there was a relationship between these two variables. It could also be possible that some respondents were concerned about jeopardising their disability grants should they earn money. In contrast, some grantees (34% or 10/29, and 24% or 7/29 respectively) found these two aspects to be very important and their opinions should be considered when planning employment generating initiatives.

4.8.2 Health services:

Table 4.18: Needs with regard to health services

	Very important	Important	Uncertain	Not important	Not at all important
Clinic closer to your home	15 (52%)	3 (10%)	0 (0%)	3 (10%)	8 (28%)
Transport to the clinic	11 (38%)	5 (17%)	0 (0%)	5 (17%)	8 (28%)
The provision of assistive devices	7 (24%)	1 (3%)	0 (0%)	0 (0%)	21 (72%)
Visit of the district sister	5 (17%)	6 (21%)	2 (7%)	5 (17%)	11 (38%)
Somebody to help you improve your physical skills	4 (14%)	1 (3%)	2 (7%)	1 (3%)	21 (72%)
Visit of the orthopaedic aftercare sister	2 (7%)	0 (0%)	0 (0%)	1 (3%)	26 (90%)
Somebody to help you with some tasks on a daily basis	1 (3%)	2 (7%)	2 (7%)	3 (10%)	21 (72%)
Somebody to care for you permanently	0 (0%)	1 (3%)	1 (3%)	3 (10%)	24 (83%)
The provision of a wheelchair	0 (0%)	0 (0%)	0 (0%)	0 (0%)	29 (100%)

Ten respondents (34% or 10/20) stated that they had needs that were not listed in the questionnaire. These were the need for more accessible services of psychiatrists and psychologists (3 persons), eye specialists (2 persons) and dentists (1 person), more readily available services of a medical practitioner employed by the state (2 persons), transport to tertiary hospitals in Cape Town (1 person) and rehabilitation for clients with schizophrenia (1 person).

In preparing section G of the questionnaire a higher prevalence of locomotor disability was anticipated, as the 1996 National Census data had indicated a considerable number (21% nationally and 24% in the Western Cape) of persons with physical disabilities (www.statssa.gov.za). The development of the questionnaire was based on these figures and the researcher's experience as a physiotherapist. Consequently, this may have resulted in the researcher having consulted with both persons with disabilities and professionals who were more familiar with physical rather than mental impairments and this clearly led to a bias in that direction. It is therefore not surprising that in this study, where the majority of respondents had situational and communication disabilities, most items were considered by them to be "not important at all" in order to meet their health needs.

The fact that very few people expressed a need for permanent care or help with some tasks on a daily basis again did not reflect that they did not require help, but rather, in their view, that no help from health services was necessary in this regard. Although 66% (19/29) of the grantees relied on caregivers to some extent, 83% (24/29) and 72% (21/29) of the study population did not expect health personnel to assist them on a permanent or daily basis respectively. This may support the notion of the Joint Position Paper on CBR that the families and immediate communities of persons with disabilities are the greatest asset in supporting persons with disabilities (ILO, UNESCO, WHO, 1994).

Fifteen (15/29) respondents or 52% of the study population wished the clinic was closer to their home and 38% (11/29) felt that they needed transport to the clinic. At present, the clinic is in the centre of Kleinmond and many grantees lived quite a distance away. Public transport is very scarce and residents often had to either walk these distances or hire cars from other community members. The Kleinmond authorities are planning a new community centre, including a clinic, near the predominantly coloured residential area, which would meet this particular need as the majority of the grantees, who do not have their own transport, live in that area. This move, which is in line with the government's primary health care (PHC) initiative,

would make the primary level clinic much more accessible for the grantees and other residents (National Rehabilitation Policy, 1998).

Considering that many grantees were found to have a situational and behavioural disability, it was understandable that three persons expressed a need for more readily available psychiatric and psychology services when they were asked about needs that were not listed in the questionnaire. Informal discussions with the nursing sisters at the clinic revealed that they also felt that this was an area of concern in service delivery. They estimated that a large proportion of the clients who consulted them suffered from mental illness. As previously mentioned, these are likely impairments in persons having behavioural and situational disabilities (Paykel and Jenkins, 1994).

4.8.3 Kleinmond community:

The findings from section I of the questionnaire highlighted the expressed needs of the grantees with regard to the Kleinmond community.

Table 4.19: Needs with regard to the Kleinmond community

	Very important	Important	Uncertain	Not important	Not at all important
Raising awareness of disability in your community	20 (69%)	3 (10%)	2 (7%)	3 (10%)	1 (3%)
Recreational facilities for disabled people	14 (49%)	4 (14%)	2 (7%)	3 (10%)	6 (21%)
Self help groups for disabled people	13 (45%)	4 (14%)	2 (7%)	3 (10%)	7 (24%)
Accessible public transport	6 (21%)	2 (7%)	1 (3%)	2 (7%)	18 (62%)
Home help volunteers	5 (17%)	3 (10%)	2 (7%)	3 (10%)	16 (55%)
Accessible pavements	4 (14%)	4 (14%)	1 (3%)	3 (10%)	17 (59%)
Accessible buildings	3 (10%)	2 (7%)	2 (7%)	2 (7%)	20 (69%)

Only 4 respondents (14% or 4/29) indicated that they had needs that were not listed. They indicated that they had a need for high schools closer to home in order to relieve the financial burden on parents (1 person), better amenities for young people (1 person), skills training for disabled people (1 person) and self-help groups for relatives (1 person).

Most participants (20/29 or 69%) regarded raising awareness of disability in the community as very important with only one person (3% or 1/29) regarding awareness raising as not important at all. Helander (1993) proposes strengthening of "all efforts aimed at sensitising the public and making it more aware of the abilities of disabled people" as one of six priorities for programmes concerning persons with disabilities in the developing countries (p 216). This is supported by the White Paper for Social Security (Government Gazette, notice 1108 of 1997) as one of the strategy guidelines to raise public awareness. Mbeki (1997) also suggests embarking on public education programmes with the aim of increasing public awareness regarding needs and rights of people with disabilities in order to change societal attitudes. The persons with disabilities in this study also clearly considered this a very important aspect.

Opinions of the subjects diverged on the issues of recreational facilities and self help groups for persons with disabilities. Although the majority found these to be either very important or important and one person also reported that there was a need for recreational facilities for the youth of the town, a considerable number of grantees did not attach any importance to these aspects.

The fact that the questionnaire was biased towards locomotor disability is highlighted again by the fact that very few persons with disabilities found the issue of accessibility a problem and did not express needs in that regard. However, observations while conducting the study revealed that buildings, pavements and transport were inaccessible to persons with locomotor disability, but this was clearly not a major need of the grantees in the present study, in which only 55% (16/29) reported locomotor disabilities.

When concluding the discussion on the findings from the sections of the questionnaire dealing with perceived needs of persons with disabilities and the use of the Lickert scales it must be noted that the category "uncertain"

was seldom utilised. Literature suggests that people tend to use this option when they do not want to commit themselves or do not understand the question (Polit and Hungler, 1983). This was not the case for this questionnaire and this study population. The response "uncertain" was never utilised by more than 10% (3/29) of the participants for each of the 28 questions. This indicated that all the grantees and their proxies had understood the questions sufficiently to be able to air their positive or negative opinions on 90% of the needs sections G,H and I of the questionnaire.

4.9 LIMITATIONS OF THE STUDY

The main limitation of this study was its small population. Preparations for the study were based on the information supplied by officials at the Department of Social Security, and a larger study population was anticipated. The fact that only those persons with disabilities who collected their grant at the Kleinmond Post Office could be interviewed, limited the external validity of this study. Although it is likely that most persons received their grant in this manner, there is a possibility that others may have had the grant paid into a bank account.

In addition the data base of the Department of Social Security appears to have a systems error. Two persons who should have had their disability grants converted to an old age pension, were in June 1999 still receiving a disability grant at the Post Office, although they were not recorded on the system as disability grant recipients. It can be argued that there were other persons with disabilities who were also not accurately recorded, which limits the internal validity of this study. Furthermore, information regarding addresses proved to be out-dated as two persons on the list no longer lived in the area.

Findings of this study cannot necessarily be considered valid for disability grant recipients who reside in other geographical areas. They can also not be extrapolated to persons with disabilities in Kleinmond who do not receive a disability grant. Both these group may have presented markedly different profiles.

The study is further limited by the researcher's insufficient insight into perceived needs of persons with disabilities, in spite of a broad literature review prior to embarking on this study. A better understanding of needs, particularly those of persons who have an impairment other than locomotor and neuro-muscular, would have been desirable prior to the development of the questionnaire. Many aspects listed in sections G,H and I of the questionnaire were indeed considered less important by the grantees. On the other hand, the researcher's desire to meet and learn from persons with disabilities she did not encounter under routine circumstances was an expressed motivation for conducting this study. In that respect the study has been successful and most enjoyable.

4.10 CONCLUSION

The main finding of this study was that most of the recipients of a permanent disability grant in Kleinmond reported disabilities in more than one of the WHO disability categories. A large percentage of the respondents had situational disabilities and most accessed the public health services on a regular basis. Demographic data indicated that most grantees were unemployed, single men who did not live alone. A considerable number of proxies were interviewed, but the majority of grantees participated. At the same time, most grantees relied on a caregiver for some activities, while utilization of such a caregiver and disability scores were associated in most disability categories. The perceived needs of the persons with disabilities in this study were varied, but some common trends could be identified.

CHAPTER 5: CONCLUSIONS AND RECOMMENDATIONS

5.1 CONCLUSIONS

The present study succeeded in establishing both demographic and disability profiles of the study population, providing an understanding and description of a defined group of recipients of permanent disability grants in a semi-rural area. The researcher found the disability catalogue of the ICIDH to be a relatively easily understandable tool on which to base the questionnaire, although some descriptions were found to be cumbersome and categories overlapped somewhat. It remains to be seen whether the newer version (the ICIDH-2) will be adopted by the WHO and lead to more consistency in disability research and more importantly, whether persons with disabilities will embrace this instrument.

In spite of the World Health Organisation's (WHO) intention to provide a framework for classification of disablement via the ICIDH, there is very little published research utilising the original disability categories of this instrument. The reason for this may be that the catalogue reinforces the medical model of disability and is, as such, rejected by disability activists and researchers. Many other definitions of disability are also based on the medical model and are extensively used for reporting purposes. In South Africa this is also true, as reflected in data collected during the National Census and previous Household Surveys. Nevertheless, the questionnaire developed for the present study was found to have high utility and feasibility at relatively low cost, in pursuing the aims of the study (Martin and Kettner, 1996).

The majority of grantees in this study reported situational, communication, body disposition and behavioural disabilities, reflecting multiple disablement. While the latter was expected, the researcher did not anticipate that the majority of grantees would have situational disabilities. Clarity on the possible underlying impairments of these disabilities would assist in future service planning and provision and warrants further investigation.

In the present study self- and proxy reported disability was established, reinforcing viewpoints in the literature of the validity of this methodological approach. The severity of disability was however, not assessed (objectively nor subjectively). This is an area for future study as well as an in-depth exploration of the subjective experience of disability.

It was a matter of concern that the present study, although conducted on a relatively small population, found nearly one third of the grantees had been disabled since birth. These disabilities may well be attributable to preventable conditions such as Cerebral Palsy or Foetal Alcohol Syndrome. This requires further investigation.

Most subjects in the present study were found to be unemployed, despite all of them belonging to a potentially economically productive age group. According to legislation, disability grant recipients are, by crude definition, not employable. However, skills training may open employment opportunities and alleviate economic hardship, especially in view of government's admission that the amount of the maximum disability grant is below subsistence level. A number of respondents in this study indicated that they needed training to learn an occupation or assistance in setting up a business.

South Africa's public health system should be based on accessible primary health care services. It was therefore not surprising that the majority of the subjects accessed health services at the primary level clinic, most of them on a regular basis. Whether they sought assistance due to their reported disabilities or unrelated impairments remains unclear. Some grantees indicated a need for psychiatric services, indicating a shortcoming in service provision in the geographical area in which the study was conducted.

Many persons with disabilities utilised caregiver assistance either on a permanent basis or for selective tasks only, and the present study found disability score and caregiver utilisation to be strongly associated. In most instances the parents of the grantees were the caregivers and also the proxies during the interviews for this study.

Persons with disabilities should at all times represent themselves in matters concerning them. Although the researcher rather than the grantees initiated the present study, it still afforded the latter the opportunity to express their needs and describe aspects about themselves. It may, however, be argued that a qualitative rather than a quantitative research methodology would have been more meaningful in capturing these aspects.

The study population confirmed reports in the literature that the amount of the disability grant in South Africa is regarded as insufficient, as over three quarters of the grantees indicated a need for the amount of the grant to be increased. Unfortunately, it is unlikely that this strongly expressed need will be met in the short term due to limited resources (Government Gazettes 1108 of 1997 and Notice 403 of 1999).

Multiple sources used as reference points prior to undertaking the study, indicated large discrepancies between figures regarding various aspects of disability at national, provincial and semi-rural (Kleinmond community) levels. This was particularly evident in respect of disability prevalence figures and percentages of persons with disabilities receiving disability grants, and carers qualifying for "grants-in-aid". These discrepancies may be one reflection of an inequitable social security system, which may also have errors in the data.

Most study subjects indicated that it was important to raise awareness of disability in their community, supporting views expressed in the literature and policy documents. This finding also reinforces government's recommendation to engage in community-based rehabilitation (CBR) strategies within a primary health care approach. Similarly, the grantees expressed a need to have access to a clinic closer to their homes and to participate in supportive group activities for themselves and/or their families.

5.2 RECOMMENDATIONS

5.2.1 Recommendations for service planning and delivery

As a direct result of the present study the researcher would like to make the following recommendations for service planning and delivery:

National and provincial government:

The current amount paid for a disability grant is insufficient to support persons with disabilities and their families (Mbeki, 1997). Government needs to address this problem nation-wide through multi-sectoral measures. In view of limited resources, alternative solutions to disability grants for poverty alleviation have to be sought.

The Department of Social Security should update the social grants data base as a matter of priority. This is likely to reduce fraud and promote equality for persons with disabilities. The Department is also advised to consult with persons with disabilities when revising eligibility criteria for disability grants. In the light of the present study, the researcher strongly supports a move towards the utilisation of criteria that are not based on impairments, but rather on disabilities and/or handicaps.

Local authorities and non-governmental organisations:

Authorities in Kleinmond may welcome the grantees' opinions regarding the proposed new community centre, which includes the clinic, since most grantees requested improved accessibility of the clinic. It is also strongly suggested that the clinic should provide psychiatric and ophthalmological services or appropriate referrals for these services.

It is recommended that the authorities and non-governmental organisations in the Kleinmond community embark on strategies to raise awareness about disability (specifically situational, behavioural and communication disabilities), initiate support groups for persons with disabilities and/ or their families, and create employment opportunities to address the high percentage of unemployment.

As the caregivers of those grantees requiring assistance were mainly the parents of the grantees, the grantees' well-being in the long term will have to be addressed, because it is likely that the children will survive their parents. Alternative caregivers may have to be identified and trained and possibly, eventually reimbursed for their services. In the short term, community based respite care may well be effective in decreasing possible caregiver burden.

As many of the grantees had been disabled since birth, it is suggested that primary and secondary prevention strategies are employed in the Kleinmond and other communities to decrease the incidence of preventable disabilities.

5.2.2 Recommendations for further studies

Recommendations for future studies, resulting from this study, include:

- Clarity and uniform use nation-wide of definitions regarding disability, in order to be able to compare findings and enable uniform planning,
- An assessment of caregiver burden (both quantitative and qualitative aspects) and identification of the needs of the identified caregivers, (action

research may be the most appropriate strategy in view of CBR implementation),

- Qualitative research on the experience of disability and a more detailed exploration of the needs of the grantees,
- The use of a measuring instrument based on the ICIDH-2 in the same study population in order to contribute to the international debate on the utility and practicality of the latter from a South African perspective,
- Use of the present questionnaire as a measuring instrument to be used in different study populations in order to increase the pool of data for extrapolations to larger populations in order to improve external validity. The present questionnaire was, in spite of the identified shortcoming, considered to be appropriate in achieving the aims of this descriptive study,
- Establishing the causes, including underlying impairments, of the reported disabilities to establish whether some of these could be prevented by appropriate service delivery, thereby reducing the financial burden on social welfare services in future,
- Quantifying the severity of the reported disabilities, possibly by utilizing the ICIDH severity catalogue, in order to allow for service planning and prevention of complications,

- Comparing of the reported disabilities with an objective assessment in order to assist with the formulation of guidelines regarding disability grant assessment.

Finally, the researcher would like to add a general recommendation for part-time students:

When resources are limited in respect of finances and time, it seems advisable to study aspects of interest in a geographically well defined and manageable population. The disadvantage of this approach is that results may stand in isolation. Part-time postgraduate students may therefore well be advised to conduct research within a larger project, of which they then may choose to investigate one or two aspects. This would have the potential of producing more meaningful and valid results.

REFERENCES

Ahmad E, Drèze J, Hills J, Sen A, (ed). 1991 Social security in developing countries, Oxford University Press, New York

Allen S, Mor V. 1997 The prevalence and consequences of unmet need. *Medical Care* 35: 1132-1148

Badley EM. 1987 The ICDH: format, application in different settings, and distinctions between disability and handicap. *International Disability Studies* 9: 122-125

Badley EM. 1993 An introduction to the concepts and classifications of the international classification of impairments, disabilities and handicaps. *Disability and Rehabilitation* 15: 161-178

Bhagwanjee AM, Stewart R. 1999 Disability research in South Africa: vision and imperatives for a national co-ordinated approach. *South African Journal of Occupational Therapy* 29: 15-17

Cape Times. 4.12.1998 Grants for disabled under review.

Clayer J, Bookless C, Air T, McFarlane A. 1998 Psychiatric disorder and disability in a rural community. *Social Psychiatry and Psychiatric Epidemiology Year* 33: 269-273

Coetzee LT. 1997 The prevalence and rehabilitation needs of individuals with locomotor disability in Mitchells Plain. Unpublished thesis M Phil in Biomedical Engineering, University of Cape Town

Coleridge P. 1993 Disability, liberation and development, OXFAM, United Kingdom and Ireland

Concha ME, Lorenzo T. 1993 The prevalence of disability in a rural area of South Africa. *South African journal of Occupational Therapy* 23: 6-15

Concha ME. 1993 Prevalence of disability – a protocol for a study in Soweto *South African Journal of Epidemiology and Infection* 8: 98-101

Cornielje H, Ferrinho P, Coetzee D, Reinach SG. 1993 Development of a community based rehabilitation programme for a poor urban area in South Africa; Part I A disability prevalence study. *CHASA Journal* 4: 26-32

Crishna B. 1999 What is community-based rehabilitation? A view from experience. *Child: Care, Health and Development* 25: 27-35

Disability Unit of Lawyers for Human Rights. 1993 Disability Rights Charter of South Africa

Disler PB, Jacka E, Sayed R, Rip MR, Hurford S, Collis P. 1986 The prevalence of locomotor disability and handicap in the Cape Peninsula: parts I-3. *South African Medical Journal* 69:349-357

Elmstahl S, Malmberg B, Annerstedt L. 1996 Caregiver's burden of patients 3 years after stroke assessed by a novel caregiver burden scale. *Archives of Physical Medicine and Rehabilitation* 77: 177-183

Government Gazette, Republic of South Africa, No. 59 of 1992, Social Assistance Act

Government Gazette, Republic of South Africa, No. 108 of 1996, Constitution of the Republic of South Africa

Government Gazette, Republic of South Africa, No. 106 of 1997, Welfare Amendments Act

Government Gazette, Republic of South Africa, Notice 1108 of 1997, White Paper for Social Welfare

Government Gazette, Republic of South Africa, No. 55 of 1998, Employment Equity Act

Government Gazette, Republic of South Africa, No. R 417 of 1998, Regulations regarding the phasing out of maintenance grants in terms of the Social Assistance Act, 1992

Government Gazette, Republic of South Africa, Notice 463 of 1999, Financing Policy: Developmental Social Welfare Services

Hangklip-Kleinmond bulletin, August 1998

Hangklip-Kleinmond bulletin, March 1999

Helander E. 1993 Prejudice and Dignity: An introduction to community-based rehabilitation, Unihel Natures Development Programme, Geneva

Hennekens CH, Buring JE. 1987 Epidemiology in medicine, Little, Brown and Company, Boston/Toronto

Howe AL, Schofield H, Herrman H. 1997 Caregiving: A common or uncommon experience? *Social Sciences and Medicine* 45: 1017-1029

ICIDH-2 workshop, 2000 Durban, unpublished proceedings

Integrated Provincial Disability Strategy, Province of the Western Cape: 1999 Draft document, condensed version

International Labour Organisation, United Nations Educational, Scientific and Cultural Organisation, World Health Organisation. 1994 Joint position paper: Community-based rehabilitation

- Jacka E, Disler PB, Sayed AR, Hoffman MN, Watermeyer GS. 1984 Coping with chronic illness Part 1: Locomotor disability. *South African Medical Journal* 65:850-853
- Jette AM. 1994 (a) Introduction: physical disability. *Physical Therapy* 74: 379
- Jette AM. 1994 (b) Physical disablement concepts for physical therapy research and practise. *Physical Therapy* 74: 380-386
- Katzenellenbogen J, Joubert G, Rendall K, Coetzee T. 1995 Methodological issues in a disablement prevalence study: Mitchells Plain, South Africa. *Disability and Rehabilitation* 17: 350-357
- Katzenellenbogen JM, Joubert G, Abdool Karim SS. 1997 Epidemiology: A manual for South Africa, Oxford University Press, Southern Africa
- Kay E, Dunleavy K. 1996 Community-based rehabilitation: an international model. *Pediatric Physical Therapy* 8: 117-121
- Knapp P, Hewison J. 1999 Disagreement in patient and carer assessment of functional disability after stroke. *Stroke* 30: 934-938
- Leavitt R. 1995 The development of rehabilitation services and suggestions for public policy in developing nations. *Pediatric Physical Therapy* 7: 112-117
- Lindquist B. 1995 Standard rules in the disability field. A new United Nations' instrument. *Scandinavian Journal of Rehabilitation Medicine* supplement 33: 7-12
- Luiz JM. 1994 Welfare state principles for the reconstruction of South Africa's welfare policy. *Social Work/Maatskaplike Werk* 30:327-334
- Marks D. 1997 Models of disability. *Disability and Rehabilitation* 19: 85-91

Martin LL, Kettner PM. 1996 Measuring the performance of human service programs, SAGE Publications, London

Mbeki T. 1997 White Paper on an Integrated National Disability Strategy. Office of the Deputy President

McLaren PA, Gear JSS, Irwig LM, Smit AE. 1987 Prevalence of motor impairment and disability in a rural community in Kwazulu. *International Rehabilitation Medicine* 8: 98-104

Murray JL, Lopez AD. 1996 The global burden of disease. Harvard School of Public Health, Harvard University Press

National Human Rights Research and Advocacy Project. 1998 Rights up your street: A guide to human rights in South Africa, Cape Town

National Rehabilitation Policy, 1998, final draft

Nordenfelt L. 1995 On the general concepts of action and ability. *International Journal of Technology Assessment in Health Care* 11: 144-152

Nordenfelt L. 1997 The importance of a disability/handicap distinction. *The Journal of Medicine and Philosophy* 22: 607-622

Oliver M. 1996 Understanding disability, MacMillan Press Ltd, London

Oliver M. 1998 Theories of disability in health practice and research. *British Medical Journal* 317: 1446 - 1449

O'Toole B, McConkey M. 1995 Innovations in developing countries for people with disabilities, Lisieux Hall Publications, Lancashire

Patel L. 1992 Restructuring social welfare, Raven Press, Johannesburg

Patel V, Todd C, Winston M, Gwanzura F, Simunyu E, Acuda W, Mann A. 1998 Outcome of common mental disorders in Harare, Zimbabwe. *British Journal of Psychiatry* 171: 60-64

Paykel ES, Jenkins R. 1994 *Prevention in Psychiatry* Gaskell, London

Polit D, Hungler B. 1983 *Nursing research: Principles and methods*, 2nd edition, J.B.Lippincott Company, Philadelphia

Pretorius L. 1995 *Victory for the people with disabilities in South Africa. Rehabilitation in South Africa*

Putterhill JS, Disler PB, Jacka E, Hoffman MN, Watermeyer GS. 1984 Coping with chronic illness; Part III: The carer. *South African Medical Journal* 65: 893-895

Reid S, Giddy J. 1998 Rural health and human rights – summary of a submission to the Truth and Reconciliation Commission health sector hearings, 17 June 1997. *South African Medical Journal* 88: 980 - 982

Robinson BC. 1983 Validation of a Caregiver Strain Index. *Journal of Gerontology* 38: 344-348

Rolland JS. 1997 The meaning of disability and suffering: sociopolitical and ethical concerns. *Family Process* 36: 437-440

Rosner B. 1986 *Fundamentals of biostatistics*, second edition, Duxbury Press, Boston, Massachusetts

Sackett DL. 1979 Bias in analytical research. *Journal of Chronic Diseases* 32:51-63

Saetersdal B. 1997 Forbidden suffering: The Polyanna Syndrome of the disabled and their families. *Family Process* 36: 431-435

Schneider M, Claasens M, Kimmie Z, Morgan R, Naicker S, Roberts A, McLaren P. 1999 Community Agency for Social Enquiry. Summary report

Schofield H, Bloch S. 1998 Disability and chronic illness: the role of the family carer. *Medical Journal of Australia* 169: 405-406

Schofield HL, Murphy B, Nankervis J, Singh B, Herrman HE, Bloch S. 1997 Family carers : Women and men, adult offspring, partners, and parents. *Journal of Family Studies* 3: 149-169

Shakespeare T, Watson N. 1997 Defending the social model. *Disability and Society* 12:293-300

Smart JF, Smart DW. 1997 The racial/ethnic demography of disability. *Journal of Rehabilitation* 63: 9-15

Statistics South Africa. 1999 The people of South Africa, Population Census 1996, Pretoria

Stuelz A. 1999 CBR in Lao – comparison of needs and services. *Disability and Rehabilitation* 21: 508-514

Swain J, Finkelstein V, French S, Oliver M. 1993 Disabling barriers – enabling environments, SAGE Publications, London

Taylor R, Ford G, Dunbar M. 1995 The effects of caring on health: a community based longitudinal study. *Social Science and Medicine* 40: 1407-1415

Tennant A. 1997 Models of disability: a critical perspective. *Disability and Rehabilitation* 19: 478-479

The Concise Oxford Dictionary 1992, 8th edition, Oxford University Press, Oxford

Verbrugge LM, Jette AM. 1994 The disablement process. *Social Sciences and Medicine* 38: 1-14

Welfare Update. 2000 Newsletter of the Department of Welfare, Population and Development. 5:1-7

Wijlhuizen GJ, Ooijendijk, W. 1999 Measuring disability, the agreement between self evaluation and observation of performance. *Disability and Rehabilitation* 21:61-67

World Health Organisation 1980 International Classification of Impairments, Disabilities and Handicaps, Geneva

World Health Organisation 1998 The World Health Report. Office of World Health Reporting, Geneva

World Health Organisation 1999 International Classification of Functioning and Disability: Beta-2 draft, Full version, Geneva

Personal communication:

Krige F., Town clerk Hangklip-Kleinmond Municipality, August 1998

Lohrentz E., Deputy Director Social Security, August 1998 and October 1999

Office of A. Brink, Department of Social Services, Cape Town, 4.1.2000

Internet:

www.statssa.gov.za

ADDENDUM 1

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

Date:

PENSION MEDICAL OFFICER

ADDENDUM 2

Questionnaire

SECTION A

1) Identification number:

2) Home Language:

1. English
2. Afrikaans
3. Xhosa
4. Other:.....

3) Respondent:

1. Self
2. Proxy
3. Both

4) Relationship of proxy to grantee:

1. Spouse
2. Child
3. Parent
4. Friend
5. Employee
6. other: specify:
7. N/A

SECTION B:

Demographic data:

Family name:

First name:

Address:

Telephone:

5) Gender: 1. male 2. female

6) Age (at time of interview):

7) Disabled since what year:

8) Disability grant since what year:

9) Family status:

1. Single 2. Married (include common law)
2. Widowed 4. Divorced

10) Number of dependents forming part of the household:

11) Number of people permanently living in household:

Employment (past and present):

12) Were you employed before receiving a disability grant?

1. Yes
0. No

13) Are you presently employed?

1. Yes
0. No

14) In your opinion, would you be able to work?

1. Yes
0. No

SECTION C

Living arrangements:

15) Are you living alone?

1. Yes
0. No

16) Type of dwelling:

1. House
2. Flat
3. Shack

17) Steps: access to dwelling

1. None
2. One
3. > one

18) Steps: inside dwelling:

1. None
2. One
3. > one

19) Toilet:

1. Inside
2. Outside

SECTION D:

Present utilization of health services:

Which health services do you use?

- | | | | |
|------------------------------------|--------|-------|--------------------------|
| 20) District sister in clinic | 1. Yes | 0. No | <input type="checkbox"/> |
| 21) District sister (home visits) | 1. Yes | 0. No | <input type="checkbox"/> |
| 22) Clinic | 1. Yes | 0. No | <input type="checkbox"/> |
| 23) Private doctor | 1. Yes | 0. No | <input type="checkbox"/> |
| 24) Orthopedic aftercare sister | 1. Yes | 0. No | <input type="checkbox"/> |
| 25) Caledon Hospital | 1. Yes | 0. No | <input type="checkbox"/> |
| 26) Tertiary hospital in Cape Town | 1. Yes | 0. No | <input type="checkbox"/> |
| 27) Traditional healer | 1. Yes | 0. No | <input type="checkbox"/> |
| 28) Other: | 1. Yes | 0. No | <input type="checkbox"/> |

Do you:

- | | | | |
|-------------------------------------------------|--------|-------|--------------------------|
| 29) Receive regular medication? | 1. Yes | 0. No | <input type="checkbox"/> |
| 30) Pay regular visits to health services? | 1. Yes | 0. No | <input type="checkbox"/> |
| 31) Receive regular visits by health personnel? | 1. Yes | 0. No | <input type="checkbox"/> |

Assistive devices:

Do you permanently use any of the following?

- | | | | | |
|-----------------|--------|-------|--------|--------------------------|
| 32) Glasses | 1. Yes | 0. No | 3. N/A | <input type="checkbox"/> |
| 33) Hearing aid | 1. Yes | 0. No | 3. N/A | <input type="checkbox"/> |
| 34) Wheelchair | 1. Yes | 0. No | 3. N/A | <input type="checkbox"/> |
| 35) Crutches | 1. Yes | 0. No | 3. N/A | <input type="checkbox"/> |

- | | | | | |
|-------------------------------|--------|-------|--------|--------------------------|
| 36) Walking stick | 1. Yes | 0. No | 3. N/A | <input type="checkbox"/> |
| 37) Walking frame | 1. Yes | 0. No | 3. N/A | <input type="checkbox"/> |
| 38) Prosthesis | 1. Yes | 0. No | 3. N/A | <input type="checkbox"/> |
| 39) Orthosis? | 1. Yes | 0. No | 3. N/A | <input type="checkbox"/> |
| 40) Bath board | 1. Yes | 0. No | 3. N/A | <input type="checkbox"/> |
| 41) Dressing devices | 1. Yes | 0. No | 3. N/A | <input type="checkbox"/> |
| 42) Stick for the blind | 1. Yes | 0. No | 3. N/A | <input type="checkbox"/> |
| 43) Life sustaining equipment | 1. Yes | 0. No | 3. N/A | <input type="checkbox"/> |

SECTION E:

Disability:

44) In your own words, why do you receive a disability grant?

.....

Do you have any of the following problems?

Behavioural:

- | | | | |
|---------------------------------------|--------|-------|--------------------------|
| 45) Neglecting your appearance | 1. Yes | 0. No | <input type="checkbox"/> |
| 46) Knowing what day it is | 1. Yes | 0. No | <input type="checkbox"/> |
| 47) Knowing where you are | 1. Yes | 0. No | <input type="checkbox"/> |
| 48) Recognising the people around you | 1. Yes | 0. No | <input type="checkbox"/> |
| 49) Keeping yourself safe | 1. Yes | 0. No | <input type="checkbox"/> |
| 50) Learning a new skill | 1. Yes | 0. No | <input type="checkbox"/> |
| 51) Interacting with other people | 1. Yes | 0. No | <input type="checkbox"/> |
| 52) Making decisions about yourself | 1. Yes | 0. No | <input type="checkbox"/> |
| 53) Behaving appropriately | 1. Yes | 0. No | <input type="checkbox"/> |

Communication (including assistive devices if used):

- | | | | |
|--------------------------------|--------|-------|--------------------------|
| 54) Understanding what is said | 1. Yes | 0. No | <input type="checkbox"/> |
| 55) Talking | 1. Yes | 0. No | <input type="checkbox"/> |
| 56) Hearing what is said | 1. Yes | 0. No | <input type="checkbox"/> |
| 57) Seeing | 1. Yes | 0. No | <input type="checkbox"/> |

- | | | | |
|-------------|--------|-------|--------------------------|
| 58) Reading | 1. Yes | 0. No | <input type="checkbox"/> |
| 59) Writing | 1. Yes | 0. No | <input type="checkbox"/> |

Personal care:

- | | | | |
|-----------------------------|------------------|-------|--------------------------|
| 60) Washing yourself | 1. Yes | 0. No | <input type="checkbox"/> |
| 61) Shaving yourself | 1. Yes
3. N/A | 0. No | <input type="checkbox"/> |
| 62) Controlling your urine | 1. Yes | 0. No | <input type="checkbox"/> |
| 63) Controlling your stools | 1. Yes | 0. No | <input type="checkbox"/> |
| 64) Dressing yourself | 1. Yes | 0. No | <input type="checkbox"/> |
| 65) Feeding yourself | 1. Yes | 0. No | <input type="checkbox"/> |

Locomotor (Include assistive devices if used)

- | | | | |
|-----------------------------------------|--------|-------|--------------------------|
| 66) Getting around inside your house | 1. Yes | 0. No | <input type="checkbox"/> |
| 67) getting around outside your house | 1. Yes | 0. No | <input type="checkbox"/> |
| 68) Getting up one step | 1. Yes | 0. No | <input type="checkbox"/> |
| 69) Getting down one step | 1. Yes | 0. No | <input type="checkbox"/> |
| 70) Getting up 2 - 5 steps | 1. Yes | 0. No | <input type="checkbox"/> |
| 71) Getting down 2 - 5 steps | 1. Yes | 0. No | <input type="checkbox"/> |
| 72) Getting up >5 steps | 1. Yes | 0. No | <input type="checkbox"/> |
| 73) Getting down >5 steps | 1. Yes | 0. No | <input type="checkbox"/> |
| 74) Running | 1. Yes | 0. No | <input type="checkbox"/> |
| 75) Getting out of bed | 1. Yes | 0. No | <input type="checkbox"/> |
| 76) Getting into your mode of transport | 1. Yes | 0. No | <input type="checkbox"/> |

Body disposition:

- | | | | |
|------------------------------------------|------------------|-------|--------------------------|
| 77) Shopping in close neighbourhood | 1. Yes | 0. No | <input type="checkbox"/> |
| 78) Preparing own meal | 1. Yes | 0. No | <input type="checkbox"/> |
| 79) Cleaning your home | 1. Yes | 0. No | <input type="checkbox"/> |
| 80) Washing your laundry | 1. Yes | 0. No | <input type="checkbox"/> |
| 81) Caring for your children | 1. Yes
2. N/A | 0. No | <input type="checkbox"/> |
| 82) Picking up objects from the floor | 1. Yes | 0. No | <input type="checkbox"/> |
| 83) Reaching for objects above your head | 1. Yes | 0. No | <input type="checkbox"/> |

If "No" to question 98 proceed to question 99.

If "no" to question 98 above:

Do you need help with:

- | | | | |
|-----------------------------------|--------|-------|--------------------------|
| 99) Getting dressed? | 1. Yes | 0. No | <input type="checkbox"/> |
| 100) Washing self? | 1. Yes | 0. No | <input type="checkbox"/> |
| 101) Getting out of bed? | 1. Yes | 0. No | <input type="checkbox"/> |
| 102) Getting into bed? | 1. Yes | 0. No | <input type="checkbox"/> |
| 103) Preparing meals? | 1. Yes | 0. No | <input type="checkbox"/> |
| 104) Feeding? | 1. Yes | 0. No | <input type="checkbox"/> |
| 105) Using toilet? | 1. Yes | 0. No | <input type="checkbox"/> |
| 106) Moving inside house? | 1. Yes | 0. No | <input type="checkbox"/> |
| 107) Moving outside house? | 1. Yes | 0. No | <input type="checkbox"/> |
| 108) Shopping? | 1. Yes | 0. No | <input type="checkbox"/> |
| 109) Collecting disability grant? | 1. Yes | 0. No | <input type="checkbox"/> |
| 110) Visiting friends? | 1. Yes | 0. No | <input type="checkbox"/> |
| 111) Taking your medicine? | 1. Yes | 0. No | <input type="checkbox"/> |
| 112) Managing own money? | 1. Yes | 0. No | <input type="checkbox"/> |

113) Who helps you with the majority of the tasks?

1. Spouse
2. Child or child -in - law
3. Sibling or sibling -in - law
4. Parent or parent -in - law
5. Friend
6. Landlord
7. Employee
8. Other; specify:

114) Does the person mentioned in question 113 above stay with you?
 1. Yes 0. No

115) Is the person mentioned in question 113 above employed (other than
 by you)?
 1. Yes 0. No

116) Does your caregiver receive a "grant-in-aid" from the Social Services
 Department? 1. Yes 0. No

117) Since having become disabled, for approximately how many years (in total) have you relied on a caregiver to help you with the tasks you mentioned above?

.....



SECTION G**Needs with regard to health services:**

I will read you a list of items with regard to health services that disabled people may find important to meet their needs. How important are these items to you ?

		very important (1)	important (2)	uncertain (3)	not important (4)	not important at all(5)	
118)	visit of the district sister						<input type="checkbox"/>
119)	clinic closer to your home						<input type="checkbox"/>
120)	transport to the clinic						<input type="checkbox"/>
121	visit of the orthopaedic aftercare sister						<input type="checkbox"/>
122	somebody to care for you permanently						<input type="checkbox"/>
123	somebody to help you with some tasks on a daily basis						<input type="checkbox"/>
124	the provision of a wheelchair						<input type="checkbox"/>
125	the provision of assistive devices						<input type="checkbox"/>
126	somebody to help you improve your physical skills						<input type="checkbox"/>

127) Are there any other health services that are important to meet your needs that were not listed above?

1. Yes

0. No

specify:.....

.....

.....

SECTION H**Needs with regards to social services:**

I will read you a list of items with regard to social services that disabled people may find important to meet their needs. How important are these items to you?

		very important (1)	important (2)	uncertain (3)	not important (4)	not important at all (5)	
128)	increase in amount of disability grant						<input type="checkbox"/>
129)	visit of a social worker						<input type="checkbox"/>
130)	the provision of a more accessible house						<input type="checkbox"/>
131)	transport to do your shopping						<input type="checkbox"/>
132)	transport to reach recreational facilities						<input type="checkbox"/>
133)	transport to collect your disability grant						<input type="checkbox"/>
134)	groups that provide interaction with other disabled people						<input type="checkbox"/>
135)	groups that provide interaction with non disabled people						<input type="checkbox"/>
136)	groups that provide support for your family						<input type="checkbox"/>
137)	training to learn an occupation						<input type="checkbox"/>
138)	help with setting up your own business						<input type="checkbox"/>
139)	home help						<input type="checkbox"/>

140) Are there any other social services you find are important to meet your needs that were not listed above?

1. Yes

0. No

specify:

.....

.....

SECTION I:**Needs with regard to the Kleinmond community:**

I will read you a list of items with regard to the Kleinmond community that disabled people may find to be important to meet their needs. How important are these items to **you**?

		very important (1)	important (2)	uncertain (3)	not important (4)	not important at all(5)	
141)	accessible buildings						<input type="checkbox"/>
142)	accessible public transport						<input type="checkbox"/>
143)	accessible pavements						<input type="checkbox"/>
144)	recreational facilities for disabled people						<input type="checkbox"/>
145)	self help groups for disabled people						<input type="checkbox"/>
146)	raising awareness of disability in your community						<input type="checkbox"/>
147)	home help volunteers						<input type="checkbox"/>

148) Are there any issues with regard to the Kleinmond community that are important to meet your needs that were not listed above?

1. Yes

0. No

specify:.....

.....

.....

Thank you for your co-operation!

Vraelys**AFDELING A****1) Identifikasienommer:** **2) Huistaal:**

1. Engels
2. Afrikaans
3. Xhosa
4. Ander:.....

3) Respondent:

1. Self
2. Gevolmagtigte
3. Beide

4) Verwantskap tussen gevolmagtigte en houer van toelaag:

1. Gade
2. Kind
3. Ouer
4. Vriend/ vriendin
5. Werknemer
6. ander; spesifiseer:
7. n.v.t.

AFDELING B:**Demografiese inligting:**

Van:

Voornaam:

Adres:

Telefoon nommer:

5) Geslag: 1. manlik 2. vroulik

6) Ouderdom (ten tye van onderhoud):

7) Gestremd sedert watter jaar:

8) Ongeskiktheidstoelaag sedert watter jaar:

9) Familie status:

1. Enkel 2. Getroud (insluitend gemeenregtelike huwelike)
3. Wewenaar/weduwee 4. Geskei

10) Aantal afhanklikes wat deel uitmaak van die huishouding:

11) Getal mense wat permanent in huishuuding bly:

Werksaanstelling (in die verlede en huidiglik):

12) Het u gewerk voordat u 'n ongeskiktheids toelaag begin ontvang het?

- 1. Ja
- 0. Nee

13) Werk u tans?

- 1. Ja
- 0. Nee

14) Sal u volgens u mening nog 'n werk kan verrig?

- 1. Ja
- 0. Nee

AFDELING C:

Huislike omstandighede:

15) Bly u alleen?

- 1. Ja
- 0. Nee

16) Tipe behuising:

- 1. Huis
- 2. Woonstel
- 3. Informele behuising

17) Trappe: toegang tot woning

- 1. Geen
- 2. Een
- 3. > Een

18) Trappe: binne in die woning

- 1. Geen
- 2. Een
- 3. > Een

19) Toilet:

- 1. Binnekant
- 2. Buitekant

AFDELING D:**Huidige benutting van gesondheidsdienste:**

Watter gesondheidsdienste benut u?

- | | | | |
|--------------------------------------------------------|-------|--------|--------------------------|
| 20) Distrikssuster by 'n kliniek | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 21) Distrikssuster wat huisbesoeke doen | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 22) Kliniek | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 23) Privaat geneesheer | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 24) Ortopediese nasorgsuster | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 25 Caledon Hospitaal | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 26) Tersiere hospitaal in Kaapstad | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 27) Tradisionele geneser | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 28) Ander: | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 29) Gebruik u gereeld medikasie? | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 30) Besoek u gereeld die gesondheidsdienste? | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 31) Ontvang u gereeld besoek van gesondheidspersoneel? | 1. Ja | 0. Nee | <input type="checkbox"/> |

Hulpmiddels:

Gebruik u enige van die volgende op 'n permanente basis?

- | | | | | |
|-----------------------------------|-------|--------|-----------|--------------------------|
| 32) Bril | 1. Ja | 0. Nee | 3. n.v.t. | <input type="checkbox"/> |
| 33) Gehoorapparaat | 1. Ja | 0. Nee | 3. n.v.t. | <input type="checkbox"/> |
| 34) Rystoel | 1. Ja | 0. Nee | 3. n.v.t. | <input type="checkbox"/> |
| 35) Krukke | 1. Ja | 0. Nee | 3. n.v.t. | <input type="checkbox"/> |
| 36) Kierie | 1. Ja | 0. Nee | 3. n.v.t. | <input type="checkbox"/> |
| 37) Loopraam | 1. Ja | 0. Nee | 3. n.v.t. | <input type="checkbox"/> |
| 38) Prostese | 1. Ja | 0. Nee | 3. n.v.t. | <input type="checkbox"/> |
| 39) Ortose | 1. Ja | 0. Nee | 3. n.v.t. | <input type="checkbox"/> |
| 40) Badbord | 1. Ja | 0. Nee | 3. n.v.t. | <input type="checkbox"/> |
| 41) Aantrek hulpmiddels1. | Ja | 0. Nee | 3. n.v.t. | <input type="checkbox"/> |
| 42) Kiere vir gesiggestremdes | 1. Ja | 0. Nee | 3. n.v.t. | <input type="checkbox"/> |
| 43) Lewensondersteunende apparaat | 1. Ja | 0. Nee | 3. n.v.t. | <input type="checkbox"/> |

AFDELING E:**Ongeskiktheid:**

44) Verduidelik in u eie woorde waarom u 'n ongeskiktheidstoelaag ontvang.

.....

.....

.....

Het u enige van die volgende probleme?

Gedrag:

- | | | | |
|--------------------------------------------|-------|--------|--------------------------|
| 45) Verwaarloosing van u voorkoms | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 46) Om te weet watter dag dit is | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 47) Om te weet waar u is | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 48) Herkenning van mense om jou | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 49) Uself te beveilig | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 50) Aanleer van 'n nuwe taak | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 51) Interaksie met ander mense | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 52) Besluite te neem ten opsigte van uself | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 53) Toepaslike gedrag/optrede | 1. Ja | 0. Nee | <input type="checkbox"/> |

Kommunikasie (insluitend hulpmiddels indien gebruik)

- | | | | |
|----------------------------------|-------|--------|--------------------------|
| 54) Om te verstaan wat gesê word | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 55) Om te praat | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 56) Om te hoor wat gesê word | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 57) Om te sien | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 58) Om te lees | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 59) Om te skryf | 1. Ja | 0. Nee | <input type="checkbox"/> |

Selfversorging:

- | | | | | |
|---------------------------|-------|--------|--------------------------|--------------------------|
| 60) Uself te was | 1. Ja | 0. Nee | <input type="checkbox"/> | |
| 61) Uself te skeer | 1. Ja | 0. Nee | 2. nvt | <input type="checkbox"/> |
| 62) U uriene te beheer | 1. Ja | 0. Nee | <input type="checkbox"/> | |
| 63) U stoelgang te beheer | | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 64) Uself aan te trek | 1. Ja | 0. Nee | <input type="checkbox"/> | |
| 65) Self te eet | 1. Ja | 0. Nee | <input type="checkbox"/> | |

Motories: (insluitend hulpmiddels indien gebruik)

- | | | | |
|--------------------------------|-------|--------|--------------------------|
| 66) Binne die woning te beweeg | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 67) Buite die woning te beweeg | 1. Ja | 0. Nee | <input type="checkbox"/> |

- | | | | |
|------------------------------|-------|--------|--------------------------|
| 68) Een trap op te kom | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 69) Een trap af te kom | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 70) 2 -5 trappe op te kom | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 71) 2 - 5 trappe af te kom | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 72) >5 trappe op te kom | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 73) >5 trappe af te kom | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 74) Om te hardloop | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 75) Uit die bed uit te kom | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 76) In u tipe vervoer te kom | 1. Ja | 0. Nee | <input type="checkbox"/> |

Body disposition:

- | | | | | |
|------------------------------------------|-------|--------|--------------------------|--------------------------|
| 77) Inkopies te doen in u nabye omgewig | 1. Ja | 0. Nee | <input type="checkbox"/> | |
| 78) U eie maaltyd voor te berei | 1. Ja | 0. Nee | <input type="checkbox"/> | |
| 79) U eie huis skoon te maak | 1. Ja | 0. Nee | <input type="checkbox"/> | |
| 80) Eie wasgoed te doen | 1. Ja | 0. Nee | <input type="checkbox"/> | |
| 81) Self u kinders te versorg | 1. Ja | 0. Nee | 2. nvt | <input type="checkbox"/> |
| 82) Voorwerpe van die vloer af op te tel | 1. Ja | 0. Nee | <input type="checkbox"/> | |
| 83) Voorwerpe bo u kop raak te vat | 1. Ja | 0. Nee | <input type="checkbox"/> | |
| 84) Regop te bly sit | 1. Ja | 0. Nee | <input type="checkbox"/> | |
| 85) Regop te bly staan | 1. Ja | 0. Nee | <input type="checkbox"/> | |

Handvaardigheid:

- | | | | | |
|-----------------------------------|-------|--------|--------------------------|--------------------------|
| 86) Krane oop te draai | 1. Ja | 0. Nee | <input type="checkbox"/> | |
| 87) Krane te gebruik | 1. Ja | 0. Nee | <input type="checkbox"/> | |
| 88) 'n Telefoon te gebruik | 1. Ja | 0. Nee | 2. nvt | <input type="checkbox"/> |
| 89) Klein voorwerpe te manipuleer | 1. Ja | 0. Nee | <input type="checkbox"/> | |
| 90) Iets vas te vat met u hande | 1. Ja | 0. Nee | <input type="checkbox"/> | |
| 91) U dominante hand te gebruik | 1. Ja | 0. Nee | <input type="checkbox"/> | |

Situational:

- | | | | |
|-------------------------------------------|-------|--------|--------------------------|
| 92) Maklik kortasem te raak | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 93) Onder die weer te voel | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 94) Dit moeilik vind om geraas te hanteer | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 95) Dit moeilik vind om lig te hanteer | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 96) Dit moeilik vind om stress te hanteer | 1. Ja | 0. Nee | <input type="checkbox"/> |

Ander:

97) Het u enige probleme wat nie hierbo genoem is nie?

1. Ja
spesifiseer:.....

0. Nee

.....
.....
.....

AFDELING F:**Afhanklikheid van 'n versorger:**

98) Is u in staat om uself te versorg?

1. Ja, altyd
2. Nee, net somtyds
3. Nee, nooit nie

Indien "Ja" op vraag 98, gaan aan met DEEL G.
Indien "Nee" op vraag 98 gaan aan met vraag 99

Indien "nee" op vraag 98 bo:

Benodig u enige hulp om

- | | | | |
|--------------------------------------------|-------|--------|--------------------------|
| 99) Aan te trek? | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 100) Uself te was? | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 101) Uit die bed uit te klim? | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 102) Binne in die bed te klim? | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 103) Kos voor te berei? | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 104) Te eet? | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 105) 'n Toilet te gebruik? | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 106) Binne in die huis te beweeg | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 107) Buite die huis te beweeg? | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 108) Inkopies te doen? | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 109) U ongeskiktheidstoelaag te gaan haal? | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 110) By vriende te kuier? | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 111) U medisyne te neem? | 1. Ja | 0. Nee | <input type="checkbox"/> |
| 112) U geld sake self te bestuur? | 1. Ja | 0. Nee | <input type="checkbox"/> |

113) Wie help u met die meerderheid take?

1. Eggenoot
2. Kind of skoonkind
3. Broer/suster of swaer/skoonsuster
4. Ouer of skoonouer

- 5. Vriend of vriendin
- 6. Landheer
- 7. Werknemer
- 8. Ander: spesifiseer:

114) Bly die persoon na wie u in vraag 113 bo verwys het by u?

1. Ja 0. Nee

115) Werk die persoon in vraag 113 (anders as by u) ?

1. Ja 0. Nee

116) Ontvang u versorger 'n "hulptoelaag" van die Departement Maatskaplike Dienste?

1. Ja 0. Nee

117) Vir hoeveel jare (in geheel) sedert u gestremd geraak het is u van 'n versorger afhanklik vir die uitvoer van bogenoemde take?

.....

AFDELING G:**Behoeftes ten opsigte van gesondheidsdienste:**

Ek sal vir u 'n lys lees van gesondheidsdienste wat vir gestremde persone belangrik mag wees. Hoe belangrik is die items vir u?

		baie belangrik (1)	belangrik (2)	onseker (3)	nie belangrik nie(4)	glad nie belangrik nie (5)	
118)	besoek deur die distrik suster						<input type="checkbox"/>
119)	kliniek nader aan my huis						<input type="checkbox"/>
120)	vervoer na die kliniek						<input type="checkbox"/>
121)	besoek deur die ortopediese nasorgsuster						<input type="checkbox"/>
122)	iemand wat u permanent versorg						<input type="checkbox"/>
123)	iemand wat u daaglik met sekere take kom help						<input type="checkbox"/>
124)	die voorsiening van 'n rystoel						<input type="checkbox"/>
125)	die voorsiening van hulpmiddels						<input type="checkbox"/>
126)	iemand wat u help om u fisiese funksie te verbeter						<input type="checkbox"/>

127) Is daar enige ander gesondheidsdienste waaraan u 'n behoefte het wat nie bo genoem is nie?

1. Ja

2. Nee

spesifiseer:

.....

.....

AFDELING H:

Behoeftes ten opsigte van maatskaplike dienste:

Ek sal vir u 'n lys lees van maatskaplike dienste wat gestremde persone belangrik mag vind.
Hoe belangrik is die items vir u?

		baie belangrik (1)	belangrik (2)	onseker (3)	nie belangrik nie (4)	glad nie belangrik nie (5)	
128)	verhoging in die bedrag van die ongeskiktheidstoelaag						<input type="checkbox"/>
129)	besoek deur 'n maatskaplike werker						<input type="checkbox"/>
130)	voorsiening van 'n meer toeganklike huis						<input type="checkbox"/>
131)	vervoer om inkopies te doen						<input type="checkbox"/>
132)	vervoer na ontspanningsgeriewe						<input type="checkbox"/>
133)	vervoer om die ongeskiktheidstoelaag te gaan haal						<input type="checkbox"/>
134)	groepe waar mense met gestremdhede met mekaar kan verkeer						<input type="checkbox"/>
135)	groepe waar mense met gestremdhede saam met mense sonder gestremdhede kan verkeer						<input type="checkbox"/>
136)	ondersteuningsgroepe vir familieledede						<input type="checkbox"/>
137)	werksopleiding						<input type="checkbox"/>
138)	hulp met die stigting van 'n eie besigheid						<input type="checkbox"/>
139)	huishulp						<input type="checkbox"/>

140) Is daar enige ander maatskaplike dienste waaraan u 'n behoefte het wat nie bo genoem is
nie?

1. Ja

2. Nee

spesifiseer:

.....

.....

AFDELING I:

Behoeftes ten opsigte van die Kleinmond gemeenskap:

Ek sal vir u 'n lys lees met betrekking tot die Kleinmond gemeenskap wat gestremde mense belangrik mag vind. Hoe belangrik is die items vir u?

		baie belangrik (1)	belangrik (2)	onseker (3)	nie belangrik nie (4)	glad nie belangrik nie (5)	
141)	toeganklike geboue						<input type="checkbox"/>
142)	toeganklike openbare vervoer						<input type="checkbox"/>
143)	toeganklike sypaadjies						<input type="checkbox"/>
144)	ontspanningsgeriewe vir gestremde persone						<input type="checkbox"/>
145)	selfhelp groepe vir gestremde persone						<input type="checkbox"/>
146)	verhoogde bewustheid van die behoeftes van gestremde persone in die gemeenskap						<input type="checkbox"/>
147)	vrywillige huishulp						<input type="checkbox"/>

148) Is daar enige items met betrekking tot die Kleinmond gemeenskap waaraan u 'n behoefte het wat nie genoem is nie?

1. Ja

2. Nee

spesifiseer:

.....
.....

BAIE DANKIE VIR U SAMEWERKING

ADDENDUM 3

Dr F Krige
Regional Director: Health
Boland Overberg Region
att.: Ms Johnson
fax: 023 - 3428501

Cape Town, 27.3.1999

Dear Dr Krige

An investigation into disability profiles, caregiver reliance and needs of disability grant recipients in Kleinmond, Western Cape, South Africa

As a part - time masters student at the Faculty of Medicine at the University of Stellenbosch I plan to conduct a research project in the Kleinmond community in 1999. The aims of the study are as follows:

- a) To collect demographic data with respect to age, gender, family status and living arrangements of disability grant recipients in Kleinmond, Western Cape, South Africa.
- b) To establish present utilisation of health services of the grantees.
- c) To establish permanent use of assistive devices by the grantees.
- d) To establish a disability profile in disability grant recipients residing in Kleinmond (based on the ICDH).
- e) To establish the proportion and degree of caregiver reliance amongst the grantees.
- f) To document needs as related to health and social services and the Kleinmond community as expressed by the grantees.

The proposal for the study has been accepted by the Research Committee C of the Faculty of Medicine (project number 99/016).

I will approach the department of Social Services in Worcester for addresses of recipients of disability grants who reside in Kleinmond and plan to conduct the interviews for the main study during June and July 1999.

In order to be able to test the draft questionnaire, I would like to conduct a pilot study in the Botrivier/Caledon area. The most sensible way of obtaining contact addresses of disability grant recipients who would agree to be interviewed during the pilot study, seems to be to approach the community sisters in Caledon. I would like to ask your permission for the sisters to supply me with this information. As I am planning to conduct the pilot study during the week after Easter, I would appreciate you sending your reply to the following fax number: 021 - 448 8157.

Should you have any questions regarding the proposed study, please do not hesitate to contact me at any of the following numbers:

021 - 406 6593 (work) or 021 - 448 81578 (fax) or afrieg@uctgsh1.uct.ac.za (e-mail)

Yours sincerely

(A. Frieg, Ms)

(J.A.Hendry, Ms)

Supervisor

Head of Department

ADDENDUM 4

AN INVESTIGATION INTO DISABILITY PROFILES, CAREGIVER RELIANCE AND NEEDS OF DISABILITY GRANT RECIPIENTS IN KLEINMOND, WESTERN CAPE, SOUTH AFRICA

REFERENCE NUMBER: 991016

STATEMENT BY OR IN LIEU OF PARTICIPANT

I, the undersigned....., recipient of a disability grant or* in my capacity as..... of that person..... that receives a disability grant, that resides at.....

confirm that:

1. I am invited to participate in the above mentioned research project which is initiated through the University of Stellenbosch.

2.1. It has been explained to me that the objective of this study is to:

- a) establish kinds of disabilities in disability grant recipients in Kleinmond;
- b) establish the use of health services en assistive devices in recipients of disability grants;
- c) establish reliance on a caregiver in recipients of disability grants
- d) establish needs with respect to health and social services of recipients of disability grants.

2.2. It has been explained 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 1999 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 of professional presentations.

3.2 It has been explained that findings from this study regarding needs of disabled people may be brought to the attention of the Kleinmond 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. There has been no force placed on me 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.

Signed at on 19....

Participant's/representative's signature or fingerprint of right thumb

Witness

STATEMENT BY RESEARCHER:

I, Annette Frieg, state that:

- 1. I have explained the information in this document to and/ or her/ his* representative;
- 2. I have invited her/ him/ them* to ask me questions in the case of uncertainty;
- 3. This conversation was held in English/ Afrikaans/ Xhosa and that no translator has been used/ that this conversation has been held in and has been translated by

Signed at on 19...

Researcher (Annette Frieg)

Witness

* Delete if not relevant

STATEMENT BY TRANSLATOR

I, confirm that:

- 1. I have translated the content of this document from..... to..... for the participant and that I have also translated questions which the participant has asked of Ms Annette Frieg, and her answers;
- 2. And that the information I conveyed in such a translation, was a factually correct representation of what I had been told.

Signed at on..... 19..

Translator's signature

Witness

IMPORTANT INFORMATION

Dear participant
Thank you very much 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:

Ms Annette Frieg

**AN INVESTIGATION INTO DISABILITY PROFILES, CAREGIVER RELIANCE AND NEEDS OF
DISABILITY GRANT RECIPIENTS IN KLEINMOND, WESTERN CAPE, SOUTH AFRICA**

VERWYSINGSNOMMER: 99/016

VERKLARING DEUR OF NAMENS DEELNEMER

Ek, die ondergetekende,....., ontvanger van 'n ongeskiktheids-
toelae of* in my hoedanigheid as..... van die persoon
..... wat die ongeskiktheidstoelae ontvang, wat woon te

bevestig dat:

1. Ek uitgenooi is om deel te neem aan bogemelde navorsingsprojek wat deur die Universiteit van Stellenbosch onderneem word.
- 2.1. Daar aan my verduidelik is dat die doel van die studie is om:
 - a) tipes gestremdhede in ontvangers van ongeskiktheidstoelae in Kleinmond te bepaal;
 - b) gebruik van gesondheidsdienste en hulpmiddels van ontvangers van ongeskiktheidstoelae te bepaal;
 - c) afhanklikheid van versorgers van ontvangers van ongeskiktheidstoelae te bepaal;
 - d) behoeftes ten opsigte van gesondheids- en maatskaplike dienste van ontvangers van ongeskiktheidstoelae te bepaal.
- 2.2. Daar aan my verduidelik is dat daar 'n persoonlike onderhoud met my gevoer sal word rondom my persoonlike ervaring met gestremdheid.
- 2.3. Ek bewus is daarvan dat dit 'n eenmalige prosedure is wat in 1999 uitgevoer sal word op 'n tyd wat vir my geleë is.
- 3.1. Daar aan my verduidelik is dat alle inligting vertroulik is en konfidensiël hanteer sal word. Inligting kan aangewend word in 'n tesis, 'n publikasie in vaktydskrifte of 'n professionele voordrag.
- 3.2. Daar aan my verduidelik is dat bevindings van hierdie studie aangaande behoeftes van gestremdes aan die owerhede in Kleinmond gemeld kan word.
4. Daar aan my verduidelik is dat ek volle toegang mag hê tot die inligting wat oor myself ingewin is tydens die studie.
5. Ek meegedeel is dat ek mag weier om deel te neem aan hierdie projek asook dat ek enige tyd deelname daaraan mag staak, en dat sodanige weiering of staking nie op enige manier my toekomstige behandeling sal benadeel nie.
6. Die inligting wat hierbo weergegee is, deur.....aan my in Afrikaans/ Engels/ Xhosa* verduidelik is en dat ek die taal goed magtig is/ dit na my bevrediging aan my getolk is deur..... en dat ek die geleentheid gegee is om vrae te vra en dat al my vrae tot my bevrediging beantwoord is.
7. Daar geen dwang op my geplaas is om toe te stem tot my deelname aan hierdie projek nie en dat ek besef dat ek deelname enige tyd mag staak sonder enige penalisasie.
8. Deelname aan hierdie projek geen addisionele koste vir my inhou nie en dat ek ook nie finasieel daarby sal baat vind nie.

Geteken te.....op.....19....

.....
Deelnemer/verteenwoordiger se handtekening of regter duimafdruk:

Getuie:.....

VERKLARING DEUR NAVORSER

Ek, Annette Frieg, verklaar dat ek:

1. Die inligting vervat in hierdie dokument aan.....en/ of sy/ haar* verteenwoordiger..... verduidelik het;
2. Hom/ haar/ hulle* versoek het om vrae aan my te stel indien enigeiets onduidelik was;
3. Dat hierdie gesprek in Afrikaans/ Engels/ Xhosa* plaasgevind het en dat geen tolk gebruik is nie/ *dat hierdie gesprek in.....getolk is deur.....

Geteken te.....op.....19...

.....
Navorsers (Annette Frieg)

.....
Getuie

* Haal deur indien nie relevant nie

VERKLARING DEUR TOLK

Ek,.....bevestig dat ek

1. Die inhoud van hierdie dokument vanuit Afrikaans na Engels/ Xhosa* getolk het aan die deelnemer en ook die vrae wat deur die deelnemer aan Me Annette Frieg gestel is en hierdie persoon se antwoorde getolk het;
2. En dat die inligting wat ek so oorgedra het 'n feitlik korrekte weergawe was van wat aan my meegeel was.

Geteken te.....op.....19....

.....
Tolk se handtekening

.....
Getuie se handtekening

BELANGRIKE INLIGTING

Geagte deelnemer. Baie dankie vir u deelname aan hierdie studie. Indien daar te enige tyd tydens die duur van die projek:

1. probleme ondervind word wat spruit uit die navorsing, of
2. u verdere inligting aangaande die projek verlang

kontak my asseblief per telefoon by:.....
Me Annette Frieg

IINKCUKACHA ZOMTHATHI – NXAXHEBA NEMVUMELWANO

UPHANDO NGOLUHLU LWABAKHUBAZEKILEYO, INTEMBEKO YABAGCINI, NEEMFUNO ZABO BAFUMANA INKAM—NKAM YABAKHUBAZEKILEYO EKLEINMOND, KWINTSHONA KOLONI, EMZANTSI AFRIKA.

INANI LONXULUMANISO : 991016

INK CAZO NGUMTHABATHI—NXAXHEBA OKANYE NGOTHABATHA INDAWO YAKHE

Mna, otyikitye apha ezantsi, owamkela inkam—nkam yokukhubazeka okanye* eegunyeni lam ndinguka..... ofumana inkam—nkam ngokukhubazeka, ndihlala e.....

Ndiyakungqina ukuba:

1. Ndimenyiwe ukuba ndizokuthabatha inxaxheba koluphando—lwazi luchazwe ngentla apha, oluqalwe yiYunivesithi yase Stellenbosch.
2. Ndicaciselwe iinjongo zoluphando—lwazi, ezi :
 - a) kukwazi iintlobo—ntlobo zokukhubazeka kubamkeli benkam—nkam yokukhubazeka.
 - b) kukwazi ngokusetyenziswa kwemithombo yezempilo nezinto eziluncedo kubantu Abamkela le nkam—nkam
 - c) kukwazi ngentembeko yabagcini babantu abamkela inkam—nkam yabakhubazekileyo.
 - d) kukwazi ngeemfuno zezempilo nezasekuhlaleni zabantu abamkela inkam—nkam yabakhubazekileyo.
- 2.2 Ndicaciselwe ukuba ndizakubuzwa ngamava am okukhubazeka.
- 2.3 Ndiyayazi ukuba lomgaqo—nkqubo uyakuqhutywa kanye, kunyaka ka 1999, ngexesha elindilungeleyo.
- 3.1 Ndicaciselwe ukuba zonke inkcukacha ziyakugcinwa ziyimfihlelo. Kodwa zingasetyenziselwa incwadi yezifundo eziphakamileyo (THESIS), nakwincwadi yeenzululwazi ikwangadandalaziswa kwinkomfa yezifundiswa.
- 3.2 Kucacisiwe ukuba iziphumo zoluphando zinokusiwa kwabasemagunyeni eKleinmond.
4. Kucacisiwe ukuba ndinokufikelela kulwazi olumalunga nam olufunyenwe koluphando.
5. Ndichazelwe ukuba ndingala ukuthatha inxaxheba koluphando nakweliphi na inqanaba/ lthuba, yaye oko angekhe kuchaphazele unyango lwam kakubi kwilixa elizayo.
6. Le nkcazelo ingentla icaciswe ngui.....ngesi Ngesi/ Bhulu/ Xhosa* yaye ndiyalazi olu lwimi kakuhle, iguqulelwe kum ngu.....yaye nemibuzo yam iphendulwe ngokwanelisekileyo.
7. Akukhange kubenasinyanzelo esibekwe kum ukuba ndivume ukuthabatha—inxaxheba kule Nkqubo, yaye ndiyazi ukuba ndingayeka nanini na ngaphandle kwesohlayo.
8. Ukuthabatha inxaxheba kulenkqubo angekhe kubenazindleko kum yaye ndingazukuzuzwa mali ngokuthabatha inxaxheba.

NDIVUMA UKUTHABATHA INXAXHEBA KULENKQUBO INGENTLA NGOKU KHULULEKILEYO :

Ndityikitya e.....ngo.....19....

.....
Umthathi nxaxheba/ omele yena
okanye fingerprint yakhe:

.....
Inggina

INKCAZELO YENZULULWAZI

Mna, Annette Frieg, ndithi :

1. Ndiyicacisile yonke into ekweliphepha ku.....okanye komele yena;
2. Ndim memile azokubuza imibuzo apho angaqondi khona;
3. Le ndibano ibibanjwe ngesiyaye akhange kusetyenziswe mguquli/ le ndibano ibibanjwe ngesi yaguqulwa ngu

Ityikitywe e.....ngo.....19...

.....
Inzulu—lwazi (Annette Frieg)

.....
Inggina

*** Susa into ongayisebenzisanga**

INKCAZELO NGUMGUQULI—LWIMI

Mna,.....ndiyavuma ukuba :

1. Ndiliguqule ulwimi ebibhalwe ngalo lencwadana ndiyisusa kwisiNgesi ndayisa esiXhoseni ndisenzela umthathi nxaxheba.
2. Le nto ndiyiguquleyo nendlela endiguqule ngayo, yinto ebendiyixelelwe.

Ndityikitye e.....ngo.....19....

.....
Umgququli—Lwimi

.....
Inggina

INKCAZELO EBALULEKILEYO

Mthathi nxaxheba obalulekileyo

Ndiyabulela ngokuthi uthabathe inxaxheba koluphando.Ukuba unemibuzo ngelilixa loluphando malunga ne:

- 1.ngengxaki oyifumeneyo ibangelwa loluphando, okanye
- 2.imibuzo malunga nenkcazelo yoluphando

nditsalele umnxeba kule nombolo :.....

Ms Annette Frieg

ADDENDUM 5

Dr V. Terreblanche
Chief Director Social Services
Fax: 021 - 4611277

Cape Town, 18.5.99

Dear Dr Terreblanche,

Request for names and addresses of residents of Kleinmond who receive a permanent disability grant from the Department of Social Security.

As a part - time masters student at the Faculty of Medicine at the University of Stellenbosch I plan to conduct a research project in the Kleinmond community in 1999. The aims of the study are as follows:

- a) To collect demographic data with respect to age, gender, family status and living arrangements of disability grant recipients in Kleinmond, Western Cape, South Africa.
- b) To establish present utilisation of health services of the grantees.
- c) To establish permanent use of assistive devices by the grantees.
- d) To establish a disability profile in disability grant recipients residing in Kleinmond (based on the ICDH).
- e) To establish the proportion and degree of caregiver reliance amongst the grantees.
- f) To document needs as related to health and social services and the Kleinmond community as expressed by the grantees.

The proposed study has been approved by the Research Committee C of the University of Stellenbosch (project number: 99/016). A copy of the protocol and a request for names and addresses of all recipients of a permanent disability grant in Kleinmond has been sent to the Social Security Department at Worcester on 31.3.99. I have phoned Mrs Tyger at that office earlier today and she does not have any knowledge of this registered letter. She also informed me that it is correct procedure to approach you in order to obtain the necessary information.

In order to enable me to interview the study population I would hereby like to request that you provide me with a list of the names and addresses of all recipients of a permanent disability grant who reside in Kleinmond.

Your co-operation is much appreciated. Should you have any questions please do not hesitate to contact me at the above address or at any of the following:

home telephone number: 021 - 522445

work telephone number: 021 - 4066402

fax number: 021 - 4488157

e - mail: AFRIEG@UCTGSH1.UCT.AC.ZA

Yours sincerely

(A. Frieg, Ms)

(J.A. Hendry, Ms)

Supervisor

Head of Department

ADDENDUM 6

Ms du Toit
Matron - in - charge
Caledon Hospital
Caledon 7230

Cape Town, 31.3.1999

Dear Ms du Toit

An investigation into disability profiles, caregiver reliance and needs of disability grant recipients in Kleinmond, Western Cape, South Africa

As a part - time masters student at the Faculty of Medicine at the University of Stellenbosch I plan to conduct a research project in the Kleinmond community in 1999. The aims of the study are as follows:

- a) To collect demographic data with respect to age, gender, family status and living arrangements of disability grant recipients in Kleinmond, Western Cape, South Africa.
- b) To establish present utilisation of health services of the grantees.
- c) To establish permanent use of assistive devices by the grantees.
- d) To establish a disability profile in disability grant recipients residing in Kleinmond (based on the ICDH).
- e) To establish the proportion and degree of caregiver reliance amongst the grantees.
- f) To document needs as related to health and social services and the Kleinmond community as expressed by the grantees.

The proposal for the study has been accepted by the Research Committee C of the Faculty of Medicine (project number 99/016).

I will approach the department of Social Services in Worcester for addresses of recipients of disability grants who reside in Kleinmond and plan to conduct the interviews during June and July 1999.

Should you have any comments and/or questions about the proposed study, please feel free to contact me at any of the following numbers:

021 -406 6593 (work)

021 - 522445 (home)

021 - 4488157 (fax)

afrieg@uctgsh1.uct.ac.za

Yours sincerely

(A. Frieg, Ms)

(J.A.Hendry, Ms)

Supervisor

Head of Department



frieg_disability_2000

