THE PREVALENCE AND REHABILITATION NEEDS OF INDIVIDUALS WITH LOCOMOTOR DISABILITY IN MITCHELL'S PLAIN

Submitted to the University of Cape Town in partial fulfilment of the requirements for the degree of Master of Philosophy in Biomedical Engineering.

Lizmory Tandeke Fehrsen Coetzee. BSc (Physiotherapy), UCT.

January 1997

DECLARATION

I, Lizmory Tandeke Coetzee, hereby declare that the work on which this thesis is based is original (except where acknowledgements indicate otherwise) and that neither the whole work nor any part of it has been, is being, or is to be submitted for another degree in this or any other University .

I empower the University to reproduce for the purpose of research either the whole or any portion of the contents in any manner whatsoever.

Signed by candidate

signature removed

L T COETZEE

January 1997

CONTENTS

ABSTRACT

Locomotor disability is a problem, reported prevalence ranging from 1% to 8.6%. Only a limited number of studies have been done in South Africa. They used different methodologies and definitions, thus leading to the variation in prevalence reported. A further factor influencing prevalence is that some locomotor disabilities are area-specific.

This study aimed to determine the prevalence and rehabilitation needs of individuals with locomotor disability in Mitchell's Plain, for planning intervention strategies as part of this community based rehabilitation service.

A cross sectional study design was employed. A stratified proportional cluster sampling technique was used to select 36 clusters resulting in a sample size of 2424 people.

Screening questions recommended by the WHO were used to identify people with impairments (Phase I). Further screening (Phase II), of those identified with impairments, using a questionnaire based on the ICIDH categories, identified people with disabilities. People with locomotor disabilities were grouped together and qualitative analysis through case studies was done on sub-groups where common themes manifested.

12.9% reported some form of impairment; 3.9% adults could be classified as having disabilities. Amongst adults with disabilities, 2.7% had locomotor disabilities. Consistent with the literature, disability increased with age, was more frequently reported amongst females, and was associated with lower socio-economic class. Multiple impairments were frequently reported, with the most common impairment being musculo-skeletal conditions.

Use of health services occurred in the public sector with the local Day Hospital used as frequently as more distant tertiary hospitals. The study revealed the need for improved and accessible medical and rehabilitation services in the community.

Their poor ability to integrate functionally and economically into the community, was reflected in the high proportion of people with mobility and occupational handicap categories. Low levels of education worsened the impact on occupational handicap.

It was further evident that multiple impairments amongst the elderly lead to greater dependence of people with locomotor disablility on their care-givers.

Even though the need for assistive equipment was high , much of assistive equipment owned was not being used. A further handicapping factor for the disabled using assistive equipment

was their environment which restricted the use of assistive equipment.

High locomotor disability prevalence was confirmed in this study. Major unmet needs were identified in the handicap categories of physical mobility and economic self sufficiency. Domiciliary based intervention was recommended as the most appropriate rehabilitative intervention for the severely physically disabled persons.

ACKNOWLEDGEMENTS

I would like to thank the following individuals and groups. Without their help and guidance this study would not have been possible:

- David Boonzaier - my supervisor.
- The Department of Biomedical Engineering (UCT) for the opportunity to further my studies and development.
- Judy Katzenellenbogen (MRC).
- Gina Joubert (MRC) - for advice and assistance with data analysis.
- Kirsty Rendal (UWC and Community Occupational Therapy Service).
- Gail Cameron (Community Occupational Therapy Service) - for field coordination.
- All the Therapy Assistants at Lentegeur Hospital - for assisting with fieldwork and interviews.
- The Community Occupational Therapy Service of Mitchell's Plain - for assisting with printing, fieldwork, and transport.
- The children and families in Mitchell's Plain who participated in this study.
- My husband, children and parents, who supported my efforts.

LIST OF TABLES

LIST OF FIGURES

DEFINITIONS AND TERMINOLOGY

Impairment:
In the context of health experience, an impairment is any loss or abnormality of psychological, physiological or anatomical structure or function.[12]

Disability:
In the context of health experience, a disability is any restriction or lack (as result of an impairment) of ability to perform an activity in the manner or with the range considered normal for a human being.[12]

Handicap:
In the context of health experience, a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfillment of a role that is normal (depending on age, sex and social and cultural factors) for that individual.[12]

Rehabilitation:
Rehabilitation includes all measures aimed at reducing the impact of disabling and handicapping conditions, and enabling the disabled and handicapped to achieve social integration.[12]

Disablement:
Umbrella term for disability and handicap.

Locomotor disability
Refers to an individual's ability to execute distinctive activities associated with moving, both himself and objects, from place to place.[12]

Cluster
A group of 15 plots in close proximity, delineated on most current municipal map (TMS3017).

Household
A group of people living in a dwelling (permanent or temporary construction) on a plot who eat together.

Demography:
Age, sex, occupation, education, marital status.

Past utilization:
Refers to the persons initial treatment, as well as any services used in the past which are no longer being used.

Present utilization:
Refers to any services which the person currently attends/ has appointments to attend in the future.

Financial support:
Sources of income.

Social support:
Frequency of social contact.

Assistive device:
Equipment assisting in gross motor activities.

Gross motor activities:
Moving/walking, stair climbing, transferring, dressing, feeding.

Suitability of assistive equipment:
- frequency of use of assistive device.
- attainment of independence in activities of daily living(ADL).

INTRODUCTION

The University of the Western Cape Occupational Therapy Department has been involved in developing the Community Occupational Therapy Service(COTS), a rehabilitation project based in Mitchells Plain since 1988. This project is supported mainly through foreign funding from the Christoffel Blinden Mission in Germany. The therapist leading this project was concerned about the future programme planning and development of the rehabilitation service. At that stage the project mainly served people with severe physical disabilities, who were referred from secondary and tertiary care hospitals. The concern was that the community - based rehabilitation service was purely an extension of institution - based rehabilitation, and that the more desirable approach of community development was not being implemented. The true needs of the disabled population in Mitchells Plain were not known or being met.

Mitchells Plain is a large , densely populated dormitory town on the Cape Flats, 30 kilometres from the centre of Cape Town. It is a relatively new area, having been established by the previous" minority government" in 1976, in an attempt to alleviate the housing shortage for the "coloured" people which followed their forced removal from central Cape Town. The majority of the housing is council owned, which residents are now allowed to purchase. Many private home ownership schemes are now mushrooming around the perimeter of Mitchells Plain.

The population is estimated at 350 000 people. Being a dormitory town, there are very few work opportunities available in the area. The majority of the people are from the working class

and many are unemployed, drug and alcohol abuse is rife, and the resulting social problems ensue.

The people in the area have limited access to health services. Public health services consist of one day hospital, a regional psychiatric hospital(Lentegeur Hospital), and municipal clinics in the suburbs. There is a private hospital and many general practitioners are practising in the suburbs.

There are various Welfare Organisations such as the League of Friends of the Blind, Cape Mental Health Society and Association for the Physically Disabled who have branches or field workers based in the area, and are attempting to serve the needs of the disabled people.

Rehabilitation staff, other than the Social Workers doing community-based work, are non-existent, partly because of the lack of government subsidy for posts in Welfare Organisations. The only Physiotherapy post at the day hospital was vacant. Thus any person requiring Physiotherapy, Speech therapy or Occupational therapy through state services has to attend one of the major hospitals at least 20 kilometres away.

At the time of the study, the Local Authorities were legally responsible for rehabilitation, however few if any were running rehabilitation programmes. (Health act No.63 of section 20. Duties and powers of Local Authorities....." iii) the rehabilitation in the community of persons

cured of any medical condition".)

Little data was available for the Cape Town area on the prevalence of disability. Studies done in the Cape Town area had contradictory disability prevalence figures for the same areas, others used hospital-based samples which are not representative of problems within the community.[1,2,3,4,5,6,7]

When the sample is not drawn from the general population, sections of the population may not be represented and results will not be generalisable to the population, for example clinic attenders are not necessarily representative of the community in which the clinic is found. Hospital based sampled data is biased because certain selection criteria determine admission of disabled persons to health institutions, such as: cost, distance, cultural and language barriers, type of rehabilitation care offered at secondary and tertiary level care institutions. The bias at secondary and tertiary hospital level is also more towards acute cases, with long-term rehabilitation patients not being adequately represented due to poor long-term follow up. Therefore a community based representative sample is needed to determine the full spectrum of disability in the population. Hospital based data is however of some value and is useful as long as the limitations are fully understood.

It was decided, in 1990, to undertake a community based survey to target the population with disabilities and thereafter individuals with locomotor disability as a sub- group, for the following reasons:

It was within the area of expertise of Physiotherapists.

There was an obvious need for rehabilitation services amongst individuals with locomotor disability

Preventative strategies could be developed out of a community based rehabilitation service.

A clear understanding of the extent of locomotor disability, and the problems and needs of the individuals with locomotor disability, was required to ensure appropriate intervention strategies as part of a community based rehabilitation service.

Aim:

To determine the prevalence and gross motor rehabilitation needs, of individuals with locomotor disability people in Mitchell's Plain.

Objectives:

1. To determine the prevalence of locomotor disabilities in Mitchell's Plain.

2. To determine the types of impairment leading to locomotor disability.

3. To obtain a demographic profile of the individuals with locomotor disability.

4. To determine the types of handicap experienced by individuals with locomotor disability.

5. To investigate the need for and suitability of, assistive devices in performing gross motor activities, amongst individuals with locomotor disability.

6. To determine past and present utilization of health care and rehabilitation services by individuals with locomotor disability in Mitchell's Plain.

7. To determine the availability of financial and social support for individuals with locomotor disability in Mitchell's Plain.

8. To determine the perceived needs and problems of individuals with locomotor disability and their families.

9. To invesigate the home environment of the individuals with locomotor disability for suitability in activities of daily living.

LITERATURE REVIEW

Medical and welfare services for disabled persons in developing countries are not coping with their rehabilitation load. Two thirds of the population with disabilities are not being exposed to any rehabilitation services. It is estimated that at least 1.5% of the total population, at any given time, could benefit from rehabilitation.[8]

The forecast is made that by the year 2000, four fifths of the disabled population of the world will be living in developing countries, and this ratio would continue to increase.[9]

Conventional tools for measuring health by life expectancy and mortality, are no longer regarded as adequate indicators of health status. Epidemiologists have generally focussed on disorders associated with high mortality rates such as cardiovascular diseases and cancer, rather than diseases that primarily affect quality of life.

In health care there has been increasing interest in people with chronic illness and the consequence of disease. Dick [2] suggest three reasons for this increased interest in chronic illness :

1) Increase in prevalence of disability due to postponed death, through improved medical intervention and resulting in long-term disabilities.

2) Increased life expectancy , with more elderly in the population who are more at risk for disability .

3) Treatment approaches used for management of acute conditions, do not effectively resolve

management of chronic conditions. [2]

In the context of chronic disease and extended life span, a traditional medical diagnosis has become insufficient on its own.[10] The shift in emphasis is from aetiology of disease, to looking at the impact of disease on the quality of life. It is therefore necessary to consider disabilities and handicaps as consequences of disease and their interrelationship with the broader environment.[9] In 1981 at Alma- Ata, the WHO proposed that the Primary Health Care approach incorporate not only medical treatment in the primary setting but also to include the prevention of disabilities and the provision of rehabilitation. [8] Primary health care should take place not only in formal health services but also in the community and home environment using support structures offered by the family.

Problems experienced on obtaining data are partly due to confused and differing concepts of "disablement " (umbrella term for Impairment , Disabilities and Handicap) and the variety of measuring techniques used and the methodological and logistical difficulties of generating disablement data.(Chaime)[11]

Disablement: concepts and definitions

In the past there was very little uniformity in the definitions used for disability and handicap. The International Classification of Impairments, Disabilities and Handicaps(ICIDH) manual

published by the World Health Organization (WHO) in 1980, was developed in response to these problems, and attempts to clarify thinking about the nature of disablement through providing a structured framework.[12]

This ICIDH provides a structure against which information can be organized, ensuring that each component of disablement is considered.[12]

These components are defined as follows:

Impairment

In the context of health experience, an impairment is any loss or abnormality of psychological, physiological or anatomical structure or function.

Disability

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.

Handicap

In the context of health experience, a handicap is a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfillment of a role that is normal (depending on age , sex, social and cultural factors) for that individual.[12]

This manual has been widely used, but not without criticism.

Impairment

The term health "experience" used in the introduction to the definition of impairment, could be viewed from an objective or subjective perspective, health experienced by the observer, or the persons whose health is being assessed.[13] Brandsma suggests that the observer is objective and the person subjective but that both the observer as well as the person have a subjective and objective view point.[13] From an objective point of view the observer may detect an impairment , but may not be experienced as an impairment by the person, therefore the observer's viewpoint is more subjective. On the other hand the person may experience an impairment without any objective evidence of an impairment.

Whether the word "experience" is important in the definition, is contested by Brandsma et al,[13] as they feel it depends on the purpose of the study. The word "experience" is an important

component in the definition, as it can emphasize the subjective as well as the objective perception of an impairment. For the purpose of first level prevention (reducing the occurrence of impairment), it is important to detect both subjective and objective experiences of impairment, to ensure early detection of impairment for prevention disabilities or handicaps.

Brandsma et al, suggest that the word "abnormal" be replaced with "deviation".[13] For many physiological and psychological functions and anatomical structures there are no universally excepted norms. This deviation from the norm would be from the norm being an average or a range.

Jaffe[14] suggests that there is no such thing as normal. "Science may assert that the average or normal stone in a riverbed is of a certain circumference, say four inches. But Jung points out, you could search and search and never find a stone in that riverbed exactly that size. Normality is an abstraction derived from the study of statistics. It does not exist in reality."

For the purpose of a survey or assessment, the investigator would need to define some norms, but the investigator also needs to respect the person's objective and subjective view of norms. If a person feels an impairment is present, but does not fit within the norms set out by the investigator, this cannot be ignored.

Disability

Using the framework set out by the WHO mentioned above, at which point does one classify a person to have moved from just having an impairment to disability or handicap? The difficulty with disability epidemiology is to define cases, and a more or less arbitrary cut-off point of what is a disability and what is normal must be established, but different investigators choose different cut-off points. The ideas about normal expected activity and behaviour may vary from person to person and is socially and culturally based, therefore subject to the interpretation of the assessor of disabilities.

When you measure disability, in the linear model of IMPAIRMENT - MILD DISABILITY- MODERATE DISABILITY- SEVERE DISABILITY- HANDICAP, are you screening / detecting people with mild disabilities which have no impact in their ability to function in society, or are you detecting moderate to severe disabilities which have an impact on their ability to perform a role which is expected of them (HANDICAP)?
For example: A person who suffered from polio (disease) developed foot drop (impairment), has difficulty running (moderate running disability) , uses a caliper and walks long distances (mild walking disability), attends university and does not see himself as having a handicap.

A further consideration is the availability and use of technological devices , which make activities possible. Dependance on devices or other persons should be incorporated into a severity scale of the ICIDH, when measuring disability. The question of dependance on others

and/ or devices regarding severity grading, is well described in the literature (Brandsma et al).[13]

When assessing an individual's health in terms of disability, one should bear in mind the problem that may arise, when there is a discrepancy between what an individual reports to be able to do and what he is doing in normal life.

Jiwa-Boerriger[15] and Jelles[16] described this as a subjective and objective view of disability. This subjective and objective description for viewing disability is also influenced by the functional system the individual lives in. A disabled person may report that he is able to walk down stairs (subjective) and the assessor could observe him going down the stairs (objective), but the person may not functionally integrate this skill into his normal daily life.

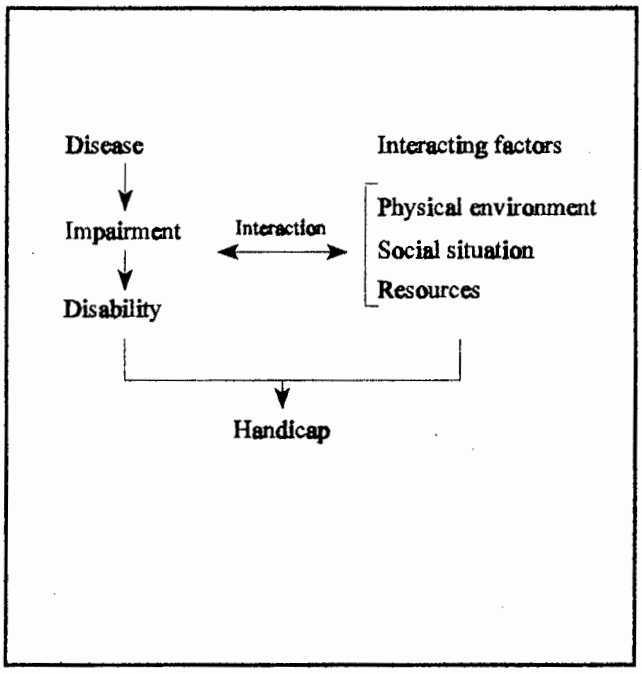
Handicap

The ICIDH and other models are part of a wider understanding of health experiences of people and populations. How these models and definitions are interpreted are influenced by people's family myths or stories, or past experiences of health and quality of life, or handicaps/ disadvantages. [17]

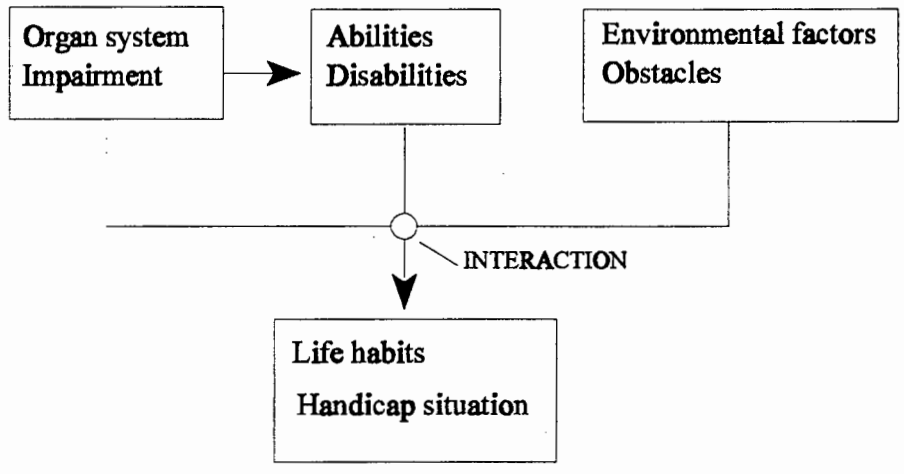
Handicap arises directly from characteristics such as race, gender, socio-economic class, culture and environment. The ICIDH recognizes that these aspects do play a part in influencing the magnitude of the disadvantages but is not part of the ICIDH.

The linear model, presented in the ICIDH, is one of impairment - disability -handicap and that a handicap is a result of an impairment or a disability. However external factors such as physical environment, family and social structure are not addressed in this model.

Badley (1995),[17] recognized the need for change in the linear model and developed a model where external factors interact with the disease process, impairment and disability to change the handicap:



Fougeyrollas et al in 1989[18] revised this model to the "Living Habits " model. Impairments and disabilities are seen as "abilities". Environmental factors are viewed as "obstacles" and obstacles are the key to the handicap creation process.

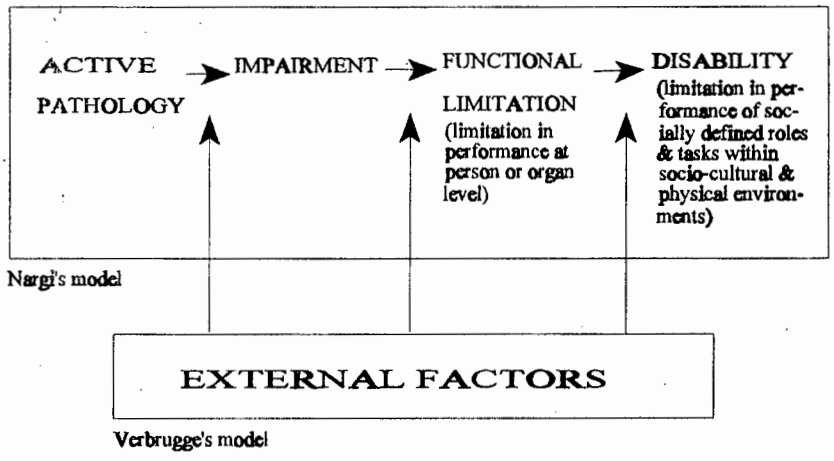


More radical models propose that Handicap arises directly from the environmental factors such as community attitudes, economic opportunity structures and socio-cultural factors, Chaime[11] and Finkelstein [19].

Interaction can be shown as occurring at any stage of the linear model. External factors

influence progress between Disorder - Impairment - Disability -Handicap.[10,11]

Nargi's[20] popular model of sequence of disease, with disability and handicap not separately categorised, was further developed by Verbrugge and Jette[21] to the concept of "Disablement Process".



External factors are described as:

1. Risk factors: demographics, social, lifestyle, behavioural, psychological , environmental and biological.

2. Extra-individual factors: medical care & rehabilitation, medication and therapeutic regimes, external support, environment.

3. Intra-individual factors: lifestyle and behaviour changes, psycho-social attributes and coping, activity accommodation.

In the model, external factors may interact at different stages of the sequence, speeding up or slowing down the process.

Verbrugge and Jette say "disability is not a personal characteristic, but is instead a gap between personal capability and environmental demand."[21]

This socio-medical model of Nargi and Verbrugge is very useful in understanding the disablement process, but has no internationally accepted classification system compatible with it.

Applying the ICIDH to this socio-medical model would group disabilities and handicaps together and as standardisation for international comparison is of concern, the ICIDH cannot be applied to Nargi and Verbrugge's model .

The ICIDH is currently under revision and the challenge is to have a classification system with the versatility to apply different models into the framework.

Currently the ICIDH is the most widely excepted classification system and therefore recommended for use in disability studies.

Prevalence

In 1976, on the bases of a comprehensive literature review encompassing 18 countries, the WHO estimated that 10% of the world's population are disabled.

In the literature however there is great variability in disability prevalence being reported internationally (3%-15.4%) : Table 1& 2 and Figure I reflects this problem.

Chamie's [11] review of the United Nation Statistical Data on disability showed prevalence rates from 0.2% to 20.9%. (Data from 49 countries world wide, Figure I.)

Taking estimates at face value, the evidence suggests that about a third of the population is impaired in some way; a third of those with impairments are disabled to some degree; and a third of the latter experience sufficiently severe restriction in activity as to be handicapped.[22]

Problems experienced on obtaining data are partly due to confused and differing concepts of "disablement " (umbrella term for Impairment , Disabilities and Handicap) and the variety of measuring techniques used and the methodological and logistical difficulties of generating disablement data.(Chamie)[11]

When comparing prevalence, it is important to keep in mind differing age structures and urban/rural distribution of populations. Contradictory figures in the same area (eg. Cape Town) have been reported. This might reflect inconsistency in methodology, definitions and sampled populations, and reduces comparability.

Table 1

Crude disability prevalence: comparison of local and international estimates.

Author and Year of study	Reference	Place of study	Prevalence %
International studies			
Bejamrvicz '78	23	Poland	7.1
Census Study '72	24	The Netherlands	8.7
Census Study '74	25	USA	14.1
Patrick '81	26	London, England	15.4
Census Study '93	27	USA	7.1*
Rodriguez '89	28	Spain	15.0
Finkelflugel '91	29	Zimbabwe	1.6
South Africa			
Dick '78	30	Cape Town (urban)	3.0
Hoffman '88	1	Western Cape (rural)	9.9
Concha '88	31	Gazankulu (rural)	4.5
Cornielje '93	32	Johannesberg (peri-urban)	8.5

* Mobility and self care disability prevalence reported.

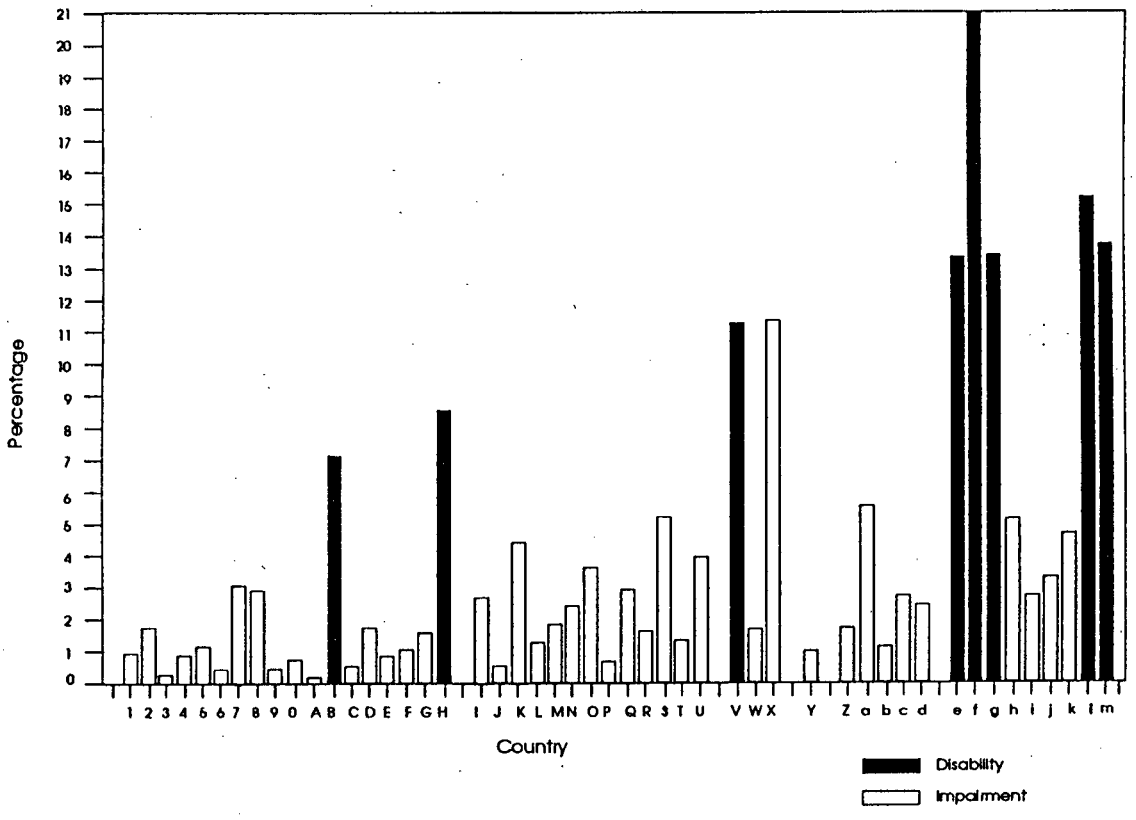
Table 2

Locomotor disability prevalence: Published South African estimates.

Author and Year of study	Reference	Place of study	Prevalence %
Disler '86	3	Cape Town (urban)	1.2
Mc Laren '86	33	Natal (rural)	8.6
Cornielje '93	32	Johannesburg (peri-urban)	2.0
Concha '88	31	Gazankulu (rural)	1.0

Figure 1

PERCENTAGE DISABLED BY DATA-COLLECTION TYPE IN SELECTED COUNTRIES



Total population			Censuses- Economically Inactive		
1	Bahrian	1981	I	Belize	1980
2	Comoros	1980	J	Myanmar	1983
3	Egypt	1976	K	Cape Verde	1983
4	Hong Kong	1981	L	Central African Rep	1975
5	Indonesia	1980	M	Cuba	1981
6	Kuwait	1980	N	Guyana	1980
7	Mali	1976	O	Ireland	1981
8	Netherlands Antilles	1981	P	Kiribati	1978
9	Pakistan	1981	Q	Mexico	1980
0	Panama	1980	R	Philipines	1980
A	Peru	1980	S	Spain	1981
B	Poland	1978	T	Trinidad & Tobago	1980
C	Sri Lanka	1981	U	Venezuala	1981
D	St Helena	1976			
E	Tunisia	1975			
F	Tunisia	1984			
G	Turkey	1975			
H	USA	1980			

Surveys			Surveys- Disability		
V	Canada	1983	e	Australia	1981
W	Egypt	1978-81	f	Austria	1976
X	Uruguay	1984	g	Canada	1986
Y	Thailand	1981	h	China	1987
Z	China	1983	i	Japan	1980
a	Ethiopia	1979-81	j	Nepal	1980
b	Fiji	1982	k	Philipines	1980
c	Swaziland	1983	l	Spain	1986
d	Thailand	1983	m	United Kingdom	1985-86

Adapted from Chamie [11]

International Prevalence

As demonstrated in Table 1, international prevalence rate for all disabilities vary form 7% to 15.4%. [23,24,25,26,27] In all these studies mentioned above the ICIDH was used as a structural framework but figures are still contradictory. The populations sampled in Poland, Netherlands and USA, studies were all census-based, therefore including rural and urban areas, higher and lower socioeconomic classes, with prevalences of 7.1% to 14.1%.[23,24,25] In these developed countries (Table 1), more minor disabilities were detected and counted.

From Chamie's review of international prevalence rates it is also evident that developing countries report lower prevalence rates.[11] This is attributed largely to screening techniques according to Chamie. Developing Countries in Asia and Africa use screening techniques that are impairment specific, resulting in the identification of the most severely (visibly) affected cases of disablement,e.g. profound vision or hearing loss, amputation of a limb or severe behavioural problems. Developed countries use broad-ranging disability survey screens concerning functional and activity limitation such as hearing, walking several blocks, seeing small print, personal care activities or work limitation etc. Broad range disability questionnaires screen in larger proportions of population as disabled (HALS- Used in Canada).[11] Added to the screening tools being more sensitive, cultural factors as well as assessors' interpretation will influence the prevalence.

O'Toole has contested the WHO prevalence of 10% and cited surveys in developing countries

results between 0.7-1.8%.[34]

Zimbabwe's reported figures range from 3.7% (UNICEF) [35] to 0.5% (Red Cross Community based rehabilitation project).[37]

Finkelflugel(1991) identified people in need of rehabilitation in rural Zimbabwe and reported a prevalence of 1.6%.[29]

What is constant is the increase of disability with age and more commonly reported by females, as described by the Royal College of Physicians[36] (England and Wales) and Hoffman et al[1] (Mamre, South Africa).

South Africa:

Historical Background in South Africa

In 1965 a survey was done by Maritz of the white urban populations in all major cities. A "handicap " prevalence of 1.6% was reported. Handicap was measured in terms of employment, as the project was funded and conducted by the Department of Labour.[38]

An editorial by van Rensburg in 1975 emphasized a team approach for successful rehabilitation, and the importance of not just physical independence but also, employment

opportunity as well as social integration.[39] Mann[40] supported van Rensburg[39] , by a plea for improved rehabilitation services in South Africa. The lack of "comprehensive" rehabilitation with complete integration , socially and economically was emphasised as apposed to pure functional independence.[40]

1986 was the National Year of Disabled People and the report produced asked the Local Authorities to consider and address:[41]

i) Accessibility

ii) Employment Opportunity

iii)Equal Opportunity

iv)Disability in Rural areas

v) Prevention and early Detection

Implementation of these recommendations is limited by resources and at Local Authority level very little has been implemented, if anything.

The most recent policy document published (March 1996) by the Government of National Unity was the green paper, Integrated National Disability Strategy. On the basis of public comment , government intends to publish a White Paper on The intergrated National Disability Stratey. Implementation of these strategies will still take considerable time.[42]

Prevalence in South Africa:

In South Africa the national disability prevalence rate has been estimated at 12.5% of the population (Committee of The Year for the Disabled, 1986). As this figure was calculated from aggregated data which may not be uniformly compiled, this figure can be contested.[41] Of more value are local studies with sound methodology which provide satisfactory figures on which to base rehabilitations services.

Prevalence figures for all disabilities in South Africa range from 3% to 8,5% (Table 1). [1,30,31,32] Comparing these figures to the above mentioned international figure, South Africa's prevalence figures are much lower. There does not appear to be any correlation within the rural areas or between different urban areas. Dick (1978), studying a urban population with substrata from different socioeconomic backgrounds (White , Coloured, Black), described a higher prevalence in the lower socioeconomic substrata.[30] This is consistent with the literature, in that greater disability is associated with lower socioeconomic status. [55] Cornielje (1993), also studied an urban population with a more uniform population(Black), dividing substrata into housing type (Formal, Old and New areas, and Informal areas) and within the substrata overall prevalence was uniform. [32]

With lower prevalence being reported in South Africa and also in Zimbabwe, minor disabilities such as learning disabilities, mild mental handicap, psychiatric disabilities , mild visual and hearing disabilities are most probably not being detected. From the literature available for developing countries the reason for the discrepancy in prevalence is not clear.[34]

Locomotor disabilities

Prevalence and Causes

Prevalence of locomotor disability can be reported for individual or otherwise for condition, therefore for extraction of information on prevalence of locomotor disablement from different studies, careful consideration needs to be given as to what prevalence is being reported. One individual may have more than one condition. When collating data from condition specific studies, one cannot add different conditions together to estimate prevalence of locomotor disability per individual.

International: Locomotor Disability Prevalence

Patrick's study (1981)[26] in London on screening for disabilities, shows a prevalence of ambulation and mobility disability of 18/1000 amongst males and 43/1000 amongst females. These results were however markedly skewed by an excess of elderly females. For age group 16-64 years the prevalence is 10.2/1000 which is similar to Disler's study in Cape Town of 11/1000 (16-59yrs).[5] Quoting Patrick's prevalence as e.g. Disler did, of "ambulation and mobility" disability, as a locomotor disability prevalence, but not the category of sensory - motor disability (8/1000 amongst males and 12.1/1000 amongst females), which may have included some individuals with neurological conditions affecting limitation of motor function, would not reflect a true locomotor disability prevalence.

Bennett's study in Lambeth (England), reported an overall disability prevalence of 7.2% for males and 9,7% for females. Amongst this disabled population, locomotor impairment was most common in females (5.1%), with only 2.5% for males.[44] In this study, estimated percentages of primary diagnosis associated with locomotor disablement were categorised into i) Cerebrovascular diseases , with males 0.6% and females 0.4%, ii) Arthritic diseases, with males 0.8% and females 1.7%. [44]

Musculoskeletal conditions were the most frequently reported impairment in the USA Health Interview Survey 1971.[45]

The chronic condition (impairments) reported by people with activity limitation in the USA revealed that Heart conditions were most common (13.4%), followed by Arthritis and Rheumatism (11.2%), Impairments of the Lower Extremities and Hips (5.9%) and Impairments of the Back and Spine(5.8%).[46,47]

When mobility limitation (locomotor disability) was considered in the USA, the reported impairment as main cause, was as follows: Arthritis and Rheumatism (22.2%) , Impairment of Lower Extremities and Hips (10.8%), Heart conditions (8.7%), Cerebrovascular accidents (6.3%) and Paralysis complete and partial (4.4%).[47] Almost one quarter of the persons who report having Arthritis and Rheumatism have mobility limitation because of it. [47]

Finkenflugen in Zimbabwe (1991) reported Orthopaedic conditions at 22% and Neurological

conditions at 28% of reported primary diagnoses for disablement of people in need of rehabilitation.[29]

South Africa : Locomotor Disability Prevalence

The prevalence of locomotor disabilities (Table 2) in South Africa ranges from 1% -2%, with the exception of Mc Laren's study having 8.6%. [3,31,32,33] The four South African studies used similar methododlogy (ICIDH classification, two stage - random cluster sampling, door to door house holdscreening), enabling a cetain amount comparability.

McLaren's study in a remote rural area, confirmed the expectation of high locomotor disability prevalence due to the high prevalence of "Mseleni joint disease", an osteoarthritic joint disease of women.[33] Cornielje proposed that rural areas have higher disability prevalence rates compared to urban areas, but this assumption does not hold true for Concha's study in rural Gazankulu.[31] The prevalence of between 1% and 2% for locomotor disability appears to be consistent, and can be due to the fact that movement disability is more visible and measurable.

Causes of locomotor disability categorised by Disler were : Congenital 5.9% , Trauma 41.2%, Illness 44.1% and Not Known 8.8%. [6]

Concha reports causes of disability in Gazankulu as: Trauma being 27% , Disease 28% , Other 20% and in 26% the cause was not established.[31]

Mc Laren's reported motor impairment rates for conditions as follows: Orthopaedic 14/1000,

Osteo- arthritis of the spine 7/1000, Neurological 4/1000 and Other 6/1000. [33]

Wood [22] suggests that the emergent dominance of chronic disorders in industrial countries, trauma is no longer a leading cause of disability. It is however evident from Disler and Concha that trauma is still one of the leading causes of disability in South Africa.[3,31]

Problems Identified Amongst Individuals with Locomotor Disability

An important aspect for individuals with locomotor disability determining their life outcome, is accessing a wide range of community environments. Intervention through altering the physical environment and providing assistive devices (an interface) for improved functional mobility can assist with integration of the locomotor disabled into society. Rehabilitation service delivery is mainly based within medical institutions, but there is a risk that the actual mobility demands incurred when functioning in a wide range of home and community environments will not be addressed. [48,49]

Some of the problems experienced by individuals with locomotor disability and the use of assistive devices were highlighted by Jacka in Cape Town[4] :

* no knowledge on use of device
* not in use - not suitable
  - not necessary any more
  - different aid in use
* in need of device but never received

Subjects were sampled from a hospital list and all had received institution-based rehabilitation prior to discharge from the hospital.

In Disler's study[3] (coloured community Cape Town), 77% of disabled had not had any contact with a "health care professional" in the three months prior to the study and 59% of the population in need of assistive devices did not possess any.

Egond's follow-up study in rural Venda [50], evaluated the performance of a individuals with locomotor disability rehabilitated through a community based intervention programme. Assistive equipment was a focus of the study.

Everyday use of equipment was reported at 91%, and the state of repair of equipment in 20% was poor. Poor compliance with the use of equipment was greater in the older population, who had intervention more than 10 years post disablement. Egmond cautions against prescribing appliances when it is not functionally important as well as in the elderly.

York [48] emphasizes that participation and feedback by the consumers is essential. Health professionals should provide the expertise, equipment and training but the individual consumer should make the ultimate decision.[48,49]

Rehabilitation

Rehabilitation aims to decrease the impact of the disabling or handicapping condition in order to achieve social integration. According to the WHO expert committee on disability prevention

and rehabilitation(1981), the disabled themselves, their families and the community they live in, should be involved in the planning and implementation of services related to rehabilitation.[8] Rehabilitation services therefore need to be community-based as well as community-orientated.

Disability prevention occurs at three different levels and rehabilitation would be implemented as the second-level and third-level prevention strategy. First level prevention would aim at prevention of impairment and the WHO proposes that this would be the most effective way of dealing with the disability problem.[8]

Once an impairment has occurred, second-level prevention aims at preventing any long term disability. This would require early detection, followed by effective curative care which includes rehabilitation. It is suggested that too low a quality of care may also cause disability.[8] Third-level prevention includes rehabilitative measures for prevention of disability progression to handicap, and diminishing handicapping effects.

In developing countries it is unthinkable that the present problem of rehabilitation could be solved by simple extension of institution-based intervention. The cost and manpower needs would be enormous, not with standing the fact that such rehabilitation intervention has often been ineffective when the individual has to function in his own environment. New types of manpower need to be implemented either through therapy assistants or community rehabilitation workers.

Helander [51] made suggestions for provision of rehabilitation at community level in developing countries, these three facts should be considered: a) simple practical techniques and procedures

could be done by any non -professional person , assisted through guidance and supervision.

b) There is enough eager manpower within the families of the disabled population.

c) Professional manpower could be set up for supervision, guidance and referral.

The broader concept of rehabilitation is poorly understood amongst some "rehabilitation" therapists, as reported by Eales 1993.[52] A postal survey on the perceptions of South African physiotherapists on rehabilitation, demonstrated the opinion that they had a major role in rehabilitation therapy and that they (therapist) and the client were the most important members of the team and the family was not at all important.[52] In stark contrast to this, it has been shown that once the disabled person is discharged from hospital, the responsibility falls entirely on the caregiver at the home, who spends a large portion of the day looking after the disabled person.[53,54]

Futter's study in Mannenberg, Cape Town shows significant improvement in functional out comes of severely disabled people through domiciliary physiotherapy intervention.[55] Similar studies in the United Kingdom also concluded that the best place to train caregivers to ensure successful carry over of rehabilitation programmes learnt in hospitals is in the home environment.[56,57]

Finkenflugel in Zimbabwe showed that community-based rehabilitation deals with a different spectrum of disabilities compared to institution based centers.[29] Community based rehabilitation centres had 37% of disabled population with conditions in the areas of mental

handicap, psychiatric, visual and speech disorders, whereas the hospital based rehabilitation centers had only 6% of the conditions in the above category. This has implication for training community based rehabilitation workers as the demands in community bases rehabilitation are different to hospital based rehabilitation.[29]

The major contribution of the ICIDH to disablement population-based surveys is a conceptual one , in that a common framework now exists as a reference point. Measurement issues remains a major stumbling block. Different screening criteria could be promoted for different purposes, depending on the assessors needs for intervention and prevention strategies. Many studies have been done, internationally as well as some locally. Prevalence figures show great variation. Because of the variation in prevalence figures between studies for similar areas and regions, it would be appropriate to undertake a community based survey in order to plan an appropriate community based intervention service.

METHODS

Study design

A cross-sectional descriptive study was employed.

Study population

The study population consisted of the inhabitants of Mitchell's Plain (approximately 350 000 residents) at the time of the survey (October 1989 to March 1990). Two suburbs (Strandfontein and Colorado) were excluded because they are geographically separate.

Sampling

Sampling strategy

A proportional stratified cluster sampling strategy was used. Stratification was according to residential suburbs. The number of clusters selected for each suburb was proportional to the population size. Thus the sample was weighted for stratum (suburb) population size. Suburb-specific population sizes were based on the 1985 census estimations.

Sample size:

Sample size calculation assumed disability to be a binomial variable (individuals were treated as either having a disability or not.). For binomial variables the formula for random sample size calculation is given as:[66]

$$n = z^2(pq)/d^2$$

n: sample size.

d: required precision (the degree to which data centres around the population proportion).

z: confidence limits of the survey result.

p: the expected proportion who are disabled.

q: the proportion of persons in the population who are not disabled (1-p).

Using this formula the calculation of sample size was based on the following assumptions: an expected crude disability prevalence of 8% (p=0.08); the precision of the disability prevalence estimate to lie within 1,5% of the population proportion (d=0,015); and 95% confidence limits (z=1.96).

A sample size of 1257 was derived from the above stipulations. This formula is specifically designed for the calculation of sample size when simple random sampling strategies are

employed. There is often a tendency for individuals who live in close proximity to share a variety of characteristics. Therefore cluster sampling may result in a loss of precision.

The design effect of cluster sampling is the ratio of variance of the estimate obtained from the cluster sample (which is a complex sample design) to the variance of the estimate as obtained by a simple random sample of the same size. The main use of the design effect is to appraise the efficiency of the cluster sample. The design effect is therefore a function of the degree of homogeneity within sample clusters. The more heterogeneous the clusters are within themselves, the more representative the clusters are of the population and the more precise and unbiased the estimate is when using cluster sampling.[66,67] The design effect of a cluster sample is usually less than two, meaning that the cluster sample size need seldomly be more than double that of a simple random sample to compensate for loss of precision. Using this principle a sample size of 2700 (just more than double 1257) was calculated. The sample size was calculated based on an estimated crude disablility prevalence of 8%.

Based on an estimate of an average of 5 persons per household and one household per plot, it was calculated that a sample of 540 (2700/5) households was required. In order to facilitate the logistics of field work a convenient cluster size was taken to be 15 households, resulting in a final sample of 36 (540/15) clusters. A household was defined as all the people living in a dwelling and eating together.

The sampling methodology consisted of the following:

(i) the most current municipal map (City Council of Cape Town Map number TMS 3017) was used to define the geographical extent of the study population, and to identify individual plots (as indicated on the map). The entire area was then delineated into clusters of 15 plots each. The field coordinator scouted the area in the week before the survey to verify the accuracy of the sampling frame, and to identify and record any recent housing developments that were not indicated on the original map;

(ii) a simple random sample of 36 clusters (proportionally stratified by suburb) was selected;

(iii) all 15 plots within each of the 36 selected clusters were included in the study. All households on a plot, and all individuals within each household, were included. In some instances there were more than one household per plot, resulting in the total number of households being greater than anticipated.

Measurements and Fieldwork

Data collection and measurement took place in two successive phases. Phase I consisted of a household screening questionnaire aimed at detecting the presence of health problems associated with disablement (locomotor and other) in individuals. In Phase II, subjects identified during Phase I as possibly having locomotor disability, were assessed individually to

confirm the presence of disability. Subjects identified during Phase II as having locomotor disabilities, form the subject of this dissertation. The evaluation of individuals with locomotor disability included a qualitative assessment through individual case studies.

Logistics and Fieldwork

The target respondent for Phase I was the female head of the household. This individaul acted as the proxy respondent for all household members. If no such person was present the most senior household member over 18 years of age was interviewed. If no appropriate respondent was present during the initial visit the household was revisited on three occasions, after which it was entered as a non-responding household.

Individuals identified during Phase I, as having health problems possibly associated with locomotor disabiltiy, were the target respondents during Phase II. A trained physiotherapist (the author) undertook home visits and administered the Phase II questionnaire.

Before commencing an interview the purpose of the study was explained and individual consent obtained. A field coordinator set up timetables for visits, allocated clusters to interviewers and checked completed questionnaires. Transport was available from the Community Occupational Therapy Service (COTS).

Measurements

Phase I

All interviews were conducted in the respondents' language of choice. Interviewers were physiotherapy and occupational therapy assistants who had been trained in the standardised administration of the questionnaire during a series of workshops and pilot study in the weeks preceding the survey (Appendix I,Appendix II).

A full census (age, sex) of each household was obtained. Eleven screening questions, based on the WHO questionnaire[58] (but including a question on regular medical/rehabilitation appointments) identified individuals experiencing health problems commonly associated with disablement (Table 3, Appendix II). The eleven questions covered the following health problems:

Table 3. Individual problems probed for in screening

1 Child development
2 Mobility
3 Hearing
4 Sight
5 Epilepsy
6 Mental Health
7 Behavioural
8 Touch Sensation
9 Other
10 Regular Appointments
11 Institutional Care

Positive responses to the initial screening questions were followed by questions related to the reported cause and duration of health problems, and the degree of limitation of functional activities.

The degree of limitation was assessed by questioning individuals on their ability to perform key age-appropriate functional activities (Table 4, Appendix II).

Table 4

Age appropriate Functional activity questions.

Age (years)	
0 - 6	Ability to play like other children.
7 - 16	Ability to attend school.
17 - 46	Ability to work.
65 +	Ability to perform self-care activity.

(Graded as: able, limited and unable)

In order to exclude all acute illness and injuries only individuals reporting health problems of more than three months duration were included as positive responses to the Phase I screening process.

Phase II

All people reported to have a health problem associated with disablement during Phase I, were individually interviewed in their home environment using the pretested Phase II questionnaire (Appendix III). Two occupational therapists assessed individuals with health problems other than those likely to have locomotor disablement. This component of the overall study lies outside objectives of the present dissertation (which focuses on locomotor disability), and has been reported elsewhere.[59]

Individuals identified during Phase I as having health problems possibly associated with locomotor disabiltiy, were followed up during Phase II, and individually interviewed by a physiotherapist (the author). These subjects are the topic of this dissertation.

Screening Questions

In addition to obtaining basic demographic information, the Phase I disability screening questionnaire (Table 3, Appendix III) was repeated in Phase II. Questions were asked directly of positively screened Phase I persons. This step served as validation of the Phase I proxy responses and a means of lessening false positive inclusions in Phase II. Diagnoses given by respondents ("cause of disability") were recorded but were not validated by medical examination, diagnostic testing, or patient health service record review.

Key Age Appropriate functional activities

The degree of limitation was again assessed by questioning individuals on their ability to perform key age-appropriate functional activities (Table 4, Appendix III). On the basis of the individual's ability to perform such activities, and the permanence of the condition, subjects were categorised into disabled and non-disabled groups.

Quantification of Locomotor Disablement

Persons classified as having a locomotor disabililty were then questioned in depth in order to fully assess the extent of their disability and handicap. These questions covered aspects of accommodation and living arrangements; health care and rehabilitation service utilisation; their perceived health and health service needs; and an assessment of the degree and nature of their locomotor disablement.

For the quantification of locomotor disablement in Phase II, a questionnaire (Appendix III) was developed in the framework of the categories proposed in the ICIDH manual.[12] The categories included occupation, social integration; economic self sufficiency; and mobility and physical independence.

Mobility and physical independence were assessed by reported limitations of physical activities and graded according to a scale of "independence" (ranging from "independent" to "not able"). The functional reasons for mobility limitation were recorded in categories (pain, physical, mental, emotional, structural), and the use of assistive devices/aids noted. By making direct observations of interviewees in their home environments the therapist judged the appropriateness of, and the need for assistive devices.

Disability and Handicap Severity Rating

Rating scales for each type of disability and handicap were determined retrospectively. Three therapists discussed each case individually in order to reach consensus concerning disability and handicap rating. The rating scale allowed for the grouping of disabilities and handicaps into the following categories: none, mild, moderate, and severe (Appendix IV).

Handicap

The series of questions relating to each type of handicap provided the raw material for arriving at "handicap" rating for each respondent. The sections of the questionnaire that were used for calculating "handicap" scores included: mental orientation, social integration, self care, occupational ability and mobility (Appendix IV).

Disability

Rating criteria for disabilities were developed from the following sections of the questionnaire: gross motor activity, fine motor activity, endurance dependence, social integration, personal care, communication, appropriate behaviour, and community coping skills (Appendix IV).

Family Perceptions

As part of the final section of the questionnaire a close family member or caretaker of the index person was interviewed in order to document the perception of the family concerning problems relating to the disability.

Qualitative Assessment (Case Studies)

Limiting the information gained from this study to a quantitative analysis would not allow for an understanding of the affected individual as part of a wider system. Each individual's system is unique, and factors influencing the disablement process are not readily gleaned from a unidimentional quantitative measurement.[60] Because of the unique perspective gained as a result of doing home visits and conducting all the interviews with the individual with locomotor disability subjects(41 in total), it was considered reasonable for the author to compile individual case studies to provide deeper insight.

Using the information from the Phase II questionnaires, case studies were compiled on each of the individual with locomotor disability. These case studies represent a profile of each disabled person, and summarise the impact of the disablement process on his/her personal and family life, and integration into society.

Case studies were grouped according to covergence of content and themes. The main groups so identified were the elderly[61] and brain injured. A Futher section of qualitative analysis was a description of one particularly dysfunctional family household with household members rendered handicap due to a genetic arthritic condition. This illustrates the impact of the disablement process on the household.

Quality of data

A 8% sample of the Phase I interviews were repeated to evaluate the reliability of collected data.

False negative responses in Phase I were not confirmed. Only the false positives in Phase I were identified during the Phase II follow up visit of all reported disabled persons.

Analysis

Completed questionnaires were checked for accuracy on a daily basis during the survey. Response data were coded and entered on a mainframe computer (IBM) data base at the Medical Research Council. Data analysis was done by the author assisted by an MRC statistician. The SAS statistical software programme was used for data analysis.[62]

The degree of agreement beyond chance, between the Phase I and repeat study, was assessed by calculation of the Kappa statistic and its associated 95% confidence interval.[63]

Categorical data are presented as frequencies and proportions. The chi-square test was used to test whether associations between variables were statistically significant at the $p < 0.05$ level.[64] The chi-square test for trend was used to test whether the associations depart from linearity.[65]

The prevalence of crude disability and of locomotor disability was calculated using only those subjects who could be identified in Phase I and Phase II of the study. Persons who were not present during Phase II were excluded from the denominator. The prevalence calculation therefore makes the assumption that those lost to follow up had the same proportion of disablement as those who were followed up. In addition to crude locomotor disability prevalence, age and stratum specific locomotor disability prevalences were also calculated. The 95% confidence intervals (CI) of all the above disability prevalences were calculated and

shown in brackets after the prevalence estimates. The overall design effect for the study was 2.2 [59] and the calculation of confidence intervals were adjusted accordingly.[66,67]

Ethical issues

The Medical Officer of Health for Cape Town was informed of the aim of the study. Informed consent was sought from all participants and confidentiality was maintained. Anonymity was not maintained as disabled people were followed up and referred to available health services where indicated. Ethical approval for this study was obtained from the UCT Research and Ethics Committee.

RESULTS

The results will be discussed under the following headings: Phase I (the total population sampled); Phase II (the subjects identified with locomotor disabilities) (Figure 2). Qualitative results will be discussed in the following chapter by means of case studies (a series of descriptions sampled from the subjects with locomotor disabilities).

Phase I - Total sample

The total sample consisted of 2424 people, grouped within 36 clusters, and distributed over 8 strata (suburbs). This constituted 540 plots, and a total of 577 households. Of these households, 474 responded (82.1% household response rate). In 355(74.8%) of the interviews, the household respondent was female with a mean age of 36 years (range 15-83 years).

The total sample (all household members) distribution according to stratum (suburb) and age group is given in Table 5. The age distribution of the sample represents a young population, with 873 (36%) under the age of 15 years, and 88 (4%), who were 60 years and older (Table 5). Stratum specific age distributions were not significantly different, apart from Beacon Valley (p 0.001) and Westridge (p 0.001). In Beacon Valley 45%, and in Westridge 26% of the sample was younger than 15 years.

Figure 2.

Flow diagram of study sample selection during phase I and phase II.

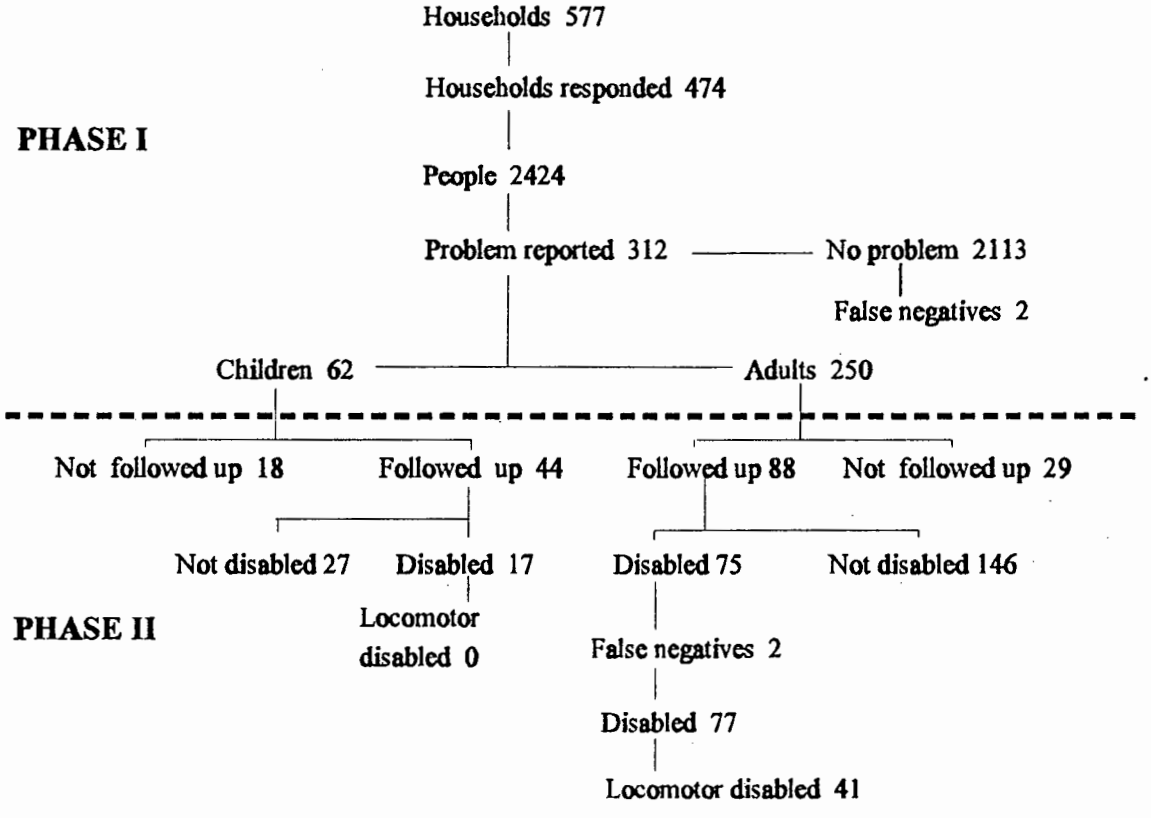


Table 5

Age distribution of household members (identified during Phase I), stratified by suburb.

Age group (years)	Suburb n (%)								Total
	Rocklands	Woodlands	Portlands	Eastridge	Beacon Valley	Tafelsig	Westridge	Lentegeur	
0 - 14	106 (35)	78 (39)	97 (31)	109 (38)	134 (45)	128 (40)	74 (25)	147 (36)	873 (36)
15 - 29	92 (30)	48 (24)	99 (32)	90 (32)	63 (21)	90 (28)	103 (36)	112 (28)	698 (29)
30 - 44	71 (24)	50 (25)	72 (23)	58(21)	74 (25)	66 (20)	54 (19)	95 (23)	540 (22)
45 - 59	20 (7)	21 (10)	33 (10)	14 (5)	17 (5)	31 (10)	46 (16)	39 (10)	221 (9)
>=60	12 (4)	4 (2)	13(4)	12 (4)	11 (4)	8 (2)	13 (4)	15 (4)	88 (4)
Total	301 (100)	201 (100)	314 (100)	283 (100)	299 (100)	323 (100)	290 (100)*	408 (100)#	2419 (100)
X^2 (4 d.f.)	3.1	5.0	4.7	8.5	19.7	3.5	34.3	0.6	
p	0.538	0.285	0.325	0.077	0.001	0.479	0.001	0.967	

* One frequency missing
d.f. = degrees of freedom

In table 6 the age and sex distribution of household members is presented. In the sample 50.5% were female, and there was no difference in the age distribution between the sexes (p 0.177).

Of the households visited 455 (96%) were living in council built homes and 19 (4%) in privately built homes. Three hundred and seven (67%) households lived in self-owned properties and the remainder in rented homes. Fifty seven (12%) of the households lived in renovated homes. There was a median of 1.3 persons per room (excluding kitchen and bathroom) (inter quartile range of 1-1.6), with no significant difference between the rented and self owned homes with respect to the number of rooms or number of people per room.

Reported problems (screening questions)

Three hundred and twelve (12.9%) persons reported problems possibly associated with disablement. Of these 250 (10.3%) were adults and 62(2.6%) were children under the age of 14 years (Figure 2). The findings of the 10 screening questions on reported problems ("difficulties") are shown in Table 7.

Table 6

Age and sex distribution of household members identified during Phase I.

Age group (years)	Male n	(%)	Female n	(%)	Total n	(%)
0 - 14	452	(38)	421	(35)	873	(36)
15 - 29	352	(29)	346	(28)	698	(29)
30 - 44	240	(20)	300	(24)	540	(22)
45 - 59	111	(9)	110	(9)	221	(9)
>= 60	43	(4)	45	(4)	88	(4)
Total	1198*	(100)	1222**	(100)	2420	(100)

Chi-square 6.3; degrees of freedom 4; p 0.177.

Legend:

* Two frequencies missing.

** Two frequencies missing.

Table 7

Problems reported by household members in response to the ten screening questions administered during Phase I and Phase II of the study.

	Phase I		Locomotor disabled	
Reported problems*	**n**	**(%)**	**n**	**(%)**
Child development	4	(0.9)	1	(0.8)
Moving difficulty	24	(5.6)	40	(32.0)
Hearing difficulty	31	(7.2)	7	(5.6)
Seeing difficulty	23	(5.3)	14	(11.2)
Fits	12	(2.8)	1	(0.8)
Mental retardation	23	(5.3)	6	(4.8)
Strange behaviour	6	(1.4)	3	(2.4)
Touch sensation	12	(2.8)	3	(2.4)
Other	158	(36.7)	24	(19.2)
Regular appointments	137	(31.9)	26	(20.8)
Total	430[+]	(100.0)	125[$]	(100.0)

Note:

* Screening questions: Appendix III, page 1.

These frequencies represent reported problems and not individuals.

+312 people reported 430 problems.

$ 41 people reported 125 problems.

Other : Any other chronic health problem.

Reliability

Reliability of Phase I data measurement was evaluated by repeating interviews on a random sub-sample of 47 (8%) households. Perfect agreement was found on type of housing and number of households on plot. Only 6 household members identified during Phase I were not identified in the repeat sample. There was exact agreement with age in 80.2% (186) of household members, with only 4.3% (10) having age discrepancies of 2 or more years between studies.

When assessing each of the 10 screening questions (Table 3, methods) individually, the most disagreement occurred on the non-specific questions asked; question 9 ("What other health problems do you have?) (kappa 0.24, 95% CI 0.10-1.38) and question 10 ("Do you have regular health appointments in the next year?)(kappa 0.41, 95% CI 0.27-0.55). (Questions 9 and 10 were additional questions added to the WHO[58] screening questions on "difficulties".[59] There was minor disagreement on reported diagnoses, but in none of the cases was there complete contradiction in the information found.[59]

Phase II

Twenty nine (11.6%) of the adults reporting problems in Phase I, could not be traced in Phase II. During the Phase II follow up visit to a household member having reported a problem, two

additional persons (false negatives) were identified as having problems and added to the sample. Seventy seven of the 223 adult subjects, with reported problems in Phase I, were followed up and classified as disabled during Phase II (Figure 2).

Forty four (71%) children were followed up in Phase II. Seventeen (38%) of these children were classified as disabled (none of whom had locomotor disability)(Figure 2).

This resulted in a total of 94 (made up of 17 children and 77 adults) disabled subjects in the sample. Excluding subjects that were not followed up in Phase II (18 children and 29 adults), the crude disability prevalence was calculated at 3.9% (95% CI 2.8, 4.9).

Locomotor Disability

Of the 77 adults with disability 41 had locomotor disabilities, resulting in a crude locomotor disability prevalence of 1.7% (95% CI 1.2, 2.2). As there were no children with locomotor disabilities, the adult locomotor disability prevalence (excluding children under 15 years) was 41/(2424-873)-29 = 41/1522 = 2.7% (95% CI 1.6,4.2)

Demographic information of individuals with locomotor disability

Amongst the 41 individuals with locomotor disability, 56.1% were females, and the difference in age distribution between the sexes was not significant (p 0.941)(Table 8). Disability prevalences specific to sex and age categories are given in Table 8. The locomotor disability prevalence increased significantly with increasing age (p 0.001).

Seventy percent (70%) of the individuals with locomotor disability had lived in Mitchell's Plain for 8 years or less. Twenty eight (28) people had been disabled for less than 10 years and the remainder had been disabled for up to 40 years. The individuals with locomotor disability originated from 36 households. Table 9 compares households with adults with locomotor disability adults to households with no reported problems with respect to home ownership, housing construction, and living density. Households with individuals with locomotor disability had a significantly higher living density (persons per room) (p 0.02) and more households per plot , compared to households with no reported problems.

In contrast to Phase I, the interviews in Phase II were conducted, where possible, with individuals with locomotor disability in persons. This resulted in 26 (63.4%) of the respondents being the person with a disability themselves, 8(19.5%) the person with a disability assisted by a care-giver and 7(17.1%)by proxy only.

Table 8

Age and sex specific prevalence for individuals with locomotor disability.

	Males					Females					Total population				
Age group (years)	**LD n**	**%**	**Pop n**	**Prev %**	**95% CI**	**LD n**	**%**	**Pop n**	**Prev %**	**95%CI**	**LD n**	**%**	**Pop n**	**Prev *%**	**95%CI**
15 - 29	2	11	352	0.6	0.0-3.9	3	13	346	0.9	0.1-4.4	5	12	698	0.7	0.1-2.6
30 - 44	2	11	240	0.8	0.0-0.6	4	17	300	1.3	0.2-5.5	6	15	540	1.1	0.3-3.7
45 - 59	8	45	111	7.2	2.2-19.0	9	40	110	8.2	2.7-20.3	17	41	221	7.7	3.6-15.2
>=60	6	33	43	14.0	3.4-38.0	7	30	45	15.6	4.3-39.2	13	32	88	15.0	6.1-30.3
Total	18	100	746	2.4	1.1-4.8	23	100	801	2.9	1.5-5.5	41	100	1547	2.7	1.6-4.2

Notation:
LD = locomotor disabled
Pop = population
Prev = prevalence

* Chi-square test for trend (total population, prevalence by age group): 86.98; df 3; p 0.001

Chi-square (male vs. female frequencies by age group) 0.4; degrees of freedom 3; p 0.941.

Table 9

A comparison of living standards and ownership between households with no reported problems (Phase I) and households with reported locomotor disability (Phase II).

	Households with no problems (n= 272)		Households with locomotor disabled (n = 36)		
	n	(%)	n	(%)	p
No. of households on plot:					
1	241	(89)	27	(75)	
>=2	31	(11)	9	(25)	0.1
Dwelling construction:					
Council	261	(96)	36	(100)	
Privately	11	(4)	0	(0)	0.4
Home ownership:					
Yes	181	(67)	24	(67)	
No	91	(33)	12	(33)	0.9
No. of people per room:					
Median	1.3		1.5		
Range	0.3 - 3.5		0.3 - 3.3		0.02

The reason for the 15 proxy responses were: 5 due to a speech and hearing difficulty, 4 were unable to answer due to some other form of impairment, 1 was unwilling and 4 were not at home. (In one instance the reason for proxy response was not recorded). In the 5 proxy responses due to speech and hearing impairments and 4 due to inability to answer questions, the disabled people were all over the age of 65 years.

The geographic distribution of individuals with locomotor disability is given in Table 10.

Reported impairments

Problems reported by individuals with locomotor disability in response to the ten screening questions administered in Phase II are given in Table 7.

The types of impairments classified according to the ICIDH categories are given in Table 11. Multiple impairments were reported by 26 (63%) of the individuals with locomotor disability.

The age specific prevalence of self-reported primary diagnoses (classified according to ICD-9 diagnostic categories) of individuals with locomotor disabled, is given in Table 12.

Table 10

Locomotor disability prevalence by suburb.

Suburb	Disabled (n)	Adults >14 years	Prevalence %	95% CI
Beacon Valley	7	165	4.2	1.2 - 12.4
Eastridge	7	174	4.0	1.1 - 11.8
Westridge	6	217	2.8	0.7 - 8.9
Tafelsig	5	195	2.6	0.5 - 9.1
Portlands	5	217	2.3	0.5 - 8.2
Rocklands	4	195	2.1	0.3 - 8.4
Lentegeur	5	261	1.9	0.4 - 6.9
Woodlands	2	123	1.6	0.1 - 10.6
Total	41	1547	2.7	1.6 - 4.2

Table 11

Distribution of ICIDH impairment categories in the locomotor disabled group.

Impairment	No. of individuals reporting specific impairments*	Prevalence (%) of impairment amongst the locomotor disabled (n = 41)+
Skeletal	33	81
Occular	11	27
Sensory and neurological	10	24
Visceral	9	22
Muscular	6	15
Psycho-social	5	12
Intellectual	3	7
Aural	3	7
Language	1	2
Disfiguring	1	2
Other	1	2

Note:

* An individual could report more than one impairment.

+Gives the percentage of locomotor disabled who have a specific impairment. Any one individual could have more than one impairment, therefore these percentages do not add up to 100%.

Table 12

Age specific prevalence of primary diagnosis by ICD-9 diagnostic category.

Age (years)	Sample n	ICD-9 diagnostic category											
		Musculo-skeletal			Neurological			Trauma			Other		
		n	Prev %	95% CI	n	Prev %	95% CI	n	Prev %	95% CI	n	Prev %	95% CI
15 - 29	698	3	0.4	0.0-2.2	0	0.0	0.0-1.5	1	0.1	0.0- 1.7	1	0.1	0.0-1.7
30 - 44	540	3	0.6	0.0-2.8	1	0.2	0.0-2.2	1	0.2	0.0- 2.2	1	0.2	0.0-2.2
45 - 59	221	10	4.5	1.6-11.2	2	0.9	0.0-6.1	3	1.4	0.1- 6.8	2	0.9	0.0-6.1
>= 60	88	7	8.0	2.2-22.1	3	3.4	0.3-16.0	1	1.1	0.0-12.7	2	2.3	0.1-14.4
Total	1547	23	1.5	0.8-2.8	6	0.4	0.1-1.3	6	0.4	0.1- 1.3	6	0.4	0.1-1.3

* Psychiatric, metabolic, circulatory, respiratory and unknown.

Utilization of Health services

The distribution of the type of health service attended by individuals with locomotor disaility during the previous year, is presented in Table 13, and the origin of their hospital appointment cards in Table 14.

Health care received and future appointments

Among those with locomotor disability, 20 received Physiotherapy on first becoming disabled. Of these twenty, 10 were never followed up, 6 had no follow up appointment in the following 3 years, and 3 had irregular visits in the past 3 years. Future appointments with health services included 15 with the Day Hospital, 15 with tertiary teaching hospitals and none with paramedical health professionals.

Only 4 people had some form of medical insurance; 2 were on medical benefit schemes and 2 on medical aid.

Expressed needs

Individuals with locomotor disability expressed the following opinions on available medical services: 13 found services to be completely inadequate; 6 required more services; and 22 were satisfied with the services available (Appendix III, question 5).

Table 13

Type of health services attended by individuals with locomotor disability in the past year.

Type of health service	n*	%
Day Hospital +	21	37
Hospital $	20	35
Family Doctor	12	21
Private Specialist	3	5
Other	1	2
Total	57	100

* Indivduals attended more than one health service.

+ Mitchell's Plain Day Hospital

$ Secondary and Tertiary Hospitals.

Table 14

The origen of health service appointment cards among individuals with locomotor disability

Place	n	%
Groote Schuur Hospital	10	39
Day Hospital	8	31
Princess Alice Hospital	4	15
Other	4	15
Total	26	100

In an open ended question regarding any felt needs, 10 individuals with locomotor disability asked for improved medical and rehabilitation services (Appendix III, question 6) .

Home health care

Home based health care consisted of the following: 10 were visited by religious leaders in the past year, 3 by a district nurse and 1 by a social worker (Appendix III, question 3).

Disabilities of Individuals with Locomotor Disability

Disability severity gradings are given in Table 15, and the grading criteria are defined in Appendix IV.

Gross motor disability

Two(2) people reported severe gross motor disability and had difficulty moving around in bed, getting up from lying or moving about in a room. Nine(9) people had a moderate gross motor disability, reporting difficulty with moving between rooms, going outside the house or doing housework due to physical inability. Twenty six (26) people had a mild gross motor disability and were limited (due to a physical inability) in walking longer distances and climbing stairs.

Table 15

Severity grading of individuals with locomotor disability within each ICIDH disability category.

Severity grading	**ICIDH Disability Category n (%)**							
	Gross motor	Fine motor	Personal care	Communic-ation	Behavioural	Endurance dependance	Social	Community coping skills
Mild	26 (63)	6 (15)	14 (34)	6 (15)	5 (12)	21 (51)	12 (29)	17 (42)
Moderate	9 (22)	1 (2)	8 (19)	1 (2)	3 (7)	8 (20)	2 (5)	20 (49)
Severe	2 (5)	0 (0)	1 (2)	1 (2)	1 (2)	0 (0)*	0 (0)	3 (7)
Subtotal	37 (90)	7 (17)	23 (55)	8 (19)	9 (21)	29 (71)	14 (34)	40 (98)
None	4 (10)	34 (83)	18 (45)	33 (81)	32 (78)	12 (29)	27 (66)	1 (2)
Total	41 (100)	41 (100)	41 (100)	41 (100)	41 (100)	41 (100)	41 (100)	41 (100)

*2 Category grading scale.

The four (4) with no gross motor disability were categorised as having a endurance dependance disability and their moving difficulty was due to a shortness of breath or pain, for longer distances.

Fine motor disability

Few people reported a problem in this category, 6 with a mild fine motor disability with some limitation in feeding, doing buttons or physically handling money or medicine and 1 with a moderate fine motor disability , needing human assistance with fine motor tasks.

Personal care disability

Disability in this category was reported in 55% of people, with 14 people reporting difficulty with personal care activities (bathing, toileting, dressing or washing) but being independent of human assistance, 8 people needing human assistance, and 1 person being totally depended on others.

Communication disability

Eight (8) people reported a communication disability and most of them only having a mild disability, needing assistance with answering questions but able to communicate.

Behavioural disability

Only one person had a severe behavioural disability, with this person's behavioural problems impacting on the whole family. The remaining 8 people with behavioural problems were unable to integrate socially , needed supervision for doing tasks, and were unable to take responsibility for certain tasks.

Endurance dependance disability

Seventy one percent (71%) of people reported an endurance dependance disability, with the majority having difficulty with walking long distances or climbing stairs and with the reason for the limitation being pain or shortness of breath.

Social disability

Thirty four percent (34%) of individuals with disability reported a social integration disability, with the majority reporting a mild disability. The median number of disability categories per person (stratified by severity grading of gross motor disability), is given in Table 16.

Table 16

Median number of disability categories per individual with locomotor disability

Gross-motor disability grade	n	Med. no of disability categories affected per person	Range
none	4	2	2-3
mild	26	4	2-6
moderate	9	5	4-6
severe	2	5	0

Handicaps of Individuals with Locomotor Disability.

The severity grading of individuals with locomotor disability within each ICIDH handicap category is presented in Table 17. (See Appendix IV for definitions of handicap categories.)

Mobility handicap

Two(2) people had a severe mobility handicap and were house-bound and needed human assistance and assistive equipment to move about. Twelve (12) people had a moderate mobility handicap needing assistance when moving out of the house. Therefore 14 people were dependent on others for shopping or any other social life outside the home. Twenty five (25) individuals had a mild mobility handicap and were limited in movement or used assistive equipment, but were independent of human assistance.

Self-care handicap

Five(5) people had severe self-care handicaps needing help with two of the following activities: dressing, toileting, or transferring. Eight (8) had moderate handicaps and needed help or supervision with self care activities. Seventeen(17) had mild handicaps in that they were limited in self care activities, but remained independent of human assistance.

Table 17

Severity grading of individuals with locomotor disability within each ICIDH handicap category.

Severity grading	ICIDH Handicap Categories n (%)				
	Mobility	**Self care**	**Orientation**	**Social**	**Occupational**
Mild	25 (61)	17 (41)	8 (24)	19 (46)	12 (29)
Moderate	12 (29)	8 (20)	2 (6)	4 (10)	15 (36)
Severe	2 (5)	5 (12)	2 (6)	*	12 (29)
Subtotal	39 (95)	30 (73)	12 (36)	23 (56)	39 (95)
None	2 (5)	11 (27)	21 (64)	18 (44)	2 (5)
Total	41 (100)	41 (100)	33 (100)**	41 (100)	41 (100)

* Social handicap had two severity grading categories only.

** The evaluation of orientation handicap used proxy respondents, eight of which were not available for interview.

Occupational handicap

Thirty nine (95%) of the group had an occupational handicap. Compared to the other four categories of handicap, occupational handicap had the highest number of people with a severe grading.

Social handicap

Twenty three (56%) reported a social handicap. Nineteen (19) had a mild to moderate social handicap, which hindered their ability to socialize. Four (4) reported a severe handicap of their social life and were dissatisfied with the amount of company they had.

Orientation handicap

This question was answered by a family member, with a resultant response rate of 80% (33/41). Twelve (12) reported an orientation handicap, having difficulty with memory, losing consciousness, and disorientation for person or place resulting in poor self care ability.

Disability and handicap categories by severity grading of gross motor disability

The distribution of disability and handicap categories of individuals within each severity grading for gross motor disability (none, mild, moderate, and severe), is given in Tables 18, 19 and 20.

Those with no gross motor disability (Table 18) but more endurance dependance disability showed disability and handicaps in fewer categories than the remaining groups, in Table 19 and 20 . Even though this group had no gross motor disability, they all had a mobility handicap (limitation in moving longer distances and climbing stairs), limiting their ability to integrate into their environment and society.

Table 19 and 20 represent individuals with greater motor disability and mobility handicap, other categories associated with these groups were community coping skill disability and occupational handicap. Greater gross motor disability also leads to greater limitation in personal care disability and physical independence handicap (Table 20).

Table 18

Grading of disability and handicap categories of individualswith locomotor disability and no gross motor difficulty. (n =4)

	Disability							Handicap				
Grading	**Fine motor**	**Personal Care**	**Commu-nication**	**Beha-vioural**	**Enduran-ce**	**Social**	**Commu-nity coping**	**Mobility**	**Physical indepen-dance**	**Orienta-tion**	**Social**	**Occupa-tional**
Mild	0	0	0	0	2	1	0	3	0	2	1	2
Moderate	0	0	0	0	1	0	3	1	0	0	0	1
Severe	0	0	0	1	0	0	1	0	0	0	0	0
Sub total	0	0	0	1	3	0	4	4	0	2	1	3
None	4	4	4	3	1	3	0	0	4	2	3	1
Total	4	4	4	4	4	4	4	4	4	4	4	4

Table 19

Grading of disability and handicap categories of individuals with locomotor disability and mild gross motor disability. (n=26)

	Disability							Handicap				
Grading	**Fine motor**	**Personal Care**	**Commu-nication**	**Beha-vioural**	**Endura-nce**	**Social**	**Commu-nity coping**	**Mobility**	**Physical Inde pendance**	**Orienta-tion**	**Social**	**Occupa-tional**
Mild	2	10	3	4	13	8	15	17	14	4	12	10
Moderate	1	2	0	3	5	1	10	7	4	0	3	12
Severe	0	0	0	1	0	0	0	0	1	0	0	3
Sub total	3	12	3	8	18	9	25	24	19	4	15	25
None	23	14	23	18	8	17	1	2	7	13	11	1
Total	26	26	26	26	26	26	26	26	26	17	26	26

Table 20

Grading of disability and handicap categories of individuals with locomotor disability and moderate to severe gross motor disability grading. (n=11)

	Disability							Handicap				
Grading	**Fine motor**	**Personal Care**	**Commu-nication**	**Beha-vioural**	**Enduran-ce**	**Social**	**Commu-nity coping**	**Mobility**	**Physical indepen-dance**	**Orienta-tion**	**Social**	**Occupa-tional**
Mild	4	4	3	1	6	3	2	5	3	6	6	0
Moderate	0	6	1	0	2	1	7	4	4	0	1	2
Severe	0	1	1	0	0	0	2	2	4	0	0	9
Sub total	4	11	5	1	8	4	11	11	11	6	7	11
None	7	0	6	10	3	7	0	0	0	4	4	0
Total	11	11	11	11	11	11	11	11	11	10	11	11

Assistive equipment

Twenty five (61.0%) people needed assistive equipment (this included people who owned equipment). Of these 25 people, 6 had no assistive equipment at all and 19 needed additional equipment. Table 21 describes the state of repair of the various types of equipment owned by individuals with locomotor disability for gross motor activity. Table 22 gives a comparison of equipment needed and equipment owned, stratified by the severity of gross motor disability grading. Of the three people using wheelchairs, none could access their home using the wheelchair; nor could they use the chair functionally inside the house due to the confined space in the council built homes.

Socioeconomic data

A description of the level of education, employment status, personal income, and social integration of the 41 locomotor disabled, is presented in Table 23.

Social interaction

Twenty five (25) people reported having between one and three close personal friends (excluding relatives). Of the remaining 16, half had no close friends, and the remainder reported having more than three friends.

Table 21

The state of repair of assistive equipment owned by individuals with locomotor disability.

Equipment type	n	State of repair of equipment			
		Good	Functional	Repairable	Not Repairable
Walking sticks	14	4	7	2	1
Wheelchairs	3	0	1	2	0
Walking frames	1	0	1	0	0
Callipers	1	1	0	0	0
Corset	1	1	0	0	0
Bath seat	2	1	1	0	0
Box next to bath	1	1	0	0	0
Total	23	8	10	4	1

Table 22

A comparison of equipment needed and owned according to gross motor disability grading.

Gross motor disability grade	No. of people	No. of people who could benefit from assistive equipment*	Itemised equipment needs		Equipment owned	
None	4	0		0		0
Mild	26	15	w/stick b/seat rail boots	10 5 2 1	w/stick corset box	7 1 1
Moderate	9	8	w/stick b/seat w/chair ramp frame	5 5 3 2 1	w/stick b/seat w/chair frame	6 1 1 1
Severe	2	2	w/chair b/seat ramp frame rail	2 2 2 1 1	w/chair b/seat w/stick	2 1 1
Total	41	25	w/stick b/seat w/chair rail ramp frame boots	15 12 5 3 4 2 1	w/stick b/seat w/chair corset box frame	14 2 3 1 1 1

*Disregarding current equipment owned.

Notation: w/stick = walking stick; b/seat = bath seat; box = box next to bath; w/chair = wheel chair; ramp = ramp into the house; frame = walking frame.

Table 23

Socio-Economic Data

	n	%
Educational level completed		
No Schooling	5	12
Primary School	18	44
High School	14	34
Not Known	4	10
Total	41	100
Previous employment satus		
Employment pre-disablement	26	63
Employment post-disablement	9	22
Never emlpoyed	6	15
Total	41	100
Income		
Disability grant/pension	26	63
No personal income	15	37
Total	41	100
Grading of social contact		
Complete limitation	5	12
Some limitation	18	44
No limitation	18	44
Total	41	100
Contentment with amount of company		
Happy	23	57
Don't mind	8	20
Would like more	8	20
Would like less	1	3
Total	40*	100

* 1 Frequency missing

Most social contact with friends occurred in the home of the disabled person. Four (4) people had not received any visitors during the past month, and 6 people had not visited their friends' homes in the past month. Even though the majority (33) had home telephones, their use was variable. Four (4) persons never used the telephone, 4 personsused it on a daily basis and the remainder used it only occasionally.

Nineteen (19) people belonged to community organizations or groups, of which 18 were church related and 1 a seniors' club.

Transport

The most commonly used form of transport was by means of a taxi or private car. Nineteen (19) people needed assistance (either in the form of equipment or human assistance) to access a car or a taxi. Only 7 people stated that a private car could be arranged for their transport. Other forms of public transport (bus or train) were inaccessible to 20 people.

Felt Needs

In an open-ended question 25(61%) people indicated their needs. The categories of general need are reported in Table 24 (Appendix III,question 6) .

Table 24

Categories of felt needs as expressed in open ended questions.

Need category	n*
Medical/Rehabilitation	10
Financial	7
Employment	6
Transport	5
Assistive equipment	5
Socialization	4
Domestic assistance	2

Note: * Each person could express up to 3 needs

Appendix III

DISCUSSION

Phase I

The age and sex distribution of the total sample (Table 5 and 6) are compatible with that of a developing population such as Mitchells Plain. This serves to indicate that the sample was adequately selected, and is representative of the population. The reason for Beacon Valley and Westridge having age distributions that were different from the other suburbs, is not apparent. One possible reason is that Beacon Valley is considered to be a suburb with a lower socio-economic status compared to Westridge. But this is speculation and was not further investigated in this study.

Agreement on reported difficulties and age-appropriate activities of daily living between Phase I and the repeat study was excellent. In terms of reported difficulties question 9 and 10 showed the poorest agreement. These two questions were not specific to any particular impairment, as was the case for the other screening questions. Validation of the screening questions was however not undertaken in this study. In a number of international studies, Durkin evaluated the validity of 10 similar screening questions for children 2 -9 years, and found them to be highly sensitive (but lacking in specificity) in detecting serious disabilities; using these 10 screening questions, without clinical confirmation, resulted in overestimation of serious disability prevalence by more than 200%.[68] In the present study the prevalence of

reported problems was 13% (312/2424). It was therefore essential to have a follow up phase (Phase II in this study) in which false positive disabilities could be identified and excluded from the sample.

Phase II

Crude disability prevalence

The crude disability prevalence of 3.9% is substantially lower than the 10% estimated by the WHO(1980).[8] However, this is more in keeping with a more recent estimate by Hellander (1992), giving a global estimate of the prevalence of moderate to severe disabilities at 5.2%.[51] This study would then reflect the proportion of people with moderate to severe disabilities in the community, rather than the full range. The Mitchell's Plain community also has a younger age distribution than that found in developed countries, and thus can be expected to have a lower crude disability prevalence. Thus the criteria for identifying respondents as disabled, plus the screening questionnaire used, determined the type of disability prevalences obtained, and different prevalence are useful for different purposes. In this study people with impairments were identified, and classified as having a disability using age appropriate activities of daily living; therefore excluding people with minor disabilities, not limiting their age-appropriate activity of daily living. Those with minor disabilities are also least likely to require rehabilitative services. Thus, the prevalence measured here is useful in planning rehabilitative

services, as only those with more severe disability are identified. The downside of this approach is that people with minor disabilities that may progress in severity are not detected, and cannot be offered preventive care.

Locomotor disability prevalence

The locomotor disability prevalence of 1.7% is comparable with that of other studies in South Africa.[3,31,32] A possible reason for this consistency is that locomotor disability can be measured with a high degree of reliability. Mobility limitations are easily detected when observing functional activity. This is in stark contrast to the detection of more subtle conditions, such as behavioural disability. The adult locomotor disability prevalence of 2.7% is comparable to Cornielje[32] of 2% (peri-urban area Johannesburg)and Disler[5,6,7] of 1.2%, 1.8% and 1.3% (Cape Peninsula).(These local studies mentioned did not include children in the sample population.) The exclusion of children from the denominator in this study, may however have resulted in an overestimation of the prevalence.

No children were classified as having locomotor disability. The 10 screening questions were not directed specifically at children, except for the first question. Screening questions may therefore have lacked sensitivity in detecting disabled children in this study. Eighteen (18) children were lost to follow up and amongst these, there could have been some locomotor disabled children.

Consistent with the findings of similar studies, the crude and age specific locomotor disability prevalence was higher for females (Table 8).[32,33] Because of the small numbers involved the age specific prevalence figures lack precision, and are not significantly different. An increase in locomotor disability prevalence with age is an recognised trend in other population studies.[11,32,33,69]

Proxy responses

The high proportion of proxy interviews during Phase II does not necessarily detract from data quality. Care givers and family members of persons with disability have an intimate knowledge of the functional abilities of those they attend to. During most of the proxy interviews (11/15) the person witha disability was present and could be observed by the interviewer. Proxy interviews may therefore have enhanced data quality.

As for the overall sample and the households with no reported problems, almost all houses in which individuals with locomotor disability live are council built and the majority of houses are privately owned. Households with no reported problems had a similarly lower living density compared to that of the overall sample (Phase I). However, compared to households with no reported problems, households with locomotor disabled had significantly more people per

room. There were also more households per plot among people with locomotor disabibility (Table 9). Both these findings indicate that the individuals with locomotor disability represent a group with lower socio-economic status.[30,43]

Geographic distribution

Even though not significantly different, the prevalence of individuals with locomotor disability was highest in Beacon Valley (4.2%) and Eastridge (4.0%). These two suburbs are recognised as having low socioeconomic status. Disability is generally more prevalent in poorer populations, and this association might to some extent explain this finding. However, due to small numbers, there were no significant differences between the suburb specific prevalence. A larger sample would be necessary to confirm the association of poverty and locomotor disability in Mitchell's Plain. Knowledge of geographical differences would be useful in planning and targeting future disability prevention programs.

Reported problems

Consistent with what would be expected for locomotor disability, movement difficulty was the problem most frequently reported. The other problems most frequently associated with locomotor disability were seeing difficulties and "other" (Table 7). A high frequency of "Regular hospital appointments" were also reported by individuals with locomotor disability. The 312 people in Phase I reported only 24 moving difficulties. However, the 41individuals

with locomotor disability (who arose out of the sample of 312) reported 40 moving difficulties. This shows that reliance on a single question related to "moving difficulty", would not have proven sensitive enough in detecting all locomotor disabilities. Thus locomotor disability is not only reported as a moving difficulty, but as a variety of other problems. The Phase I screening questions were all answered by the head of the household, and not by the person with a disability. Because the 41 individuals with locomotor disability were interviewed in person, more accurate reporting of specific problems could have been achieved.

Impairments

The high prevalence of skeletal impairments (81%) among individuals with locomotor disability is consistent with what would be expected in this group (Table 11). International studies from developed and developing countries have also reported skeletal impairments (including arthritis and rheumatism; impairments of the lower extremities and hips; and trauma) as being most prevalent.[29,31,33,47] Following on skeletal impairments, ocular, sensory and neurological impairments were most prevalent. Visceral impairments were also frequently reported, and include conditions such as cardiovascular diseases (including hypertension), and diabetes. In turn, these are often predisposing factors for neurological impairments (such as cerebrovascular accidents) and other skeletal impairments (such as amputations).

The high proportion (63%) of individuals with locomotor disability and two or more

impairments is comparable with other reported studies.[1,2,26,32] Because individuals may have multiple impairments, the calculation of a crude impairment prevalence does not constitute the sum of condition specific impairment prevalence. As all impairments were self reported and not validated against medical records or clinical examination, a proportion of impairments could have been misclassified. The extent of such misclassification was not investigated. Such misclassification could have resulted in an overestimation or underestimation of the prevalence of multiple impairments. However, the lack of validation of impairments would not have influenced the validity of the locomotor disability prevalence, as limitation of functional activity (and not impairment) defined disability. It is evident from the case studies (reported below) that multiple impairments were a major contributing factor for disablement in the elderly.

The higher prevalence of musculo-skeletal conditions (1.5%) (compared to neurological (0.4%) and traumatic conditions (0.4%)), is consistent with what would be expected in locomotor disabled individuals (Table 12). In each of the ICD-9 diagnostic categories there is a consistent increase in prevalence with increasing age. Even though these age specific prevalence figures are valid, the small frequencies result in low precision. None of these age specific prevalence figures are significantly different. Again, these are self reported primary diagnoses, and their validity was not verified. Misclassification may have resulted in over or under estimation of specific diagnostic categories. The high prevalence of musculo-skeletal conditions, which is consistent with other studies, does however give some assurance of validity.[44,46,47]

Health service utilisation

Predictably, the day hospital in Mitchell's Plain was the health service most frequently chosen for care. Of note is high attendance at hospitals (at secondary and tertiary levels). This implies that some people with locomotor disability are travelling considerable distances to receive care at hospitals such as Tygerberg, Groote Schuur and Conradie. The need for seeking health care at these distant hospitals could be explained by the fact that at the time of the study there were no public health rehabilitation services in Mitchell's Plain. More that 70% of the health services chosen by individuals wiht locomotor disability were within the public sector. This finding was supported by the information obtained from hospital appointment cards (Table 13). Also, there also was poor follow up care for those who had received rehabilitation at secondary and tertiary institutions in the past. Very few individuals with locomotor disability were using private sector health services, and none used the rehabilitation therapists practicing in the Mitchell's Plain private hospital. As only four (4) people had medical aid or medical benefit scheme coverage, they were dependent on services provided by the public sector.

The low frequency of domiciliary visits by caring professionals is a reflection of the dependance of disabled people on the generally inaccessible public health services. This also indicates the inability of institution-based rehabilitation services to provide follow up of individuals with disability in their home environment. The one exception is religious leaders, and they might provide a link for community based rehabilitation services in the future.

In expressing their needs, individuals with locomotor disability clearly indicated that they require access to local health services that could improve their disabling conditions.

Disabilities

Amongst those with locomotor disability the highest proportion of disability was reported in the categories of gross motor movements and community coping skills (Table 15). Gross motor disability is the defining factor for having locomotor disability, and this explains the high proportion of disability in this category. The four (10%) individuals with locomotor disability and no gross motor disability had an endurance dependance disability such as difficulty in climbing stairs or walking long distances, due to shortness of breath or pain (Table 18). The high proportion (98%) of disability in the category of community coping skills, illustrates the impact that locomotor disability has on their ability to do tasks such as shopping , house work, handle their own finances and take their own medicine.

Within each disability category most people had mild and moderate disabilities, and very few could be graded as having severe disabilities. This could be a true reflection of the prevalence of severe disabilities or otherwise the grading criteria set out by the researcher were not adequate or sensitive enough. The issue of standardization of severity grading for disabilities and handicaps is being addressed in the revision of the ICIDH.

The median number of disability categories per person was directly related to the severity of

gross motor disability (Table 16). Increase in severity of gross motor disability has a greater impact on an individual's ability to function (as defined by disability categories). The impact of moderate to severe gross motor disability affected a median of five different disability categories. Rehabilitation for such individuals would therefore require a wide spectrum of interventions to improve their quality of life.

Handicaps

Mobility handicap and occupational handicap is the most frequently reported handicap categories and this is supported in the literature by Finnstam (Pakistan). [70] The high proportion of occupational handicap is not more common in individuals with greater gross motor disability, but reported to be a problem in the whole group. This could also be contributed to the screening tool used. Individuals screened positive for having a disability when they had an occupational handicap.

The next most reported handicap was self care handicap. Unlike occupational handicap, self care handicap was associated with the individuals with higher severity grading of gross motor disability (Table 19 and 20)

Assistive Equipment

A high proportion of individuals with locomotor disability were in need of assistive equipment, and all those who already owned equipment were not appropriately or adequately supplied.

Walking sticks and wheel chairs were the most commonly owned equipment, and only 35% of all equipment pieces were in good order. Even basic equipment pieces, such as walking sticks, needed only minor repairs and adjustments. The majority of equipment repairs would therefore not require sophisticated workmanship.

Equipment need clearly increases with the severity of gross motor disability. Those with no gross motor disability needed or owned no equipment, but almost all the individuals with moderate to severe categories were in need of equipment (Table 22). The type of assistive equipment varies with the severity of motor disability. Those with mild disability need more walking sticks, and those with moderate or severe disability need walking frames and wheel chairs. Walking sticks are the most commonly needed pieces of equipment. Because of the basic technology and low cost, walking sticks are also readily available within the community. The greatest unmet equipment need is for bath seats. This may be due to a lack of awareness and usefulness regarding this option. A plank over the end of the bath, or using a plastic garden chair in the bath or shower, are simple solutions that would have great impact.

The implication of supplying wheel chairs, is that the living environment must be made easily accessible, as is demonstrated by the need for ramps. Rehabilitation that takes place in the home environment of the person with a disability would ensure better outcomes following intervention, as the intervention is integrated into the environment in which the person needs to function.[48]

Housing in MP is unique in that almost all the units were designed and built by the Cape Town

City Council, and only a small proportion of these had been renovated. Only four basic house plans were used by the City Council, and this has resulted in persons with disability experiencing similar structural and design barriers in their home environment, especially when using assistive equipment. This interaction of the environment, physical mobility and the use of assistive equipment will be further illustrated in the qualitative results to follow.[61]

Socioeconomic status

The very low levels of education predispose this group to more severe occupational handicaps. Higher levels of education allow people with physical disabiility an opportunity to take up employment as white collar workers, whereas those with no education are limited to semi or unskilled labour. The high degree of unemployment post disablement could also be related to the poor educational levels of this group. Even though disability grants (or pensions) are the main source of personal income, a high proportion of those with disability were not receiving such grants.

This group was reasonably content with their amount of social contact, even though the majority reported that their disability limited their ability to integrate socially. Limited social contact does not necessarily indicate dissatisfaction with their situation. Being self conscious about their disability may be the reason why some in this group prefer to limit their social contact.

Almost all the self reported needs of this group were directly related to their poor socioeconomic status. (Table 24) In developed countries some of these needs would be considered as basic rights of people with disability. A higher degree of economic prosperity and independence (in terms of access to care, transport, and equipment) could have had a dramatic impact on their disablement process.

QUALITATIVE DATA

This chapter discusses results of individuals with locomotor disability through qualitative analysis of individual case studies. Two subgroups were identified where common themes manifested, namely the elderly and the brain injured. These two groups are analyzed using the framework of:

A Sociodemographic profile; Physical mobility; Functioning (as an individual, in a family and in the community.) The third section of this chapter describes one household where the members are all affected by a genetic arthritic condition and the impact of this on the quality of life of the family.

Elderly

The population of 2424 people sampled, yielded 24 over the age of 70 years with 9 who were classified as having a disability. (The sample yielded no people between 65 and 70 years.) The elderly were classified as having a disability when they were unable to care for themselves without assistance, thus selecting "disabled" people with handicaps for activities appropriate to the expectations of the elderly.

Sociodemographic profile

In this group of 9 there were 7 females and 2 males. All of them, except one, had schooling of

up to two years and all had done some form of domestic or unskilled work during their working life. One had completed school and had done semi-skilled labour. All in this group were receiving pensions and lived as dependents of their families in council built homes.

Physical Mobility

Physical mobility is dependent on a) the type(s) of impairment leading to a disability or disabilities, b) the specific environment and c) the particular assistive equipment available to the individual.

a) Impairments

A major feature of disablement in this group was the presence of **multiple impairments**, as illustrated by the following two people. (Pseudonyms are used throughout.)

Aziza is a lady, 79 years of age, who was involved in a motor vehicle accident 10 years before, and then developed severe arthritis. She has profound hearing loss, has had a visual impairment since she was of school going age and presently has cataracts. She walks with great difficulty, needing assistance.

Gabiba is a 86 year old lady with poor eyesight, hearing loss and suffers from severe arthritis. She also fell and fractured her hip 8 years before. She is crippled by pain from the arthritis and moves slowly about the house holding onto furniture.

It is clear that the majority of these elderly people had three or more impairments. One does expect a high incidence of hearing and visual impairment in this age group, but when these are added to other impairments, it makes it so much more disabling: a combination of poor eyesight, reduced hearing ability and as well as restricted locomotion, (in the form of arthritis or a cerebral vascular accident which all of them had had), is extremely disabling. All the people in this group were assisted, or had to have proxy reporting for this interview due to a communication disability. The proxy reporting did not negatively influence the data, but rather improved the quality of information as it was mostly the caretakers doing the reporting. It was also interesting to note that all the disabled people had care giver available for the interviews, which suggests that they needed full time supervision. Thus multiple impairments in this group was associated with greater dependance on their caretakers.

b) Environment

The environment, especially the housing structure, posed a real problem, as illustrated by the following example:

Anne, 80 years old, who is wheelchair bound, lives in a single storey council built house with four stairs leading to the front door. An impractical sunken lounge effect was created by adding a little wall at the entrance to the lounge with two stairs leading up and another two stairs leading down. Her bedroom can only be accessed through this lounge and therefore is inaccessible by wheelchair. The standard council size bathroom cannot accommodate a wheelchair at all. When asked about extending the bathroom, (as there were household

members with building skills), it was pointed out that the house was semi-detached and the bathroom could only be extended lengthwise and not in its width, which would still make it inaccessible for a wheelchair. The bathroom leads off the kitchen which is furnished with a table and chairs. Thus her wheelchair is confined to the entrance area of the house. Her 52 year old niece carries her to the bedroom, to the lounge or to the bathroom when necessary. This family with their sunken lounge, demonstrates how one can manipulate an environment to meet one's own aesthetic needs, but it also demonstrates the lack of insight (or motivation) to adapt the environment to accommodate a disabled family member.

All the people in this group live in an environment which is restrictive: all live in simplex or duplex council built homes with tiny rooms and most lived in double storey homes, where the standard design dictates that the living and kitchen areas are downstairs and bedrooms with bathroom are upstairs. The standard bathroom is very narrow and has a bath, basin and toilet with very little space to move. All the council homes are semi-detached with the neighbour's bathroom adjacent, which makes extensions difficult or very expensive. All the homes are small and often very densely furnished, restricting the full use of assistive devices such as wheelchairs and walkers.

c) Assistive Equipment

All 9 people were either using assistive equipment for locomotion, or were in need of some aid as illustrated in the following situations:

Jan uses a walking stick assisted by a tripod bar stool, (or a person, when available,) to move around the house. He solved the problem of the instability of just a walking stick by using a barstool. He received the walking stick from a tertiary hospital at no cost and it is still in good repair. He expressed the need for a wheelchair as he is a very sociable person and would like to use the wheelchair to visit the neighbours. (After evaluation by a professional, a wheelchair and walking frame were recommended for Jan.)

Gabiba has two walking sticks which she also received from a tertiary hospital, also at no cost, but she never uses them. She has a walking frame, which she received from a secondary care hospital, and this is only useful on a very even surface outside the house. It is too clumsy to use inside, so she uses the furniture for support instead. She also requested a wheelchair to improve her mobility in the neighbourhood and for other outings.

Marlene, aged 74, is able to move around the house independently, but when going out to see friends in the neighbourhood, she needs assistance to get out of the house and to cross the road. She asked for an "ysterhand" (a walking stick) to give her the confidence and mobility to go out independently. These three persons show clearly the need for assistive equipment to make them mobile, but also the importance of prescribing appropriate equipment sensitive to

the environment and the individual's specific needs.

Only one person had appropriate assistive equipment and that she inherited from her husband. She had no need for more aids or further intervention to improve physical independence. Four of the nine people needed wheelchairs; of these four, two already possessed chairs: the first had just received a wheelchair from a social worker but had no idea how it functioned. The second person was using a child size wheelchair which she received from neighbours many years ago. This chair was in a bad state of repair, with flat tires, broken foot plates and damaged armrests. She was ingeniously using an old cupboard door over the armrests as a lap-tray. After the home assessment the therapist recommended wheelchairs to the same people who expressed the need for them. These chairs were all predominantly needed for outside use. As reported in the literature, ambulatory disabled people do not use wheeled mobility inside the home [48]. People using wheeled mobility methods, travel much longer distances out door, without using motor vehicles, than those who walk and use assistive devices[44] . With the overcrowding and structural problems of the council-built homes, conventional wheelchairs are not practical for inside use. A chair on casters which can convert into a commode, should be further investigated for inside use.

Seven people had walking sticks; three used them regularly, indicating that these were appropriate for these individuals' needs. Of the walking sticks that were in use, one was privately bought, the second inherited from a husband and the third was received from a sister at the Day Hospital on her request. This shows the important role of the person's own initiative and responsibility taken in deciding on a particular aid. The other four walking sticks were all

still in good repair but inappropriate for the people's needs. A real problem has been identified in the way that aids are being supplied. The aids supplied by institutions far removed from the community, are mostly not appropriate, and are insensitive to the needs of the locomotor disabled person.

Four aspects are crucial and interrelated: the type of disability, the person, the environment and the assistive equipment. They should all be taken into account when determining an intervention to improve the quality of physical mobility of such people.

Functioning as an Individual, a Family Member or a Community Member

Functioning as an Individual (Self-care)

Self-care was chosen as a means by which to screen for "handicap" in this age group, as age-appropriate activity of daily living. For all nine people there was some form of assistance needed in the area of self-care. Those with moderate disabilities, needed some assistance with washing and often with grooming. The more severely affected people also needed assistance with transfers. Neither of the two people with wheelchairs could access the bathroom or accommodate a wheelchair in the bathroom. Two families independently had a self-engineered bath board to assist them with transfers and with bathing. This eases the burden of the helper and makes the elderly person less dependent and more confident in caring for him- or herself.

Functioning as a Family Member (Dependence)

Families often have to take the responsibility on themselves to care for their disabled, elderly relatives, as there are no homes or home help service available for this community. Old Jan, 92 years old, is living with his daughter who has taken care of him for ten years since his stroke. She would like to " put him in a home, as he needs someone at home for him all the time"

Anne, whom we have already discussed, has only been with her niece for one year. She moves to different family homes every few months.

Joan has been living with her daughter for two years, and feels very isolated as all her friends are still in Stellenbosch. She had to leave her home there due to her disabling arthritis.

The onset of a disability seems to force the elderly to move in with relatives. Others, who have been disabled for many years, are moved around to different family homes. This moving around of the disabled to different homes, has also been noted by the Community Occupational Therapy Service(COTS) working in Mitchell's Plain . The dynamics within the family often have to change to accommodate the locomotor disabled dependent family member. Modifying each home environment for the "mobile" disabled person, as he or she moves to different homes would also have economic implications.

Functioning in the Community

The disabled elderly are still part of society but what social contact do they have? Gabiba, with both sensory and motor impairments often enjoys visitors at home, but only gets out to visit others by car, or goes to church when she feels well enough. Her church leader also pays regular visits to her at home when she is unable to attend church. She needs assistance to get out of the house but requires a private car for transport. The family does not have a car or a telephone in the house, and any social contact for her is a big effort.

This group of elderly people felt that their disability has affected their social life. By living in family homes they do become part of the social activities at home, but the rest of the family often feels burdened as their own social life outside the home is restricted due to the dependence of the live-in elderly member. This implies that all people who belong to religious groups are visited at home by their religious leaders, in many instances as often as three times a month. Those with telephones at home and with a minor communication disability, use the telephone regularly to contact their own friends and relatives. The majority of the visitors to the home are friends of the family, not necessarily the elderly person's particular friends. Yet, the elderly who are living with their relatives and not in institutions, are naturally exposed to much more social interaction.

The next person demonstrates clearly the complexity with which many themes interact on the disablement process.

Aziza has severe visual and hearing loss and is crippled with arthritis. She is unable to climb stairs or even walk independently, and lives in a double storey council type house with her daughter. With any flare up of her arthritis, she is limited to the top storey of the house as this is where her bedroom and the only bathroom of the house are situated. Because of the confined space in the bedroom, and the size of the bathroom, her newly acquired wheelchair cannot be used upstairs. The wheelchair can also not move about down-stairs in the living area due to the furniture arrangement and the small space available. Her wheelchair was used as an armchair instead. The caretaker was overjoyed when shown that the wheelchair could actually fold up, and had many other functions as well! The wheelchair was ordered and delivered by a social worker two weeks prior to our visit but Aziza had been taken out for a walk only once since acquiring the wheelchair. Her caretaker carried her outside, put her into the chair, took her for a walk and carried her back inside. She cannot care for herself: she needs help with dressing, with toileting and with bathing. In the bathroom the family had devised a bath board to assist with transfers, which enables them to still get her into the bath. The daughter said that she found it difficult to cope by herself as her mother needs total care, and this she found too demanding as she has to run the household as well. She felt she needed extra domestic help to cope with the situation. When feeling better, the elderly mother gets out to visit friends once a month. She also reported that people only tend to visit her when she is ill. She felt her disability affected her contact with other people. When asked how she felt about the amount of company she had, she was happy . Their home however has no telephone. Her religious leader does pay her visits at home on a regular basis.

For the purposes of this section, different themes were dealt with separately, and illustrated by vignettes. These themes are all so interlinked that in order to do a true quality of life assessment, the person must be assessed considering all aspects of life in a system's approach and Aziza clearly illustrates this.

Multiple impairments complicate the disablement process and lead to different disabilities and handicaps. These need different or unique solutions, sensitive to the specific needs of the person in his specific family and social environment. A traditional medical diagnosis, while very useful as a starting point, is reductionistic and thus real depth and meaning is lost.

Adult brain injured people

Sociodemographic profile

There were 10 people who could be categorised with brain injury as the primary impairment. The age range was 35 to 92 years, with 8 males and 2 females. Amongst the brain injured there were 4 over the age of 70 years who were part of the elderly group discussed above. The 6 younger people in this group had slightly better schooling but all 10 people in this group had been employed in the semi-skilled or unskilled work sectors. Four of the people had no source of income and were dependent on their families or friends.

Both Moegamat(89 years), and Peter(53 years) are stroke victims and have no income. They are both living with a friend, a 23 year old mother with 2 toddlers.

John, 31 years old, was involved in a motor vehicle accident 5 years previously, is living with his parents and has no income. He has aggressive outbursts, and this causes severe stress within the family. He has nothing to do and is bored, this then causes him to wander around in the neighborhood.

Mike aged 53, was involved in a motor vehicle accident 2 years previously. He lives with his wife and children and they have no income at present. He suffers from depression and avoids any social contact outside the family. His wife has kept the family together but says she is now desperate.

The remaining six people were on disability grants or pensions and therefore were not fully dependent on their families or friends financially.

The four households living as nuclear families with the breadwinner rendered disabled, manifested greater social and financial difficulties, especially as three of the persons were involved in motor vehicle accidents which is often associated with behavioural and personality disturbances. The spouses in these households reported the great amount of stress they were experiencing in coping with running a household and caring for the family.

Physical Mobility

All 10 in this group had poor gait patterns due to brain injury, but were independent for walking on the level inside the home (some needing walking aids for independence). Most reported difficulty with negotiating stairs and needed assistance or a grab rail. Eight out of ten used or needed assistive equipment for mobility. Five people used walking aids of which 3 were used regularly, all were received from friends, and 2 needed repair. Four people needed aids in the bathroom and one person needed a wheelchair.

Functioning as an individual, as a family member, in the community.

Functioning as an individual

In the area of self-care 7/10 needed assistance in the bathroom and with getting dressed. Assistive equipment in the form of a chair or a bath board with grab rails on the wall, would render people independent in the bathroom.

Functioning as a family member

Five of the people were the breadwinners of their families prior to becoming disabled and the change of role within the family, especially the three who were involved in motor vehicle accidents, had great impact on the family dynamics. The difficulties in functioning as a happy nuclear family unit, were evident.

Functioning in the community

Only 2 of the 10 reported that their disability had not influenced their social life.

Moegamat, 89 years, who suffered a stroke which resulted in severe speech and locomotor disabilities, feels he has always been a loner and his disabilities have had no effect on his social life.

Again, those who had personality changes after brain injury, had difficulty in coping socially according to their care givers, either by being awkward in company or totally withdrawn from society, or, at the other end of the spectrum, being socially inappropriate, always being out visiting friends but never receiving friends in their own homes and having no close friends.

Rod, 35 years old, was a victim in a motor vehicle accident 5 years before, lives with his wife and children. He is socially awkward in front of other people and therefore never socialises outside the home.

Health and rehabilitation services used

Three people had never received physiotherapy and presently none are on any rehabilitation programme. Six had regular hospital appointments of which 4 were with the local Day Hospital and 2 with both the general practitioner and Groote Schuur Hospital. Half (5/10) were of the opinion that the medical services were too few.

Mike, whom we have discussed before, has a minor locomotor disability and also suffers from depression, has attended the Day Hospital, a general practitioner, Groote Schuur Hospital, and a private specialist in the past year- the only person who has attended more than two different health services in the past year, and he is of the opinion that the health services are" much too few". From the assessor's point of view Mike is receiving adequate medical follow-up, but from his own point of view, health services are "much too few". This difference highlights the problems encountered when determining health service needs, yet the person who is being assessed, often with a strong subjective viewpoint , has to be considered as well.

Moegamat, whom we have discussed before, has attended no health services in the past year, is of the opinion that medical services are adequate.

The opinions on the perceived need for medical services by the people with needs, vary, and at

times seem contradictory to the need for intervention assessed by the medical services, the outsiders.

Many themes discussed in the elderly group are common to the brain injured, but to a lesser degree. With lesser physical mobility handicaps, the physical environment does not have as great a restrictive impact on the activities of daily living as with the elderly. What seems to cause greater handicap is the area of social and financial circumstances and their implications on the family unit.

Household family impairment

This household with all members affected by an osteoarthritic disease, with the exception of one child, are discussed as a unit, to illustrate the impact of the disease on families.

Barbara is a 42 year old lady living with Regina, her sister, and their children, all in a simplex council-type house. The husbands of both these sisters left them because they could not "cope" with their families' disabilities. This household reported difficulty in getting out to socialise outside the home and attribute this to their limitation in physical mobility.

Barbara and her daughter, Jessica aged 17, are both handicapped by the disease. Her 4 other children were positively diagnosed as having osteoarthritis but are not showing obvious

permanent disabling symptoms at present. Barbara, a morbidly obese lady has been affected by osteoarthritis for the past 30 years. On first becoming disabled, she received no rehabilitation therapy. She and her whole family are monitored at Princess Alice Orthopaedic Hospital twice a year. She does, however, feel that medical services are far too few. Financially she is dependent on a maintenance grant which she receives for her family. Her divorced husband does not pay any maintenance. Barbara walks very slowly and often needs assistance from two of her children to move about.

She is able to do all her self-care activities independently but is restricted by pain. She is not able to climb stairs and this poses a problem as a taxi is her only means of accessible transport. Due to her difficulty with walking she expressed the need for transport and domestic help. She would benefit from a walking stick, especially for longer distances eg. getting to public transport.

Jessica, aged 17, still attends the local school and is in standard 7. She has received physiotherapy and occupational therapy at Princess Alice Hospital in the past three years. She received crutches from the Hospital, but these now need repairing. Her opinion on available medical services is that there are enough, but she would like to stop school as she feels she can't cope physically any more. Jessica dislikes using crutches, finding it socially embarrassing, but is forced to, due to pain. She is independent for all her activities of daily living by using her crutches.

Regina, a sister of Barbara, aged 35 and her daughter Carmen, age 16, are both disabled by

osteoarthritis. They are both limited by pain in all their activities of daily living but fully independent. Mother Regina, the only physically independent adult of the household, often gets painful spells and the children are left to run the house. Carmen feels limited by the osteoarthritis as she is unable to partake in the school sports activities. This family is in need of outside domestic help as only the younger children of the family are not disabled by the disease as yet.

When this whole household was noted, on analysis of the quantitative data, it was viewed as a skewed representation of disability prevalence, but from a qualitative point of view it made good sense to note that is was due to their disabling conditions that these two sisters and their children were forced together.

Conclusion

Qualitative analysis was used as " Measurement is not the goal, but rather knowing and understanding."[71]. Through qualitative study, data collection and concept generation often occur simultaneously, the one complementing the other.[72]

An interview in the home environment gives a better understanding of the person's needs, where the person comes from and how the person and the carers have to cope. To assist a disabled person to greater independence and better quality of life, a health care worker needs to go to the living environment of that persons, listen, and be sensitive to all the aspects of this particular individual's life. This is supported by the literature. York[48] also recommends that evaluation and training of the disabled need to happen in the environment in which the person needs to function.

To help disabled people, quantitative data relating to the disability and circumstances of the person is necessary to make technically correct decisions. To help them in an appropriate and comprehensive way, we are dependent on the qualitative data that can only be obtained by entering and observing the person's own environment.

CONCLUSION

The prevalence of locomotor disability in this study was slightly higher than other reported studies in the Cape Town area. This high prevalence confirms the great need for rehabilitation services in the Mitchell's Plain community.

This study was completed a few years ago, but no new public health services or expansion of services have been developed in the Mitchell's Plain area since. With the time that has passed, the population has grown and the needs can only be greater.

The impairment- based screening questions which were used, identified only people with severe impairments, whereas activity limitation screening questions could have resulted in an even higher prevalence.

Even though some of the individuals with locomotor disability have had some exposure to rehabilitation services, the level of physical, social and economic integration was limited. Their movement disability resulted in poor mobility in their homes and in the wider neighbourhood, which resulted in the high mobility handicap rate.

Qualitative analysis of individuals in their home environments was most useful in identifying and understanding how the locomotor disabled cope within their own systems.

The interrelationship of their impairments, physical and social environment and wider community helps to understand the uniqueness of each individual's problems. Because of this in depth knowledge, more appropriate intervention strategies can be sought.

RECOMMENDATIONS

Measurement of disability must be appropriate for developing appropriate interventions. Surveys for detecting minor impairments are not useful for planning rehabilitation strategies. Studies should be directed to specific communities rather than large scale population surveys. Because of differences in endemic diseases, environmental factors (housing design, streets and side walks, access to services and socio-economic status), rehabilitation needs are area- and community specific.

For future study in detecting children with disabilities, the screening questions need to be child specific to ensure adequate screening. This would mean the sample population needs to be children, or a separate questionnaire needs to be administrated to detect the children with disabilities.

With the overcrowding and structural problems of council built homes, conventional wheelchairs are not practical for inside use. A chair on casters which can convert into a commode, should be futher investigated for inside use.

A community-based rehabilitation service is recommended as the most appropriate means of rehabilitation of individuals with locomotor disability in Mitchell's Plain: domiciliary based intervention would be functionally orientated, realistic equipment would be provided

and realistic referrals would be made. This would help those with locomotor disability by decreasing their travelling cost to health or rehabilitation services.

The Community - based Occupational Therapy Service (COTS), which is currently still providing a service through private funding, should be taken over by the public health services and used as a model for future rehabilitation services.

REFERENCES

1) Hoffman M, Pick W, Joubert G et al. Morbidity profile of Mamre community. S Afr Med J 1988;**74**: 358-361.

2) Dick B, Wolf E, Watermeyer G S, et al. Chronic illness in non-institutionlised persons I. S Afr Med J 1978; **53**: 892-904.

3) Disler P. Trends and future development in the Western Cape. Patterns and predictions in the area of health: Physical Disabilities. Conference on the Western Cape, July 1986. Centre for African Studies, University of Cape Town.

4) Jacka E, Disler P.B, Sayed A, Hoffman M.N, Watermeyer G.S, Coping with chronic illness. Part I. Locomotor disabled. S.Afr Med J 1984; **65**: 850-853.

5) Disler P B, Jacka E, Sayed A R, Rip M R, Hurford S, Collis P. The prevelance of Locomotor disabilities and hadicaps in the Cape Peninsular. Part I S. Afr. Med. J.1996; **69** : 349-352.

6) Disler P B, Jacka E, Sayed A R, Rip M R, Hurford S, Collis P. The prevelance of Locomotor disabilities and hadicaps in the Cape Peninsular. Part II. S. Afr. Med. J.1996; **69** : 353-355.

7) Disler P B, Jacka E,Sayed A R, Rip M R, Hurford S, Collis P. The prevelance of Locomotor disabilities and hadicaps in the Cape Peninsular. Part III. S. Afr. Med. J.1996; **69** : 355-357.

8) WHO Tech Rep series No. 668. Disability prevention and rehabilitation.WHO, Geneva, 1981.

9) Greenwood J G, Disability dilemmas and rehabilitation tension, a 20th Century inheritance. Soc. Sci. Med. 1985; **20**: 1241-1252.

10) Minaret P, Disease, Illness and Health- theoretical model fo the disablement process. Bulletin of WHO 1992; **70** (3): 373-379.

11) Chamie M, Survey design stratergies for study of disability. World Health Statistics Quaterly 1989; **42**: 122-147.

12) International Classification of Impairments, Disabilities and Handicaps. WHO, Geneva, May 1976.

13) Brandsma J W, Lakerveld-Heyl R, van Ravensberg C D, Heerkens Y F. Reflection on the definition of impairment and disability as difined by the WHO. Disability and Rehabilitation. 1995; **17** (3/4): 119-127.

14) Jaffe L W.Liberating the Heart: Spirituality and Jungian Psychology. Inner City Books, 1990:83

15) Jiwa-Boerriger H, Engelen H G M, Lankhorst G J. Application of the ICIDH in rehabilitation medicine. International Disability Studies. 1990; **12**: 17-19.

16) Jelles F, Bennekom C A M, Lankhorst G J. Revalidatie - activiteiten protiel gebaseerd op de ICIDH. [Rehabilitation Activity Profile based on the ICIDH] Bewegen & Hulpvelening. 1993; **10**: 36-40.

17) Badley E M. The genesis of handicap: definition, models of disablement, and role of external factors. Disability and Rehabilitation. 1995; **17**(2): 53-62.

18) Fougeyrollas P, St-Michel G, Blouin M. Proposal for revision of the third level of the ICIDH: handicap. Quebec: Canadian Society for the ICIDH/Quebec Committee on the ICIDH. ICIDH International Network. 1989; **2**: 9-17.

19) Finkelstein V. Planning sevices together with disabled people: the importance of a common language. World Health Statistics Quarterly 1989; **42**: 177-179.

20) Nargi S Z. Disability concept revisted: implications for prevention. In disability in America: Toward a National Agenda of Prevention (Edited by Pope A M and Tarlow A R) pp309-327. Division of Health Promotion and Disease Prevention, Institute of Medicine. National Acadamy press, Washington DC 1991.

21) Verbrugge L M, Jette A M, The disablement process. Soc.Sci. Med. 1994; **38**(1): 1-14.

22) Wood PHN. Prospects of control. Capter 7. Disability prevention: the globle challange. ed Wilson J . Oxfort University Press1983; 87-97.

23) Bejnarowicz J. Disabled persons in Poland. Soc Sci Med 1984; **19**: 1141-9.

24) The Physically Handicapped in the Netherlands 1971/1972, p12. Staatsuitgevery, The Hague,1976.

25) National Center for Health Statistics. Limitation of Activity and Mobility Due to Chronic Conditions: United States 1974, p.3. Vital and Health Satistics Series 10,No.111, Rockville, MD, 1977.

26) Patrick D L, Darby S C, Green S, Horton G, Locker D, Wiggins R. Sceening for disability in the inner city. J Epidemiol.Community Health. 1981; **35**: 65-70.

27) Prevalence of Mobility and Self-Care Disability - United States 1990. MMWR, CDC 1993; **42**(39): 760-767.

28) Rodriguez P,G. Using the ICIDH in surveys: The case of Spain. World Health Satistics Quaterly 1989; **42**: 161-166.

29) Finkenflugel HJM. Identifying people in need of rehabilitation in rural Zimbabwe. Central African Journal of Medicine 1991; **37**: 105-110.

30) Dick B, Spencer I W F, Watermeyer G S, Bourne D E, Woff E M P, MoyleG D. Chronic Illness in Non-institutionalized Persons, Part I. Prevalence and Epidemiology. S.Afr.Med.J. 1978; **53**: 892-903.

31) Concha M, Lorenzo T. The prevalence of disability in a rural area of South Africa, with special reference to moving disabilities. S A Occupational Therapy 1993 (November):6-15.

32) Cornielje H, Ferrinho P, Coetzee D, Reinach SG. Development of a community based rehabilitation programme for a poor urban area in South- Africa. A Disability prevalence study- Part I . CHASA Journal 1993; **4**(1): 26-32.

33) Mc Laren P.A, Gear J.S.S. et al. Prevalence of motor impairment and disability in a rural community in KwaZulu. Int. Rehab. Med. 1987; **8**: 98-104.

34) O'Toole B. Community based rehabilitation (CBR): Problems and Possibilities. European Journal of Special Needs Education 1987; **2**(3): 170-190.

35) Ministry of Labour and Social Services. UNICEF Report on the National Disability Survey of Zimbabwe. Harare, 1982.

36) Journal of the Royal Collage of Physicians of London 1986; **20**: 59-194.

37) Zimbabwe Red Cross Society. 6 Months Report- April, May, June, July, August, September 1996, for Mutoko Project. Internal publication, Harare, Zimbabwe 1986.

38) Maritz JS. Handicapped people in the Republic of South Africa. Rehabilitation in S A 1965 (September) : 111-12.

39) van Rensburg NJG. An overall perpose in rehabilitation. Rehabilitation in SA 1975 (March): 1.

40) Mann GA. The case for comprehensive rehabilitation. Rehabilitation in S A 1976(December) :81-85.

41) Disability in the Republic of South Africa. Co-ordination Committee: Year of Disabled Persons1986. Department of National Health and Population Development. Main Report. 1987(November); **1**:15.

42) Integrated National Disability Stratery of the Government of National Unity. Government Gazette. Mach 1996 ,Vol 369 : No 17038.

43) Taylor D. OHE Briefing No 15 London: Office of Health Economics. 1981; 1-12.

44) Bennett A E, Garrad J, Chronic Disease and Disability in the Community: A Prevalence Study. British Medical Journal. 1970; **3**: 762-764.

45) Prevalence of Selected Impairments ,United States, 1971. National Centre for Health Statistics. 1975. Series 10, Number 99.

46) National Centre for Health Statistics.1974. Chronic Conditions Causing Activity Limtation. United States, 1969-1970. Series 10, Number 96.

47) Kelsey J L. Epidemiology of M usculoskeletal Disorders.Oxford University Press. 1982.

48) York J. Mobility methods selected for use in home and community environment. Physical Therapy . 1989; 69(9): 736-744.

49) Lerner -Frankiel MB, Vargas S, Brown M, et al: Funtional Community Ambulation: What are your criteria? Clinical Management in Phyical Therapy 1986; **6**(2): 12-15.

50) Egmond KC, van den Broek CJ, Rehabilitation in rural areas: A study to evaluate the effectiveness of a rehabiltiation programme in a group of locomotor disabled Vendas. S Afr Fam Prac 1987; 8: 79-86.

51) Hellander E. Prejudice and dignity - An Introduction to community Based Rehabilitation. Unihel Natures Development Programme, Geneva Switzerland 1992.

52) Eales C J, Nowitz L, Motona B. South African Physiotherapy perception of rehabilitation. S A Journal of Physiotherapy 1993; **49**(3): 45-49.

53)Gloag d. Needs and Opportunities in Rehabilitation. British Medical Journal 1985; **290**: 368-372.

54) Putterhill J S, Disler P B, Jacka . Coping with chronic illness. Part II. The carer. S Afr. Med. J1984; **65**: 891-894.

55) Futter MJ. Fostering community development, utilising domicilary physiotherapy as a tool. S A Journal Physiotherapy 1996; **52**(3): 62-66.

56) Frazer FW. Rehabilitation within the community. Faber and Faber 1982.

57) Foster A, Young J. The Role of Community Physiotherapy for stroke Patients. Physiotherapy 1990; **76**(8): 495-496.

58) Helander E, Mendis P, Nelson G. Training disabled people in the community. A manual on community based rehabilitation for developing countries. WHO, Geneva, 1983.

59) Katzenellenbogen J, Joubert G, Rendall K, Coetzee T. Methodological issues in a disability prevelance study : Mitchell's Plain, South Africa. Disability and Rehabilitation 1995; **17**(7): 350-357.

60) Patton M.Q, Qualitative Evaluation Methods. Sage Publications. Beverly Hills,1980.

61) Coetzee LT, Katzenellenbogen J, Rendall K. Coping in Mitchell's Plain: A Qualitative Analysis of a Group of Handicapped Elderly in the Community . S Afr Fam Pract 1993; **14**: 341-346.

62) SAS Institute Inc. SUGI Supplemental Library User's Guide,1983 Edition Cary, NC:SAS Institute,1983.

63) Fleiss J.L. Statistical methods of rates and proportions.2nd Ed. John Wiley and Sons. New York,1981:217-225.

64) Armitage P, Berry G. Statistical Methods in Medical Research .2nd Ed.Oxford: Blackwell Scientific Publications,1987.

65) Fleiss J.L. Statistical methods of rates and proportions.2nd Ed. John Wiley and Sons. New York,1981:143-146.

66) Cochran WG. Sampling Techniques 3rd ed. New Delhi: Wiley Eastern,1977.

67)Kish L. Survey sampling.John Wiley and Sons. New York,1967:88.

68) Durkin M S, Hasan Z M, Hasan K Z. The ten question screen for childhood disabilities: its uses and limitations in Pakistan. J.Epidemiol Community Health 1995; **49**(4): 431-436.

69) Badley E.M, Tennant A. A Suvey of disablement in a British population using an action-orientated measure, physical independence handicap: proplems with activities of daily living and level of support. Intr. Disabil. Studies1991; **13**: 91-98.

70) Finnstam J, Grimby G, Rashid. Use of the WHO classification in assessing the prevalence of disease, impaimants and handicaps in Punjab province, Pakistan. World Health Statistics Quaterly 1989; **42**: 157-160.

71) Brink H. Quantitative verses Qualitative research. Nursing RSA Verpleging. 1991; **6** (1) : 14-18.

72) Pinder R. Ways of seeing; Doctor Patient talking about the diagnosis of Parkinson's disease. S Afr. Fam. Pract. 1993; **14**: 244-249.

APPENDIX I

Interviewer training and pilot study

The Phase I interviewers were trained over three days. This included:
- overview of the study
- interviewing techniques and role plays
- checking completed questionnaires and coding
- involvement in pilot study

The Phase II interviewers were also trained over a two day period. This included :
- role plays
- standardization of questions and recording of responses
- pilot study

Pilot Study:

Phase I was piloted in an area of Mitchell's Plain not falling in the chosen sample.
The Phase II pilot study was conducted among Heideveld day hospital attenders (disabled) at their homes. The pilots aimed to:
- evaluate the questionnaires
- improve standardisation (through repeat interviews)
- additional training

APPENDIX II

MITCHELLS PLAIN DISABILITY STUDY
PHASE 1

Card no: 1   1

Area no

Cluster no: 4

Household no:

Interviewer team: 8

Address of house: ....
....
....
....

How many families are living on this plot/house?

Number of households in unit: (household = all those who live together and share food)

Response: 1. Yes 2. No

If no response: Reason for non-response: 11

Telephone number:

Respondent:

Name:.................................... Age:...... Sex: 14

Family member: 1. Yes 2. No
Member of household: 1. Yes 2. No

Type of dwelling:
1. Council built house
2. Private developer built house
3. Flat
4. Other (specify ....)   17

Is this house renovated? 1. Yes 2. No

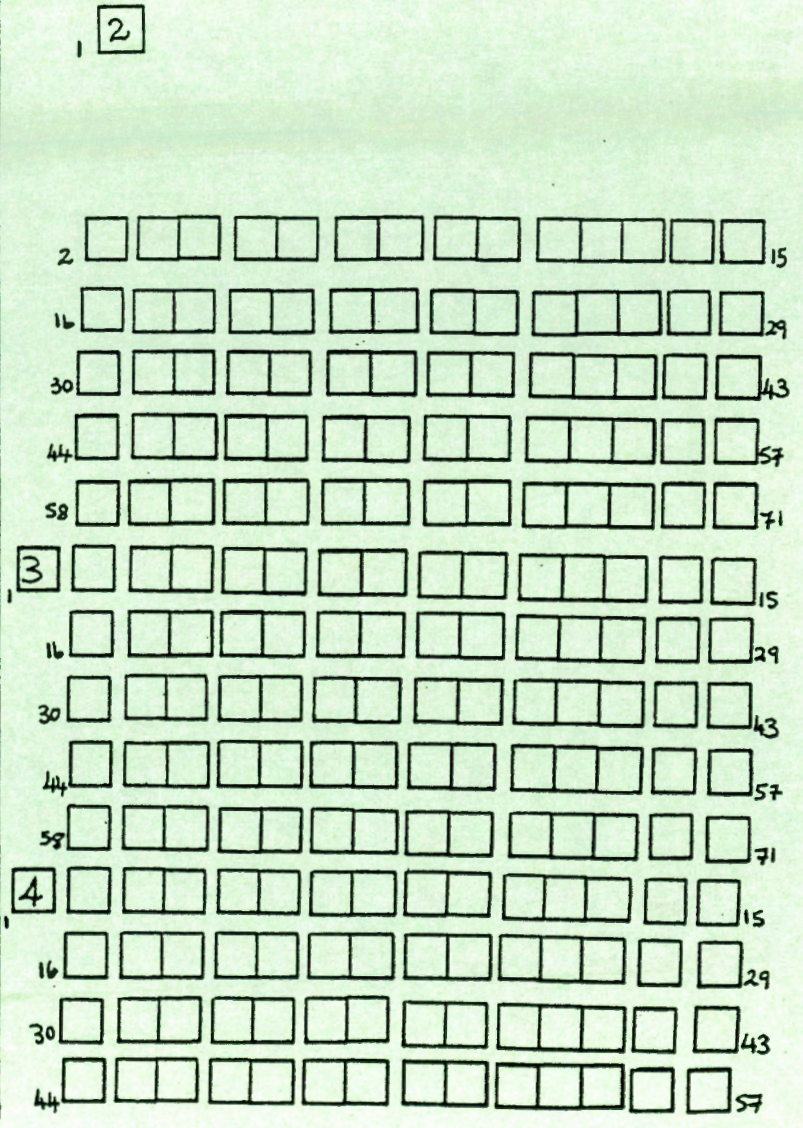
Tenure:
Do you own this house? 1. Yes 2. No

If NO, do you
1. rent
2. sublet
3. other (specify ....)

Number of rooms (excluding bathroom and kitchen):   22

Residents: (Everybody living in this household):

Surname	First names	Sex	Age	Difficulties 1. child 7. strange 2. moving 8. sensory 3. hear/talk 9. other 4. seeing 10 appointment 5. fits 11 institution 6. mental	Reason for difficulty	Key activity 1. not at all 2. limited 3. able	Duration of limitation
1.							
2.							
3.							
4.							
5.							
6.							
7.							
8.							
9.							
10.							
11.							
12.							
13.							
14.							



SCREENING QUESTIONNAIRE

PHASE 1

If YES to any of questions below, fill in details next to name of appropriate person on census sheet

1. Are there amny children in this household who are different to other children of the same age?

2. Does any person have difficulty with moving?

   for example:
   - walking
   - holding/carrying/lifting things
   - does anyone use a wheelchair/calipers/crutches/walking stick/special shoes

3. Does anyone have difficulty hearing and/or talking.

4. Does anyone have difficulty seeing (well enough to go to the shops by him/herself?

5. Does anyone have fits/epilepsy?

6. Does anyone have a mental problem - is anyone slower in thinking or learning than other children or people?

7. Does anyone have strange behaviour?

8. Does anyone have difficulty with feeling in any part of his/her body?

9. Does any person have any other problems not described above? Describe.

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

10. Does anyone in the house have regular hospital/clinic/doctor's appointments? What for?

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

APPENDIX III

Card Number: [1] 1

MITCHELLS PLAIN DISABILITY STUDY

PHASE II QUESTIONNAIRE

Disability number: [ ][ ][ ] 4

Area number: [ ]

Cluster number: [ ][ ] 7

Household number: [ ][ ]

Interviewer number: [ ] 10

Date of interview: [ ][ ][ ][ ][ ][ ] 16

Name of index person: _____

Respondent: 1. Self 2. Proxy 3. Both [ ]

IF PROXY, reason: .....

Relationship of respondent to index person: _____ [ ] 19

DOB: [ ][ ][ ][ ][ ][ ] 25

Age: [ ][ ]

Sex: 1. Male 2. Female [ ]

SCREENING CHECK

1. Is this child different to other children of the same age? [ ]

2. Do you / does X have problems with moving? [ ] 30
   for example: - walking
   - holding / carrying / lifting things
   - does anyone use a wheelchair / calipers/ crutches/ walking stick / special shoes

3. Do you / does X have difficulty hearing hearing and/or talking? [ ]

4. Do you / does X have difficulty seeing even when you are wearing glasses? [ ]

5. Do you / does X have fits / epilepsy? [ ]

6. Do you / does X have a mental problem - are you slower in thinking or learning that others? [ ]

7. Do you / does X have strange behaviour? [ ]

8. Do you / does X have difficulty in feeling in any part of of your body? [ ] 36

9. Do you / does X have any other problems not described above? Describe: ☐ 37

.....

10. Do you / does X have regular hospital / clinic / doctor's appointments? What for? ☐

.....

11. Is there anyone in this household, who is living in an institution because of a disability? ☐

IF YES TO ANY OF THE ABOVE QUESTIONS:

Key: 1 - Unable
2 - Limited
3 - Able

IF THIS PERSON IS A PRESCHOOL CHILD (BELOW 6/7):

Can he/she take part in play? ☐ 40

If yes, when he/she plays, is it

* fully
* limited in type or amount of play ☐ ☐ 0

IF THIS PERSON IS A CHILD OF SCHOOL GOING AGE (7 - 16):

Can he/she attend school? ☐

If yes, is it

* an ordinary school
* a special school ☐ ☐
* an ordinary school which makes special provision for the child to attend classes

IF THIS PERSON IS AN ADULT:

Can he/she work? ☐

If yes,

* Is he/she limited in the type or amount of work he/she can do? ☐ ☐ 45

IF THIS PERSON IS AN ADULT WOMAN:

Can she do housework? ☐

If yes,

* is she limited in the type or amount of housework she can do? ☐ ☐ 47

IF THIS PERSON IS AGED (65+):

Can he/she care for him/herself? ☐ 48

If yes,

* Is he/she limited in the type or amount of self-care the he/she can cope with? ☐ ☐

What caused(s) your problem/disability.
Description in own words: (prompt for natural vs unnatural causes)

How did the doctor describe the cause(s) of your problem? (Diagnosis)

	Unprompted	Prompted
1.		
2.		
3.		

☐☐☐ ☐☐☐ 55
☐☐☐ ☐☐☐ 61
☐☐☐ ☐☐☐ 67

How long have you been disabled? .....months ☐☐

.....years ☐☐ 71

(Prompt with age or dates if needed)

IF THERE IS NO DISABILITY, DISCONTINUE.

LIVING ARRANGEMENT

CARD 2 ☐ 1

Are you living:

	Yes	No	
1. alone			☐
2. as a boarder			☐
3. with parent(s)			☐
4. siblings			☐
5. with legal or common law spouse			☐
6. with your child(ren)			☐
7. with other relatives			☐
8. with friends			☐
9. other (specify .....)			☐ 10

How long have you lived in Mitchells Plain? .....years .....months ☐☐ ☐☐ 14

HEALTH CARE AND REHABILITATION SERVICES

Please fetch all hospital or clinic cards.

	Hospital/clinic	Number	
Card 1			☐☐ ☐☐☐☐☐☐☐☐☐☐ 26
Card 2			☐☐ ☐☐☐☐☐☐☐☐☐☐ 38
Card 3			☐☐ ☐☐☐☐☐☐☐☐☐☐ 50

Utilization

CARD 3 ☐ 1

1. In the past year, what health services have you used for any complaint?

	1. Yes 2. No	Specify complaint	
Day hospital			☐ ☐☐ ☐☐ 6
House/family doctor			☐ ☐☐ ☐☐ 11
Hospital			☐ ☐☐ ☐☐ 16
Private specialist			☐ ☐☐ ☐☐ 21
Other			☐☐ ☐☐ ☐☐ 27

2. I would like to know what health services you received when you were first disabled?
A few services will be named which might not apply to you.

	1. Yes 2. No 3. Don't know	Specify place	When last 1. Not since first disabled 2. Not in last 3 years 3. Irreg. in last 3 years 4. regular in last 3 years	
Operations				☐☐☐31
Physiotherapy(exercises)				☐☐☐
Occupational therapy				☐☐☐39
Speech therapy				☐☐☐
Psychological support				☐☐☐47
Any involvement in groups (specify .....)				☐☐☐☐52
Other				☐☐☐☐57

3. Who has visited you at home to render a social or health service in the past year?

	Unprompted 1. Yes 2. No 3. Don't know	Prompted 1. Yes 2. No 3. Don't know	When last	
District sister				☐☐☐60
Social worker				☐☐☐
Religious leader (example)				☐☐☐66
Occupational/physiotherapist				☐☐☐
Organisation (specify .....)				☐☐☐72
Other				☐☐☐75

4. I want to know which health services are you going to in the next year.
(prompt: weekly, monthly, infrequently or once a year)

CARD 4 1

Do you have an appointment at:

	1. Yes 2. No	Specify name	Frequency	Reason
Day hospital				
Private general practitioner				
Hospital: medical				
social				
paramedic				
Private specialist				
Other				

☐☐☐☐
☐☐☐☐
☐☐☐☐
☐☐☐☐
☐☐☐☐
☐☐☐☐
☐☐☐☐ 4

Needs

5. Concerning services for your disability, would you think there are

1. enough
2. some, but would like more ☐ 44
3. much too few.

6. Mention three things that you need that would help your condition or help your family
(do not prompt, only rephrase)

1. _____ ☐☐
2. _____ ☐☐
3. _____ ☐☐ 50

7. Are you on a medical aid? 1. Yes 2. No ☐ ☐

Are you on a medical benefit scheme? 1. Yes 2. No ☐ ☐

Comments:

☐☐

Name of general practitioner or family doctor _____ ☐☐ 56

HANDICAP

I am now going to ask you about how you manage your everyday life.

I. MOBILITY AND PHYSICAL INDEPENDENCE

Level of independence

KEY

1. Independent
2. Independent but limited
3. Use of equipment
4. Human assistance
5. Supervised
6. Equipment and human help
7. Not able

LIMITATION REASON KEY

1. Pain
2. Physical inability
3. mental inability
4. feeling that you are unable/unwilling
5. structural problem
6. other (specify .....)

CARD 5 ,

1. Movement:

Do you:

	Grade	If applic. specify aid	Reason for limitation	
- move around in bed				☐☐☐☐ 5
- move within a room				☐☐☐☐
- move between rooms				☐☐☐☐ 13
- move out of the house				☐☐☐☐
- cross the street				☐☐☐☐ 21
- go around 4 blocks/1km				☐☐☐☐

2. Stairs:

Do you:

	Grade	If applic specify aid	Reason for limitation	
- go up one step				☐☐☐☐ 29
- go up 2-5 steps				☐☐☐☐
- go up to the first floor				☐☐☐☐ 37

3. Transfers:

Are you able to:

	Grade	If applic. specify aid	Reason for limitation	
- get up from lying to sitting and stay sitting				☐☐☐☐
- get into and out of bed				☐☐☐☐ 45
Discontinue subsection if unable				
- get on and off the toilet				☐☐☐☐
- get into bath/shower				☐☐☐☐ 53
- get out of bath/shower				☐☐☐☐ 57

ONLY FOR LOCOMOTOR DISABLED

What assistive devices do you have? (Must be seen or accounted for & write down on list below)

KEY FOR FREQUENCY OF USE
1. Daily
2. 2 - 3 times per week
3. Once a week
4. Once a month
5. Irregularly
6. Never

KEY FOR STATE OF REPAIR
1. Good
2. Functional
3. Repairable
4. Irreparable

Assistive device	Where received	How often used (see key)	State of repair (see key)	Had repairs done	Where	How long	Problems	Suggestions

III SOCIAL

CARD 7 1

a) About how many families in your neighbourhood are you well enough acquainted with that you visit each other in your homes?

.....families

b)* About how many close friends do you have - people you feel at ease with and can talk with about what is on your mind (can include relatives)

1. None 2. 1-3 3. more than 3 ☐ ☐4

c) During the past month, about how often have you had friends over to your home? (excluding relatives)

1. Every day
2. Several days a week
3. About once a week
4. Two or 3 times in past month ☐ ☐
5. Once in past month
6. Not at all

d) About how often have you visited with friends at their homes in the past month?

1. Every day
2. Several days a week
3. About once a week
4. Two or 3 times in past month ☐ ☐
5. Once in past month
6. Not at all

e) About how often did you talk with close friends or relatives on the telephone during the past month?

1. Every day
2. Several days a week
3. About once a week
4. Two or 3 times in past month ☐ ☐
5. Once in past month
6. Not at all
7. No telephone

f) About how many voluntary groups or organisations do you belong to - like church groups, clubs, parent groups

..... groups or organisations Specify .....
.....
.....

☐☐ ☐ ☐11
☐ ☐

g) Some people are happy with the amount of company they have. Others would like more company and some don't mind either way. How do you feel about the amount of company you have?

1. Happy
2. Don't mind
3. Would like more ☐ ☐14
4. Would like less

h) How does you disability effect you contact with other people?

1. No effect 2. Limits some 3. Limits completely 4. Other (specify effect .....) ☐ ☐

Please explain if limits:.....
.....

☐☐ ☐☐ ☐☐

IV ECONOMIC SELF SUFFICIENCY

Highest standard reached at school? _____ □□ 23

I am going to ask you about training and education that you did after school.

1. studies at university	1. Yes 2. No	□
2. diploma or technical training (a year or more)	1. Yes 2. No	□
3. short formal courses (less than a year)	1. Yes 2. No	□
4. in-service training	1. Yes 2. No	□ 27
5. informal training (specify.....)	1. Yes 2. No	□ □
6. other (specify .....)	1. Yes 2. No	□ □ 31

Where do you get money to live on?

	Unprompted	Prompted	
	1. Yes	2. No	3. Don't know
1. Wages/salary			□ □
2. Home industry			□ □
3. Grant/pension			□ □
4. Family			□ □ 39
5. No income			□ □
6 Other (specify .....)			□ □ □ 44

If respondent is over 15 years and not at school.

1. Have you ever worked for money? 1. Yes 2. No □ □

IF YES

2. Are you currently employed? 1. Yes 2. No □ □

IF YES:

a) Town/suburb of employment ..... □□ 48

b) Describe your job .....
.....
..... □

c) Employment sector:
1. Open labour market - formal sector
2. Protected workshop
3. Informal sector
4. Other □ □

□□□ 53

d) How often do you work?
1. Full day, every day (5-7 days a week)
2. Half day, every day (5-7 days a week)
3. 3-4 days a week
4. 1-2 days a week
5. irregularly

☐ ☐54

e) Does this support you?
1. Completely
2. More than half
3. Less than half
4. None

☐ ☐

3. Have you worked since your disability? 1. Yes 2. No ☐ ☐

If YES: ☐

Describe the first job you had after the disability ☐☐☐60

Place of work ..... ☐☐

4. Did you work before you were disabled? 1. Yes 2. No ☐ ☐

Describe the job you had before you were disabled ☐64 ☐☐☐

Place of work ..... ☐☐69

Subjective judgement on quality of information. ☐ ☐

Observation:

Activity observed: _____ ☐☐

Grade: ☐ ☐74

Description in words: _____

_____

_____

_____

_____

_____

_____

_____

CARD 8 1

FAMILY QUESTIONNAIRE

Index person: .....

Family response: 1. Yes 2. No ☐

Reason for non-response: .....

Respondent:

- Relationship to index person .....
- Caretaker 1. Yes 2. No ☐
- Age .....
- Sex 1. Male 2. Female ☐

I would like to ask you about .....

What caused(s) his/her problem/disability.
Description in own words: (prompt for natural vs unnatural causes)

How did the doctor describe the cause(s) of his/her problem? (Diagnosis)

	Unprompted	Prompted
1.		
2.		
3.		

How long has s/he been disabled? .....months

.....years

(Prompt with age or dates if needed)

Orientation

1. Does he/she sometimes loose consciousness?

   1. Yes 2. No ☐

2. Does he/she sometimes get confused about where he/she is or who he/she is?

   1. Yes 2. No ☐

   IF YES:

   Does this effect his/her ability to take care of his/herself?

   1. Yes 2. No ☐

☐☐

☐

☐ 5

☐

☐

☐☐

☐ 10

☐☐☐ ☐☐☐ 16

☐☐☐ ☐☐☐ 22

☐☐☐ ☐☐☐ 28

☐☐

☐☐ 32

☐

☐

☐ 35

3. Does he/she sometimes lose his/her memory to the extent that it effects his/her ability in taking care of self?

1. Yes 2. No ☐ ☐36

KEY
1. Yes
2. No
3. Partial

4. DOES S/HE::

	Knowledge	Physical ability	Responsibility
a) take his/her own medicines			
b) handle his/her own money			
c) use the telephone			
d) shop for groceries or clothes			
e) do his/her housework			
f) prepare his/her own meals			

☐☐☐39
☐☐☐
☐☐☐45
☐☐☐
☐☐☐
☐☐☐54

CARD ☐9☐1

5. I want to know which health services are s/he is going to in the next year. (prompt: weekly, monthly, infrequently or once a year)

Does s/he have an appointment at:

	1. Yes	2. No	Specify name	Frequency	Reason
Day hospital					
Private general practitioner					
Hospital: medical					
social					
paramedic					
Private specialist					
Other					

☐☐☐☐
☐☐☐☐
☐☐☐☐
☐☐☐☐
☐☐☐☐
☐☐☐☐
☐☐☐☐
☐☐☐☐4

Needs

6. Mention three things that .... needs that would help his/her condition or help the family (do not prompt items, only rephrase)

1. .....
2. .....
3. .....

☐☐45
☐☐
☐☐49

7. Concerning services for ...., would you think there are

1. Enough
2. Some, but would like more
3. Much too few

☐ 50

8. How has X's disability affected the way household chores are managed in the family?

Effect (unprompted):

☐☐ ☐☐ 54

Reason:

☐☐ ☐☐ ☐☐ 60

9. How has X's disability affected the amount of contact with other people the family has?

Effect: 1. more contact
2. less contact
3. same as before
4. other (specify .....)

☐ ☐

Reason:

☐☐ ☐☐ ☐☐ 67

CARD 1 ☐1☐0

10. How has X's disability affected the way money matters are in the family?

Effect:

☐☐ ☐☐ 6

Reason:

☐☐ ☐☐ ☐☐ 12

11. How has X's disability affected the way people relate in the family?

Effect:

☐☐ ☐☐ 16

Reason:

☐☐ ☐☐ ☐☐ 22

12. How has X's disability affected the way the family spends its free time?

Effect:

☐☐ ☐☐ 26

Reason:

☐☐ ☐☐ ☐☐ 32

13. Mention three things that .... needs that would help his/her condition or help the family (do not prompt items, only rephrase)

1. .....
2. .....
3. .....

☐☐ 34

☐☐

☐☐ 38

Subjective observations about family

Category of impairment

- intellectual	1. Yes 2. No	☐ 39
- psychosocial	1. Yes 2. No	☐
- language	1. Yes 2. No	☐
- aural	1. Yes 2. No	☐
- occular	1. Yes 2. No	☐
- visceral	1. Yes 2. No	☐ 44
- muscular	1. Yes 2. No	☐
- skeletal	1. Yes 2. No	☐
- disfiguring	1. Yes 2. No	☐
- general sensory or neurological ...	1. Yes 2. No	☐
- other (specify .....)	1. Yes 2. No	☐ 49

APPENDIX IV

DISABILITY SEVERITY GRADING IN PHASE II

Each case was dicussed by the researchers on the basis of the information in the full phase II questionaire. The diagnosis and the memory of the actual interview sometimes influenced disability grading. They were graded on a scale of 1-3, where 1= mild, 2= moderate, 3= severe. Grading was done on a concensus basis

The method used for arriving at a grades for each case in each category is as follows:

Gross Motor (Appendix III p 7)

Mild = any limitation in ability to go around 4 blocks or go up to first floor, or go shopping due to physical inabilities.

Moderate = any limitation in ability to move between rooms, or go out of the house, or do housework due to physical inabilities.

Severe = any limitation in moving around in bed and within a room, and from lying to sitting due to physical inabilities.

Fine Motor

Any limitation in ablity to feed, comb hair, butten a shirt, handle money or medication, due to physical limitations-Appendix III p8 and 9.

Mild = where grading is 1-3.(ie. independent,independent but limited, use of equipment.)

Moderate = where grading is 4-5.(ie. human assistance, or supervised.)

Severe = where grading is 6-7. (ie. equepment and human help, or not able to at all.)

Personal Care

Any limitation in ability to use the toilet, bath or wash body, dress and take medicine for any reason. Appendix III p8 and 9.

Mild = where grade is 1-3 (ie. independent, independent but limited, or use of equipment.)

Moderate = where grade is 4-5 (ie. human assistance,or supervised.)

Severe = where grade is 6-7 (ie. equipment and human help, or not able at all.)

Communication

Factors taken into account in allocating mild, moderate or severe were :

* needing assistance with answering the questionaire or unable to answer for self , due to mainly a speech impairment rather than intellectual or behavioural problems.

* sensory problems ie. blindness or deafness affecting ability to make self understood or understand others. (It was found that there was not adequate information to use for categorising this section easily.)

Behavioural

Factors takine into account in allocating mild moderate, or severe =

* the need for supervition due to mental inability on any function.

* the expressed feeling of inability/unwillingness

* the family responce on questions about how the person's disability has affected household chores; social contact; money matters; relationships in the family; and how the family spends it's free time.

* social isolation indicated on p10, appendix III

* ability to take responsibilty for aspects of occupational performance indecated on p9 appendix III

Endurance / Dependance

This was graded the same way as the gross motor score except that the main reason for limitation was pain or shorness of breath. Appendix III p7

Social

Factors used to score this aspect were =

* social isolation linked to communiation or behavioural problems.
* expressed need for more company
* contact with others limited by impairment
* relationships in the family affected due to disability

Community Coping Skills

Factors used to grade this aspect were:

* difficulties in coping with any of the occupational sphere questions. Appendix III p9.
* age and usual role were taken into account when judging severity.

HANDICAP GRADING IN PHASE II

The handicap rates for each case were calcutated on computer by collapsing the scores of various sections into mild moderate and severe categories.

Mobility

The grade was computed from the scores relating to the key in the questionaire. Appendix III p7-8

The key is as follows:

1 = independant

2 = independant but limited

3 = use of equipment

4 = human assistance

5 = supervised

6 = equipment and human assistance

7 = not able

No handicap = if grading was 1 for all tasks

Mild = if grading include 2's and 3's

Moderate = if grading included 4, 5, 6 or 7 on outdoor tasks

Severe = if grading included 4, 5, 6 or 7 on indoor tasks.

Self care

The questions on self care were felt to be inappropriately detailed which affected the weighting, therefore some of the questions were combined and single score given. The categories were then : feeding, combing hair, dressing, tioleting, washing and doing transfers

The key is the same as for the mobility, above.

Mild = at least one 2 or 3.

Moderate = at least one 4 or 5

Severe = at least two gradings greater than 5 or at least two scores from dressing, tioleting and transfers greater than 3

Occupational

It was necessary to switch the figures on the key so that grading in this table could be added horizontally to indecate an overall score for that task ie. 1 = yes, 2 = partial, and 3 = not able.

Appendix III p 9

The table of tasks were responded to under the headings of knowledge, physical ability,and responsibility, with a score from the key. To get an overall score for each task the highest score given for one of the three aspects was taken.

The last two tasks an the table are generally applicable to the role of the woman therefore they were left out of the computation for males.

<u>For males the following rating applied:</u>

no disability = score of five when each task is added together

mild = score of 6-8 when the overall score for each task is added together

moderate = score of 9 -11 when the overall score of each tasks is added together

severe = score of 12-15 when the overall score for each task is added together

For femanles the following rating applied:

No disability = score of 7

Mild = score of 8 - 10 when the overall scores for each task is added together.

Moderate = score of 11-15 when the overal score for each task is added together.

Severe = score of 16-20 when the overall score for each task is added together.

Social contact

As there are no norms for regularity of feceived visits and paying visits, and qualitative data was limited , it was decided to use the questions g) and h)(Appendix III p 10)of socialisation to grade social contact.

A table was devised by which a rate could be computed. On the one axis of the table the possible answers to questions g) were plotted ie. 1= happy , 2 = don't mind, 3 = would like more, 4 = would like less compony

On the other axis, in response to question h) (wether their disability has effected there social live), 1 = no effect, 2 = limits some, 3 = limits completely

Various percentages were obtained from this, but a basic rate of 1, 2 or 3 from the effect of the disability column was reported as an indecation of social limitation ie. 1 = no effect on social life, 2 = limits a bit, 3 = limits a lot.

Orientation

This was judged from the information of the family questionnaire from 4 questions on orientation where a yes/ no response was recorded.Appendix III p13-14

Mind = did not lose conciousness but positive response on one of the other questions.

Moderate = Positive response to loosing conciousness or confusion.

Severe = positive response to all four questions.